



## Adopting a learning pathway approach to patient partnership in telehealth: A proof of concept

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### ABSTRACT

**Background:** Amidst the acceleration of digital health deployment in the province of Québec, the need to clarify the role of patients and caregivers was deemed essential to guide the deployment of telehealth strategies. A patient learning pathway (PLP) approach to patient and caregiver engagement was developed, containing knowledge, abilities, and skills mobilized by patients and caregivers at key moments of the life course with an illness, as well as emerging educational needs.

**Objective:** The objective of the current paper is to present the innovative PLP approach to patient and caregiver engagement in telehealth by applying it to three medical specialties within the context of the Québec healthcare system: dermatology, oncology, and mental health/psychiatry.

**Methods:** The PLP methodology is constituted of five chronological phases: 1) identification and engagement of main stakeholders; 2) exploration; 3) recruitment of patient and caregiver partners; 4) co-development of PLP first draft; and 5) validation and consensus building regarding competencies.

**Results:** Three PLPs (dermatology, oncology, and mental health/psychiatry) have already been mapped using this participatory approach, showing that the proposed PLP approach to patient and caregiver engagement in telehealth is feasible.

**Conclusions:** Mapping patient and caregiver competencies organized throughout patients' life course with an illness can lead to a highly operationalizable tool, which relevant stakeholders can use in a way that promotes patient self-management, shared decision-making, and empowerment.

**Innovation:** The five-step PLP methodology developed proposes an innovative and structured approach to partnership with patients and caregivers in telehealth by outlining their roles throughout their life course with an illness.

### 1. Introduction

The COVID-19 pandemic has highlighted telehealth's benefits and led to the acceleration of digital health shifts on an international scale [1]. The province of Québec (Canada) is no exception, with significant investments in diverse telehealth projects [2]. In 2021, the Centre for

Excellence on Partnership with Patients and the Public (CEPPP) was mandated by the *Institut de la pertinence des actes médicaux* to propose a telehealth strategy for partnership with patients and the public in collaboration with the Quebec Health and Social services Ministry (*Ministère de la Santé et des Services Sociaux*; MSSS). Partnership in care, or patient partnership, is a model of care developed in 2010 by a team at

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the Université de Montréal in which the patient and their family members are considered full members of the healthcare team [3]. It recognizes that patients and caregivers play an active role as effective carers for themselves and therefore develop a specific set of knowledge and skills throughout their life course with an illness, which are complementary to the expertise of healthcare professionals [4].

The telehealth projects currently being developed by the MSSS follow different medical specialties by developing new trajectories specific to telehealth based on existing clinical trajectories. Clinical trajectories present certain limitations in defining the role of patients and their caregivers, mainly that their journeys with an illness are lived beyond the healthcare system [5,6]. Hence, understanding the patients' life course with a particular illness, including the multiple spheres of their life that are impacted (relational, financial, etc.), is necessary. Clinical trajectories do not consider what patients *do*, and therefore *learn to do*, often outside of the clinical context, with their caregivers or in their communities. Partnership with patients and caregivers promotes their role as active and full members of the healthcare team, requiring a new approach had to be developed that would allow telehealth teams to integrate this role into their strategies [7,8].

In this context, the CEPPP developed a patient partnership strategy in telehealth that would be adaptable to each specialty. The project's goal was to clarify the patients' and caregivers' role for each medical specialty in a way that would be easily applicable to telehealth. The first operational aim of the project was to accompany provincial telehealth stakeholders in developing and optimizing online platforms such as patient portals. The second aim is to provide criteria to sort and select existing telehealth tools that are relevant for patients and their families, including websites, online digital content, and mobile applications. An innovative approach, the *patient learning pathway* (PLP), was developed to respond to the aforementioned objectives. PLPs consist of knowledge, abilities, and skills in the form of competencies that are mobilized by patients and caregivers at key moments of their life course with an illness.

The proposed PLP approach to patient engagement in telehealth is relevant and useful to respond to patients' and caregivers' current needs. This process will allow for issuing effective recommendations on how telehealth tools could support patients and caregivers in their role, and ultimately alleviate the burden of illness (see Fig. 1). At an ulterior time, a review of digital tools that respond to patients' needs will be made available, as well as an optimization process of governmental digital platforms for use by patients and caregivers. Effectively, the PLP approach to patient and caregiver engagement in telehealth aims to clarify and value their active role in order to guide the deployment of telehealth strategies according to their needs. The objective of the current paper is to present the PLP methodology by applying it to three medical specialties within the context of the Québec healthcare system: dermatology, oncology, and mental health/psychiatry.

## 2. Methods

The PLP methodology is constituted of five chronological phases: 1) identification and engagement of main stakeholders; 2) exploration; 3) recruitment of patient partners; 4) co-development of PLP first draft; and 5) validation and consensus building regarding competencies (see Fig. 2). At the time of this publication, the PLP methodology has been applied to three clinical trajectories, including oncology, mental health/psychiatry, and dermatology. Two more PLPs are currently going through the fifth phase of validation and consensus building. Two more PLPs are scheduled to be developed in the upcoming months.

### 2.1. PHASE 1: identification and engagement of main stakeholders

During this preliminary stage, the project team identifies the major stakeholder groups that should be involved in the PLP for each medical specialty. This includes patient associations and peer support groups, as well as medical professional associations. In some cases, ministerial direction offices were also identified. Meetings are organized with these

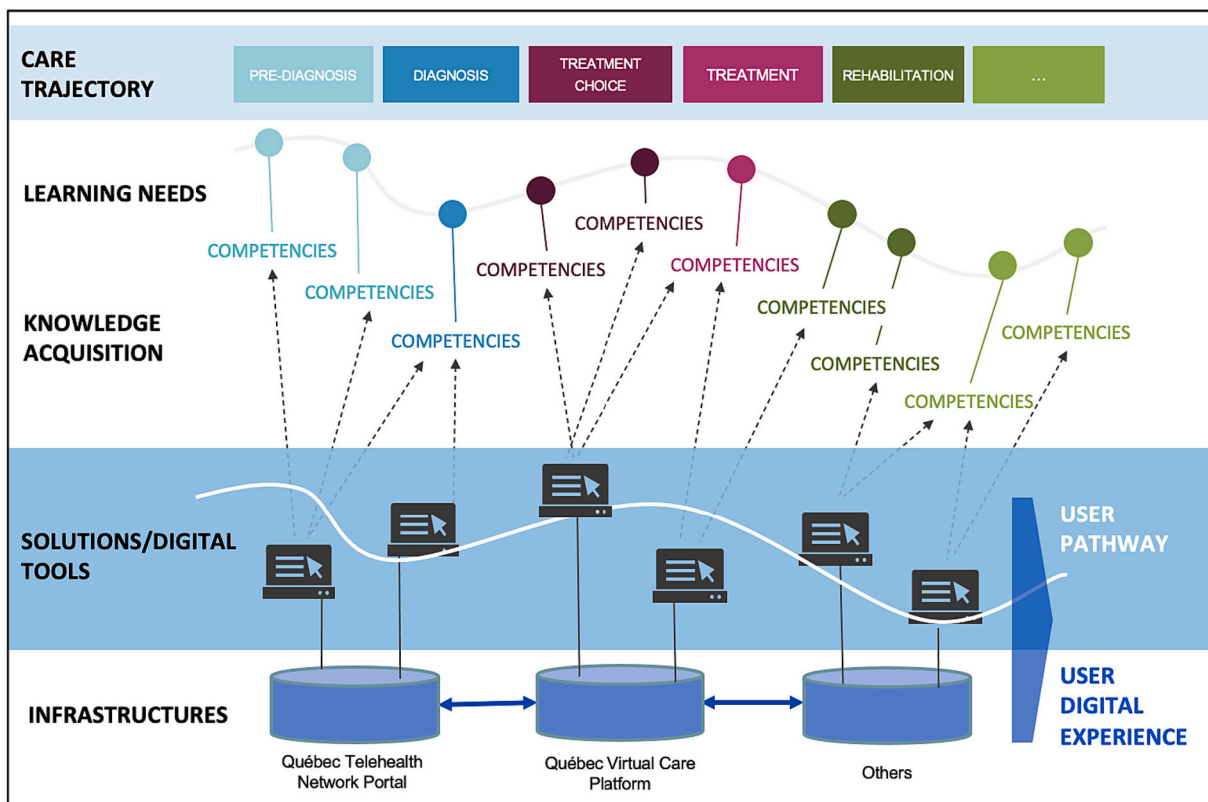


Fig. 1. Schematic representation of the use of a learning pathway approach to patient partnership in telehealth in Québec.

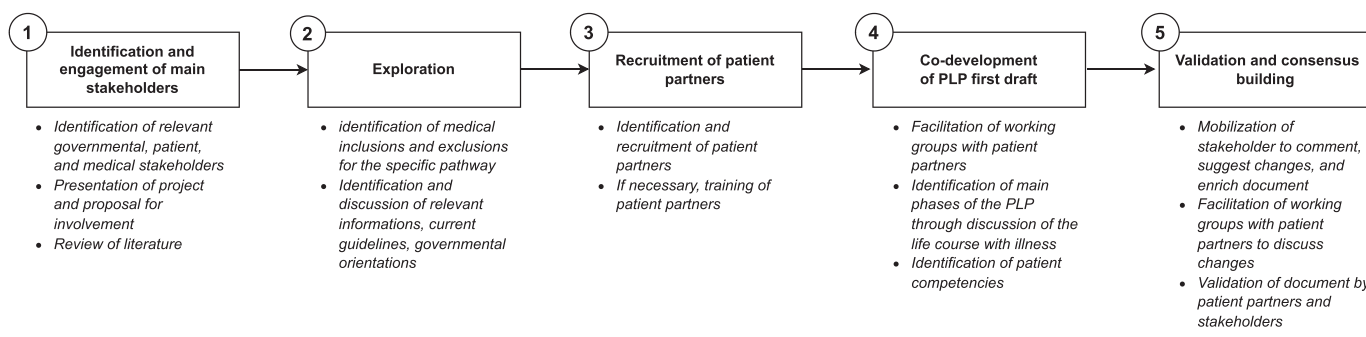


Fig. 2. Five-step methodology to develop Patient Learning Pathways (PLP).

different stakeholders to present the project and determine if they wish to collaborate with the project team. In addition, existing literature is reviewed to help guide the meetings. Input from professional and patient groups is necessary to integrate complementary perspectives and ensure that the experiences and realities of patients and caregivers of different backgrounds are included.

## 2.2. PHASE 2: exploration

Discussions are planned with stakeholder groups who have agreed to participate in the project. The first objective of these meetings is to determine which illnesses and specific patient pathways should be included within this medical specialty. These discussions will specify the boundaries and scope of the PLP in relation to current medical specialties. For example, should skin cancer be included within a dermatology PLP, on its own as a specific PLP, or even as part of a broader oncology PLP? An interview guide is used to structure discussions.

The second objective is to discuss any noteworthy elements pertaining to a specific field or illness. Various dimensions and information regarding the life course with a specific illness can be identified during these discussions, including aspects related to physical or mental health, prevention, care, and major repercussions on different spheres of life. This information may also relate to specific recurring stages in the care trajectory, such as care or treatments, difficulties in accessing particular care or services, or particular needs such as information, resources, or respite that are poorly addressed. Finally, these elements may also concern the actors involved in the life course with illness, such as significant moments during which family members or healthcare professionals play a particular role.

## 2.3. PHASE 3: recruitment of patient partners

A minimum of three patient partners are recruited for the working group, and at least one caregiver partner. They are recruited for their expertise with care and the life course with the illness in question.

Recruitment is conducted following the Model of Montreal patient partner recruitment methodology [3,9,10]. This methodology focuses on patient and caregiver competencies to mobilize experience-based knowledge derived from their experience of life with an illness. Through a series of interviews, recruiters identify desired patient partner competencies (e.g., *narrating one's life journey with illness in a pedagogical manner*), detailed in the patient partner competency framework, which summarizes patient partners' expertise [9,11]. Recruitment is carried out with respect for the person and their interests. The person may refuse to participate at any time during the process.

Patient partner recruitment must follow a strict methodology to guarantee that their contribution is based on their knowledge and skills, not as representatives of larger groups, which is the role of patient associations [12]. The contribution of the latter is included during the initial and final steps of the PLP methodology process. Note that, in this context, patient partners do not need to sign informed consent forms for

ethical purposes since they are expert co-authors of the PLP rather than research participants.

## 2.4. PHASE 4: co-development of PLP first draft

The patient and caregiver partner working groups are facilitated using the CEPPP's co-construction method [8]. This method places the facilitators in a position of receiver and note-taker in relation to the patient and caregiver partners, who assume the role of experts. Therefore, they develop and approve the content written in the shared document as the discussion evolves. The working groups usually meet five to seven times for two-hour work sessions, depending on the progress and rhythm of the working group in reaching a consensus on the contents of the document.

The first two working sessions are dedicated to the identification of the main phases in the PLP. To do this, the working group starts by co-constructing a cartography of the life course with a particular illness, which is built upon existing resources, literature, and references. This process allows the group to confirm, modify, or erase certain elements that were identified during the literature review and during the exploration discussions (phase 2). The patient and caregiver partners also identify key elements, such as actions or types of knowledge that they mobilize throughout the life course with a particular illness. The cartography is used as a basis to determine the main phases of the PLP from the perspective of patients and caregivers of the group. The PLP is not developed with a specific setting or care pathway in mind and integrates the different possible pathways within the same healthcare system. The following three to five work sessions focus on identifying patient and caregiver competencies throughout every step of the PLP. Competencies are written using verbs in the infinitive form.

## 2.5. PHASE 5: validation and consensus building

After the patient and caregiver partner working group has completed the first PLP draft, the document is sent for validation to all the main stakeholders who were identified during the first phase. This is done through multiple rounds of validation. In each round, the project team sends the document in a modifiable text file format and requests comments, add-ons, or corrections before a specific date, generally within a few weeks. All comments are then integrated into the document by the project team. In cases of important changes or rework, integration might require going back to the patient and caregiver partner working group for additional information. This process is repeated until all main stakeholders approve of the document and accept to be identified as collaborators in the final published version.

The objective of this step is two-fold. First, it aims to enrich and validate the documents produced during the working groups with the patient and caregiver partners. This ensures that elements not highlighted by the working group are included, for example, issues concerning specific subgroups of people living with a specific illness (e.g., access to care in rural vs. urban contexts). Indeed, the stakeholder

groups are generally the best suited to ensure adequate representativity is covered by PLPs, since their missions are of a representative nature.

The second objective of this step is to ensure all the main stakeholders agree on the final document. If this consensus can be reached, it suggests all parties involved perceive an added value to the document, and that the PLP contains a valid and pertinent set of competencies to guide and evaluate telehealth. This facilitates the uptake of the PLP by all parties involved in developing telehealth, from regional telehealth teams to high-level decision-makers at the ministry level. To guarantee this step is conducted thoroughly, all main stakeholders are identified on the final PLP document, which is then published, ensuring stakeholder buy-in.

### 3. Findings

During the first phase, identification and engagement of main stakeholders, extensive stakeholder identification allowed a comprehensive overview of the specialty's landscape. Establishing contact and engagement in the project of different stakeholder groups before the working sessions took an average of two months, more than the expected one-month period. Reviewing the literature and current political landscape, as well as being referred by personal contacts was necessary in finding the right stakeholders who should be involved. The number of associations and groups involved was quite variable from one PLP to the next, depending on the complexity of the stakeholder landscape for each field. For instance, the input of over 20 patient and professional stakeholder groups was solicited in the mental health/psychiatry PLP (few providing feedback), whereas dermatology mobilized four extremely productive and available groups. The team perceived that federating stakeholders working together, associative groups with time and important resources, and shared objectives and values were favorable to this type of exercise. Potential issues were brought up during the psychiatry/mental health PLP, with stakeholders perceiving that a patient competencies approach was akin to putting all the responsibility of recovery onto patients. The complexity of the PLP developed, as well as current social issues associated some specialties (e.g., psychiatry/mental health) are major factors to take into consideration.

In the three PLPs developed, stakeholders included the Association of Dermatologists of Québec, the Canadian Skin Patient Alliance, Chronic Urticaria (dermatology), the Quebec Ministerial Oncology Direction, the Canadian Cancer Society – Quebec (oncology), the MSSS National Mental Health Services Direction, and Peer Support Quebec (mental health/psychiatry). The CEPPE team closely involved in the project included three employees (who are also patients or caregivers themselves), two CEPPE co-directors, one professor-researcher and CEPPE co-director, the manager of the patient partnership office at the Université de Montréal, and students completing internships (psychology, political sciences).

The exploration phases were short, lasting around one month for each PLP. The team met with one very knowledgeable stakeholder for each PLP. For the dermatology pathway, the exploration phase helped determine how to orient the working group in a context of more than 3000 skin conditions. The Canadian Skin Patient Alliance was instrumental in delineating and identifying areas of patient needs, which currently lack appropriate response (e.g., inflammatory skin diseases vs. skin cancer and skin burn). For certain conditions, a pre-existing documented patient journey can also serve as a base from which to develop a PLP. For instance, the oncology PLP was based on the Canadian Cancer Society's Cancer Continuum.

During the recruitment phase, patients were recruited through the patient partners database of the patient partner office at the Faculty of Medicine at the Université de Montréal. The database is composed of 200 trained patient and caregiver partners who had been identified and referred by health professional collaborators in the healthcare system across the province, or other patient partners. They are then recruited using a reference framework of skills [9,10], which is centered around

selecting patient partners based on their experience with illness, and ability to share their expertise and produce change at different transformational levels. Diversity based on sociodemographic characteristics is secondary, and not specifically aimed. In our case, most patient and caregiver partners interested in working on the three PLPs lived in the metropolitan region of Montréal, the largest city in the province, home to some of the major healthcare institutions providing specialized care and community resources. There were four patient and caregiver partners working on each PLP.

During the co-development phase, the working groups met five to seven times for two-hour work sessions. Each PLP necessitated an average of 12 h of work on their part. Work sessions with patient partners and caregivers were scheduled within a short time frame of between two to three weeks in order to maintain a high level of engagement from the working group members. The working group identified, within the life course, the main moments in which learning occurs. These do not necessarily include all important moments of a patient's journey since they are not necessarily all learning moments. For example, in a cancer journey, the point in time when a patient receives his diagnosis is not necessarily when they engage in learning. Learning might occur at a certain time after the diagnosis when the patient has had the opportunity to digest the news and start preparing for their journey. The elements identified by patient associations and healthcare professionals represent essential parts to address in an illness-specific life course. In addition, their identification allows a global understanding of the issues and stages of this journey and helps orient the following discussion groups. For example, these discussions led to the inclusion of skin cancer in the dermatology PLP.

PLPs reflect what patients and caregivers do, as well as what they have to learn in a consistent format. For example, a competency could describe a specific action, such as "self-administering medication," or a specific learning, such as "understanding one's diagnosis." In addition, competencies may be detailed into sub-competencies if needed. For example, "self-administering medication" could contain "knowing how to store medication properly" and "performing an intravenous injection."

Each PLP took around three to four months to complete from start to finish. It was found that recruiting a large number of patient and caregiver partners was not conditional to the success of the PLP methodology. Patients with substantial and diverse experiences of a type of illness (e.g., multiple diagnostics, caregiver experience) can identify competencies common to other diagnoses. For example, the group of four patients and caregivers who worked on the oncology PLP were able to produce a document that was relevant to all types of cancer and was approved by all stakeholders during the following steps of the project. The PLP documents produced following this process contain a considerable number of competencies. For instance, the dermatology PLP is divided into eight sections reflecting the principal learning phases of the patient journey. These phases contain a total of 44 competencies, most of which are detailed into sub-objectives. Each objective and sub-objective is written in the infinitive form, such as the following (translated) examples from the different PLPs (Table 1).

The phase of validation and consensus building took an average of two months and a half for oncology and dermatology, while mental health/psychiatry is still being finalized a year later. Consensus building in the oncology and dermatology PLPs was more straightforward due to the limited data available, the innovative nature of the project and the availability of stakeholders involved. Oncology stakeholders were more familiar with working with patient and caregiver partners, which had a positive impact on their perceptions of the document developed. As some stakeholder suggestions focused on changes in the healthcare system, it was important to remind them that PLPs are centered around building and reinforcing patient and caregiver capacity in the current system.

The validation of the document produced was essential for different reasons. It reduces possible blind spots, such as minority patient

**Table 1**  
Examples of competencies and sub-competencies from the dermatology, oncology, and mental health/psychiatry PLPs.

Dermatology		
Phase	Competency	Sub-competency
Discovery, self-examination, or observation of a change	Documenting an anomaly	Documenting the evolution of the anomaly with pictures Noting the physical sensations associated with the abnormality (e.g., itching) Noting the changes in the environment or daily life (e.g., contact with new products, relationship with exposure to the sun or cold)
Oncology		
Phase	Competency	Sub-competency
Treatments	Managing one's treatment and the necessary equipment (e.g., syringes)	Understanding the roles of oncology and community pharmacists Establishing a medication schedule (e.g., Excel file) Understand the specifics of each medication Administering medications (e.g., injections) Manage prescription refills ...
Mental health/ Psychiatry		
Phase	Competency	Sub-competency
Diagnosis	Living with the diagnosis	Understanding the impact of the diagnosis on one's life plan Accepting your new life with the diagnosis Mourning the loss of a life one had planned, of a certain life plan Adjusting one's life plan

subgroups or particular clinical cases that may not be included during expert working group discussions. Engaging all, or most of these stakeholders also works toward encouraging PLP uptake by these same stakeholder groups at the end of the process. Our team identified that maintaining relationships throughout the project and building trust with and between stakeholders was key. The final document contains patient competencies organized across patients' phases of life with illness, the names of the patient and caregiver partners, and stakeholders involved (with consent), as well as a summary of the methodology.

#### 4. Discussion and conclusion

##### 4.1. Discussion

In light of the digital changes being implemented to ensure the modernization of the healthcare system [13,14], patient and caregiver learning needs will increasingly be taken into consideration as more innovative tools are at their disposal to help them self-manage their illness or condition [15]. To respond to these needs, the PLP compiles patients' and caregivers' actions, responsibilities, and learnings throughout the main stages of their life course with an illness in a consistent form, easily applicable to telehealth evaluation, development, and implementation.

Preliminary analyses of telehealth tools and solutions by our team using the PLP have shown potential. The use of the competency form has proven effective for identifying different types of digital tools and tool functionalities, as well as educational content. For example, the patient

competency titled *Managing one's treatment and the necessary equipment* (e.g., *syringes*) can help identify new tools and functionalities to help patients manage their treatment (e.g., the possibility to renew prescriptions, to consult treatment stock at home, or to communicate with the treatment team). However, this patient competency is also indicative of educational needs (e.g., treatment shelf-life, possible side effects, possible treatment interactions, etc.). Therefore, in the context of telehealth, patient and caregiver competencies promote education and functionality in an integrated manner.

##### 4.2. Innovation

Organizing competencies in a consistent format across patients' life course with an illness produces a highly operationalizable tool that different actors of telehealth can easily refer to, including high-level decision-makers, digital technology firms, middle management, and clinical teams. The PLP methodology is feasible; it is time and resource-efficient, accepted by stakeholders, and produces useful, relevant, and actionable output. The PLP is a new telehealth reference framework focused on patients' increasing competence toward self-management, shared decision-making, and empowerment. This tool attempts to identify patient and caregiver needs, as well as their role as valuable actors in healthcare, and to integrate them into organizational processes as high-priority needs. If supported, we believe it could substantially impact the quality, safety, and value of healthcare and services. It could also ensure that patient priorities are known and included, rather than assumed [16]. The intention is not to add responsibility to patients' shoulders, rather shining a light on what they already do, and learn to do, to better support them with targeted resources and tools throughout the arduous journey of life with an illness.

Limitations of the project first include the lack of validation of the methodology used. However, validation of the PLP methodology through rigorous evaluation is underway. The tangible impacts of PLPs on healthcare and services should be demonstrated in the coming years. Another limitation is the use of medical specialties to guide and delineate PLPs, as there could be multiple ways to accomplish this and different criteria from which to include or exclude certain diseases and populations. As our team further develops this methodology, new categorizations should emerge. This highlights the importance of partnering with medical and patient associations to develop a common language. Finally, PLPs are time-bound and evolve as practices change. This makes it important to keep them current and relevant, as they are intended to be living tools that should be adapted over time.

##### 4.3. Conclusion

The five-step PLP methodology developed proposes an innovative and structured approach to partnership with patients and caregivers in telehealth by outlining their roles throughout their life course with an illness. To our knowledge, it is the first attempt to use patient and caregiver competencies as a reference for both patient education and telehealth functionality. PLPs will be used to conduct a series of guided inquiries with key stakeholders in the province of Quebec, which should lead to precise recommendations to the Ministry on which telehealth solutions should be implemented and/or developed. In addition, a proposal for a more detailed evaluation of the impacts of the PLP methodology on telehealth development is underway. Following the demonstration of substantial effects, PLPs could prove to be a useful tool for all stakeholders involved in telehealth around the world.

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## Declaration of Competing Interest

The authors have no competing interests, monetary or not, to declare.

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