

A Strategic Framework for Data Governance in Curative Health Information Systems in Low-Resource Settings

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Abstract

In many healthcare systems, allopathic services provide both preventive and curative care. With the growing adoption of Health Information Management Systems (HIMS) in the curative sector, the need for robust data governance is increasingly evident. However, comprehensive frameworks remain limited, and existing literature lacks depth. This study explores key domains and strategies for implementing effective data governance in curative sector HIMS, particularly in resource-constrained settings. A mixed-method approach was used in three phases. A structured three-phase mixed-method approach was used. Phase 1 involved a literature review to identify existing data governance domains and strategies. Phase 2 employed qualitative interviews with 15 purposively selected stakeholders, including medical administrators, clinicians, informaticians, nurses, and healthcare assistants in the Western Province, to uncover current data governance challenges. Phase 3 used the Nominal Group Technique with six domain experts to validate and refine the framework based on the findings from the earlier phases. The literature review revealed eight domains and 50 strategies. Thematic analysis of interviews identified seven critical data governance issues in clinical systems. Expert validation confirmed 49 strategies as essential, leading to the development of a comprehensive framework for data governance in Sri Lanka's clinical HIMS. The proposed framework addresses all key components of data governance and is adaptable for use in other low- and middle-income countries. The study highlights a significant knowledge gap among stakeholders and the presence of information silos, suggesting a need for targeted training and further investigation. Future studies should incorporate patient perspectives to enrich the framework.

Keywords: Health data governance, Clinical information systems, Low resource setting, IT governance and strategies, IT governance frameworks.

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Introduction

Health data is a fundamental asset in the delivery of effective, efficient, and equitable healthcare services. As the healthcare sector increasingly digitizes, the generation, use, and sharing of data have grown exponentially. This digital shift presents vast opportunities for improving clinical decision-making, resource allocation, and public health monitoring. However, these benefits are only fully realized when data is managed responsibly, securely, and ethically, which highlights the critical importance of robust health data governance (HDG). HDG refers to the frameworks, principles, policies, and processes that guide the responsible collection, use, sharing, and protection of health data. In high-resource settings, such mechanisms are well-established, ensuring data quality, interoperability, privacy, and accountability. However, in low- and middle-income countries, including Sri Lanka, HDG practices often remain fragmented or underdeveloped, leaving systems vulnerable to inefficiencies, data breaches, and ethical challenges.

Sri Lanka has made significant strides in digitizing its healthcare system, particularly within the curative sector, through initiatives such as the National Digital Health Blueprint and the implementation of electronic Health Information Management Systems (HIMS) across major hospitals. Despite this progress, the absence of a unified and context-sensitive data governance framework poses a major barrier to achieving national health objectives and ensuring the secure and effective use of digital health data. Existing national policies, such as the National Policy on Health Information (Ministry of Health, 2017) provide general guidance but do not adequately address the multidimensional governance needs of a rapidly evolving digital health ecosystem. Moreover, legal instruments like the Personal Data Protection Act (2022) and the Electronic Transactions Act (2006) only partially cover the ethical, technical, and procedural aspects of health data management (ICTA, 2016). These gaps highlight the need for a strategic, evidence-based, and contextually appropriate framework to guide HDG practices in Sri Lanka's curative sector.

Global efforts, including the HDG Principles introduced by the Transform Health, have emphasized the importance of protecting people, promoting the value of data, and prioritizing equity. However, such frameworks must be adapted to the institutional, legal, and cultural contexts of low- and middle-income countries. This study seeks to bridge the gap between international best practices and local implementation needs by developing a strategic HDG framework specifically for Sri Lanka's curative sector HIMS.

The literature suggests that the earliest evidence of research on data governance dates back to the early 1980s. Since then, researchers have conducted significant work on various components of data governance. However, most studies have focused on specific elements, and holistic investigations remain limited (Niemi, 2013). Recent Ministry of Health reports indicate that although over 68% of secondary and tertiary hospitals have implemented at least one form of HIMS, the systems remain highly fragmented, with no unified mechanisms for reporting data breaches or monitoring interoperability performance (Ministry of Health Sri Lanka, 2023). This lack of coordinated governance mirrors global concerns highlighted by the Transform Health, which advocates for equity-driven data governance frameworks that address fragmentation, trust, and responsible data use in low-resource settings (Transform Health, 2022). This study addresses this gap by developing a comprehensive framework tailored to the unique challenges and

opportunities of low-resource settings. Focusing on such environments is particularly important, given the critical role that effective data governance can play in improving healthcare outcomes. The framework developed in this study aims to enable low-resource countries to manage health data more effectively, thereby contributing to improved healthcare delivery and outcomes.

Building on these aspects, the study is guided by the central research question: How can data governance be facilitated in the curative sector Health Information Management Systems (HIMS) in Sri Lanka? To address this question, the study sets out a general objective of identifying strategies to facilitate data governance within the curative sector HIMS in Sri Lanka. In this context, specific objectives are; (1) to identify the key domains of data governance as they relate to curative sector HIMS in the existing literature, (2) to determine relevant data governance strategies from the literature, (3) to explore current data governance issues within Sri Lanka's curative sector HIMS, and (4) to formulate a comprehensive data governance framework tailored to the needs and context of the curative sector in Sri Lanka.

This paper presents the findings of a mixed-methods study that identified governance gaps, synthesized applicable global strategies, and validated a locally relevant HDG framework through expert consultation. The study adopted a mixed-methods approach implemented in three sequential phases. The first phase involved a structured literature review. The second phase used qualitative in-depth interviews with key healthcare stakeholders to uncover practical governance issues. The final phase applied the Nominal Group Technique (NGT) with expert participants to validate and finalise the proposed data governance framework. The proposed framework aims to support policymakers, hospital administrators, and informatics professionals in strengthening data management, enhancing patient safety, and ensuring the ethical use of health data in the Sri Lankan context.

Related Studies

Health Data Governance

The scientific community commonly perceives the health system as a complex entity as it demonstrates complex system characteristics. In order to deliver high-quality health services, effective collaboration and a comprehensive understanding among diverse professional groups are imperative due to the complex nature of the system (Greenhalgh & Papoutsis, 2018; Sturmberg & Martin, 2012). Compared to other disciplines, the health system generates an extensive volume of data at a rapid pace, further amplifying the system's complexity. Consequently, there is an escalating demand for the collection, retrieval, and utilization of health record information in electronic format to enhance flexibility. This enables the retrieval and presentation of data in numerous locations and formats, irrespective of the origin of the data (Hovenga & Grain, 2013). However, unless properly administered, health information systems have the potential to escalate the complexity of the health system. Healthcare organizations should implement appropriate data governance mechanisms to ensure health data availability, usability, integrity, quality, and security (Virantha & Lankasena, 2023). By adopting a data governance framework, healthcare organizations can optimize the value of their data. While implementing data governance mechanisms can pose challenges, the benefits are considerable, as proper data governance can substantially enhance the overall quality of healthcare.

Principles of Health Data Governance

The organization “Transform Health” has introduced the principles of HDG. The Transform Health is a United States based non-profit organization committed to transforming the healthcare system, which was founded in 2019. It is comprised of individuals and organizations, including Asian eHealth Information Network. Transform Health advocates for healthcare policies that promote health equity, improve access to care, and address the social determinants of health (Transform Health, 2022). Three objectives of HDG introduced by the Transform Health are “Protect people”, “Promote Health values”, and “Prioritise equity” (Health Data Principles.org, 2023b).

Key domains of HDG: Key domains of data governance in health are protecting individuals and communities, building trust in data systems, ensuring data security, enhancing health systems and services, promoting data sharing and interoperability, facilitating innovation using health data, promoting equitable benefits from health data, and establishing data rights and ownership (Health Data Principles.org, 2023b).

Strategies of Data Governance in Health: The section contains strategies that should be followed to maintain quality data governance mechanisms. Table 1 outlines key strategies for ensuring effective health data governance, aligned with principles identified in recent literature.

Table 1. Strategic Guidelines Across Key Domains of HDG

S1: Protect individuals and communities	S2: Build trust in data system
Address individual and collective risk (Health Data Principles.org, 2023b)	Align with best practices for data protection and privacy (Abraham et al., 2019; Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022)
Collect data with a defined purpose (Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)	Ensure consent is informed and understood in all its complexities (Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)
Collect personal or sensitive data only when necessary and with informed consent (Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Kaye et al., 2018)	Obtain collective consent where appropriate (Health Data Principles.org, 2023b)
Use secure data collection and storage mechanisms (Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2017, 2022)	Define concrete exceptions to informed consent (Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022)
Use de-identification and anonymization (Health Data Principles.org, 2023b; Ministry	Ensure data quality, availability, and accessibility (Abraham et al., 2019; Al-

of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)	Ruithe et al., 2016; Health Data Principles.org, 2023b)
Define inappropriate uses of health data (Health Data Principles.org, 2023b)	Reinforce health data governance with evidence (Health Data Principles.org, 2023b)
Institute safeguards against discrimination, stigma, harassment and bias Health Data Principles.org, 2023b)	Establish transparent and accessible processes and systems (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b; Kaye et al., 2018)
Provide guidance specific to marginalised groups and populations (Health Data Principles.org, 2023b)	Institute feedback and accountability mechanisms (Health Data Principles.org, 2023b)
S3: Ensure data security	S4: Enhance health systems and services
Require strong technical security measures for data processing (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022)	Evaluate the benefits of health data (Health Data Principles.org, 2023b)
Mitigate risks related to security threats (Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)	Encourage a culture of data-led insights and action (Health Data Principles.org, 2023b)
Ensure transparency around data breaches (Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2022)	Use data to enhance health services for individuals and communities (Health Data Principles.org, 2023b)
Consider federated data systems (Health Data Principles.org, 2023b; Kaye et al., 2018)	Address health system efficiency, effectiveness, and resilience (Health Data Principles.org, 2023b)
S5: Promote data sharing and interoperability	Strengthen community ownership of health data (Health Data Principles.org, 2023b)
Establish data sharing rules and guidelines (Abraham et al., 2019; Health Data Principles.org, 2023b; Kaye et al., 2018)	Enable and empower frontline health workers (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2022)
Validate informed consent before sharing data (Kaye et al., 2018)	S6: Facilitate innovation using health data
Promote interoperability of data systems- (Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)	Apply health data governance to emerging technologies (Health Data Principles.org, 2023b)

Define common data structures across health systems (Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)	Address the use of non-health data in health contexts (Health Data Principles.org, 2023b)
Define multiple levels of data access (Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022)	Build public health data infrastructure (Health Data Principles.org, 2023b)
Use common definitions and global standards (Abraham et al., 2019; Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)	Employ policy innovation (Health Data Principles.org, 2023b)
S7: Promote equitable benefits from health data	S8: Establish data rights and ownership
Represent all groups and populations equitably in data (Health Data Principles.org, 2023b)	Apply a human rights lens to health data governance (Health Data Principles.org, 2023b)
Consider the unique needs of marginalized groups and populations (Health Data Principles.org, 2023b)	Define clear governance roles and responsibilities (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2022)
Mitigate data bias (Health Data Principles.org, 2023b)	Codify data rights and ownership (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b)
Use accessible language and plug knowledge gaps (Health Data Principles.org, 2023b)	Extend data rights and ownership to products and services (Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023)
Implement inclusive data feedback mechanisms (Health Data Principles.org, 2023b)	Develop health data trusts and health data cooperatives (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2022)
Promote equitable impact and benefit (Health Data Principles.org, 2023b)	Employ participatory data governance mechanisms (de Freitas et al., 2021; Health Data Principles.org, 2023b; Kaye et al., 2018)
	Connect to broader accountability mechanisms (Health Data Principles.org, 2023b)

Source: Authors' presentation

The strategies stated in the above table in each key area of HDG provide a clear and practical guide for managing health data in a safe, fair, and responsible way. These strategies focus on protecting people's rights, building trust, improving health services, and using data wisely and securely. For countries with limited resources such as Sri Lanka, following these strategies can help make better decisions, improve healthcare delivery, and ensure that health data is used for the benefit of all, especially those in vulnerable communities. Building a strong data governance system also supports long-term improvements in the healthcare system and helps gain the trust of both patients and healthcare workers.

Health Information Systems and Data Governance in Low and Middle-income Countries

Adaptation of electronic Health Information Systems (HISs) is relatively less common in low- and middle-income countries than in high-income countries. However, over the last decade, these countries have increasingly adopted electronic systems to improve healthcare quality, often with support from donor agencies. Despite this progress, many developing countries struggle to maintain and expand HISs due to limited resources, lack of governance mechanisms, insufficient stakeholder involvement, poor coordination among actors, and weak leadership. For example, Koumamba et al. (2021) highlight that African countries face HIS implementation failures primarily due to these governance and coordination issues. In contrast, Bangladesh has made significant progress in digital health by ensuring strong leadership, comprehensive stakeholder involvement, the introduction of governance frameworks, and the adoption of open-source platforms like District Health Information Software Version 2 (DHIS2) (Azad et al., 2019). The literature provides evidence that existing studies do not explicitly address the combined technical, organisational, and ethical dimensions required for effective data governance in resource-constrained environments. This gap reinforces the need for a comprehensive and contextualised framework tailored to low-resource healthcare systems such as Sri Lanka. In Sri Lanka, the healthcare sector has adopted information technology to improve service quality.

The Ministry of Health acknowledges the importance of data governance, yet a comprehensive framework is still lacking. Nevertheless, Sri Lanka has several laws and policies that touch on aspects of data governance, including the ICT Act No. 27 of 2003, Electronic Transactions Act No. 19 of 2006, Computer Crimes Act No. 24 of 2007, Personal Data Protection Act No. 9 of 2022, and others such as the National Digital Health Standards and Information Security Guidelines (ICTA Sri Lanka, 2016; Ministry of Health Sri Lanka, 2023). However, the mere implementation of electronic HIS does not ensure quality improvement in healthcare. Achieving this requires robust governance frameworks, adequate infrastructure, continuous financial investment, trained human resources, and regular evaluation against institutional goals (Faujdar et al., 2019; Kazi et al., 2020; Menachemi & Collum, 2011). This study focuses specifically on the data governance aspects within curative sector HIMSs in Sri Lanka's public hospitals.

Theoretical Aspects of the Study

To explore the governance challenges and develop a context-specific framework, this study employs Grounded Theory (GT). GT is an inductive research methodology designed to generate

theory grounded in data, making it well-suited for understanding complex systems such as healthcare (Glaser & Strauss, 1965; Stewart & Klein, 2016). While GT is widely used, its methodological variations require researchers to be intentional in selecting an appropriate version for their context (Makri & Neely, 2021). The GT approach begins with data collection, followed by open coding, memo writing, category development, and iterative refinement. Through this process, codes evolve into conceptual categories and ultimately form a substantive theory or framework. Rigour in coding and continuous analysis are essential to ensure a robust and grounded output (de la Espriella & Gómez Restrepo, 2020).

Methodology

The study was conducted as a mixed-method study and completed in 3 phases. The visual illustration of the study is given in Figure 1.

Phase 1

Phase 1 of the study was conducted to identify the key domains of data governance and to identify the strategies of data governance in relation to curative sector HIMSs. In the literature review, we explored the current state of HDG, drawing upon various sources, including PubMed, Elsevier journals (Science Direct), IEEE databases, and Google Scholar databases. The databases were accessed through the Postgraduate Institute of Medicine, University of Colombo.

Phase 2

Phase II of the study focused on exploring DG issues within HIMS in state-sector hospitals in the Western Province of Sri Lanka, which is the region with the highest number and most established curative sector HIS implementations. A qualitative study design was employed, targeting healthcare workers in these hospitals.

Phase 1 and Phase 2 were independent of each other. However, the results obtained from these phases were used in phase 3 to develop the strategic framework.

A purposeful sample of 15 participants was selected across five employment categories: medical administrators, clinicians, health informaticians, nursing staff, and healthcare assistants, with three individuals from each group. Inclusion criteria ensured participants had at least two years of experience in the setting and recent experience with HIMS. Unwilling participants were excluded.

Data collection was conducted through in-depth interviews guided by a semi-structured interview tool, which was developed using literature and supervisor input, and refined through a pretest. Ethical clearance was obtained from the ethic Review Committee, Postgraduate Institute of Medicine, University of Colombo and necessary permissions for carrying out the study in relevant study settings were obtained from the Ministry of Health and the provincial directorate of health services.

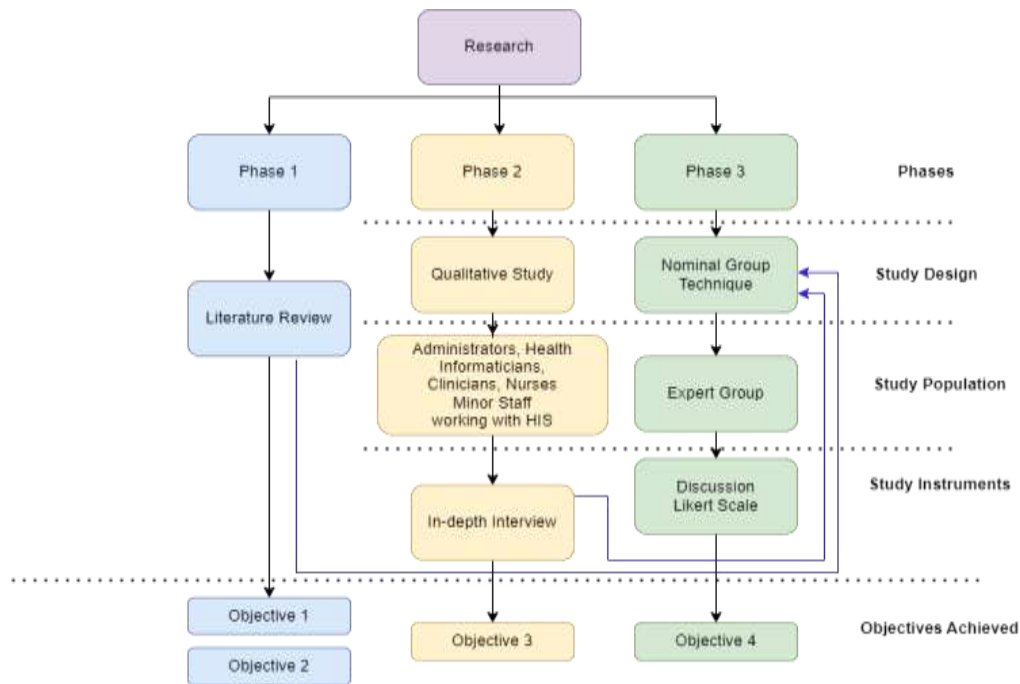


Figure 1. Visual Outline of the Study

Source: Author's presentation

Participation was voluntary, data were anonymised during transcription, and confidentiality was maintained throughout analysis and reporting. Interviews lasted an average of 24.6 minutes, were recorded with consent, transcribed, and translated when necessary. Manual thematic analysis was used to analyse the data, with non-relevant content excluded to maintain focus on the research objectives. The coding and theme development were conducted by the first author and validated through supervisory review to ensure consistency and confirm interpretive accuracy, rather than formal inter-coder reliability testing, following grounded-theory principles (Makri & Neely, 2021). The approach allowed for comprehensive insights into existing data governance challenges within HIMS in the curative healthcare sector.

Phase 3

The third and final phase of the study focused on developing a strategic data governance framework for HIMSs in Sri Lanka's curative sector. This phase utilized a mixed-method design based on the Nominal Group Technique (NGT) to achieve expert consensus, building upon the findings from Phases I and II.

A 6-member expert panel was purposively selected, comprising two health informaticians, two medical administrators, and two software engineers, all with significant experience in HIMS and data governance. While the expert panel included six members, this size is consistent with prior applications of the NGT in health system research, where smaller, balanced groups facilitate deeper discussion and consensus. The expert diversity (two from each of three distinct domains: informatics, medical administration, and software engineering) ensured representation of technical,

managerial, and operational perspectives relevant to curative sector HIMS. Nonetheless, we acknowledge the absence of patient and policy-level stakeholders as a limitation.

Inclusion criteria ensured participants had relevant qualifications and work experience, while individuals from Phase II were excluded to avoid overlap. Due to logistical constraints, the NGT process was conducted via video conferencing and followed a modified structure. The NGT followed four structured stages: idea generation, clarification and discussion, individual ranking, and final consensus building, consistent with standard NGT procedures (Potter et al., 2004). The initial ranking phase replaced traditional idea generation with insights from Phases I and II. Participants ranked 50 proposed strategies using a Likert scale, maintaining anonymity throughout. After presenting the first-round results, a structured discussion allowed participants to critically assess each strategy. A second round of ranking followed, and the process concluded after two rounds due to time limitations. This phase resulted in a consensus-based set of prioritized strategies to address clinical data governance challenges, forming the foundation of the proposed data governance framework for the curative health sector in Sri Lanka. Although the amount of data generated was modest, it was sufficient to achieve thematic saturation during interviews and consensus during the NGT process. Given the exploratory and framework-development focus, the emphasis was on the depth and contextual relevance of insights rather than on quantitative generalizability.

The use of the Nominal Group Technique (NGT) is well-established in health system and governance research, particularly for achieving expert consensus in multi-stakeholder settings (Potter et al., 2004). Similarly, thematic analysis was applied in Phase 2 following the principles outlined by Braun and Clarke (2006), which have been widely adopted in qualitative health research for identifying patterns and insights.

Results

Phase 1

Phase 1 of the study was conducted to identify the key domains and strategies of data governance in relation to curative sector HIMS in the existing literature. The key domains and strategies under each domain are summarized in Table 1. Accordingly, fifty strategies were identified under the 8 key domain areas during the literature review.

Phase 2

In Phase 2, a total of 15 in-depth interviews were conducted with 5 stakeholder groups to explore data governance issues within HIMS. The total duration of the interviews was 369 minutes (6.15 hours). The average interview duration of each stakeholder category is shown in Figure 2.

All the interviews were transcribed just after the interviews, and data were analysed using thematic analysis. The issues unrelated to the study's scope were excluded from the analysis.

Overview of Major Themes – Mentions vs. Minor Themes Count: Figure 3, illustrates the relative prominence and complexity of the seven major themes that emerged during thematic

analysis of stakeholder interviews. Two metrics are used to assess each theme: the number of minor themes (reflecting thematic depth) and the total number of mentions across all interview transcripts (indicating practical relevance and concern among participants).

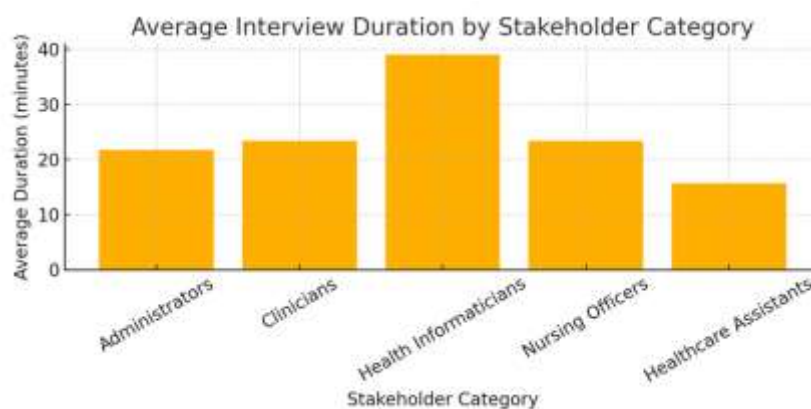


Figure 2. Average Interview Duration for each Stakeholder Category

Source: Author's presentation

Except health informaticians, all other stakeholders did not properly understand the data governance.

The major theme, “poor data quality”, was established through 4 minor themes: data duplication, data accuracy issues, inconsistency in data, and lack of data validation.

The major theme, “information silos and data fragmentation”, was established using three minor themes. The minor themes were “lack of interoperability in systems”, “limited data sharing between institutes”, and “unwillingness of data sharing”. The relevant codes were identified by examining the transcripts.

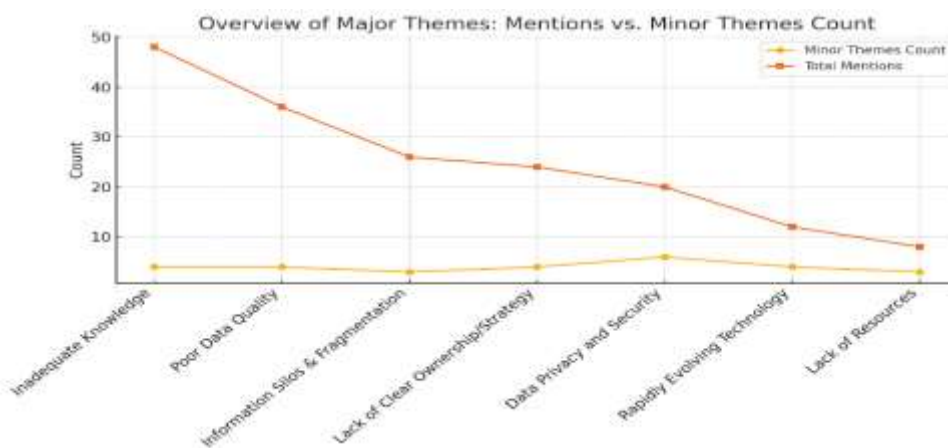


Figure 3. Overview of Major Themes (Mentions vs. Minor Themes Count)

Source: Author's presentation

“Lack of clear ownership, strategies and objectives” was established as a major theme using minor themes, namely “unclear data governance framework”, “unclear roles and responsibilities”, and “inadequate communication between stakeholders”.

The major theme, “data privacy and security”, is established by using 6 minor themes mainly. Inadequate data security measures, lack of data protection training, non-compliance with data privacy regulations, lack of data breach response plan, third-party data sharing risks, and inadequate monitoring and auditing of data access.

Only health informaticians consider “rapidly evolving technology” as a problem area in DG in relation to clinical information systems. They discuss compatibility and integration issues, challenges in keeping pace with technological advancements, security and privacy considerations with new technologies, and vendor management and dependency as issues related to data governance. Health informaticians provide evidence for minor themes under the “rapidly evolving technology” theme.

The last major theme was “lack of resources”. Interestingly, only health informaticians consider the lack of resources as a problem related to data governance. The major theme was developed using minor themes, namely, “insufficient budget allocation”, “shortage of skilled personnel”, and “resource allocation conflicts”.

Phase 3

Phase 3 of the study was to formulate a data governance framework for the curative sector HIMS of Sri Lanka. The nominal group provided their concurrence for relevant strategies twice. A discussion round was conducted between two rounds. The discussion yielded no new strategies other than those obtained during the literature review. However, the opinions of group members were changed during two rounds. The responses of the nominal group were summarized in Table 2.

Table 2. Nominal Group Responses for Strategies

Strategy Number(s)	Outcome	Comment
1–38, 40–47, 49	Accepted R1	Received 100% agreement in Round 1
39, 48, 50	Accepted R2	Improved to 100% agreement in Round 2
7, 8, 20, 25, 39, 48	Mixed Response	Included due to discussion-based relevance
11	Rejected	Removed due to consistent disagreement

Source: Authors’ estimation

All group members agreed with the 8 domain areas identified in the literature review as a data governance domain for HIS of Sri Lanka. Of the 50 strategies identified in the literature review, 48 got 100% votes for a strong agreement in round 1.

Out of 10 strategies that did not receive 100% votes on “strong agreement” in the first round, 3 strategies got 100% votes on “strong agreement” in the second round. 6 strategies did not receive 100% votes on “strong agreement” in both rounds. However, the nominal group agreed

that 5 out of 7 strategies (strategies 7, 8, 20, 39, and 48) were important and needed to be in the final framework.

After two rounds nominal group decided to remove the strategy “Obtain collective consent where appropriate” (number 11) from the final framework. Similarly, the nominal group gave mixed votes (similar level of agreement and disagreement) to the strategy “strengthen community ownership of health data” (number 25). Therefore, we have decided to keep the “Strengthen community ownership of health data” strategy in the final framework.

After two rounds of the nominal group, the domains and strategies were finalized. Below, Figure 4 illustrates the finalized domain areas and strategies for the DG framework for curative sector HIMs of Sri Lanka. The final framework consisted of 49 strategies under 8 domain areas.

This visual framework illustrates the eight key domains and associated strategies essential for implementing holistic data governance in curative sector Health Information Management Systems (HIMs). Each segment of the circular diagram represents a specific domain (e.g., protect individuals and communities, etc.). Strategies within each domain are labeled with short identifiers (e.g., BTD1, FIHD2, EDS4) and describe specific actions such as ensuring transparency, managing risks, empowering communities, fostering innovation, and guaranteeing data ownership. This infographic provides a comprehensive and concise overview of the 49 strategies developed through literature synthesis and expert validation, offering a practical guide for policymakers and implementers in strengthening health data governance frameworks.

Discussion

Phase 1

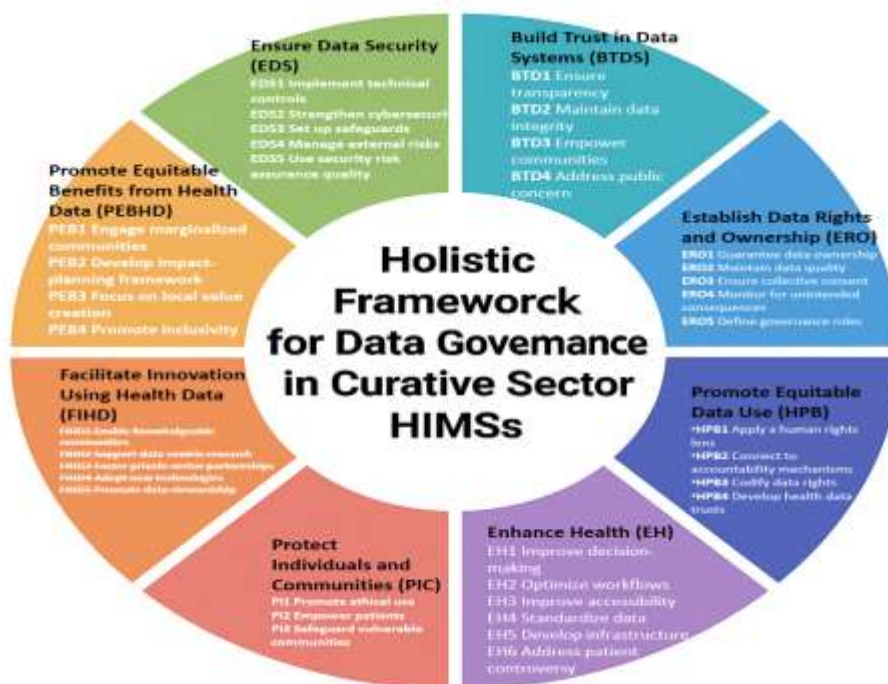


Figure 4. Framework for Data Governance in Curative Sector HIMs

Source: Author's presentation

The identified key domains and strategies in relation to the objective of this phase were discussed in the literature review. The principles, domains and strategies introduced by the Transform Health address the subdomains of HDG. Therefore, we have considered the strategies of the Transform Health as a baseline and built upon them using scientific literature published in peer-reviewed journals and international and local laws and guidelines.

50 strategies which should be considered for health data governance were identified under the 8 key domain areas, and the literature review only yields literature that focuses on single or several aspects of HDG. It was compatible with the statement of Niemi (2013) that “most of the research has focused on specific components of DG and holistic studies on data governance have been limited”.

In contrast, the Transform Health attempts to introduce holistic health data governance strategies, and its effort has already been endorsed by the Ministry of Health, Sri Lanka (Health Data Principles.org, 2023a). The development of HDG principles drew upon existing standards, ideologies, agreements, resolutions, and guidelines. Currently, low-resource countries prioritize universal health coverage and the achievement of sustainable goals by 2030. Integrating human rights and equity aspects into health data governance presents excellent prospects for attaining these objectives.

Phase 2

The objective of Phase 2, identifying issues related to data governance in the HIMs of state-sector hospitals in Sri Lanka's achieved using in-depth interviews of stakeholders of HIMs of state-sector hospitals in the western province. The variation in interview durations during data collection was due to differences in participants' roles, expertise, and experience. Health informaticians, with greater subject knowledge, provided more in-depth input, while healthcare assistants contributed less due to limited expertise. Although this may affect the depth of data across groups, all stakeholder perspectives were essential to the study and could not be excluded. The study identified 7 major issues related to data governance that exist in the research setting. It is evident from the above scenarios that curative sector HIMs have issues related to data governance. Also, these issues were multifactorial, and the human factor significantly contributed to the development of these issues.

To clearly present the key findings of Phase 2, the seven major data governance issues identified through thematic analysis are summarised in the following Table 3. Each issue is accompanied by a brief description based on the study's qualitative insights and supported by relevant literature. This summary highlights the multifaceted challenges that hinder effective health data governance within curative sector HIMs in Sri Lanka.

Table 3. Nominal Group Responses for Strategies

Major Issue	Description/Findings	Supporting Citations
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1. Inadequate Knowledge	Most stakeholder groups (except health informaticians) lacked awareness of data governance, related laws, the value of data, and human rights perspectives.	Abraham et al., 2019; Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2022
2. Poor Data Quality	Issues included data duplication, inaccuracies, inconsistencies, and lack of validation mechanisms, leading to reduced trust in systems and poor decision-making.	Abraham et al., 2019; Al-Ruithe et al., 2016; Health Data Principles.org, 2023b
3. Information Silos & Fragmentation	Fragmentation was due to lack of interoperability and limited or unwilling data sharing between institutions.	Abraham et al., 2019; Health Data Principles.org, 2023b; Kaye et al., 2018; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Weediawatta P.K.G.P, 2022
4. Lack of Clear Ownership, Strategies, and Objectives	Unclear governance frameworks, roles, and poor communication resulted in low accountability and unclear responsibilities.	Abraham et al., 2019; Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023
5. Data Privacy and Security	Weak safeguards, limited training, and non-compliance with data protection guidelines. Practices such as public display of credentials posed serious risks.	ICTA Sri Lanka, 2016; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022; Yeo & Banfield, 2022
6. Rapidly Evolving Technology	Compatibility issues, vendor dependency, and inability to cope with fast-changing technology created system vulnerabilities and integration challenges.	Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022
7. Lack of Resources	Budget constraints and lack of skilled personnel hindered implementation of effective governance practices.	Abraham et al., 2019; Health Data Principles.org, 2023b; Ministry of Health Sri Lanka, 2022

Source: Authors' computation

Phase 3

The study's final phase was to develop a data governance framework for curative sector HIMS. The key 8 domain areas of HDG were captured through a literature review and validated through a nominal group. The key domain areas touch the areas of human rights and equity in relation to DG. Most studies focused on single or multiple aspects of DG without focusing on a holistic approach (Niemi, 2013). The framework developed through this study primarily focused on providing quality data to correct individuals on time to take correct decisions by maintaining human rights, equity, and protection of individuals. The framework consisted of 49 strategies, and they were organized under the 8 key domain areas.

Some strategies addressed different aspects of a single concept under different key domain areas. The strategies regarding consent are the best example of strategies that fall under several domain areas. Out of 49 strategies, 4 strategies discussed consent under 3 domain areas. The concept of informed consent is fundamental in modern medical practice that prioritizes patient autonomy. It promotes a collaborative approach between healthcare providers and patients, fostering shared decision-making in their interactions (Pietrzykowski & Smilowska, 2021). The framework discussed the following aspects of consent for clinical data governance:

- Collection of personal or sensitive data only when necessary and with informed consent.
- Ensure consent is informed and understood in all its complexities.
- Defining exceptions to informed consent.
- Validate informed consent before sharing data.

In the current context, the Sri Lankan health system does not take consent from the patient to collect health data, use health data and share health data while seeking care. The study did not collect the perspective of patients regarding the issues of data governance, especially consent. Therefore, we cannot interpret the patient's perception regarding the consent. Also, during phase 2, the stakeholder groups did not perceive the “Consent” as an issue of data governance in the curative sector HIMSs of Sri Lanka. However, the nominal group discussed consent and where to place it in the framework.

Riordan et al. (2015) described that 91% of the study sample (study conducted in West London, United Kingdom) expected to be explicitly asked for informed consent before using the health data for health provision, research, or planning. Heslop et al. (2020) described that most people in the UK are happy to consent to use their data for ethically approved research rather than commercial research. However, in the Sri Lankan setup, no peer-reviewed journals address the aspect of the patient perspective of the utilization of health data.

Although, currently, clinical information system does not collect informed consent from the patient to collect, use and share the data, multiple legal provisions are already established concerning the consent to use and share health data. Chapter 6 of National Digital Health Standard and Guidelines version 2 describes how to maintain privacy, confidentiality and security of health data throughout the information life cycle (Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023).

Several strategies discussed the concept of data sharing and interoperability, namely the use of federated data systems, establish data sharing rules and guidelines. promote interoperability of data systems, define common data structures across health systems, define multiple levels of data access, Use common definitions and global standards, Support multi-sector partnerships.

Proper data sharing maximises data's value and generates insights from multiple stakeholders across multiple sectors (Health Data Principles.org, 2023b). As shown above, the proposed framework described multiple strategies to improve data governance. Also, the National Digital Health Standard and Guidelines version 2 described multiple strategies to improve data sharing and essential aspects to be considered during data sharing. The Ministry of Health, Sri Lanka, has already introduced the HL 7 FHIR profile for Sri Lanka to promote data sharing. Also, the ministry has introduced concepts like patient health numbers, Master patient index, registry services (Facilities, Healthcare providers), Data interchange standards, and standardised clinical vocabularies to promote data sharing and interoperability (Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023).

Implementing a data governance framework within the curative sector HIMSSs is a difficult task. The proposed framework has some strategies that can be useful in implementing sustainable data governance mechanisms. The following strategies (available in the proposed framework) can be considered valuable measures for sustainable data governance mechanisms apart from improving data governance.

- Employ participatory data governance mechanisms.
- Reinforce health data governance with evidence.
- Establish transparent and accessible processes and systems.
- Institute feedback and accountability mechanisms
- Ensure transparency around data breaches.
- Evaluate the benefits of health data.
- Implement inclusive data feedback mechanisms.
- Define clear governance roles and responsibilities.
- Codify data rights and ownership.
- Extend data rights and ownership to products and services.
- Develop health data trusts and health data cooperatives.
- Connect to broader accountability mechanisms.

The participatory design approach is a well-established user-centred design approach for developing new tools (systems, policies, or mechanisms). It involves the voice of all the relevant stakeholders affected by the change (Estiri et al., 2016). The method will increase the acceptability of the change and increase sustainability. Also, the proposed framework will improve data rights, ownership and data stewardship by clearly defining data governance roles and responsibilities (Health Data Principles.org, 2023b). These measures will improve the accountability of curative sector HIMSSs, thereby increasing the sustainability of data governance mechanisms and data governance.

The proposed data governance framework extensively discussed data protection in relation to the curative sector HIMs of Sri Lanka, and the following strategies were placed to achieve data protection:

- Use secure data collection and storage mechanisms.
- Align with best practices for data protection and privacy.
- Require strong technical security measures for data processing.
- Mitigate risks related to security threats.
- Ensure transparency around data breaches.
- Consider federated data systems.

The existing literature extensively discussed data protection and its importance in data governance (Al-Ruithe et al., 2016; Health Data Principles.org, 2023b; Ministry of Health Nutrition & Indigenous Medicine of Sri Lanka, 2023; Ministry of Health Sri Lanka, 2022). These results are consistent with prior studies that identified similar governance weaknesses in low- and middle-income health systems, including fragmentation and insufficient oversight mechanisms (Abimbola et al., 2019; Koumamba et al., 2021). Such alignment reinforces the validity of the proposed framework and its responsiveness to challenges observed globally in digital-health governance.

Data security is necessary to protect individuals from unnecessary problems and organizations from financial and reputational damages. Ministry of Health Sri Lanka has established Information Security Guidelines for Healthcare Institutions for data protection in the curative sector HIMs. Although its name suggests ‘information’ rather than ‘data’, the guideline covers data and information security. The guidelines extensively cover information assets management, physical and environmental security, access control, third-party security management, information security incident management and information sharing (70) (Ministry of Health Sri Lanka, 2022). The latest version of the Information Security Guidelines for Healthcare Institutions covers information security incident management. However, it does not cover how to ensure transparency around data breaches.

Quality data is essential in making quality decisions and improving healthcare quality. The proposed data governance framework incorporates the strategy ‘Ensure data quality, availability, and accessibility’ to improve data quality. However, indirectly all other strategies contributed to improve data quality. The proposed framework has the following strategies to protect marginalised communities, overall human rights, and prevent bias.

- Institute safeguards against discrimination, stigma, harassment, and bias
- Provide guidance specific to marginalised groups and populations
- Represent all groups and populations equitably in data
- Consider the unique needs of marginalised groups and populations
- Mitigate data bias
- Use accessible language and plug knowledge gaps
- Promote equitable impact and benefit
- Apply a human rights lens to health data governance.

By the time of writing this paper, same-sex relationships are illegal in Sri Lanka (few discussions are going on for legalizing same-sex relationships in Sri Lanka). The social stigma on lesbian, gay, bisexual, and transgender communities in the country is high in the community due to the cultural and religious background of the country (Ranaweera K.G.N.U, 2022). Sri Lanka provides free health services to all, irrespective of gender or sexuality. However, discrepancies may be conducted by the healthcare provider level while providing healthcare services. Therefore, improving the knowledge of healthcare workers on data governance is an important aspect. The proposed framework describes a strategy to improve knowledge of data governance of healthcare workers in relation to curative sector HIMSs of Sri Lanka. Phase 2 of the study identified that the knowledge of data governance was inadequate among stakeholders. Therefore, strengthening the knowledge of data governance is an essential aspect of improving data governance.

In summary, the study identified the issues related to data governance in curative sector HIMSs and described the methods of minimizing these issues using the proposed data governance framework. The proposed data governance framework was developed by aligning with the principles of Health Data Governance introduced by the “Transform Health” and validated the strategies using an expert panel for data governance of curative sector HIMSs of Sri Lanka. Data governance is an essential aspect of improving healthcare quality. By adhering to the proposed data governance framework, Sri Lanka can successfully achieve UHC and sustainable development goals.

Limitations

The study only accounted for the HIMSs of the western province of Sri Lanka. Therefore, the generalizability of the study to the entire country was limited. Also, this study does not analyze the public health HISs and issues related to data governance in public health HISs. The study's scope was limited to components of curative sector HIMSs due to time constraints. However, the study's validity would be increased if it had adequate time to examine the public health HISs. Furthermore, the study did not examine the patient's perspective on analyzing the issues related to data governance. The proposed framework also addresses the healthcare provider's perspective. Incorporation of the patient's perspective into the proposed framework will improve the validity of the study. The study solely focused on concepts of data governance. It did not focus on other governance domains related to information technology due to time and other resource constraints. Implementing strategies related to other governance domains will tremendously improve healthcare quality. A further limitation is that the study focuses primarily on the Sri Lankan context without incorporating detailed comparisons with other low income or middle-income health systems. This was largely due to time constraints and limited access to comparable international datasets during the study period. As a result, the analysis prioritized depth and contextual relevance within Sri Lanka rather than cross country benchmarking, which may limit the broader generalizability of the findings.

Future Work

The primary recommendation is implementing the proposed framework within the clinical setting to enhance data governance in curative sector HIMSs. By adopting and integrating the suggested framework into the existing infrastructure, healthcare organizations can establish a

holistic approach to data governance. Evaluation, as a distinct research area, presents a promising avenue for further exploration and can be pursued as an extension of this study. While this current research focuses primarily on developing and implementing a holistic data governance framework for curative sector HIMSSs, conducting a separate study dedicated explicitly to evaluating the framework's effectiveness and impact would yield valuable insights. The study identified the existence of information silos within curative sector HIMSSs. However, to gain a comprehensive understanding of this phenomenon, further investigation is warranted to identify the underlying factors contributing to the development of these information silos. Future research should empirically assess the impact of the proposed data governance framework on mitigating information silos and improving interoperability across multiple healthcare institutions. Comparative analyses among low- and middle-income countries could help validate the framework's adaptability to different governance and infrastructural contexts. Additionally, mixed-method evaluations focusing on user compliance, data-sharing behaviours, and the effectiveness of technical safeguards would offer a more comprehensive understanding of how governance frameworks influence real-world data management practices.

Conclusions

This study explored strategies for developing a holistic data governance framework for Sri Lanka's clinical Health Information Management Systems (HIMS). With the increasing complexity of health data and the limitations of traditional data management approaches, effective data governance is essential to ensure secure, ethical, and efficient data use. The proposed framework aims to address these challenges, enabling improved decision-making, patient care, and health outcomes. Findings from phase 2 confirmed the absence of a comprehensive data governance mechanism in Sri Lanka's curative sector HIMS, despite existing laws and guidelines addressing specific aspects like data protection. A major issue identified was the limited understanding of data governance among most stakeholders, except for health informaticians. The framework includes strategies for improving stakeholder awareness and emphasizes the need for capacity-building initiatives to support effective implementation. The evidence suggests that the framework incorporates the key components required for holistic data governance. However, its successful application depends on real-world implementation, ongoing monitoring, and iterative refinement. The study also identified information silos within clinical health systems, likely influenced by the lack of integrated governance, though further investigation is needed to explore all contributing factors. Finally, while the framework was developed for Sri Lanka, its relevance extends to other low-resource countries. To maximize its impact, it should be adapted to the unique contexts and governance needs of each setting.

Abbreviations

DG - Data governance

GT - Grounded Theory

HDG - Health Data Governance

HIMS - Health Information Management Systems

NGT - Nominal Group Technique

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