Original article

**Title:** Involving (or not) citizens-patients in the development of telehealth services: A qualitative study of experts’ and citizens-patients’ perspectives

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Abstract

Background

Decisions regarding telehealth services in Quebec (Canada) have been largely technocratic by nature for the last 15 years, and the involvement of citizen-patients in the development of telehealth services is virtually non-existent. In view of the societal challenges that telehealth raises, citizen-patient involvement could ensure more balance between evidence from traditional research methodologies and technical experts, and the needs and expectations of populations in decisions about telehealth services.

Objective

This study aimed to explore the perception of various stakeholders (decisions-makers, telehealth program and policy managers, clinicians and citizens-patients) regarding the involvement of citizens-patients in the development of telehealth services in Quebec. In particular, we explored its potential advantages, added value, obstacles and challenges it raises for decision-making.

Methods

We used a qualitative research approach based on semi-structured individual interviews with a total of 29 key actors. Respondents were identified by the contact network method. Interviews were recorded and transcribed verbatim. A pragmatic content thematic analysis was performed. To increase capacity for interpretation and analysis, we were guided by the principle of data triangulation.

Results

Citizen-patient involvement in decision-making is more perceived as a theoretical idea than as a practical reality in healthcare organizations or in the health system. There is very little connection between citizen involvement structures or patient and user groups and telehealth leaders. For the respondents, citizen-patient involvement in telehealth could increase the accountability and transparency of decision-making, and make it more pragmatic within an innovation-driven health system. This involvement could also make citizens-patients ambassadors and promoters of telehealth, and improve the quality and organization of health services while ensuring they are more socially relevant. Challenges and constraints that were reported include the ambiguity of the “citizen-patient”, who should be involved and how; “claimant” citizen-patient, the risk of professionalization of citizen-patient involvement and the gap between decision time vs. time to involve the citizen-patient.

Conclusions

This study provides a basis for future research on the potential of involving citizens-patients in telehealth. There is a great need for research on the issue of citizen-patient involvement as an organizational innovation (in terms of decision-making model). Research on the organizational predisposition and preparation for such a change becomes central. More efforts to synthesize and translate knowledge on public participation in decision-making in the health sector, particularly in the field of technology development, are needed.

Keywords: citizen-patient involvement, public participation, telehealth, health technology assessment, stakeholders’ perspectives, decision-making.
Introduction

Telehealth, defined as “health care and services, as well as social, preventive and curative services, delivered remotely by means of a telecommunication, including audiovisual exchanges for information, education and research, and treatment of clinical and administrative data purposes” [1], has become an inescapable part of health system reform strategies [2,3]. In recent years, many projects and programs have been initiated with the objective to develop new models of service delivery, capitalizing on the potential of telehealth to improve accessibility, quality, continuity, efficiency and integration of health care and services, especially for populations with chronic diseases and those living in rural and remote areas [2,4-9].

In order to maintain its health system in a capacity to respond to population’s needs, while addressing the problems of shortage or unequal geographical distribution of health professionals, the province of Quebec (Canada) considers telehealth as a major lever [10,11]. However, telehealth raises several challenges, including e-literacy, confidentiality and privacy, patient’s data protection, and the medicalization of the living space, in addition to the symbolism that technology might endorse for some people or communities [12-15]. In the same vein, telehealth also raises issues related to digital democracy and the right of all citizens to equally benefit from advances made in digital health, which leads several authors to call for a better consideration of the perspectives of people and communities who are, or could be, affected by these issues [12,15-19]. In order to overcome such issues, at least in part, the idea of involving citizens-patients (the term refers to patients or their representatives, their family, as well as citizens, public and communities who are actual or potential users of health services) in the decisions concerning the development of telehealth services has been proposed [19-22]. Moreover, this involvement should not only occur in the evaluation of telehealth as a “technical object” (e.g. survey about technology acceptance and satisfaction), but in the prioritization, planning and implementation of telehealth services [13,23].

Public participation in the health sector and in telehealth

Public participation is attracting increased interest from health sector decision-makers [24]. It has come, in a way, to compensate for the limits of the historically dominant technical knowledge from expert systems by giving more voice to the various actors from different knowledge sources [25]. This context is accompanied by a movement of institutional
relocation of collective action for more consideration of different perspectives and opinions [25], which could be described as “lay”.

Public participation in decision-making is also a way of narrowing the gap between evidence from traditional research methodologies and the expectations, real needs and subjectivities of populations [26][27]. Thus, public participation could help to make informed decisions and reach a consensus (or at least a compromise), which would increase the legitimacy and scope of the policies and programs implemented [28].

In the field of e-health, some studies report experiences of citizens-patients involvement. In the United Kingdom (UK), citizen juries contributed to explore the barriers and facilitators to the implementation of e-health services [22]. This study showed that citizens expressed a desire to be included in the development of e-health and that their suggestions were taken into account by decision-makers. Also in the UK, volunteer delegates were recruited to form a panel of citizens to discuss the issue of integrating e-health into healthcare services [19]. This study showed that citizens have a good knowledge of issues related to the use of new technologies and thought that their involvement in the development of e-health programs would be very illuminating. Another study in Denmark explored the potential to involve the public in telehealth implementation [29]. The authors conclude that the success of telehealth depends strongly on the inclusion of the public in the process of planning and development of services. In fact, this perspective would provide an opportunity to reduce the tension between “universal and unbiased” assessment of the instrumental value of a technology and the values, judgments and perceived needs of end-users [30,31].

The relevance and necessity of considering the citizen-patient perspective in telehealth development has led us to question its feasibility in the context of Quebec. In this province, there is a will to involve citizens and patients in decisions that could affect their health, at least in the political discourse. In 2014, a document called “Clinical telehealth in Quebec: an ethical perspective” was produced to inform and sensitize decision-makers, researchers and the public on some ethical issues related to telehealth utilization [32]. This report emphasizes that telehealth should focus primarily on relevance and demand, not on the offer and technology development. Traditionally, decisions regarding telehealth in Quebec have been largely technocratic by nature, and the involvement of citizens-patients in the development of telehealth services is virtually non-existent, except in some research projects. Therefore, many questions remain regarding the meaning, feasibility, and implementation of the citizens-patients’ perspective in the development of telehealth services.
Objective of the study

This study aimed to explore the perspectives of various stakeholders (decisions-makers, telehealth program and policy managers, clinicians and citizens-patients) regarding citizen-patient involvement in the development of telehealth services in Quebec.

Our primary interest was to understand the meaning of citizen-patient involvement in telehealth decision-making in terms of potential advantages, added value, obstacles and challenges it raises for decision-making. In this study, we used the term “involvement” generically without focusing on any particular form. This choice allowed us to explore the notion of involvement in general, and what it meant to the stakeholders.

Methods

Data collection

We used a qualitative research approach based on semi-structured individual interviews with stakeholders involved in, or affected by, decisions related to the development of telehealth services in Quebec. The interview guide covered dimensions related to the perception, added value, relevance as well as the challenges of citizen-patient involvement in telehealth. Most questions were the same for all participants, but some specific questions were asked according to the status of the respondent.

Potential respondents were identified by the contact network method [33]. For decision-makers and managers, we contacted people through the network of our team that is active in the evaluation of telehealth programs and projects in Quebec. We contacted citizens-patients who had collaborated on some research projects in the past [33,34]. Internet searches were also conducted to identify other potential participants, particularly via government, organizational, corporatist or associative documents related to telehealth. This choice was justified by the need to have data and information from various sources to cover the perspectives of different stakeholders. In addition, during the interviews, some participants also referred us to other people.

Data analysis

The interviews were recorded and transcribed. We performed a pragmatic content thematic analysis [35], using a deductive-inductive approach. To increase our capacity for interpretation and analysis, we were guided by the principle of data triangulation [36]. This was done at two levels: 1) methodological triangulation through the use of multiple data...
collection techniques (e.g. semi-directed interviews, informal discussions); and 2) triangulation of data sources consisting in the search for information from various stakeholders [37,38]. The use of multiple techniques and data sources is recognized as being able to increase the credibility of the results [37,38].

We obtained ethical approval from the ethical committee of our institution (number “2015-2016-18 MP”).

**Results**

A list of nearly 64 potential respondents was identified. In total, we were able to interview 29 people (table 2).

<table>
<thead>
<tr>
<th>Type of participants</th>
<th>Number</th>
<th>Gender (F/M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-makers</td>
<td>4</td>
<td>2 / 2</td>
</tr>
<tr>
<td>Managers, technicians and clinicians-managers</td>
<td>11</td>
<td>9 / 2</td>
</tr>
<tr>
<td>Citizens-patients representatives</td>
<td>7</td>
<td>2 / 5</td>
</tr>
<tr>
<td>Telehealth experts (evaluation + research)</td>
<td>7</td>
<td>3 / 4</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>16 / 13</td>
</tr>
</tbody>
</table>

_Table 1 : Summary of interview participant’s characteristics_

The results are structured according to the following themes: 1) Telehealth as technocratic or expert “object”; 2) Relevance and potential contributions of citizen-patient involvement in telehealth; 3) Challenges and constraints to involvement.

Respondents’ quotes are marked with symbols (e.g. R1, R2). All interview quotes were translated from French to English.

**Telehealth as technocratic or expert “object”**

All stakeholders recognize that telehealth decision-making is dominated by a top-down and technocratic perspective. Here, we can distinguish two levels: 1) the central level, emanating from the Ministry of Health or funding agencies that have a major role in the prioritization and choice of telehealth services and programs to implement, and prioritize the use of telehealth in some specialties, levels or locations rather than others; 2) the local level, consisting of projects that are often initiated by clinical, managerial and technological champions in collaboration with researchers, usually funded through some research budgets, and offer telehealth services, often on an experimental basis and responding to the needs identified by those champions. At this level, there are some attempts to involve patients, mainly to evaluate the usability (e.g. ergonomics) of the technological device downstream of
its design and implementation, but less about how the service is delivered or organized (e.g. relevance of the service).

“(…) Are people happy with technology (…) because people can love technology but not like how it is organized (…)” (R1).

Here, respondents recognize that there is very little connection between citizen involvement structures or patient and user groups and telehealth leaders. Thus, the involvement of patient-citizens in the development of services remains very anecdotal or non-existent.

Relevance and potential contributions of citizen-patient involvement in telehealth

- **Accountability and transparency of decision-making**

The fact that decisions on public policy choices, including those regarding health services, need to be discussed, affordable and understandable to the populations concerned has been reported regularly. Respondents believe that healthcare computerization policies involve issues that are important enough for individuals and communities to express themselves and be associated. As telehealth involves significant financial issues in terms of investments and expenditures for the health system, it is even more relevant to have a citizen perspective that helps ensure accountability of decisions on such investments.

“(…)People will not all look for the Cadillac (…) There is also a question of simplicity and use. I think to put citizens, users around a table…. It creates a minimum of obligation being to some extent transparent (…) than if it is only companies and healthcare providers who are together to choose the technology (…)” (R2).

Citizen-patients could also contribute to help to implement relevant services and to remedy the current situation where technologies are developing without a real overview and sometimes exponential costs.

“(…) When I look at the innovations in which we will invest a lot: both public funds and private funds for 7 years, 10 years of development, and then at the end of the race, have a technology that sometimes, doesn’t always meet the needs, or doesn’t meet the most pressing needs, and I think that perhaps if, early in the design of innovation, we had better examined both the needs of clinicians and populations? I think we would have avoided … useless expenses and useless turns (…)” (R3).

- **Pragmatic decision-making and an innovation-driven health system**

Citizen-patient involvement was also seen as a means to influence and accelerate change and adoption of telehealth and integrating it into the health system. Here, reference is made to the repeated failures of telehealth and computerization projects in Quebec. According to some respondents, telehealth in Quebec today is associated with “it doesn’t work”. They estimate
that leadership could come from the population, especially those living in rural and remote areas or living with chronic diseases. They can put pressure on organizations and decision-makers and advocate telehealth as the center of priorities and strategic directions.

Tensions and conflicts between professional orders, unions, organizations and the ministry regarding reserved acts, insurance, reimbursement and remuneration issues accompany the use of telehealth. These challenges significantly contribute to the difficulties experienced by telehealth programs in Quebec today. This situation often leaves the right of access to services for the entire population as a “secondary objective”. Involving citizens-patients could help refocusing the debate on improving access, continuity and quality of services for the population.

“(…) Well, but if the pressure comes from the population, in an environment where we say: “if we had such types of services in a region where there is a lot of diabetes, if we could treat like that, but we cannot because the union doesn’t want, you know … or the worker or manager says: “I cannot. My union doesn’t want to”, you know (…) Oh well listen, me, what I think, sincerely … as long as the patient will not stand up and say: “I am tired. I’m not waiting anymore. There are technological systems that make me no longer have to wait or travel ”(…) There is no counterweight. There, I think we touch the system the most … We touch the crux of the problem (…)” (R4)

Respondents recognized that the involvement of citizens-patients would increase the awareness of decision-makers and health professionals of the potential of technology, but also shed light on its importance in people’s life. In addition, it would make decision-making more pragmatic and rooted in the real needs and expectations, and highlight the level of “acceptable risk” for individuals and communities. On this point, respondents believe that confidentiality and privacy requirements are rigidly addressed by the responsible authorities, which slows down the use of telehealth.

“(…) We, health system experts, have shown that we were unable to do it, and you know that it has been demonstrated, I think. And then, we even mentioned confidentiality reasons very, very often: "it is not safe; it’s not confidential…” It’s like if we didn’t include in the discussion those who are the main concerned by technology; that is to say, the citizens-patients themselves, because there is, in all this adventure, a risk that is never zero, but which was acceptable considering the benefits of technology. And it seems to me that the acceptable risk arbitration can only be made by citizens-patients and not by the health system actors. It’s a big mistake not to have associated them from the beginning, so that these elements of acceptable risk can be addressed and discussed and decided by citizen forums (…) How far am I willing to take a risk that occasionally there is information that can circulate compared to the benefits it gives? Only the citizen or the patient can conclude on this acceptable risk (…)” (R5)

For example, current safety standards and regulations still greatly limit the use of Wi-Fi networks in healthcare organizations, or prohibit that clinicians communicate with their
patients via common chat technologies. Some respondents acknowledge that despite all these restrictions, there are clinicians using these “unsafe” technologies to communicate and monitor their patients, while knowing that it is legally prohibited, because they estimate that the benefits are greater than the risks for the patient. In such cases, citizens-patients should be given the opportunity to estimate the “risk-benefit” and decide whether or not they want to use these technologies to communicate with their providers because ultimately, the information and data belong to them.

“(...) Me, if we had a Face Time service, because I like Face Time. I like to see who I am talking to (...) It would be nice if it was more with a visual contact for me and for many people (...) It improves the exchange, the exchange ... I think, for a person who gets older, see the person you talk to [physician, nurse], if she has a smile, it's like an encouragement .... It's reassuring, it's encouraging and there are many people who live alone as they get older and have not prepared for their old age. You know, it's getting ready, loneliness (...)” (R6).

This argument was also supported by the fact that people have to travel great distances, sometimes several hundred kilometers for a simple routine consultation that can last 10 minutes.

“(...) So, we had clinicians and also clients who wanted to use Skype (...). There were obstacles. For the clinician, it was just more convenient to communicate like this with the client at home, but because we were not in the standards of confidentiality, Skype was banned from the clinical services, but clients, they agreed to use it (...) they are agreeing and consenting. They want! (...)” (R7)

It was also reported that the rigidity of the health system and its difficulty in adapting to the trend of increasing use of digital technologies in people’s life, in addition to its inability to capitalize on the potential of these technologies in the production and the provision healthcare and services, could lead people to search for health services through unconventional means and channels, including digital platforms that offer online health services, with all the risks that this might present for them. Respondents recognized that the possibility to have access to services quickly and cheaply could be attractive to some people. However, in cases where people are victims of medical errors or receive harmful prescriptions via these platforms, the health system will have to assume their care, sometimes with serious complications that would result in significant costs to the public. In addition, it was also admitted that the ability of some people to have rapid access to health services goes against the idea of an equitable and universal health system.

“(...) As long as there was nothing else than that, it was fine, but someone comes to offer something else, you know. And that was the Internet and the optics companies in the USA that sold ... It's the same as the taxi: "It doesn't make sense; it's illegal". Well that's what they say. Opticians still say it. OK? Well, people buy the glasses (...) Me, it's striking what happened
with taxis. Everyone thought taxis were fine. Overnight, someone who took “Uber”, he opens
the door, the car is clean. Hey, that could be the taxi! (…)” (R4)

In this vein, respondents believe that the citizen-patient perspective could help managers and
decision-makers to be more innovative. This will make them more aware of the new uses of
digital technologies and see how they could capitalize on it to improve services. On this point,
participants acknowledge that there is a significant gap between what health organizations and
health system are able to offer in terms of technology-based services and how people use
technology today. It is feared that such a gap will continue to widen, particularly in view of
the bureaucratic heavity of the system.

“(…) In general, patients are very, very open and even wish to use ICTs, and it’s rather the
health system that has reservations. When I look at how we can currently communicate with
the health system, patients want to use e-mail, for example. While the system is very, very
refractory; doctors are refractory; the Canadian Medical Protective Association warns
doctors about this use. So, the obstacles are, in my opinion, much more at the level of the
institution than at the level of the patients. It’s very rare, patients … we see it with the Quebec
Health Record … patients who have withdrawn their consent are extremely rare (…)” (R8)

- The citizen-patient as ambassador and promoter of telehealth

Many citizens-patients are more and more informed about health and technology. They are in
the capacity to propose alternatives or service improvements. Some of them even do
information monitoring on the latest technologies for a given service. They can advocate for
technology with organizations and decision-makers, as well as the community.

“(…) Me, I have a Facebook that is read a lot, and from time to time, I post. Here’s an
application. People thank me “ah thank you, I’ll try it” (…)” (R9)

Respondents considered that the citizen-patient can become an ambassador and promoter of
telehealth services to the population. On this last point, there is a great ignorance of telehealth
and its potential within the population:

“(…) Well, the word itself, I never heard that word. Heh no, me “telehealth”, I would have
thought that it’s medicine classes that are given at the university. Honestly, I have never
heard. Yet, I read the press and I think I am a pretty informed woman, and still the two
committees where I am, I have never heard (…) Are there many people who use that? (…) First, we should talk about it (…) It would be wonderful (…)” (R6)

In addition, another part of the population is still reluctant to use telehealth. There is also the
idea that telehealth is associated with lower quality services or “poor medicine”, which pushes
people to seek services in large urban centers. Respondents recognize that communication and
pedagogy are necessary to explain and convince. They suggest that this could be done by
people who had a positive experience with telehealth, sometimes better than professionals or
experts. Thus, integrating citizens-patients in telehealth project teams would make them ambassadors to their families and communities. Respondents acknowledge that the voice of users is more credible and listened by others, with more weight than that of professionals and decision-makers in some cases. Their opinion can thus influence other users, positively or negatively, because they speak the same language and share certain experiences.

“(…) There is nothing like a doctor to talk to another doctor, well, there is nothing like a patient to talk with another patient (…)” (R1)

On another level, some respondents report that the citizen-patient could also be an ambassador of technology to health professionals, including doctors (advocacy). Examples have been reported of patients in rural areas asking their doctor to be consulted via telehealth while the latter was not using it.

“(…) This is an element that is very important and we, we live it and we have lived in some of our regions where the patient or the professionals tell the visiting doctor from the south: “can we do it by telehealth?” So, yes, there’s a huge lack of information. The population must be more and more aware to ask the doctor: “Can I do it by telehealth?” There are cases where we cannot and cases where yes, we can and we avoid moving the patient (…)” (R10)

- Relevant and better organized services

Opinion, comments and suggestions of citizens-patients have a significant weight with health organizations, clinical teams and decision-makers. Their feedback is in a way the “mirror” that reflects the relevance of the services offered to the population. For instance, in a telehomecare project, some patients have pointed out that they didn’t want to be “plugged in” the technology all day or on weekends; others asked that the service be provided to them at particular times during the day, when the health professional could contact or consult them. These considerations lead to review and reshape the organizational model and adapt the service in the light of the reality of the patient.

- Perceived clinical quality vs. “lived” quality

From a utilitarian perspective, some respondents also recognized that citizen-patient involvement in telehealth would reduce complaints received by professionals or organizations. This is a way to reduce the gap between the “perceived quality” by the health professional and the “lived quality” by the patient. Patients often lack the opportunity to express themselves, thus involving them could be a means to gauge their satisfaction or dissatisfaction with services, and to prevent that technology creates unrealistic expectations.
“(...) Because it’s me who handles the complaints in the organization and sometimes, we don’t understand between what the client wants and what we want for him. Sometimes, we want more for him or we want it differently. I think that if we had more client partners, we might better understand what they want and better adapt our services from the perspective of customer (...)” (R7)

- **Social relevance of technology**

Respondents underscored the importance of considering the cultural particularities, subjectivities and social contexts of individuals and communities.

“(...) Especially in an Indigenous communities where the mentality is not the same. You know, you have to talk about culture. Culture is not the same. So, if you want your project to work, you are better off to join the community with you, because you may be rejected (...)” (R11)

Thus, citizens-patients can challenge the ethical and societal aspect of telehealth and raise awareness about the subjective and lived experience of people. So, it is central to develop services centered on individuals and communities, and better take into account the diversity of backgrounds, paths of life, family, social and cultural contexts. This would limit potential derivatives of the technology (“technological solutionism”) with a tendency to the standardization of services. Technology may not to be for everyone (“you talk to a TV (...) it’s scary for some” (R3)), recognizing the need for a better understanding of the conditions in which telehealth is useful or not, and for what type of population.

“(...) In palliative care (...) the nature of the needs is different ... the nature of the care and how to provide it also. Just to care for people who suffer from dementia, when we question the family caregivers (...) to ask them what is the thing that would make a difference in your life? Do you know what they tell us? Is it baths? Is it respite? (...) Our main need is that you recognize us as a human person. How are you going to solve that with technology? Once again, it is the capacity to recognize the caregiver not as an instrument at the service of the demented person, but a human being who has needs (...) The rigidity of our programs makes that we can’t meet the real needs (...) How, through technology, can we make this happen? It’s a challenge (...)” (R5)

Some respondents considered that involving citizens-patient as necessary as it is urgent to think of telehealth as a philosophy (“societal question”) that challenges the ways of producing and providing services for the population. Such a change requires clear and transparent communication with those concerned, so that telehealth can allow providing services differently but not with less quality:

“(...) Telehealth should bring a new philosophy of care; not a logic of support at any cost. It must also be logical that telehealth is there to make sure that people are more autonomous at home (...) Unfortunately, it’s more complicated, because we’re, again, in this kind of obsession to offer the same types of services, regardless of the tool we use; the same levels (...) It’s not a question of offering less services; it is to offer the service differently with another way to do it (...) Telehealth is not just a tool (...) It grows a distant vision of the care;
it grows a delegated vision of care (...) It affects the empowerment of people to take care of themselves (...)” (R12)

Respondents also mentioned that telehealth should avoid increasing the digital divide (e.g. literacy, e-literacy) at the population level, and consider people and groups without sufficient education, knowledge or means to use it. Thus, involving citizens-patients would make it possible to refocus the priorities, relevance and needs in decisions surrounding the implementation of telehealth services, often reduced to questions of norms, standards and administrative issues.

“Yes, but here, telehealth, and if someone doesn’t have the Internet at home, what are you doing with that? (...) The rest of us, we have everything at hand; we will not ask the question. We say yes, it will work (...)” (R13)

Challenges and constraints to involvement

Despite the added value and perceived usefulness as well as the opportunities inherent to citizen-patient involvement in the development of telehealth services, the observation is that there is a lack of practical and concrete experience reported in health organizations or at the health system level.

- Ambiguity of the “citizen-patient”

From the point of view of decision-making, citizen-patient involvement is seen as the introduction of an element of uncertainty. Decision-making processes still remain structured and codified environments that share common referents, a common language and converging visions. The addition of citizens-patients, who have their own values, language and expectations, as stakeholders in the decision-making makes it possible to question existing equilibriums, which makes managers fear the loss of control over the decision.

Some respondents raised also the issue of decision-making accountability: who is responsible for a decision made with the citizen-patient? What is the degree of responsibility of the latter? Thus, several questions emerge about the place of the citizen-patient in this new decision-making configuration. In this vein, respondents recognized that decisions in telehealth services are largely formulated at the higher level (e.g. ministry or administrators), which leaves little room for maneuver to integrate this new actor.

In addition, the idea that the citizen-patient becomes an element of “triangulation” in delicate decision-making situations where their role could be perverted to put pressure on decision makers or on clinical teams, especially when there is a divergence in visions. Another issue
that was raised is that citizens-patients could become spokespersons of the industry or consumer advocacy associations, in other words, “lobbyists”.

“(…) Patients who have dissatisfaction, who have something to say, do they deal with him? Is it likely to bring us to triangulation rather than people talking directly to managers? (…) How does it fit? How are you going to live? What are the case trajectories and in which cases will they deal with situations? In connection with the complaints commissioner too. That's what you know, you have the users’ committee, you have the complaints and quality commissioner, and you have the patient … the person … I do not know how they can be called (…)” (R14)

In the same vein, there is a risk that citizen-patient involvement be "symbolic" or even perverted to legitimize certain decisions without the people having really contributed, but whose presence could be used as validating such a choice.

Some respondents were reluctant about the idea of citizen-patient involvement. For them, the "fashion" of citizen-patient involvement meant that, for some decision-makers and professionals, the discourse has taken over the development of instruments to do so. It is recognized as a major and rapid change that destabilizes all levels of governance. There is learning to do because of the significant change it brings in the work of decision-makers and managers. Here, some respondents referred to incidents where information leaked during sensitive decision-making processes (e.g. closing a rural emergency service), where it took a lot of energy and time to calm down media, reassure municipalities and communities. Such experiences made some decision-makers very dubious:

“(…) How can we explain to a rural community that the retiring physician will not be replaced, and that the service will now be provided via telehealth from experts based in Quebec City or in Montreal?(…)” (R5)

- A “complainant” or “claimant” citizen-patient

For some respondents, the involvement of citizens-patients in decisions was seen as confrontation. They considered them as mere claimants or complainants, and not true partners or collaborators. Citizen-patient involvement is also perceived as slowing down the decision-making process.

“(…) To open the discussions to the citizens, to the patients? It's not natural. Managers and decision-makers must be convinced that patients bring added value, and I’m not sure, at present, in Quebec in any case, that the majority of managers are convinced of this and, on the contrary, I think that they see the patient as a drag, an obstacle … in any case, something that slows down the process much more than a decision aid (…)” (R8)

Some respondents also believed that the ambient discourse may fall into the caricature stating that citizen-patients are a virtuous source of good ideas at any times, hence the challenge of
articulating the mechanisms to be able to produce the ideas, confront them, discuss and question them publicly.

“(…) We must also be careful to not fall into excess and say that the citizens run the solution. That, I'm against (…) They can participate in the decision, but is not for them to make it (…)”

(R11)

- **Professionalization of citizen-patient involvement**

With the new role that the citizen-patient can, or will, have in decision-making, the issue of the professionalization of citizen-patient involvement emerged, even pushing some people to question whether citizens-patients will hold a “professional title”, be overseen by union conventions and compete for budget within an organization.

“(…) A patient representative spoke to someone at the Ministry and said, "The patient's voice needs to be taken into account. We have to be involved in the decision" and the guy from the Ministry said," Are we going to put you in the Union? "(…) Me, I have already been told by a famous researcher that if we integrate patients into research projects, they will highjack research (...) The big question was what budget item are we going to put this in?” (R15)

- **Decision time vs. time to involve the "citizen-patient"**

Decision-makers work within a decision-making frame, often subjected to time and calendar constraints. Involving the citizen-patient would result in slow decision-making process, as it involves consultations and exchanges with an actor who does not necessarily have knowledge of the functioning of the health system. In fact, according to the respondents, from the moment the citizen-patient is involved, the process must be transparent and not be stingy with information, but also be concerned to transmit the right information in a suitable language, free of jargon and technical acronyms. Also, the question of when and how would citizen-patient involvement be useful and necessary emerged.

“(…) I think it’s not a habit, first. Then, well, there may be an unwillingness to do so, because it makes the process heavier. Because we were looking for Mr. Everyone who may not understand the language, for whom we have to take time to explain. Maybe we have a vision of the result and we … to share with the client, it will be a too long process (…) Because it will delay time of implantation and things like that (…)”(R13)

- **Which citizen-patient should be involved?**

The question of the “right” citizen-patient to involve was often mentioned and respondents pointed out the diversity of profiles, knowledge, opinions and experiences of individuals and communities.
“(...) Then, you see, the citizen, in relation to technology, it takes citizens who are awfully informed to be able to understand. So if we think about citizen participation in developing, better documenting needs, acceptable levels of risk, it must be citizens who have been informed, to whom we are able to explain the issues and who are able to give us a point of view on it (...)” (R5)

- **The question of how**

Many respondents rose the question on how to make the most benefits from citizen-patient involvement. Their main fear was that with increasing calls to involve them, it becomes more a tokenistic participation, so that decision-makers and managers can say that they have associated the citizen-patient in their approach.

“(...) I tell you that with the patient partner, yes, it’s a beautiful concept, but how does it translate into real life, the recipe did not come with it.... It’s fine in terms of diagnosis, but no one offered me instruments (...)” (R17)

**Discussion**

To the best of our knowledge, this work is the first to address the issue of citizen-patient involvement in decisions related to the development of telehealth services in the Quebec health system. It is also one of the few studies that explore this potential from stakeholders’ cross-perspective (policy-makers, managers, health professionals, citizens-patients).

This study shows, at least from a theoretical point of view, that citizen-patient involvement can constitute a major lever to build a health system more innovation-oriented and able to offer services adapted to the needs, subjectivities, constraints and real expectations of the populations. This involvement could contribute so that all citizens benefit from the potential of digital technologies in improving, maintaining or restoring their health and well-being. It could also influence the health system to make more pragmatic decisions for the successful implementation and scaling-up of telehealth. In addition, involving citizen-patient would require time to refocus and sensitize decision-makers on the social, cultural and ethical relevance of the services to be implemented. However, this cannot be done without better communication between decision-makers, organizations and the population [27].

Our findings highlight the significant gap between the relevance and theoretical added value of citizen-patient involvement and decision-making regarding the development of telehealth services in Quebec. Indeed, there is still an ambiguous perception and a certain caution towards the involvement of citizens-patients in decision-making. As reported in this study, there are still many issues to be clarified, particularly regarding the taxonomy of involvement, and the development and availability of concrete instruments and mechanisms to
operationalize it. This observation leads us to consider that citizen-patient involvement in the
development of telehealth services is still at the stage of “innovation” in decision-making,
both for conventional decision-makers and for citizens. Indeed, it is introduced into the actual
decision model, mainly technocratic, where policy-makers, managers and (sometimes)
clinicians are the only ones at the table. Thus, as an innovation, citizen-patient involvement
should provide evidence of its relevance and added value for these actors.

Here, innovation means a set of new routines and working methods that aim to improve the
results, efficiency, profitability, relevance or experience of the actors [39]. It is also a set of
practices, ideas or objectives that are considered new by an individual, a group or within an
organization [40]. In telehealth, decision-making takes place in a context of uncertainty,
where several alternatives are possible, since solid evidence of efficiency, effectiveness,
quality, security and social relevance is still fragmented, incomplete, sometimes contradictory
or inconsistent [41,42]. In this context, taking into account the different available options and
resources as well as the values, expectations and needs of individuals, communities and
society as a whole, could lead to an “optimal” decision that is expected to increase the
benefits while mitigating the risks to the population [43]. That being said, conflicts remain
ubiquitous in any decision-making situation, especially when there is no single choice that is
best for all stakeholders [44,45].

As an innovation, citizen-patient involvement in telehealth may be in competition with other
existing practices, balances, dynamics, cultures (organizational and professional) and powers
(or hierarchies), which could lead to a confrontation between different visions or conception
of reality. Indeed, user acceptance also depends on their perception of how the innovation will
affect them in their practice and the interactions that exist between the actors in the specific
context [39,40,46]. Analyzing our findings through the lenses of the diffusion of innovations
theory [39,40], we found the following: 1) different stakeholders were able to identify benefits
and advantages of citizen-patient involvement in telehealth decisions (relative advantage).
For them, this perspective could be relevant to the work to be done and improve relevance of
decision (tasks and activities). Thus, several respondents who had experience with
participation, or had experiences as health service users, saw the benefits. For others, the
benefits are to be demonstrated, which is necessary to convince them (observability); 2) a
major issue is the operationalization of citizen-patient involvement: how can it be adapted to
find solutions that meet the needs and values of the actors involved, given the differences in
current working methods and standards? (compatibility). In addition, a majority of
respondents have never tested or experienced citizen-patient involvement before in decision-making in their organizations (trialability); and 3) citizen-patient involvement is still perceived by key stakeholders as complex to use and to implement (complexity). In fact, it is expected to have a high degree of uncertainty (risks), which would make it difficult to adopt and operationalize. In addition, for some respondents, there is a need of knowledge and instruments to properly involve the citizen-patient in decision-making (knowledge).

On this last point, this study also showed that there is a problem of knowledge transfer and sharing of research results on citizen-patient involvement in the decision-making. Some stakeholders still hold mixed or negative opinions about this involvement, such as power issues, management of complaints and claims, risks of blocking or complicating of the decision-making processes (time and means required), possibility of lobbying, etc. However, the international literature reports a wide range of experiences and initiatives, involving both patients and the public, that can help inform decision-making and make it more relevant: healthcare prioritization and health policy analysis [47,48], resource allocation and redistribution [49,50], services governance [51,52], and health technology assessment (HTA) [53]. On this point, our finding supports, to some extent, those of Chalmers et al., (2014) that addressed the question of the actual use of research results in decision-making [54]. In our situation, either this research is not really relevant to decision-makers - which is not theoretically the case here - or that there is a missing link between this and the decision-makers concerned, which seems to be the case in our work. Therefore, it is important to focus on the issue of synthesizing, sharing and transferring existing knowledge in terms of contribution and value-added of citizen-patient involvement in decision-making.

In addition, the issue of change management should be better addressed. Indeed, we noted that the resistance and reluctance of some decision-makers and managers are more due to the ambiguity associated with citizen-patient involvement as well as the nature and importance of the changes, in particular of cultures and models, that it brings to decision-making processes. For example, respondents reported that their training does not cover this aspect and that they are not prepared for decision-making with the public. Thus, the involvement of the citizen-patient as a new decision-maker requires codifying and marking the process, better defining the concepts and developing a clear taxonomy as well as ensuring the availability of necessary instruments (e.g. implication strategy, training, toolboxes, evaluation tools, etc.) in order to operationalize and integrate it into the decision-making routine. Future studies in Quebec, or in other similar jurisdictions, should establish a clear taxonomy of involvement to allow
differentiating between the nature of the mandates, the levels (strategic, tactical or operational) and the nature of involvement (e.g. information, partnership) [55]. It is a fundamental step in order to better use the existing modalities of participation, and to adapt or develop others if necessary. Indeed, according to the literature, the relevance (even necessity), nature, level and degree of participation depend on contexts, issues, projects and interventions [31,56].

Moreover, there is also a need to clarify what voice to consider: citizen-patient or consumer [57]. Indeed, it is important to consider the emerging debate on the duality between “consumerist” (e.g. consumer's rights associations, consumer lobbying) and “democratic” discourses regarding the relationship of citizens and populations with public services; which has a strong impact on the nature of governance to be put in place [58].

Finally, in light of the challenges and questions raised by the omnipresence of digital technologies in the choices and priorities regarding the development and implementation of health services, the consideration of the citizen-patient perspective becomes unavoidable, this regardless of how it takes shape. Indeed, digital health involves a number of societal choices and orientations that affect the values and the foundations of health systems: what role should digital technologies play in future directions? What are the inherent risks of using these technologies (equity, ethics, social relevance, data governance)? These questions can no longer be treated by experts within the health system in a way that is disconnected with the expectations and concerns of citizens and communities. In this study, we have addressed the case of telehealth in the provision of care and services, but other issues that arise for countries, such as big data, social networks, robotics, artificial intelligence, nanotechnologies, personalized and predictive medicine, would also require societal debates to find the best ways that these innovations can benefit the whole population, while keeping in mind issues of ethics, equity and health democracy. Indeed, to improve the acceptability of the technology and its subsequent use, the expectations, concerns and needs of the various stakeholders involved should be taken into account [29], making information available and transparent. On this point, it is recognized that one of the success factors of the implemented programs and policies would be a more active and explicit conception of expertise emanating from the experience of citizens-patients as well as their expectations [59].

Strengths and limitations

Our study explored stakeholders’ perceptions of citizen-patient involvement in the development of telehealth services in Quebec. Our findings highlight a number of points that
could guide future works on the contribution of citizens-patients in the development of digital
health for the production and provision of care and services in a manner that respects ethics,
social relevance, equity, justice and the protection of citizens.

The diversity of study participants allowed considering a wide range of opinions and
perspectives about opportunities as well as challenges to be met before citizens-patients can
be involved in telehealth decision-making process. In addition, the broad experience of the
interviewees at all levels of decision-making (policy, managerial, clinical, technical), or as
health system users increases the validity and reliability of our findings. Indeed, our sample
made it possible to achieve saturation, diversification, redundancy, repetition and stability of
interpretations [60,61].

However, we recognize that the timing of the study coincides with a major reform of the
Quebec health system (the largest since 1971), which may have impacted on the results.
Indeed, many potential participants (managers and decision-makers) could not be identified or
joined because they changed positions or were unable to respond to our solicitation. Others
had no visibility on the issue since they had just joined posts related to our research question.
However, the particular context of the reform has been helpful in pointing out the gaps
between the political discourse held in the reform, which calls for greater involvement of the
public in decisions, and the reality of the actors, in the health organizations in particular, who
are required to translate these directives on the ground. That said, our results could have been
different in a non-reform context. Although our study was conducted in a single jurisdiction,
the findings could possibly apply to other health care systems that are facing the same
challenges regarding the need for more citizen-patient involvement in decisions and the
blooming of digital health.

**Conclusion**

In this study, we explored the perception of various stakeholders regarding the involvement of
citizens-patients in the development of telehealth services in Quebec. Thus, the study provides
a basis for future research on the potential of considering the citizen-patient perspective in
planning and implementing telehealth services for a better alignment with the expectations,
needs, subjectivities, and contexts of individuals and communities, while promoting a relevant
and socially responsible integration of technological innovations into the health systems.

Our findings show that citizen-patient involvement in decision-making is more perceived as a
theoretical idea, carried as much by attractive idealistic and utilitarian discourses, than as a
practical reality lived in organizations or in the health system. Here, there is a great need for research on the issue of citizen-patient involvement as an organizational innovation. The adoption of this new decision-making model with the citizen-patient would imply adaptations and adjustments by the various stakeholders concerned by telehealth, which is accompanied by changes and transformations in practices and cultures in organizations. Moreover, efforts to synthesize and translate knowledge on citizen-patient involvement in decision-making in the health sector, particularly in the field of technology development, are needed.

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**Authors’ Contributions**

HA, MPG and JPF conceived and designed the study and were involved in data collection, analysis, and interpretation of results. HA produced the first draft of this manuscript, and received input from MPG and JPF. All authors read and approved the final manuscript.

**Conflicts of Interest**

Authors declare that they have no competing interests.

**Ethical issues**

Not Applicable.
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