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Murphy, S., Reilly, P. orcid.org/0000-0002-6890-778X and Murphy, T. (2021) Assessing the potential use of blockchain technology to improve the sharing of public health data in a western Canadian province. Health and Technology, 11 (3). pp. 547-556. ISSN 2190-7188

https://doi.org/10.1007/s12553-021-00539-5

Title: Assessing the potential use of blockchain technology to improve the sharing of public health data in a western Canadian province.

Purpose

This exploratory, qualitative study set out to identify the encountered and perceived barriers to Public Health (PH) data sharing in a Canadian province with a view to assessing blockchain technology as a potential solution.

Methods

A topic guide was developed, based on previous research in the area. This was then utilised for ten in-depth, semi-structured interviews with PH professionals between 27 May and 18 June 2019. Each stage of research was congruent with the philosophical underpinning of Gadamerian hermeneutic phenomenology.

Results

The major themes that emerged from the data collected were related to the information systems in use, data quality and ownership, as well as client identity management. The recurring core theme throughout all interviews was related to ineffective leadership and management, contributing to each major theme. Overwhelmingly the results show that the majority of barriers faced in this province are human-related.

Conclusion

It is concluded that while blockchain technology shows promise for enhancing data sharing in healthcare, it is still many years away from being implemented in this Canadian province. Future work should explore the perspectives of other stakeholders, such as the Ministry of Health to fully understand the potential for using blockchain to share PH data in this context.

1 Introduction

The increasing complexity of the healthcare ecosystem has inevitably led to a number of data privacy and security challenges for key stakeholders in countries like Canada. While the majority of medical records have been digitised, they are often stored in silos dispersed across medical facilities around the globe. This has implications for Public Health (PH) intelligence, which relies on the sharing of complete and accurate information between organisations. Blockchain technology is being touted as having the potential to address these issues of information sharing within the healthcare sector. This paper sets out to identify the encountered and perceived barriers to data sharing in PH within a western Canadian province through a qualitative analysis of ten semi-structured interviews with a range of healthcare professionals between 27 May and 18 June 2019. The aim of this study was to understand how blockchain technology can be used to share PH information provincially and subsequently nationally.

2 Current State of Data Sharing in Public Health

Health data sharing is essential at an individual level for patient care, and at a broader level for population health and outbreak management. It is a complex task to achieve, as all healthcare stakeholders including patients, clinicians, pharmacists, biomedical laboratories, national and international PH agencies depend on it. Data sharing is further complicated by the fact that valuable PH information may be generated from many different sources. These range from disease surveillance, family health, biostatistics and informatics, communicable disease prevention and immunisation programmes [1]. Pertinent data is also stored in the form of electronic medical records (EMRs) held by hospitals, public health units and general practitioners. This data is acquired, stored and accessed in a variety of formats, which makes it difficult to create and maintain an accurate comprehensive and accessible database of PH information. Nevertheless, the consensus amongst researchers is that PH agencies need timely access to such data in order to effectively plan and operate services to improve population health [2,3]. The response to the 2003 severe acute respiratory syndrome (SARS) epidemic displayed the power of real-time data sharing in supporting swift PH responses [4]. More recent health emergencies, such as the 2014 Ebola epidemic and the ongoing COVID-19 pandemic, further highlight the importance of rapid data sharing beyond geographic boundaries. The availability of accurate data is critical for epidemiological modelling, prioritisation of surveillance, as well as understanding infection risk factors and transmissibility of disease at all levels of public health management [5,6]. At the local level, PH data supports targeted interventions, at the national level the data informs federal planning and policy making, and globally the data provides essential metrics for managing international health crises [7]. The lack of interoperability between each level remains an issue for PH, as the systems are often disjointed providing inadequate communications, leading to costly workarounds. For example, a PH clinical and surveillance system implemented in Canada, at a cost of 115 million CAD, went 420 percent over budget and has an estimated annual cost of 14 million CAD [8]. Similar issues exist elsewhere, in relation to the number of systems created within the same jurisdiction. Due to years of single purpose, disease specific systems created at the US Centre for Disease Control and Prevention (CDC), there are reportedly now more than 110 surveillance systems in existence [9]. The call for greater data exchange capabilities between PH information systems provides an undeniable business need for a better solution [10,11]. PH data is also valuable for secondary uses, such as research and the development of technology. The advantages of improved data sharing and availability are well documented, and include the development of more effective PH programmes, reproducible and consistent research and cost efficiencies [12–14]. The barriers to the sharing of health data in general, are also well known. A recent systematic review identified twenty barriers, such as restrictive data format, protection of privacy, language barriers and lack of resources and guidelines [7]. This paper sets out to build on this review, which focused at the global level, by exploring the specific perceived barriers encountered within a more narrowly defined jurisdiction.

3 Blockchain Technology in Healthcare

A blockchain is a distributed ledger, or database, of transactions which are immutable [15]. There have been few studies exploring its potential application within the healthcare sector to date, particularly for PH data. According to the Gartner Hype Cycle, which interprets evolving technology hype, blockchain technology has moved from the ‘Peak of Inflated Expectations’ where there were some success stories but also many failures, to the ‘Trough of Disillusionment’. This phase typically sees a sharp decline in interest when there is a failure to deliver on the implementations to date, and where mass adoption is estimated to be 5-10 years away as of 2019 [16]. To date, much of the hype over blockchain has surrounded its application in the financial sector. The first blockchain supported a cryptocurrency named Bitcoin, which was introduced in 2008 by Satoshi Nakamoto [17]. A detailed explanation of its technical aspects is beyond the remit of this paper, but it worth noting that it was conceived as a decentralised digital cash system, independent of a central third-party validating transactions, that employed cryptography and a shared, distributed ledger [17]. This concept effectively removes intermediaries by creating a system where two strangers can transfer value to each other, without prior established trust, in a secure, indisputable way [15].

Research suggests that blockchain is an appropriate solution in those situations where there are several stakeholders, trust is lacking, and reliable and accountable tracking is required [18]. PH data certainly qualifies as an area requiring further research around blockchain technologies. Blockchain technology is a complementary solution that can be combined with existing processes to enhance them. In the context of healthcare, this technology has already been successfully deployed in several contexts. Recent systematic literature reviews by Engelhardt (2017), and Agbo, Mahmoud and Eklund (2019) regarding the use of this technology in healthcare found that enhancing data sharing, EMR management and access control are the at the forefront [19,20]. Estonia, for example, was the first country to implement blockchain technology at a national level, with 'Guardtime' being used to manage the EMRs for over 1 million citizens [19,21,22]. The healthcare records of each citizen are protected by blockchain technology, affording them the right to grant or refuse permission for their data to be accessed and used by third parties [23]. The CDC in America has also begun to explore how distributed ledgers can help PH practitioners respond more quickly to crises, inviting proposals for how blockchain could be integrated into healthcare in the US [24,25]. Yet, to date there has been very little research exploring the potential barriers to the implementation of blockchain within the healthcare sector.

This paper sets out to address this gap by exploring how PH data might be shared using these technologies within BC. In Canada, there are thirteen individual health care insurance plans, with each province and territory being responsible for the management and delivery of healthcare services to their residents [26]. Within BC, there are a number of health authorities (HAs) both provincial and regional, each with a further level of autonomy regarding the management and delivery of health care including PH. Due to the limited amount of information available specific to this Canadian province, and the exploratory nature of the research, a qualitative research design has been chosen. This research was guided by the philosophical hermeneutics of Gadamer, which seeks to expand understanding through dialogue between people, and between researchers and text [27]. Through qualitative semi-structured interviews, the perspectives of PH professionals were obtained with the goal of identifying barriers to sharing PH data in the province. A phenomenological design was adopted as it allows the researcher to explore the essence of a particular phenomenon through the narratives of individuals with relevant experience and knowledge regarding the phenomenon [28,29]. The interviews drew on the experiences and knowledge of the participants, based on their involvement in the industry. For this reason, hermeneutical phenomenology, which focusses on the subjective experience of the individual, was the chosen research methodology [30]. The research was undertaken with an inductive approach and an interpretive understanding of the findings. The questions within the study elicited the participants' individual perspectives and beliefs regarding barriers to data sharing within the PH system, and the impact of this. This flexible, qualitative research design aims to provide an answer to the following research question:

What are the barriers to data sharing and can blockchain technology enhance data exchange in the context of PH in a Canadian province?

4 Sample

A purposive, non-probability sampling strategy was employed in order to identify PH professionals with relevant roles in both the sector and jurisdiction under analysis. The ten participants had between five and thirty years of experience in the sector, eight of whom were employed by the Public Health Organisation (PHO), one by a HA and one by a neighbouring territory. It was considered important to include both the perspectives of the provincial organisation and their typical partners in PH data sharing. A number of the interviewees could also speak about PH with reference to their experience holding multiple roles, such as Participant A, who had worked as a PH informatics manager and a registered nurse (see Table 1.0).

Participant	Role(s)
A	Public Health Informatics Manager; Registered Nurse
B	Public Health Informatics Lead; Registered Nurse
C	Public Health Privacy Officer
D	Communicable Disease Analyst
E	Director of Health Informatics Projects
F	Project Manager of Health Informatics Projects
G	Public Health Informatics Specialist; Registered Nurse
H	Public Health Informatics Director; Registered Nurse
I	Territorial Public Health Informatics Manager; Registered Nurse
J	Public Health Medical Director; Medical Doctor

Table 1.0 Participants' roles

In-depth, semi-structured interviews were the chosen method of data collection. Data were collected between 27 May and 18 June 2019. Interviews were conducted face-to-face with eight of the participants in the boardroom of the PHO. One interview had to be suspended halfway through due to a PH emergency, but was completed a few days later. The remaining two interviews were conducted via teleconference, due to participant location. Open-ended questions were used to allow for individual interpretation and for participants to direct the conversation based on their own experiences. A topic guide was followed to ensure a level of consistency and structure across interviews, while also affording a level of flexibility for the discussion to naturally evolve. To ensure the scope of the interviews was satisfactory, the topics discussed were informed by previous research in the area; the interview schedule was also piloted in May 2019 in order to ensure the questions were easily understood. The information gathered in each interview added to the researcher's horizon and was brought into the subsequent interview, deepening the circle of understanding with each interaction. Gadamer believed that every individual has a unique perspective, or view of the horizon, based on their own life experiences and knowledge [31]. In line with previous work [32], no further participants were sought once data saturation was reached.

5 Gadamerian Hermeneutic Phenomenology and the Role of the Researcher in Data Collection

For a Gadamerian hermeneutic phenomenological study, it is critical to acknowledge but not bracket the assumptions, biases and prejudices of the researcher relating to the phenomenon under investigation [31]. Rather than eradicate, or bracket researcher prejudice, the aim was to discuss the perceived and encountered barriers to data sharing in PH; thus, creating a 'fusion of horizons' about this phenomenon throughout the interview process. Data was collected by the lead researcher, a public healthcare professional with insider status due to their employment within the same organisation as the majority of participants. This increased the level of trust and confidence shared in the researcher/participant relationship, allowing for rapport to be easily built. This also meant that the language and jargon used by participants were immediately understood, allowing for efficient data collection and the ability to clarify any points after the fact as required [33].

6 Ethics

Ethical approval was granted by the host institution prior to data collection beginning, in October 2018. The lead researcher also sought permission from the primary research site before key stakeholders were approached to participate in the study. Each interviewee was provided with an information sheet outlining the objectives of the study and their right to withdraw at any point. In order to respect their anonymity and confidentiality, their respective organisations are not identified. All interviews were recorded and transcribed prior to analysis.

7 Data Analysis

Gadamer's hermeneutics dictated the approach to data analysis. A qualitative thematic approach was used to analyse the data [34]. Once the interviews and transcription were completed, the next step was to listen to the audio recording for each interview repeatedly. This allowed the researcher to become extremely familiar with the participants' experiences and perspectives prior to the data analysis. Transcripts were then printed and subjected to a manual, iterative coding process, which involved noting common phrases and words used by the interviewees and devising codes in a systematic way [32]. Once initial themes were identified, the transcripts were reviewed once more, with further common words and phrases identified and added to the documented barriers. Through this interaction with, and interrogation of the text, data analysis continued. This method aligned with Gadamer's hermeneutic circle, where the researcher moves from the whole to the parts, and back to the whole again [31,35].

8 Limitations

As is typical for a qualitative research project, the results were derived from the researcher's analysis, which was by definition interpretive. However, this was congruent with the Gadamerian hermeneutic phenomenology research design which does not bracket one's assumptions and pre-judgements from the data analysis.

9 Results

10.1 Barriers to Data Sharing within the Provincial PH System

All of the participants reported that data were collected for PH functions such as disease surveillance, clinical documentation, programme evaluation and planning, as well as identifying outbreaks. Nevertheless, there was a multitude of barriers and challenges described by each participant, informed by both their role and direct experience working in the PH sector. Having analysed the data generated during the interviews, the following themes and subthemes emerged (see Table 2.0).

Major Theme	Subtheme (n)
Legislative	Information Systems in Use (10)
	Mandate on Information Sharing (8)
	Interpretation of Privacy Legislation (6)
	Privacy Breaches (4)
Technical	Data Integrity (6)
Cultural	Data Territorialism (7)
Social	Client identity management (4)
Political	Policies that limit access to government datasets (6)

Table 2.0 Perceived barriers to public health data sharing

10.2 Information Systems in use

The majority of the HAs in the province document and store PH data in their own, siloed information systems with limited, or no integration with the Public Health System (PHS). All of the interviewees argued that the PHS had thus far failed to provide a cohesive provincial system due to factors such as inadequate system design, lack of stakeholder engagement early in the project and poor direction and leadership which resulted in multiple PH information systems across provincial jurisdictions. The Public Health Informatics Lead reflected on this barrier, *"where I think it started to go off the rails is the [PHS] itself was initially conceived by the surveillance team"* (Participant B). Surveillance personnel typically access the data from the database directly, and were said to be less concerned with the front-end design, which meant that it didn't meet the medical legal requirements for clinical documentation: "*they hit the nail on the head from a surveillance perspective, but missed the boat on it being a really effective and slick front-end clinical system, both in terms of ease of use, but also it doesn't meet all the medical legal requirements for clinical documentation. For example, you can delete information out of the system and when you're documenting medical legal information, that's the equivalent of tearing a page out of a paper file"* (Participant B). All participants described the disjointed PH system in the province as a major barrier to data sharing. The Public Health Informatics Manager detailed how the delivery of PH programmes had previously been provincially controlled until the Ministry of Health (MoH) had transferred this management function to the numerous HAs, who did not have concurrent access to, or use of the same PH information system. The Public Health Medical Director also articulated this frustration: "*it's a detriment for the public health programme and it does allow [the HAs] to not share specific variables with us. Even if those variables might be in their information system, they simply haven't come over [to the PHS] and it's been very difficult to understand, are those variables even collected? If they're collected, are they entered?"* (Participant J).

It was suggested that this was one of the main reasons that the majority of HAs refuse to use the PHS directly. Compounding this issue, Participant B confirmed that the largest HA, responsible for 40 percent of the province's population, had exercised their right to move away from using the PHS in June 2019 and deployed another separate PH information system. This point was echoed by the Public Health Medical Director (Participant J) who noted that *"historically, there hasn't been a mandate or a requirement for all health authorities to use the same information system"*. This theme emerged from all the interviews and was widely viewed as a root cause of many of the problems related to sharing PH data in the province. The Public Health Informatics Manager stated that "*the majority of the work done in public health is provincially driven and there's provincial outcomes that need to be given to the minister of health; I think one of the big things is bring it back under the same provincial umbrella"* (Participant A). Two of the participants, both registered nurses, reflected on the huge variation across the HAs but nevertheless felt that there was no rationale for using a variety of information systems across the province: *"you don't have to implement programmes the same way because each community is different. And I get that but to have people on the same system would help"* (Participant H). The Communicable Disease Analyst, who worked with all the HAs in their role at the PHO, expressed their frustration at the lack of cohesion between the authorities: "*it's always going to be difficult when we have battling health authorities that each want to go their own way and aren't putting in the full effort to get the data into the required system"* (Participant D).

10.3 Mandate on Information Sharing

Eight of the interviewees believed that the MoH should provide greater clarity in terms of the scope of PH information sharing. The Public Health Informatics Manager emphasised the need for the Ministry to enforce standards: *"I think there needs to be the enforcement on what information needs to go in and how. I think that's where in [this province] in particular we're really lacking. If a health authority chooses not to follow that, sure we can escalate to the Ministry of Health, but sometimes it falls on deaf ears"* (Participant A). Participants perceived that some of the HAs resisted sharing data with the province and wanted to retain it within their silos. For example, the Public Health Informatics Lead felt that patient interests should be paramount: *"the news flash is, everybody's paid by the Ministry of Health. So, buck up, shut up and do what's in the best interest of the patient"* (Participant B). One participant who had previously worked in other Canadian provinces, and was familiar with the PH system in the United States, argued that they had never experienced anything like this 'tribal carve-up': "*it's never been the position in [other provinces] public health. You know, it was a much more collaborative public health process. I think there's more of a sense that we're all in the same mission. I don't mind going on record but that's not the perspective in this province. It's very tribal. And that's too bad because it makes it harder to do work, there's enough work for everyone without having to deal with these kinds of extra issues"* (Participant J). All were enthusiastic about two mandates recently introduced by the provincial government to ensure the PHS was updated regularly with relevant data pertaining to immunisation records and reportable communicable diseases (RCD) for the provincial population. Some of the more experienced interviewees had a 'wait and see' attitude to these new mandates: "*Each health authority has signed letters of understanding for these mandates. Now at least there is a formal mechanism to leverage that should someone be so bold as to have the kahunas to do it. So, when there is resistance, I'm hoping that they won't, just bend in the breeze under the pressure because there will be pressure"* (Participant B).

10.4 Interpretation of Privacy Legislation

Most participants identified varying interpretations of privacy legislation across the HAs as a major barrier to PH data sharing in the province. While legislation regarding PH data was considered amongst the most robust in Canada, the Public Health Privacy Officer conceded that *"some areas will interpret more conservatively than other areas with respect to their obligations"* (Participant C). The Director of Health Informatics Projects provided further insight into this issue based on the implementation of a portal which enabled the public to view their laboratory results. Efforts to extend this portal to other HAs were initially hampered by the interpretations of 'conservative people' and this interviewee was frustrated by the delay and the waste of taxpayer money: *"if I go back to how much did the taxpayers pay to actually have one health authority basically accept the findings and realism, from the experience of another health authority - way too much time."* (Participant E). This participant felt strongly that HAs should be working in unison and should trust the due diligence done by each other when implementing these systems, Similarly, the Public Health Informatics Director criticised the "*very complex roles and permission sets that were required at the beginning of this journey of the public health system"* (Participant H). They felt strongly that the professional judgement of PH staff should be given greater weight, rather than implementing solutions which actually turned out to be barriers to PH data sharing.

10.5 Privacy Breaches

Prior privacy breaches were cited by four of the participants as the reason why there was limited data sharing between HAs. The Territorial PH Informatics Manager argued that lawsuits, particularly relating to the release of patient data without their consent, meant that staff were often cautious about developments such as PHS: *"It's people's experience. I tend to be a little bit more on the secure side only because I've lived in [two provinces] when they both had the lawsuits*" (Participant I). The Public Health Informatics Manager spoke of the difficulties in managing inappropriate access to clinical data within these systems, often not knowing whether there was a legitimate reason for client records being examined by health professionals. The Public Health Informatics Lead provided examples of serious data breaches they witnessed while working as a frontline nurse, such as *"an entire therapeutic abortion list coming across our fax machine in a unit where that should not have come"* (Participant B). Hence, there were policies and training in place for PH staff to assist with proper data management. However, this was said to be only effective for users of the PHS and for data in electronic format. Some data is collected on paper forms which allow a variety of responses which are inconsistent. Moreover, not all participants believed these breaches were a new phenomenon linked to the development of sophisticated information systems; the Public Health Informatics Manager asserted that *"there was breaches probably way more often with paper. It just doesn't have quite the same impact"* (Participant A).

10.6 Data Integrity

Participants described the difficulty in accurately mapping data from numerous systems into one provincial system. The data is entered into the PHS manually by PH staff or by bulk uploads, data feeds or interfaces from other PH information systems. For those that did not use PHS as their clinical documentation system, the required data was often sent via fax machine to the province or not submitted at all. The Communicable Disease Analyst acknowledged the gaps in PH data as a result of these variations: *"if we're looking at our surveillance data for the past year, we're finding gaps in how it's been entered"* (Participant D). The quality of the PH data was a great concern for the majority of the interviewees. A variety of methods was employed to ensure data quality within the PHS. Proactive approaches included the configuration of the information system to include mandatory fields for information gathering. However, this can only be applied to the HAs that directly used the PHS system and there was no mechanism to reject data submitted in paper format or via fax, which meant extra work for both the province and the HAs. Other methods included technical and business conformance standards such as specific messaging format: *"the latest and the greatest on the market right now for health is FHIR, it's Fast Healthcare Interoperability Resources*" (Participant F). Due to the fact PHS had recently been mandated by the MoH as both the provincial immunisation and RCD repository, participants reported there was now the ability to enforce requirements on those data senders. The HAs sending required information to the province had to build their data feeds to these specifications, with specific code set values. According to the Project Manager of Health Informatics Projects: "*the code set values that we've tried to use are the ones that we've discussed nationally, to make sure that if we ever want to be interoperable with other provinces, let's all talk the same language and the same code sets"* (Participant F). The Public Health Informatics Director confirmed that the intention was to put the onus on HAs to maintain data quality and completeness, with data not meeting these standards rejected: *"our fundamental principle is that data is fixed at source. If there's an issue on translation through our adapters and things like that, we have already started hiring a team that will fix the data" (*Participant H). Reactive methods included regular audits to identify issues with the existing data in PHS. In those cases, individual users or teams managing data feeds were often contacted to correct the data. The Director of Health Informatics Projects emphasised the importance of ensuring data integrity from these feeds; *"At the end of the day you have to have good data. Crappy data leads to crappy decision making. So, having those proactive processes to go and actually make sure that data is as accurate as possible is absolutely critical."* (Participant E). Cross-referencing the data in PHS with other sources was already said to have ensured more accurate PH data: *"for example, if for meningococcal disease, what's been reported into [PHS] is different than what the laboratory has as a serogroup. Then we would follow up with the Public Health Unit and say, look, this was 'w' in the lab system, you've got it recorded as a 'y'."* (Participant J). Obvious discrepancies were easily identified in some cases, such as "*an immunisation that was supposed to be administered by intramuscular injection but had been recorded as being given orally"* (Participant I).

10.7 Data Territorialism

Those HAs that did not directly use PHS were said to be 'territorial' about the data in their individual systems. The majority of participants raised this as a major barrier to data sharing in the province. Most notably, the Public Health Informatics Manager asserted: *"maybe it's they don't want to share because they don't want us to see what kind of work they are doing in their health authority, or they don't feel that it's secure. If there's that level of ownership, then they don't want to share"* (Participant A). The Project Manager of Health Informatics Projects provided some insight into this based on their experience creating the provincial immunisation repository. Each HA had a degree of autonomy in how they delivered their PH programmes, and one HA had a different schedule for childhood immunisations to the others, which meant that some of its records appeared invalid in the PHS and valid in the HA's system. The Public Health Privacy Officer had also experienced this sense of data ownership amongst the HAs: *"you do see is a fair amount of data territorialism. We have (a number of) different health authorities with a fair amount of autonomy. That says, I own this section of data, I own that section of data."* (Participant C). The "

Privacy Officer provided further insight into the 'lack of control' felt by some of those HAs sharing data: *"once you share data out that's your weakest link. You no longer, in a lot of ways, have control over that data. So, people naturally have concern around that"* (Participant C). Overall, most participants felt that 'data territorialism' made no sense given that the MoH was ultimately funding the activities of all health authorities.

10.8 Client Identity Management

During the in-depth interviews the topic of client identity management was raised by four of the participants, all of whom have worked as frontline PH nurses in the past. This barrier was reported as an evolution of some of the care that was provided in the 1980s. Patients were presenting with an unknown illness that did not yet have a name, now known as HIV and AIDS *"We just knew that people were getting really ill and we knew that it was in a segment of our population that were primarily gay men and that there was a lot of stigma associated with that"* (Participant B). As a result of the associated social stigma, patients used pseudonyms which propelled this PH intensity to being anonymous *"...trying to hide your identity because there were such significant consequences if you were inadvertently identified as someone that had essentially a fatal disease at that time. You couldn't get insurance and you could lose your job. And, you know, there were all sorts of ramifications and we've come a long way, but it's a bit of a cling on."* (Participant B). This led to a lot of anxiety about having this sensitive information in clinical systems. Patients began to avoid providing their real identifiers. This was accepted by the PH care system as testing and treatment were prioritised; *"At the time there was no process in place within public health to provide any kind of anonymity or cloaked identity. So, people made it up. They just kind of did their own thing, we were working in isolated databases at the time, so everybody kind of knew the rules by which they were playing within their own sandbox. But now that we're amalgamating this data and it's all coming into the same repository that creates incredible challenges*." (Participant B). It was reported that PH has evolved with lax client identity rules as result of this and not because they were ever formalized anywhere. This creates complex challenges today, as described by the Public Health Informatics Lead for Provincial eHealth *"what record does this go on and how do you ensure that the person comes back and has continuity within their record when you're not validating that they are who they are. This issue leads to fragmented health records in some cases and in others can lead to incorrect information being recorded on the wrong clinical record"* (Participant B). The Public Health Informatics Manager felt that *"there's just this like cultural issue beyond public health where there is this fear of people finding out my business*" (Participant A). When working as a PH nurse in a youth clinic, this participant also experienced concerns from the youths, an example was given as "*they didn't want to provide their care card number because they didn't want their parents to find out that they were using the services. Likewise, they don't want it in a provincial computer system. Because what happens if my friend's mom is a public health nurse, she's going to go look up my information and she's going to go tell my mom"* (Participant A). The impact of these client identity issues is still present today. The Director of Health Informatics Projects said "*the basic fundamentals of who is the patient, we have a hard time actually reconciling that. So, we built, unfortunately with taxpayers' money, a reconciliation process"* (Participant E). This has proved a very costly and time-consuming issue, the repercussions of which are still emerging today.

10.9 Policies that Limit Access to Required Datasets

Another major barrier described by participants was the lack of access to and integration with other MoH/government data sets. PH relates to population health, and in order to have a clear picture of the health of the population and accurately plan programmes, participants felt that access to denominators was critical. Lack of active integration with the master patient index (MPI) was cited as a challenge for data sharing by six of the participants. The MPI is a MoH patient database and every patient that receives any healthcare services in the province has a record in this system. The data consists of demographic information, including a unique identifier and is the source of truth for this information provincially. Participants felt that active integration with this database would alleviate some of the client identity issues described above. The Director of Health Informatics Projects felt that this issue could have been avoided with effective leadership many years ago *"again, the executive leadership perspective, 15 years ago someone in that role should have said hello province of BC, you want to play in our market. You will be connected to MPI in a matter of two years. And if not, we want to see the decommissioning plan for your system"* (Participant E). If integration with MPI had been enforced, the foundation behind interoperability would be taken care of because issues of mismatching data would be minimised and access to the unique identifiers would be readily available for verification.

10.10 Mixed views on future of blockchain in PH sector

Four participants had never heard of 'blockchain', and therefore were unsure how it could be used to enhance data management and sharing in healthcare. *"I am not familiar with blockchain, I've never heard of that term"* (Participant G). However, the majority were familiar with the concept and felt that the technology might be useful in the areas of data privacy, security and auditing. The Public Health Privacy Officer expressed enthusiasm for blockchain but acknowledged that they did not fully understand it: *"There is talk about it in the sense of being a privacy positive way of, of sharing information. I would say fundamentally, uh, despite having gone to a number of sessions that have tried to explain it and its involvement within different areas that involves sensitive information, banking, healthcare etc. I still do not really understand it"* (Participant C).

The Director of Health Informatics Projects shared the same feeling *"I'm familiar with the high level 50,000-foot concept behind it. Um, I have no understanding of how it could be applicable"* (Participant E). Two participants were more concerned with the current state of information management and felt that efforts should be focussed on addressing these issues before looking at blockchain and other technological solutions *"...in Canada we're still behind about actually getting to the point of being able to share data. The method of sharing data. That's another question."* (Participant C). The Director of Provincial Projects concurred *"...it kind of scares me just in the sense of we've got this thing called the fax machine that we have to get rid of. So, you know, I'm torn between the let's go, let's go take us out of the 70s to even the two thousand's, um, and while it's a fantastic opportunity, I'm told, but, you know, where does it fit in?"* (Participant E).

10 Discussion

The results of this study were broadly in alignment with the technical, economic and legal barriers identified in previous research into data-sharing within the healthcare sector [7]. However, this paper also identified cultural barriers that might impede the integration of blockchain into PH within this Canadian province. While there were some technological issues identified by the participants, the vast majority of these barriers could be linked back to ineffective leadership and direction. Technological solutions might theoretically address issues such as poor data quality, but they can do little to 'fix' the mandates on the use of information systems and data sharing within the province, or varying interpretations of the legislation and obligations relating to HAs. This paper provided some evidence that the province was in alignment with Gartner Hype Cycle, which stated blockchain technology was five to ten years away from mass adoption. The study suggested that these technologies were not well understood by PH informatics professionals. However, in order for blockchain to be successfully implemented in healthcare, it may not be necessary for each stakeholder to be au fait with the technical underpinnings of the solution; rather, the case for integrating blockchain will be made through empirical evidence of its benefits within the sector. Future research should build on this study by examining the views of other stakeholders in the province such as the HAs, the provincial HAs and the MoH, and evaluating pilot projects that have introduced blockchain into PH in Canada and overseas.

While blockchain technology may be considered an 'immature' technology in healthcare, it already appears to be having an impact in other sectors in Canada. The Canadian government, specifically Canada Border Services Agency, is piloting a blockchain solution named 'TradeLens' for digital supply chain management for all shipments entering the country [36]. The National Research Council of Canada recently completed an experiment, a proof of concept use case of blockchain technology to publicly display contributions and grants in real time to support proactive disclosures to the public [37]. A 2018 study investigated the use of blockchain technology to link the existing EMR across various health organisations via a unique identifier [38]. This province has a unique health identifier for each citizen, and all this information is held within a Master Patient Index database. To expedite the implementation of blockchain technology this could be harnessed by the province in the future as a way to connect the dispersed health data of the citizens across the various systems currently in use. This could potentially minimise the disruption to the users of the disparate systems, while allowing for secure data sharing across geographical boundaries, initially provincially and subsequently nationally and beyond.

11 Conclusion

The results of this study show there are a number of barriers towards the use of blockchain in the health arena. These include technical issues, but overwhelmingly were of a human nature relating to interpretation of legislation, and a lack of effective management. In terms of the applicability of blockchain technology to counteract these barriers, efforts could be focussed on ensuring the existing systems are connected in a safe and secure manner. This allows for the existing systems to be built upon and integrated without the need to start from the beginning again. This research concludes that while blockchain technology shows promise for enhancing data sharing in healthcare, it is still many years away from being implemented in this Canadian province. Future work should explore the perspectives of other stakeholders, such as the Ministry of Health to fully understand the feasibility of using blockchain to share PH data in this context. Future research at a national level would also be beneficial to investigate whether similar barriers exist in other provinces and territories, with the goal of a pan-Canadian public health system, particular important in the context of disease management. However, immediate efforts should focus on the human barriers identified by the participants in this study.

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