

Patient & Family Partners on Research and Improvement Teams: Supporting Meaningful Engagement – Preliminary Findings

Agnes Black¹, Clayon Hamilton^{2,3}, Christine Wallsworth^{4,5}, Kimberly Strain⁴, Sara Charlton¹, Wilma Chang¹, Kate McNamee¹

1 Providence Health Care; 2 Department of Physical Therapy, University of British Columbia; 3 Arthritis Research Canada;
4 Patient Voices Network; 5 Community Engagement Advisory Network

Context

Patient & Family Partners (PFPs) are volunteers with experience in the healthcare system as either patients, family members or informal caregivers. PFPs say their engagement on healthcare research and improvement teams is mixed, because sometimes they are not well oriented to the role, their involvement is tokenistic, and they are not treated as full team members.

Aim

To better understand the experiences and preferences of PFPs who have been involved in healthcare research and improvement projects.

Methods

We recruited participants using social media, email & posters. Focus groups and interviews were held with 19 individuals:

- 10 women, 9 men
- 19 to 85 years old
- 16 Caucasian, 1 Asian, 2 African-Canadians

We used Thematic Analysis to organize themes from our data.

Preliminary Results

Four global themes emerged from our data: Expectations, Support, Value, and Research Environment.

Impact

Findings will be shared with healthcare leaders, PFPs and researchers. Our recommendations will assist leaders and researchers to enhance the engagement of PFPs on healthcare project teams.

Support: A variety of items, actions and attitudes that contributed to (or reduced) participants' feelings of support on teams, included training, financial incentives, and other helpful support.

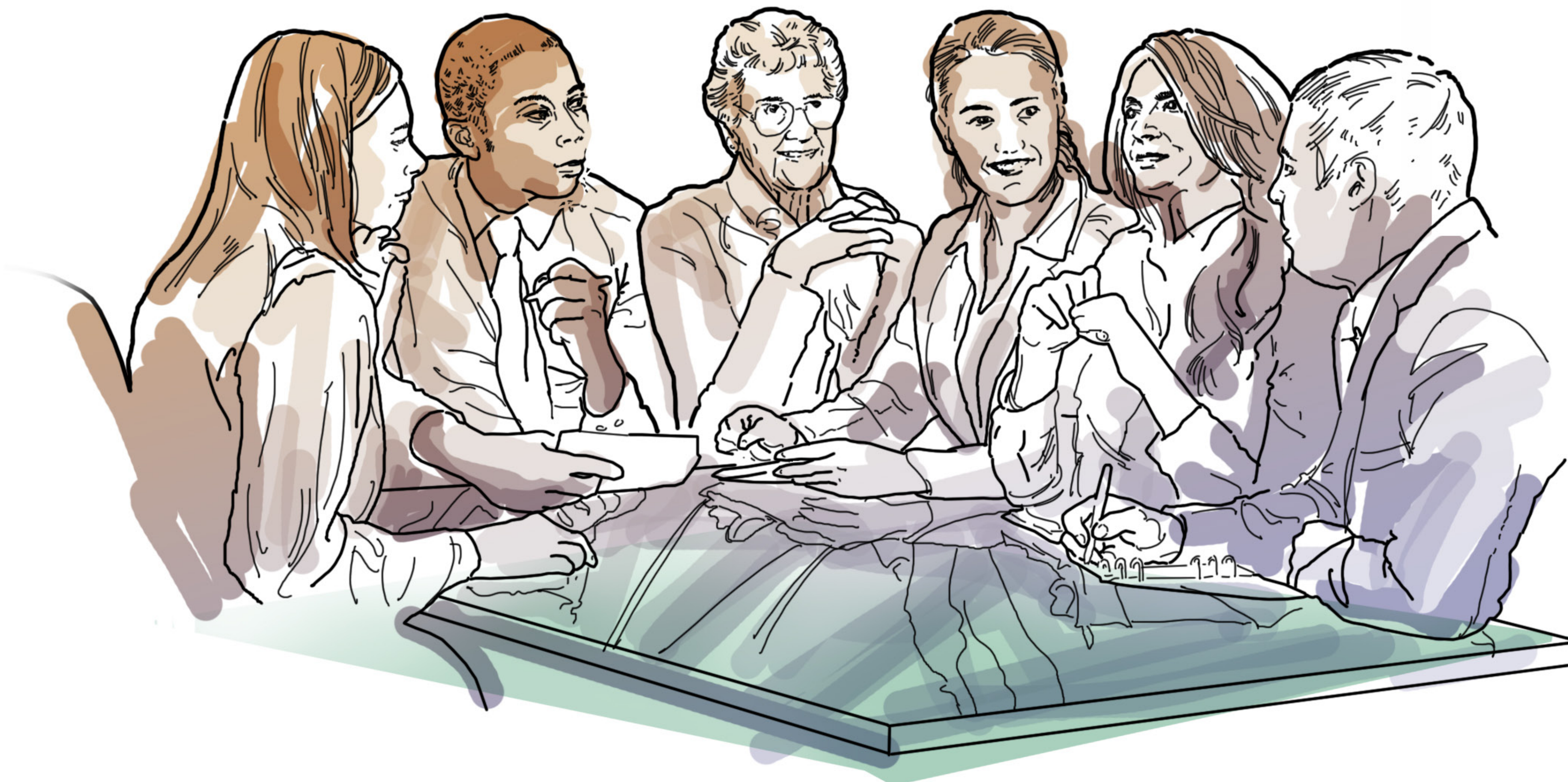
Training: "I felt very unprepared...It's like you're on their turf and they all know one another and you're the stranger in the room and as friendly as they try to be, if you're not well-prepared, you really don't know what to open your mouth and sound stupid when you don't know enough."

Financial incentives: "...there should be fair remuneration for the work that a person does...it doesn't inspire people to contribute and put in the effort...if they're not being paid for travel and for their costs at a bare minimum...."

Expectations: Many participants discussed their expectations regarding defining their role on the teams, and gaining closure on the projects.

Defined role: "...people again are very open to having me there...very appreciative of the input that I've been able to provide but I think a little bit unclear as to 'What is this person who is not a trained academic?'"

Closure: "Follow-up after a study is completed is something that is sorely lacking right across the board. I think it is a massive way in creating value for people participating in the research...Just show them that their efforts weren't in vain."



Value: PFPs described the value of co-learning, contributing to the healthcare system, and obtaining personal benefits: "Researchers, they're very, very intelligent people but they're not - they don't live with these conditions, that the people they are trying to study do."

Research Environment: Participants noted the atmosphere on the team and the role of "super patients" were important factors. "...some people are more open to hearing what you have to say and some people just treat you like you're part of the woodwork."

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