

When patient engagement in research really means co-creation

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Conclusion:

- Both researchers and patient partners have to be ready to be involved in POR.
- POR allows researchers to look further into what constitutes a good way to address a clinical problem.
- Researchers have to consider the paradigm shift: patient as a subject to patient as a co-researcher.
- Patient partners have to put aside their personal interests for the common good.
- The timeline needs to take into consideration the time patient partner's wish to invest and the time needed to collect their feedback.
- Researchers have to guide patient partners towards activities where their knowledge will be the most useful.
- The research team has to consider the emotional impact of conducting interviews on patient partners.
- Patient partners have to be prepared to conduct interviews or to participate to data collection process.
- National guidelines according to POR could be helpful to support research team to conduct a research project without tokenism.
- The research team must undertake an evaluation of POR process and outcomes throughout the research project process.

References

1. Canadian Institutes of Health Research. Strategy for Patient-Oriented Research: Canada: Government of Canada; 2017 [cited 2018]. Available from: <http://www.cihr-irsc.gc.ca/e/41204.html>
2. Pomey M-P, Flora L, Karazivan P, Dumez V, Lebel P, Vanier M-C, et al. The Montreal Model: The Challenges of a Partnership Relationship between Patients and Healthcare Professionals. Santé Publique. 2015;S1(HS):41-50.

Background

- The patient partnership approach was initiated in Quebec (Canada) in 2011 by the Collaborative Patient Partnership Direction - Université de Montréal.
- Since 2013, the Canadian Institutes of Health Research supports research teams interested in integrating patients into their research project (Strategy for Patient-Oriented Research)¹.
- Patient-oriented research (POR) is a scientific continuum that engages stakeholders on priorities established by patients².
- The project Decisional needs and interprofessional shared decision making for patients with complex care needs who frequently use healthcare services is a part of the Demonstration project (Unité de Soutien SRAP du Québec).

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Objective:

To identify from the perspective of stakeholders:

- Decisional needs of patients
- Facilitators, barriers for future decisions
- Facilitators, barriers and strategies for implementation of the decision aid

To demonstrate the feasibility of conducting POR

To transfer learning acquired during the project to knowledge users

The research team:

- 2 principal investigators
- 3 co-investigators
- 4 partner patients (PP)
- 1 research coordinator

Team's vision:

- Valuing the experiential knowledge of all partners and encouraging co-construction
- Innovate partnership with patients
- Thinking out of the box

Patient partners' contribution:

- Research protocole
- Interview guides
- Analysis grid
- Data collection and analysis
- Data interpretation
- Dissemination

How we built together?



Learning about POR:

- Engagement capacity of patient partners
- Knowledge about environment, the work of health professionals and the world of research
- Importance of communication
- Importance of humility and openness

Strengths of POR:

- Inclusion of patient partners in an optimal way
- Capacity to stay devoted to the research project
- Team spirit
- Co-construction or cocreation
- Commitment of the patients
- Group dynamic
- Allows to validate the results of the research

Most rewarding activities:

- Conducting interviews
- Participating in focus groups with clinicians
- Attending the meetings between co-researchers
- Interpreting the data and results

Most difficult activities:

- Revision of the data collection grid
- Conducting interviews with person in a vulnerable situation

Contributions about POR:

- Experiential knowledge
- Patient partners' engagement capacity
- Unique experience

Weaknesses of POR:

- Communication between patient partners, clinicians and researchers
- Necessity to consider the rhythm and the conditions of the patient partners
- Lack of training in POR
- Wide variety of roles and ways to collaborate
- Financial compensation for patient partners' contribution
- Big investment in time and money
- Expectations of the patient partners
- Lack of awareness of the real impact of the patient partners' collaboration on the results of the research