Study Title: Patient and caregiver perspectives on virtual care: a patient-oriented qualitative study using a grounded theory approach

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1 Abstract

Background: Since the onset of the COVID-19 pandemic, virtual care solutions have been rapidly adopted across the country to provide safe, quality care to diverse patient populations. The objective of this qualitative case study was to 1) understand patient and caregiver experiences of virtual care, 2) identify barriers, and 3) gather recommendations to address them.

Methods: We conducted a constructivist, qualitative study guided by grounded theory methodology. One researcher member and one patient partner member of the study team co-facilitated focus group interviews. One researcher employed in-vivo coding to maintain fidelity to the participants' intentions as much as possible. The analysis was followed by axial coding, which included focus group participants, followed by selective coding with the study team.

Results: We conducted six focus groups with 13 patients and 5 caregivers across Ontario and British Columbia. The analysis resulted in six major themes and twenty minor themes. Categories included the following: access to technology and Internet barriers; language barriers and cultural differences; caregiver and family involvement; privacy, consent, and confidentiality; patient-physician relationship; and future research directions or calls to action.

Interpretation: Patient engagement is fundamental to ensuring that virtual care can be equitable, accessible, and safe to all users. Social determinants may unfold in novel ways in virtual health. Illiteracy can serve as both a barrier to technology use and as a language barrier. Special consideration must also be paid to the ways virtual care may change relationships between patients, caregivers, and providers.

Plain language summary: While virtual care has been rapidly adopted and scaled up in health care institutions across the country, few improvements informed by patient/caregiver experiences have been made. Driven by concerns expressed by patient partners, our study team undertook a patient-partnered

qualitative study to understand the barriers of virtual care from the perspectives and experiences of patients and caregivers. Our study team collectively created the interview guide drawing from our previous patient-oriented qualitative studies and designed an orientation package to provide resources related to the focus groups and to introduce to participants to the study team. Drawing from local health teams, clinics, and patient advisory groups, the study team recruited thirteen patients and five caregiver participants to six focus group interviews. An analysis based on grounded theory was undertaken, with participation from both the study team and participants. Lack of access to technology or Internet and language barriers were determined to be the primary barriers to virtual care. Special considerations to caregiver and family involvement, privacy and confidentiality, as well as the physician-patient relationship were considered priorities to improving access to virtual care. Participants offered recommendations and potential solutions to address barriers and challenges in virtual care which can serve to encourage large-scale policy and programmatic changes in patient-centred ways.

Keywords: PPI, patient and public involvement, virtual care, health equity, caregivers

2 Introduction

Virtual care has gained increasing prominence within the Canadian health care system(1). The COVID-19 pandemic has propelled virtual care into unprecedented rates of use to provide safe, alternative care (2-4). Ongoing research has found virtual care to be patient-centred as it can save money, time, and energy for patients and caregivers (5, 6) and provide the option to receive care in their home or at any location they choose. Virtual care may be particularly useful for patients who must travel long distances to receive specialist care or have mobility issues. Yet, the rapid scale up and growth of virtual care across Canada must be regarded with caution as virtual care can bring with unique barriers in creating equal and equitable access(7, 8).

Virtual care is viewed as patient-centred but there is a dearth in patient-oriented research or patient engagement in this area. The Canadian Institutes of Health Research (CIHR) defines patient engagement as "meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation"(9). Patient engagement is particularly important in the continuation of virtual care as patients may experience different barriers than previously identified in mainstream, traditional modes of in-person care(10). For instance, differential access to virtual care may stem from access to digital technologies, social supports, digital literacy, and Internet connectivity(11).

We sought out to understand the experiences and barriers faced by patients and caregivers with virtual care in hopes of spurring other policy and programmatic decision makers to consider a patient-oriented strategy to virtual care moving forward. This study was run and reported based on the Consolidated criteria for reporting qualitative research (COREQ) reporting guideline.

3 Methods

3.1 Study Team, Study Conception, and Patient Engagement

Our study draws on the Canada Institutes of Health Research's (CIHR) Strategy for Patient-Oriented Research (SPOR) to improve health care for patients and build capacity for equitable health care systems(9). The SPOR increases accountability by ensuring their involvement from the conception of the project to the dissemination of the knowledge translation tool. Patients can increase scientific rigour by offering suggestions and perspectives which can lead to the establishment of relevant research goals,

methodologies, interpretations, and research outcomes ($\frac{12}{12}$). The study team drew on other strategies across Canada, US, and the UK to better engaging patient and family advisors in research ($\frac{13-15}{12}$).

The study team consisted of seven individuals which included two patient partners (AM & AOR), a clinician scientist (RA), two academic researchers (SC, EYL), a patient-research liaison (EM) and a graduate student trainee (VL). Prior to this project, researchers SC & RA has worked closely with AOR, a patient partner member, to carry out patient-centred research(5). The details of the patient and public involvement in research are presented according to the GRIPP2 short form. In commitment to enhancing patient engagement throughout the research project, the patient partners (AOR), a member of the hospital Patient and Family Advisory Council (PFAC) and (AM) Lead Patient and Family Centred Care, Kingston Health Sciences Centre, played a significant role in the conception and in providing insight on the research direction for the project including patient engagement methods and best practices from a patient perspective. The patient-research liaison (EM) provided guidance using best practices for meaningful and genuine patient engagement according to the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) and the International Association for Public Participation (IAP2). The patient-research liaison was formally trained in patient-oriented research with the Ontario SPOR Support Unit and has many years of working to improve patient experiences in research(16).

The study team began meeting in 2019 with the goal of highlighting the experiences and barriers faced by patients accessing virtual care. Apart from the graduate student trainee who entered the project after the study design stage, all study team members were involved in the study conception, study design, data collection, data analysis, interpretation, and knowledge translation efforts. The study was carried out collaboratively with patient partners at all stages of the project using the consensus building process. Input was welcomed in both synchronous (e.g. bi-monthly team meetings) and asynchronously (e.g. email; feedback surveys) in order to accommodate for and respect different working styles and commitments from all team members. More details on patient engagement are below.

3.2 Study Participants

A convenience sampling approach was employed. The study team contacted local and provincial health teams, clinics, and patient advocacy groups (30 teams) and disseminated study posters and information sheets for recruitment by email over a 3-week period. The study team was unable to disseminate the study information in-person due to COVID-19 related regulations. The selection criteria for the study included participants who were 18 years of age and able to participate in a telephone or video conference interview in English. The study team was prepared to accommodate for non-English speakers as the study team members were fluent in Hindi, Japanese, Korean, Cantonese, and Portuguese. However, none of the team members were fluent French speakers and planned for interpretation services if there was a need.

Prospective participants had opinions of virtual care they wished to share but were not required to have experienced virtual care themselves. The study team's decision to include participants who had not used virtual care was to understand why some participants choose not to use or did not have the opportunity to use virtual care. Both patient and caregiver groups were invited to participate in the study as our study team worked on the premise that patients and caregivers may have slightly different experiences and challenges related to virtual care. All participants were offered an honorarium following their

participation in the focus group discussions. Consent for use and analysis of anonymized audio recorded transcripts was provided by participants prior to the focus groups.

3.3 Study design

Grounded theory is a research method used to generate new understandings and theories about social processes and human behaviours (17-19). Our study team employed a constructivist grounded-theory approach to gain an in-depth understanding of the shared, diverging, and multiple ways patient and caregivers experience barriers to virtual care. This approach was employed to ensure a variety of contexts and factors were captured from the perspectives of patients and caregivers.

3.3.1 Supporting patient participation

Prior to the focus groups, the participants were provided with an orientation package. The study team co-created an orientation package which included a carefully curated list of ground rules, frequently-asked-questions, interview guide questions, and brief biographies of each study team member (See Appendix A). The purpose of the welcome package was to orient the participant to the study and build rapport with the participant despite the virtual nature of the research project. A Zoom tutorial, in form of a PDF attachment, was included to reduce technological challenges (Appendix B). Participants were given the opportunity to practice or ask questions about Zoom prior to the scheduled focus group discussion. In the orientation package, participants were given the interview guide questions to help them reflect on their experiences of virtual care prior to their scheduled focus group session. All materials disseminated by the study team were accessible in compliance with the Accessibility for Ontarians with Disabilities Act (AODA).

3.3.2 Focus group design and conduct

Focus groups are used capture the nuances of virtual care from the perspective of patients and caregivers and their suggestions for improvement(20). In-person focus group discussions were planned initially but were later modified to accommodate for the COVID-19 restrictions. Due to the virtual nature of the focus groups, it was decided to limit the participation to 2-4 participants per focus group. The study team developed the interview guide questions drawing on our team's previous research on patient experiences and virtual care and through multiple rounds of iterative revision (5). All questions were open-ended to allow for nuanced responses and every question was asked for consistency.

One academic researcher (SC) and one patient partner (AOR) of the study team co-facilitated each focus group. The researcher (SC) carried out the introduction and other administrative tasks while the patient partner (AOR) carried out the interview. During the last focus group, the patient-research liaison (EM) facilitated the group as both patient partners were unable to facilitate that discussion due to an unanticipated event. The graduate student trainee (VL) played a "tech support" role and stayed for the entire duration of each focus group to assist participants with technological difficulties. In each focus group session, the researcher shared a Powerpoint slide of the questions on their screen to ensure all participants could follow along if they did not have their orientation package on hand (Appendix C). Each question was also read out loud for those participants who joined by phone. During the focus groups, both facilitators took detailed notes and consolidated them at the end of each two hour session.

All focus group interviews were recorded using the record function on the Zoom platform and transcribed by a professional transcriber. Following the focus groups, an exit survey was disseminated asking participants to provide feedback about whether they felt the study was patient-oriented and

whether they would like to participate in future related studies. The study team conducted a thematic analysis and sent the results to all participants who indicated their interest in participating in a validation process. This process was to ensure that the themes reflected the responses of the participants.

3.4 Data Analysis

Three rounds of coding was applied to the transcripts using NVivo 10 qualitative data software. In the first round of coding, one researcher (SC) independently created the coding framework using in-vivo coding approach where the words spoken verbatim of the participants were used as codes. Keywords drawn from the quotes to create codes. While a grounded theory approach usually begins with a round of open-coding, in-vivo coding was chosen as the main analytical technique because it emphasizes the by-verbatim words of the participants to ensure that the coder does not deviate their analysis away from the intended meaning of the participants. In other words, the aim of in-vivo codes is to stay as close as possible to the research participants' intentions (21). This practice is consistent with the principles of patient-oriented research where patients should be reflected in and through the research. Secondly, as the study team had only one coder and qualitative researcher, in-vivo coding increases accountability to the data in the preliminary rounds of coding.

In the second round of coding, axial coding was undertaken by the researcher. At the end of the coding, six codebooks were created based on each discussion group. Each codebook was reformatted into a fillable report with a coding tree of major and minor themes and corresponding quotes. All participants received a report based on the codes derived from their discussion group. To ensure validity, trustworthiness, and consensus over the themes, the study team asked 14 participants to provide feedback on the accuracy of their group's codebook based on their willingness to review the themes as indicated in a study exit survey (Appendix D). Six focus group participants provided feedback on the themes which was incorporated into the coding framework. All feedback was minor and all participants agreed on the coding of the themes. Based on the feedback provided by the participants, the entire study team also reviewed each codebook and worked together to refine the themes. All codebooks were merged into a master codebook. In the third stage of coding, the study team used the master codebook to validate and create three overarching categories. The patient partners reviewed and validated the master codebook to ensure the themes meaningfully captured the nuances of virtual care as well as the patient experience.

3.5 Ethics Approval

All participants provided informed consent. This study obtained ethics clearance from the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (DMED-2387-20).

4 Results

A total of six focus groups with eighteen participants (thirteen patients, five caregivers) were conducted during the study period. No individuals were deemed ineligible. Two individuals dropped out of the study due to conflicting schedules. No other individuals were present during the focus groups. Twelve participants (67%) identified as women, five participants (28%) identified as men, and one participant (5%) chose not to disclose their sex. The age range of the participants varied between 29 and 94 years. Table 1 details the sociodemographic profiles of the participants. Table 2 details the categories, major and minor themes identified in the study.

4.1.1 Common barriers to virtual care

Two major topics of concern were identified as major barriers to virtual care access.

4.1.1.1 Access to Technology and Internet

One of the most reported barriers to virtual care is limited access to technology or Internet. Concerns around reliable access to Internet and digital technology were particularly of concern for rural residents and aging individuals. Participants warned against making assumptions that everyone can adopt and use digital health technologies to receive virtual care. While it has become clear that patients may not know how to use digital health technologies, patients have also noted that they were not offered virtual care options because they suspected that their health care providers did not know how to use technology themselves.

4.1.1.2 Language Barriers and Cultural Differences

It was commonly expressed that lack of proficiency in English could serve as a barrier to receiving virtual care successfully. Patients who are recent immigrants may not know that virtual care is an option. Virtual care may also be difficult to explain to patients who have had no exposure to the service. Efforts to understand the patient's rights and preferences can help to relieve some of the difficulties associated with cultural differences.

4.1.2 Special considerations to make with virtual care

Three major themes were related to the special considerations that virtual care researchers and practitioners must make in virtual care sessions moving forward.

4.1.2.1 Caregiver and family involvement

Caregivers have been noted to be crucial in helping some patients receive virtual care. Caregivers experience virtual care in different ways depending on the degree of involvement of the caregiver and their own level of digital literacy or access. Some caregivers may find it hard to participate in virtual care for various reasons. Health care providers may inappropriately rely on caregivers to assess the patient during a virtual care session which may increase the burden they already experience with caregiving. Health care providers should check with caregivers separately to assess their comfort level in participating in a virtual care session and offer supports provided there is patient consent or the caregiver is the power of attorney for care.

4.1.2.2 Privacy, consent, and confidentiality considerations

Different privacy considerations may apply in virtual care to ensure patient autonomy and confidentiality. Even between family members, there may be instances where patients wish to discuss an issue with their health care provider in private but find that it is not possible due to space constraints or overbearing caregivers. This could cause unnecessary tension between patients and caregivers. Informed consent must be obtained from patients informing their preference for whom they want present in a virtual care session.

4.1.2.3 Patient-physician relationship

Some participants reported that their interactions with their health care provider felt 'mechanical' through virtual care. Participants reported having an "artificial feeling" and that certain virtual care modalities, such as email, was replacing the face-to-face component that they may desire in health care.

Other participants expressed concern over whether the health care provider was being truly attentive to them over the phone or on video conference. Other participants felt that it was difficult to interrupt the health care provider to ask for clarification or convey their concerns. Thus, some of the participants argued that it was easier for them to make their concerns known through in-person clinics. Due to difficulties mentioned above, some participants felt that they did not have the same personal connection with their health care provider through virtual care.

4.1.3 Future research directions/Calls to action

A broad overarching theme included recommendations and calls to action from the perspective of patients and caregivers. As concerns around access to technology and Internet were raised, participants asserted that universal access to Internet must be made readily accessible if virtual care were to become a standardized option of care for all Canadians moving forward. Participants also suggested that patient outcomes could be improved in virtual care if there was a better integration of services and data sharing between health care platforms and organizations. An integrated approach to virtual care could reduce patient and caregiver burden and increase ease of use, reducing the difficulty of navigating through virtual care options.

5 Discussion

This study is one of the first qualitative studies co-designed by patients for the purpose of examining the barriers of virtual care from patient and caregiver perspectives in Canada. We consider this research to be a timely contribution to the growing body of literature touting the benefits of virtual care, particularly in the midst of COVID-19(2, 6, 22-24). While there are undeniable benefits to virtual care, the rapid implementation of virtual care, even with the best intentions, can pose challenges to both providers and patients unprepared to use or provide virtual care due to lack of access or familiarity. Such concerns have strong implications for patient safety and access to equitable care moving forward in Canada(10, 25).

Our study findings add to the growing body of literature detailing the barriers of virtual care and special considerations that must be undertaken to ensure that virtual care remains a patient-centred practice. Our study found two prominent barriers to virtual care – lack of access to technology or Internet and language barriers and/or cultural differences, the latter of which is also a common barrier to access to in-person care. These challenges point to the effect of traditional social determinants, such as income and social support networks, which have been identified to impact an individual's health outcomes (26, 27). However, other determinants may unfold in novel ways. For instance, illiteracy can serve as both a barrier to technology use and as a language barrier. Health care providers must be cognizant that illiteracy may manifest in multiple ways. Health care organizations should also be cognizant that providers may lack digital literacy, which can influence their decision to offer virtual care(28). Recognition and addressing issues around digital literacy for both patients and providers is important.

Special consideration must also be paid to the ways virtual care may change relationships between patients, caregivers, and providers. In a study examining the implementation of a virtual diabetes consultation program during the COVID-19 pandemic, the study found that patients may be wary about discussing distress brought on by diabetes or related psychological issues virtually(11). Participants in our study also found that it was sometimes difficult to approach their provider about certain topics because the nature of their relationship felt different over virtual care. Patients may find it difficult to

express their concerns to their provider because they are unable to engage in virtual care privately at home. Understanding a patient's preference for virtual or in-person care and finding ways to establish rapport may alleviate some of the patient's concerns. Health care providers should always gather consent from the patient privately and should confirm consent if someone else is joining the virtual care session. Our study found that caregivers may also take on disproportionate burden to assist with a virtual care session. Should caregivers be involved a virtual care session, providers should seek to understand the extent of a caregiver's responsibilities and offer support whenever possible.

Involving patients in virtual care research can provide meaningful ways to address some of the issues explored in this paper. Patients can provide unique solutions due to their vantage point as recipients of virtual care(29). Universal access to Internet and integrated virtual care patient portals were identified as two recommendations that could improve patient experiences with virtual care. Further patient-oriented research in these areas could address key challenges related to access to virtual care for Canadians moving forward.

5.1 Limitations

The restrictions posed by the pandemic limited our ability to advertise and reach out to a wider audience and enrol participants with diverse socioeconomic status, health conditions and experiences. We aim to address this in the future by reaching out to community groups to establish rapport and improve recruitment. Our experience reflects the struggle to conduct research during the COVID-19 pandemic, especially meaningful patient oriented research. Barriers to virtual care access may differ greatly by age group, as supported by our findings (e.g., access to technology/Internet for elderly persons). Given that our study included participants with a wide range of age groups, future study may restrict age groups to tease out age-specific barriers to virtual care.

This study was originally intended to take place in person. However, given the COVID-19 pandemic, it took place virtually. One of the challenges of this study was to capture voices from those who experienced barriers to virtual care, as the same barriers likely made it difficult for them to participate in the study. The study team also noted that participating virtually in a study had inherent differences to in-person participation in the study. For instance, the study team had initially envisioned a series of poll questions that could be answered anonymously through a feature offered by Zoom. However, there was not an option for the phone participants to take part or do so anonymously, so the poll portion of the study was not conducted for those groups who had phone participants.

5.2 Lessons learned from patient engagement

Patient engagement played a pivotal role in anchoring this project with a patient-centred lens. The level of patient engagement in this study reflected 'Collaborate' to 'Empower' on the International Association for Public Participation (IAP2) spectrum (permission received by © International Association for Public Participation (IAP2) www.iap2.org) (30, 31). All team members participated in Patient Engagement training. The patient partner team members were involved in every stage of the project and informed critical logistical directions that served to build rapport between the study team and the participants. Some of their suggestions involved having at least one patient advisor facilitate all focus group discussions, creating an orientation package with study team biographies, having a revolving slide of frequently asked questions, and providing the focus group questions to the participants in advance of the scheduled sessions to help them follow along, and suggesting voiceovers during the virtual meetings

whenever possible. These recommendations served to foster a patient centred setting for the participants.

The patient partner members also provided critical methodological directions for the project. Their previous experience in research as patient participants lent a careful eye to the phrasing of the questions and the execution of the study itself. They also provided crucial input on the themes and in the revision of all iterations of data analysis. In other words, our project largely benefited from the careful oversight of the patient partners.

6 Conclusion

Virtual care initiatives are increasingly becoming mainstream across Canada due to COVID-19; however, there is little research featuring a patient-oriented approach. Our findings confirm the necessity of including patients and caregivers into the research process as they can identify unique challenges and solutions associated with virtual care, whose significance may be overlooked by well-intentioned practitioners or researchers. This research has the potential to improve patient safety and identify ways to better support both patients and caregivers in virtual care. Negotiating and adopting patient engagement within the virtual research process is crucial to understanding how virtual care can be more patient-centred. We hope our study encourages other researchers and practitioners to include patient voices and consider the nuances of patient engagement and experiences within virtual care moving forward.

7 Data Sharing Statement

In accordance to the Queen's University Health Sciences Review Ethics Board, only members of the research team have access to the data.

8 Contributor's Statement

SC: Conception of study, study design, data collection; participated in data analysis, interpretation of data, drafted the article; gave final approval; guarantor of the work

AOR: Conception of study, study design; participated in data collection, data analysis, interpretation of data, critical revisions; gave final approval; guarantor of the work

AM: Conception of study, study design; participated in data analysis, interpretation of data, critical revisions; gave final approval; guarantor of the work

EM: Conception of study, study design; participated in data collection, data analysis, interpretation of data, critical revisions; gave final approval; guarantor of the work

EYL: Conception of study, study design; participated in data analysis, interpretation of data, critical revisions; gave final approval; guarantor of the work

VL: Conception of study, study design; participated in data collection, data analysis, interpretation of data, critical revisions; gave final approval; guarantor of the work

RA: Conception of study, study design; participated in data analysis, interpretation of data, critical revisions; gave final approval; guarantor of the work

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Table 1 Sociodemographic profile of all participants

Chara	acteristics	Number of participants
A		(%)
Age	20.20	7 (20 5)
	20-39	7 (38.5)
	40-59	2 (11.1)
	60-79	8 (44.4)
	80-99	1 (5.5)
Sex	Man	5 (27 7)
	Men	5 (27.7)
	Female	12 (66.6)
	Prefer not to answer	1 (5.5)
Diver	•	
	Visible minority	3 (16.6)
	Person with disability(ies)	7 (38.5)
	Indigenous person of Canada	1 (5.5)
	Identifies as an immigrant	1 (5.5)
	LGBTQ community	3 (16.6)
Work	status	
	Working for pay on a casual or on-call basis	1 (5.5)
	Not in labour force, unable to work	1 (5.5)
	Retired	9 (50)
	Student (includes students working part time)	4 (22.2)
	Homemaker	1 (5.5)
	Prefer not to answer	2 (11.1)
Educa	ation	
	Completed high school	1 (5.5)
	Some post-secondary (college, university, technical training) education	3 (16.6)
	Completed college	4 (22.2)
	Completed technical training (e.g., apprenticeship)	1 (5.5)
	Completed university	4 (22.2)
	Completed post graduate, professional, or graduate degree	5 (27.7)
Persp	pective	
	Patient/patient advisor/patient partner	13 (72.2)
	Family member/caregiver	5 (27.2)

Table 1 Major and minor subthemes derived from the master codebook

	T						
Categories/Major themes	Minor themes						
Category: Common barriers to virtual care							
Access to technology and	 No or limited access to technology or Internet 						
Internet are barriers	 Rapid technology changes challenging and overwhelming 						
	Digital literacy can impact virtual care access						
	 Inability to afford technology and/or Internet is a barrier 						
Language barriers and	Inability to express concerns						
cultural differences can	Cultural barriers could impact knowledge of virtual care						
impact virtual care	 Traditional and digital literacy important to virtual care 						
Category: Special consideration	ns improve patient and caregiver experiences with virtual care						
Caregiver and family	Caregiver support is crucial to virtual care access						
involvement	Heavy burden on caregiver to provide care and support virtual						
	care access						
	 Nuances of caregiving must be considered 						
Privacy, consent, and	 Appointments can include sensitive information that patients 						
confidentiality	want to discuss privately						
considerations	 Tension could arise between patients and caregivers because 						
	of lack of understanding or agreement over confidentiality						
	 Caregiver opinion should not be taken at greater value 						
Different patient-physician	 Patients feel they did not have a personal connection 						
relationship	anymore						
	Mechanical interaction with health care provider virtually						
Category: Recommendations							
Future research directions/	 Technology and Internet must be universally accessible 						
Calls to action	 Integration of virtual care modalities will improve patient care 						
	(e.g., consolidated patient portal)						
<u> </u>							

Table 1 Selected quotes from participants according to the discussion themes

Major themes	Quotes						
Access to technology and Internet are barriers	I was speaking with one patient who said that she can't afford internet so she gets in her wheelchair and goes to the library and sits outside the library and picks up their internet. But during the pandemic when they closed the library they also shut down the internet (Group 4, Caregiver 1).						
	My husband had two strokes and both of them were during the pandemic, so everything was done through Zoom which we'd never used before. He is not computer literate and he wouldn't really be there for a lot of the discussions. Physio, how do you do physio over Zoom? That's pretty tricky. OT and speech were all done by Zoom. But after about 10 minutes we kind of lost his interest, so it was really hard to keep him involved (Group 4, Caregiver 2).						
	For the first one, income, like I said, I don't own a computer myself so I can't afford a computer right now, especially with COVID times and not working so I'm sure I'm not the only one in that boat right now (Group 6, Caregiver 1).						
	The thing about virtual care would be so great, but you guys are talking about in your room being a place where there's a dead zone, we've got whole roads that are dead zones (Group 5, Patient 1).						
Language barriers and cultural differences can impact virtual care	English is not my mother tongue and then I just remember one of my appointment with a doctor. It was about my shoulder, so even though I have a degree in physical education, I got to know all the muscles in Latin, I was unable to explain my problem in English (Group 5, Patient 2)						
	I mean in my family, my parents don't speak English very well, so it happens that I often have to call back and just get them clarification on some of the results or anything that's happened at their appointments or my sibling's appointments (Group 1, Patient 3)						
Caregiver and family involvement	My husband can't use a computer. He has no idea even how to turn it on. All the appointments have to be set up when I'm there. He can't answer the phone, he has no strength in his hands, so I have to make all the arrangements to get the phone and get it on speaker and it's really difficult for him to deal with technology (Group 4, Caregiver 2).						
	It's impacted my mother because she doesn't own a cell phone and she doesn't have Wi-Fi or a computer. [] I feel like I need to be there all the time. I'm only two blocks away from my mom, but we speak quite a few times during the day and I just feel like I need to be around all the time, yeah. (Group 6, Caregiver 1)						
	You might not have access to virtual care and it would be up to the doctor to realize that you live separately. The caregiver may have access to a computer and internet, but the patient may not. Does that mean the caregiver has to go and take all their phone or whatever over to the patient every time? There's a lot of moving parts there that you need to think about (Group 4, Caregiver 1).						
Privacy, consent, and confidentiality considerations	I think the issue of privacy comes up to my mind and I put something in the chat about that as well just, if you're at home and you have other family at home and maybe you want to have a private conversation, your family might listen in and you don't want them to. That impacts things (Group 3, Patient 1).						
	But also I was thinking about privacy, what if the person doesn't want to share some of private it doesn't have to be private but your health is part of your privacy. So you may not want to share certain parts of your health issues with whoever the person is next to you. So it's sort of I don't know, creates a sort of tension where privacy is questioned 'cause if I say I don't want you to be present, but we are in a partnership,						
Patient-physician relationship	why don't you want me to hear this, etc., etc (Group 1, Caregiver 1). There was kind of a little bit of an almost artificial, like you're talking to somebody but						

to-face, so there was some of that but the care was, in all but one instance, was very good (Group 1, Caregiver 2).

Lastly, when I need to talk to my GP I email her and that seems to work, although I have a sense that emailing is replacing face-to-face contact and I'm not so happy about the future of that (Group 2, Patient 2).

I don't know, it's just an assumption 'cause you don't see the person and then another thing, you don't know if the person is talking to you attentively. They might be doing something on computer and then talking to you on the side, so there's always this hesitant ... I don't know (Group 5, Patient 2).

I found too that when doctors know that you're actually online for the kids and for yourself, I found that it's hard to find yourself sometimes feeling weak and feeling scared in appointments especially online, but still have to advocate. I find it easier to advocate in person and say, you know, this needs to be done, or feeling weak in person, but then you have to find yourself in between to find any support (Group 4, Caregiver 3).

Future research directions/ Calls to action

I think when things are integrated it makes my life a whole lot easier. The service that I mentioned when I have tried video conferencing I really liked that I could see the doctor's notes and that I could specify the pharmacy of my choice and it would be sent. I think that's really helpful to have all those components put together and not have all these different parts that you have to follow up on (Group 3, Patient 3).

I think the technical side has to develop so it becomes universally accessible to the physicians and patients in an efficient way (Group 2, Patient 1).

Virtual Care Access Tool-Kit Research Project

Virtual Care Access Tool-Kit (VCAT) Project: Discussion Groups

Housekeeping Rules and Frequently Asked Questions (FAQ)

Housekeeping Rules

It is important that the discussion groups are beneficial and welcoming to all participants. Here are some ground rules to create a respectful space of sharing.

- 1) All responses are valid and there are no right or wrong answers.
- 2) Please respect the opinions of others even if you do not agree.
- 3) Practice active listening. When you are not speaking, please mute your microphone. This way, all participants can hear one another.
 - a. If you know you will be joining by a landline phone that cannot mute, you can mute your phone by placing your hand over the receiver. Finding a quiet place may also be helpful.
- 4) Try to stay on topic; the study team may need to interrupt so that we can cover all the material.
- 5) It's all right to abstain from discussing specific topics if you are not comfortable.
- 6) Help protect others' privacy by not discussing details outside the group.
- 7) There are multiple ways of participating in discussions! If you are joining by Zoom, feel free to utilize the chat group but, keep the chat focused on what other participants saying.
 - a. Message the host directly if you are experiencing technological or audio problems with Zoom or if you would like to express a thought privately.
- 8) The discussions will last between 90-120 minutes. Feel free to prepare some drinks and snacks for yourself to keep energized during this time.

Frequently Asked Questions (FAQ)

Q: What should I do if I think of something to say after the discussion group?

A: Write down your thoughts and send your answer to Sophy Chan (swsc@queensu.ca). We would love to hear your responses even after the discussion group!



EXPERIENCES WITH VIRTUAL VISIT

Definition of Virtual Care: Virtual care is the use of video, telephone and/or email for communication and the delivery of healthcare between health care providers and patients.

- 1. What experiences have you had with virtual care such as video conferencing, if any?
 - a. How many did you have? In what setting? Who was the health care professional you were seeing? Type of appointment new patient appointment/follow-up? Modality used? Duration of the appointment?

QUALITY OF CARE

- 2. In what ways do you think the quality of patient care through virtual care is different than inperson care?
- 3. What do you think are aspects of a successful virtual care visit?

TECHNOLOGY AND DIGITAL LITERACY

4. How might familiarity with technology impact one's ability to use virtual care?

COMMUNICATION

- 5. In what ways do you think that virtual care may change your relationship (as a patient, family member or caregiver) with the health care professional, if at all?
- 6. How might the ability to speak or understand English impact someone's ability to use or access virtual care?
- 7. How might cultural differences impact access to or the experience of virtual care?

GEOGRAPHY

- 8. How might rural residents benefit from virtual care?
- 9. What challenges might rural residents face in virtual care?

*********BREAK******

SOCIAL FACTORS

- 10. How might income or the lack of income impact access to virtual care?
- 11. How might social support systems impact access to virtual care? Some examples of social support systems include family, friends, community groups, church, social support services.
- 12. How might sex or gender impact access to virtual care?

HEALTH CARE & DIVERSITY

- 13. To what extent do you think virtual care is more suitable for some patients rather than others?
- 14. How might aging impact access to virtual care?
- 15. What challenges might persons with mental health issues face in virtual care?
- 16. How might persons who are unable to provide consent, such as children or persons with cognitive disabilities, experience virtual care?

CAREGIVERS

17. What might be some important considerations of conducting virtual care with a patient where caregivers and family members are also present?

CONCLUSION

18. If you had one final thought about our discussion today, what would it be?

These are all the questions we have for you today. Do you have anything else you would like to discuss about virtual visits or any questions for us at this time?

About the Study Team

[A table was presented here. The left hand column included a picture of the study team member and right hand column included a brief biography written by each study team member]



Zoom Tutorial

You can join the meeting by clicking the **meeting link** or going to join.zoom.us and entering in the meeting ID and passcode. A Zoom account is not required.

• The meeting link, ID/passcode, and a telephone number will be included in the email invitation and participant package

You may use a computer, laptop, smartphone, or tablet. (It is recommended you be connected to the internet or wifi for these options). You can also join by telephone.

1. To Join:

From the email invitation:

- Click the link that looks like this:
 Click here to Join Group Discussion on Zoom
- If the meeting has not yet started you may see the message: "Waiting for the host to start the meeting"
- If joining online, you will be asked to type in your name. (you may use your first name or the name you prefer to be called)
- You will then see the message: "Please wait, the meeting host will let you in soon."

2. In the Meeting:

Once you are in the meeting, check the bottom left side of the screen to ensure your audio and video are on.



or

Join with Computer Audio

If possible, we ask that you have your video on during introductions. If you would be more comfortable not appearing on the screen, you may turn off your video by clicking on the 'Video' button after the group introductions.

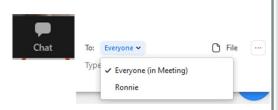
If you do not have a webcam on your computer or if you are joining by phone, we will still be able to hear you and see your name in the meeting.

3. Chatting:

Throughout the meeting, we ask that you have your audio muted. If you are joining us by video, you can do this by clicking on the Mute option in the far left corner of the screen. If you are joining us by phone, please use your phone's muting capabilities or press *6



If you are joining from the link, you are welcome to type in questions on the group 'chat' which is located at the bottom of the zoom screen:



4. View the Group:

If you would like to see everyone with their video on, you can change your viewing options: In the top right corner of the Zoom screen, you will see the View icon. Clicking this will allow you to change how many people you see * We recommend **Gallery** view.



To "raise your hand" in the meeting you may physically do so if your video is on. You can also use the 'raise hand' Zoom feature in the <u>More</u> option at the bottom of the zoom screen.

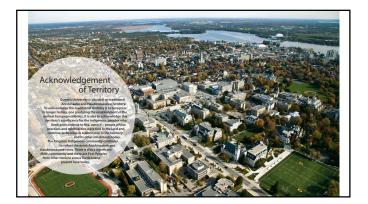
When using a phone call, participants can raise their hand by clicking on *9 on the keypad.

If at anytime you wish to leave the meeting, you may click *Leave meeting* at the bottom right of the Zoom screen. The meeting will also automatically end once the host ends the meeting.











- 1. What has been the most interesting thing you have done or a new hobby you have taken up since the pandemic?
- 2. What led you to want to participate today?

Housekeeping Rules



- 1. All responses are valid.
- 2. Please be respectful of others
- 3. Practice active listening. Mute when not speaking.
- 4. Stay on topic.
- 5. It's okay to not participate.
- 6. Protect one another's privacy.
- 7. Participate by speaking or through the chat group!
- 8. This discussion will last 90-120 minutes with a break in between.
- 9. Message the host if you have a problem or question.

Virtual care is the use of video, telephone and/or email for communication and the delivery of health care between health care providers and patients.

Experiences with Virtual Care

- What experiences have you had with virtual care such as video conferencing, if any?
 - How many did you have?
 - In what setting?
 - \bullet Who was the health care professional you were seeing?
 - New patient appointment or follow-up?
 - What did you use?
 - Duration of the appointment?

Poll: Health Care

Quality of Care

- In what ways do you think the quality of patient care through virtual care is different than in-person care?
- What do you think are aspects of a successful virtual care visit?

Poll: Ability to choose

Technology and Digital Literacy

 How might familiarity with technology impact one's ability to use virtual care?

Communication

- In what ways do you think that virtual care may change your relationship (as a patient, family member or caregiver) with the health care professional, if at all?
- How might the ability to speak or understand English impact someone's ability to use or access virtual care?
- How might cultural differences affect access to or use of virtual care?

-----BREAK-----

Geography

- How might rural residents benefit from virtual care?
- What challenges might rural residents face in virtual care?

Social Factors

- How might income or the lack of income impact access to virtual care?
- How might social support systems impact access to virtual care?
- How might sex or gender impact access to virtual care?

Health Care and Diversity (1)

- To what extent do you think virtual care is more suitable for some patients rather than others?
- How might aging impact access to virtual care?

Health Care and Diversity (2)

- What challenges might persons with mental health issues face in virtual care?
- How might persons who are unable to give consent, like children or persons with cognitive disabilities, experience virtual care?

Caregivers

 What might be some important considerations of conducting virtual care with a patient where caregivers and family members are also present?

Poll: Caregivers

Conclusion

- If you had one final thought to share, what would it be?
- These are all the questions we have for you today. Do you have anything else you would like to discuss about virtual visits or any questions for us at this time?

Virtual Care Discussion Group Exit Survey

Thank you very much for participating in our Virtual Care Discussion Groups!

Your responses will help us improve the discussion groups moving forward. You may finish the survey in one sitting or you may save it and finish it at a later date. The survey should take between 15-20 minutes to complete.

This survey is hosted on REDCap, a secure web application. All responses will be encrypted and only the study team members can read it. All your responses are confidential and we value any information you can give us.

As noted in the Letter of Information, you do not have to answer any or all of the questions if you do not wish to. Please select the option "Prefer not to answer" in this case.

Please note that there will be a series of questions related the honorarium near the end of the survey. If you would like to receive the honorarium, please be sure to fill out that section.

If you should have any questions or concerns about this study, please do not hesitate to contact Sophy Chan (swsc@queensu.ca).



Section 1: Demographic Questions

What year were you born? (Please type	'PNA' if you prefer not to	answer this question)
---------------------------------------	----------------------------	-----------------------

11/1	:_		
What	15	vour	sex:

- Male
- Female
- Other
- Prefer not to answer

If other, please indicate a response if you are comfortable:

REDCap

03-09-2021 16:59

Are you a mer	mber of any of the following groups? (Check all that apply)
☐ Indigenous	ith disabilities s people of Canada migrant to Canada mmunity ow
If you identify	as belonging to another identify group, please indicate a response if you are comfortable:
Note: Some p	ighest level of education that you have completed? eople may have completed multiple types of education. If this applies to you, please select the highest ation that you have achieved.
☐ Some high ☐ Completed ☐ Some post ☐ Completed ☐ Completed ☐ Completed	ompleted elementary school a school d high school c-secondary (college, university, technical training) education d college d technical training (e.g., apprenticeship) d university d post graduate, professional, or graduate degree
○ Working fo○ Working fo○ Not in labo○ Retired	DW .
Have you eve	er worked for pay in a healthcare profession?
Note: We are	interested in paid experience in health care due to the health focus of this work.
Yes,NoI don't knoDo not knoPrefer not	





projectredcap.org

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What perspective did you bring to the Virtual Care Access Discussion Group project?
 Patient/patient advisor/patient partner Family member/caregiver Community member Community partner Other Do not know Prefer not to answer
If other, please specify:

For Peer Review Only



Section 2: Communication and Supports for Participation:									
Please indicate your level of agreement with each of the statements below:									
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Do not know	Prefer not to answer		
I had a clear understanding of the purpose of the discussion group.	0	0	0	0	0	0	0		
The supports I needed to participate were available (e.g., travel, childcare, etc.).	0	\circ	0	0	0	0	0		
I had enough information to contribute to the topic being discussed.	0	0	0	0	0	0	0		

What else would you like us to know about how your participation in the Virtual Care Access Discussion Group Project was supported?





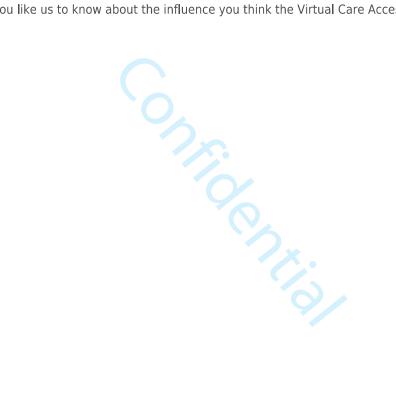
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Do not know	Prefer not to answer
I was able to express my views freely.	\circ	\circ	\circ	\circ	\circ	\circ	\circ
I feel that my views were heard.	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
A wide range of views on the topics discussed was shared.	0	\circ	\circ	\circ	\circ	\circ	0
The individuals participating in the discussion group represented a broad range of perspectives on the topic.	0	0	0	0	0	0	0

What else would you like us to know about how you were able to share your views?



	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Do not know	Prefer not to answer
I think that the discussion group achieved its objectives.	0	\circ	\circ	\circ	\circ	\circ	\circ
I am confident the input provided through this initiative will be used by the study team.	0	0	0	0	0	0	0
I think the input provided through this activity will make a difference to the work of the organization.	0	0	0	0	0	0	0

What else would you like us to know about the influence you think the Virtual Care Access Discussion Groups Project



Section 5: Final Thoughts								
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Do not know	Prefer not to answer	
As a result of my participation in the discussion group, I am better informed about virtual care.	0	0	0	0	0	0	0	
Overall, I was satisfied with this engagement initiative.	\circ	\circ	0	0	0	\circ	\circ	
This engagement initiative was a good use of my time.	0	0	0	0	0	0	0	
What were the strengths of the discussion group?								
What could be improved about your discussion group?								

What else would you like us to know about your experience with the Virtual Care Discussion Group project?

There is a secondary portion of this study. We are looking for individuals to help review some of the themes, ideas, and thoughts shared during their discussion group session. This is a voluntary activity but it will help to ensure that the research team is accurately capturing what was shared in the discussion groups.

Interested participants will receive a document summarizing the points explored in their discussion group session and will be asked to revise the themes in another online meeting with the research team or through email.

Would you like to participate in revising the results of your discussion group session?

\bigcirc	Yes
\bigcirc	Nο

Thank you very much for participating in our study!



