



2019

# Involving patients and families in a social robot study

Lillian Hung

*Simon Fraser University, lillian.hung@vch.ca*

Annette Berndt

*Community Engagement Advisory Network, annsber2011@gmail.com*

Christine Wallsworth

*Community Engagement Advisory Network, annel1@telus.net*

Neil Horne

*Community Engagement Advisory Network, neil\_horne@telus.net*

Mario Gregorio

*Community Engagement Advisory Network, bulakbolero48@gmail.com*

*See next page for additional authors*

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Health Information Technology Commons](#), and the [Health Services Research Commons](#)

## Recommended Citation

Hung, Lillian; Berndt, Annette; Wallsworth, Christine; Horne, Neil; Gregorio, Mario; Mann, Jim; Liu, Cindy; Woldum, Evan; Au-Yeung, Andy; and Chaudhury, Habib (2019) "Involving patients and families in a social robot study," *Patient Experience Journal*: Vol. 6 : Iss. 2 , Article 12.

DOI: 10.35680/2372-0247.1362

Available at: <https://pxjournal.org/journal/vol6/iss2/12>

---

# Involving patients and families in a social robot study

## **Cover Page Footnote**

We gratefully acknowledge the participation of the people with dementia as well as the staff at Vancouver General Hospital who participated in this social robot study. The first author received support through a postdoctoral fellowship from the Alzheimer Society of Canada. The Woodward Foundation funded the purchase of a social robot for patient use at the Vancouver General Hospital. This article is associated with the Innovation & Technology lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_InnovTech](http://bit.ly/PX_InnovTech)

## **Authors**

Lillian Hung, Annette Berndt, Christine Wallsworth, Neil Horne, Mario Gregorio, Jim Mann, Cindy Liu, Evan Woldum, Andy Au-Yeung, and Habib Chaudhury

## Involving patients and families in a social robot study

Lillian Hung, *Simon Fraser University*, [lillian.hung@vch.ca](mailto:lillian.hung@vch.ca)

Annette Berndt, *Community Engagement Advisory Network*, [annsber2011@gmail.com](mailto:annsber2011@gmail.com)

Christine Wallsworth, *Community Engagement Advisory Network*, [annel1@telus.net](mailto:annel1@telus.net)

Neil Horne, *Community Engagement Advisory Network*, [neil\\_horne@telus.net](mailto:neil_horne@telus.net)

Mario Gregorio, *Community Engagement Advisory Network*, [bulakbolero48@gmail.com](mailto:bulakbolero48@gmail.com)

Jim Mann, *Community Engagement Advisory Network*, [cbsj@telus.net](mailto:cbsj@telus.net)

Cindy Liu, *University of British Columbia*, [cindy.liu15@gmail.com](mailto:cindy.liu15@gmail.com)

Evan Woldum, *University of British Columbia*, [evanwoldum@gmail.com](mailto:evanwoldum@gmail.com)

Andy Au-Yeung, *Vancouver General Hospital*, [Andy.Au-Yeung@vch.ca](mailto:Andy.Au-Yeung@vch.ca)

Habib Chaudhury, *Simon Fraser University*, [chaudhury@sfu.ca](mailto:chaudhury@sfu.ca)

### Abstract

Innovative research in care practice for older people can benefit from the active involvement of patient and family partners. Involvement may begin with identifying priorities, then move to formulate research questions and to plan the research methods, to data collection, and finally to analysis and knowledge dissemination. However, in the field of dementia care, actively engaging patients and families in co-research is a novel practice that needs exploration. This paper describes the experiences and perspectives of two patient researchers and three family researchers, along with four clinicians (two physicians, a nurse, and an occupational therapist) within a social robot project in dementia care. Meeting notes, team reflection focus groups, follow-up interviews, and a research journal were used to document the research process. The results are presented in three themes: (a) identify challenges and lessons learned, (b) co-inquire enriched learning, (c) co-produce knowledge for care improvement. All team members agreed that an inclusive environment was important to facilitate meaningful partnerships for undertaking research together. Trust and respect were seen as vital for a rewarding and productive experience in the co-inquiry journey. Some of the challenges to sustaining participant engagement were competing priorities and a risk of tokenism. This article provides a rich description as well as practical details of the research experiences among team members. We offer examples of lessons learned and practical tips to help others increase the engagement of patients and families in research.

### Keywords

Patient engagement, patient experience, person-centered care, co-research, social robot

### Background

Involving patients and families in co-research has recently been considered as a means to improve accountability for public spending in healthcare research as well as adding to the robustness of research.<sup>1-3</sup> Patient and family engagement in research can help increase the relevance and quality of a project, facilitate knowledge transfer, and enhance public trust, transparency and accountability.<sup>4</sup> Moving away from the traditional biomedical model, ‘patient-oriented research’ is a novel approach and is building momentum in a new paradigm, shifting toward a philosophy of more inclusiveness. ‘Patient-oriented research’ demands that academic researchers and healthcare clinicians view patients and families as active and respected equal partners or co-researchers.<sup>5</sup> The Canadian Institute for Health Research (CIHR) defines ‘patient-oriented research’ as “patients meaningfully and actively collaborating in the governance, priority setting, and conducting of research, as well as in summarizing,

distributing, sharing, and applying its resulting knowledge”.<sup>6</sup> A recent review of literature by Manafo et al. (2018) identified gaps in theoretical frameworks and practical lessons from patient-oriented research that help to guide patient involvement in research. In the patient-oriented research literature, ‘patient’ can be considered as “an over-arching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.”<sup>7</sup> In our research team, “patient partners” are individuals who are living well with dementia in the community; “family partners” are individuals who have or had a family member with dementia.

Tokenism, an unauthentic attempt to incorporate patient partners into the research team,<sup>5</sup> is a major concern in patient-oriented research.<sup>8</sup> A recent article by Black et al (2018) offered useful recommendations to avoid tokenism by: (a) creating a welcoming environment, (b) outlining expectations, (c) providing support, and (d) recognizing

the value of patient partners' contributions.<sup>9</sup> Currently, only a small amount of research in healthcare (less than 10%) actually involved patients and families throughout the entire research process from design to dissemination.<sup>10</sup> In the field of dementia care, the engagement of patients and families in research is even rarer.<sup>11,12</sup> The majority of dementia studies is still studying or observing patients rather than inviting patients and families to research together. There is much to learn about co-researching with patient and family researchers in dementia studies.<sup>13</sup> Here, we report on the experiences of patient and family research partners involved in a social robot research project with a team of interdisciplinary clinicians.

## Social Robot Research

The social robot research project aimed to explore how hospitalized patients with dementia respond to a social robot and to identify strategies to support the effective use of the social robot, PARO. PARO, a baby harp seal is a technology-enabled pet, specifically designed to assist older people living with dementia. The robot interacts with the older person in response to touch, voice, light, and motion that it recognizes. Our scoping review has shown that PARO can help decrease stress, improve mood, reduce loneliness, and ease anxiety in older adults with dementia.<sup>14-16</sup> Previous robotics studies were primarily researcher-focused, and we found that there was only one study that consulted healthy older adults living at home about their perceptions of PARO.<sup>17</sup> The voices and perspectives of people with dementia and their families in care settings have been missed in research. Older people with cognitive impairment have unique age-related preferences and specific needs associated with cognitive and functional disabilities.<sup>18</sup> For example, ease of use and social connection are considered important and highly valued in older adults.<sup>18</sup>

This study involved ten in-patient participants on a geriatric unit of a large urban hospital. The research team included patient and family partners who worked together with a team of interdisciplinary healthcare clinicians (a nurse, two physicians, and an occupational therapist) to conduct the study. An academic professor in the Gerontology department of a local university provided mentorship support. The team worked closely together throughout the lifecycle of the research. The first author recruited the patient and family partners from a local Community Engagement Advisory Network (CEAN). CEAN members are volunteers and receive training from the local health authority organization to support patient-oriented projects. The clinicians all work in the hospital under study. The two patient partners and three family partners in the research team are key 'co-researchers' because of their joint contributions and active involvement in the process of research (e.g., joint research planning, undertaking fieldwork for data collection, collective team

analysis, promoting the research and its findings). Patient and family partners are respected, treated, and included in publication as equal co-researchers. Our collaborative approach allowed us to capitalize on the skills and knowledge of all research team members with diverse backgrounds. In this paper, we reflect on how we worked together and discuss challenges. Drawing on our experiences, we offer practical solutions to the challenges raised so that the paper holds values to researchers who conduct patient-oriented research. Ethics approval was obtained from both the University Research Ethics Board (H18-03483) and the local health authority (V18-03483).

## The Research Process

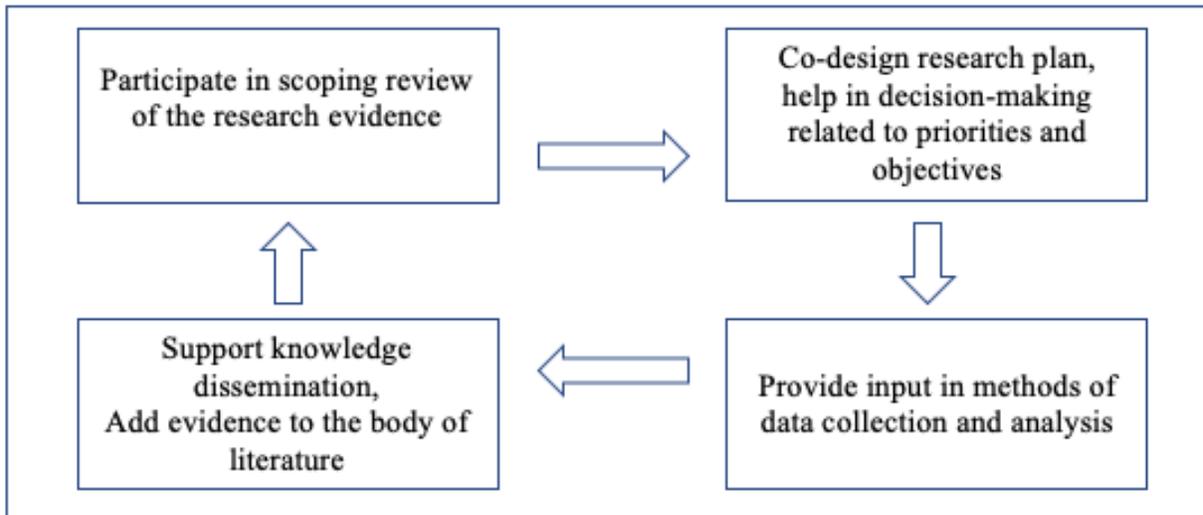
Patient and family co-researchers contributed to the study at every stage of the process. We began by completing a scoping review of the evidence on the role of social robots in dementia care. Based on the review findings, the full team co-designed the research questions and methods. Patient and family co-researchers undertook fieldwork and supported data collection by conducting patient and staff interviews, as well as video-recording interactions between patient participants and the robot. The first author facilitated team analysis by reviewing the video footage with the team. All team members provided input related to analysis and study results. The first author wrote the first draft of findings manuscript (under review) and the team collaborated in providing feedback and decision-making in revisions. Patient and family co-researchers shared and promoted the research by co-presenting results at academic and professional conferences. Figure 1 shows patient and family engagement in the full research cycle.

## Methods

### *Data Generation*

Qualitative data collection methods were used to gain rich information. To support patient-oriented research, we were committed to challenge traditional assumptions and acknowledge experiential knowledge that patients, families and clinicians brought to the study. The data for this paper was generated from meeting notes, email exchanges, field notes, and a research journal kept by the first author. We focused on two main questions: What was the research team's experience in involving patients and families? What were the lessons learned - what worked well and what kind of practical lessons were learned to overcome challenges? An external facilitator (an educator in dementia care) moderated a one-hour focus group for team reflection and gathered feedback from the whole group. Team members spoke about what worked well and what challenges they encountered. The team shared stories about the specifics in each of the steps of the research process (e.g., data collection and team analysis) to articulate their individual experiences and any impacts that they felt the project

Figure 1. Patient and family engagement in the research cycle



engendered. The first author had follow-up emails and face-to-face conversational meetings to elicit more information and tease out details. The focus group and interviews were digitally recorded and transcribed verbatim by a professional transcriptionist.

**Data Analysis**

Data analysis involved deductive and inductive methods. The Patient Engagement In Research (PEIR) framework<sup>19</sup> and the ASK ME framework<sup>5</sup> were chosen to guide the research and analysis as the PEIR offered helpful questions in eight domains for team discussion and ASK ME gave specific tips for engaging people with dementia in research. Deductive codes were drawn from the theoretical frameworks of PEIR and ASK ME (see Box 1 and Box 2); inductive codes were developed based on emergent data. Thematic analysis techniques were used to organize codes and quotations into sub-themes and themes. Common and divergent patterns were systematically compared and carefully examined to refine categories and develop empirically grounded themes with rich details that represent team members’ experiences. See Table 1.

**Box 1. The Patient Engagement in Research Framework: domains of meaningful engagement**

1. Procedural requirements
2. Convenience
3. Contributions
4. Support
5. Team interaction
6. Research environment
7. Feel valued
8. Benefits

**Box 2. The ASK ME framework: Tips for engaging person with dementia in research**

1. Avoid assumptions
2. Support the person to do their best
3. Knowledge needed to be put into action
4. Meet early and regularly
5. Ethical sensitivity and responsibility

**Results**

Research team member characteristics are summarized in Table 2. Six research team members are male (N=6/10), and four are female. The team has a wide age range. Patient and family partners made up 50% of the research team. The rest of the team included a nurse, two physicians, an occupational therapist, and an academic professor. While all team members had some research experience in general, three had more experience in patient-oriented research. It is worthwhile mentioning that patient-oriented research embodies a broad scope of inquiry that ranges in levels of involvement. The International Association for Public Participation describes patient involvement in health research as existing on a spectrum from providing consultation to deep involvement to co-produce knowledge for improving patients’ care experiences and health outcomes.<sup>7</sup>

**Themes**

The experiences of the team members in the research were collectively analyzed and thematically sorted into three themes: (a) identifying challenges and key lessons learned,

**Table 1. Themes and sub-themes of co-research experience**

Themes	Subthemes	Code examples
1. Identify challenges and key lessons learned	<ul style="list-style-type: none"> <li>• Role clarity and expectations</li> <li>• Risk of tokenism and competing priorities</li> </ul>	<ul style="list-style-type: none"> <li>• Flexibility</li> <li>• Openness to adapt</li> <li>• Trust and respect</li> </ul>
2. Co-inquire to enrich learning and understand patient experiences	<ul style="list-style-type: none"> <li>• Shifting the mindset</li> <li>• Creating an inclusive environment</li> </ul>	<ul style="list-style-type: none"> <li>• Research with and by</li> <li>• Lived experience as interpretative resources</li> <li>• Diversity, every perspective matters</li> </ul>
3. Co-produce knowledge for care improvement	<ul style="list-style-type: none"> <li>• Make positive impact</li> <li>• Collective commitment</li> </ul>	<ul style="list-style-type: none"> <li>• Challenging assumptions</li> <li>• Patient-focused outcomes</li> <li>• Acknowledge contributions</li> </ul>

(b) co-inquiring to enrich learning, and (c) co-producing knowledge for care improvement. Table 1 above shows the themes, subthemes, and coding examples of members’ research experiences.

**Theme 1: Identifying Challenges and Key Lessons Learned**

The research team provided insightful feedback on individual experiences during the research, the challenges, and the recommendations for patient-oriented research in dementia care. Role clarity and expectations were important to many team members. All researchers felt that

the research process must be meaningfully adapted to effectively meet individual and team needs.

*1.1 Role clarity and expectations*

The team had diverse perceptions of role expectations. Some patient and family co-researchers had experiences of uncertainties and feeling lost. A family co-researcher CW explained:

I didn’t know how I would react to seeing people with dementia again because I actually haven’t seen anybody with dementia since my husband passed away two years ago. I was very unsure about how I would feel coming into the hospital ward to do interviews and filming with patients with dementia, but it was actually okay! (CW, Family co-researcher)

**Table 2. Descriptive characteristics of the research team members**

Variable	N
Age (years)	
25-35	2
35-45	2
45-55	3
over 55 years of age	3
Gender	
Female	4
Male	6
Disciplines	
Nurse	1
Physician	2
Occupational therapist	1
Patient	2
Family	3
Academic professor	1
Research experience in general	
Yes	10
Experience in patient-oriented research	
Yes	3

All team members reported that including patient and family partners in research was beneficial because the experiential knowledge humanized knowledge production and created more meaningful patient outcomes. However, due to the evolving nature of the project, it was challenging to define clear roles and expectations for each member at the outset. The intention of co-research was to allow openness for team members to decide and shape the project along the process. The nurse researcher commented:

“We were exploring together - which made the research challenging but also interesting because we are learning together. It was challenging because I did not know what each team members’ preferences and strengths, and what I could do to make sure the needs of each team members are accommodated. It was interesting because through the journey, I’ve learned so much about each person’s style and I saw the magic of us working together”. (LH, Nurse researcher)

In the planning process, the opinions of patient and family co-researchers influenced the decision making regarding the research priorities, objectives, questions, and methods for data collection. It took time for the team to get to know and feel confident to be open with each other. Some team members alluded to the idea that ‘you never know till you try’. One family co-researcher said:

I had no idea what I would be getting into. I didn’t know I would not be comfortable with data collection actually. This experience helped me narrow down my role and I think it was great that you [LH] left it totally open for me to choose whatever I want to do, like data analysis and other things. I didn’t know what I’d like to do before I got into it so I appreciated the flexibility and openness. (AB, Family co-researcher)

### *1.2 Risk of tokenism and competing priorities*

A risk of tokenistic engagement and competing priorities were identified as challenges to a rewarding experience. Open communication and authentic engagement were highly valued among members in the research team. Having ample time for conversations and moving the research at a good pace were both considered as critical to building a genuine partnership in the project. A family co-researcher expressed:

It would be great if we had a clear timeline and have more time for team discussion. The videos - there’s a lot of depth there. I wish we could spend more time to ask questions and hear interpretations from each other. (AB, Family co-researcher)

Another patient co-researcher underscored the salience of regular meetings and holding onto the momentum by keeping moving forward.

I like the pace in this research. We met every other week and kept moving. You could lose focus of what you’re doing if it’s been too long or if the research is too stretched out. You kind of go, la di da, and then you might forget and lose interest and just don’t want to do it anymore. (MG, Patient co-researcher)

In this project, the team had to tolerate uncertainties and shared a willingness to explore the research journey together and learn collaboratively. Compared to previous experiences in other research projects, a family co-researcher said:

If there is mutual learning, I think things should grow more organically along the way to incorporate input and adjust directions. Versus like in another project, I’ve already been prescribed the tracks that people are in. Then it’s really bound to become tokenistic.

Another team member added: “The organic nature is what really is kind of enticing in a way. It keeps you”. (NH, Family co-researcher).

Building mutual trust was vital in the process to reduce the risk of tokenism. When members were trusted to have positive intentions and collective commitment, the partnership was strengthened and the contribution of each was valued. “I think the secret of the success is - all of us know what we wanted to find out and what we aimed to achieve”. (NH, Family co-researcher)

### *Theme 2: Co-inquiring enriched learning*

The users’ experiences of the social robot were not well understood, making it clear that and the adoption of technology in the hospital setting is more than a technical adoption. Reducing social stigma and gaining a better understanding of the needs of older adults in the care setting were key drivers for the team to do this research. Previous research on the social robot focused on experimental design, with an absence of direct voices and perspectives from older people.

#### *2.1 Shifting the mindset*

Based on the review of the literature, the team unanimously agreed that within healthcare services, the patient voice is needed in social robot research. The concept of patient engagement in dementia research and technology adoption is a new road that requires more exploration as a family co-researcher explained:

“I don’t think we have a very good idea of what people with dementia are going through. When someone gets dementia, the rest of their life doesn’t turn off, and I don’t think it’s uniform. There’s been so much to learn.” (NH, family co-researcher)

Another research team member added:

“We are trying to get to some of the fundamental biases. Rather than just parachuting in and saying - this pill will work! Yes, the pill may make the person lie down but meaningful? When people interacted with the robot in their own way, we can see how the social robot can actually help people cope with dementia.” (CW, family co-researcher)

A family co-researcher shared a previous experience that her involvement was regarded by the research project committee as an afterthought:

“I think a practical tip was that patient partners were included right at the beginning; a lot of projects don’t do that. In another project, they included people after they had already set up their committee; they decided which way they were going to go already. The top-down approach was not helpful.” (CW, family co-researcher)

The research team agreed that all team members needed to feel validated and acknowledged as co-researchers. The research journey was seen as educational and a rich learning experience. One of the important impacts was about shifting the mindset towards the research approach towards a more democratic and inclusive model.

### *2.2 Creating an inclusive environment*

When asked what worked well in this research project, team members felt the inclusive environment allowed them to co-create meaning for the work taking place. Having opportunities to contribute their diverse perspectives and lived experiences to influence research enriched the learning.

With this research, I am able to prepare myself by looking all these things up about PARO. You should see my binder about PARO. Also, I like watching video data with other people in the team meetings. Now I see how we can work together by listening to others and talking about our thinking and lived experiences. I'm quite amazed at how we can frankly discuss how we feel. (MG, patient co-researcher)

Patient and family co-researchers ensured the research was based on patients' priority needs so many deep-seated assumptions were brought to surface for questioning:

I like the fact that this is a co-learning experience. I appreciate the inclusive nature of this [research]. It really helps to move [dementia research] from a biomedical paradigm to a new model. Our work underscores the transition from the old paradigm, where patients are subjects, to the new model - we can look at how people experience psychosocial means like PARO, a non-pharmacological... (AB, family co-researcher)

A patient co-researcher declared that the deeper the involvement he had, the greater influence he was able to make in the research. In turn, the work gave him a sense of being productive and experiencing fulfilling satisfaction:

This is the first time that I've gotten so involved. When you are involved in this kind of decision making and interaction, this helps people with whatever disability feel their lived experiences are valued. We are not just a name, a rubber stamp or a check box to get a research grant. This kind of involvement gives a very fulfilling feeling for the person. I like that everybody would have an opportunity to look at different research tools and then decide whether that was the right tool or whether we would proceed in a different way. (MG, patient co-researcher)

### ***Theme 3: Co-producing knowledge for care improvement***

Values, goals and priorities in healthcare can mean different things to different stakeholders. The team

stressed that researchers should look at dementia care and the adoption of technology from multiple perspectives. All voices and perspectives should be valued. What patient participants said about the social robot should be carefully listened to. Because some patient participants were limited in linguistic expression and cognitive performance, the subjectivity, lived experience, and deep engagement of patient and family co-researchers are crucial interpretive resources to help gain a fuller understanding of patient experiences.

### *3.1 Making positive impact*

Team members all agreed that patient-oriented research should produce knowledge to benefit what matters most to the patients. Patient and family co-researchers provided their experience-based perspectives – perspectives that the clinician researchers did not have. Also, research knowledge should be used beyond the local setting, extending to a broader context (e.g., long-term care) to make positive impact. As one family co-researcher suggested:

Here's a lot in the footage that would be subsidiary. I can see a good teacher sitting down with students to use our research for education about patients' experiences of dementia. People can learn a lot. It's complex and multi-layered. I'm going to write a book when I'm all finished with this (NH, family co-researcher)

Another family partner alluded that the research products (e.g., videos of robot and person interaction) would be useful materials for dementia education.

I think it's a good sort of a training or education materials. There's a lot of depth. It would be a good model for people to learn how to introduce the robot and what you can do with it, like the different scenarios in which you can use it to help the patients. (NH, family co-researcher)

When asked about compensation or getting paid for the research work, all patients and families involved in the research team echoed that they did not want to be paid. The monetary value suggests that the value and spirit of volunteering diminish. One patient co-researcher said:

I volunteer because I want to be involved. I want to create value that is meaningful for me by contributing something good to help people. For me, getting paid is monetary value. Getting paid means, I'm just going to work or doing a job". So, it diminishes my sense of value to help as a volunteer. (MG, patient co-researcher)

Regarding gift cards, team members had diverse opinions. Some felt gift cards are okay, others did not like the gift card and gave them away (e.g., coffee card). Several members suggested conference attendance would be a much more meaningful acknowledgment for them.

Reflecting on experiences with other previous projects, one family co-researcher said: “it’s nice to have the parking reimbursed, the food and a nice t-shirt but sometimes the compensation was very weird as in one instance, I participated for one hour and was compensated monetarily for my time, which was fine, but then last week I actually had a huge bouquet of flowers delivered to my home, which to me -it was over the top and I’m allergic to pollen.” (CW, family co-researcher)

**Implications, Practical Lessons, and Discussion**

Learning about patient engagement in research requires more than identifying barriers and guiding development. It also requires knowing how to apply theoretical frameworks in practice to overcome challenges. Drawing upon our experience of integrating patients and families as full co-researchers, we offer the following practical tips for others who wish to collaborate with patients and families in co-producing dementia care research: (a) address the needs of team members, (b) build trust and respect to enable effective partnership in all phases of the project, (c) center on shared purpose and collective commitment, (d) demonstrate openness to learn together, (e) ensure that research findings get into the hands of those who can use them. See Table 3.

We have identified lessons learned and practical tips. Our experience in the social robot research demonstrated a unique opportunity that clinicians can forge effective collaborations with patient and families in dementia care research. Our findings are consistent with those written in current guidelines regarding public and patient involvement in research.<sup>10,19,21</sup> This paper offers a unique contribution to the literature of patient-oriented research by adding evidence related to population-specific needs, knowledge users’ related perspectives. In the past, research related to dementia care and technology was often conducted by scientists and academic researchers, while patients’ perceptions remain unrecognized or misunderstood.<sup>22</sup>

Consistent with the evidence in the literature, patient engagement in our study improved the research design. The diverse perspectives made data collection and analysis more effective. There was a deep learning curve for the team to work together as team members were uncertain about the roles and steps. It was important to learn about and adjust each partner’s work style and preference. For example, booking team meetings to fit everyone’s schedule was challenging at times. Effective engagement requires thoughtful considerations of team dynamics and processes, a patient and family-centered attitude, competent knowledge and skills in project management.

**Table 3. Practical lessons and quotations from patient and family co-researchers**

Practical lessons	Quotations from patient and family co-researchers
<b>A</b> ddress the needs of team members	I like getting the meeting booking and agenda way ahead of time and then reminders. That helps a lot. If it’s not there, I will forget. I also like you [LH] kept the meetings focused on purpose. I like to research things, so I am more prepared for participation. (MG, Patient co-researcher)
<b>B</b> uild trust and respect to enable effective partnership in all phases of the project	I am not looking for the box that says here you fit in. I trust you to tell me to do what is needed and at the same time you have to trust me too. I love the flexibility and I have good feelings every time we meet. This is important (JM, Patient co-researcher)
<b>C</b> enter on shared purpose and collective commitment	The goal of the whole team is to help people with dementia. For me that is meaningful. I really think that we were helping the people involved with the research. If we just came in to experiment on people, then I wouldn’t be involved. (CW, Family co-researcher)
<b>D</b> emonstrate openness to learn together	I think there are many scientists out there still have the “know it all” attitude. I think it is up to us [persons living with dementia] to tell people the reality. (JM, Patient co-researcher)
<b>E</b> nsure that research findings get into the hands of those who can use them	The director of care has been asking me about the social robot and insisted that PARO needs a field trip to the care facility. I really think we’ve got to get our research out there. Sooner, not later. It’s important that we move ahead. (NH, Family co-researcher)

Future research in dementia care should apply theoretical frameworks to build and refine theories in patient-oriented research for increasing capacity of patient and family involvement. To fully understand how to create successful and meaningful engagement, more evidence of patient and family experiences are needed. Early career researchers will benefit from synthesizing, testing, and utilizing practical tools and guidelines. Knowledge exchange events organized by national funding agencies and regional institutions will not only support sharing learnings but also motivate a new culture of patient engagement in research. Having formal structures and resources to support a new cultural movement, more novice and experienced researchers will join in to raise the quality and quantity of patient-oriented research, and in turn, contribute to the health and outcomes of patients.

Lastly, the recent political movement of patient and public involvement may increase the likeliness of producing disingenuous involvement – tokenism. There is still tension, reservation and mistrust among scientists, clinicians, patients and families. A broader scale of cultural shift is required to help all stakeholders realize that taking the time and effort to involve patients and families in research is worthwhile and rewarding.

### Strengths and Limitations

Trust and mutual respect in the research team enabled active collaboration and allowed diverse perspectives to enrich learning. This paper contributes to new knowledge in patient-oriented research in dementia care and potentially serves as an exemplar to motivate further growth of patient and family engagement in dementia studies.

There are limitations to the study. It takes time, effort, and commitment on the part of each co-researcher to work together in patient-oriented research. Our team reflection and evaluation of impact was constrained by limited meeting time. Active involvement demands an open mindset to listen to diverse opinions and time to build relationships. There were uncertainties, inadequate trust and confusion at times, especially at the beginning of the research. To challenge the traditional power relationship and mistrust between groups, team members needed to be courageous to voice different opinions and question each other perspectives. Without trust, mutual respect and relationship, it is not possible for the team to have a positive, productive, and rewarding experience.

### Conclusions

The findings demonstrate that active involvement of patients and families in dementia research is feasible and rewarding. The research team perceived the successful partnership increased team capacity and robustness of

research impact. We identified lessons learned and practical tips for improving patient and family engagement in dementia research. This paper offers useful insights into the benefits of patient-oriented research in dementia care. Early and active involvement and flexibility in role allowed for more productive and rewarding experience. Future involvement of patient and family as co-researchers warrants more exploration and sharing of knowledge to support a new culture that brings more patient-oriented answers to research and better healthcare outcomes.

### References

1. Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res.* 2014;14(89):1-9.
2. Wyer M, Iedema R, Hor S-Y, Jorm C, Hooker C, Gilbert GL. Patient Involvement Can Affect Clinicians' Perspectives and Practices of Infection Prevention and Control: A " Post-Qualitative " Study Using Video-Reflexive Ethnography. doi:10.1177/1609406917690171.
3. Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, et al. Patient and service user engagement in research: A systematic review and synthesized framework. *Heal Expect.* 2015;18(5):1151-1166. doi:10.1111/hex.12090.
4. Allard J, Ballesteros F, Anthony SJ, et al. What does patient engagement mean for Canadian National Transplant Research Program Researchers? *Res Involv Engagem.* 2018;4(13):1-10. doi:10.1186/s40900-018-0096-0.
5. Mann J, Hung L. Co-research with people living with dementia for change. *Action Res.* 2018;147675031878700. doi:10.1177/1476750318787005.
6. CIHR. Patient Engagement: What is patient engagement? 2018:1-3. <http://www.cihr-irsc.gc.ca/e/45851.html>.
7. BC SUPPORT Unit. *Ensuring the Ethical Conduct of Patient-Oriented Research : A Guide for Researchers October 2018;* 2018.
8. Bombak AE, Hanson HM. A Critical Discussion of Patient Engagement in Research. *J Patient-Centered Res Rev.* 2017;4(1):39-41. doi:10.17294/2330-0698.1273.
9. Black A, Strain K, Wallsworth C, et al. What constitutes meaningful engagement for patients and families as partners on research teams? *J Health Serv Res Policy.* 2018;135581961876296. doi:10.1177/1355819618762960.
10. Bishop AC, Elliott MJ, Cassidy C. Moving patient-oriented research forward : thoughts from the next generation of knowledge translation researchers. 2018:1-6.
11. Gove D, Diaz-Ponce A, Georges J, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public

- involvement). *Aging Ment Heal*. 2017;0(0):1-7. doi:10.1080/13607863.2017.1317334.
12. Swarbrick CM, Doors O, EDUCATE, Davis K, Keady J. Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice). *Dementia*. 2016. doi:10.1177/1471301216674559.
  13. Pomey M-P, Hihat H, Khalifa M, Lebel P, Néron A. Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. *Patient Exp J*. 2015;2(1):29-42.
  14. Moyle W, Jones C, Murfield J, et al. Using a therapeutic companion robot for dementia symptoms in long-term care: reflections from a cluster-RCT. *Aging and Mental Health*. <http://www.tandfonline.com/action/journalInformation?journalCode=camh20>. Published 2017. Accessed July 3, 2018.
  15. Bemelmans R, Gelderblom GJ, Spierts N, Jonker P, de Witte L. Development of Robot Interventions for Intramural Psychogeriatric Care. *GeroPsych (Bern)*. 2013;26(2):113-120. doi:10.1024/1662-9647/a000087.
  16. Jøranson N, Pedersen I, Rokstad AMM, Ihlebæk C. Effects on Symptoms of Agitation and Depression in Persons With Dementia Participating in Robot-Assisted Activity: A Cluster-Randomized Controlled Trial. *J Am Med Dir Assoc*. 2015. doi:10.1016/j.jamda.2015.05.002.
  17. McGlynn SA, Kemple S, Mitzner TL, Aaron King C-H, Rogers WA. Understanding the potential of PARO for healthy older adults. *Int J Hum Comput Stud*. 2017;100:33-47. doi:10.1016/j.ijhcs.2016.12.004.
  18. Vandemeulebroucke T, Dierckx de Casterlé B, Gastmans C. The use of care robots in aged care: A systematic review of argument-based ethics literature. *Arch Gerontol Geriatr*. 2018;74(September 2017):15-25. doi:10.1016/j.archger.2017.08.014.
  19. Hamilton C. *Workbook to Guide the Development of a Patient Engagement In Research ( PEIR ) Plan.*; 2018.
  20. Johannesen J. *Patient Views on "LADDERS OF ENGAGEMENT."*; 2018.
  21. Kirwan JR, de Wit M, Frank L, et al. Emerging Guidelines for Patient Engagement in Research. *Value Heal*. 2017;20(3):481-486. doi:10.1016/j.jval.2016.10.003.
  22. McGlynn SA, Kemple SC, Mitzner TL, King CH, Rogers WA. Understanding older adults' perceptions of usefulness for the Paro Robot. *Proc Hum Factors Ergon Soc*. 2014;2014-Janua:1914-1918. doi:10.1177/1541931214581400.
  23. Bellows M, Burns KK, Jackson K, Surgeoner B, Gallivan J. Meaningful and effective patient engagement: What matters most to stakeholders. *Patient Exp J*. 2015;2(1):Article 5. <http://pxjournal.org/journal%0Ahttp://pxjournal.org/journal/vol2/iss1/5>.

## Appendix. Patient & Family Partners

