

# A Review of Cross Organizational Healthcare Data Sharing

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## Abstract

Increasingly, healthcare is provided by a team of care providers from different organizations. Cross-organizational healthcare data sharing is a major issue in interoperable healthcare organizations. Studies have shown that quality of care can be put at risk when patients are transferred from one organization to another, while the need for protecting patient privacy is sometimes an inhibitor to providing information computing technology (ICT) solutions. This paper presents a systematic literature review of cross-organizational healthcare data sharing. The review includes research related to laws and regulations as well as proposed methodological and ICT solutions. Our methodology for querying, filtering and selecting relevant papers from scientific, academic and general repositories is explained and the selected papers are categorized and compared in terms of scope, contributions, and future directions. Based on this analysis, we outline a possible research direction for developing ICT solutions that healthcare providers and regulators would be willing to adopt. Based on our review, we concluded that in spite of the liberal regulations around data sharing among authorized healthcare providers, these organizations are utterly reluctant to collaborate on patient information. Fear of a breach of personal health information, and the shortage of technological facilitators that are compatible with the existing health information systems, are the main causes of the cross-organizational interoperability problems in the healthcare sector. The existing collaborative technologies require considerable initial investments that the current healthcare system is not willing to spend funds on.

## Introduction

Healthcare organizations understand the importance of sharing data is critical to their business. They are increasingly sharing data with each other using information computing technology (ICT) to provide better services<sup>21</sup>. Cross-organizational healthcare data sharing is a major issue in patient care. Studies have shown that quality of care can be put at risk when patients are transferred from one organization to another<sup>6</sup>, while the need for protecting patient privacy is sometimes an inhibitor to providing ICT solutions<sup>3</sup>. Our own empirical observations of both hospital and community care in Ottawa, Canada as well as community care providers, indicated a fear of breaching patient privacy had made healthcare stakeholders reluctant to commit to real-time cross-organizational data sharing even if it was limited to authorized data custodians. We conducted a systematic literature review to analyze the current body of research to see how to address this issue. We followed the guidelines for a systematic literature review in software engineering<sup>24</sup>. Our study can be summarized in three stages: planning, conducting, and reporting<sup>20</sup>.

## Planning the review

Our research identified problems that stemmed from a lack of interoperability between healthcare organizations in Canada. Under current practices in Canada, a healthcare provider has limited knowledge about what's been done in another healthcare institution. As an example, when a patient is discharged from a hospital to the community, the

community care service providers have no knowledge of the procedures and treatments that had been offered to the patient during their hospital stay. Community service providers on the other hand, won't send any information to the hospitals nor to the corresponding family physicians.

### ***Specification of Research Questions***

In the context of the aforementioned problem, the main goal of this study is to find out why data interoperability is almost non-existent among different Canadian healthcare organizations. We first asked if the laws governing the inter-organizational data interoperability are confining in which case there won't be much tolerance for offering technological solutions. Then, we questioned the existence, efficacy, and adoption feasibility of available solutions for data sharing across organizational boundaries. Therefore, our questions are mainly focused on two streams: Patient Data Ownership, Privacy, and Laws:

- P1. Are there any regulations that would inhibit cross-organizational healthcare data access and sharing?
  - P2. What/who are the actors involved in cross-organizational healthcare data access and sharing?
  - P3. What type of data classifies as patient healthcare data?
  - P4. Who owns Personal Health Information (PHI) in Ontario and what laws regulate healthcare data sharing?
  - P5. What are the risks related to patient healthcare data handling? And how can they be addressed?
- Existing Manual and/or Automated Frameworks/Tools:
    - T1. Are there any existing tools in practice for cross-organizational healthcare data access and sharing?
    - T2. What are some of the most important evaluation criteria for such systems?
    - T3. What are the factors and determinants of technology adoption by users for such systems?
    - T4. What are the organizational or technical challenges and obstacles in developing or acquiring such systems?

### ***Development of a Review Protocol***

Based on our research questions, we identified a preliminary set of search keys by brainstorming relevant terms and combining synonyms. Then, we conducted an initial exploratory search to identify important and relevant studies. Next, we performed a quick scan of studies found to see if we should add more keywords. The final set of keywords was then formulated into advanced search queries. The keywords were run on the following databases:

Google Scholar, PubMed, Science Direct, ACM Digital Library. After obtaining the initial set of articles, we started reviewing them to determine if they are truly relevant. As part of our study selection criteria, we arbitrarily decided to focus on papers published after the year 2000 mainly because the use of electronic health record applications was not prevalent before that year<sup>22</sup>. To ensure our selection process was systematic, we evaluated the retrieved papers against the following qualitative metrics<sup>24</sup> to create a study quality assessment checklist.

- Q1. Were the results relatively new (recent publication)?
- Q2. Were the findings of the paper credible?
- Q3. If the results of the paper were credible, were the findings important with regards to research questions?
- Q4. Were data collection methods and their inclusion and exclusion criteria well defined and justified?
- Q5. Were the findings of the paper well aligned with original goals of the paper?
- Q6. Were the findings of the paper reported in a coherent and clear manner?

## Conducting the review

### *Identification of Research*

The initial set of key words included: patient data, data ownership, data sharing, healthcare data, Cross-organizational interoperability, healthcare evaluation, and Canadian laws on patient data ownership. We formulated the aforementioned key terms into simple queries such as: ((patient data Title/Abstract]) AND data ownership Title/Abstract]), ((healthcare data) AND cross organization) AND interoperability, Canadian laws on patient data ownership, Healthcare + Evaluation + data interoperability (all keywords). These queries were run on three scholar search engines: Google Scholar, Search+ (IEEE, ACM library, and several others), and PubMed. At this stage, we kept the scope of the search wide open to be able to catch as many papers as we could, in order to establish a relative familiarity with the most common keywords that we may have missed in our brainstorming session. The new key words identified were: data linkage, data system, integrated system, shared repository, hospital, community care,

physician, and information systems. We then applied advanced search syntax strategies such as use of quotation marks, more logical expressions to formulate conditions. Our final search queries, the electronic repositories of scholar studies, and the number of returned results are summarized below in Table 1.

By reviewing the retrieved papers, it became clear to us that we had gathered four categories of studies:

- C1. Laws and regulations of patient data privacy, ownership and sharing
- C2. Interoperability perspective
- C3. Technical tools and solutions to share and access healthcare data
- C4. Evaluation criteria for healthcare data systems

Any paper about laws and regulations on healthcare data ownership and sharing as well as proposed methods/frameworks to protect patient data privacy are grouped in the first category. Any framework, methodology, or management approach to achieve data interoperability in a healthcare setting was grouped in the second category. Furthermore, any software application or toolset that facilitates data sharing and accessing falls within “Technical tools and solutions to share and access healthcare data” category. Finally, any study that lays out a set of success factors or evaluations criteria for healthcare data sharing and accessing falls in the “Evaluation criteria for healthcare data systems” category. Study selection process was then followed by excluding any article older than the year 2000. Then we continued by reviewing and scanning through titles, keywords, and abstract sections of the retrieved articles. These steps reduced our 392 papers down to 44 papers. We then added 6 more articles based on backward citation strategy i.e. we went through the articles that were referenced by those 44 papers. We classified 17 studies in category C1, 14 in C2, 6 in C3, and 13 in C4. At this stage, we realized that there haven’t been many scholarly publications reporting technical solutions for a wide range interoperable healthcare information system. Therefore, a future research endeavor can focus on implementation of an interoperability solution in healthcare industry that can

attract any kind of healthcare entity and operate at a national level.

### *Study Quality Assessment*

At this stage, we ranked all 50 papers based on the aforementioned quality assessment questions. If the questions were completely satisfied, a score of 2 was given to the study. Semi satisfactory results would incur a score of 1. Finally, no proper answer for the quality question would lead to a score of 0. All the papers that obtained a score below 8 were excluded from this report.

Table 2 summarizes 17 papers that passed the quality assessment (a total score higher than 8) and presents the grade obtained for each quality assessment metric. For quality assessment metric Q1, we looked at the date that the study was conducted or when the results were achieved. The second metric Q2, which looks at the credibility of the results, focuses on the method that the study had used to prove their results. No matter if the study had used qualitative or quantitative methods, if the results were proven in a scientific manner such as statistical analysis, use of questionnaires, case study, or interview with the experts, it received the full score. Q3 determines the degree of which the results of the study were able to assist in answering our research questions. Q4 requires a well articulated scientific research method and well defined research scope. The fifth metric, Q5, assesses the study based on the goals, questions, or problems that the study thrives to address. This metric evaluates if the goals of the study were satisfied with their published results. Finally, the last metric, Q6 evaluates if the study was reported in a coherent, easy to read, and logical rhythm.

Table 2. Study Quality Assessment Summary

Category	Paper	Q1	Q2	Q3	Q4	Q5	Q6	Total
C1	(Cavoukian, 2004)	2	2	2	2	2	2	12
C1	(El Emam, Jonker, Arbuckle, & Malin, 2011)	2	1	2	2	2	2	11
C1	(Beardwood & Kerr, 2005)	1	2	1	1	2	1	8
C1	(Tu, 2010)	2	2	2	2	2	2	12
C1	(El Emam, et al., 2010)	2	2	2	2	2	2	12
C1	(El Emam, Jabbouri, Sams, Drouet, & Power, 2010)	2	2	2	2	2	2	12
C1	(Luchenski, Reed, Marston, Papoutsi, Majeed, & Bell, 2013)	2	2	1	2	2	2	11
C2	(Haux, 2006)	1	2	2	1	2	2	10
C2	(Kuziemy, 2013)	2	2	2	1	2	2	11
C2	(Webster, 2013)	1	2	2	1	2	1	9
C3	(Pietro, 2014)	2	2	2	2	2	2	12
C3	(Cars, et al., 2013)	2	2	1	2	2	2	11
C3	(Local Health Integration Network, 2011)	2	2	2	2	2	2	12
C4	(Abernethy, Wheeler, & Bull, 2011)	2	2	2	1	2	1	10
C4	(Korst, Signer, Aydin, & Fink, 2008)	2	1	1	2	2	1	9
C4	(Leonard, 2000)	1	2	2	0	2	2	9
C4	(Moutham, Kuziemy, Langayan, Ling, Peyton, & Pereira, 2012)	2	2	2	1	2	2	11

### *Data Extraction*

From the selected papers, we extracted some general data such as the title, authors, publication year, keywords, and other publication details. We also extracted anything that could help us rate the study by quality assessment evaluation metrics such as date of the study, research methodology definition, contributions of the study, research

questions, and the flow of the discussions. Table 3 provides a quick summary of the collected studies that passed the quality assessment metrics. The last column refers to section 2.2 and the question addressed by the study.

Table 3. Extracted Information and Questions Answered

Title Primary	Year	Counties presented	Research Method	How were findings proven	Problem tackled	Answered Our Questions
(Cavoukian, 2004)	2004	Canada	Qualitative		Regulations Interpretation	P1, P2, P3, P4
(El Emam, Jonker, Arbuckle, & Malin, 2011)	2011	Canada, USA, UK, Germany	Quantitative	Statistical testing	PHI Protection Techniques	P5
(Beardwood & Kerr, 2005)	2005	Canada	Qualitative		Regulations Description	P2, P4
(Tu, 2010)	2010	Canada	Quantitative	Statistical testing	De-identifications techniques	P5
(El Emam, Jabbouri, Sams, Drouet, & Power, 2010)	2010	Canada	Quantitative	Statistical testing	De-identifications techniques	P5
(El Emam, et al., 2010)	2010	Canada, USA	Quantitative	Empirical study	PHI disclosure risks	P5
(Luchenski, Reed, Marston, Papoutsi, Majeed, & Bell, 2013)	2013	UK	Quantitative	Questionnaire	Public opinion about a national HER system	P2
(Haux, 2006)	2006	Germany, Austria, Italy	Quantitative	Empirical	Evolution of HIS	T1
(Kuziemy, 2013)	2013	Canada	Qualitative	Grounded theory	Types of Interoperability	T3, T4
(Webster, 2013)	2013	Canada	Qualitative	Domain experts	Interoperability of EMR systems	T4
(Pietro, 2014)	2014	Italy	Quantitative	Case study	Integration in healthcare services	T1
(Cars, et al., 2013)	2013	Sweden	Quantitative	Case study	Cross-organizational HIS data	T1
(Local Health Integration Network, 2011)	2011	Canada	Industry report	Technology Deployment	Integrated decision support system	T1
(Abernethy, Wheeler, & Bull, 2011)	2011	USA	Quantitative	Case study & pilot-testing	Success factors of HIS	T2, T3
(Korst, Signer, Aydin, & Fink, 2008)	2008	USA	Qualitative	Case study	HIS integration	T1, P5
(Leonard, 2000)	2000	Canada	Qualitative	Personal perspective	HIS implementation problems	T2, T3, T4
(Moutham, Kuziemy, Langayan, Ling, Peyton, & Pereira, 2012)	2014	Canada	Qualitative	Case study	Overcoming interoperability issues	T1, P5

#### 4. Reporting the review

##### *C1 - Laws and regulations of patient data privacy, ownership and sharing*

In the context of laws and regulations, Personal Health Information Protection Act (PHIPA) provides detailed guidelines for all the players involved in producing and handling Personal Health Information (PHI)<sup>5</sup>. PHIPA defines Health Information Custodian (HIC) as “persons involved in delivering healthcare services” and “patient” would be the person receiving this healthcare service. PHIPA also identifies the “recipients” who are individuals receiving information from a HIC. PHI includes information about an individual’s physical or mental health, the provision of the healthcare services, the length of stay on the healthcare program, payment information, eligibility for healthcare services, results of tests /examinations on the individual, details of donation of body parts, identity of the individual’s substitute decision maker, and individual’s personal health number also known as Health Card Number (HCN).

PHIPA authorizes HICs to use PHI to share and access information among themselves for the purpose of continuation-of-care. HICs may disclose PHI to another HIC without an explicit consent from the patient. Therefore, the consent is implied unless the patients specifically withdraw their consent. We realized that the regulations are more liberal than what’s been practiced in healthcare industry in Ontario. Although PHIPA permits data sharing for legitimate purposes among HICs, agents of these organizations find it safer not to share any PHI all together.

Considering the beneficial outcomes<sup>11, 26</sup> of interoperability on patient's care along with its compliance with PHIPA, we find this level of caution, excessive. Beardwood and Kerr<sup>2</sup> describe the administrative obligations of HIC and how remedies suggested by PHIPA shall be reinforced. Their paper elaborates on the general practice, designation of a contact person, guarantee of information accuracy, guarantee on information security, stakeholder notice requirements, and the rights to access PHI that is produced and handled by HICs. In 2013, a study about the public views on the use of electronic health records was conducted in United Kingdom<sup>18</sup>. The study reported a positive public perspective towards having a national health record system that can be used for continuation of care, planning health services and policies, and health research purposes.

Although, there has been regulatory and public support for PHI sharing and accessing by authorized individuals, we have to bear in mind that these processes should be extremely secure and reliable. There have been some studies that question the efficacy of recent ad-hoc data sharing efforts. El Emam<sup>8</sup> explored some P2P file sharing software such as LimeWire and Morpheus to estimate the risk of PHI disclosure. The authors modified an open source P2P file-sharing client to automatically download files that were shared through P2P mechanisms. When a file was downloaded, it was stored in a repository and the IP associated with the sender was recorded. According to their study, there has been a significant risk of disclosure of PHI through P2P file sharing applications.

In another study<sup>7</sup>, El Emam reviewed 14 re-identification attacks on de-identified datasets. Of these 14 attacks, 6 involved healthcare data. Only two out of 14 attacked datasets were successfully de-identified. The de-identified datasets, however, were not in healthcare domain. The paper implies that putting proper de-identification methods can lower the risk of re-identification attacks. Later on, El Emam explored the success rate of two de-identification methods in the context of Electronic Medical Records (EMR)<sup>9</sup>. Tu et al. also attempted to modify an open source de-identification software in order to protect a healthcare EMR system<sup>25</sup>. They recorded the success rate and statistically concluded that their techniques could reasonably de-identify EMR free-text. These studies prove that there are reliable toolsets for securing data sharing efforts.

### ***C2 - Interoperability perspective***

Webster reflects the opinion of a few healthcare executives in Ontario by quoting them on their dissatisfaction of the disintegrated EMR systems and the incompatible data stored and retrieved. According to the paper, 70% of Canadian Physicians' offices are burdened by a system that generates incompatible data. There are numerous different EMR vendors in Ontario whose systems generate incompatible data<sup>27</sup>. With everything that's been achieved in the past 30 years in EMR domain and the evolution of healthcare data from paper based to computer based processing, storage, retrieval, and reporting, there are still prominent fields of work. In 2006, Haux<sup>10</sup> studied past, present, and future of health information systems (HIS). He reported "patient-centered" characteristics of HISs in Austria, Germany, Italy, or Switzerland in the 00s vs. the former "institution-centered" HISs. He pictures an ideal health information system that's integrated at a regional and even global calibre.

Kuziemy<sup>15</sup> writes about three types of interoperability: Technical, Semantic, and Process. He believes data and technical interoperability have progressed to a fair level but process interoperability is still problematic. Therefore, he highlights process interoperability as a key to a successful interoperability endeavor. He categorizes the process interoperability into three levels of a) knowledge as a mechanism to draw knowledge from research carried out by any healthcare entity, b) clinical processes as the interoperability of the low level and operational processes, and c) collaboration interoperability as collaboration among multiple asynchronous care deliveries. Other aspects affecting interoperability are contextual factors such as social or political rules. National and regional privacy laws and mobile access to the data are of contextual factors that need to be factored in an interoperability framework.

### ***C3 - Technical tools and solutions to share and access healthcare data***

While thriving to facilitate data sharing among healthcare practices with respect to privacy, Esposito et al. have proposed an asynchronous notification of clinical documents for primary and secondary care providers<sup>22</sup>. After receiving the notification, health professionals are to receive the required documents through traditional systems. This system is aiming at eliminating duplicate health services offered by different providers.

Based on our observations from an ad-hoc data-sharing attempt between a local hospital and a community service corporation in Ottawa, it's not unfair to say that healthcare organizations in Ontario are reluctant to disseminate their datasets with other qualified healthcare providers. Current data sharing solutions, at best are limited to an ad-hoc dataset shared temporarily through a secure Drop Box-like application. The ad-hoc datasets are generated by a specific query designed for a specific problem by a data analyst. The analysts within each organization have to match the shared dataset with their internal data structure and this can take weeks if not months. Our case study showed a high rate of record loss when it comes to finding a cohesive shared dataset that can describe a patient in one single record. The first dataset from the community care provider included 58000 records for readmission problems, which was then reduced to 27000 after multiple rounds of matching.

The Local Health Integration Network (LHIN) in Hamilton Niagara Haldimand Brant (HNHB) in Ontario has achieved a number of successful integration projects, one of which is an integrated decision support strategy that includes a data repository<sup>12</sup> that combines patient records from Community Care Access Centers (CCAC) and 28 hospitals in HNHB region. It also offers a web portal (ClinicalConnect) for healthcare providers in the region such as doctors, nurses, and pharmacist to access real time access to their patient's PHI<sup>17</sup>. However, this system is restricted to the HNHB region and is not integrated with the rest of the province.

Some European countries like Sweden have their own solution to this problem. A group of healthcare providers and hospitals in Stockholm have acquired one integrated electronic health record system -Takecare- across the entire city, which covers 22% of the 9.5 million inhabitants of Sweden<sup>4</sup>. The significant outcome of this system is one single record per patient that is shared between general practice, geriatrics, psychiatry, and hospital services.

Of the solutions presented above, all of them fall within healthcare systems that share PHI except Pietro's notification delivery system<sup>23</sup> where a new examination/test triggers a notification delivery (meta-data) to the different healthcare providers. As efficient as Pietro's solution is, it cannot accommodate all requirements of interoperability. The ad-hoc data sharing, and HNHB LHIN solution haven't been convincing enough as they still have low adoption/participation. Finally, the Scandinavian approach -Takecare system- require large investments as this system should be purchased by each participating healthcare provider (on top of their existing internal HIS), which would translate to expensive bills for the healthcare provider and the overall healthcare system.

#### ***C4 - Evaluation criteria for healthcare data systems***

Moutham, et al.<sup>19</sup> and Korst, et al.<sup>14</sup> point out the obstacles faced when implementing their proposed solutions from an IT developer point of view, while Leonard<sup>16</sup> mentions the top 15 reasons why health information systems fail from the standpoint of a health administration expert. Finally, Abernethy, Wheeler and Bull<sup>1</sup> list a set of success factors in implementing a health information system from clinicians' viewpoints. Moutham, et al.<sup>19</sup> lay out the various interoperability obstacles encountered when they completed the development of a patient tracking and data entering web-based and mobile application for a shared use among hospital residents, community care nurses and hospital administrative staff and managers. Their paper explains the difficulties of developing an interoperable application e.g. how different actors can have conflicting requirements. Korst et al. investigate and report on the difficulties faced when four hospitals decided to cooperate in order to create a cross-organizational regional perinatal shared data system. They identified four requirements for cross-organizational data sharing efforts: intra and inter organizational readiness and incentives; perceived mandate; cross-organizational governance structure; and competitive third party IT component who are familiar with the intricacies of healthcare industry<sup>14</sup>.

Kevin Leonard's interoperable HIS failure reasons include: Lack of a thorough cost benefit analysis due to the complexity of measuring benefits such as "ability of someone doing their job better"; lack of industry-wide homogeneous data; absence of a universally unique patient identifier mainly due to security and privacy reasons; the gap between application developers and healthcare professionals; misunderstanding that technology alone can solve all the problems; and development of various disintegrated repositories in different healthcare agencies as opposed to a centralized repository<sup>16</sup>. On the other hand, success factors explained by Abernethy<sup>1</sup> include: supervision by a "project champion"; involvement of stakeholders in development process; and considering future internal organizational needs such as reporting, affordability, provision of long term support, and long term co-operation of actors and sites involved.

Based on the studies in this section, we deduced the following evaluation criteria for an interoperable HIS: the extent of end user requirement satisfaction; report-ability of the system; Cost efficiency; flexibility to accommodate future clinical process changes; timeliness of the record updates; and possibility of future expansions in order to include more healthcare partners.

## Conclusions and Future Work

Based on the papers reviewed, laws and regulations allow for cross-organizational sharing of healthcare data. The existing tools are not cost-efficient, fully automated, or truly real time. There's still a need for a feasible interoperable health information system (HIS) across all healthcare providers from hospitals to private physician offices and pharmacies that does not require a large investment and is built up on their existing HIS. Future research should investigate the development of a methodology and tool support for cross-organizational healthcare data sharing to bridge the gaps identified in the current interoperability solutions. Part of this research will need to address socio-political and regulatory factors that can inhibit such solution. In particular, it will be necessary to define a healthcare region from a regulatory, political and technical point of view to enable data sharing between organizations within a health region. At the same time, this will leave open the research question of how to share healthcare data between regions that are separated from a regulatory, political or technical point of view.

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