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Step-by-step Strategies for an Integrated Patient-Oriented Research: Lessons Learned from a Multicentered Study Stratégies pour une recherche intégrée axée sur le patient : apprentissages issus d'une étude multicentrique

Marie-Eve Poitras, Isabelle Godbout, Vanessa T Vaillancourt, Béatrice Débarges, Annie Poirier, Karina Prévost and Claude Spence

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Article abstract

Introduction: The literature on Patient-Oriented Research (POR) and, more specifically, on the collaborative experience between research teams and patient partners (PPs), varies in the way it reports experiences. In Canada, since a few years, POR has been upgraded and literature now provides several guidelines and tools to support effective engagement of PPs in research. However, scientific literature most often presents elements from the researchers' or from the PPs' perspective, but rarely from both simultaneously. **Objective:** This paper objective is to enhance the current literature and provide examples of day-to-day pre, per, and post POR activities. **Methods:** Based on the 4 guiding principles of the Strategy for POR of the Canadian Institutes of Health Research, we present a step-by-step description of our POR strategies used during our research project. We also give concrete examples and tips shared by PPs and researchers. **Discussion and conclusion:** We favored 3 steps to engage positively our team in a POR approach. These steps led us to 3 main lessons. First, there is a necessity to adapt training on POR. Second, researchers must demonstrate open-mindedness and humility throughout the collaboration. Third, PPs' recognition needs to be emphasized including a normalization of financial aspect. The reflections made in this article will help, hopefully, research teams to begin their patient-centered research process by building on the previous experiences of other teams, such as ours.



Step-by-step Strategies for an Integrated Patient-Oriented Research: Lessons Learned from a Multicentered Study

Stratégies pour une recherche intégrée axée sur le patient : apprentissages issus d'une étude multicentrique

Marie-Eve Poitras, RN, Ph.D., Principal investigator, Département de médecine de famille et de médecine d'urgence/École des sciences infirmières, Université de Sherbrooke, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean

Isabelle Godbout, M.Sc, Research Coordinator, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean, Unité de soutien SRAP du Québec - Composante de renforcement des capacités et perfectionnement professionnel

Vanessa T Vaillancourt, M.Sc, Research Coordinator, Département de médecine de famille et de médecine d'urgence/École des sciences infirmières, Université de Sherbrooke, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean

Béatrice Débarges, M.Sc, Patient Partner, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean

Annie Poirier, M.Sc, Patient Partner, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean

Karina Prévost, Patient Partner, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean

Claude Spence, M.Sc, Patient Partner, Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Saguenay-Lac-Saint-Jean

Correspondance | Correspondence:

Marie-Eve Poitras, RN, Ph.D.

Professeure

Département de médecine de famille et de médecine d'urgence, École des sciences infirmières

Faculté de médecine et des sciences de la santé

Université de Sherbrooke

3001, 12^e Avenue Nord, Sherbrooke, QC, Canada, J1H 5N4

marie-eve.poitras@usherbrooke.ca



Keywords

patient-oriented research;
patient partner;
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reflexive practice

Abstract

Introduction: The literature on Patient-Oriented Research (POR) and, more specifically, on the collaborative experience between research teams and patient partners (PPs), varies in the way it reports experiences. In Canada, since a few years, POR has been upgraded and literature now provides several guidelines and tools to support effective engagement of PPs in research. However, scientific literature most often presents elements from the researchers' or from the PPs' perspective, but rarely from both simultaneously. **Objective:** This paper objective is to enhance the current literature and provide examples of day-to-day pre, per, and post POR activities. **Methods:** Based on the 4 guiding principles of the Strategy for POR of the Canadian Institutes of Health Research, we present a step-by-step description of our POR strategies used during our research project. We also give concrete examples and tips shared by PPs and researchers. **Discussion and conclusion:** We favored 3 steps to engage positively our team in a POR approach. These steps led us to 3 main lessons. First, there is a necessity to adapt training on POR. Second, researchers must demonstrate open-mindedness and humility throughout the collaboration. Third, PPs' recognition needs to be emphasized including a normalization of financial aspect. The reflections made in this article will help, hopefully, research teams to begin their patient-centered research process by building on the previous experiences of other teams, such as ours.

Résumé

Introduction : La littérature sur la recherche axée sur le patient (RAP), particulièrement celle relatant l'expérience collaborative entre les patients partenaires et les équipes de recherche, varie dans la façon dont l'expérience est rapportée. Au Canada, depuis quelques années, la littérature concernant la RAP émerge et fournit davantage de recommandations sur les façons efficaces d'engager les patients dans la recherche. Cependant, celle-ci rapporte le plus souvent l'expérience soit des chercheurs ou des patients partenaires, mais rarement celles des deux perspectives mises en commun. **Objectif :** Cet article a pour objectif d'enrichir la littérature sur la RAP et de fournir des exemples d'activités quotidiennes avant, pendant et après la RAP. **Méthodes :** En nous basant sur les 4 principes de la RAP des Instituts de recherche en santé du Canada, nous présentons les stratégies « pas à pas » utilisées pendant notre projet de recherche. Nous fournissons également des exemples et des astuces partagées par les patients partenaires et les chercheurs. **Discussion et conclusion :** Afin d'engager positivement notre équipe dans une démarche de RAP, nous avons retenu 3 étapes qui nous ont permis de dégager 3 leçons de cette expérience. Premièrement, il est nécessaire d'adapter les formations portant sur la RAP selon les publics concernés dans le projet de recherche. Ensuite, les chercheurs doivent faire preuve d'humilité et d'ouverture d'esprit pour reconnaître les expériences variées. Puis, la contribution des patients partenaires doit être reconnue incluant la normalisation d'une rétribution financière pour leur travail effectué. Les réflexions apportées dans cet article aideront, nous l'espérons, des équipes de recherche à construire leur RAP en bénéficiant des expériences comme celle que nous rapportons.

Mots-clés

recherche axée sur le patient;
patient partenaire;
savoir expérientiel;
pratiques collaboratives;
pratique réflexive

INTRODUCTION

Patient-Oriented research (POR) refers to “a continuum of research that engages patients as partners, focuses on patient-identified priorities, improves patient outcomes and healthcare systems and practices” (Canadian Institutes of Health Research [CIHR], 2017, p. 5). This shift from patients as research subjects to patients as collaborators reflects the desire of several organizations to conduct evidence-based research centered on patient goals, concerns and outcomes (Black et al., 2018; Gooberman-Hill et al., 2013; Seely & Grinspoon, 2017). In Canada, POR has emerged around 2010 since patients and communities have been more involved in research and is growing rapidly. This approach was built upon participatory action research and has developed a lot since (Bell et al., 2019; Kaur & Pluye, 2019; Swazey & Fox, 2004). This field is still relatively new in Canada, compared to Europe where POR was implemented before the 00s (Harrison et al., 2019; INVOLVE, 2020). Since 2013, the Canadian Institutes of Health Research (CIHR) support researchers who wish to integrate patient partnership into their projects by the implementation of the Strategy for POR (SPOR). CIHR ask each province of Canada to implement a SPOR SUPPORT Unit. SPOR SUPPORT Units are a coalition of federal, provincial and territorial partners all dedicated to the integration of POR into care improvement.

LITERATURE REVIEW

The clinical demonstration of patient engagement and the description of its real impact on research results are poorly explored (Manafa et al., 2018). The literature on POR and, more specifically, on the collaborative experience between research teams and patient partners (PPs), varies in the way it reports experiences (Brett et al., 2014; Domecq et al., 2014; Manafa et al., 2018; Pomey et al., 2015; Witteman et al., 2018). In addition, literature most often presents elements from the researchers’ perspective or from the PPs’, but rarely from both simultaneously (Brett et al., 2014; Crocker et al., 2017; Domecq et al., 2014; Manafa et al., 2018; Pomey et al., 2015).

In Canada, since a few years, POR has been upgraded and literature now provides several tools to support effective engagement of PPs in research. Those tools are less theoretical and provide specific examples to support research teams in the realisation of POR (de Wit et al., 2018; INVOLVE, 2018; Kent, 2019; Saskatchewan Center for Patient-Oriented Research, 2016; Witteman et al., 2018). As they were often described as inconsistent (Pushparajah, 2018; Smith et al., 2019), an important effort has been made to enhance the literature and guidelines about POR. The CIHR now also provides guidelines for many aspects of the POR (2019a, 2019b).

OBJECTIVE

This paper objective is to enhance the current literature and to provide examples of day-to-day pre, per, and post POR activities. With a view of sharing our knowledge and contributing to improve training programs on POR, we present the POR strategies we used from a collaborative experience in a multicenter qualitative research project (Poitras et al., 2020). The present paper reports POR and lessons learned that emerged from a research project conducted between 2017 and 2019. This research project was entitled “Patients with Complex Care Needs who Frequently Use Healthcare Services: Decisional Needs and Interprofessional Shared Decision-Making” (Poitras et al., 2020). It was composed of four PPs, five researchers and one research coordinator (RC). The principal investigator (PI) of this research project is a junior researcher in nursing sciences. Through this project, the PI and the research coordinator (RC) investigated the benefits and barriers to the research process by collecting thoughts, ideas and impressions of the PI and PPs at several occasions and those were integrated in this article.

METHODS: STEP BY STEP

Based on the four guiding principles of the Strategy for POR of CIHR (2017), we present a step-by-step of the POR strategies used during our research project and give some examples and tips

shared by PPs and researchers. The authors (four PPs, the RC and the PI) gave their verbal consent to report their perspective.

STEP 1: SELECTION OF PATIENT PARTNERS

Selection of PPs is certainly the first step to achieve to begin a POR project. Those patients must have an experiential knowledge, appropriate skills and should (if possible) have an experience in research as PP. In this project, the PI approached PPs with an experiential knowledge consistent with the studied population (defined as patients with complex care needs who frequently use healthcare services) and the research project as a process. Thus, four PPs, who were at that time active workers in the labor market, and who suffered from multiple chronic diseases and also were (or still are) frequent users of health services, have been involved in this research project. The Strategy for POR (SPOR) SUPPORT Unit provided training to PPs on the conceptual basis of POR to improve their knowledge of the research process, the know-how to transmit their experiential knowledge, to reinforce their ability to assume leadership within a research team and more. Some of them are involved in organizations representing POR in Quebec.

STEP 2: DETERMINE PATIENT-ORIENTED STRATEGIES

We determined patient-oriented strategies to build the research project and team operating. This helped us to face difficulties when they occurred but also to support the team members co-creating and becoming a team. To do so, we used different POR strategies, informed by the four guiding principles for SPOR of CIHR (2017), namely, inclusiveness, support, mutual respect and co-building, and present those in the following paragraphs.

Inclusiveness. Inclusiveness is defined as the integration of multiple patient's point of view and experiences (CIHR, 2017). Their experiential knowledge must be integrated in the project at the same level as scientific knowledge. In our research project, the PI and the RC were concerned about meeting PPs' expectations and how to integrate their experiences and background into the

research. The PPs gave their feedback across the project and helped to keep focus on the research question and on the importance of patient-oriented outcomes. For example, on several occasions, the PI and the RC asked specific questions to the PPs to validate results. PPs contributed to the interpretation of data and to the dissemination of the project's outcomes. The RC also had discussions on a regular basis with the PPs to document their interpretation of their contribution and their feeling about the different steps of the research project. During data collection, PPs also help participating clinicians to understand patients' perspectives during focus groups. Their involvement in data collection was mainly significant to conduct interviews with participants as in the presence of PPs, participants were confident and felt understood regarding their own experiences.

Support. Support is essential to operate wisely in a team. It represents a way of being flexible and provides opportunities for PPs to contribute to discussions and governance, according to their skills and competencies (CIHR, 2017). In our project, researchers have offered safe conditions by avoiding putting pressure and a feeling of judgment on PPs. For us, this principle also meant a financial compensation for PPs' involvement and reimbursement for their expenses.

As a good communication strategy is crucial to ensure collaboration and engagement of PPs, we have used several medium to stay connected. The RC adapted her communication methods to the reality of PPs and provided technical support to help them use different technologies. The PI and the RC also offered methodological support to the PPs when they were involved in activities for which they felt less competent or confident. For example, the frequency of meetings and discussions was increased during data collection and data analysis to meet PPs' needs and expectations. Creation of several tools to facilitate PPs' work and communication have enabled them to develop their confidence in carrying out research activities. Feedback meetings were also held after each intervention of the PPs during the data collection. Those allowed all team members to improve the quality of the data collection as it was carried out.

Mutual respect. To form a meaningful and successful team, mutual respect and trust are key elements to rely on. Mutual respect is a way to recognize knowledge and experience of team members and to emphasize on their competencies and skills (CIHR, 2017). Already in the start-up meeting of this project, the PI and the RC expressed their respect regarding PPs' experiential knowledge (living with a disease) and acknowledge how their expertise is essential to reach research goals. They gave them space to discuss their experience and to share the way they conceived their involvement within the team. Also, the PI did not position herself as an expert but as a team member like any other.

In recognition of PPs' specific life context, the PI and the RC also adapted the project's timeline to fit their rhythm and preferences. As an example, we adapted our schedules and methodology to be coherent with PPs working schedules and the specific characteristics of each PP such as their health condition, their personality and their skills. PPs have also expressed their respect in regard to knowledge and competencies of the RC and the PI and recognized specific research activities that fell out of their competencies' boundaries. The mutual respect within the team towards the various competencies of its members was so strong that PPs have alternatively presented the project to different audiences.

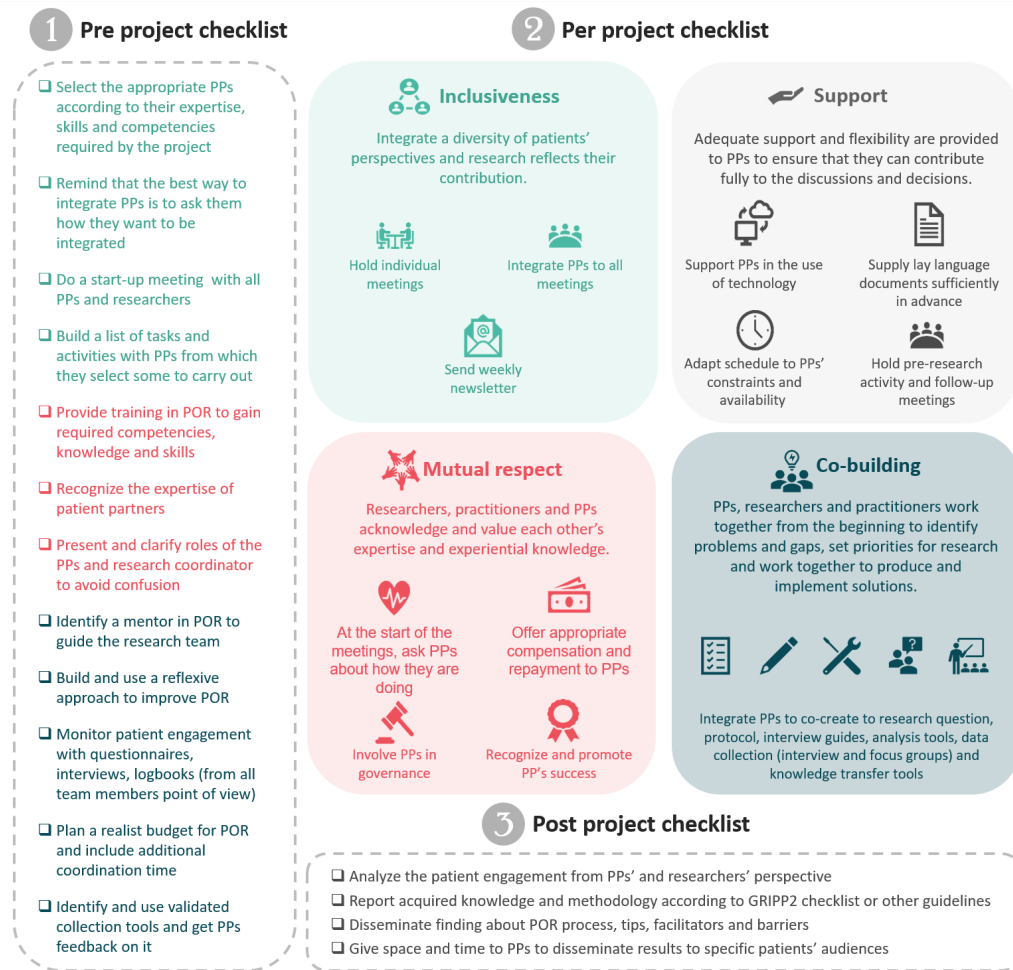
Co-building. Co-building involves that all team members work together from the beginning, to plan, prioritize, discuss and resolve problems and implement and disseminate research outcomes. Co-building must be put in place as soon as an idea of a research project emerges (CIHR, 2017). In our project, we held a start-up meeting with all research team members to discuss the process, needs, expectations, availability, concerns and thoughts of everyone. During this activity, we discussed each team member's level of involvement.

We created a list of types of involvement (Table 1). The PI and the RC took the time to discuss, explain and improve it according to PPs' comments. PPs were then invited to choose research activities in which they wanted to contribute. This list helped PPs to see concretely all the range of activities that they could be involved in. They usually selected activities in which they were more comfortable with and for which they felt competent and interested in.

STEP 3: EVALUATION OF PATIENT ENGAGEMENT

According to several authors (Alberta SPOR SUPPORT Unit, 2018; Aubin et al., 2019; Boivin et al., 2018), the evaluation of patient engagement (quantitatively and qualitatively) is essential to identify barriers and facilitators of POR and to inform researchers and funders while we improve our understanding of patient engagement. However, reported data are limited and no validated tool is available (Domecq et al., 2014). To evaluate patient engagement, we performed different monitoring activities through the process. First, the RC conducted weekly individual follow-ups to document PPs feelings and needs. To achieve that, we held five post-mortem team meetings, at significant steps of the research project. An online questionnaire was also sent to PPs at the end of the research project to identify POR's strengths, benefits and barriers, as well as any learning made during this POR. Finally, thoughts, ideas, impressions and observations on the research process and POR activities were compiled into a logbook by the RC according to the GRIPP2 reporting checklists (Staniszewska et al., 2017). Based on the currently available literature and our experience as a team, we have developed a scheme (Figure 1) summarizing the POR strategies used to facilitate patient engagement before (pre), during (per) and after (post) a research process.

Figure 1. Strategies used to facilitate patient engagement.



Legend: Figure 1 shows strategies used by the research team to facilitate patient engagement in the research project, based on the four guiding principles for patient engagement into research of CIHR (2017). We also provide concrete examples for each principle (Aqua=Inclusiveness, Gray=Support, Red=Mutual respect, Blue=Co-Building).

DISCUSSION: LESSONS LEARNED

This article aimed to present the strategies used pre, per and post our POR research project. We favored three steps to engage positively our team in a POR approach. These steps lead us to the following lessons.

NECESSITY FOR AN ADAPTED TRAINING

At the beginning of the project, despite the theoretical training received on POR, the PI and the RC felt underqualified to integrate PPs adequately

into the research project. They did not have access to standardised practices, broadly accepted tools, and procedures on patient engagement. Many questions emerged during the research project regarding the appropriate moment to involve PPs, how to properly benefit from their expertise and experiential knowledge, how to recognize their contribution while meeting their expectations, and respecting their needs and limits.

PPs involved in our research project felt better prepared to collaborate on a research project than the researcher, which is consistent with literature (Belisle-Pipon et al., 2018; L'Espérance et al., 2018). As a junior researcher led the research

project (the PI), this feeling was accentuated. Training is even more important if ones wish to prepare team members to face difficult situations and find innovative ways to resolve problems. POR support and process can still be improved and be better understood by researchers in healthcare fields. A recent scoping review (Frisch et al., 2020) supports this thought by reporting that researchers have to possess some main competencies to make efficient POR, such as communication, teamwork and conflict management as well as research knowledge/skills and cultural competencies. For example, PPs identified the lack of training in POR of the researchers and the wide variety of roles they could enact and of the collaboration models available as barriers to a successful POR. It was difficult for the PI to find the appropriate level of involvement for each PP without over-solicited them, which is consistent with Bailey and colleagues (2015).

Also, training should be more oriented on operational way to conduct POR than on the conceptual importance of involving PPs in research. We believe that testimonials or mentoring from senior researchers with experience in POR would have allowed us to better support the research project inception and to gain confidence in how we should collaborate with PPs. Coaching is in fact a relevant and efficient strategy in POR as mentioned by de Wit and colleagues (2018) and it also helps build competencies (Kirkpatrick & Kirkpatrick, 2016; Pearce et al., 2012).

OPEN-MINDEDNESS AND HUMILITY

The PI and the RC learned an important human lesson through this project: the importance of humility and openness in conducting POR. This lesson helped both working in collaboration with PPs by not positioning themselves as experts. This open-mindedness helped them to put aside their methodological and scientific knowledge to better understand the reality and the life stories of PPs. PPs experienced the same thing being aware of the vulnerability of some participants. This awareness pushed them to realize that some participants had a heavier health condition than they thought. Each team member felt that open-mindedness and humility were helpful to develop competencies

related to POR. We must recognize that most of us did not receive required initial training in POR in our curriculum. POR is completely different from what researchers learned in academic curriculums.

RECOGNIZE PPs CONTRIBUTION AND NORMALIZE FINANCIAL ASPECT

Along with an efficient communication base (Richard et al., 2018), the research team members discussed their expectations regarding their contribution to the research and compensation and reimbursement method. Financial aspect, including calculation mode and terms and conditions should have been discussed at the beginning of the project to ensure that each team member was comfortable with the procedure. A clear statement about the distinction between payment of expenses versus compensation should be done early in the process as suggested by several guidelines (Richard et al., 2018; Unité de soutien SRAP du Québec, 2018).

Another important point is that research involving PPs is more time-consuming and therefore more expensive than research not oriented towards patients. Indeed, researchers should have planned for additional coordination work for preparation of lay documentation and required phone calls or email exchanges to support and inform PPs.

MUTUAL UNDERSTANDING OF ROLES AND ACTIVITIES

The research team co-built a project which left space for PPs and provided them an opportunity to participate in all stages of the project, from developing the research question to disseminating results, including data collection and analysis. However, some tasks were more difficult to perform, such as conducting interviews with patients and validating codes used in the qualitative analysis. While having PPs choosing the activities they want to take part in, the PI and the RC should have led them towards activities where their knowledge were the most relevant, such as research question validation, interview guides review, results discussion and assisting in research conferences. These types of involvement ensure the relevance, quality and validity of research (de Wit et al., 2011) and avoid exposing PPs to

situations or contexts in which they might feel less comfortable. At the time of such changes in the way of conducting research, the PI and the RC should have ensured that PPs' expectations of POR were respected and that the role they wanted to endorse was a good fit. Then they should have supported them in this role. Indeed, involvements and expectations should have been clearly settled out and discussed upstream.

MONITOR YOUR POR PROCESS AND CONDUCT EVALUATION

We believe that it is important to undertake an evaluation of POR not only at the end of the project but throughout it. It allows to verify if the performance of the research project could be linked to POR (Smith et al., 2018) and to validate if POR is the best approach to address a particular clinical problem (de Wit et al., 2011). To include all aspects of patient engagement, the evaluation must be based on a framework of theoretical models (Staniszewska et al., 2011). Several tools are now available to evaluate patient-engagement in research, but they present limits and possess low transferability (Boivin et al., 2018). Research teams have to choose a tool according to the POR components they want to monitor. Our team has monitored the strengths and weaknesses of POR and the challenges faced by PPs and researchers. This monitoring was useful to adjust our team functioning and POR process. As an example, the monitoring allowed us to increase the frequency of the meetings and favoured face-to-face ones to better meet PPs' needs and expectancies regarding team functioning and communication. We also offered supplemental coaching related to data collection and analysis.

CONCLUSION

We applied step-by-step strategies to meaningfully integrate PPs and to recognize their contribution. The reflections made in this article will help, hopefully, research teams to begin their patient-centered research process by building on the previous experiences of other teams, such as ours. Furthermore, institutions that promote POR

must continue to improve the literature on patient-oriented research in order to make the operationalization of POR recommendations more accessible and feasible. To do so, research teams should continue to disseminate their POR processes, strategies and lessons learned, by including both PPs' and researchers' perspectives. This will help to strengthen actual guidelines and give more support to research teams who embrace POR as a way to conduct research and will allow achieving Patients-Oriented research outcomes.

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Ethical considerations: The research from which the method came from was approved by the *Comité d'éthique du Centre intégré universitaire de santé et de services sociaux du Saguenay-Lac-Saint-Jean* (2017-004-Volet 2B). All the authors gave their consent to report their point of view.

Abbreviations and acronyms

CIHR: Canadian Institute of Health Research

FRQS: *Fonds de recherche du Québec - Santé*

GRIPP: Guidance for Reporting Involvement of Patients and the Public

POR: Patient-Oriented research

PP: Patient partner

SPOR: Strategy for Patient-Oriented research

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Table 1

Types of involvement developed with the patient-partners in the research process

1. Data collection tools:
<ul style="list-style-type: none">▪ Write individual and group interview guides▪ Build focus group interviews observation grid▪ Create socio-demographic questionnaires
2. Ethical documents:
<ul style="list-style-type: none">▪ Write consent forms▪ Design recruitment posters
3. Training to other patient-partners for:
<ul style="list-style-type: none">▪ Animate/Co-animate individual interviews▪ Animate/Co-animate focus groups▪ Prepare individual interviews▪ Prepare focus groups▪ Observe focus groups▪ Analyze qualitative data in a basic software (Microsoft Word, instead of a specialized one)
4. Individual interviews:
<ul style="list-style-type: none">▪ Recruit participants (poster distribution, communication through networks, e.g. health and social services professionals)▪ Contact the recruited participants (description and explanation of the project)▪ Arrange appointments with participants▪ Reserve recording devices and batteries▪ Print documents (interview guides, questionnaires, consent forms)▪ Print receipts for compensation (\$)▪ Animate/Co-animate
5. Focus groups:
<ul style="list-style-type: none">▪ Recruit participants (poster distribution, communication through networks, e.g. health and social services professionals)▪ Draft the agenda▪ Contact the recruited participants (description and explanation of the project)▪ Arrange appointment considering participants' availability (Doodle)▪ Book of a meeting room▪ Reserve two recording devices and batteries▪ Create badges with the names of the participants▪ Print documents (interview guides, questionnaires, consent forms)▪ Arrange the meeting room (tables and chairs) for convenience▪ Print receipts for compensation (\$)▪ Animate/Co-animate▪ Be an observer
6. Data analysis (e.g.: themes' validation):
<ul style="list-style-type: none">▪ Code the verbatim from individual and focus groups interviews▪ Interpret data
7. Knowledge transfer:
<ul style="list-style-type: none">▪ Write summaries for participants and conference summaries▪ Create pamphlets for the general population▪ Design posters▪ Write scientific articles or plain language articles for local, national and international newspapers▪ Create PowerPoint presentations▪ Participate to a workshop with the research team and the piloting committee▪ Participate to knowledge transfer activities (local, national and international conferences)
