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Color coded health data: factors related to willingness to share health information in South Asian community members in Canada

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Abstract

Introduction
Data unavailability poses multiple challenges in many health fields, especially within ethnic subgroups in Canada, who may be hesitant to share their health data with researchers. 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.

Methods
We employed a qualitative descriptive approach to better understand willingness to share health information by South Asian participants and operated through a lens that considered the cultural and sociodemographic aspect of ethnocultural communities. A total of 22 in-depth interviews were conducted between March and July 2020.

Results
The results of this study show that health researchers should aim to develop a mutually beneficial information-sharing partnership with communities, with an emphasis on the ethnocultural and socio-ecological aspects of health within populations.

Conclusion
The findings support the need for culturally sensitive and respectful engagement with the community, ethically sound research practices that make participants feel comfortable in sharing their information, and an easy sharing process to share health information feasibly.

Keywords
health; information; willingness; immigrants; South Asian

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What is already known about this topic?

Data unavailability poses challenges in health fields which may be exasperated when it comes to ethnic subgroups in Canada. These ethnic communities may not want to share their health data with researchers due to multiple factors such as fear of discrimination, mistrust of medicine and researchers, or culturally insensitive research programs

What this study adds?

The results of this study show that researchers should aim to develop a mutually beneficial and trustworthy information-sharing partnership with ethnic communities, with an emphasis on the ethnocultural and socio-ecological aspects of health.

How might this study affect research, practice, or policy?

It is imperative that data be available for ethnocultural communities to push forward the understanding of ethnic health disparities, where mutually beneficial research practice and trustworthy information-sharing partnership can emerge.

Introduction

A country with a long history of immigration, Canada welcomed 401,000 permanent residents in 2021, adding to its ethnic diversity [1]. Canadians today speak many languages, suggesting the vast range of nations and cultural backgrounds that they come from. According to the 2021 census, it is estimated that 12.7% of Canadians speak a language other than English or French predominantly at home [2]. The most prevalent visible ethnic minority groups are South Asian (individuals from Pakistan, India, Bangladesh, and Sri Lanka), Chinese, Filipino, and West and Central Asian (individuals from Afghanistan, Iran, Iraq, and the United Arab Emirates), African, and Caribbean [3]. This ethnic variation is reflected in how Canadians perceive health or interact with healthcare, and can often highlight ethnicity-related inequalities in healthcare systems [4]. Researchers have identified numerous pathways to health inequities related to ethnicity, including the psychological stress of dealing with systemic racisms; unequal economic opportunities; and inequitable access to education and other social resources to name a few [5, 6].

Many researchers have taken advantage of health data in Canada to try and understand the multiple health outcomes faced by visible minority ethnic groups today. Predictive models such as precision public health are used to address the needs of entire populations and require the use of data and evidence to stage interventions [7]. Unfortunately, these models often rely on 'big data', which involves robust yet limited sociodemographic data collection on ethnic communities. Since health research is reliant on data, meaningful comparisons amongst ethnic groups cannot be made if there is a lack of high-quality relevant information. Data unavailability poses multiple challenges in a plethora of health fields in general, and those challenges are exasperated when it comes to ethnic subgroups in Canada [8]. However, one key aspect to note is the fact that patients and participants ultimately control the generation and flow of their own health information. A reluctance to provide health information in the first place can result in lacking and low-quality data. Exploring the willingness, interest, and motivation of ethnic subgroups to provide health information is an important endeavor in the pursuit of better data for ethnic groups in Canada [9].

Data on health status and social determinants of health are owned by individuals within society and need to be willingly shared with researchers for investigative purposes. However, people from ethnic communities may not want to share their health data with researchers due to multiple factors such as fear of discrimination, mistrust of medicine and researchers, or culturally insensitive research programs [10]. Employing transformative health research methods like participatory action research can boost the quality, uptake, and knowledge translation of [11]. However, the continued and enthusiastic will to share health information can sway throughout a research partnership, as these relationships are sensitive to many factors such as information security, altruism, or even personality traits [12]. For instance, one study showed that having a positive and trusting relationship with the researcher or research team actually increased the willingness to share information [13]. Understanding the factors for willingness to share health information within the context of ethnic populations will provide valuable insight into improving available research data, which is the main purpose of this study.

While many studies to date predominantly utilize various local and national-level survey and administrative health data, it is important to note, that there are limitations to what these datasets can accomplish in understanding the cognitive and contextual factors associated with willingness to share health information. Further, although many studies include ethnicity as a population attribute, to our knowledge, no research has been done to understand health data-sharing preferences amongst specific ethnic groups. Focusing on ethnic groups will allow for a deeper understanding of the preferences, contexts, and cognitions in the data sharing process. Finally, a study is required to understand data sharing within a more generalized health information context, instead of health information only in the form of electronic health records. Especially, at this current state electronic health records often do not have sufficient social determinants of health as well as race and ethnicity related data [14]. Our objective was to explore and understand the factors associated with the willingness to share health information within the South Asian community using a qualitative phenomenological study.

Methods

This study employed a qualitative descriptive approach as its methodology [15]. This methodology is fit for studies that aim to describe the phenomena of interest as is, rather than provide evidence for an existing or emerging theory. Thus, this study aims to take an inductive approach to better understand

what willingness to share health information by South Asian participants looks like.

Study setting

This study was set in Calgary, a major metropolitan city in Alberta, Canada with a population of over 1.5 million. The largest visible minority group in Calgary is South Asian (7.5%) [16]. Adults (18 or older) living in Calgary, who were of South Asian ethnicity were eligible to participate in this study. Participants were included based on self-reported ethnicity during recruitment and were welcomed regardless of immigration status. Only participants who could converse in English were eligible to participate in the study, which facilitated the consent process.

Participant recruitment

We used a snowballing sampling method in this study. Initially, we advertised our study in major community health clinics, research facilities, community organizations, and high-vehicular traffic areas within the city. We requested that our study recruitment materials be disseminated to former participants and study clients within those organizations, provided they previously consented to be informed of future projects. Interested participants were recruited based on a predefined inclusion criterion. Participants willing to refer someone else to the study were given a short script outlining the study objective to communicate to their referee. Potential referred participants were informed of the study mainly via phone or email and asked if they would be interested in participating. 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). Informed consent was obtained from the individual participants in this study for participation and publication and participants were communicated the objectives of the study, and the risks and benefits associated with participation.

This study has been approved by an appropriate ethics committee at the University of Calgary Conjoint Health Research Ethics Board (CHREB - REB19-0184) and conforms to the principles embodied in the Declaration of Helsinki.

Data collection

Semi-structured in-depth interviews were employed as the main form of data collection in 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 [17]: 1) ensuring interview questions aligned with research questions; 2) constructing an inquiry-based conversation; 3) receiving feedback on interview protocols; 4) piloting the interview protocol. In alignment with the research questions, the interview protocol examined participants' willingness to share their health information and any factors that they would consider while making that decision. We also asked participants to provide their perceptions of community-level factors related to health information sharing. All interviews were conducted over the phone. Transcription of the audio file was done using Microsoft Word (Microsoft Office 2016, Microsoft Corporation), and the interviews were transcribed verbatim. Interviews continued until the research team found that data saturation had been reached.

Data analysis

A thematic analysis of the data was conducted using Nvivo (a qualitative data analysis software), as a tool with continuous input and discussion from the research team [18]. After the data were thoroughly examined, a list of codes was generated using an inductive coding approach. 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. The research team discussed each theme and finalized them after reaching a consensus on how well they made sense in answering the research questions. Throughout the analysis, we attempted to identify and represent the lived experiences shared by the participants in the semi-structured interviews.

Results

Demographics

A total of 22 in-depth interviews were conducted between March and July 2020. All interview participants were of South Asian descent, with 36% from India, 27% from Bangladesh, 18% from Pakistan, and 18% from Nepal (Table 1). The largest proportion of the participants was within the 25-35 years age group (41%), with the smallest proportion being in the 55+ year's 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 $30,000 a year, and 95% of participants had a college or higher degree. No participant reported poor health within this study, and 90% reported their health to be either good or very good.

Factors associated with willingness to share health information

When participants were asked if they would be "willing to share their health information", 90% ($n = 21$) of participants responded with 'yes'. When asked if sharing health information for research was important to them, 86% ($n = 18$) responded with 'yes', whereas one participant responded with 'no'. When asked open-ended questions regarding why participants were willing to share and what factors would make it more or less likely for them to share health information, participants discussed a range of reasons including those that were personal and non-personal. Further, participants also discussed their thought processes that occurred before the process of sharing their health information. Four major themes emerged from the data through the thematic coding process: 1) manners of health information collection, 2) characteristics of health information recipient, 3) perceived usage of health information, and 4) privacy, security, and confidentiality concerns.

Table 1: Qualitative interviews – study demographics

	Count (n=22)	Percentage (%)
Gender		
Female	11	50
Male	11	50
Age (years)		
25–35	9	41
35–45	5	23
45–55	7	32
55–65	1	5
Country of Origin		
Bangladesh	6	27
India	8	36
Nepal	4	18
Pakistan	4	18
Income (CAD$)		
<15,000	3	14
15–29,999	2	9
30–59,000	9	41
60–79,999	4	18
>80,000	4	18
Highest Level of Education		
Up to High School	0	0
College Degree or Higher	21	95
Technical Training/Some College	1	5
Self-Rated Health		
Poor	0	0
Fair	5	23
Good	12	55
Very Good	5	23

Manners of health information collection

Participants reported that when the process of sharing information was made easy, they were more likely to share (Table 2). It was important for the participants that the data collection interface helped with information collection, such as through smartphone technology to make the process of entering their information easier, and more accurate. The participants also expressed that a live interaction with the data collector would help them build trust and stated this to be a common theme among South Asians. Having the live interaction was seen as overcoming a barrier, likely caused by the anxiety of having to share information with a faceless, unknown interface.

The type and amount of information to be shared was a major issue that almost half ($n = 10$) of the participants expressed as a factor related to their decision for health information sharing. Generally, participants were hesitant to share information that was overly specific to them. Clinical information, such as blood pressure, height, and weight were acceptable to participants for sharing. The degree of specificity of the requested information was also a factor – and having the choice of specificity when sharing health information was something the participants reported. Another participant also expressed that the sharing process should take into account the risks associated with sharing certain types of information, and how that information could potentially be misused by others. The participant emphasized the importance of weighing these risks carefully before deciding to share any information.

Characteristics of health information recipient

The person, organization, or institution who requests health information was an important factor associated with sharing health information and was expressed by almost half of the participants ($n = 10$). If the stakeholder requesting the information was credible, the participant felt safe to share their information. Affiliations (such as funding) with the local health service organizations were of enough credibility for certain participants to feel comfortable when sharing their information. The results also show a comparison of the types of stakeholders that could request information. One participant (Table 3) indicated hesitancy to share health information with pharmaceutical companies, which operate on a for-profit basis, as compared to governmental health services in Canada. Both organizations were open to criticisms about trust and safety of data; however, participants trusted government health organizations more than the private industry, partly due to their ultimate use of the information that they offered. At a

Table 2: Manners of health information collection codes and quotes

Overarching theme	Nascent codes	Quotes
Manners of Health Information Collection	Ease of information sharing	**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."
	Have a Live Interaction with the Stakeholder Requesting Information	**Participant 4: "**(. . .) having like a, someone else on the other end talk to you (. . .) 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	**Participant 1**: "(. . .) I don't mind giving away my information, but I would be a LOT more comfortable when I'm giving away my information that is not so specific (. . .) 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 rather than giving my specific address, or if my age group, I prefer to have it within a group, rather than the exact number."

personal level, other participants expressed that they only felt comfortable sharing information with their family physicians, healthcare providers, or very close family or friends.

Perceived usage of health information

The perceived usage of the health information that was being shared by participants was the most commonly coded theme. Participants reflected deeply (Table 4) on what their information would be used for and what were the personal and community benefits of their information sharing. 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. Participants understood and were able to articulate the benefits of research on themselves and their communities and were more willing to share if they knew that their information was being used for a good purpose. The participants expressed the importance of transparency in the research process and keeping them informed about the way their information was going to used along with how the research was funded and will be disseminated.

Privacy, Security, and Confidentiality Concerns

Concerns with privacy, security and confidentiality of data shared was a factor, which was explicitly reported by nine (40%) participants (Table 5). The results suggest that this is an important theme that threads through the other discussed results. Anonymisation was important for participants, especially when sharing information that was potentially sensitive. Participants were hesitant to share if the outcome of the sharing process violated their privacy and influenced their daily lives in a negative way. Participants expressed that having the autonomy to conduct their own investigation into who they were giving their information to, and having the ability to weigh risks associated with sharing information were important factors in sharing health information

Another major concern within the manners of health information collection was highlighted by some participants noting that live interactions with stakeholders requesting information involved trust. This depended on the type and amount of health information that participants shared, along with their level of comfort in ensuring the privacy and security of their data. Further, the confidentiality of the data collected weighed heavily in the decision of participants to share. For example, participants understood that certain stakeholders with more credibility may be able to assure data confidentiality when compared to others.

Community views on sharing health information

Participants in the study were asked to focus on their respective communities (defined as a group the participant most identified with) and to share their views on their community's perceptions of sharing health information. Specifically, participants were asked to share any barriers and solutions to sharing health information within the community. The thematic coding process revealed two major themes within the context of community perspectives related to sharing health information: 1) cultural aspects related to sharing information, and 2) knowledge about information sharing.

Cultural aspects related to sharing information

Participants ($n = 11$) reported (Table 6) 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*. Participants understood that a cultural barrier existed within the community when

Table 3: Characteristics of health information recipient

Overarching theme	Nascent codes	Quotes
Characteristics of Health Information Recipient	Credibility of Stakeholder Requesting Information	**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 (. . .) 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."
	Only Comfortable with Sharing with Healthcare Providers	**Participant 1: "**(. . .) 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..(. . .) I would be more willing to put my information in it."
	Only Comfortable with Sharing with Family Friends or Other Trusted People	**Participant 22**: "(. . .) 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."

Table 4: The perceived usage of health information codes and quotes

Overarching theme	Nascent codes	Quotes
Perceived Usage of Health Information	Health Information is Being Used for Public Good	**Participant 3**: "(. . .) If my information help the other people to get some positive feedback, some kind of concern about, yes, I am okay with that."
	Health Information Sharing is Harmful to Participant	**Participant 18**: "(. . .) If I am working in a job requiring a 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 it will affect my work."
	Health Information is Helpful to Stakeholder Requesting Information	**Participant 1**: "(. . .) 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 (. . .) I definitely believe in contributing to research related health in that way"
	Sharing Information for Health Research is Important	**Participant 12: "**(. . .) 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 time 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."

sharing health information, where the South Asian community was not willing to discuss specific aspects of their life, including certain health issues. Some cultural aspects of information sharing can be related to the sensitivity of certain topics, or closely related to the stigma around sharing certain type of information within the community.

Participants made comparisons of the differing contexts in their previous country of residence, as compared to Canada. Differing values related to privacy and information sharing in non-western cultures influenced how the community reacted to the idea of sharing their health information in Canada. Participants spoke about these values and practices with

Table 5: Privacy, security, and confidentiality concerns codes and quotes

Overarching theme	Nascent codes	Quotes
Privacy, Security, and Confidentiality Concerns	Concerns about Privacy and Security	**Participant 10: "**(...) If I know who is accessing it and we find no, the security of that (...) information collection data (...) you know, how secure that is, then I would be more likely to share."
	Concerns about Confidentiality	**Participant 7**: "(...) If it's going to be an anonymous or something, probably I'll be more confident sharing my stuff."
	Leaving a Digital Footprint	**Participant 2**: "(...) 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."
	Previous Negative Experiences with Sharing Information	**Participant 8: "**Like sometime your information get leaked.(...) 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."

an implied sense of the collective within the community. 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 sensitive health issues. Interestingly, some participants noted that the openness in sharing information in the home-country resulted in open sharing in the Canadian context.

Participants highlighted the healthcare context within Canada as an important determinant of information-sharing preferences. Trustworthiness of the government and confidentiality related to their shared information were two aspects of the home-country context that participants reported. Participants explained that knowledge and understanding of the Canadian healthcare system would help in improving sharing preferences in their community. The comparison of the home-country and Canadian context by the community members as reported by participants in the study is closely associated with age and sharing preferences. 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 home-country context.

Knowledge about information-sharing process

Knowledge about the information sharing process was a large theme 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 (Table 7) that the community was perceptive to the trustworthiness of institutions requesting information, and would be more willing to share with certain individuals as compared to others. One participant shared that building trust within the community, especially with a provincial health service organization required understanding of the community's contexts, including newcomer community members that may face language barriers. The importance of the purpose of collecting information from the community and building trust was also highlighted by another participant, who stated that community members will be more willing to share information 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.

Participants reported that more communication with the community regarding health issues or the research that is being conducted and the expected benefits of the research will aid in more information sharing amongst community members. This 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, was noted by some participants. This would allow for exposure of community members to the phenomena 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 stigmatising health information (e.g., contagious disease) which can be de-stigmatised through conversation and education.

Discussion

Our study aimed to address the lack of health data in certain ethnic groups, by understanding the factors associated with

Table 6: Cultural aspects related to sharing information codes and quotes

Overarching theme	Nascent codes	Quotes
Cultural Aspects Related to Sharing Information	Sensitivity of Topic when Sharing	**Participant 6:** "(...) 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."
	'Cultural Barrier' to Sharing Health Information	**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.
	Knowledge About Healthcare Systems	**Participant 20**: "First of all, we have to, to educate the community people (...), inform them about (...) health system (...), social structure, (...) 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."
	Sharing Preferences Differ in the Native Versus Canadian Community Contexts	**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."
	Stigma Around Sharing Health Information	**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".

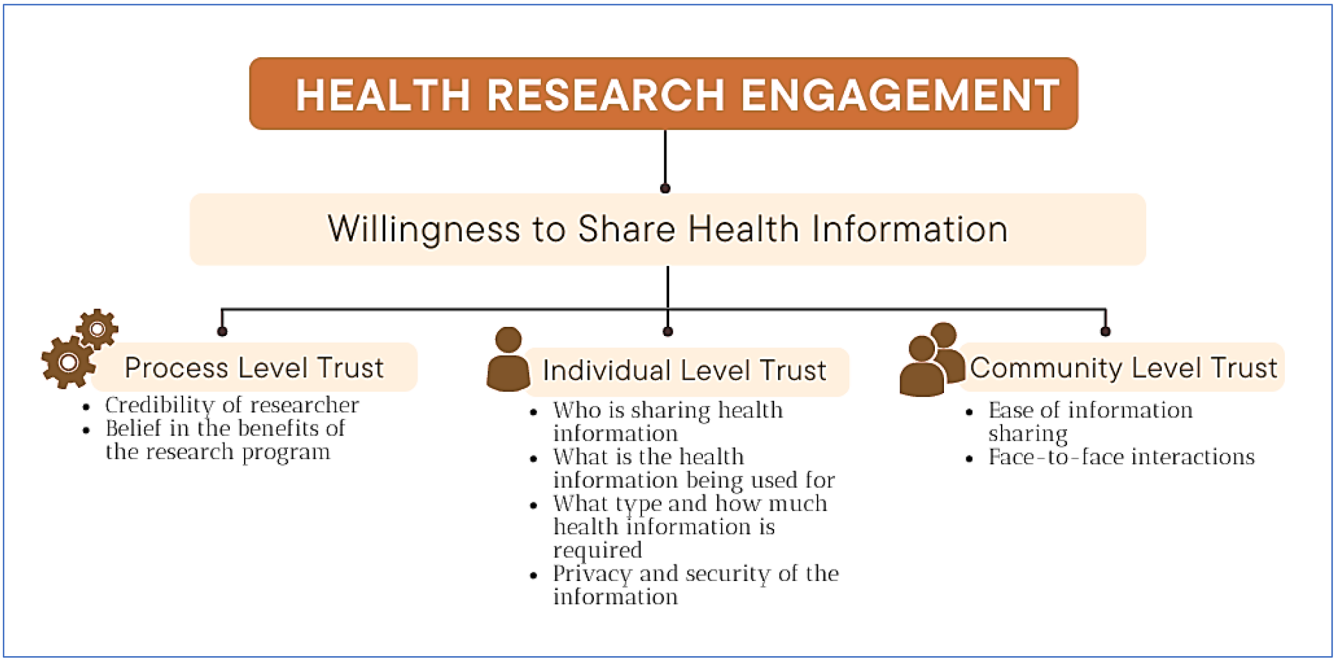
the willingness to share health information in a South Asian sample population, using qualitative interviews. We identified four major themes that constitute some decision-making aspects for participants in consideration of sharing their health information. These themes include: 1) Characteristics of Health Information Recipient, 2) Perceived Usage of Health Information, 3) Privacy, Security, and Confidentiality Concerns, 4) Manners of Health Information Collection. These factors substantiate the importance of developing trust within the community [19, 20]. Trust is generally defined as imparting authority to another while accepting the vulnerability associated with the process, given that a set of expectations are met [21]. When assessing the overlapping and unique themes found in this study, trust seems to be operating at multiple levels: 1) community level, 2) individual level, and 3) process level (Figure 1). The results of this study have also illuminated the importance of the socio-demographic and cultural components of participants' willingness to share health information.

There is a paucity of literature describing the manners of collection of health information when it comes to participants' willingness to share health information. Within ethnocultural communities, the ease of information sharing can have a large influence on how a participant will engage in sharing their health information, if at all. 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 [22, 23]. Also, complex factors, such as sociodemographic diversity within an ethnocultural community must be considered while contemplating health information

Table 7: Knowledge about information sharing codes and quotes

Overarching theme	Nascent codes	Quotes
Knowledge About Information Sharing	Participants Do Not Know The Benefits of Information Sharing	**Participant 6: "**(. . .) 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. (. . .) We are more willing to share the information if we know the purpose of the thing."
	Community Education and Sharing Health Information	**Participant 4: "**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."
	Trust and Sharing Health Information	**Participant 3**: "(. . .) If there is barriers, maybe community health service can (. . .) can help them to (. . .) 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."

Figure 1: Factors associated with sharing health information and their influence on trust at multiple levels



collection. For example, some ethnocultural communities, including the South Asian communities, may have first and second-generation migrants who may have differing needs when it comes to ease of information sharing [24]. 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. Previous studies commensurate with our findings in terms of the need for easy and trusted ways of sharing information to improve willingness for sharing health data [25, 26]. 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 [27].

The results of this study show that individual-level trust can be built by facilitating a data-sharing environment. It has been reported that individuals who regularly visit their physicians have a psychosocial expectation of benefit and trust from the physicians [28], a phenomenon that we observed among our study participants as well. As such, having a regular and interpersonal relationship built on trust may be an important aspect of creating a space where health information sharing can occur. Participants in this study often stated that they were more inclined to share health information with government-affiliated organizations, as compared to those affiliated with pharmaceutical companies. This provides evidence for the fact that the quality, length, and nature

of the trusted relationship between the individual and the stakeholder is an important factor when deciding to share health information [21].

Community level trust was a major discussion point during our interviews. Participants in this study understood the difficulties of engaging an entire community in sharing their health information, where building a level of trust can be a difficult and slow process. Credible institutions that back-up stakeholders are important [29] and this was especially true in our study if the institutions were well-known and had a good reputation. Further, the characteristics of the health information recipient are particularly important for ethnocultural communities that have had historically less access to power and privilege or have been exploited in the name of health research. Popular examples include the Tuskegee syphilis study, which used race-based data to fuel state-sponsored propaganda against ethnic groups [30, 31]. Understanding that certain communities have been historically disempowered and disenfranchised is critical for researchers. Increased credibility of stakeholders can also indicate that there is an appreciation of diversity, and a willingness to engage and understand communities and their perspectives [32]. A recent scoping review of South Asian participants found low levels of health research engagement due to poor understanding of research intentions and importance, and perceptions that research benefits will not extend to the community [32]. As such, it is important for health researchers to build effective data-sharing partnerships. 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 in the control and direction of the data-sharing partnership [33].

Altruism and reliance on healthcare systems, research studies, or institution stakeholders to deliver positive change, are reported psychosocial factors that influence information-sharing behaviours [21]. Concerns with the privacy and security of data were another important aspect of willingness to share health information, especially with the information on socio-cultural aspects and genetic information that have a higher likelihood of being misused [34]. This sentiment is echoed in our study, with participants expressing that they were more likely to share their information if they felt they could have granular control over their shared data, overlapping with concerns about maintaining privacy. As such, confidentiality can be characterized by an agreement between the individuals and stakeholders requesting the information [35]. A study can maintain excellent privacy and confidentiality within its protocol but may still conduct research that is framed in a way that is disrespectful to ethnocultural communities [36]. In this case, implementing a culturally sensitive informed consent process and appropriate confidentiality and disclosure policies would be essential to address this major factor in participants' willingness to share their information.

Since our study findings indicate the importance of researchers engaging with ethnocultural communities when building lasting information-sharing partnerships, studies to empirically measure real engagement outcomes are required. Further, our findings point toward the development of frameworks that can assist researchers in developing and documenting partnerships with ethnocultural communities. This can be contrasted to researchers who completely control the collection, analysis, dissemination, and benefits of their study, with little input from participants. There is also a paucity in literature when it comes to the process of rapport and relationship building with communities about the 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 [32]. 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 to help expand the future scope of this research. 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. Finally, as healthcare becomes increasingly dependent on digital technologies, understanding trust and data sharing within the digital health realm and what that means for health research is important. A systematic understanding of research engagement in building data-sharing partnerships needs to be studied from the perspective of multiple stakeholders including community, practice, and policy makers.

The study finds its strengths in its unique narrative synthesis of factors associated with willingness to share health information, which was organized into cohesive themes using a validated thematic coding process. Additionally, our study utilized one-on-one interviews with participants rather than focus groups, which increased confidentiality and preserved a favourable environment to discuss sensitive and personal aspects. The results of this study should be seen considering some limitations. Firstly, there is a limitation of the applicability of the findings from this study to other communities, as the study reports on only the experience and views of South Asian participants that may not be comparable to other ethnocultural communities. Further, most participants interviewed in this study were of high socioeconomic status (income and education), therefore their views may not be transferable to people of other social groupings. Also, we may have missed engaging community members who generally do not participate in research projects due to linguistic barriers. A snowball sampling method was used in this study, which may sometimes lead to limited external generalisability of study findings.

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 was aimed at exploring factors associated with sharing health information within an ethnocultural group through qualitative interviews with South Asian participants. The results of this study show that researchers should aim to develop a mutually beneficial and trustworthy information-sharing partnership with communities, with an emphasis on the ethnocultural and socio-ecological aspects of health. 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 process to share health information feasibly.

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Conflicts of interest/competing interests

Nothing to declare.

Patient and public involvement

While preparing this manuscript, we interacted with community scholar and citizen researchers of our program of research. The results were presented at events where community members were the main audience. The feedbacks and insightful inputs shaped our understandings about this issue.

Code availability

Not applicable.

Authors' contributions

TCT, IN, VS, and HQ conceived of the paper. IN and TCT collected the data. IN, MA, NC, and TCT conducted the analysis and drafted the paper. All authors provided critical input to multiple drafts.

Ethics approval

Ethics approval was obtained from the Conjoin Health Research Ethics Board of University of Calgary.

Consent to participate

Informed consent was obtained from the study participants.

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