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Towards a Unified Framework for Information and Interoperability Governance

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Abstract. Challenges in health data interoperability have highlighted overall health care system inefficiencies. Many organizations struggle to establish a robust data governance infrastructure to meet the increasing demands of advanced data uses, let alone sharing it with a large number of other organizations. There is a need for health care organizations to adopt information governance frameworks that encapsulates interoperability as a core attribute as this can improve data processing, knowledge translation and participation in the larger health data ecosystem. To establish interoperability between healthcare organizations, standards must exist in relation to how information is governed and circulates in the healthcare system, not just on how it is structured, stored and used within an organization. In this paper we demonstrate that interoperability between organizations cannot coherently exist without consideration of information governance within organizations. Lack of coherence can lead to lack of data accessibility, decreased organizational efficiencies, and poor data quality. With this in mind, we propose a unified framework that integrates the principles of both information and interoperability governance to increase the adaptability, flexibility, and efficiency of health information usage across the entire healthcare system.

Keywords. Information governance, data governance, interoperability governance

1. Introduction

Health data interoperability is becoming an increasingly urgent challenge in Canada's healthcare system, as many parts of the healthcare system have been computerized for over a decade [1]. However, many organizations struggle to establish a robust data governance infrastructure to meet the increasing demand of advanced data uses, let alone sharing it with large numbers of other organizations. As more than 80% of health care data are digitalized [1], there is a need for health care organizations to adopt data governance frameworks that incorporate interoperability as an important element that enhances the processing and translation of data for health system transformation. A robust data governance framework could lead to improved clinical decision making and reduced operational costs. However, challenges persist as data governance and interoperability are often considered to be separate entities. The most significant barrier

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to enhancing interoperability in health care systems is related to how data is governed and managed within organizations [2].

In today's rapidly evolving digital healthcare landscape, the application of artificial intelligence (AI) and machine learning (ML) to health care processes places even greater emphasis on the importance of how these technologies can produce insights and analytics more consistently [3]. To increase trust and value in these technologies, data governance and interoperability governance principles need to be integrated and aligned to meet business and operational goals. Through the process of developing the unified framework, we identified a key difference between data and information; information has meaning while data needs more context to have meaning. We therefore changed our focus from data governance to information governance to ensure that only meaningful information is shared between healthcare providers. With this in mind, we propose a framework that will integrate the principles of both information and interoperability governance to increase the adaptability, flexibility, and efficiency of health care and aid in health system transformation [2].

2. Methods

We developed a set of requirements for information governance and interoperability based on the challenges faced by and the data needs of key stakeholders in the healthcare system, including patients, providers, payors, policymakers, researchers, data managers and administrators. These requirements drove the development of our framework. We reviewed a variety of existing data governance frameworks to identify components that could satisfy the requirements [4-6].

The unified framework was developed through an iterative process of selecting components that addressed the requirements and developing new requirements based on components found in the various frameworks that were relevant in the healthcare system. We iteratively revised the framework until no new requirements or components were identified. Based on extensive literature search in Google Scholar and PubMed, to our knowledge, this is the first study to focus on a unified information and interoperability governance (UIIG) framework.

3. Challenges with Unified Information and Interoperability Governance

Some of the common challenges in information governance include access management, fragmented and siloed data, lack of resources, lack of training, and lack of professional accountability. All these challenges lead to poor clinical decision-making, decreased stakeholder efficiency, and an unsustainable digital health care landscape. To uphold the value of data assets, organizations need to carefully consider their approach to IIG.

As each health care organization uses varying health information systems, there is a need to recognize the importance of health information exchange, usability, and translation of clinical data. To establish interoperability between health systems, standards must exist in relation to how information is governed and cycles in health care organizations. Therefore, interoperability cannot exist without the consideration of information governance as it can lead to the lack of data accessibility, decreased organizational efficiencies, and poor data quality [7].

4. Requirements for a Unified IIG Framework

Table 1 lists the requirements identified by our team. Many of these requirements are discussed in a variety of digital discourses but are rarely listed in one place.

Table 1. List of stakeholder requirements.

Stakeholder	Requirements
All stakeholders	Collect once, use many; easily transformable for a variety of uses; easily accessible by authorized individuals; easily visualized; easy to act upon; high quality data
Patient	Improved safety; minimal loss of privacy; access to own data.
Policy-maker	Compliant with legislation; integrates with multiple EMRs; compatible with international standards.
Funder	Cost-effective; value for money.
Healthcare Provider	Not burdensome for entry or retrieval; access to knowledge bases; tools for risk profiling; compatible with multiple data entry forms; ability to share clinical data across institutions;
Administrator	Risk profiling; collect process data; value for money.
Researcher	Quick access to data; easily link to additional datasets (exposures, deprivation index, etc.); captures data from a variety of systems; ability to conduct controlled experiments.
Data manager	Tools for cleansing; statistical modeling and visualization.

5. Proposed Unified IIG Framework

The resulting combined information and interoperability governance framework is shown in Figure 1.

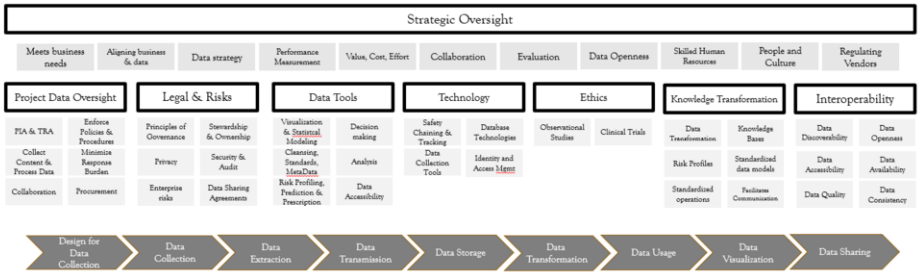

Figure 1. Proposed unified information and interoperability governance framework.

Strategic oversight is essential in the implementation of an effective unified information governance and interoperability framework across the health care system. This allows for organizations to align and secure data assets, conduct reviews, and monitor organizational goals, mission, and vision consistently and systematically. There are 11 elements identified within the strategic oversight layer of this framework. These include the following key drivers in achieving optimal strategic oversight: 1) Meet Business Needs, 2) Aligning Business & Data, 3) Sets Data Strategy, 4) Performance Measurement, 5) Optimize Value, Cost, Effort, 6) Collaboration, 7)

Evaluation, 8) Data Openness and FAIR compliance, 9) Skilled Human Resources, 10) People and Culture, 11) Regulating Vendors.

There are seven key components along with their associated operational requirements to establish a robust IIG program within any organization. The following is a brief description for each framework component:

- Project Data Oversight is foundational to the management of data collected, transmitted, stored, and used in projects within the organization and defines what processes, tools, and principles are required to achieve oversight.
- Legal and Risks should be considered as data is viewed as an asset and having value. It is also highly regulated in the healthcare sector.
- Data Tools needed for visualization and statistical modelling. Ensures value of data for all stakeholders is achieved. Can also be shared across the system.
- Technology for automating risk management wherever possible.
- Ethics assessment is necessary throughout each phase of the data pipeline to ensure organizations continually assess data practices and policies with a focus on how this impacts data owners and society. Ethics is required for research studies and to ensure AI used by the organization is unbiased.
- Knowledge transformation. Data should be easily transformable and produce meaningful and useful clinical, administrative, research, policy and resource allocation insights across all institutions.
- Interoperability. Information should be easily shared, utilized, and translated across systems. Focus should be on utility of information, not data transfer.

Below the framework key components and requirements is the data lifecycle layer. The data lifecycle identifies all the stages of the data lifecycle, which need to be governed, including the stage when the data collection and use is being contemplated and designed.

6. Policy Options

Our healthcare system has three options with regards to information governance and interoperability governance. The first option is to continue to keep the two separate. This has the benefit of not having to invest in additional stakeholder engagement, redesign of governance frameworks and training for a new governance framework. The cons are that the current approach does not work and has not worked for many years, leading to fragmented data, poor performance and inability to share information effectively for patient care and provider effectiveness. Lack of unified governance will make it difficult to take advantage of new technologies like artificial intelligence and generative AI.

The second option is to create a shared health information governance framework [8] that creates a multi-stakeholder governance structure for overseeing the management of all data in the healthcare system. The benefits of this approach are appealing in a democratic setting where everyone contributes to identifying shared goals, identifying risks and then working together to oversee the tracking of information across the system. The key issues with this framework are that it is very difficult to operationalize and puts too much emphasis on the stakeholders and very little on the day-to-day operational aspects of IIG.

The third and recommended option is the Unified Information and Interoperability Governance (UIIG) framework whose benefits are that it codifies best practices,

enables rapid updates across the system because everyone is on the same page and enables sharing of tools and methods across similar types of organizations. The issues with this framework are the high initial investment requirements in converting from current approaches to the new approach.

7. Benefits of a Unified IIG Framework

Adoption of a UIIG framework will enable organizations to promote operational efficiency and more readily comply with regulatory requirements. A unified framework will speed up training, onboarding and decision-making. It will also enable consistency, improve data quality, and improve decision-making within and across organizations. Additionally, it will set clear and standardized guidelines across the country which will increase efficiency in system-wide and organizational oversight as data is managed, governed, and exchanged according to similar guiding principles and concepts.

A unified framework will promote trust, security, and alignment of organizational goals. It will also enable sharing of best practices and tools that could speed up the adoption of the UIIG framework and lower the costs of interoperability.

8. Conclusion and Recommendations

For our healthcare system to become more proactive, actionable information needs to be available at key pivot points in a patient's health trajectory. Opportunities for proactive care, once lost, are lost forever and the patient is destined for heavy health system use. Our proposed UIIG framework could potentially enable safer and more efficient sharing of information across the healthcare system 1) without overwhelming patients with too many access points (or none at all), 2) without overwhelming healthcare providers with data that has more noise than signal, 3) making it easier to train and on-board employees and providers and 4) making it easier to share tools and best practices across the healthcare system. We highly recommend governments and key stakeholders consider adoption of the Unified Information and Interoperability Governance framework.

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