

2020-09-22

# Color Coded Health Data: Factors related to willingness to share health information in South Asians

Naeem, Iffat

---

Naeem, I. (2020). Color Coded Health Data: Factors related to willingness to share health information in South Asians (Master's thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>.

<http://hdl.handle.net/1880/114473>

*Downloaded from PRISM Repository, University of Calgary*

UNIVERSITY OF CALGARY

Color Coded Health Data: Factors related to willingness to share health information in South  
Asians

by

Iffat Naeem

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES  
IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE  
DEGREE OF MASTER OF SCIENCE

GRADUATE PROGRAM IN COMMUNITY HEALTH SCIENCES

CALGARY, ALBERTA

SEPTEMBER, 2020

© Iffat Naeem 2020

## **I Abstract**

**Background:** Canada is becoming an increasing multicultural society welcoming individuals of various ethnicities. Ethnicity has become an established modifier of health in Canada, where ethnocultural communities face health disparities for multiple health outcomes. To understand these health disparities further, a call for high quality health data for ethnocultural communities has been made. Since health information availability is controlled by the participant, it is important to understand the willingness to share health information by an ethnic population to increase data availability within ethnocultural communities.

**Objectives:** The objectives of this study aimed to explore and synthesize factors associated with willingness to share health information via a rapid review of literature and qualitative interviews with (South Asian) SA participants, the largest ethnic group in Canada.

**Findings:** Triangulating results from both the rapid review of literature and the qualitative interviews, revealed that factors associated with sharing health information operated at 3 different levels: 1) community level, 2) individual level, and 3) process level. These factors also operated through a lens that considered the cultural and sociodemographic aspect of ethnocultural communities.

**Conclusions:** The results of this study reveal important factors associated with sharing health information for ethnocultural communities, and support the need for culturally sensitive and respectful engagement with the community, ethically sound research practices that make participants feel comfortable to share their information, and an easy and incentivised process to share their information feasibly. Future study should aim to understand and measure data-sharing partnerships between researchers and ethnocultural communities to maximize data availability for ethnic populations.

## **II Preface**

The following thesis is an original work by I. Naeem. It follows a social justice lens to increase research in ethnic, immigrant, and refugee populations of Canada. This work was envisioned as part of a larger research agenda to inform data collection and research engagement within ethnic communities of Canada. More work is needed to understand health within these disadvantaged communities that face differences in the life they experience in Canada, a country that promises equal opportunity and care. This thesis hopes to be added to this important field of inquiry.

The author declares no conflicts of interest. This study has been approved by the University of Calgary Conjoint Health Research Ethics Board (CHREB - REB19-0184).

Chapter 2, discussing the rapid review of literature, has been submitted for publication and is under review.

**Naeem I., Quan H., Singh S., Chowdhury N., Chowdury Z., Saini V., Chowdury T.T.**  
(2020). Factors associated with willingness to share health information: A rapid review.

### **III Acknowledgements**

This thesis is an important personal accomplishment not only for me, but also my family who went through the immigrant experience in Canada. My parents gave up their comfortable life and precious culture to provide me and my siblings with the best life and education in Canada, for which I feel forever indebted to. Finishing this thesis and working towards an MSc. is the perfect culmination to a long, often arduous, journey. I dedicate this work to my family for sticking together and finding happiness in the little things in life. I also dedicate this to my husband, who apparently has a hidden stash of never-ending support, love, and care. How did I get so lucky?

This work would not be possible for the extreme patience displayed by my supervisor Dr. Turin Tanvir Chowdhury, who's kindness, guidance, and high standards have transformed me as a professional. Thank you for believing in me sir. I also have the pleasure to thank Dr. Hude Quan and Dr. Vineet Saini for their commitment and support, which was so appreciated.

The journey to this thesis would not be complete without special support from friends and colleagues who find themselves in the same boat, including Benedicta Antepim, who has been the most sincere of friends. Thank to all who have had a part to play in my work.

## IV Table of Contents

<b>I Abstract</b> .....	2
<b>II Preface</b> .....	3
<b>III Acknowledgements</b> .....	4
<b>IV Table of Contents</b> .....	5
<b>V List of tables</b> .....	7
<b>VI List of figures</b> .....	8
<b>VII Abbreviations</b> .....	9
Chapter 1: Introduction .....	10
1.1 Ethnic diversity and health disparity in Canada.....	10
1.2 The importance of data from ethnic populations .....	12
1.3 Conceptual framework: willingness to share health information.....	15
1.4 Study aims.....	17
1.5 Study Objectives .....	18
Chapter 2: Rapid Review of Literature .....	20
2.1 Methods.....	20
2.1.1 <i>Literature search strategy and screening</i> .....	20
2.1.2 <i>Data extraction and analysis</i> .....	23
2.2 Findings.....	23
2.2.1 <i>Sociodemographic factors</i> .....	28
2.2.2 <i>Incentives to share health information</i> .....	29
2.2.3 <i>Previous experience with IT</i> .....	29
2.2.4 <i>Type and amount of health information</i> .....	30
2.2.5 <i>Data privacy and security</i> .....	31
2.2.6 <i>Stakeholder requesting health information</i> .....	32
2.2.7 <i>Outcomes of health information</i> .....	33
2.3 Conclusions.....	34
Chapter 3: Qualitative Interviews .....	35
3.1 Methods.....	35
3.1.1 <i>Epistemology and study methodology</i> .....	35
3.1.2 <i>Context and study participants</i> .....	36
3.1.3 <i>Data collection</i> .....	38

3.1.4	<i>Data analysis</i> .....	41
3.1.5	<i>Reflexivity</i> .....	42
3.2	Ensuring rigour .....	43
3.2.1	<i>Credibility</i> .....	43
3.2.2	<i>Confirmability</i> .....	44
3.2.3	<i>Dependability</i> .....	44
3.2.4	<i>Transferability</i> .....	44
3.3	Ethical considerations .....	45
3.4	Findings.....	47
3.4.1	<i>Study demographics</i> .....	47
3.4.2	<i>Factors associated with willingness to share health information</i> .....	49
3.4.3	<i>Community factors and solutions to sharing health information</i> .....	60
3.5	Triangulation results .....	70
3.5.1	<i>Triangulation methods</i> .....	70
3.5.2	<i>Triangulation results</i> .....	71
Chapter 4:	Discussion .....	74
4.1	Summary of results .....	74
4.2	Community level trust.....	76
4.3	Individual level trust .....	77
4.4	Process level trust .....	80
4.5	Implications for health research engagement in ethnocultural communities.....	80
4.6	Limitations, strengths, and next steps .....	83
4.7	Conclusion .....	83
References	.....	85
Appendix A	.....	97
Appendix B	.....	100
Appendix C	.....	107
Appendix D	.....	109

## **V List of tables**

<b>Table 1</b> Inclusion and exclusion criteria for rapid review of literature .....	22
<b>Table 2</b> Qualitative interview protocol themes and guiding questions. ....	40
<b>Table 3</b> Qualitative interviews study demographics .....	48
<b>Table 4.</b> Thematic coding results of participants interviews and creation of overarching themes.....	50
<b>Table 5.</b> Thematic coding results of participants interviews and creation of overarching themes is response to question about community views on sharing health information. ....	61



## **VI List of figures**

<b>Figure 1</b> Schematic of willingness to share health information preceding health information contribution .....	16
<b>Figure 2</b> Rapid review of literature flow diagram.....	24
<b>Figure 3</b> Factors related to willingness to share health information inductively coded within included papers and collated into major themes. ....	26
<b>Figure 4</b> Number of studies reporting each major theme. ....	27
<b>Figure 5</b> Visualization of the triangulated factors associated with willingness to share health information from rapid review of literature and qualitative interviews .....	72
<b>Figure 6</b> Factors associated with sharing health information and their influence on trust at multiple levels .....	76

## VII Abbreviations

CCHS	Canadian community health survey
NPHS	National population health survey
IMDB	Longitudinal immigration database
LSIC	Longitudinal survey of immigrants to Canada
SLCDC-MA	Chronic disease in Canada – mood and anxiety disorders component
CPSN	Canadian perinatal surveillance network
EHR	Electronic health records
EMR	Electronic medical records
PHR	Personal health records
IRCC	Immigrant, refugee, and citizenship Canada
SA	South Asian

## Chapter 1: Introduction

The following chapter will aim to introduce the ethnic diversity that Canada boasts within its society, along with a definition of ethnicity within the Canadian context. Next, the chapter will discuss how ethnic subgroups within Canada experience disparities when it comes to health, which may be associated with the process of migration, material deprivation, and discrimination within the healthcare system. The chapter will go on to discuss evidence for the health disparities in ethnic subgroups associated with mortality, prevalence of disease, and healthcare as reported by research studies. Next, gaps within the literature of health outcomes within ethnic subgroups will be discussed, and how they may be due to the lack of availability and/or quality of data. The chapter will go on to discuss the importance of data in healthcare and how it informs public health policy and interventions, along with highlighting the key gaps in available data for ethnic populations. Finally, the chapter will introduce the rationale and aims of this study, which highlights the importance of understanding willingness to share health data amongst ethnic groups in Canada in order to increase data availability for ethnic populations. The chapter will end with the listing of the study objectives.

### 1.1 Ethnic diversity and health disparity in Canada

Canada is becoming an increasingly multicultural society, welcoming 321,055 permanent residents in 2018, adding to the ethnic diversity of the country. The 2016 census estimated that over 20% of Canadians were foreign born, with 17.7% being second generation immigrant population (1). The main categories to enter Canada, as outlined by the Immigration, Refugee and Citizenship Canada (IRCC), includes economic immigrants, family class, and refugees. The most prevalent ethnic groups include European, Indigenous, South Asian (SA) (individuals from Pakistan, India, Bangladesh, and Sri Lanka), Chinese, Filipino, west central Asian (individuals

from Afghanistan, Iran, Iraq, and the United Arab Emirates), African, and Caribbean (2). The terms race and ethnicity are often used interchangeably, and are contentious, complex, and always changing within health research. Although race is strictly a social construct, ethnicity includes overlapping social and cultural features such as ancestry, customs, food, and language (3). Statistics Canada defines ethnicity as the '*ethnic or cultural group(s) to which the respondent's ancestors belongs*' with similar definitions being used by national representative Canadian surveys including the Canadian Community Health Survey (CCHS) and the National Population Health Survey (NPHS) (4).

Despite the complexities in its definition, ethnicity is an established modifier of health, where scholarship from the last 20 years from primary studies, epidemiological studies using large population level health information, survey studies, and qualitative data have highlighted ethnicity-related inequalities in health (3). Health inequalities can result from systematic and avoidable differences in health between groups of people that differ in wealth, power, or prestige. These differences in health add burden to already disadvantaged groups due to their underlying social positions, which is influenced by a person's ethnicity (5). Researchers have identified numerous pathways to health inequities related to ethnicity, including: the psychological stress of living in a racist environment; unequal economic opportunities; inequitable access to education and other social resources; lack of adequate housing; exposure to environmental toxins; engagement in risky health behaviours; victimization through social trauma such as spousal and sexual abuse, and other forms of violence; mistrust of the health-care system; and under-utilization of screening programs (6, 7). Many of these pathways are directly related to socioeconomic variables (income, education), however, non-material factors such as racism and discrimination are also important in determining health inequalities (8, 9). To

understand these explanatory pathways of ethnic health disparities, researchers have taken advantage of the available data in Canada to further understand disparities for multiple health outcomes, including self-rated health, healthcare use and barriers, maternal and child health, health risk factors, prevalence and incidence of disease, and mortality (10-15).

Availability of usable data ultimately results in an enhanced healthcare system that is more integrated and coordinated in tackling public health issues. This can be achieved using precision public health largely that relies on ‘big data’, which involves robust collection of multiple types of information about ethnic communities (e.g. administrative health data, primary surveillance, genomic data, wearable technology), and storage of that information for integration, manipulation, and analysis (16). Better healthcare systems can also be informed by qualitative data, which is important to not only understand the lived experiences of ethnocultural communities, but also developing theory associated with health and wellness within ethnocultural communities (17). It has become clear that meaningful comparisons amongst ethnic and racial groups can not be made if there is a lack of available data, or if the data is available, but is low quality. Low quantity and quality of data makes it difficult within the Canadian context to identify not only individuals facing disparities in disease outcomes and healthcare usage, but also to measure the effectiveness of public health interventions and health policy.

## 1.2 The importance of data from ethnic populations

Currently, ethnicity health research is reliant on national self-reported surveys such as the CCHS, and NPHS, along with the linking of data with the Longitudinal Immigration Database (IMDB) and the Longitudinal Survey of Immigrants to Canada (LSIC) (17). However, there are multiple fields of inquiry guided by meaningful research questions attempting to

understand health and wellness within ethnic subgroups in Canada, but are unable due to availability of data. For example, detailed data on prevalence, presentation, risk factors, and outcomes of psychological conditions of ethnic groups in Canada is lacking, even though studies have found a high prevalence of mood disorders in certain ethnic groups (12). Other national surveys such as the Neurological Conditions in Institutions lack information on ethnicity of its participants, and the Living with Chronic Disease in Canada – Mood and Anxiety Disorders Component (SLCDC-MA) only records immigrant status and not ethnicity. Further, information from certain national surveillance systems (e.g., Canadian Primary Care Sentinel Surveillance System) is only able to obtain ethnicity information if that information is present within patient electronic medical records (EMRs), which are often incomplete, especially for jurisdictions that do not require the collection of such data (12). Finally, review of research in ethnic populations have found an overrepresentation of SA and Chinese immigrants. However, even within these large groups, many health topics remain unexplored (18).

Data quality, especially pertinent to administratively collected data, influences health guidelines that may not benefit ethnocultural communities. For example, the Canadian Perinatal Surveillance Network (CPSN) research team attempted to construct birthweight reference data using linked administrative data from a representative Canadian population. However, the cohort they comprised lacked information from Ontario, a province with high ethnic variability, and used data sources that lacked information on ethnicity, including ultrasound measurements, and birth certificate (19). Derivation of these references from low quality data has resulted in a lack of generalizability to a diverse population, as is the case in Canada. These references have a harmful impact for classification of infant birth size for ethnic subgroups, and ineffective surveillance of population differences in child health. Further, faulty reporting of ethnicity in

administrative data may contribute to underestimation of racial health disparities, especially when race/ethnicity is missing or unknown within the data (20).

Data on the influences of racial discrimination, social determinants of health and the intermixing of race and socioeconomic status has also been criticized to be lacking within Canada (21). Researcher have called for recognition of discrimination as a population-health phenomenon that requires systematic collection of ethnicity data with adequate sample sizes (22). Further, longitudinal health data for ethnic subgroups is lacking, which would allow for better analysis of disease risk factors and development, and the influences of social determinants of health in producing adverse health outcomes (23). Other criticism about the collection of data in ethnic subgroups includes the lack of disaggregated data, such as data on immigrant status (first or second generation), and Canadian-born visible minorities. Finally, there is also a lack of data on the health of older individuals within ethnic subgroups (25). Finally, lack of collection of ethnicity classification for Canada's patient population in administrative data has been criticized due to lack of standardization, validity, and reliability of the data (24).

Examples of the positive impacts of having high quality health data from ethnic population can be seen within the US context, where it is mandated federally to collect information on ethnicity. Health agencies within the US, such as Centers for Disease Control and Prevention, formulate specified guidelines for ethnic American, such as African and Latino Americans. For example, guideline recommended data collection on cancer presentation for black, Hispanic, and white women in the US have allowed for the development of preventative measures, including earlier mammography screening for women of east African ethnicity, who have been found to be at a higher risk of more aggressive and early types of breast cancer as compared to white and Hispanic women (25). Similar collection of national level data has been

done routinely in United Kingdom and New Zealand (26). Within the Canadian context, a call for similar disaggregated and ethnic-specific health data that is nationally representative has been made, which can be used in understanding the not yet explored ethnic disparities in health (27).

The above discussion emphasizes the ethnic disparities in health and the need for collection of ethnic health data to inform precision public health. Ultimately, however, health information generation and flow are controlled by the patient or participant within research programs; therefore, understanding the willingness, interest, and motivation to provide health information within ethnic groups is an important endeavor that has the potential to improve data availability for ethnic groups in Canada (28).

### 1.3 Conceptual framework: willingness to share health information

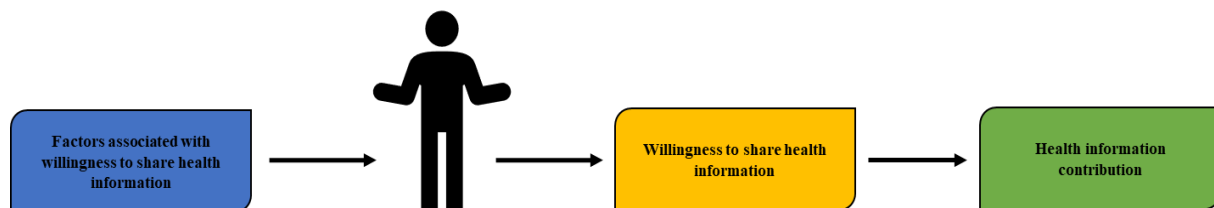
Engagement of ethnocultural communities in health research is lacking and disparities in medical research participation in minority groups have been well reported. Under representation can be due to multiple factors including fear of discrimination, mistrust of medicine and researchers, culturally insensitive research programs and lack of community engagement (29). To address this, transformative health research methods (e.g., participatory action research) have been explored that aim for patient engagement, and have reported positive outcomes in the quality, uptake, and knowledge translation of research findings (30). However, although attempts to increase research engagement have been well explored, participants can be engaged in research but still feel unmotivated, or uncomfortable, to share their data, or, they may start an information sharing partnership with a researcher but change the nature of that partnership based on factors that influence their willingness to share (31).

Willingness to share information pertains to the *intention* to perform the sharing behavior and can be defined as the extent to which a person is ready to share their intellectual capital to



other individuals. Willingness may be viewed as a mediator between the factors that influence sharing health information, that make-up a sharers cognitive thought process, and the act of sharing (34) (Figure 1). The concept of the intention (or willingness) to share precedes the sharing behavior following the theory of planned behavior, as posited by Ajzen (32). This theoretical framework outlines that the attitudes, subjective norms, and the perceptions of control a person has, influences the intention to perform a behavior. In the case of willingness to share health information, willingness to share may be dependent on the perception of that individual regarding how favourable, or unfavourable, the result of sharing would be (33). In this case, willingness to share health information may be a careful weighing of factors that may operate as positive or negative to influence a person to contribute their information.

**Figure 1** *Schematic of willingness to share health information preceding health information contribution*



Previous studies have reported high proportions of participants willing to share their health information for multiple purposes, including health-care improvement, research, and surveillance. (34-36). Privacy concerns and type of information shared are considered as important factors in studies understanding sharing preferences amongst patients sharing information towards electronic health records (EHR) or personal health records (PHR). However, sharing of health information is nuanced by many other factors, which can include information security, uncertainty about the use of information, altruism, personality traits, illness histories, and other attributes related to the context around information sharing partnerships (37). Synthesizing and understanding these factors within the context of ethnic populations may be an important endeavour that can aid in understanding the willingness to share health information.

#### 1.4 Study aims

Studies thus far on the topic are predominantly survey data, however; there are limitations to what survey data can accomplish when understanding the cognitive and contextual factors associated with willingness to share health information. Further, although many studies include ethnicity as a population attribute, and seek to understand associations between ethnicity and factors associated with sharing health information, to our knowledge, no research has been done to understand data sharing preferences amongst specific ethnic groups. Focusing on particular ethnic groups will allow for a deeper understanding of the preferences, contexts, and cognitions in the health information sharing process. Further, the focus on ethnic subgroups will fit within the wider agenda of the need for ethnicity-specific data, as understanding willingness to share such data is an essential first step. Finally, studies so far have focused on the sharing of health information in the form of EHRs and PHR. A study is required to understand data sharing within a more generalized health information context..

Qualitative methodologies present excellent opportunities to gain an in-depth understanding about a phenomenon that otherwise cannot be measured using quantitative methods. Qualitative methods allow for an investigation about topics in health or illness from specific community perspectives and individuals in an attempt to understand their lived experience (38). In the case of this study, qualitative methods will be useful to add breadth and depth to the understanding of the perceptions of factors related to willingness to share health information and understand their inter-relatedness within the social context that they operate. Further, the use of qualitative methods in this study have the opportunity to contribute to middle-range theory or explanatory models associated with willingness to share health information, which do not currently exist within the health-care setting.

### 1.5 Study Objectives

This study considers two objectives aimed at exploring and understanding the factors associated with willingness to share health information within South Asians.

Specifically, the objectives of this study include:

1. Synthesize and summarize factors related to willingness to share health information as reported in the literature via a rapid review.
2. Understand factors related to willingness to sharing health information in a SA population via qualitative interviews.

The first objective pertains to a rapid review of literature to find and synthesize the literature reported factors associated with willingness to share health information and will be the discussion of chapter 2. The rapid review offers an alternative form of knowledge synthesis as compared to systematic review, where the process of review conduction is simplified and

synthesis results can be done in a timely fashion. The results of the rapid review are usually descriptive and provide readily available knowledge about a topic in order to inform further investigation and decision making (39). For the purposes of this study, conduction of the rapid review is an essential first step in the understanding and conceptualization of the literature reported factors associated with willingness to share health information. Only with this conceptualization, a well-informed qualitative inquiry would have been possible. Specifically, the results of the rapid review greatly influenced the qualitative interviews employed in objective 2.

In the qualitative component of the study, discussed in chapter 3 participants were sampled from the SA ethnic group and were asked to participate in interviews, keeping with the objectives of this study of the importance of data and information exchange within ethnic subgroups. South Asians remain the largest (and growing) ethnic groups in Canada (40). Studies controlling for major diseases risk factors, and markers of socioeconomic status still find ethnic differences in disease risk and outcomes for SAs as compared to other ethnic groups (43). Studies looking at composite outcomes of disease (e.g. composite cardiovascular health scores) have found SA groups to have higher disease prevalence than white groups, following a trend of increasing risk of disease starting from Chinese, black, white, and SAs (43, 44). The focus on the SA population will allow for the understanding of factors associated with health information sharing, which may inform research projects that engage in understand further the obvious health disparities within this group.

## Chapter 2: Rapid Review of Literature

The following chapter presents a rapid review of the literature reporting of factors related to health information sharing via a rapid review methodology. The search was completed in October 2019. The specific objectives of this review included: 1) to locate literature that reported factors associated with health information sharing, 2) to synthesize factors into cohesive themes and explain their relevance to the data sharing process.

### 2.1 Methods

#### 2.1.1 *Literature search strategy and screening*

A search was conducted in Medline to gather literature regarding willingness to share health information within the context of health care and research, which includes EHRs, PHRs, and mobile health information, general health information, or information on social determinants of health. Additional records were also identified using Google Scholar. The search keywords included “EHRs” AND “data sharing” OR “sharing preference” OR “willingness to share”. The search was limited to any population that was not healthcare workers or practitioners, and the participants were aged 18 years or older within the USA or Canadian context (see Appendix A for complete search strategy).

One reviewer (IN) conducted an initial screening of the title and abstract. All included papers from the first round of screening were then full text screened . Both levels of screening followed the inclusion and exclusion criteria outlined in Table 1. Studies were included if they reported on a population over 18 years of age, are not health care professionals, and reported on factors associated with sharing health information. Included records were limited to the primary peer-reviewed journal articles. Reviews, editorials, commentaries, and letters were excluded.

Records that were deemed unclear in following this criteria during the title abstract screening were still included for full-text screening.

**Table 1** *Inclusion and exclusion criteria for rapid review of literature*

	<b>Included</b>	<b>Excluded</b>
<b>Population</b>	<ul style="list-style-type: none"><li>▪ General adult population</li><li>▪ Patient population</li><li>▪ Participants aged 18 years and older</li></ul>	<ul style="list-style-type: none"><li>▪ Healthcare professionals, researchers</li><li>▪ Participants under the age of 18</li></ul>
<b>Intervention</b>	<ul style="list-style-type: none"><li>▪ Not applicable</li></ul>	<ul style="list-style-type: none"><li>▪ Not applicable</li></ul>
<b>Comparator</b>	<ul style="list-style-type: none"><li>▪ Not applicable</li></ul>	<ul style="list-style-type: none"><li>▪ Not applicable</li></ul>
<b>Outcome</b>	<ul style="list-style-type: none"><li>▪ Patient reported factors associated with sharing health information</li><li>▪ Sharing information to personal health records (PHRs)</li><li>▪ Sharing information to electronic medical records (EHRs)</li><li>▪ Sharing information with health care providers or hospital staff</li></ul>	<ul style="list-style-type: none"><li>▪ Information sharing not within the health context</li><li>▪ Information sharing preferences not reported by the patient or participant</li></ul>
<b>Design</b>	<ul style="list-style-type: none"><li>▪ Primary research studies</li><li>▪</li></ul>	<ul style="list-style-type: none"><li>▪ Reviews</li><li>▪ RCTs</li><li>▪ Editorials</li><li>▪ Commentaries</li><li>▪ Letters to the editor</li></ul>

### 2.1.2 *Data extraction and analysis*

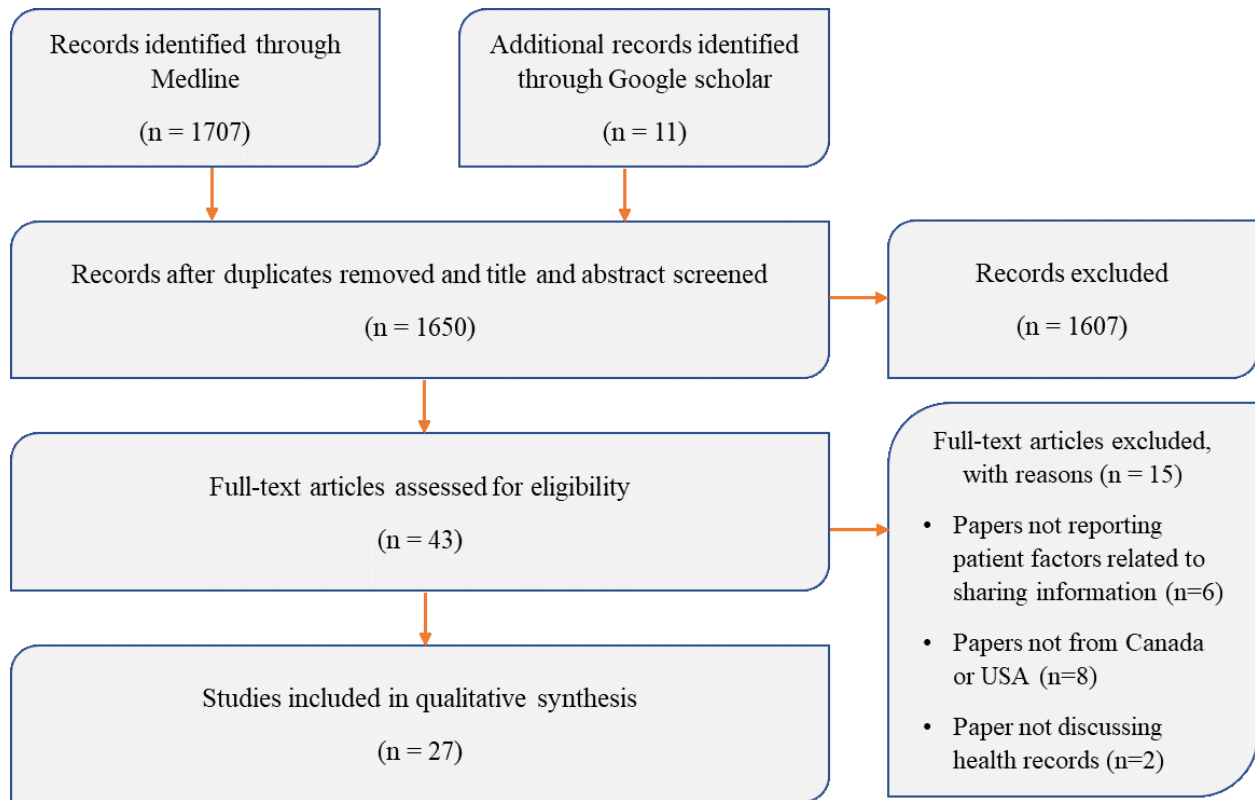
The final record list was imported to NVIVO™ 12 (Provo, UT, Texas) for data abstraction. This process included an aspect of thematic analysis where any factors associated with sharing health information were highlighted and coded inductively within each article. Based on shared meaning, the final factors were classified into major themes that emerged from the research team discussions. Additional information about each record was abstracted using a predesigned Excel spreadsheet form (Microsoft office 2016; Microsoft Corporation). Extraction included information such as study author, publication date, study type, main objectives, population, sample size, the type of health information discussed, and major conclusions. A narrative synthesis of patient-reported factors related to health information sharing is reported below.

## 2.2 Findings

Initially, a total of 1707 records were identified through Medline. Further, a google scholar search yielded 11 records for review. A total of 1650 unique records, after de-duplication, were title and abstract screened, at which stage 1607 were removed. Forty-three full-text articles were screened for relevance, of which 27 met our inclusion criteria and were analyzed for this review (Figure 2) . Study characteristics are summarized in Appendix B.

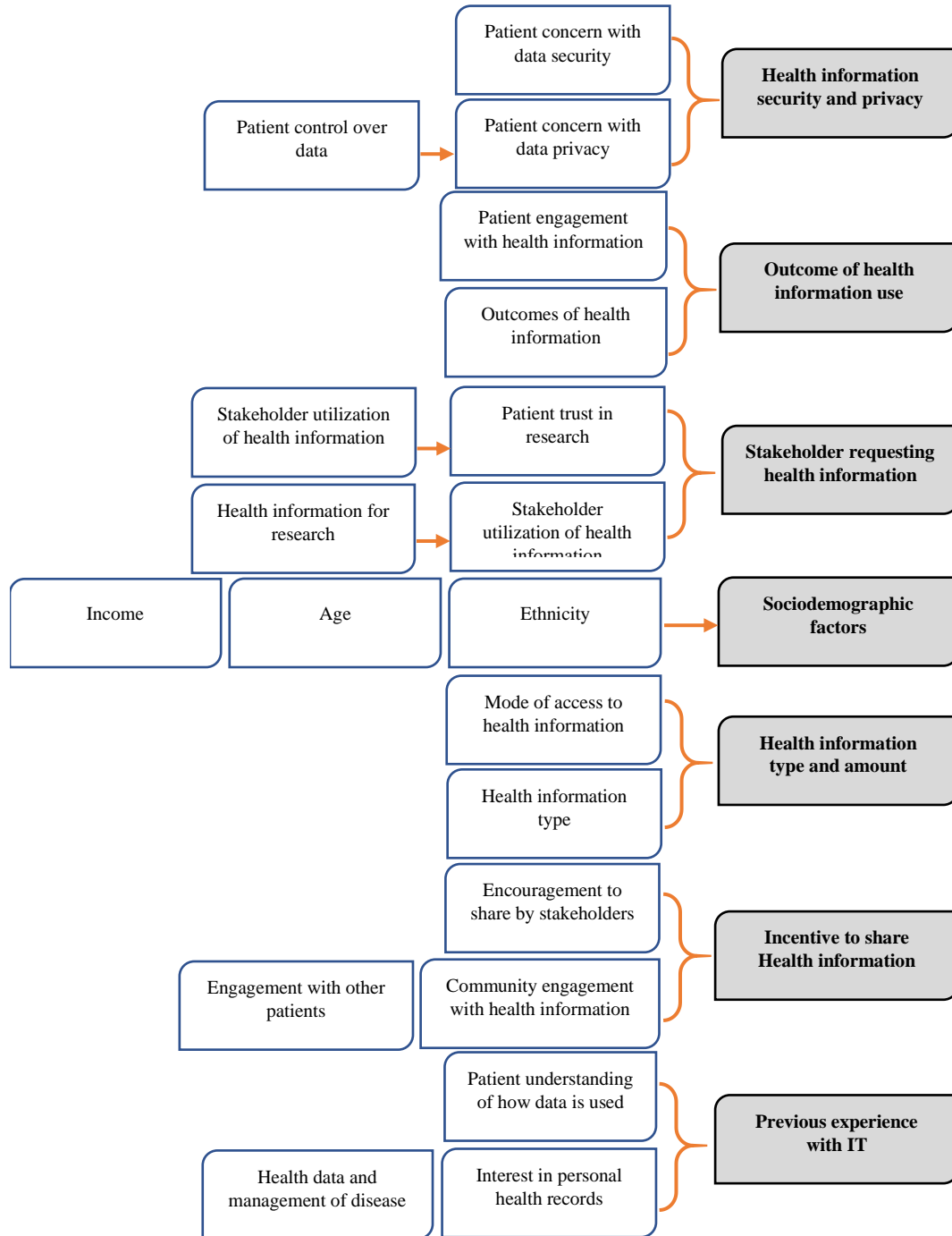


**Figure 2** Rapid review of literature flow diagram

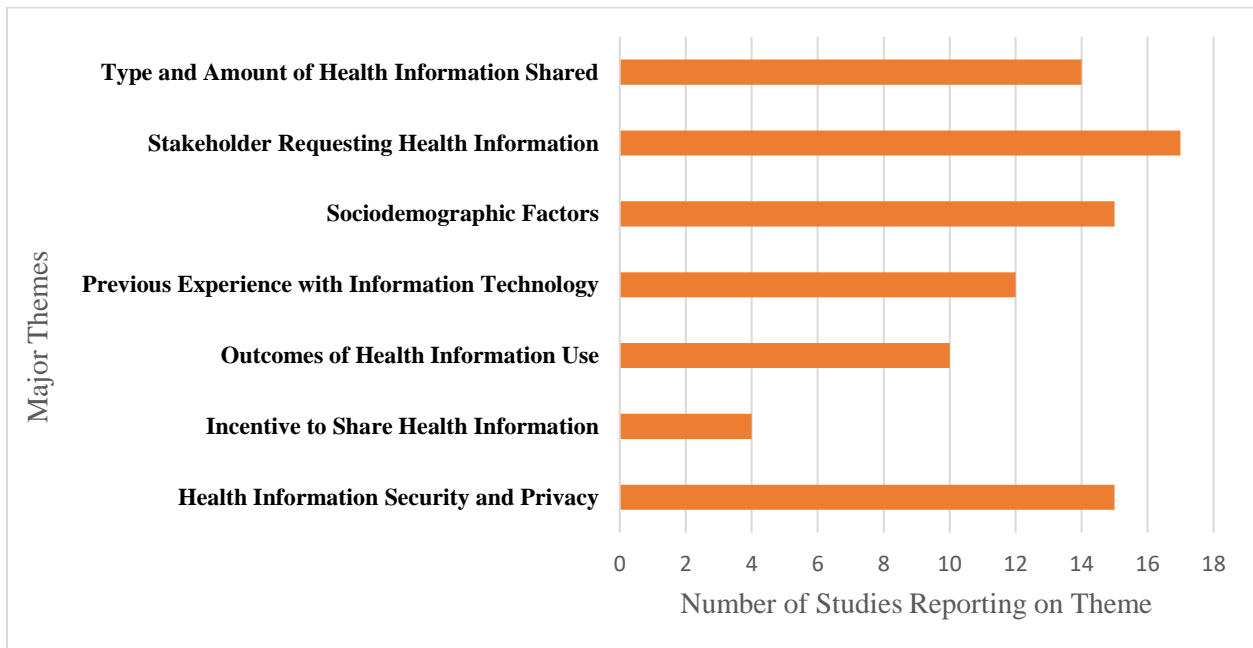


The inductive thematic coding process revealed multiple factors related to willingness to share health information, as reported by study participants (Figure 3). A single study often reported a multitude of factors related to sharing information and are listed for each study (see Appendix B). The multiple factors were then sorted into major themes related to sharing health information. For example, multiple studies reported an association between age, income, or ethnicity, and the willingness to share information, and were grouped under the major theme "sociodemographic factors". A similar process was followed for all other factors coded within the papers, from which seven major themes emerged, shown in Figure 4. The following is a narrative synthesis of all major themes discovered in the review process.

**Figure 3** Factors related to willingness to share health information inductively coded within included papers and collated into major themes.



**Figure 4** *Number of studies reporting each major theme.*



### *2.2.1 Sociodemographic factors*

Fifteen articles reported sociodemographic factors associated with willingness to share health information. A common theme was the relationship between age and willingness to share health information, which seems to be contested. Brown et al. (41) reported that older people were more comfortable with sharing health information because of a higher level of involvement with the healthcare system. Alternatively, Cocosila and Archer (42) found that older users were less comfortable with IT (information technology) and, therefore, less likely to share health information, this being especially true via mobile applications. Others have found no influence of age (or other demographic variables) to be related to sharing health information for research purposes or improving clinical care (43, 44).

Measures of social capital have an unclear association with willingness to share health information. Some papers have reported that higher education and income increases willingness to share health information and such individuals see the benefits of sharing information (44-47), whereas other have found no influence of these factors on sharing health information (34, 43, 48). It should be noted that income and education are often covariates and their individual effects on outcomes are difficult to discern. Further, mediators, such as inequitable access to technology by lower socioeconomic groups, cannot be ignored when understanding willingness to share health data (49). Further, although ethnic disparities have been noted regarding health information sharing (50), others have found no effects of ethnicity and sharing health information (34, 43, 48). The evidence suggests an incomplete exploration of the sociodemographic factors that operate in an inter-related manner to influence the willingness to share health information.

### *2.2.2 Incentives to share health information*

Four studies report the importance of incentives to increase willingness to share health information. Individuals report various incentives that may motivate them to share health information. These can include monetary and material incentives, including shopping credits or money (51). Further, individuals are more likely to share health information if they can connect with other individuals who share the same health conditions (51). This aspect of connection is especially relevant to mHealth applications that offer engagement with an online community of users. Finally, individuals also respond to incentives and encouragement from their healthcare providers. For example, primary care physicians may encourage the use of mHealth application for blood sugar monitoring and further information sharing with healthcare or research teams (52).

### *2.2.3 Previous experience with IT*

Twelve research articles reported previous experience with IT as a factor associated with willingness to share health information. Respondents who showed interest and engagement in IT were more accepting of sharing health records (42, 46). Further, apprehension and anxiety perceived to using computers or wearables technology is a determinant of intention to share (e.g., computer anxiety). Researchers argued for improving internet access and computer literacy as critical to increasing engagement and willingness to share health information, especially in a diverse population (46). However, other studies have found that the mere presence of experience with technology for consumers is not indicative of acceptance of electronic sharing of health data. It has been suggested that higher sharing may be an unintended consequence of higher technology use (34).

Self-management of health as a result of health information sharing is another motivator of health information sharing, including the improvements in the understanding of the participants own health (46). As individuals have an increased awareness of the ability to manage their health, this motivates people to share their health information. Health management can include actionable things such as knowing the likelihood of developing certain diseases, the current state of the person's health, how health affects the social environments of the person, and receiving recommendations to improve health (36, 51). For example, the day-to-day management of health markers that some mHealth applications may offer (e.g., physical activity tracking, blood pressure readings, and blood glucose readings) may be an incentive for users to be more engaged with the collection and sharing of health information (53).

Finally, participants who perceived the outcomes and implications of their health information as useful were more likely to share their health information. Participants were more likely to share their data if it was viewed as a contribution to society (37). A study by Kerath et al. (43), reported that participants were interested in receiving their genetic testing results and how their testing was contributing to genomics research. Indeed, participants who believed and were shown that their EHR positively impacts healthcare quality and research were more likely to consent to electronic data sharing (34). The data suggested that the public fundamentally cares about the purpose for which their information is being used and is more likely to share the information if it is being used for a good purpose (54).

#### *2.2.4 Type and amount of health information*

Fourteen studies reported factors related to type and amount of health information in association with willingness to share health information. Studies have found that the type of data collected determined willingness to share. Caine & Hanania (55) wanted to understand whether

patients considered some information to be more sensitive to others, using various classifications of sensitive information (e.g., sexual activity or orientation, adoptions, abortions, and substance abuse). The study found a hierarchical relationship with willingness to share and health information sensitivity, and that no participants were willing to share their health information completely with any one recipient. Similar results were found for the sharing of health information about contagious diseases (47). Confidentiality was a concern to participants, as concluded in their study on participants willing to share health information from a clinic specialising in sexually transmitted infections (48). The authors found that although most participants agreed with sharing their health information, they were less likely to be tested if participant knew that their clinical information was being shared by provincial healthcare systems. The results suggest that individuals prefer control over the type and amount of health data, where they can control the information being shared.

### *2.2.5 Data privacy and security*

Fourteen studies reported data privacy and security as a factor related to willingness to share health information. With the growing trend of information technology and the creation of large data repositories, security and privacy are a major concern for data producers and are closely linked to the confidentiality of sensitive information, as discussed in the previous section. Major opponents of collecting health information through ubiquitously used devices such as mHealth applications argue for data security and privacy as a major factor needed to be addressed when designing systems. Many large-scale consumer studies were concerned about the security and privacy of their health data (42).

Courtney (56) offers a multidimensional look into what privacy and security means within the health data field and found that patient mistrust results in withholding of health



information. Fuji, Abbot, and Galt (53) found that privacy existed at both personal and technical levels, where some participants expressed themselves to be private, and disliked sharing any information, while others stating that some technologies (e.g., cloud sharing technology) may not be equipped to ensure total data security. Similar results in patients' sensitivities to sharing health information have been found in genomics research (37, 43).

In practice, although health information privacy and security are valued concepts for patients when sharing their EHRs, concerns about privacy decreased in specific patient groups, such as those who were chronically ill. In such cases the benefits of sharing medical records may have outweighed privacy risks perceptions (42). However, Gaylin et al. (57) discussed the opposite, where privacy concerns were more important than sharing health information and its potential benefits to society. Further, mitigation of privacy concerns may increase willingness to share, such as anonymization (49, 58). However, researchers discussed that with the increases in IT systems to share information (e.g., using social media), individuals may still be willing to share information regardless of privacy and security concerns. This paradox might be due to the fact that consumers become relaxed in sharing their information over time (51).

### *2.2.6 Stakeholder requesting health information*

Willingness to share health information is also influenced by who will use the information, which was reported by 17 studies. Studies showed that participants were more likely to share health information with their primary physicians, depending on the nature of the information (55). Researchers and public organizations (non-clinical staff) were least likely to be on the list of participants' willingness to share health information (55, 58, 59). Hesitancy to share was especially true when the recipients of health information were doing research that was not relevant to the participants sharing information (45). Participants were more likely to contribute

information for research purposes if they knew that it would benefit themselves or the public in some way (37).

Having a positive relationship with the recipient of the information was important in determining willingness to share (60). Having a positive and trusting relationship with the researcher or research team increased willingness to share information (45). Participants in a genomic research study reported that regular contact between researchers and participants facilitated this trust and affected willingness to share information. However, this trust was dependent on the affiliation of the research organization (37). If the research organization had an affiliation with the government, such as in a public healthcare system, participants were less trusting and had concerns regarding privacy (34). In an exploration of the sharing of PHRs Weitzman, Kelemen, and Mandl (47) found multiple reasons for reticence to share, including distrust in how data will be used, concern about disclosure, risk of stigma and discrimination, and lack of transparency. Therefore, in order for research and public health authorities to obtain and benefit from patient-reported and shared data, the above factors of trust and transparency must be addressed.

### *2.2.7 Outcomes of health information*

Ten studies reported that participants were influenced by the intended use and outcomes of their information when sharing health data. Anderson and Agarwal (52) found that the outcome and the role their health information had to play was important for sharing health information, as established trust was an important determinant of information sharing. Hasnain et al. (61) found that 90% of their study participants needed to know who was using their health information and for what purpose. Other individuals felt a strong desire to advance and contribute to science and reflecting on their illness history motivated them to share health

information to benefit disease research. To these individuals, contributing health information was akin to contributing to society.

Patel et al. (46) found that individuals who perceived the positive benefits of sharing health information to EHRs, such as understanding of their health, control over their healthcare, ability to make decisions together with their healthcare team, improvement in the quality of care, and satisfaction with healthcare, were more motivated to share their information. Brown et al. (41) found that individuals who feel like they are contributing to an improvement of healthcare are more likely to share health information.

### 2.3 Conclusions

This rapid review synthesized the results of 27 studies that reported factors associated with sharing health information. Seven themes were found during this process that influence the sharing process for individuals. The results of this rapid review were utilized to inform the interview protocol for the qualitative component of this study and were triangulated with the results of the interviews. The results of this rapid review were also discussed within the context of the result of the qualitative component and explanatory evidence in the discussion (Chapter 4: Discussion).

## Chapter 3: Qualitative Interviews

The following chapter explains the methodology, methods, and results of the objective 2 qualitative interviews conducted in Calgary, Alberta, Canada during the months of March-June of 2020. The consolidated criteria for reporting qualitative research (COREQ) was used as a guideline to report all aspects of the qualitative study, including study design, analysis, and reflexivity (Appendix C) (62). The chapter also described how rigour within the research was achieved. Finally, the results reflected the thematic coding process, where the construction of the major themes associated with willingness to share health information were described. These were aided by participant excerpts from the dataset.

### 3.1 Methods

#### 3.1.1 *Epistemology and study methodology*

The epistemological positioning of the qualitative interviews was interpretive, which acknowledges the subjective nature of reality and knowledge that is shaped by people within their environments. This positioning aims to answer questions about why the phenomenon of interest arises, and how does it unfold. Popular interpretive approaches include phenomenology (understanding experiences based on lived experience) and ethnography (understanding the influence of culture) (38). Specifically, this qualitative study uses a constructivist epistemology, as discussed by Guba, Lincoln, and Denzin (63). Constructivism focuses on the individual's mind, and its meaning-making activity to the phenomenon of interest, and understanding is cocreated by the participant in the research and the researcher. The results in the understanding of phenomena is not only the subjective experience of the participants of interest as influenced by their individual meanings, but also a result of the process of creating this understanding. The

constructivist positioning in this study considered the cognitive, social, psychological, and contextual aspects associated with willingness to share health information (63).

This study employs a qualitative descriptive approach to its methodology (64). This methodology is fit for studies that do not take on a specific qualitative underpinning and aim to describe the phenomena of interest as it is, rather than provide evidence for an existing theory. Bradshaw, Atkinson, and Doody (64) describe qualitative descriptive approach to be naturalistic approach, with a relativistic ontological position. This study aims to take an inductive approach to better describe a picture of willingness to share health information by SA participants. This methodology also focuses on subjectivism, where each participants perspective is respected, and the subjectivity of their experiences behind willingness to share information is valued.

This study also takes on a person-centered lens. The person-centered approach is readily used in health care delivery and clinical care, with a focus on vulnerable populations (65). This positioning emphasizes the rights of individuals as persons and employs an attitude of respect for individuals to hold their own opinions, make rational decisions, and determine their/ own needs (69). The person-centered lens is appropriate for this study as it aims to understand and respect the individual opinions of participants on their willingness to share health information and note them with a sympathetic benevolence. Further, understanding the context of being from a SA ethnicity and the unique perspective that is associated with this distinction is considered through this lens.

### *3.1.2 Context and study participants*

This study was set in Calgary, a major metropolitan city within the province of Alberta, Canada, and has a population of 1,547,484. In 2019, Calgary was ranked as the most livable city in North America, as per the Economist Intelligence Unit, where population density is low and

quality of life is high (66). More than quarter of the Calgary population belongs to an ethnic subgroup, with 78% of immigrants arriving to Calgary belong to a visible minority group. The largest visible minority group in Calgary are SA (7.5%) (67).

Participants of this study included adults over the age of 18 living within Calgary, Alberta who were of SA ethnicity. Ethnicity was self-reported by the participant during recruitment, therefore participants were included if they were from, or born in, India, Pakistan, Bangladesh, Sri Lanka, and Nepal. Participants were also included if they did not explicitly state they were from, or born in, the above-mentioned countries, but simply stated they were Indian, Pakistani, Nepali, Bangladeshi, or Sri Lankan. Participants were included regardless of their immigration status (immigrant, naturalized Canadian citizen, permanent resident, 2<sup>nd</sup> generation immigrant, or non-immigrant). Participants were included regardless of their socioeconomic background. Only participants who were comfortable speaking English were included in the study, as this aided in the consent process. However, the interviews were offered to be conducted in the participants native language if requested.

Participants were recruited from major community health clinics, research facilities, and community organizations and high traffic areas within the city. Participants were also recruited if they had previously participated in research projects within the research team, and who had consented to participate in future projects. The convenience sampling approach was also utilized, which involved asking participants if they knew of other individuals who would be interested in participating in the study. Participants who were willing to refer someone else were given a short script outlining the study objective to communicate to their referee. Participants were asked to do this only if they were comfortable and referees were free to decline to participate based on the

information that was communicated by the participant. This process was done throughout the data collection stage.

The method of approach to participants was by phone and email. Participants were contacted and asked if they would be interested in participating in the study. If the participant indicated interest, a time was set up for a formal interview, where the participant would have the opportunity to learn more about the study (if necessary) and give their informed oral consent. Before the start of the formal interview, participants were (via email) sent a letter from the research team outlining objectives of the study, any risks associated with participation, and benefits of participating, along with details about the ethics certification of the study. Participants were awarded a 15\$ gift card for their participation.

### *3.1.3 Data collection*

Semi-structured in-depth interviews and open conversations were employed as the main form of data collection for this study. A total of 22 interviews were conducted (11 women and 11 men). An interview protocol was developed which followed the four phases of interview protocol refinement (68): 1) ensuring interview questions align with research questions; 2) constructing an inquiry-based conversation; 3) receiving feedback on interview protocols; 4) piloting the interview protocol (see Appendix D for final interview protocol). In alignment with the research question, the interview protocol examined participant willingness to share their health information, their willingness to share their information for research, and any factors that would make them more or less likely to share their information (Table 2). The interview protocol went through an iterative cycle of refinement through discussions within the research team, and via pilot interviews with initially four participants.

All interviews were conducted over the phone at the participants convenience by IN. No one was present during the interview conversation other than interviewer and the participant. The phone conversation was recorded using a Samsung smart phone audio recording application which could record and convert the phone conversation into an MP3 file. Additional notes were taken by the interviewer as the conversation took place. On average, the interviews lasted 40 minutes to 1 hour. All MP3 files were uploaded to a secure file location on the researcher's computer and were prepared for transcription. Transcription of the audio file was done using Microsoft Word (Microsoft Office 2016, Microsoft Corporation), and the interviews were transcribed verbatim by IN. Interviews continued until the research team found that saturation had been reached.



**Table 2** *Qualitative interview protocol themes and guiding questions.*

Theme	Guiding questions	Open discussion? (yes/no)
Willing to share health information?	<ul style="list-style-type: none"> <li>▪ Would you be willing to share health information?</li> </ul>	Yes
	<ul style="list-style-type: none"> <li>▪ Would you be willing to share your health information for research</li> </ul>	Yes
Factors associated with willingness to share health information	<ul style="list-style-type: none"> <li>▪ What factors will make it more likely to share your health information</li> <li>▪ What factors make it less likely to share your health information</li> <li>▪ What factors can be overcome for you to feel comfortable sharing your information</li> </ul>	Yes
Community perceptions associated with sharing health information	<ul style="list-style-type: none"> <li>▪ How do you think your community feels about sharing health information?</li> <li>▪ Would your community be willing to share their health information for research?</li> <li>▪ Can you think of any barriers in sharing health information within your community?</li> <li>▪ Can you think of ways to overcome those barriers to sharing health information in your community</li> </ul>	Yes

### 3.1.4 Data analysis

Analysis of the data was ongoing throughout the research process using NVIVO. A single coder (IN) conducted the analysis process, with heavy input and discussion from the research team. Thematic content analysis, as outlined by Braun and Clark (69), was employed for this study. This flexible analysis method allows for a complex analysis of the data set keeping within the scope of a prespecified research question. Thematic analysis is also systematic and will allow for the identification and detailed description of participant reported factors associated with willingness to share health information. It was assumed that the final identified themes through the coding process will contain multiple factors associated with sharing information. The process of generating the themes was inductive but the researcher was aware of the major themes associated with willingness to share health information. However, as best as possible, theme generation was data-driven, as it was expected that novel themes associated with sharing health information would be reflected in the dataset that were not found in the rapid review analysis in Chapter 2.

The coding process was as followed:

*Data familiarization:* This not only included the transcription of the data, but also rereading and thinking about the dataset in terms of how to proceed with the initial code generation.

*Generation of initial codes:* A very free and inductive approach was taken during the initial coding stage, where excerpt from the data were highlighted and given a short descriptive name on the spot. As more text was read, these descriptive names were re-used or new ones were created as needed. Again, the focus here was to let the data drive the coding process. Multiple codes were developed in this manner

*Searching for themes:* At this stage, the codes were examined and collated into nascent codes, which were logical categorizations of the individual codes. These nascent codes were then organized into major themes associated with willingness to share health information.

*Reviewing themes:* Coded extracts which formed the initial codes were visualized (using a table format) into the major themes identified in the previous step. Here the themes were reassessed in relation to the coded extracts. Critical analysis of the themes resulted in collapsing of themes into one major theme, or the deletion of themes due to the lack of data to support them.

*Defining and naming themes:* The final themes created through the process were logically and coherently named through discussions with the research team.

### 3.1.5 Reflexivity

The interview was performed by Iffat Naeem (IN), who is a graduate student at Department of Community Health sciences at the University of Calgary. The interviewer identified herself as a cis-gender straight female of SA ethnicity and is a first-generation immigrant. The interviewer has a bachelor's degree in human biology and neuroscience and two years of graduate school within the community health sciences department of University of Calgary. Here IN has received training in health research methods, qualitative research methods, along with research experience in conducting interviews, analyses, and knowledge syntheses.

Although IN immigrated to Canada, she was 7 years old when she did so, therefore spent the large majority of her life within the Canadian culture. She considered English as her first language, but also speaks Urdu, Hindi, and Punjabi fluently. In her interaction with the SA participants, IN felt very comfortable in speaking in their native tongue if they choose to do so,

however she recognizes that there may be a language or a cultural barrier in deeply understanding the participants of this study. Overall, IN does her work with a social justice lens and firmly believed more scholarship and research is needed within ethnic populations in Canada and believes in community engagement when it comes to health research.

### 3.2 Ensuring rigour

Demonstrating rigor and quality in the research process and the methods associated with data collection are essential for research. Valid and reliable results are a cornerstone for quantitative research; however, such measures do not translate within qualitative paradigms. Although multiple methods exist to establish rigor and trustworthiness within qualitative results, Krefting (70) summarizes the most popular, including Guba's (71) model describing four criteria: 1) Credibility; 2) Transferability; 3) dependability; and 4) confirmability. Bradshaw, Atkinson, and Doody (64) rightly adopt these concepts within the qualitative descriptive approach as described below within the context of this study.

#### 3.2.1 *Credibility*

Credibility of this study stems from developing a trusting and engaging relationship with participants so they may openly share their views on willingness to share health information. This study employed a person-centered theoretical lens and values the freedom of participants to speak their truth. Further, through the interview protocol refinement process, the data collected through the interviews were participant-driven, where the design of the interview protocol was flexible enough for participants to guide the conversation. Further, to ensure the participants voices were heard, probing and clarification questions were employed along with building rapport with the participants. Finally, to ensure the participants perceptions were accurately recorded, the transcriptions of conversations were member checked for accuracy.

### *3.2.2 Confirmability*

This pertains to the researcher being as objective and neutral as possible by presenting results that are representative of what the participants reported. This was done through keeping an audit trail throughout the research process, including raw data and field notes, data reduction and analysis, and data reconstruction and synthesis. The triangulation protocol (discussed in section 3.5) as employed by this study ensured these items were well recorded within the study. Further, as the results of the in-person interviews were triangulated with literature informed factors associated with willingness to share health information, the results were enhanced in their breadth. Finally, both the member checking process, along with use of direct quotations within the final synthesis ensured confirmability within the study.

### *3.2.3 Dependability*

This criterion related to the consistency in the findings within the study. Using the triangulation protocol, a well-established analytical method described in a stepwise process, along with triangulation of results enhances replicability. Further, the study established an audit trail along with facilitating discussions within the research team, as outlined within the triangulation protocol, with the goal of established dependability.

### *3.2.4 Transferability*

The study provided a rich description of theoretical standing and a detailed analysis protocol, allowing enhanced transferability of the results. Although generalizability within qualitative studies should be done so with caution, the effective sampling strategy and dense information about the informants and context should allow others to assess how transferable the findings are.

Throughout the research process, investigators undertook a critical reflexive stance on their influences within the progression of the research in every phase. This includes sampling of participants, conducting interviews, and data analysis. To be reflexive is to ‘bend back upon oneself’ to facilitate a thoughtful and self-aware analysis of the intersubjectivity dynamics between researcher and study participants. Investigators analyzed their own positioning as researchers, their background, their assumptions, and behavior within certain context, and how these may affect the research process (72).

### 3.3 Ethical considerations

This study has been approved by the University of Calgary Conjoint Health Research Ethics Board (CHREB - REB19-0184). The study followed an informed consent protocol, where participants were communicated about the study objectives, risks, and outcomes if they choose to participate, and were invited volunteers to the study without any coercion, persuasion, or induction against their will. Further, participants were given full control over their data, and had options to disclose certain aspects of the data over others. This study presented minimal to no risk to participants, as there was little chance for the sharing of information that may cause the participant physical, emotional, or psychological harm. The study’s objectives were to understand willingness to share health information, of which some could be of sensitive nature. In this case, the research employed a careful line of questioning and allowed the participants to guide the conversation as they saw fit.

To maintain confidentiality for the research participants, this study removed all identifiable information from the interview transcripts and applied participant numbering. Further, all interview transcripts and other study data were stored in a password protected computer and any sharing of transcripts were tracked. Further, to maintain anonymity,

information regarding participant place of work or congregation, family members, or other identifiable information were not collected or were excluded from the transcripts (e.g. if the participant is the leader of a religious organization). Identifiable information was not be reported in any dissemination materials created from this study.

## 3.4 Findings

### 3.4.1 *Study demographics*

A total of 22 in-depth interviews were conducted between the period of March to July 2020. There were no dropouts in this study. All interview participants were of SA descent, where 36% were from India, 27% from Bangladesh, 18% from Pakistan, and 18% from Nepal. A large proportion of the participants were within the 25-35 (41%) age group, with the smallest proportion being from the 55+ age group (5%). An equal number of males and females participated in the interviews. Measures of socioeconomic status found that most participants made more than the minimum yearly household income (30,000), and 95% of participants had a college degree or higher. No participants reported poor health within this study, and 90% reported their health to be either good or very good (Table 3)



**Table 3** *Qualitative interviews study demographics*

	Count (N=22)	Percentage (%)
<b>Gender</b>		
Female	11	50
Male	11	50
<b>Age</b>		
25-35	9	41
35-45	5	23
45-55	7	32
55-65	1	5
<b>Country of Origin</b>		
Bangladesh	6	27
India	8	36
Nepal	4	18
Pakistan	4	18
<b>Income (CAD)</b>		
<15,000	3	14
15-29,999	2	9
30-59,000	9	41
60-79,999	4	18
>80,000	4	18
<b>Highest level of education</b>		
Up to high school	0	0
College degree or higher	21	95
Technical training/some college	1	5
<b>Self-rated health</b>		
Poor	0	0
fair	5	23
good	12	55
very good	5	23

### 3.4.2 *Factors associated with willingness to share health information*

When participants were asked if they would be “willing to share their health information”, 90% of participant responded with a yes. When asked if sharing health information for research to be important to them, 86% responded with a yes, where 1 participant said no. When asked open ended question regarding why participants were willing to share and what factors would make it more or less likely for them to share, participants discussed their personal reasons for sharing along with any reasons that would make them hesitant. Further, participants also discussed thought processes that occurred before the process of sharing their health information. Table 4 summarizes the inductive coding process of these discussions, where nascent codes were collated into overarching themes. Four major themes emerged from the data through the thematic coding process: 1) process of health information sharing, 2) credibility of stakeholder requesting information, 3) outcome of health information sharing, and 4) privacy, security, and confidentiality.

**Table 4.** *Thematic coding results of participants interviews and creation of overarching themes*

<b>Nascent codes</b>	<b>Number of participants reporting code</b>	<b>Number of references of code*</b>	<b>Overarching Theme</b>
<i>Ease of information sharing</i>	2	5	Process of health information sharing
<i>Have a live interaction with the stakeholder requesting information</i>	1	1	
<i>Type and amount of health information shared</i>	10	19	
<i>Credibility of stakeholder requesting information</i>	8	13	Credibility of stakeholder requesting health information
<i>Only comfortable with sharing with healthcare providers</i>	1	1	
<i>Only comfortable with sharing with family friends or other trusted people</i>	1	1	
<i>Health information is being used for public good</i>	5	5	Outcome of health information sharing
<i>Health information sharing is harmful to participant</i>	4	5	

<i>Health information is helpful to stakeholder requesting information</i>	4	5	
<i>Sharing information for health research is important</i>	5	8	
<i>Concerns about privacy and security</i>	9	13	Privacy, security, and confidentiality
<i>Concerns about confidentiality</i>	6	10	
<i>Leaving a digital footprint</i>	1	1	
<i>Previous negative experiences with sharing information</i>	1	1	

\* Number of times this code was expressed by all participants interviewed

## Process of health information sharing

This themes focused on aspects related to the process of sharing health information with the stakeholder, which could include how the information is shared and the type and amount of information shared.

### *Ease of sharing information*

Participants reported that when sharing information was made easy, they were more likely to share. One participant reported that the ‘user-friendliness’ of the platform they were sharing their information would make them more likely to share. In this case, the participant assumed that a survey-type information collection protocol on a computer interface is being used to share their information:

**Interviewer:** right, any other factors that you can think of maybe factors related to the sharing itself, any other... maybe some social factors that might be the reason for you to... make you more likely to share your health information?

**Participant 1:** I think one factor would also have to be the fact that if it's user-friendly, if it's too much and you have to do a bunch of stuff to access it, and every time you have to go in, you have to enter in your password or enter information..

The participant went on to express that having the option to not enter your entire information and not having to go through the process of online registration would make it more likely for them to share. Similar thoughts were expressed by another participant, but this time, with a mobile application that may be requesting information.

**Interviewer:** Great. Um, now are there any specific factors that you can think of that would make it less likely for you to share? So that would just make it very uncomfortable, uh, for you to share your health information? So anything like that?

**Participant 17:** Not really. I think the ease of sharing is the biggest factor. So the last time I tried an app[lication], it asked so many details that it burns me out. I only wish if I could have taken a snap of it [the information] and upload it and you are done. You rather than, uh, rather than keying in information, uh, you know, if the app allows me to take a snap and does its own analysis, I would probably be 80% accurate. But then the attempt of being a hundred percent accurate, it's no point in spending a couple of minutes updating everything that you're eating or you know, doing or Oh, maybe, you know, checking a blood pressure and then uploading it rather than the app, does the job for you, then it makes sense.

The participant expressed frustration in the tedious process of entering their information into the application, along with the worry of it being accurate. It was important for the participants for the data collection interface to help with the information collection through recognizing information in a picture format, or having, in this case, smartphone technology to make the process of entering your information easier. As per the participant, this would ideally make the sharing process not only easier, but more accurate.

#### *Having a live interaction with stakeholder requesting information*

One participant also expressed the importance of having a live, face-to-face interaction with the stakeholder requesting information in a research setting. The participant expressed that live interaction would help them build trust and stated this to be a common theme in the SA populations. Having the live interaction was seen as overcoming a barrier, likely caused by the anxiety of having to share your information to face-less, unknown interface. The participant expressed that even a phone or chat conversation to make the information sharing process more personable would be much better than not having that.

**Interviewer:** So, um, can you think if those aspects that would that make you more likely to share [your information]?

**Participant 4:** Yeah, maybe. Um, I think another thing is, um, having like a, someone else on the other end talk to you like, yeah, like, uh, I don't know, it has to be kind of like a live interaction that if possible, I know sometimes it's not because usually those are just apps and like even talking through a phone as opposed to just like sometimes you have these chats, like how can I help you when you go to a different website? Um, even getting over that barrier and having like a phone conversation will definitely ease, um, that for sure. And I, I know I am not the only one who feels like that. I think this is a common theme in south asian community because of the issue of trust.

#### *Type and amount of health information shared*

The type and amount of information shared was a popular theme that almost half (n=10) participants expressed as a factor related to health information sharing. Although most participants were fine with sharing their information, the sharing was nuanced by the type and amount of information

shared. Generally, participants were hesitant to share information that was of a private nature, or information they believed could be harmful in some way. This harm could be a result of that information shared being used against them. Clinical information, such as blood pressure, height, and weight were usually fine with participants to share. Further, information that was not specific or personal to the person, such as a rare disease or other identifiable information, participants were comfortable to share. Further, the degree of specificity of the information was a factor – where participant 1 reported that although they have no problem sharing the quadrant of Calgary she lives in, they would have a problem with the specific location. Having the choice of specificity when sharing health information is something the participant appreciated.

**Interviewer:** Sure, so can you think of factors that could really be overcome when for you to feel comfortable in sharing health information to a mobile application? So, you know, just make you really comfortable and just have zero doubts in your mind in terms of sharing your information with a mobile application, if you can think of certain factors that could be overcome to help you feel that way, if you could describe them or talk about them now.

**Participant 1:** Oh okay, so let me know if I'm answering your question correctly, too, so one thing I like when I give away information, is like, I don't mind giving away my information, but I would be a LOT more comfortable is when I'm giving away my information the is not so specific for example. So for example, if you ask me what part of the city I live in, and I had the option of giving you just a quadrant of my city, I would feel a lot more comfortable than rather than giving my specific address, or if my age group, I prefer to have it within a group, rather than the exact number. I'm more comfortable with my age when given that out, but my..the.. extent to which the specific personal information that you give, I would be a lot more comfortable.

Another participant explained that the sharing process could be a weighing of risk, where depending on the circumstance, they would share certain types of information depending on if they felt it was worthwhile or safe to them. Participant 2 also shared specific types of health information they were willing to share, all under the understanding that these types would be least harmful to them if they were shared. Participant 8 expressed the fear of fraud if certain types of information was shared, such as the social insurance number or date of birth.

**Participant 2:** Um, I would say just those basic information probably regarding my person last name and um, no, it is your first and last name and if they need my [inaudible] probably date of birth. I am also not pretty sure about date of birth. Probably I would prefer not to, but I mean what about they need and um, I if we feel like it's not too confidential to me, depending on situation, I will probably say so. I would say first and last name and if you need my like blood group, if they want to know or, or any blood pressure measurement or height. Weight.

**Participant 8:** Like sometime your information get leaked. Like you know, your, your personal information, then people use it for other reason. For instance, if somebody know my date of birth and my social insurance number, there will be fraud against me, they can find, people can do fraud stuff, right? So if they know my health information, it is just adding to that. So they know detail about me. Right. So..

### Credibility of stakeholder requesting information

The person, organization, or institution who is requesting the information was an important factor associated with sharing health information and was expressed by almost half the participant (n=10). Credibility, being the quality of trustworthiness or believability, was an important aspect of the stakeholder for participants. If the stakeholder requesting the information was credible, the participant felt safe to share their information

**Participant 1:** And again, the source of who is providing that? So for example, if I went to be provided and it was just some random pharmaceutical company that wanted me to put my information in there, I do not think I would be inclined to do that. But for example if it was my doctor's office and it was supported by the government of Alberta..Yeah, I am like... And I would be more willing to put my information in it.

**Participant 18:** If it was not developed by a company like Apple or Microsoft, Google or like the app developers have to be vetted or verified or have a bigger name or if it is by the government of Canada, right. Or health Canada. Right. Um, I would be very smart to give my data there, not that any data is safe, but it will be safer than most of it will be the only decision I would believe.

**Participant 7 (08:37):** Uh, if it is like, you know, mostly if it is the organization, [inaudible] lets say Alberta health services and if you have an research or if someone is belonged or if someone is getting funding for AHS or something like that. If it is reliable organization who is doing research, I probably that, I would be more comfortable.



Participants 1, 18, and 7 give examples of specific organization such as Alberta Health Services (AHS) or Health Canada as trusted organization that they would be willing to give their information to. Even stakeholder affiliations (such as funding) from such organization as AHS were enough for certain participants to feel comfortable when sharing their information. The results also show a comparison in the types of stakeholders that could request information. For example, participant 1 indicated hesitancy to share with pharmaceutical companies, which are operated on a for-profit basis, as compared to government essential services such as health care organization. Both organizations may be open to criticisms about trust and safety of data, however participants still trusted government health organization more, partly due to their ultimate use of the information they offered. On a more personal level, other participants did express that they only felt comfortable sharing information to their physicians or healthcare providers, or very close family or friends.

#### Outcome of health information sharing

Outcomes of the information that is being shared by participants was the most commonly coded theme and is closely related to the credibility of the stakeholder requesting information. Participants reflected deeply on what their information would be used for and what were the benefits to their information sharing to them personally and to their communities. Again, a weighing aspect was used where participants share their information if they understood the benefit it could have for them:

**Interviewer:** Okay. Um, would, can you think of any factors that would make it more likely for you to share information to an application? So we already talked about, you know, data privacy. Um, is there anything else that you can add that would really make it comfortable for you to share?

**Participant 17:** Primarily it is about what I get out of sharing that information. So if I do not get anything then, I mean it's a waste of time and then I would not want to do that. But yeah, you know, it does that with me. If it's a, it's a smart app and, you know, it does tell me that as in you've walked so many steps and you've consumed so much of food and, or maybe you're not just says that's two hours and even not had water, something of that size, then you really don't mind.

**Participant 2:** Um, I would then mind to put some information unless I know it's harming me or it's collecting my information and it's effecting on me, on the kind of, I know, kind of harmful way unless I know. And so far I am pretty careful about putting my information anywhere I normally avoid most of the time that if I feel like it's, um, it's going to help me most, I will compare actually to see which will get it. Does it happen kind of good impact, more or bad impact more? And base it on that. And I feel like I am, I normally do that a lot, especially my blood pressure or height, weight unless it's not my sin number. Yeah. So, so far this information, so I feel like it is a general information.

### Sharing health information for research

Overall, participants expressed an altruistic attitude towards sharing, where they were more willing to share if it meant that the sharing process could benefit the community. This was especially true when participants were asked if they are willing to share their health information for research. Participants understood and were able to articulate the benefits of research on themselves individually and also communities and were more willing to share if they knew their information was being used for a good purpose.

**Interviewer:** So you talked about, you know, if it is, you know, you talked about if it's used for community wellness, that is something that would make you feel more comfortable to share. Is there anything else that you can say to that?

**Participant 3:** Um, I say my purpose is if something helpful for people. Uh, so I am okay with that. Like if my information help the other people to get some positive feedback, some kind of concern about, yes, I am okay with that.

**Participant 1:** I think I would say that it helped provide better tools or find better message. I do not know, I don't know if as the right terminology, but for dealing with an illness. So if you are able to study a large group of people, and get information from them, you might notice that there's common factors in them and that might be a problem area that we can be in solving. So I definitely believe in contributing to research related health in that way, as well,

One participant (participant 10) also expressed their understand in collecting information for certain ethnic groups and its positive effects on health research and informing communities.

The participants emphasized the benefit this could have for future generations of ethnic groups.

**Participant 10:** Mmm. Mainly because, um, I mean throughout my whole life, um, I, I mean this is my own understanding from a layperson's, this one, I find that, uh, um, different ethnic groups have tendency to get different diseases and, you know, so I would be, um, you know, curious to know with the changing diet, like it has impact in, you know, they do seem that that's make, uh, you know, tendency to get those diseases and then, you know, that will be a learning for us and you know, for all future generations to, you know, keep improving the dietary plans. Right. So I think that the search would help future generations. So I will be happy to have that shared with research.

Themes related to credibility of the stakeholder conducting research, outcome of the information shared, and confidentiality of information shared intersect for some participants when they express motivation to share, but only if the sharing process is safe for them and the outcomes of the research is not harmful in any way. Further, participants expressed that they are more likely to participate in research from a known source, such as a trusted researcher, as compared to a survey conducted through computer technology. Further, research transparency was important for one participant (participant 4) who seemed to be informed about the academic research process, including dissemination of research findings. The participants expressed the importance of transparency in the research process and keeping them informed about the way their information is used along with how the research is funded and will be disseminated.

**Participant 2:** Uh, used for research purposes. Um, yes, I, I do, but I have to know the source is safe. It is really for research because I did find lots of, um, kind of, um, the app or does sometime just, you know, quick something pop up the just do a survey, peer research. So, but if it just something pop up and ask me to do ours for research, I definitely will not do that. But if I know someone is trusted and it will help in the research, I am willing to help.

**Participant 4:** I think more, more transparency in a way. Um, like what you had sent me, like that email with the information is great, but maybe even, and I'm probably saying this from an academic standpoint, like I would love to know more information, more research about, um, like the purpose of the research. Who like funded all of those things in a more detailed way to help me understand what I'm getting myself into? So just having like that ongoing conversation ongoing like transparency and not like this one-off interview kind of. That is it. That is like I get my gift

card and I'm kind of like done with that. I need some, I, if I'm contributing something valuable to an interview, I need to know if, um, that was going to be used in an article and if it is published, I should be notified that, you know, I have, we have published this in disability and society or any other kind of journal or wherever, not just the journal, but like my information was presented at this conference or things like that.

### Privacy, security, and confidentiality

Issues with privacy, security and confidentiality of data shared was a factor which was explicitly reported by 9 participants. The results suggest that this is an important theme that threads through the other discussed results. Within the process of health information sharing theme, having live interactions with the stakeholder requesting information involves trust. Further, the type and amount of health information that participants share depends on their comfort in the privacy and security of their data. When it comes to the credibility of the stakeholder requesting information and outcomes of the information sharing process, confidentiality of the data weighs heavily in the decision of participants to share. For example, participants understand that certain stakeholder with better credibility may be able to assure data confidentiality as compared to others. One participant reports:

**Participant 10:** Um, if I know who is accessing it and we find no, the security of that, uh, information collection data, like, you know, how secure that is, then I would be more likely to share. Yeah.

Further, anonymization was important for participants, where if they are going to share data that could be potentially sensitive, they would like to share anonymously.

**Interviewer:** Okay. Now, are there any factors that would make it more likely for you to share information to a mobile application?

**Participant 7:** If I am pretty sure that my personal information will not be shared. It is going to be, if it's going to be an anonymous or something, probably I'll be more confident sharing my stuff.

This is especially important within the context of the outcome of the health information sharing, where participants were hesitant to share if the outcome of the sharing process violated

their privacy and influenced their daily lives in a negative way. One participant reports the negative effect this could have in their work life:

**Interviewer:** Now I guess the opposite of that question. So are there any factors that would make you less likely to share that would just really discourage you from sharing?

**Participant 18:** Um, if it is a disease that uh, if it is unique? No, I do not think so. I, there was an example of coming to my head, but I do not think it was just something that, uh, that core thing back in my job. If I am working in a job prior to certain kind of health standard, I would definitely be, uh, not normally willing to share all the data because I'd like to keep a secret if I can to the fact of my work.

Overall, participants expressed that having the autonomy to conduct their own investigation into who they are giving their information to and the ability to weigh risks associated with sharing information as important factors to sharing health information

**Participant 22:** Like if it has good reputation or if I have heard good things about it, but I've seen good research about that kind of,

**Interviewer:** So like word of mouth is important to you

**Participant 22:** Sometimes. Not really, but I will do my own verification.

**Interviewer:** Right. Okay. So you do your own research and you sort of find that this is useful or not, or good for you and then you continue to use.

**Participant 22:** Yeah.

### 3.4.3 *Community factors and solutions to sharing health information*

Participants in the study were asked to focus on their respective communities (defined as a group the participant most identifies with) and to share their views on the community

perceptions of sharing health information. Specifically, participants were asked to share any barriers and solution to sharing health information within the community. Participants shared multiple factors that influenced information sharing within the community, which are presented in Table 5.

The thematic coding process revealed two major themes within the context of community perspectives related to sharing health information. These included cultural aspects to sharing health information and community knowledge about the health information sharing process. Participants suggested barriers and solutions within these themes. Other participants also reported there were no perceivable barriers to sharing health information within their communities. Although this was not considered as a thematic factor associated with sharing health information, it will also be discussed.

**Table 5.** *Thematic coding results of participants interviews and creation of overarching themes is response to question about community views on sharing health information.*

<b>Nascent codes</b>	<b>Number of participants reporting code</b>	<b>Number of references of code*</b>	<b>Overarching Theme</b>
<i>Sensitivity of topic when sharing</i>	2	3	Cultural aspects related to sharing information
<i>'Cultural barrier' to sharing health information</i>	5	5	
<i>Knowledge about healthcare system</i>	1	1	
<i>Sharing preferences differ in the native versus Canadian community contexts</i>	6	8	
<i>Stigma around sharing health information</i>	4	4	
<i>Participants do not know the benefits of sharing information**</i>	8	10	Knowledge about information sharing
<i>Community education and sharing health information**</i>	5	5	
<i>Trust and sharing health information**</i>	4	5	

\* Number of times this code was expressed by all participants interviewed  
\*\* Participants also reported these codes as possible solutions to encourage information sharing within the community

### Cultural aspects of related to sharing information

Participants (N=11) reported the cultural aspects related to their community as predominantly barriers associated with health information sharing. In order to describe 'culture'

as a factor related to information sharing, participants used words such as *traditionally speaking*, *society*, *religious customs*, and *the way it is back home*. Together, these terms attempt to encapsulate the collective views of a distinct society, in this case, people of SA descent.

Participants understood that a cultural barrier existed within the community when sharing health information, where the SA community were not willing to discuss specific aspects of their life, including certain health issues. One participant stated:

**Interviewer:** Thinking about that community, can you share with me, uh, about the general feeling about sharing health information and can you think of any barriers to sharing health information? And if you can think of any barriers, can you think of factors that can overcome these barriers?

**Participant 6:** Yeah, we have the cultural barrier, or some of the diseases we do not want to share. I have to say something,

**Interviewer:** Right. So do you think that is a big barrier in the community?

Participant 6: Yes. Yes. Not only for the health kind of information, we [the community] have not been open to some things about health, wealth, and property, we are not very willing to say it, not even within the community.

This cultural aspect of information sharing can be related to the sensitivity of certain topics. One participant commented on how certain language can make people within their community uncomfortable and resistant to discussing sensitive health topics (e.g., reproductive health).

**Participant 1:** I think that, for me, what I did was I just was like, Okay, well why is this conversation not normally? And then bringing community experts that actually talk about the benefits of referring to your vagina as a vagina for example, is actually really important. You know what I mean? And like, stuff like that, we've also done stuff at work, where you also do health campaigns and having fitness place at lunch hour or promoting the fact that you can actually take a break, and go for a walk and how that's actually helpful for you. So having stuff like that has been helpful, but more so I think it is just beginning to have that conversation, that kind of changes me that changes the dialogue and being there for quite some time, so that's been beneficial for me.



This aspect of cultural influence on information sharing is closely related to stigma around sharing certain types of information within the community. Stigma around sharing information was predominantly related to the type of information the community was willing to share, which was information that was not identifiable, or did not illicit ostracization within the community.

**Participant 17:** So I think when I have to talk about Indian or issues more on that side, the social stigma attached a huge impact on sharing information. For example, somebody having HIV positive who are suffering from AIDS, he or she will never, never share because there is a social stigma. Um, uh, people would not sharing information or including myself. Also, information like community of anything that is contagious. Uh, again, I think one influencing factor is that they might not be well received in the social gap or people not wanting to engage with them socially. So, uh, so that's where there is an issue, uh, sharing information.

In order to understand why participants reported that their community felt sensitive or stigmatized about sharing certain types of information, participants made comparisons of the differing contexts in their native country, as compared to Canada. Being brought up with certain values in their native country influenced how the community reacted towards the idea of sharing their health information in Canada. Again, participants spoke about these values and practices with an implied sense of collective within the community. Further, some participants felt there was a difference in community perceptions of information sharing in their native country as compared to the Canadian context, being more accepting within the Canadian context *and* vice-versa. As one participant mentioned, sharing preferences were more open in their native country (Bangladesh) as compared to Canada.

**Participant 2:** If I talk about my community, where it belongs to Bangladeshi community, um, I guess now they are more careful. But my experience when I was in my country, they wouldn't mind sharing their information at all. They do not even, they don't even, I guess don't know them. Whereas privacy and no, like they would not pretty much care. Like really, I think they do not know. Most of them. They do not know that, um, or same [inaudible]. They do not know what the information can be used. And it could be harmful on them. So

**Interviewer:** would you say that the Bangladeshi community here is the same or would you say that their different?

**Participant 2:** Um, no, I would say it is different here. I guess they are pretty, um, very cautious and very thinkable before giving, I guess they think about it. So here in my country I think opposite.

Another participant noted that the openness in sharing information in the native-country results in open sharing in the Canadian context also:

**Interviewer:** I mean, the Asian community, they are sort of less worried about sharing and they're more open

**Participant 22:** I think. But then yeah.

**Interviewer:** Can you explain why that would be?

**Participant 22:** I think that that's because where they come from back home and like, they are, these things are not considered as bad sharing Everybody knows if it's like the family system and all the people know one, everyone, but in the Western culture everybody's on their own and they don't even share much stuff within their family that they don't want to. And there is no social pressure. So in an Asian community, that is not considered bad to share your information if they're not well or sick something, but nothing like posted everybody's make more or less. Yeah.

Further, participants highlighted the healthcare context within Canada as an important determinant in information sharing preferences. Trustworthiness of the government and confidentiality related to their shared information were both aspects of the native-country context that participants reported that influenced their sharing preferences. Participants explained that knowledge and understanding of the Canadian healthcare system would help in improving sharing preferences in their community. This is especially true for newly immigrated community members that may not trust the new system they have been introduced to, simply because they do not know it as compared to community members who have been in Canada longer.

**Participant 20:** First of all, we have to, to educate the community people in about, uh, the, inform them about, uh, health system, uh, uh, social structure, uh, healthcare structure, how to navigate that, how to go to the physician, how to make the new doctor, that kind of thing. So if

we are able to provide the basic information for them and educate them, inform them about the positivity of those kinds of things, maybe they will change and they will certainly share some information which will be beneficial for the [inaudible] for the only few things to make the attendees in the system. Otherwise they will not.

**Participant 20:** that they have to navigate when you know a lot of people from the community, they first immigrated here, it is very hard for them and with the language barrier and everything.

**Interviewer:** But do you think it is the same for people who have been here for a long time?

**Participant 20:** Um, the people there so if they are here so and then learned that many things would be the private eye and the people think that everything should be kept private. So the longer the people stay in, in Canada, then they are unwilling to share the information. I would say.

The comparison of the native-country and Canadian context by the community members as reported by participants of the study is closely associated with age and sharing preferences. Participants who reported that community members' native-country cultural aspects associated with sharing information could be due to a generational difference. Participants explained that older generation community members are more 'traditional' and may not be interested in sharing their information as compared to the younger generation, as they have more exposure to the native-country context.

**Participant 16:** Uh, yeah. Um, I would, uh, I would, I would say like, they, they do not have, you know, that kind of a traditional background with which they were brought up. Um, as we had the 50 years back, uh, when, um, you know, in my parents taught us to be like more intro worked or you know, more, more secured or more, you know, um, it's, it was a nuclear family group, so everything through also her own home and, uh, you know, family, everything. But right now the generation is more willing to come out of the nucleus family. Uh, they are living like separate, uh, like, uh, living together or you know, they do whatever they want, all these things, uh, you know, giving them more, kind of a freedom to do whatever they want to share whatever they want. Um, but, uh, as a new guest, family grown, people like me, uh, it is pretty hard to get information out of the family

#### Knowledge about information sharing process

Knowledge about the information sharing process is a large theme that was reported by participants, and summarized perceptions about the benefits and challenges associated with the sharing process. A prominent theme was trust in the sharing process, where participants reported

that the community is perceptive to the trustworthiness of the institutions requesting the information and would be more willing to share with certain individuals as compared to others. One participant indicated that community health services are important for community members to feel comfortable in sharing their information, who would otherwise only share with their healthcare providers:

**Interviewer:** Right. Okay. Now, uh, okay. So if you can think of any barriers, can you think of any solutions to those barriers that would help people share more in your community?

**Participant 3:** Mm, uh, currently so far you do not find any kind of barriers. So if there is barriers, maybe community health service can um, can help them to, uh, yeah, find out the solution of that problem because as people who can, um, some people are not willing to share that their personal information with within the community, but they are more willing to share with a healthcare provider to get a solution to solve their problems.

Misuse of information is a real fear within their community, which again some participants stated that this may be an outcome of the lack of knowledge in the sharing process, specifically the reason for sharing:

**Participant 20:** it depends because people do not know why, why I have to share my personal information. Maybe they don't know the reason. Maybe they already scared about the being misused their information. Maybe they think somebody will be, uh, at bond get advantage from their information. So there is so many, so many reasons people don't know. People don't have the knowledge about it.

Participants reported that more communication with the community regarding health issues or the research that is being conducted will aid in more information sharing amongst community members. This will allow for exposure of community members to the phenomenon of interest, and also help community members build trust in the stakeholder that is requesting the information. One participant commented that changing community preferences is a slow process

and multiple modes of communication that are relevant to the community should be utilized.

This is especially true for stigmatizing health information (e.g., contagious disease) which as participant 17 suggest below, can be de-stigmatized through conversation and education.

**Participant 12:** Uh, so they need to come forward and, uh, have a lot of forums. They can go and have a discuss discussing these things widely. Uh, so that people know when there is the discussions on the TV or in the news, then people listening this team and that will change slowly, slowly the whole community to be more actively taking part of this kind of surveys and information. So people need more like educational things, uh, to be placed, uh, in different media. Social media is so, you know, people slowly, slowly change their mind. I think these are the shortcomings for my, my group that I know or the community that I work or are the community that, uh, presents hair. Uh, so that is all I think.

----

**Interviewer:** That's a great, anything else that you can, that you can think of in terms of how to overcome some of these barriers?

**Participant 17:** Um, so it's a, it's more about holding the data for privacy. Uh, it's more about saying that that information will be used to solve problems and instead of negative publicity or commercialization of products, uh, be the, if somebody's getting convinced that the data being collected is being collected for the good. And probably if I talk about my genetic disorders are contagious diseases or, uh, even something like an HIV, uh, the idea is, you know, to help me or to help the generations and future would solve this barrier. I'm not sure if we're going to ever remove the social stigma around it, but that's another thing that, is that something that we can look at.

One participant shared that building trust within the community, especially between large scaled organizations such as Alberta Health Services (AHS) required understanding of the community's contexts, including newcomer community members that may face a language barrier. Trust also includes communication with the community to emphasize the need to collect information in the first place or, what good will come to the community if they share their information. The importance of the purpose of collecting information from the community and building trust was also highlighted by another participant (participant 6), who stated that community members will be more willing to share within their own community as compared to outside of the community. Although the participant described this as a barrier, this can certainly be viewed as a facilitator to encourage individuals to share if they know the community will benefit from the sharing process.

**Participant 4:** Part of the reason is they don't know. They're not educated in the ways that Canada does things. So, um, their own rights and responsibility, the way that the Canadian government runs all of these information, a lot of people are not used to like the transparency thing. Um, and even in their own country too. Like they, a lot of them come from different countries where the is in or out or the healthcare is not as strong. So they being in a foreign country with new information and new language, um, like that adds to their stress that they don't really, I feel like there's not, there's no trust established yet with like the mainstream healthcare like AHS or whoever. Um, for them to provide that information, like they ha they're having to trust is the foundation of everything. They, they are not gonna come to you if they don't trust you or if they don't like you that you're going to help them in some way.

----

**Participant 6:** Okay. Uh, uh, this like, why you need to share? We don't know why we need to share, we are going to share it that makes a difference. Like the purpose or good mission, we can do. Definitely like more than that without knowing this thing. We are more willing to share the information if we know the purpose of the thing. But one thing I can say, it is more it is more possibility to share information within the community than other community. If we can keep it our of community, we may want to share the same advances with other community people. There is a barrier, they are most comfortable to say it within our community.

## 3.5 Triangulation results

### 3.5.1 *Triangulation methods*

Triangulation is multimethod approach to improve the confidence in the research results and to overcome research bias. Triangulation methods were used here to synthesize the user reported factors related to willingness to share health information from the rapid literature review and the qualitative interviews. Multiple techniques exist for the triangulation of results within qualitative literature: 1) methodological triangulation; 2) data triangulation; 3) theoretical triangulation; 4) investigator triangulation. Here, a methodological triangulation protocol is used as suggested by Farmer et al. (73) that outlines a stepwise systematic way to allow for meaningful comparison between two data sources. Although this protocol is primarily used for comparing two primary sources, this study will triangulate themes related to willingness to share health information as found through rapid review of the literature, and themes found during in-person interviews.

The triangulation involved the sorting of findings from both data sources (literature review and qualitative interviews) into similarly categorized segments that address the research question. The categorization involved sorting the major themes related to willingness to share health information.

After identifying the themes from each data source, the findings were compared to determine the degree of convergence and agreement in both the meaning and prominence of the theme. The degree of agreement was at two levels: 1) agreement: the two data sources agreed on the theme 3) silence: only one data sources reported that theme. Next, within chapter 4, discussion, the nature, and scope of the topic areas in each data source was compared to enhance

the completeness of the united set of findings. This stage will also present an opportunity to define the key difference in the scope/coverage of findings and themes in each data source.

### *3.5.2 Triangulation results*

The triangulation results are shown in Figure 5. The themes that were agreement between the two data sources are shown first, where the sizes of the circles represent the relative reporting of the theme. For the rapid review, this meant the number of papers reporting that theme, and for qualitative interviews, the size of the circles is the number of participants that reported the theme.



**Figure 5** Visualization of the triangulated factors associated with willingness to share health information from rapid review of literature and qualitative interviews



Themes that overlapped between the two data sources included factors associated with sharing health information related to the stakeholder requesting information, outcomes of health information used, type and amount of health information that needs to be shared, and security of health information. Privacy and security of health information also overlapped as a factor associated with sharing health information and was relatively more reported in both data sources. The rapid review data also provided unique evidence for sociodemographic factors, incentives to share health information, and previous experience with information technology as factors

associated with sharing health information. The qualitative interviews provided evidence for the influences of the cultural environment, the process of information sharing, and knowledge of information sharing.

## Chapter 4: Discussion

### 4.1 Summary of results

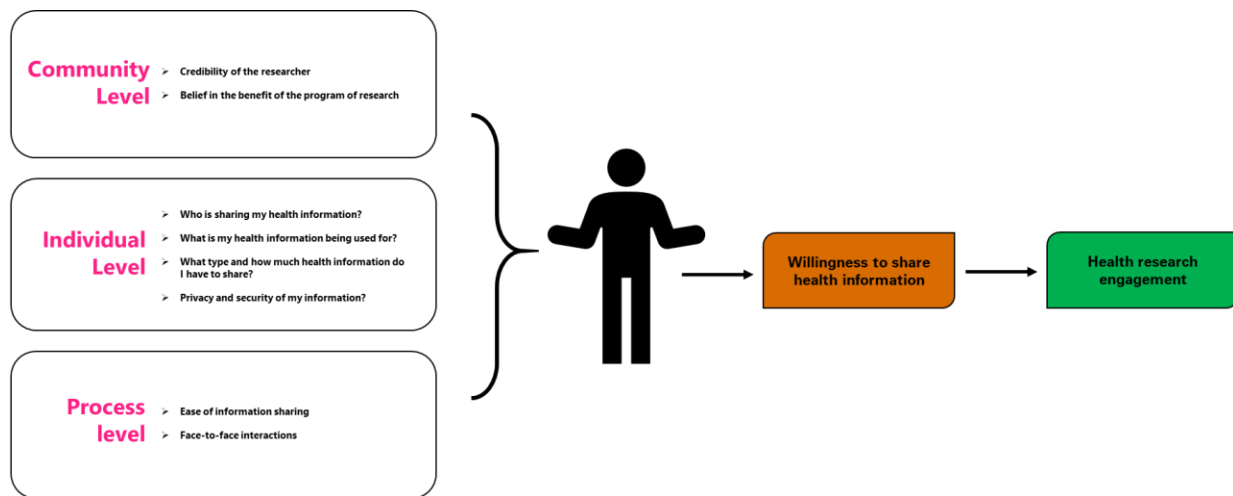
Availability of health data is lacking for certain ethnic groups, which can have negative outcomes in identifying disadvantaged populations and effective preventative strategies. In order to increase data availability, ethnocultural communities must be willing to sharing their information to be truly engaged in research. To address this, the current study aimed to understand factors associated with willingness to share health information in a SA population and did so through a rapid review of the published literature and qualitative interviews. The triangulation of the rapid review and interview results showed themes that overlapped and were unique amongst the two data sources. Overall, themes associated with the type and amount of health information shared, privacy and security of health information, outcome of health information, and the stakeholder requesting health information are important themes in both the rapid review and qualitative interview results. The qualitative interviews with SA participants revealed that community knowledge and information about the sharing process along with the cultural aspects of information sharing are important.

The factors associated with willingness to share health information reported here ultimately suggest the importance of developing trust. Trust is complicated, and often a philosophical concept, but generally defined as imparting authority to another and accepting the vulnerability associated with that, given that a set of expectations are met (74). When sharing their health information, an agreement of trust is made between the individual sharing and the stakeholder accepting the information. Participants share their information accepting that they have become vulnerable by sharing their intellectual capital, and rightly expect the outcome of that sharing process to meet their expectations. It is then up to the stakeholder to upkeep those

expectations, or not, ultimately building or eroding that trust. Trust during the sharing process is multifaceted, and the factors associated with willingness to share health information that were found through this study illuminate some of these facets. When assessing the overlapping and unique themes found in this study, trust seems to operate at multiple levels: 1) community level, 2) individual level, and 3) process level (Figure 6).

The results of this study have also illuminated the importance of the sociodemographic and cultural components of participants willingness to share health information. These are aspects of a community that cannot be changed, and therefore must be accommodated and respected by the researcher and other stakeholders. The ethnocultural lens was an important finding that primarily arose from the qualitative interviews with SA community members, who reported that their community considered aspects of their religion, their customs *back home*, and generational differences as important when deciding to share their information. Researchers have appreciated that a ‘rotating lens’ that shifts to accommodate the perspectives of racialized and minority ethnic communities is an important aspect of successful research. This has been done to understand nutritional literacy and engagement with hard to reach communities, amongst others (75, 76). These ethnocultural and sociodemographic aspects of willingness to share health information are recurring themes in the following discussion of the three levels of trust.

**Figure 6** Factors associated with sharing health information and their influence on trust at multiple levels



## 4.2 Community level trust

Community level trust was a major discussion point within the qualitative interviews. Participants in this study understood the difficulties of engaging an entire community in health research, and more so when sharing their data, where building a level of trust can be a difficult and slow process.

This includes the importance of the credibility of the stakeholder requesting the information. Credibility in the institutions that back-up the stakeholder are important, which was especially true if the institutions were well-known and had a good reputation. The credibility aspect is particularly important for ethnocultural communities who have had historically less access to power and privilege and have been exploited in the name of health research. Exploitation has ranged from direct harm, to using information to stigmatize populations. Popular examples include the Tuskegee syphilis study, which exploited black Americans, along with the use of race-based data to fuel state sponsored propaganda against ethnic groups (77, 78). Credibility of the stakeholders can also mean that stakeholder appreciate the diversity within

communities and are willing to engage with the community to understand their perspectives (79). Further, the relatively less willingness to share health information that is sensitive in nature may be a universal aspect of sharing for all participants, but the compounding of historical research practices, mutual stereotypes, and differences in cultures and ethnicity can influence trust building between researcher and ethnic communities.

Having knowledge about the purpose, benefits, and downsides to sharing their health information was also an important factor associated with willingness to share information. Understanding that sharing health information can benefit the participants individually or benefit the entire ethnocultural community builds resilience and contributes to the sense of community. A recent scoping review of barrier and facilitators of recruitment of SA participants found that engagement with health research was low in this population due to lack of knowledge about the scientific importance of the work, poor understanding of the research intentions, and the perception that the research benefits will not extend to their community (79). This is especially true when health research that they are giving their data to, can directly benefit the community researchers are trying to engage with.

### 4.3 Individual level trust

The results of this study show that individual level trust is built by a data sharing environment where participants feel safe in sharing their health information. These contextual factors include the four major themes that agreed between the rapid review of literature and qualitative interviews within the SA population. These factors evidently constitute a major decision-making aspect for participants when sharing health information. These factors include: 1) stakeholder requesting information, 2) outcomes of health information, 3) security and privacy of health information, 4) type and amount of health information shared. More importantly, the

relative importance of these themes in the current study may be due to their interrelatedness and connection with building individual level trust through good research ethics.

The concept of data security and privacy of health data are well explored within the domain of health care, as health information is at times the most intimate, personal, and sensitive information that is maintained by the individual. Within most jurisdictions, privacy laws allow for total control over health information to the individuals, only to be disclosed if consent is authorized. Confidentiality goes a step beyond that and is usually characterized by an agreement between the individuals and stakeholder requesting the information (80). Concerns with the privacy and security of their data was an important aspect of the willingness to share health information within the qualitative component of this study, corroborating the evidence synthesized from published literature in the rapid review. Indeed, participants felt that that they would be more willing to share their health information if the information was going to be protected and private to a degree that they were comfortable with. Other studies have also found the sharing of information to be enhanced within the context of EHRs when privacy and security concerns were addressed (80, 81).

Privacy and security of the data are closely linked to the outcome of that data, the stakeholder requesting the health information, and the type and amount of information shared. Participants are more likely to share their information if they feel they can have granular control over their shared data, which is also a form of maintaining privacy. If participants are able to control how much of their data and what type they are able to share, they have more control and feel safer in the sharing process. Participants also feel safe when they know the information is being used for its intended purpose, which is also communicated to them. For example, studies

have shown the socio-cultural aspects of collecting genetic information, which can be harmful or beneficial to the participants based on their familial and social circumstances (82).

Outcome of the health information has a facet of altruism, where participants in the qualitative interviews reported they were more willing to share if they knew the outcome is something positive for themselves, their families, or their communities. Altruism and positive outlook on the ability of the healthcare system, research studies, or institution stakeholders to be able to make a positive change, are reported psychosocial factors that influence information sharing behaviors (74).

Finally, who is using the health information is an important aspect of trust. Participants within the study regularly stated they much preferred sharing their information with their physician or whomever primarily cared for them, health-wise. Studies have reported that individuals who regularly visit their physicians have a psychosocial expectation of benefit and trust from the physicians (83). Having that interpersonal relationship built on the basis of day to day trust may be an important aspect to creating a space where health information sharing can occur. The lack of sharing of participants to other stakeholders, including organizations not associated with the healthcare of the participant, also points to the lack of trust and scepticism about the maintenance of privacy by these organizations. Participants of the qualitative component of this study often stated they trust sharing their information to stakeholder if they know the stakeholder is somehow affiliated with well known government organizations such as Alberta Health Services, as compared to pharmaceuticals. This provides evidence for the fact that the quality, length, and nature of the trusted relationship between the individual and stakeholder are an important factor when deciding to share health information (74).



#### 4.4 Process level trust

There is a paucity of literature describing the process of information sharing as having a role in participants willingness to share their information. Within ethnocultural communities, the ease of information sharing process can have a large influence on whether or not a participant will engage in sharing their health information. Factors as simple as language barriers, health literacy, and type of data collection instrument can determine a study's success in engaging its population of interest (84). Also, complex factors, such as the sociodemographic diversity within an ethnocultural community must also be addressed. For example, some ethnocultural communities, including the SA communities, may have first and second generations migrants who may have differing needs when it comes to ease of information sharing (85). Older generation participants may require translation services or a different mode of data collection (face-to-face versus on the phone) to successfully share their information.

#### 4.5 Implications for health research engagement in ethnocultural communities

The results of this study show that research organizations should introduce policy changes that aim to develop a mutually beneficial information sharing partnership between the community of interest, with an emphasis on the ethnocultural and social-ecological aspects of health. Ultimately to motivate individuals to share their health information, their situations within their community must be appreciated, and equal power should be divided amongst the researcher and community members on the control and direction of the data-sharing partnership, a sign of true equality (86). This is compared to researchers controlling the collection, analysis, and dissemination of the information along with reaping its benefits, with little input from participants. Indeed, the global health research field has many examples of the wariness of ethnocultural communities to have western researchers engage with them for information. These

researchers have then been criticized to place their professional and academic interests above the needs of the community (87) . To build effective data-sharing partnerships, researchers should be able to work in collaboration with community members, and understand the community living, working, and socializing conditions. To do this, credible and respectful access to the community should be pursued by building relationships with community champions and organizations that have a long-standing dedication to their communities. This can be done through training, and development of guidelines that assist within building such relationships, which can exist at the institutional and national research level.

Although there is a great amount of literature using and describing methodologies that view research participants and the community as partners throughout the research process (e.g., community-based participatory research, integrated knowledge translation), there is little discussion of the process of rapport and building relationships with communities regarding building of an information sharing partnership. Documentation of this process, along with a systematic way of collecting the community perspectives on barriers and facilitators to sharing information has been suggested (83). Indeed, more exploration is required to create policy and guidelines for effective documentation of rapport building.

A deep understanding of conducting ethical research, the abstract nature of maintaining confidentiality, and respect for the individuals and their experiences is essential throughout the research process to develop trust. Many research studies suffer from the simplistic assumption that a single consent form is enough to assure ethical standards for their participants. However, the results of this study show that within an ethnocultural community, more is needed. Indeed, a study can maintain excellent privacy and confidentiality within their protocol but may still conduct research that is framed in a way that is disrespectful towards ethnocultural communities

(88). Understanding that certain communities have been historically disempowered and disenfranchised, researchers should be aware of the untoward influence that they can have on their study participants. Further, as found in this study, it is essential to understand the diversity within a population, along with the individuals ethnocultural context. For example, participants who went through the immigration process hold different, often conflicting, perceptions of information sharing in their native countries as compared to their host country. This is something researchers can benefit from knowing, and address within the study recruitment process. In this case, implementing a culturally sensitive informed consent process and appropriate confidentiality and disclosure policies is essential to address this major factor in participants willingness to share their information. Consent, confidentiality, and disclosure have implication in reassessment of research ethics evaluation processes at the institutional levels, which may need to be improved and adjusted to address differences in conducting research in ethnic communities.

Sharing of health information that is easy, accessible, and feasible for the participant can also cultivate trust. Having evidence informed standards and clear guidelines for collecting health information can not only benefit researchers by increasing reproducibility, but also benefit the information sharing partnership (89). That being said, researchers should consider the population they are hoping to collect information from when choosing or creating these standards. For example, simply measuring the concept of ethnicity can be difficult, as some participants may not see their ethnicity, or diversity within an ethnicity, being reflected in the type of questionnaire they are given. Further incentives are known to increase research engagement and may be an important aspect of building information sharing partnerships in ethnocultural communities. However, simple financial incentives may not be enough to garner

continued information sharing. Studies have demonstrated that incentives for ethnic and minority communities such as co-learning activities and a chance to contribute to the research development, are sustainable incentives that build trusting partnerships (31).

#### 4.6 Limitations, strengths, and next steps

The results of this study should be seen in light of important limitations. Firstly, the rapid review methodology discussed in chapter 2, although a timely way to synthesize evidence, is not systematic and fails to conduct a broader search of the literature, and critically analyse the included studies. For example, the review contained studies with a variable sample size, which could contribute to the generalizability of the results of studies with smaller sample sizes. Further, the included studies report on the incomparable context of individuals, where some participants are hospitalized patients, as compared to the general adult population. A common criticism of the qualitative methodology is its generalizability, where the views reported by the SA participants may not be comparable to other ethnocultural communities. Further, the majority of the interview participants were of high socioeconomic status (income and education), therefore their views may not be generalizable to people of other social groupings.

The study finds its strengths in its unique methodology to triangulate the results from two methods of data collection, resulting in a deeper understanding of the factors associated with willingness to share health information. Further, the study presents a concise reporting of the narrative synthesis of factors associated with willingness to share health information into cohesive themes using a validated thematic coding process.

#### 4.7 Conclusion

With the growing importance of health data, it is imperative that data be available for ethnocultural communities to push forward the understanding of ethnic health disparities. This

study aimed to explore the factors associated with sharing health information within an ethnocultural group through the conduction of a rapid review, and qualitative interviews with SA participants. The triangulated results revealed factors associated with sharing health information that operated at the community, individual, and process level. The factors revolved around the concept of trust, and how developing a trustworthy information sharing partnership can look different within an ethnocultural community. The findings support the need for culturally sensitive and respectful engagement with the community, ethically sound research practices that make participants feel comfortable to share their information, and an easy and incentivised process to share their information feasibly.

An important next step would be a systematic search of the literature where research engagement in building data-sharing partnerships is studied from the perspective of multiple stakeholders. This study discusses implications for researchers to engage with ethnocultural communities to build lasting information sharing partnerships, therefore, studies to empirically measure real engagement outcomes is required. Further, the study points to the development of frameworks that can assist researchers to develop and documents partnerships with ethnocultural communities. Above all, more research in understanding ethnocultural community perspectives in participating in research is needed, with more appreciation for the diversity and complex historical and socio-cultural influences. Finally, as healthcare is becomes increasingly dependant on digital technologies understanding trust and data sharing within the digital health realm and what that means for health research is important.

## References

1. Rose E, Kazemipur A. The role of social capital and ethnocultural characteristics in the employment income of immigrants over time. *Statistics Canada*. 2019. p. 1-16.
2. Rambihar VSJ, D. G. Ethnocultural heart: another challenge for an emerging diversity. *The Canadian journal of cardiology*. 1995;11(5):441-2.
3. Sheth T, Nargundkar M, Chagani K, Anand S, Nair, C, Yusuf S. Classifying ethnicity utilizing the Canadian Mortality Data Base. *Ethnicity & health*. 1997;2(4):287-95.
4. Quan H, Wong A, Johnson D, Ghali WA. The public endorses collection of ethnicity information in hospital: implications Chagani for routine data capture in Canadian health systems. *Healthcare Policy*. 2006;1(3):55.
5. Braveman P. Health disparities and health equity: concepts and measurement. *Annu Rev Public Health*. 2006;27:167-94.
6. Brondolo E, Gallo LC, Myers HF. Race, racism and health: disparities, mechanisms, and interventions. *Journal of behavioral medicine*. 2009;32(1):1.
7. Krieger NJ. Does racism harm health? Did child abuse exist before 1962? On explicit questions, critical science, and current controversies: an ecosocial perspective. *American journal of public health*. 2003;93(2):194-9.
8. Du Mont J, Forte T. Perceived discrimination and self-rated health in Canada: an exploratory study. *BMC Public Health*. 2016;16(1):742.
9. Priest N, Williams DR. Racial discrimination and racial disparities in health. 2018. *Oxford library of psychology. The Oxford handbook of stigma, discrimination, and health, 163-182.*

10. Anand SS, Yusuf S, Vuksan V, Devanesen S, Teo KK, Montague PA, et al. Differences in risk factors, atherosclerosis, and cardiovascular disease between ethnic groups in Canada: the Study of Health Assessment and Risk in Ethnic groups (SHARE). *The lancet*. 2000;356(9226):279-84.
11. Calvasina P, Muntaner C, Quiñonez CJ. Factors associated with unmet dental care needs in Canadian immigrants: an analysis of the longitudinal survey of immigrants to Canada. *BMC Oral Health*. 2014;14(1):1-9.
12. Chiu MJ. Ethnic differences in mental health and race-based data collection. *Healthcare Quarterly*. 2017;20(3):6-9.
13. Ganann R, Sword W, Thabane L, Newbold B, Black M. Predictors of postpartum depression among immigrant women in the year after childbirth. *Journal of Women's Health*. 2016;25(2):155-65.
14. Subedi RP, Rosenberg MWJ. Determinants of the variations in self-reported health status among recent and more established immigrants in Canada. *Social Science and Medicine*. 2014;115:103-10.
15. Veenstra G, Patterson AC. South Asian-White health inequalities in Canada: intersections with gender and immigrant status. *Ethnicity and Health*. 2016;21(6):639-48.
16. Dash S, Shakyawar SK, Sharma M, Kaushik S. Big data in healthcare: management, analysis and future prospects. *Journal of Big Data*. 2019;6(1):54.
17. Gibbs BK, Nsiah-Jefferson L, McHugh MD, Trivedi AN, Prothrow-Stith D. Reducing racial and ethnic health disparities: exploring an outcome-oriented agenda for research and policy. *Journal of Health Politics*. 2006;31(1):185-218.

18. Wang L. Immigrant health, socioeconomic factors and residential neighbourhood characteristics: A comparison of multiple ethnic groups in Canada. *Applied Geography*. 2014;51:90-8.
19. Koehn S, Neysmith S, Kobayashi K, Khamisa H. Revealing the shape of knowledge using an intersectionality lens: Results of a scoping review on the health and health care of ethnocultural minority older adults. *Aging and Society*. 2013;33(3):437.
20. Kramer MS, Platt RW, Wen SW, Joseph K, Allen A, Abrahamowicz M, et al. A new and improved population-based Canadian reference for birth weight for gestational age. *Pediatrics*. 2001;108(2):e35-e.
21. Kressin NR, Chang B-H, Hendricks A, Kazis LE. Agreement between administrative data and patients' self-reports of race/ethnicity. *American Journal of Public Health*. 2003;93(10):1734-9.
22. Moy E, Arispe IE, Holmes JS, Andrews RM. Preparing the national healthcare disparities report: gaps in data for assessing racial, ethnic, and socioeconomic disparities in health care. *Medical Care*. 2005:I9-I16.
23. Siddiqi A, Shahidi FV, Ramraj C, Williams DR. Associations between race, discrimination and risk for chronic disease in a population-based sample from Canada. *Social Science and Medicine*. 2017;194:135-41.
24. Siriwardhana C, Abas M, Siribaddana S, Sumathipala A, Stewart R. Dynamics of resilience in forced migration: a 1-year follow-up study of longitudinal associations with mental health in a conflict-affected, ethnic Muslim population. *BMJ open*. 2015;5(2).



25. Khan M, Kobayashi K, Lee SM, Vang Z. (In) Visible minorities in Canadian health data and research. Population Change and Lifecourse Strategic Knowledge Cluster Discussion Paper Series. 2015;3(1):5.
26. Cowden JD, Flores G, Chow T, Rodriguez P, Chamblee T, Mackey M, et al. Variability in Collection and Use of Race/Ethnicity and Language Data in 93 Pediatric Hospitals. Journal of Racial and Ethnic Health Disparities. 2020:1-9.
27. Newman LA, Kaljee LM. Health disparities and triple-negative breast cancer in African American women: a review. JAMA surgery. 2017;152(5):485-93.
28. Varcoe C, Browne AJ, Wong S, Smye VL. Harms and benefits: collecting ethnicity data in a clinical context. Social Science and Medicine. 2009;68(9):1659-66.
29. Rodney P, Copeland E. The health status of black Canadians: do aggregated racial and ethnic variables hide health disparities? Journal of Health Care for the Poor and Underserved. 2009;20(3):817-23.
30. Lodhia V, Karanja S, Lees S, Bastawrous A. Acceptability, Usability, and Views on Deployment of Peek, a Mobile Phone mHealth Intervention for Eye Care in Kenya: Qualitative Study. JMIR Mhealth Uhealth. 2016;4(2):e30.
31. Delman J, Progovac AM, Flomenhoft T, Delman D, Chambers V, Cook BL. Barriers And Facilitators To Community-Based Participatory Mental Health Care Research For Racial And Ethnic Minorities. Health Affairs. 2019;38(3):391-8.
32. Brynskov M, Foth M. Participatory action research for civic engagement. Civic Media: The MIT Press; 2016. p. 563-80.

33. Mozersky J, Parsons M, Walsh H, Baldwin K, McIntosh T, DuBois J, et al. Research Participant Views regarding Qualitative Data Sharing. *Ethics and Human Research*. 2020;42(2):13-27.
34. Du TC, Lai VS, Cheung W, Cui X. Willingness to share information in a supply chain: A partnership-data-process perspective. *Information and Management*. 2012;49(2):89-98.
35. Whiddett R, Hunter I, Engelbrecht J, Handy J. Patients' attitudes towards sharing their health information. *International Journal of Medical Informatics*. 2006;75(7):530-41.
36. Kim KK, Sankar P, Wilson MD, Haynes SC. Factors affecting willingness to share electronic health data among California consumers. *BMC Med Ethics*. 2017;18(1):25.
37. Medford-Davis LN, Chang L, Rhodes KV. Health Information Exchange: What do patients want? *Health Inform J*. 2017;23(4):268-78.
38. Seltzer E, Goldshear J, Guntuku SC, Grande D, Asch DA, Klinger EV, et al. Patients' willingness to share digital health and non-health data for research: a cross-sectional study. *BMC Med Inform Decis Mak*. 2019;19(1):157.
39. Jamal L, Sapp JC, Lewis K, Yanes T, Facio FM, Biesecker LG, et al. Research participants' attitudes towards the confidentiality of genomic sequence information. *Eur J Hum Genet*. 2014;22(8):964-8.
40. Green J, Thorogood N. *Qualitative methods for health research*: sage; 2018.
41. Tricco AC, Antony J, Zarin W, Strifler L, Ghassemi M, Ivory J, et al. A scoping review of rapid review methods. *BMC Med*. 2015;13:224.
42. Ng E. Canadian Health Measures Survey: A tool for immigrant health research? *Health Reports*. 2015;26:3-9.

43. Anand SSY, S.; Vuksan, V.; Devanesen, S.; Teo, K. K.; Montague, P. A.; Kelemen, L.; Yi, C.; Lonn, E.; Gerstein, H.; Hegele, R. A.; McQueen, M. Differences in risk factors, atherosclerosis, and cardiovascular disease between ethnic groups in Canada: the Study of Health Assessment and Risk in Ethnic groups (SHARE). *Lancet*. 2000;356(9226):279-84.
44. Chiu MA, Peter C.; Manuel, Douglas G.; Tu, Jack V. Comparison of cardiovascular risk profiles among ethnic groups using population health surveys between 1996 and 2007. *CMAJ*. 2010;182(8):E301-10.
45. Brown SM, Bell SK, Roche SD, Dente E, Mueller A, Kim TE, et al. Preferences of Current and Potential Patients and Family Members Regarding Implementation of Electronic Communication Portals in Intensive Care Units. *Ann Am Thorac Soc*. 2016;13(3):391-400.
46. Cocosila M, Archer N. Perceptions of chronically ill and healthy consumers about electronic personal health records: a comparative empirical investigation. *BMJ Open*. 2014;4(7):e005304.
47. Kerath SM, Klein G, Kern M, Shapira I, Witthuhn J, Norohna N, et al. Beliefs and attitudes towards participating in genetic research - a population based cross-sectional study. *BMC Public Health*. 2013;13:114.
48. Spooner KK, Salemi JL, Salihu HM, Zoorob RJ. eHealth patient-provider communication in the United States: interest, inequalities, and predictors. *J Am Med Inform Assoc*. 2017;24(e1):e18-e27.

49. Bartlett G, Macgibbon B, Rubinowicz A, Nease C, Dawes M, Tamblyn R. The Importance of Relevance: Willingness to Share eHealth Data for Family Medicine Research. *Front Public Health*. 2018;6:255.
50. Patel VN, Abramson E, Edwards AM, Cheung MA, Dhopeswarkar RV, Kaushal R. Consumer attitudes toward personal health records in a beacon community. *Am J Manag Care*. 2011;17(4):e104-20.
51. Weitzman ER, Kelemen S, Kaci L, Mandl KD. Willingness to share personal health record data for care improvement and public health: a survey of experienced personal health record users. *BMC Med Inf Decis Mak*. 2012;12:39.
52. Pedersen H, Taylor D, Gilbert M, Achen M, Lester R, Ogilvie G. A cross-sectional survey exploring attitudes towards provincial electronic health record implementation among clients attending the Provincial Sexually Transmitted Infections Clinic in British Columbia. *Sex Transm Infect*. 2015;91(1):44-8.
53. Weitzman ER, Kaci L, Mandl KD. Sharing medical data for health research: the early personal health record experience. *J Med Internet Res*. 2010;12(2):e14.
54. Garrido T, Kanter M, Meng D, Turley M, Wang J, Sue V, et al. Race/ethnicity, personal health record access, and quality of care. *Am J Manag Care*. 2015;21(2):e103-13.
55. Pickard K, Swan M, editors. Big desire to share big health data: a shift in consumer attitudes toward personal health information. 2014 AAAI Spring Symp 2014: Ser.
56. Anderson CL, Agarwal R. The Digitization of Healthcare: Boundary Risks, Emotion, and Consumer Willingness to Disclose Personal Health Information. *Information Systems Research*. 2011;22(3):469-90.

57. Fuji KT, Abbott AA, Galt KA. A qualitative study of how patients with type 2 diabetes use an electronic stand-alone personal health record. *Telemed J E Health*. 2015;21(4):296-300.
58. Padrez KA, Ungar L, Schwartz HA, Smith RJ, Hill S, Antanavicius T, et al. Linking social media and medical record data: a study of adults presenting to an academic, urban emergency department. *BMJ Qual Saf*. 2016;25(6):414-23.
59. Caine K, Hanania R. Patients want granular privacy control over health information in electronic medical records. *J Am Med Inform Assoc*. 2013;20(1):7-15.
60. Courtney KL. Privacy and senior willingness to adopt smart home information technology in residential care facilities. *Methods Inf Med*. 2008;47(1):76-81.
61. Gaylin DS, Moiduddin A, Mohamoud S, Lundeen K, Kelly JA. Public attitudes about health information technology, and its relationship to health care quality, costs, and privacy. *Health Serv Res*. 2011;46(3):920-38.
62. Whiddett R, Hunter I, Engelbrecht J, Handy J. Patients' attitudes towards sharing their health information. *Int J Med Inform*. 2006;75(7):530-41.
63. Teixeira PA, Gordon P, Camhi E, Bakken S. HIV patients' willingness to share personal health information electronically. *Patient Educ Couns*. 2011;84(2):e9-12.
64. Yeo Y, Park J, Roh S, Levkoff S. Use of electronic personal health records (PHRs) for complementary and alternative medicine (CAM) disclosure: Implications for integrative health care. *Complement Ther Med*. 2016;26:108-16.
65. Hasnain-Wynia R, Taylor-Clark K, Anise A. Collecting race, ethnicity, and language data to identify and reduce health disparities: perceptions of health plan enrollees. *Med Care Res Rev*. 2011;68(3):367-81.

66. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. 2007;19(6):349-57.
67. Bradshaw C, Atkinson S, Doody O. Employing a Qualitative Description Approach in Health Care Research. *Glob Qual Nurs Res*. 2017;4:2333393617742282.
68. Edvardsson D, Sjogren K, Lood Q, Bergland A, Kirkevold M, Sandman PO. A person-centred and thriving-promoting intervention in nursing homes - study protocol for the U-Age nursing home multi-centre, non-equivalent controlled group before-after trial. *BMC geriatr*. 2017;17(1):22.
69. Greenfield G. GPs should be rewarded for patient experience to encourage a person centred NHS. *Bmj*. 2014;349:g6422.
70. Calgary named most livable city in North America 2019 [Available from: <https://calgaryeconomicdevelopment.com/newsroom/calgary-named-most-livable-city-in-north-america/#:~:text=For%20the%2010th%20year,livable%20city%20in%20North%20America>].
71. Calgary demographics Calgary economic development [Available from: <https://calgaryeconomicdevelopment.com/research-and-reports/demographics-lp/demographics/>].
72. Castillo-Montoya M. Preparing for interview research: The interview protocol refinement framework. *Qualitative Report*. 2016;21(5):811-31.
73. Braun V, Clarke V. *Thematic analysis*. 2012.
74. Krefling L. Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*. 1991;45(3):214-22.
75. Guba EG, Lincoln YS. Competing paradigms in qualitative research. *Handbook of Qualitative Research*. 1994;2(163-194):105.

76. Finlay L, Gough B. Reflexivity: A practical guide for researchers in health and social sciences: John Wiley & Sons; 2008.
77. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and implementing a triangulation protocol for qualitative health research. *Qual Health Res.* 2006;16(3):377-94.
78. Platt J, Kardia S. Public trust in health information sharing: implications for biobanking and electronic health record systems. *Journal of Personalized Medicine.* 2015;5(1):3-21.
79. Goopy S, Kassan A. Arts-based engagement ethnography: An approach for making research engaging and knowledge transferable when working with harder-to-reach communities. *International Journal of Qualitative Methods.* 2019;18:1609406918820424.
80. Mansfield E, Wahba R, De Grandpré E. Integrating a Health Literacy Lens into Nutrition Labelling Policy in Canada. *International Journal of Environmental Research and Public Health.* 2020;17(11):4130.
81. Christopher S, Watts V, McCormick AKHG, Young S. Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health.* 2008;98(8):1398-406.
82. Lewis YR, Shain L, Quinn SC, Turner K, Moore T. Building community trust: Lessons from an STD/HIV peer educator program with African American barbers and beauticians. *Health Promotion Practice.* 2002;3(2):133-43.
83. Quay TA, Frimer L, Janssen PA, Lamers Y. Barriers and facilitators to recruitment of South Asians to health research: a scoping review. *BMJ Open.* 2017;7(5).
84. Gostin LO, Turek-Brezina J, Powers M, Kozloff R. Privacy and security of health information in the emerging health care system. *Health Matrix.* 1995;5:1.

85. Ancker JS, Edwards AM, Miller MC, Kaushal R. Consumer perceptions of electronic health information exchange. *American Journal of Preventive Medicine*. 2012;43(1):76-80.
86. Burgess MM. Beyond consent: ethical and social issues in genetic testing. *Nature Reviews Genetics*. 2001;2(2):147-51.
87. Appari A, Johnson ME. Information security and privacy in healthcare: current state of research. *International Journal of Internet and Enterprise Management*. 2010;6(4):279-314.
88. Van der Velde J, Williamson DL, Ogilvie LD. Participatory action research: practical strategies for actively engaging and maintaining participation in immigrant and refugee communities. *Qual Health Res*. 2009;19(9):1293-302.
89. Hennekam S, Bacouel-Jentjens S, Yang I. Perceptions of diversity management practices among first-versus second-generation migrants. *Employment and Society*. 2019:0950017019887335.
90. Anderson EE, Solomon S, Heitman E, DuBois JM, Fisher CB, Kost RG, et al. Research ethics education for community-engaged research: A review and research agenda. *Journal of Empirical Research on Human Research Ethics*. 2012;7(2):3-19.
91. Bernal G. The itinerant researcher: Ethical and methodological issues in conducting cross-cultural mental health research. *Silencing the self across cultures: Depression and gender in the social world*. 2010:73.
92. Godard B, Ozdemir V, Fortin M, Egalite N. Ethnocultural community leaders' views and perceptions on biobanks and population specific genomic research: a qualitative research study. *Public Underst Sci*. 2010;19(4):469-85.



93. Hajduk GK, Jamieson NE, Baker BL, Olesen OF, Lang T. It is not enough that we require data to be shared; we have to make sharing easy, feasible and accessible too! *BMJ Global Health*. 2019;4(4):e001550.
94. Beyer KM, Comstock S, Seagren R. Disease maps as context for community mapping: a methodological approach for linking confidential health information with local geographical knowledge for community health research. *J Community Health*. 2010;35(6):635-44.
95. Gerber DE, Laccetti AL, Chen B, Yan J, Cai J, Gates S, et al. Predictors and intensity of online access to electronic medical records among patients with cancer. *J Oncol Pract*. 2014;10(5):e307-12.
96. Donovan-Kicken E, Mackert M, Guinn TD, Tollison AC, Breckinridge B, Pont SJ. Health literacy, self-efficacy, and patients' assessment of medical disclosure and consent documentation. *Health Commun*. 2012;27(6):581-90.
97. Patel VN, Dhopeswarkar RV, Edwards A, Barron Y, Likourezos A, Burd L, et al. Low-income, ethnically diverse consumers' perspective on health information exchange and personal health records. *Inform Health Soc Care*. 2011;36(4):233-52.

## Appendix A

#	Searches	Results
1	exp Data Collection/	2126668
2	exp Medical Records Systems, Computerized/ or exp Electronic Health Records/ or exp Hospital Information Systems/	60682
3	"data collection".ab,ti.	72258
4	EMR.ab,ti.	6231
5	EHR.ab,ti.	6563
6	exp Information Dissemination/	16219
7	"electronic health record* ".ab,ti.	14133
8	"electronic medical record* ".ab,ti.	15264
9	"open data".ab,ti.	764
10	"health information sharing".ab,ti.	61
11	"health data sharing".ab,ti.	42
12	"data sharing".ab,ti.	3400
13	"health data".ab,ti.	6462
14	(sharing adj3 data).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	5699
15	(sharing adj3 "health data").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	119
16	(sharing adj3 "health information sharing").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	61
17	exp Patient Preference/	8061
18	exp Privacy/	15135
19	exp Confidentiality/	52388
20	"patient preference".ab,ti.	3876
21	(preference adj3 patient).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	12366

22	privacy.ab,ti.	14644
23	confidentiality.ab,ti.	10908
24	exp Social Responsibility/	23579
25	accountability.ab,ti.	12449
26	"social responsibility".ab,ti.	1431
27	(preference adj3 sharing).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	31
28	"sharing preference".ab,ti.	3
29	exp Security Measures/	14215
30	security.ab,ti.	44536
31	"willingness to share".ab,ti.	199
32	exp Health Personnel/ or students, health occupations/ or students, dental/ or students, medical/ or students, nursing/ or students, pharmacy/ or students, public health/ or Social Workers/ or ((acupuncturist* or allergists or anatomist* or anesthesiologist* or anesthetist* or audiologist* or cardiologist* or chiropractor* or clinican* or dental hygienist* or dentist* or dermatologist* or diabetologist* or dietician* or doctor* or doula or doulas or endocrinologist* or gastroenterologist* or general practitioner* or geriatrician* or gynecologist* or haematologist* or (health or health care or healthcare)) adj2 (worker* or practitioner* or provider or professional or navigator* or student*)) or hospitalist* or internist* or medical resident* or medical student* or midwife or midwives or neonatologist* or nephrologist* or neurologist* or neurosurgeon* or nurse or nurses or nursing student* or nutritionist* or obstetrician* or oncologist* or ophthalmologist* or optometrist* or osteopath or osteopaths or otolaryngologist* or pathologist* or pediatrician* or pharmacist* or pharmacolog* or phlebotomist* or physician* or podiatrist* or prosthetist* or psychologist* or psychiatrist* or pulmonologist* or radiographer or radiologist* or radiotherapist* or rheumatologist* or social worker* or sonographer* or surgeon* or therapist* or toxicologist* or urologist* or veterinarian*).mp.	4879452
33	exp Canada/	155406
34	Canada.ab,ti.	81758
35	exp United States/	1329708
36	USA.ab,ti.	98966
37	"United States of America".ab,ti.	3609
38	2 or 4 or 5 or 7 or 8 or 9 or 13	86935
39	1 or 3 or 6 or 9 or 10 or 11 or 12 or 14 or 15 or 16	2192576
40	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31	165373
41	38 and 39 and 40	6675

42	41 not 32	5146
43	33 or 34	191136
44	35 or 36 or 37	1404184
45	42 and 43	135
46	42 and 44	2088
47	45 or 46	2210
48	limit 47 to (English language and yr="2008 -Current" and "all adult (19 plus years)")	105
49	39 and 40	42748
50	49 not 32	29556
51	43 and 50	1075
52	44 and 50	8907
53	38 and 40	7949
54	53 not 32	6111
55	43 and 54	149
56	44 and 54	2448
57	51 or 52 or 55 or 56	10249
58	limit 57 to (English language and yr="2008 -Current" and "all adult (19 plus years)")	1707
59	48 or 58	1707

## Appendix B

Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
<b>Anderson &amp; Agarwal (52)</b>	2011	Cross-sectional survey	Consumer willingness to provide access to PHI in order to inform changes to policy.	Adult public of USA	<b>N=1089</b>	PHI = personal health information	<ul style="list-style-type: none"> <li>▪ Stakeholder utilization of health information</li> <li>▪ Outcomes of health information</li> <li>▪ Incentives to sharing health information</li> </ul>	Contextual factors related to the requesting stakeholder and the purpose of information being requested influence patient trust on willingness to provide health information.
<b>Bartlett et al. (45)</b>	2018	Cross-sectional survey	To determine the factors that impact family medicine patients' decision to allow their eHealth data to be used for research purposes.	Attendees of Family medicine clinics in Canada	<b>N=474</b>	Electronic health data	<ul style="list-style-type: none"> <li>▪ Age and willingness to share health information</li> <li>▪ Health information for research</li> </ul>	Patients in family medicine clinics are more likely to refuse to contribute their de-identified eHealth data for research purposes. Relevance of the research to the patient was an impacting factor.
<b>Beyer, Comstock, &amp; Seagren (90)</b>	2010	Observational study	To explore the implications of having community engagement in the exploring and interpretation of a GIS disease mapping methodology for cancer.	Rural community in USA	<b>N=60</b>	Geographic information system	<ul style="list-style-type: none"> <li>▪ Community engagement with health information</li> <li>▪ Patient concern with data security</li> </ul>	This study found that community interaction with GIS data for cancer was informative and allowed participants to build hypotheses and understanding of community health facilitating the ownership of their health data.
<b>Brown et al. (41)</b>	2016	Survey	A survey study to understand the desirability and functionality of a communication portal in an ICU (intensive care unit).	Adult ICU patients and family in USA	<b>N=2205</b>	Electronic health data	<ul style="list-style-type: none"> <li>▪ Stakeholder utilization health information</li> <li>▪ Mode of access to health information</li> <li>▪ Age and willingness to share health information</li> <li>▪ Patient engagement with health information</li> </ul>	Current and potential ICU patients support the feasibility and effective information sharing facilitated by an electronic health information portal. Such a portal would help in providing clinical updates, documentation of family meetings, and information regarding healthcare staff roles.
<b>Caine &amp; Hanania (55)</b>	2013	Cross-sectional survey	A survey to understand patient preferences in sharing EMR	Adult public receiving healthcare in USA	<b>N=30</b>	Electronic medical records (EMR)	<ul style="list-style-type: none"> <li>▪ Stakeholder utilization of health information</li> </ul>	Participants were found to have preferences in type and amount of health information shared as a function of requesting stakeholders.

Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
			(electronic medical records)				<ul style="list-style-type: none"> <li>▪ Health information type and amount</li> <li>▪ Patient engagement with health information</li> <li>▪ Patient concern with data security and privacy</li> <li>▪ Patient control over data</li> </ul>	
<b>Cocosila &amp; Archer (42)</b>	2014	Cross-sectional survey	Understand the consumer motivations to implement the used of PHRs (personal health records) by understanding individual barriers and motivators	Adult public in Canada	<b>N=772</b>	Electronic personal health records (PHRs)	<ul style="list-style-type: none"> <li>▪ Stakeholder utilization of health information</li> <li>▪ Mode of access to health information</li> <li>▪ Age and willingness to share health information</li> <li>▪ Engagement with IT and interest in PHR</li> <li>▪ Patient engagement with health information</li> <li>▪ Patient concern with data privacy and security</li> </ul>	Participants with and without major illness are more likely to adopt and share electronic personal health records if they perceive it as useful and an advantage to themselves. Perceptions of data security, privacy, and trust are also important.
<b>Courtney (56)</b>	2008	Qualitative	Understand concerns regarding willingness to adopt smartphone IT (information technology) In senior citizens	Adults aged 65 years or older in residential care facilities in the USA	<b>N=14</b>	Smartphone information technology information collection	<ul style="list-style-type: none"> <li>▪ Age and willingness to share health information</li> <li>▪ Engagement with other information sharers/patients</li> <li>▪ Patient concern with data privacy and security</li> </ul>	Senior participants of this study indicate privacy as a barrier to the adoption of smartphone IT within their homes; however their perceptions of the usefulness of the technology may be a mitigating factor.
<b>Fuji et al. (53)</b>	2015	Qualitative	To understand the barriers and facilitators to sustained use of PHR in patients with type 2 diabetes patients in managing their disease	Adult type 2 diabetes patients in the USA	<b>N=59</b>	Personal health records (PHR)	<ul style="list-style-type: none"> <li>▪ Health data and management of disease</li> <li>▪ Health data and management of disease</li> <li>▪ Patient concern with data privacy and security</li> <li>▪ Patient control over health information</li> </ul>	Patients with type 2 diabetes experience multiple benefits of using PHRs, including disease management and facilitation of behavioural change. Sustained PHR use and can be achieved via building strong-patient provider relationships

Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
<b>Garrido et al. (50)</b>	2016	Retrospective observational study	Investigate the impact of race and ethnicity on PHR registration along with other factors.	Adult members of healthcare network in USA	<b>N=1,764,121</b>	Personal health records (PHR)	<ul style="list-style-type: none"> <li>▪ Ethnicity and willingness to share health information</li> </ul>	Non-white racial groups were less likely to register for PHRs when controlling for other factors.
<b>Gaylin et al. (57)</b>	2011	Cross sectional interviews	Understand public attitudes regarding EMRs.	General adult population of USA	<b>N=1014</b>	Electronic medical records (EMRs)	<ul style="list-style-type: none"> <li>▪ Income and willingness to share health information</li> <li>▪ Ethnicity and willingness to share health information</li> <li>▪ Patients concern with data privacy and security</li> </ul>	The overall public view of using EMRs in healthcare delivery are positive, and that participants who had previous experience with IT are more likely to use and adopt EMRs
<b>Gerber et al. (91)</b>	2014	Retrospective observational study	Understand the prevalence and patterns of PHR within an oncology population	Patients within a cancer center who had access to a secure online portal with their PHR in the USA	<b>N=6495</b>	Electronic medical records (EMRs)	<ul style="list-style-type: none"> <li>▪ Patient engagement with IT</li> <li>▪ Ethnicity and willingness to share health information</li> </ul>	Oncology patients readily adopt the use of EMRs. Explanatory factors are the greater health care need by these patients leads to increased portal use.
<b>Hasnain-Wynia, Taylor-Clark, &amp; Anise (61)</b>	2011	Qualitative	Understand health plan members perceptions of the collection race, ethnicity, and primary language data	Health plan members in the USA	<b>N=54</b>	Health related information	<ul style="list-style-type: none"> <li>▪ Ethnicity and willingness to share health information</li> <li>▪ Patient engagement with health information</li> <li>▪ Outcome of health information</li> </ul>	Virtually no participants in the study had problem with discussing primary language but participants had issues with sharing information regarding their ethnicity and race.
<b>Jamal et al. (37)</b>	2014	Qualitative	Understand research participant attitudes towards confidentiality and data sharing of genomic information for research purposes	Adults who consented to genomic sequencing projects in the USA	<b>N=30</b>	Genomic data	<ul style="list-style-type: none"> <li>▪ Patient trust in researchers</li> <li>▪ Health information for research</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Outcomes of health information</li> <li>▪ Patient concern with data security and privacy</li> <li>▪ Patient control over data</li> </ul>	A complex interplay of perception of data security and privacy, individual altruism, and situational collection and use of genomic information influences information sharing.

Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
<b>Kerath et al. (43)</b>	2013	Cross-sectional survey	Understand attitudes related to the collection, storing, and consent towards use of genetic information for research purposes	Long Island health system patients and their families	<b>N=1041</b>	Genomic data	<ul style="list-style-type: none"> <li>▪ Health information type and amount</li> <li>▪ Patient trust in research</li> <li>▪ Stakeholder requesting health information</li> <li>▪ Age and willingness to share health information</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Previous interaction with information technology</li> <li>▪ Patient concern with data security and privacy</li> </ul>	Most participants were willing to share health information, where limitations to sharing were related to data privacy and consent procedures, along with importance of the studies being conducted.
<b>Donovan-Kicken et al. (92)</b>	2012	Cross-sectional survey	Explore factors related to health literacy in the comprehension and assessment of medical disclosure and consent forms.	General adult population of USA	<b>N=254</b>	Health related information	<ul style="list-style-type: none"> <li>▪ Type and amount of health information shared.</li> </ul>	Health literacy and the comprehensible nature of consent documents for health research affect participation, especially with participant engagement with medical disclosure and consent documents.
<b>Kim et al. (34)</b>	2017	Cross-sectional survey	Understanding consumer characteristics, attitudes, and beliefs regarding consent to sharing electronic health data for healthcare and research purposes.	General adult population of USA	<b>N=800</b>	Electronic health records (EHRs)	<ul style="list-style-type: none"> <li>▪ Type and amount of health information shared</li> <li>▪ Stakeholder utilization of health information</li> <li>▪ Patient trust in researchers</li> <li>▪ Health information for research</li> <li>▪ Age and willingness to share health information</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Patient control over data</li> <li>▪ Patient concern with data security and privacy</li> </ul>	Individual experiences and attitudes towards sharing of electronic health records needs to be considered when using electronic health records for research.
<b>Padrez et al. (54)</b>	2016	Cross-sectional survey	To explore the feasibility and data availability to linking patient's social media	Adult Facebook/Twitter users who presented to an emergency department.	<b>N=1433</b>	Electronic medical records (EMR)	<ul style="list-style-type: none"> <li>▪ Previous engagement with IT</li> </ul>	Most individuals presenting to an emergency department that used social media consented to sharing and providing access to integrated information of their social media and EMR. The study presents a



Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
			content with their EMR data.					discussion on possible data repositories that link cross-platform data.
<b>Patel et al. (93)</b>	2011	Cross-sectional survey	To explore consumer attitudes and support for physician use of HIE (health information exchange) within a low-income, ethnically diverse community	Adults population presenting to an emergency and ambulatory care sites.	<b>N=214</b>	Personal health records (PHRs)	<ul style="list-style-type: none"> <li>▪ Type and amount of health information shared</li> <li>▪ Stakeholder utilization of health information</li> <li>▪ Health information for research</li> <li>▪ Age and willingness to share health information</li> <li>▪ Health data and disease management</li> <li>▪ Outcomes of health information use</li> <li>▪ Patient concern with data security and privacy</li> <li>▪ Patient control over health data</li> </ul>	Over half of participants supported use of PHRs by themselves and their healthcare providers. Potential benefits of health information influences sharing.
<b>Pedersen et al. (48)</b>	2015	Cross-sectional survey	To understand the acceptability of EHRs in a STI (sexually transmitted infection) clinic, and its impact on intention to be screened for STI	Patients of an STI clinic in Canada	<b>N=1004</b>	Electronic health records (EHRs)	<ul style="list-style-type: none"> <li>▪ Type and amount of health information</li> <li>▪ Stakeholder utilization of health information</li> <li>▪ Age and willingness to share health information</li> <li>▪ Patient concern with data security and privacy</li> </ul>	One third of participants reported that they were not comfortable with sharing their health information and are less likely to use STI clinic
<b>Pickard &amp; Swan (51)</b>	2014	Cross-sectional survey	Explore consumer attitudes towards sharing health information for research purposes	General population of USA	<b>N=128</b>	Health related information	<ul style="list-style-type: none"> <li>▪ Health information type and amount</li> <li>▪ Stakeholder utilization of health information</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Health data and management of disease</li> <li>▪ Patient engagement with other patients</li> <li>▪ Encouragement to share by stakeholders</li> <li>▪ Patient control over data</li> </ul>	Authors propose that health information sharing can be increased with trust, motivation, community, and informed consent.

Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
							<ul style="list-style-type: none"> <li>▪ Patient concern with data security and privacy</li> </ul>	
<b>Rhodes (35)</b>	2017	Cross-sectional survey	Understand patient acceptability and benefit to sharing, consent to sharing, and benefit of health records.	General population of USA	<b>N=1017</b>	Electronic health records (EHR)	<ul style="list-style-type: none"> <li>▪ Health information type and amount</li> <li>▪ Health information for research</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Outcome of health information use</li> <li>▪ Patient control over data</li> <li>▪ Patient concern with security and privacy</li> </ul>	Most participants of the study are in favor of HIE but would like more control of their health information through consent. Primary concerns with sharing health information includes concerns with privacy and security.
<b>Seltzer et al. (36)</b>	2019	Cross-sectional survey	Explore participants willingness to share data, understand data content, and preferences related to sharing that data.	Adults population presenting to an ED department in USA	<b>N=206</b>	Health related information	<ul style="list-style-type: none"> <li>▪ Type and amount of health information shared</li> <li>▪ Health information for research</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Patient concern with security and privacy</li> </ul>	Participants of the survey use a variety of modalities to generate data. Willingness to share health information for research increases for health-related insights.
<b>Spooner et al. (44)</b>	2017	Cross-sectional survey	Describe online health seeking behaviors and to identify patient level factors to sharing of health information electronically with health care providers.	General adult population of the USA	<b>N=3677</b>	Health related information	<ul style="list-style-type: none"> <li>▪ Mode of access to health information</li> <li>▪ Stakeholder utilization of health information</li> <li>▪ Age and willingness to share health information</li> </ul>	Participants of this study have high interest but low prevalence of health information exchange electronically.
<b>Teixeira et al. (59)</b>	2011	Cross-sectional survey	Explore HIV patients' attitudes about having their personal health information stored and shared electronically and what factors affect influence their	Patients presenting to a HIV clinic in USA	<b>N=93</b>	Personal Health information (PHI)	<ul style="list-style-type: none"> <li>▪ Stakeholder utilization of health information</li> <li>▪ Ethnicity and willingness to share health information</li> </ul>	Results indicate patients have a high trust in their primary care provider and HIV care teams and are willing to share information with these persons.

Author	Year	Study Type	Objective	Population	Sample size	Health information format discussed	Factors discussed influencing health data sharing	Major findings
			willingness to share.					
<b>Weitzmann et al. (49)</b>	2010	Cross-sectional survey + qualitative	Investigate the willingness to share information contained in an electronic health record for use in public health monitoring and research.	General population of USA	<b>N=181</b>	Electronic health records (EHR)	<ul style="list-style-type: none"> <li>▪ Type and amount of health information shared</li> <li>▪ Health information for research</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Patient control over data</li> <li>▪ Patient concern with data privacy and security</li> </ul>	High levels of willingness were found in participants in sharing electronic health records with public health for the purpose's disease monitoring, evaluation, and needs assessment, as guided by themes of altruism and pragmatism.
<b>Weitzman et al. (47)</b>	2012	Cross-sectional survey	Investigate attitudes and practices related to sharing health information from an electronic health record to support patient care and public health monitoring	Patients and/or guardians who used electronic health records in a hospital patient portal system	<b>N=261</b>	Electronic health records (EHR)	<ul style="list-style-type: none"> <li>▪ Type and amount of health information shared</li> <li>▪ Stakeholder utilization of health information</li> <li>▪ Age and willingness to share health information</li> <li>▪ Patient understanding of how data is used</li> <li>▪ Interest in personal health records</li> <li>▪ Patient engagement with health information</li> <li>▪ Patient control over data</li> </ul>	The study found moderate levels of willingness to share electronically stored health information. Participants are more likely to share with public health authorities as compared to other stakeholders.

## Appendix C

No. Item	Guide questions/description	Reported on
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	3.1.3 Data collection
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	3.1.5 Reflexivity
3. Occupation	What was their occupation at the time of the study?	3.1.5 Reflexivity
4. Gender	Was the researcher male or female?	3.1.5 Reflexivity
5. Experience and training	What experience or training did the researcher have?	3.1.5 Reflexivity
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons, and interests in the research topic	3.1.5 Reflexivity
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	1.3Conceptual framework: willingness to share health information  3.1.1Study Methodology and lens
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3.1.2Context and study participants
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	3.1.2Context and study participants
12. Sample size	How many participants were in the study?	3.4.1Study demographics
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	3.1.3 Data collection
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	3.1.3 Data collection

16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	3.4.1 Study demographics
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was its pilot tested?	3.1.3 Data collection
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	3.1.3 Data collection
20. Field notes	Were field notes made during and/or after the interview or focus group?	3.1.3 Data collection
21. Duration	What was the duration of the inter views or focus group?	3.1.3 Data collection
22. Data saturation	Was data saturation discussed?	3.1.3 Data collection
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	3.1.4 Data analysis
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	3.4 Findings
27. Software	What software, if applicable, was used to manage the data?	NVivo
28. Participant checking	Did participants provide feedback on the findings?	5.6 Limitations, strengths, and next steps
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	3.4 Findings
30. Data and findings consistent	Was there consistency between the data presented and the findings?	3.5 Triangulating results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Discussion
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A

## Appendix D

### Introduction

**STUDY PURPOSE:** We want to understand what makes people share and what makes people not willing to share their health information for a mobile health application that will tell you hypertension risk information.

**WHAT WOULD I HAVE TO DO?** If you decide to be in this study, you will have to participate in an interview that will last 1-2 hours. A researcher will ask you questions about your background information such as your name, education, and income, and then go on to ask you about your views on sharing your health information. The interview will be tape recorded and converted to written text for us to use in our study.

**SCRIPT:** I would like to ask you for your informed consent in participating in this interview and also inform you that you are allowed to withdraw from the interview at any part of the process. If it is okay with you, I will be recording our conversation, as it may be hard for me to write down your views as the discussion moves along. Everything you say will remain confidential, and your information will only be shared with the research team. Please feel free to ask any question throughout this process. This study has also been approved by the University of Calgary Conjoint Ethics Board.

## Demographic Questions

**Age:**

**Gender:**

**Ethnicity:**

**Were you born in Canada?**

- a) No → how long have you been in Canada?
- b) Yes

**Highest level of Education:**

- c) Up to Highschool
- d) Technical training/some college
- e) College degree of higher

**What is your level of income<sup>1</sup>:**

- a) Less than \$15,000
- b) \$15,000 to \$29,999
- c) \$30,000 to \$59,999
- d) \$60,000 to \$79,999
- e) More than \$80,000

**Geographic location**

- a) Urban
- b) Rural

**Do you have any other health concerns?**

- a) If yes, please list if comfortable
- b) No
  - cholesterol
  - glasses
- c) Unsure

**How would you rate your health overall?**

- a) Poor
- b) Fair
- c) Good
- d) Very Good

---

<sup>1</sup> Categories taken from CCHS

## **Willingness to Share Health Information**

- 1. Would you be willing to share your health information, such as blood pressure readings with anyone?**
  - a. No → why not?
  - b. Yes → Can you describe why?
- 2. What factors will make it more likely to share health information to a mobile application for risk information?**
- 3. What factors will make it less likely for you to share your health information to a mobile application for risk information?**

-
- 4. Do you find sharing health information for research to be important?**
  - a. No → why not?
  - b. Yes → why is it important
  - c. Unsure → what makes you unsure about sharing?
- 5. Would you be willing to share your health information to a project if that information were used for research purposes?**
  - a. No → why not?
  - b. Yes → Can you describe why?
- 6. What factors can be overcome for you to feel comfortable to you sharing health information to a research project?**

## **Community**

**How does the community you most identify with, feel about sharing health information? Are there any barriers that you can think of? What do you think can be done to overcome these barriers?**

## **Closing Discussion**



**Is there anything else you would like to add regarding our discussion today?**

**SCRIPT:** Thank you for your participation. We will now analyze the information you have given us. All of your personal information will be kept protected and your answers will remain confidential throughout the study. Please note, we will be contacting you to send you the final results of your interview. You will then have a chance to review and change anything that you see fit.