A roadmap to engaging patients in research: The experience of a large academic research hospital in Canada

Rabia Zaheer
Sunnybrook Health Sciences Centre

Sara Morassaei
Sunnybrook Health Sciences Centre

Sander L. Hitzig
Sunnybrook Health Sciences Centre

Laurie Legere
Sunnybrook Health Sciences Centre

Mary Jane Torrie
Sunnybrook Health Sciences Centre

See next page for additional authors

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Rabia Zaheer, Sara Morassaei, Sander L. Hitzig, Laurie Legere, Mary Jane Torrie, and Lisa Di Prospero

Case Study

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Rabia Zaheer, *Sunnybrook Health Sciences Centre, rabia.zaheer@mail.utoronto.ca*
Sara Morassaei, *Sunnybrook Health Sciences Centre, sara.morassaei@sunnybrook.ca*
Sander L. Hitzig, *Sunnybrook Health Sciences Centre, sander.hitzig@sunnybrook.ca*
Laurie Legere, *Sunnybrook Health Sciences Centre, laurie.legere@sunnybrook.ca*
Mary Jane Torrie, *Sunnybrook Health Sciences Centre, torriemj@gmail.com*
Lisa Di Prospero, *Sunnybrook Health Sciences Centre, lisa.diprospero@sunnybrook.ca*

Abstract

Recent definitions of patient engagement in research (PER) emphasize that engagement should be meaningful, active and an equal collaboration across the research continuum. The increased interest in patient engagement is predicated on the recognition by researchers of the unique experiential knowledge provided by individuals with lived experience, ethical obligations to democratize science and that patient involvement can potentially lead to improved outcomes for patients and researchers. Sunnybrook Health Sciences Center is a large academic research hospital in Toronto, Canada which aimed to create clearer pathways for patients to have a more prominent voice in the development, implementation, and dissemination of research. However, to ensure that the policies, practices and resources to support PER would be viewed as meaningful to all stakeholders (including, but not limited to, administrators, clinicians, clinician researchers, scientists, patients, family members and caregivers), a series of structured activities were undertaken to foster collective buy-in and co-create an operational implementation plan for PER. The activities consisted of a consecutive mixed methods approach of three phases of discovery: a survey, focus groups and interviews, and an in-person town hall. We describe our approach to implementation and operationalization of PER at an academic hospital based on five identified priority themes: education and training, partnerships, matching programs, policies and measures.

Keywords
Patient engagement, researcher, hospital, patient partner

Introduction

There has been a recent cultural shift towards the broader engagement of patients in research.[1–4] More commonly, patients have played a more passive role as participants or recipients in research,[5,6] but recent definitions of patient engagement in research (PER) emphasize that engagement should be meaningful, active and an equal collaboration in all phases across the research continuum.[7] The increased interest in patient engagement is predicated on the recognition by researchers of the unique experiential knowledge provided by individuals with lived experience,[1,5,6,8], ethical obligations to democratize science[1,4,9] and that patient involvement can potentially lead to improved outcomes for patients[4,6,10] and researchers.[4,10]

A driver of PER in North America is that it is now a critical aspect for consideration of research funding by grant organizations.[5,8,11–14] For example, the Canadian Institutes for Health Research (CIHR) established the Strategy for Patient-Oriented Research (SPOR) unit in 2011[2,3] which was allocated 60.5 million dollars to build capacity for PER.[8] Although scientists and healthcare professionals recognize the value that patient engagement can bring to research, some have expressed hesitation regarding the cultural shift in scientific thinking with regard to engaging patients in research. As a result, they are unclear how to implement this approach within their own research projects.[15] There is still a dearth of research and a lack of an established model on how to effectively integrate PER across the entire research continuum.[3,8,13,16]

There are several challenges and barriers in engaging patients that may account for lower and infrequent engagement.[3,4] One commonly noted barrier is that researchers and potential patient partners have limited experience collaborating authentically as partners in research projects.[12,13] Although patients have lived experience, they may lack awareness of the research process[8] hindering their ability to participate meaningfully as stakeholders.[13] Conversely, researchers also may not understand how to integrate patient partners nor how to share decision-making.[8] This may create an unequal power

dynamic between researchers and patient partners [8]. Given these challenges, patient engagement is often tokenistic in nature.[12] There are also logistical barriers that may limit patient collaboration such as conflicting schedules, transportation costs, childcare and caregiver arrangements,[13,14] and thus we need to understand how to increase accessibility and create a meaningful experience for both patient partners and researchers.

Sunnybrook Health Sciences Center (Sunnybrook) is a large academic research hospital in Toronto, Canada with a prominent research agenda that spans from bench to bedside. Specifically, Sunnybrook's strategic plan between 2015 and 2018 aimed to create clearer pathways and mechanisms for patients, family members and the public to have a more prominent voice in the development, implementation, and dissemination of research. However, to ensure that the policies, practices and resources to support PER would be viewed as meaningful to all stakeholders (patients, family members, caregivers and community members, as well as clinical and research staff, and management), a series of structured activities were undertaken to foster collective buy-in and co-create an operational implementation plan for PER. The activities consisted of a consecutive mixed methods approach of three phases of discovery: a survey, focus groups and interviews, and an in-person town hall; with each phase informing the next.

Issue

The aim of this paper is to outline how a large academic research hospital is co-creating their PER strategy to understand the needs and priorities of their stakeholders. This paper further describes the approach to implementation and operationalization of PER. The processes and outcomes of this work can serve as a useful case-example of how to introduce PER into a similar organization.

Process

For the present initiative, an interprofessional team of academic, clinical, policy, and patient stakeholders undertook a Town Hall style meeting to co-design a PER strategy at Sunnybrook Health Sciences Centre. The Town Hall was structured using "world café" methodology — a simple, effective, and flexible format for hosting large group dialogue.[17] This bottom-up participatory method facilitates dialogue between stakeholders and promotes sharing of diverse opinions and collaborative decision-making.[18] Institutional ethics approval was attained from the Research Ethics Board at the Sunnybrook Health Sciences Centre.

Identification of Town Hall Participants

A variety of recruitment processes were used to identify Town Hall participants. This included relying on the professional network of the core team members, which included hospital-based researchers, clinical staff and policymakers, as well as patient partners with lived experience. Second, the members of the hospital's patient and family advisory council (PFAC) were consulted to obtain suggestions on who to approach to take part in the event. Third, a series of pre-planning activities were undertaken to gauge the hospital's state of readiness for PER via: a) a survey asking hospital research and clinical staff about their knowledge and experience with PER; b) qualitative interviews with researchers and patients assessing attitudes, beliefs and/or experiences with PER.[19] Participants from these activities were asked if they could be contacted for further input about PER at the hospital. For those who consented to be approached for future PER initiatives, as well as the other mechanisms described above, a mailing list of potential research, clinical, policy and patient participants was generated. All patient partners who attended the Town Hall were reimbursed for expenses incurred, including transit costs and parking; refreshments were provided throughout the event.

Town Hall Meeting Structure

A three-hour Town Hall event was organized in February 2020, which used a World Café methodology. For the first component of the meeting, presentations on the preparatory work undertaken by the core investigation team about the state of PER at the hospital, which included an overview of the survey findings (see Figure 1 for a summary) and a high-level summary of the qualitative findings (see Figure 2 for a summary). The survey findings included representation from the hospital's research platforms (Biological Sciences, Physical Sciences, and Evaluative Clinical Sciences) and provided meeting attendees an understanding of the state of PER at Sunnybrook. The qualitative findings highlighted to attendees what our team learned about how Sunnybrook staff and patients defined PER, how they would like PER to work for them, and what the challenges and facilitators were to engage in PER.

This initial overview of findings was then followed by a brief presentation by a patient partner with experience engaging in research who shared their perspectives on PER. This background information was intended to orient the Town Hall attendees about the meeting objectives, to provide working definitions of PER, and to illustrate what the state of PER was at the local context. Importantly, the top five PER priorities initially identified through the background work included: a) Education and Training; b) Partnerships; c) Matching Program; d) Policies and; e) Measures (see Table 1 for a brief description of each PER priority).
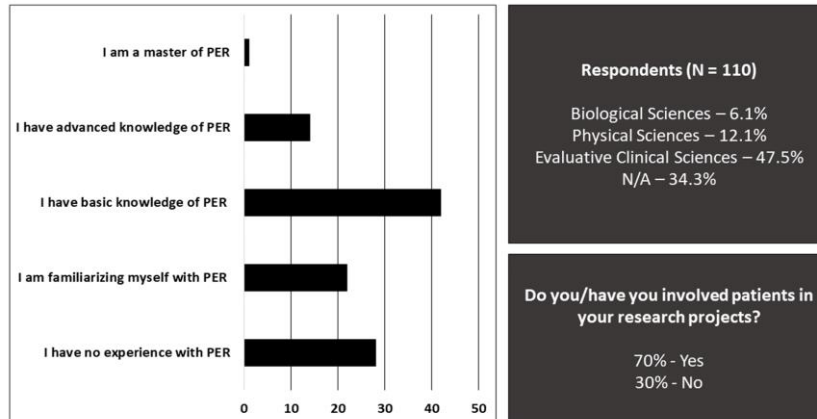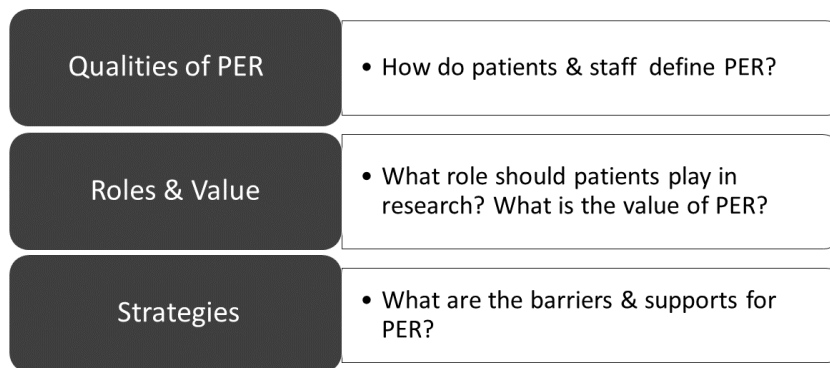
Figure 1. PER Survey Highlights

Figure 2. PER Qualitative Preliminary Themes

Following the presentations, the attendees were engaged to participate in a series of small group discussions to generate ideas and prioritize tactics to improve PER at the hospital (see Table 2). The first small group sessions were structured to obtain initial reactions, and feedback on the preliminary findings (e.g., survey findings, qualitative interview highlights) shared by the core investigation team. To ensure that the patient voice would be embedded within all small group dialogue, patient partners were pre-assigned to each table while other attendees could freely choose where to sit. As well, each table included a facilitator (a member of the core study team) that moderated the discussion and recorded notes. A large group report-back was then facilitated to exchange knowledge about key discussion points.

The next set of small group discussions were organized to enable participants to rotate across six different stations across the meeting room. Five of the stations were organized by the priority themes (see Table 1). The aim of rotation through the stations was to ideate activities that would pragmatically operationalize the identified priority themes. A sixth station was organized to enable

participants to offer other ideas and thoughts that the core investigation team should keep in mind to enable successful implementation and sustainability of PER at the hospital. At this 'cool ideas' station (station six), five guiding principles were shared with participants, and included: no box thinking, creativity, thinking big, being curious and stretching oneself.

Each station was also moderated by a study team member who documented the discussion on a flip chart for group viewing and to stimulate further discussion. Some guiding questions were available to ensure that discussions remained focused and on topic. Ideas that were brought up repeatedly were noted on the flip chart with a star (asterisk). Following the town hall, participants were also asked to complete an evaluation questionnaire to offer input on the overall organization, content and structure of the event, as well as to provide any additional feedback via an open text comment section.

Town Hall Discussion Synthesis
Following the Town Hall event, the study team reviewed all the flip charts and facilitator notes to reach consensus

Table 1. Table Top Discussion & Rotating Station Guiding Questions

	Guiding Question(s)
Table Top Discussion	Thinking of our very early plans to support patient engagement in research: • What stands out about the initial plan? What resonates? • Is there anything missing that we should be thinking about to prioritize?
Station 1: Education and Training	What type, if any, education and training should be available to our researchers and patient partners?
Station 2: Partnerships	How should we facilitate partnerships between researchers and patient partners? • How to recruit for a patient partner? • How to perform onboarding? • What kinds of things do partners need to know about? • How to keep partners engaged? • How to offer recognition? • How to maintain sustainability and retention?
Station 3: Matching Program	How would a matching program be created and implemented between our researchers and patient partners?
Station 4: Policies	What are some policies and procedures that are needed to support a PER strategy?
Station 5: Measures	How will we evaluate the PER strategy? • How will we know we are doing a great job? • How will we know we are making a difference?

on overall main themes that emerged from the sessions as well as to create an implementation plan for PER. With consent, flip charts and facilitator notes were transcribed verbatim. Data were analyzed using thematic analysis, which is appropriate for introductory studies.[20] The transcripts notes were independently reviewed and analyzed by two researchers, which began with in-depth reading of the transcripts. This was followed by coding and grouping codes into potential similar activities that would operationalize priority themes. The study team met to review the identified activities and discuss in detail to achieve consensus. Once activities were identified within each priority theme, they were discussed in detail to determine which should be prioritized based on an impact-effort matrix exercise.[21]

Measurable Outcomes

Seventy-seven participants responded to the broad email invite that was sent to all of Sunnybrook's PFAC members. Fifty-six (72%) of those respondents attended the Town Hall. Demographic information, including the participant's role (either internal or external to the hospital) was not recorded as part of the attendance records for the town hall.

Following the presentations of the preparatory work undertaken by the core investigation team, the first round of small group discussions critically reflecting on the findings indicated that participants overwhelmingly agreed that the initial priority themes resonated with them and that there were no outstanding elements missing. From the small group discussions at each rotating station, key activities that would operationalize each priority theme were generated and described below. It should be noted that priority themes 2 (partnerships) and 3 (matching programs) were collapsed into one group as the identified activities aligned with one another.

Priority Theme #1, Education and Training: Flexible, convenient and adaptive education and training. Education and training for both patient partners and researchers was deemed crucial to successful implementation of a PER strategy. Participants discussed the format, nature, and content of the training, and identified flexibility and convenience as key to building capacity. Training offered online with

Table 2. Meaningful Measures of PER

Type of Measure	The Metric
Experience	• Evaluate researcher and patient experience using a standardized experience survey • Evaluate a narrative of the experience using 'most significant change' methodology
Engagement	• Number of unique users accessing the digital hub • Number of patient partners and researchers attending education and training • Number of new patient-researcher partnerships
Long-term Impact	• Number of joint publications that include patient partners as part of authorship • Number of patient partners co-presenting at conferences with researchers • Impact of patient-oriented outcomes as a result of PER • Amount of research funding obtained as a result of either patient partners as part of the research team and/or specific PER funding calls

consideration of different learning styles was emphasized. Participants indicated that they would prefer both general and targeted training, such as additional workshops for advanced research skills. In terms of content, they felt that training should cover the basics of research, such as administrative aspects (e.g., timelines, budgets) and the research ethics approval process. Interestingly, patient partners indicated they would prefer a train-the-trainer model to be incorporated as they could better relate to training led by their peers.

Priority Theme #2 and #3, Partnerships and Matching Program: Recruitment process and patient partner appreciation. Participants were asked to share their thoughts on patient partner recruitment and a potential matching program to assist researchers and patient partners in collaborating together on potential research projects. Participants underscored the need for a centralized online portal that would help facilitate this process. Participants also felt that a special, dedicated role should be created that would help patients and researchers collaborate (for example, a research liaison). Moreover, participants felt that time and space should be allocated by the institution to support PER, for example, a centralized office for both interested patient partners and the researchers seeking support and advisement.

Participants discussed how important it was to show appreciation to patient partners for their time and contributions. Participants supported the use of honorariums, and other tokens of appreciation, such as free parking, food, and refreshments. Participants also discussed the importance of being recognized for their contribution where they emphasized the value of their 'lived experience'. For example, creating opportunities for patient partners to co-present research findings (e.g., conferences, workshops, etc.) and co-author publications were seen as valuable incentives to engage in PER. As well, participants stress the importance of researchers sharing the final outcomes of the research a means of essentially '*closing the loop*' on the research study.

Priority Theme #4, Policies: Policies that provide structure and guidance for PER. To ensure the success of implementing a PER strategy, it was acknowledged that organizational policies and procedures needed to be established covering the roles, expectations and rights of each stakeholder (researcher and patient partner), ethical/equitable/legal considerations of patient partner recruitment, compensation of patient partners, and conflict resolution. These policies could build on existing standard operating procedures (SOPs) to develop a new patient engagement mandate. Some participants voiced that these policies and procedures should not hinder patient engagement but rather support it; hence they should be kept simple and clear. Simply, the policies and procedures should serve to safeguard the reciprocal rights of both research and patient partners as well as to document each of their responsibilities in their partnership.

Priority Theme #5, Measures: *Evaluation plan from the start of implementation and integration of PER.* Participants indicated that an evaluation plan should be developed prior to implementation of the PER strategy. They encouraged

continual evaluation to identify strengths and weaknesses and improve the strategy, for example the capture of agreed upon metrics and indicators on a continuous basis to track how the plan is performing across various domains. More specifically, participants stated that mixed methods approaches should be used to evaluate both the patient and researcher experience. When participants were encouraged to reflect on how to define the success of this strategy and how can be measured, they identified success within three key domains: experience, engagement and impact (Table 2). Participants also recommended collection of key metrics for PER, such as the number of visits on the patient engagement website and social media pages, number of patient-researcher partnerships, patient and researcher satisfaction measures via self-reported survey to assess experience, repeat participation, adherence to research timelines, number of Research Ethics Board (REB) applications listing PER, number of joint publications, number of patient partners at conferences, and number of attendees at PER events.

It should be noted that the 'cool ideas' activities were covered within the other five priority theme stations. Hence, there were no further unique activities offered by participants.

Post-Town Hall Meeting Evaluation

Almost half (34/77) of participants completed the evaluation questionnaire. Results from the town hall evaluation revealed that almost 90% of respondents rated the event as very good or good. A similar percentage indicated the event flowed well, was well organized, and provided opportunity for interaction and contribution of input. Priorities related to the implementation of the PER strategy that stood out for respondents included meaningful engagement across all points of the research process as well as ensuring that patients are aware of the outcomes of the research, as indicated by this participant's quotation that was included as part of the open comments section of the town hall evaluation.

"There are opportunities for partnership between patients and researchers. - Sharing the results with patients who participated in the research study - Opportunity to listen to a patient who has become a voice within the community and has influenced researchers on potential and future studies - The story behind the numbers play a key role in humanizing the research findings and making a difference for patients, families and caregivers. - Partnership with communities to ensure they are aware of what Sunnybrook has to offer - Publish research studies completed in Sunnybrook internet."

Implications

This project reports on a three-pronged approach to implementing a PER strategy within a large academic research hospital in Canada with an overall mandate to increase patient engagement across the research continuum. A co-design process was selected to ensure all relevant stakeholders were able to provide their insight and input to the success of implementing a PER strategy. Participants identified concerns and ideas consistent with other sources in literature such as the need for education and training[2,12] as well as robust evaluation.[1,4] The Town Hall helped guide the PER strategy into an operational work plan that focused on how to support and facilitate best practices related to PER.

The education and training priority focused on providing foundational knowledge on best practices related to PER to both patients and researchers. To support this priority, members of the core development team initiated a plan to develop a digital resource hub for both researchers and patient partners, workshops to train research teams on PER, and plans to develop a foundational research course for patient partners. With regards to the implementation of the work plan, Sunnybrook has created a one-stop digital resource hub for researchers to build capacity for PER, launched in March 2021. This hub aims to increase ease of accessibility to resources and tools by storing all relevant content in one location in an online format, which was noted as the preferred method of delivery. The hub provides resources and tools for researchers to guide their research teams on the involvement of patient partners as true and genuine members of the research team from the beginning of the research continuum through to evaluation and knowledge translation.

The preliminary feedback on the hub has been overwhelmingly positive and Google analytics have identified greater than 800 views over a six-month period (March to August 2021) across all content areas of the hub. Current work is focused on the creation of an accompanying digital hub for patient partners with content informed by the town hall and its further development following a virtual co-design model.

The Canadian Institutes of Health Research's Strategy for Patient-Oriented Research (CIHR SPOR) lists providing support for patient partners as a key guiding principles for PER, which includes training and education as well as compensation to mitigate logistical barriers.[22] Findings from our town hall demonstrated that continuous education and training for both researchers and patient partners is fundamental to successful PER. Education and training has been identified as an integral facilitator in building capacity for PER[2] and a driver in improving authentic, meaningful engagement by empowering patient partners in the decision making process.[13] However, PER training is an area that requires more research.[12] Although the emphasis on patient and public engagement in research is expanding, training in patient and public engagement has received little research attention and it is believed that funding and publication requirements have outpaced evidence about the practical aspects of patient and public

engagement.[5,8,9] There are mixed views on researchers' needs for training in the field where most researchers had either received training or indicated that they would find it helpful, while others had practical experience and felt that there was insufficient evidence to inform training needs.[5] Further findings suggested that in order to provide training and improve uptake, there is a need to better understand and articulate what both researchers and contributors can expect to gain from training in patient and public engagement.[5] Furthermore, findings indicated a further need to consider how training is conceptualized, designed, promoted and delivered in order to enhance its uptake and relevance.[5] This study adds to and confirms the limited evidence on how researchers and patient partners identify education and training as integral to the success of PER, including what content should be developed, as well as the delivery format.

The existing evidence focused on training in relation to PER is generally consistent with findings from this PER initiative. For example, Bell et al.[2] discuss that patients want their training to cover the REB process and the nature of their involvement, whereas researchers are interested in learning about the benefits of PER and how to integrate patient partners, as well as other logistics (e.g., compensation) to support the success of their research. Similarly, Bell et al.[2] highlighted the need to co-develop training materials following both an iterative process and using a train-the-trainer model, which was a recommendation brought forward at the Town Hall. Furthermore, a study exploring the needs of PER training highlighted that researchers require support and guidance from the onset and throughout the process.[12] Crockett et al.[12] specifically mentioned that tools and resources such as a website may aid this process, which is similar to what was expressed in the Town Hall discussions.

A formalized process for PER was identified as necessary to ensure that expectations, roles and responsibilities were met for both researchers and patient partners. The policies would be owned by the organization and informed by current evidence and stakeholder engagement. Clear expectations must be explicitly described and documented in study protocols especially in building a meaningful reciprocal relationship.[23] Published evidence of the experience of these patient-researcher partnerships has indicated that successful approaches include the development of comprehensive guidelines to steer and define the engagement.[4] As part of the work plan, the organization is reviewing and rewriting current policies especially those linked to patient partner activity that include guidelines for inclusive recruitment, addressing barriers to participation, role clarity, appropriate compensation, and creating an inclusive, safe environment for all partners, in alignment with the organization's equity, diversity and inclusion objectives.

Participants identified the importance of creating a new position with a dedicated role to facilitate PER. This has been previously noted to help bridge the gap between patient partners and researchers[24] and to facilitate a matched partnership that is based on reciprocal needs, expertise and goals. Sunnybrook does have an existing position within its patient relations portfolio that facilitates engagement and equity across all pillars of practice, education, research and leadership. Although the study team felt this would be of value and in support of the PER strategy at our organization, given the limited operational budget for this strategy, the creation of such a role was not deemed feasible.

A key part of successful implementation is the evaluation phase which allows for an assessment of strengths and weaknesses of a strategy or program[4,25]; Indeed, Vat et al.[26] believe that evaluation should be added to the definition of PER. They recognize the gap in evaluation of PER and the lack of consensus on how to do so, particularly in Canada. Consistent with the current study approach, they advocate for including patients in the evaluation design process. Through the Town Hall discussions, participants generated useful metrics and indicators that will be used to develop the evaluation process of the PER strategy. There have been some preliminary efforts to collect some of this data. For example, Sunnybrook's REB is currently tracking metrics related to PER by having primary investigators of Sunnybrook-initiated research studies identify whether their study includes an element of PER. This metric was embedded into the 2018-21 corporate strategic plan with high level accountability to the senior leadership team. In addition, Sunnybrook has continued to ask researchers and patient partners for testimonials on their experience. Future research might include a more formalized process of collecting narratives based on the "most significant change methodology."[27]

Although the study team attempted to ensure a diverse representation of patient partners attending the Town Hall, participants did not represent the broad diversity of the community. Furthermore, the Town Hall program and discussions were only held in English, and therefore, participants would have included those with English fluency and comprehension. Similarly our analysis was limited as thematic analysis did not include a patient partner and findings were not reviewed by patient partners to ensure that they resonated with them.

Despite these limitations, a strength of our initiative was the inclusion of patient partners at all major stages of this initiative. This included having three patient partners review the initial grant application and including them as core members of the investigation team. Throughout the various stages of the initiative, our patient partners provided feedback on our processes. This included having

a strong representation of persons with lived experience (for example, having engaged in PER) take part in the Town Hall event.

Conclusion and Shared Recommendations

Patient engagement in research is supported by prominent institutions in Canada yet this remains an area with limited research. Real-world application in a large academic research hospital has not yet been documented. This work may inform future efforts to build capacity to support patient engagement in research within healthcare organizations. Four shareable key learnings are: 1) inclusive and active engagement of all stakeholders across the entirety of the strategic planning and implementation process; 2) formalized infrastructure including governance, funding and senior level reporting of the organization's PER; 3) tracking of progress and success using agreed upon standardized measures; and 4) continuous change based on an iterative engagement framework.

Future research should include the downstream impact of PER to patient partners, researchers as well as to the organization as a whole. In addition of interest would be the longer-term experience and impact of PER on the uptake, spread and scale of research findings to the local and broader healthcare system.

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