

ORIGINAL RESEARCH

Health Data Sharing with the Goal of Value Creation; Trying to Develop a Framework Using Qualitative Content Analysis

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Abstract: **Introduction:** Within the field of data sharing, discussions surrounding privacy concerns and big data management are extensive. This study aimed to provide a comprehensive framework for health data sharing with the objective of creating value. **Methods:** This study is a qualitative content analysis, which was conducted using a combination of written sources through a systematic review method, in conjunction with content derived from interviews with experts in information technology and healthcare within hospital and emergency settings. Grounded theory serves as the qualitative methodology, involving three coding phases: open, axial, and selective, facilitated by MAXQDA software. **Results:** Qualitative content analysis of the interviews revealed seven main (core) categories and 44 subcategories as driving factors in promoting healthcare data sharing. Simultaneously, inhibiting factors resulted in six main categories and 36 subcategories. The driving factors encompassed technology, education, patient management improvement, data utilization for various purposes, data-related considerations, legal and regulatory aspects, and health-related factors. Conversely, inhibiting factors encompassed security and privacy concerns, legal issues, external organizational influences, monitoring and control activities, financial considerations, and inter-organizational challenges. **Conclusion:** This study has identified key driving and inhibiting factors that influence the sharing of healthcare data. These factors contribute to a more comprehensive understanding of the dynamics surrounding data sharing within the healthcare information system.

Keywords: Health information systems; Information dissemination; Computer security; Confidentiality

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1. Introduction

Healthcare organizations collect and maintain patient data and records for specific purposes, including patient care, communication, legal documentation, quality management, research, and government policy determination(1, 2). The adoption of health information systems (HIS) in Europe in the early 1980s paved the way for the introduction of HIS in Iran in 1999, which became fully operational in 2001. The volume of data generated today has significantly ex-

panded humanity's capacity to consume, comprehend, and harness it for well-informed online decision-making in non-obvious circumstances(3). Health information system data inherently possess primary value within the operational healthcare landscape, aligning with predefined objectives. Moreover, health data also hold the potential to create secondary value for other industries through data sharing. Data and information sharing harbor significant and distinctive dimensions.

When health system employees share their information, the accrued knowledge gains added value(4). Data sharing in health plays a pivotal role in enhancing the quality of disease diagnosis(5).

However, data sharing, especially in the context of health information systems, is not without challenges and concerns, hindering the full realization of its inherent value(6). In numerous conducted studies, safeguarding individuals' privacy

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when sharing health information within HISs has been identified as of paramount importance and a significant deterrent factor(7, 8). Challenges and obstacles persist in the utilization and sharing of data within HISs, where the protection of individual privacy is a critical concern, particularly in the secondary use of clinical data(9). For example, sharing genomic data holds the potential to advance precision medicine, personalized treatments, and various other medical interventions. Nonetheless, these opportunities come with personal privacy concerns, as data misuse can pose risks to the privacy of individuals and their blood relatives(10).

Certain studies have concentrated on presenting models to address challenges and capitalize opportunities within the realm of HISs(11). Health data presents unique challenges and opportunities for users and stakeholders, and due to the personal and sensitive nature of health data, special attention must be devoted to the legal and ethical aspects concerning privacy protection and privacy-preserving technologies. Data sharing can yield benefits at both individual and societal levels.

Big data technologies open up new possibilities, enabling descriptive, diagnostic, predictive, and prescriptive stages of decision-making through extensive data analysis. Private and governmental organizations can take suitable technical and organizational measures to mitigate privacy risks. In a research study, researchers proposed a conceptual model for the quality of electronic health services based on information systems. This model comprises three main components: potential quality, process quality, and outcome quality, all of which make meaningful and positive contributions to the model and are quantifiable through meaningful indicators(2).

The application of artificial intelligence to health data promises to deliver significant value in clinical and research contexts. Despite extensive global research efforts, only a handful of AI-based applications have effectively harnessed health data(7). Key barriers to widespread acceptance of health data sharing and valid AI applications in this field include non-standardized medical records, limited access to generated datasets, and stringent legal and ethical requirements governing patient privacy protection.

The importance of data quality in health information systems is a significant driving force for data sharing(12). Defining, measuring, and managing data quality necessitate the documentation of data characteristics and various dimensions of data quality. Timely, accurate, complete data recording encompasses diverse facets of data quality within information systems. In Iran, the lack of an integrated HIS, the fragmented nature of hospital information systems, and the challenges related to data analysis and exchange have spurred the development of the Electronic Health Record system with the aim of integrating hospital information sys-

tems(13).

The concept of value creation has emerged as a central focus for various stakeholders, including managers, investors, governmental institutions, and the subject of extensive research within academic and professional domains. According to Porter's perspective(14), the approach to value creation can be dissected into two fundamental components: an understanding of activities central to value creation and a comprehensive exploration of the economic facets associated with these activities. This approach encompasses the following key stages: firstly, delineating the organizational business strategies; secondly, pinpointing the core activities aligned with the defined strategies; and thirdly, rigorously analyzing the value yielded by each of these activities to fortify competitive advantage. In essence, from Porter's standpoint, an organization proves profitable when the value derived from its activities surpasses the costs incurred in providing those services.

Data sharing has assumed considerable importance due to its myriad of benefits, including enhanced service quality for individuals, reduced operational costs, heightened program efficacy, improved policymaking, and more informed decision-making(15).

Beyond serving as a powerful management tool for all healthcare-related activities, encompassing functions such as planning, monitoring, coordination, and informed decision-making, the health information system also plays a pivotal role in organizational management. It empowers healthcare sector managers to make sound and effective decisions, thereby significantly enhancing their overall performance(16, 17).

Based on the points mentioned above, this study aimed to provide a comprehensive framework for health data sharing with the objective of creating value.

2. Methods

2.1. Study design and setting

Given the objectives and inherent characteristics of this study, a qualitative research approach was employed, relying on interviews with subject matter experts. In this research, qualitative content analysis was conducted using a combination of written sources (including books, articles, theses, and other relevant literature in the field) through a systematic review method, in conjunction with content derived from interviews with experts in the domains of information technology and healthcare (Figure 1). The qualitative research approach adopted in this study aligns with grounded theory methodology. Drawing on the input of experts and professionals, indicators derived from qualitative content analysis of the interviews were utilized in the presentation of the framework for sharing health data with the aim of creating

value.

2.2. Participants

The study's target population consisted of individuals well-versed in the subject matter, comprising information technology and healthcare professionals affiliated with Shahid Beheshti University of Medical Sciences hospitals. The sampling method employed was theoretical sampling, characterized by the selection of events and phenomena to be examined rather than individuals per se. Participants for the interviews were selected based on the following criteria:

1. Possession of documented studies in the subject area of the research
2. Experience in conducting at least one research project related to the research topic
3. Completion of specialized coaching courses relevant to the research area
4. Publication of at least one article in the field of the research topic
5. Involvement in translating or authoring a book in the domain of the research topic
6. Teaching experience in fields related to the research topic
7. A background in health management or information technology

2.3. Approach

In this study, the primary focus was on events, but individuals were also approached for their insights. While there are no strict rules regarding sample size in qualitative research, it is generally recommended to include 6 to 8 participants for homogeneous groups and 12 to 20 participants for heterogeneous groups. Interviews were conducted until theoretical saturation was achieved, which occurred with a total of 12 respondents consisting of IT and healthcare professionals from hospital settings.

In the foundational theory-building process, data integration holds significant importance. Following data collection, analysis, and interpretation in the research process, the subsequent steps involved model presentation, drawing conclusions, and summarizing the research. Initially, by examining the existing context, the collected data were categorized into 13 main categories. Subsequently, in the second step, the objective was to formulate a framework for sharing health information system data with the goal of creating value based on the theoretical model. Finally, in the third step, the model was presented.

2.4. Data gathering and analysis

Sampling in this study was carried out using logical qualitative methods and followed a purposive approach. Two specific sampling techniques, namely purposive sampling and snowball sampling, were employed. Purposive sampling is

commonly utilized in qualitative research to capture a maximum amount of information, with an emphasis on selecting participants who are considered "information-rich." This approach aligns with the qualitative research principles and aims to choose participants who can provide a comprehensive representation of the phenomenon under investigation. The selection of participants was conducted through purposive sampling from senior managers and stakeholders within the university who were willing to participate in interviews.

2.5. Trustworthiness

During the interviews, efforts were made to ensure the ongoing collection of information until a consensus in results was achieved. This is because part of the interview's validity relies on experts agreeing on the questions asked by the researcher during the interview. The interviews were conducted until a consensus was reached among the respondents regarding the compilation of components and sub-components in the interview process. To validate the interview questions, the opinions of experts and research professionals were sought.

2.6. Data analysis

The qualitative phase of the study was based on grounded theory, also known as theory-data-driven or theoretical framework. Three types of coding—open, axial, and selective coding—were applied, aided by the use of MAXQDA software. Grounded theory, an encompassing, inductive, and interpretive research approach, was developed by Barney Glaser and Anselm Strauss in 196(18).

2.7. Ethical considerations

This study was conducted in accordance with ethical standards, and informed consent was obtained from all participants during the recruitment process.

3. Results

This section presents the outcomes of the research, encompassing the identification of data sharing indicators, categorization of topics, contextual conditions, the central phenomenon, strategies and actions, intervening conditions, consequences paradigms, as well as selective coding. Additionally, a framework for sharing HIS data with the objective of creating value is detailed.

3.1. Identification of data sharing Indicators

Table 1 provides a descriptive summary of the initial coding derived from interviews conducted with 12 experts in the field of HIS (80 codes). Moreover, table 2 provides a comprehensive breakdown of 80 codes categorized into 13 main topics. These topics include inhibiting factors (security and confidentiality, legal issues, external factors, super-

visory and control activities, cost and expenses, and inter-organizational challenges) and motivating or driving factors (technology, training, improving patient management, data utilization for various purposes, factors related to data, laws and regulations, and health-related factors). The thematic maps depicting the motivating factors and inhibiting factors obtained from the software are visually presented in figures 1 and 2, respectively.

3.2. Central encoding factors

For presenting a framework for sharing data with the goal of creating value, the linkage of categories to the core category achieved through six titles (factors), which include fundamental conditions, causal conditions, central phenomenon, strategies and actions, intervening conditions, and consequences (table 3). After establishing these categories, the primary layers of the theory were identified in the subsequent stage. Figure 3 illustrates the model for sharing HIS data with the objective of creating value.

In this paradigm model, the causal factors, contextual conditions, intervening factors, and strategies related to sharing healthcare information system data were centred around the main concept or phenomenon that significantly influences data sharing, namely education and technology. This, in turn, results in various outcomes related to data sharing with the goal of creating value, such as enhancements in patient management and health-related factors.

4. Discussion

Recent years have witnessed a substantial surge in the volume of health data, stemming not only from healthcare information systems (such as MRI scanners, radiology devices, pathology slides, emergency patients, DNA tests, etc.) but also from wearable devices. This era has transformed organizations into knowledge-based entities, where data-driven services are produced and provided, positioning information as a crucial source for gaining a competitive edge and creating value across various sectors(19). The motive behind data sharing is to create value and enhance services, resulting in cost savings, improved program efficacy, better policymaking, and enhanced decision-making(15). Data sharing, both in terms of information and employee data, has distinct advantages, leading to increased value and synergy(4). This research reveals a multitude of factors involved in this endeavor, emphasizing the significance of various elements in sharing healthcare information data with the goal of creating value. These findings corroborate some previous research studies(2, 9, 11, 20, 21), while also introducing novel insights, particularly in the realm of external organizational factors that hinder data sharing. These external factors include data undervaluation, political concerns, emotional

considerations, patient information dispersion, insufficient specialized personnel in data sharing, stakeholder apprehensions regarding redundant data and information generation, and the existence of time-consuming administrative regulations.

The results of this study underscore the substantial advantages of sharing healthcare information data to create value, which encompass improved services, cost savings, heightened program effectiveness, and enhanced policymaking and decision-making. A range of factors essential for sharing healthcare information data with value creation in mind were identified, including technology, education, improved patient management, versatile data utilization, data-related considerations, legal and regulatory elements, health aspects, security and privacy factors, legal issues, external organizational dynamics, monitoring and control activities, costs and expenses, and inter-organizational challenges.

External organizational factors emerged as inhibiting elements in data sharing, encompassing data undervaluation, political concerns, emotional factors, patient information dispersion, a shortage of specialized personnel in data sharing, stakeholder concerns related to redundant data and information generation, and the presence of time-consuming administrative regulations. These findings are consistent with prior research in this domain, affirming the notable role of external organizational dynamics in hindering data sharing.

Security, privacy, and legal issues were identified as fundamental inhibiting factors in healthcare data sharing. Given the strategic and invaluable nature of information, safeguarding it is of paramount importance. Every organization must develop tailored solutions for safeguarding its informational assets based on the level of information it possesses. Information security becomes crucial in any project involving the storage or manipulation of sensitive data. In the healthcare domain, information security holds even greater significance due to patients entrusting their personal and health-related information to healthcare teams. Maintaining the security of healthcare information aligns with professional ethics and is a standard requirement for accrediting healthcare organizations. An effective healthcare information security program should be structured around three dimensions: "administrative safeguards, physical safeguards, and technical safeguards"(22).

Supervisory and control activities represent another inhibiting factor in healthcare data sharing and should be addressed with greater scrutiny in light of technological advancements. Inter-organizational challenges also pose hurdles to data sharing, particularly in cases where poor data quality within healthcare information systems disrupts information exchange. Information exchange in many healthcare information systems heavily relies on data quality, and

the absence, inaccuracy, or delayed input of information can lead to unsuccessful exchange and the return of information to the source information system(13).

One of the prevailing challenges in the healthcare system is the lack of collaboration among healthcare systems. The diverse and heterogeneous nature of healthcare information systems introduced by various vendors across different electronic health platforms has given rise to collaboration capability issues. Achieving interoperability among electronic health systems is a formidable task due to their inherent complexity. Therefore, to establish integrated communication in information systems like HIS, the architecture should be designed to enable collaboration among all existing information systems within and even beyond the hospital. This entails deploying collaboration capabilities in information systems to facilitate cooperation, enhance efficiency, transparency, responsiveness, and overall system integration(13). The enabling factors for healthcare data sharing encompass technology, education, patient management improvement, versatile data utilization, data-related elements, laws and regulations, and health-related factors. Technology and adequate education on its use are pivotal enabling factors in healthcare data sharing.

Additionally, other enabling factors for healthcare data sharing include enhancements in patient management, the utilization of data for various purposes, data-related considerations, and health-related elements. Efficient information systems can significantly improve efficiency, effectiveness, service quality, and patient satisfaction in the healthcare sector. As the healthcare data landscape experiences rapid growth, the sector's requirements are undergoing substantial transformation. Healthcare facilities are increasingly adopting computerized information systems and establishing healthcare information systems.

In subsequent research stages, an Interpretive Structural Modeling (ISM) will be employed to determine the relationships between data sharing factors and assess the importance and impact of each factor, with the results to be published.

Within the realm of driving factors, our analysis highlights the pivotal roles played by technology, education, enhancements in patient management, versatile data utilization, considerations related to data, adherence to laws and regulations, and health-related considerations. These factors collectively propel the sharing of healthcare information data, driving value creation and improvements in healthcare systems.

Conversely, a range of inhibiting factors has been discerned, each posing its unique challenges to the effective sharing of healthcare information data. Notably, security and privacy concerns emerge as paramount barriers, followed by legal issues, external organizational influences, surveil-

lance and control activities, financial implications, and inter-organizational challenges. Understanding these inhibiting factors is essential in devising strategies to mitigate their impact on data sharing efforts.

The theoretical gap identified in the literature review serves as the central problem addressed by this research. Prior studies have touched upon some of these findings, particularly pertaining to the hindrances posed by external organizational factors. These factors encompass the devaluation of data, political considerations, emotional dimensions, the dispersion of patient information, inadequacies in specialized personnel for data sharing, concerns among stakeholders regarding redundant data and information generation, and the burden of time-consuming administrative regulations. Notably, our study adds nuance by shedding light on aspects that have not received due attention in previous research, thus contributing a fresh perspective to the discourse on healthcare information data sharing within the literature.

5. Conclusion

The analysis of findings in this research delineates a data sharing framework for the health information system with the goal of creating value, comprising 7 primary driving factors and 6 core inhibiting factors. The interplay of other components with these main categories is articulated across six axes, encompassing causal conditions, central phenomenon, intervening conditions, strategies and actions, background conditions, and consequences. Among these main components, some have been addressed in previous research studies.

Notably, the categories of external organizational factors, monitoring and control activities, inter-organizational challenges, and security and confidentiality have not been previously explored in the literature.

6. Declarations

6.1. Acknowledgments

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6.2. Conflict of interest

The authors declare no conflicts of interest.

6.3. Funding and supports

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6.4. Authors' contribution

All authors played integral roles in the design, execution, and composition of all sections of this research. All authors read and approved the final version of manuscript.

6.5. Using artificial intelligence chatbots

None.

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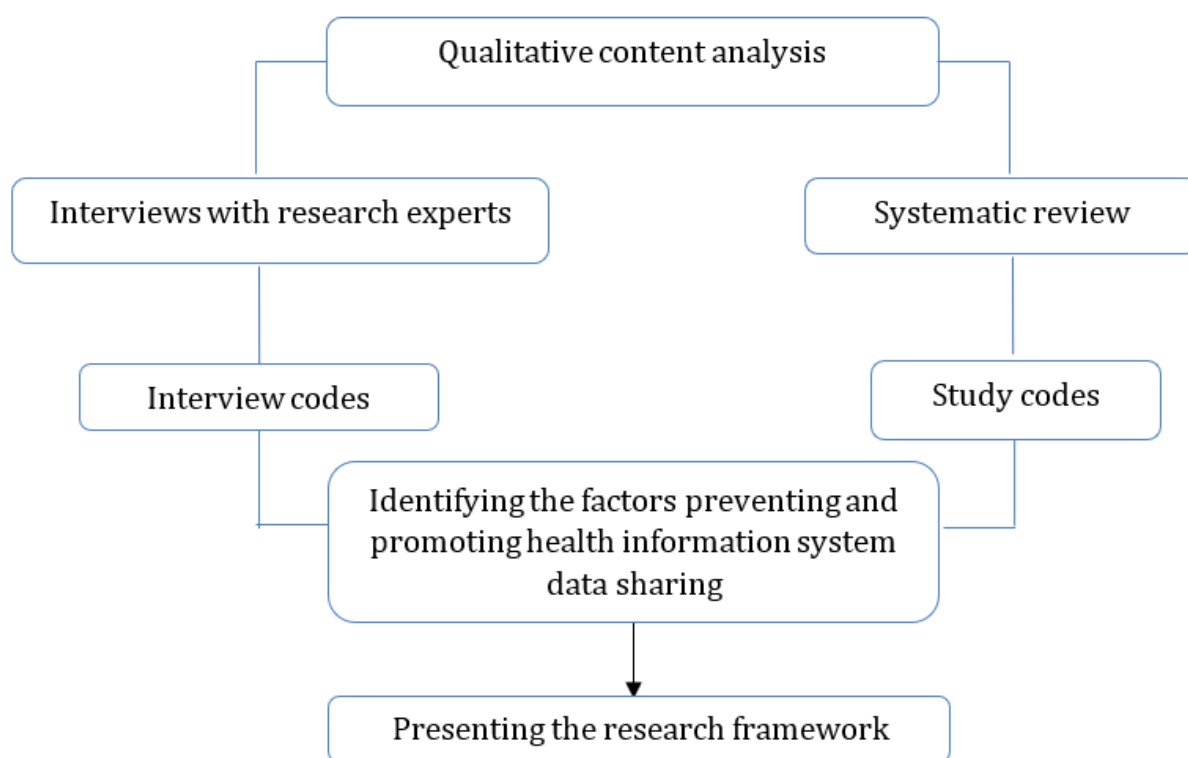


Figure 1: Study steps for developing a framework for health data sharing based on a qualitative content analysis.

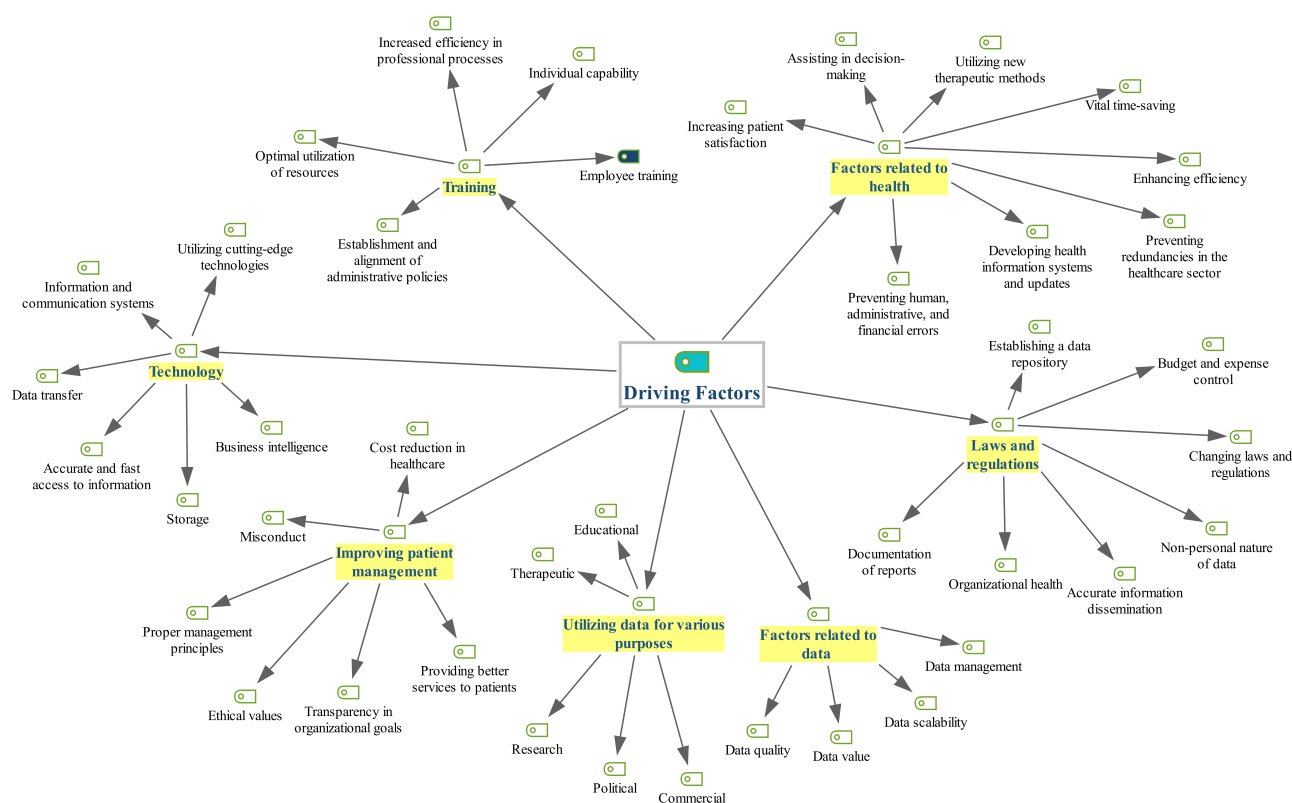


Figure 2: Thematic map illustrating the driving factors of data sharing.

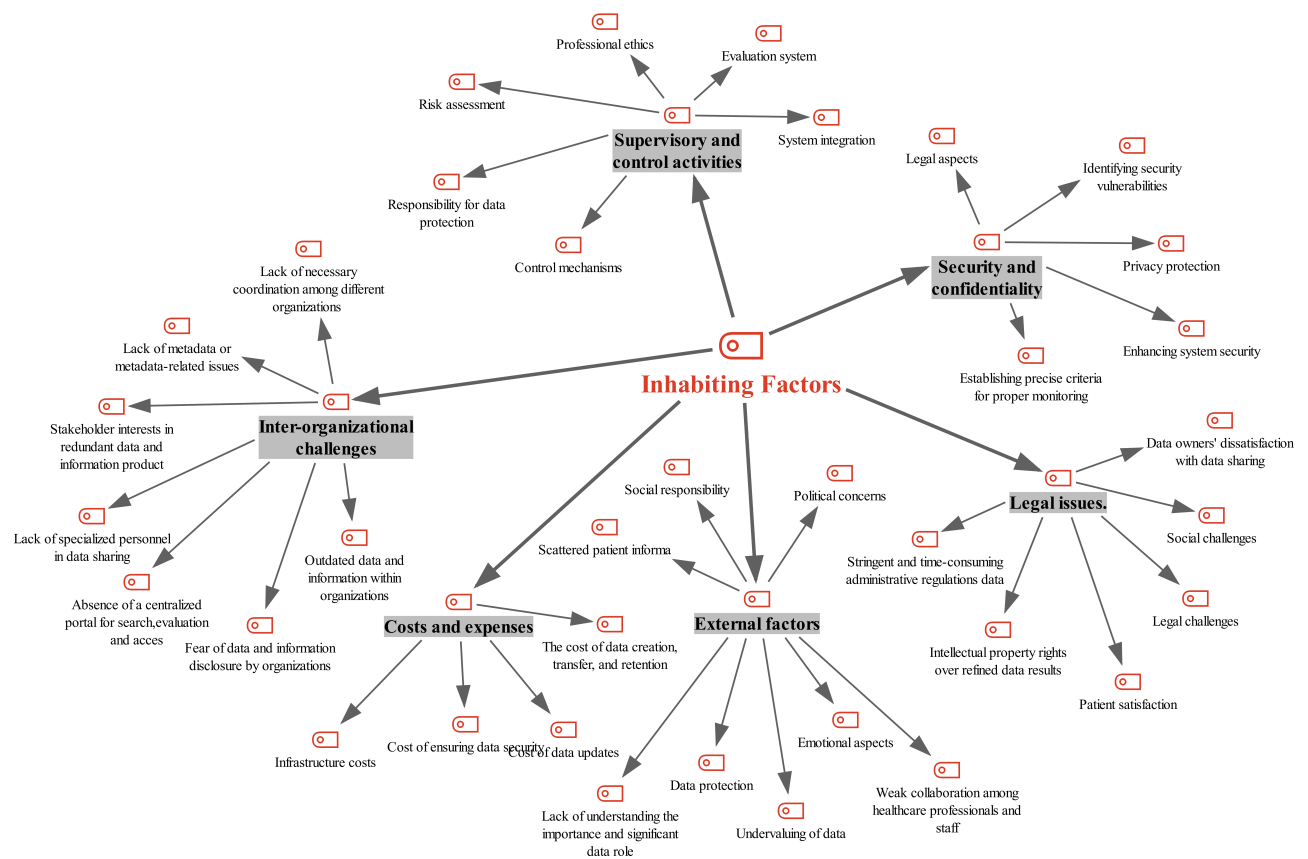


Figure 3: Thematic map illustrating the inhibiting factors of data sharing.

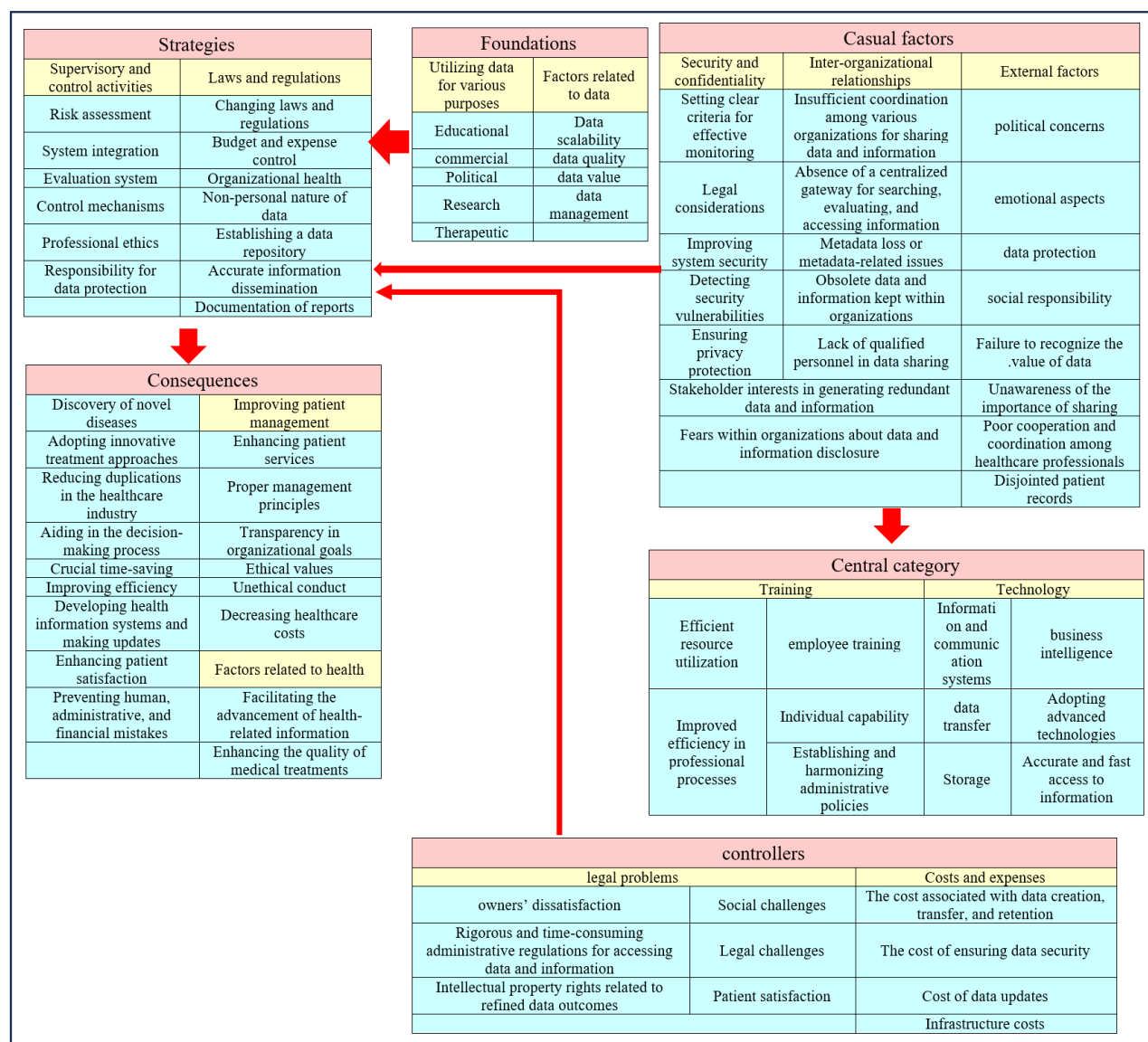


Figure 4: A framework for sharing health information system data with the objective of creating value.

Table 1: Initial derived coding from the interviews by experts in health information system (HIS) regarding health data sharing

Related Document	Open coding
Interview 3	Business intelligence
Interview 5,7,9	Utilization of modern technologies
Interview 6	Accurate and fast access to information
Interview 7	Information systems and communication
Interview 5	Data transfer
Interview 9	Storage
Interview 2, 7, 12	Employee training
Interview 1, 3, 4	Individual capabilities
Interview 3	Establishing and aligning administrative policies
Interview 4, 6, 9	Optimal use of resources
Interview 6	Higher efficiency in professional processes
Interview 10	Providing better services to patients
Interview 9	Sound management principles
Interview 11	Transparency of organizational goals
Interview 2, 7	Ethical values
Interview 12, 9, 8	Violations
Interview 6, 8	Reducing healthcare costs
Interview 9, 11	Educational
Interview 12	Business-related
Interview 7	Political
Interview 11	Research-related
Interview 6	Medical
Interview 3	Data scaling
Interview 5	Data quality
Interview 1	Data value
Interview 1, 2	Data management
Interview 6	Changing laws and regulations
Interview 11, 12	Budget and cost control
Interview 2, 7, 10	Organizational health
Interview 4	Non-personal nature of data
Interview 10	Creating a data bank
Interview 9, 11	Accurate information dissemination
Interview 6, 7, 8	Documentation of reports
Interview 8	Assisting in the progress of health-related information
Interview 6, 9	Improving the quality of treatments
Interview 2	Identifying new diseases
Interview 1	Adopting new treatment methods
Interview 10	Preventing redundancies in the healthcare sector
Interview 7	Vital time savings
Interview 7, 10	Assisting in decision-making
Interview 2	Better productivity
Interview 11	Developing a health information system and updating it
Interview 10	Preventing human, administrative, and financial errors
Interview 5, 7, 9	Increased patient satisfaction
Interview 2	Privacy
Interview 1	Legal aspects
Interview 10	Enhancing system security
Interview 5	Identifying security vulnerabilities
Interview 6, 8	Defining accurate monitoring criteria
Interview 6	Data owners' dissatisfaction with sharing
Interview 10, 11	Social challenges
Interview 9	Legal challenges
Interview 1, 3, 9	Patient satisfaction
Interview 2	Stringent and time-consuming administrative access to data and information

Table 1: Initial derived coding from the interviews by experts in health information system (HIS) regarding health data sharing (continue)

Related Document	Open coding
Interview 9	Intellectual ownership of refined data results
Interview 12	Political concerns
Interview 6, 7	Emotional aspects
Interview 11, 12	Data protection
Interview 12	Social responsibility
Interview 7	Lack of understanding the importance significant role of data sharing
Interview 11	Undervaluing data
Interview 6	Lack of collaboration between physicians and various staff members
Interview 3	Scattering of patient information
Interview 5	Risk assessment
Interview 1, 2, 5	System integration
Interview 1	Evaluation system
Interview 6	Control mechanisms
Interview 1, 3, 7	Professional ethics
Interview 2, 5, 9	Responsibility for data preservation
Interview 4	Costs of data creation, transfer, and preservation
Interview 10	Cost of data security
Interview 9	Updating data
Interview 6	Lack of necessary coordination among organizations for data and information sharing
Interview 8	Fear of data and information disclosure by organizations
Interview 5, 7, 8	Outdated data and information of organizations
Interview 2	Lack of a centralized portal for search, evaluation, and access
Interview 1	Lack of or issues with metadata
Interview 10	Lack of specialized individuals in data sharing
Interview 7	Self-interest of certain organizational individuals or organizations in redundant data and information production
Interview 7	Business intelligence

Table 2: Breakdown of 80 driven codes from the interviews into 13 main topics and Subtopics

Main Topics	Subtopics
Motivating factors of data sharing	
Technology	Business intelligence Adopting advanced technologies Accurate and fast access to information Information and communication systems Data transfer Storage
Training	Employee training Individual capability Establishing and harmonizing administrative policies Efficient resource utilization Improved efficiency in professional processes
Improving patient management	Enhancing patient services Proper management principles Transparency in organizational goals Ethical values Unethical conduct Decreasing healthcare costs
Utilizing data for various purposes	Educational Commercial Political Research Therapeutic
Factors related to data	Data scalability Data quality Data value Data management
Laws and regulations	Changing laws and regulations Budget and expense control Organizational health Non-personal nature of data Establishing a data repository Accurate information dissemination Documentation of reports
Factors related to health	Facilitating the advancement of health-related information Enhancing the quality of medical treatments Discovery of novel diseases Adopting innovative treatment approaches Reducing duplications in the healthcare industry Crucial time-saving Aiding in the decision-making process Improving efficiency Developing health information systems and making updates Preventing human, administrative, and financial mistakes Enhancing patient satisfaction
Inhibiting factors of data sharing	
Security and confidentiality	Ensuring privacy protection Legal considerations Improving system security Detecting security vulnerabilities Setting clear criteria for effective monitoring
Legal issues	Owners' dissatisfaction Social challenges Legal challenges Patient satisfaction Rigorous and time-consuming administrative regulations for accessing data and information Intellectual property rights related to refined data outcomes

Table 2: Breakdown of 80 driven codes from the interviews into 13 main topics and Subtopics (continue)

Main Topics	Subtopics
External factors	Political concerns Emotional aspects Data protection Social responsibility Failure to recognize the value of data Unawareness of the importance of sharing Poor cooperation and coordination among healthcare professionals Disjointed patient records
Supervisory and control activities	Risk assessment System integration Evaluation system Control mechanisms Professional ethics Responsibility for data protection
Costs and expenses	The cost associated with data creation, transfer, and retention The cost of ensuring data security Cost of data updates Infrastructure costs
Inter-organizational challenges	Insufficient coordination among various organizations for sharing data and information Fears within organizations about data and information disclosure Obsolete data and information kept within organizations Absence of a centralized gateway for searching, evaluating, and accessing information Metadata loss or metadata-related issues Lack of qualified personnel in data sharing Stakeholder interests in generating redundant data and information

Table 3: Central encoding factors of health data sharing

Factors	Main topics
Fundamental conditions	Utilizing data for various purposes Factors related to data
Causal conditions	External factors Inter-organizational challenges Security and Privacy
Central phenomenon	Technology Training
Strategies conditions	Laws and regulations Supervisory and control activities
Consequences conditions	Cost and Expenses Legal problems
Consequences conditions	Improving patient management Factors related to health