

DIVERSITY IN
PATIENT ENGAGEMENT
LEARNING EXCHANGE

ÉCHANGE DE CONNAISSANCES
SUR LA DIVERSIFICATION DE
LA PARTICIPATION DU PATIENT

Report of the Diversity in Patient Engagement Learning Exchange

Canadian Foundation for **Healthcare Improvement**

Fondation canadienne pour **l'amélioration des services de santé**



EXECUTIVE SUMMARY

The Diversity in Patient Engagement Learning Exchange took place on March 4-5, 2019 in Ottawa. It was co-hosted by the Canadian Foundation for Healthcare Improvement (CFHI) and national and provincial supporting organizations and was moderated by the event partners and supporting organizations on the Steering Committee. Patient engagement leaders, including provincial/organizational leaders in patient engagement, patient partners/leaders and community members from across Canada were brought together to consider diversity in patient engagement methods and resulting improvements in healthcare and service delivery. In total, seventy-four leaders from eight provinces and one territory contributed to this learning exchange.

The Learning Exchange consisted of a keynote address, focusing on health equity through an intersectional and trauma-informed care lens, and six case studies that featured engagement initiatives of organizations across Canada that had engaged with diverse patient and community populations to support improvements in care, service delivery, and system level change. Case studies were highlighted in three categories:

1. Provincial-level initiatives
2. Mental Health
3. Community-based initiatives.

Livestreaming of this event supported participation of other patient and public engagement leaders and patient partners/leaders across Canada. Recordings of the event are available on CFHI's website.

Evaluation of the Learning Exchange indicated that most participants felt they had learned about new approaches/strategies to engagement for diverse populations and gained new insights and understanding of engaging with diverse populations to progress their work. All participants agreed that the event was a valuable learning opportunity.

Partners for the Learning Exchange included:

British Columbia Patient Safety and Quality Council¹
Canadian Partnership Against Cancer¹
Canadian Patient Safety Institute¹
Centre of Excellence on Partnerships with Patients and the Public
Health Quality Council of Alberta
Health Quality Ontario
Saskatchewan Health Quality Council

¹ Also a supporting organization.

BACKGROUND

The Canadian Foundation for Healthcare Improvement (CFHI) supports partners to accelerate the identification, spread and scale of proven healthcare innovations. CFHI works with partners to improve health and care for everyone in Canada. In particular, CFHI supports initiatives that engage patients and families in designing, delivering and evaluating health services, with the goal of improving the quality and experience of care to meet the needs of patients and families.

CFHI recognizes that patient engagement efforts have been rapidly evolving and expanding across all levels of the healthcare system in Canada, and that many of these efforts do not necessarily capture the patient populations they serve, including those from ethnocultural backgrounds, patients who do not speak English, those in lower socio-economic backgrounds, and those underserved. In conversations with patient engagement leaders and health quality councils across Canada, the issue of engaging more diverse patient populations was a common challenge across the country; ongoing discussions with these leaders led to the development of a proposal for a joint learning exchange event specific to diversity in patient engagement. Initial discussions began amongst engagement directors at the health quality councils in British Columbia, Alberta, Saskatchewan, Ontario and CFHI. Further discussions were initiated with other provincial engagement leaders, and Pan Canadian organizations, and together, members from these organizations and patient advisors formed a steering committee to ensure the Learning Exchange was available to diverse groups across the country. The Steering Committee wanted to learn from those healthcare organizations that have implemented novel methods to better understand the experiences of care of patients/clients from diverse backgrounds, and then used these experiences to drive improvement efforts to further engage with broader segments of patients/clients.

LEARNING EXCHANGE PLANNING AND STEERING COMMITTEE

Members of the Steering Committee included²:

- CFHI staff as the administrative lead for the Steering Committee and the Learning Exchange
- Representatives from provincial quality councils and Pan-Canadian Organizations who led patient engagement and/or health equity efforts
- Patients and family members and persons with lived experience
- As agreed upon by the Steering Committee, other subject matter experts or stakeholders were also invited to attend meetings when requested/needed

The 19-person steering committee, of which 6 were patient partners, was formed with the goal of learning and collaboration to provide guidance to develop the learning exchange. A co-chair model was used, which included a CFHI patient engagement leader and a patient partner.

The purpose of the steering committee was to:

- Articulate the purpose, goals, and audience for the learning exchange event
- Provide clarity in terms of 'diverse' populations
- Develop criteria to identify initiatives that demonstrated novel engagement approaches and improvements within diverse populations
- Provide suggestions of organizations/programs that exemplified innovative engagement practices with resulting program/system change
- Consider opportunities to share learnings from the event

² A full list of the Steering Committee members can be found in Appendix A.

Between August and December 2018, the steering committee met four times to refine the original draft proposal for the learning exchange and to identify exemplar organizations deemed leaders in emerging practices in patient engagement that would be showcased at the learning exchange. The Steering Committee provided insights and perspectives based on experience and expertise, reach consensus on the purpose, goals and audience for the learning exchange, as well as criteria for exemplar organization. All member-submitted recommendations were reviewed by all Steering Committee members and ranked, identifying the top ten initiatives. Decisions regarding inclusion of the initiative for the learning exchange were reached by consensus with consideration of a range of engagement approaches, patient/community populations, and geographical representation. The perspectives of patients and family members and persons with lived experiences were embedded throughout the design and delivery of the learning exchange event.

AIMS OF THE LEARNING EXCHANGE

The aims of the learning exchange were to:

1. To collectively develop common principles that will progress engagement initiatives with diverse populations.
2. To identify and share emerging and proven wise engagement approaches in the Canadian context that demonstrate the value of engagement that lead to improvements for diverse patient populations that can be promoted, spread, and adapted for use within health jurisdictions/organizations across Canada.
3. To gain new insights and understanding into the complexities of engaging with diverse patient populations to help progress engagement work across Canada.
4. To learn new and innovative ways to maximize engagement opportunities, and how to manage challenges appropriately and effectively.
5. To enhance the capacity of PE leaders (patient, healthcare, system leaders) to consider and advocate for varying methods of engagement that can progress engagement work to be shared locally.

The keynote presentation, case studies and facilitated discussions were designed to meet these aims of the learning exchange through an interactive format while showcasing emerging practices in patient engagement focusing on better understanding the experiences of care from more diverse patient populations.

PARTICIPANTS

Seventy-four patient engagement leaders and patient partners/leaders in organizations across Canada from eight provinces and one territory attended the learning exchange. Fifty-one participants also joined via the livestream throughout the day.

Partner organizations worked together to determine the participant list for the closed event. To include as many diverse opinions as possible, invitations were extended to patient engagement leaders from other provinces and territories that were not represented through those on the Steering Committee, and to leaders from other Pan-Canadian organizations.

SUMMARY OF PROCEEDINGS

The learning exchange consisted of two sections:

1. An evening event with a keynote presentation and networking opportunity.
2. A full day event with presentations and opportunities for interaction amongst participants in small and large groups. An abbreviated agenda and link to the recordings of the sessions can be found in Appendix B.

1. Evening reception and keynote presentation

The event was led by the Canadian Patient Safety Institute and Patients for Patient Safety Canada. Opening remarks and welcome were provided by Mr. Vincent Dumez, Patient Partner Co-Director at the Centre of Excellence on Partnerships with Patients and the Public and CFHI Board member. Ms. Allison Kooijman, Patients for Patients Safety Canada introduced the keynote speakers, Carolyn Shimmin, Patricia Roche and Serena Hickes from the Manitoba SPOR Support Unit at the George & Fay Yee Centre for Healthcare Innovation. In their keynote address, titled “Valuing All Voices: Developing a Trauma-Informed, Intersectional Framework for Patient and Public Engagement in Health Research,” they shared how they advocate for social justice and a health equity lens through the incorporation of a trauma-informed, intersectional analysis and critical reflexive practice in engagement. They focused on the importance of recognizing different experiences and expertise, and of building relationships and trust in research beyond checking a box. Through this recognition of different experiential expertise, they shared that there are intersections of identities, power and trauma that must be considered when engaging voices who are traditionally less heard. They further emphasized the importance of aligning health equity with research and the understanding that trauma can be intertwined with intersectionality, and the importance of critical reflection to avoid re-traumatization. Through this work, they developed a framework for engaging with patients from diverse populations.

Ms. Ioana Popescu, Canadian Patient Safety Institute facilitated the question and answer period following the keynote presentation. Closing remarks were provided by the Learning Exchange Steering Committee Co-Chairs, Carol Fancott and Angela Morin, CFHI.

2. Full day event

The following day was a full day of presentations and interactive dialogue. Opening remarks were provided by Ms. Maria Judd, Vice President, Programs, CFHI. Carol Fancott and Angela Morin, CFHI, followed by setting the stage and identifying the common aims for this learning exchange. Carol and Angela reflected on the multiple layers of intersectionality and diverse perspectives present within the audience and posed three questions for participants to reflect on over the course of the day:

- What is the purpose of diversity in engagement?
- What does diversity mean to you?
- What questions do you still have from today?

Participants were invited to answer these three questions and encouraged to create a brave space and to be open to the ideas of others as opportunities for learning, to consider their engagement practices, and what they wanted from the learning exchange.

Session 1: Setting the Stage: Review of the Literature and Terminology

The day formally began with Anila Sunnak, Canadian Partnership Against Cancer (CPAC), who set the stage by sharing work commissioned by CPAC regarding best practices for engagement of underserved populations.

Anila grounded participants in a review of the literature, environmental scan, and subsequent identification of best practices in reaching underserved groups for deliberative engagement and public dialogues. Numerous engagement approaches were identified, with various channels and opportunities for feedback. Lessons learned in the process of conducting the scan included the importance of language and the need to be reflexive, which included changing the language from marginalized to underserved to avoid stigmatization. Closing with an emphasis on learning together, Anila emphasized a key lesson: Learn to evaluate and evaluate to learn.

Session 2: Case Studies of Provincial Initiatives

The first set of case studies highlighted two provincial initiatives: The Equity in Engagement Framework by Cancer Care Ontario and Rainbow Health Ontario, and the Collaboration d'un parent et consultation d'adolescents – À l'élaboration d'un guide de pratique clinique visant l'autonomie des jeunes de 6 à 21 ans présentant une déficience intellectuelle by L'Institut national d'excellence en santé et en services sociaux (INESSS) in Quebec. Following the presentations, Caroline Beck and Jocelyn Watson (Health Quality Council - Saskatchewan), and Audrey L'Espérance (Centre of Excellence for Partnerships with Patients and the Public) facilitated a question and answer period, as well as small group discussions.

THE EQUITY IN ENGAGEMENT FRAMEWORK

Cancer Care Ontario & Rainbow Health Ontario

Brett Nicholls and Tamara Boric shared Cancer Care Ontario's journey with Rainbow Health Ontario to create the Equity in Engagement Framework; a comprehensive guideline for creating equitable engagement opportunities for those patient populations who have been under-represented. The framework was co-designed with 3 high priority, under-engaged groups in the cancer care context and moves beyond traditional methods of engagement and contains considerations for organizations to revisit their culture and facilitate equitable engagement. The framework emphasizes engaging earlier and working to develop the engagement strategy together. Lessons learned from the presenters included:

- Being mindful of population-specific considerations and how this will change the engagement process
- Conventional engagement methods, which heavily emphasize council structures, need to be augmented with tailored engagement methods to effectively engage whole populations
- When you tailor the engagement process, population-specific opportunities for improvement will become available
- Partner with organizations that have existing and trusted relationships with under-engaged groups
- Systems work well for specific populations when those are the people informing the system

COLLABORATION D'UN PARENT ET CONSULTATION D'ADOLESCENTS : À L'ÉLABORATION D'UN GUIDE DE PRATIQUE CLINIQUE VISANT L'AUTONOMIE DES JEUNES DE 6 À 21 ANS PRÉSENTANT UNE DÉFICIENCE INTELLECTUELLE

L'Institut national d'excellence en santé et en services sociaux

Michel Mercier and Julie Bergeron walked participants through the development of draft clinical practice guidelines aimed at supporting greater self-reliance among youth with intellectual disabilities. This work was done in partnership with parents and through consultations with the youth themselves. This expertise and insights resulted in recommendations that directly reflect the needs and priorities of the youth and their families. Meanwhile, the values and principles that form the basis of the guide were a result of the consultations with youth with intellectual disabilities, positioning their life goals as a driver for the proposed interventions. The presenters shared their learnings:

- The importance of moving beyond conventional methods of engagement (E.g., meetings) and employing different levels of engagement
- The importance of clarifying roles and purpose of engagement, and ensuring regular follow-up between working sessions throughout the project
- Ensuring support through ascertaining readiness for engagement, comfort, and providing compensation
- Understanding and preparing for different barriers, as well as potential ethical underpinnings to engagement
- Using tools, language and facilitators that are known to the group to promote trust and relationship

Session 3: Case Study: Mental Health

The afternoon continued with two featured case studies focusing on engagement of patient populations in mental health. Saskatchewan Health Authority presented their work with their Adult Addictions Advisory Committee. The Youth Mental Health Coalition from Parkland Alberta followed with their presentation outlined a new integrated model for youth mental health. Alison Dennis, Kathryn Proudfoot and Karen Estrin (British Columbia Patient Safety and Quality Council) facilitated the question and answer period, as well as the small group discussion.

ADULT ADDICTIONS ADVISORY COMMITTEE

Saskatchewan Health Authority

Tracy Muggli and Shane Partridge, co-chairs of the Adult Addictions Advisory Committee from the Saskatchewan Health Authority, discussed the purpose of their committee: to collaborate with clients, families and staff to enhance experience and recovery for individuals and families, and how they prioritize the lived experience voice through co-leadership and co-design. This includes a recognition of the different phases of a recovery journey, the importance of meeting people where they are at, and ensuring a 2:1 ratio for patient/family members and Mental Health and Addictions Staff to ensure the prioritization of the client and family voice. Shane grounded participants by sharing his lived experience with the mental health and addictions system that led to his involvement with the committee and concluded by saying "I am only involved because my voice matters, and I know what we are working on does not go away."

YOUTH MENTAL HEALTH COALITION

Parkland Alberta

Alison Connors, Marti Pickett, Amanda Wheeler and Trisha Vyse discussed the formation of the Youth Mental Health Coalition, with an emphasis on lived experience and response to community need. The coalition formed to ensure youth needs were being met with improved coordination and access to mental health and addictions support, leading to the launch of a Primary Care Mental Health Clinic and hiring community connectors to directly support youth. Speaking from their lived experience as parents, Amanda Wheeler and Trisha Vyse identified a lack of resources for mental health and addictions, as well as a lack of resources for parents, and a system in which everyone was feeling overwhelmed. Through outreach and increased services to vulnerable youth communities, the coalition was built on existing relationships, the formation of new relationships, and the understanding of expertise by experience. Enabling factors in their work included:

- Fostering safety and friendship with community members, including meeting them in community spaces
- The co-designed nature of the supports and partnerships
- Building relationships through trusted partners
- Stepping outside of mandates to look at what is best for the community and who is being served, as opposed to what's best for the organization

Session 4: Case Studies – Community based initiatives

The learning exchange concluded with presentations from two community organizations with presentations by Edmonton Inner City Health and their work Involving People Who Use Drugs in Co-Designing Health Services, and the Nova Scotia Health Authority showcasing their Community Health Teams – Building Healthier Communities. Len Auger and Kristina Watkins (Health Quality Council of Alberta) facilitated the question and answer period, as well as the small group discussions.

INVOLVING PEOPLE WHO USE DRUGS IN CO-DESIGNING HEALTH SERVICES

Edmonton Inner City Health

Co-presenters Ginetta Salvalaggio and Shanell Twan shared their learnings from the Inner City Health and Wellness Program, a collaborative group of academics and clinicians committed to excellence in patient care, and building strong relationships between community and healthcare services, and the Addiction Recovery Community Health program (ARCH). The co-designed and co-led programs take direction from community members and their needs. The program is action oriented, takes a harm reduction approach and is inclusive of a broad definition of health. Emphasis was placed on the importance of co-design in success, shared decision making at the planning level, harm reduction at all points in the journey and meeting people where they are at. Fundamental to this work has been relationship building and trust within the community. The strong partnerships and relationships have directly led to success in service planning and design, and the presenters offered the conclusion: “Relationships reduce harm.”

COMMUNITY HEALTH TEAMS – BUILDING HEALTHIER COMMUNITIES

Nova Scotia Health Authority

Joanne Probert, David Surette, Shannon Ryan Carson and Lisa Sutherland shared their engagement experience with the Community Health Teams in the Nova Scotia Health Authority. Shannon Ryan Carson and Lisa Sutherland began by grounding participants in the context and function of the Community Health Teams in Nova Scotia – a service with primary health care functions that involves a focus on community responsiveness and outreach through engagement, community development and priority populations. The Community Health Teams use customized engagement approaches, depending on the population. Sharing an example of a targeted approach for newcomers, the presenters shared their success working with a trusted partner before engaging, asking people if they want to be engaged, and the co-designed engagement process that followed. Joanne Probert and David Surette, Community Health Team Clients, shared with participants how the teams live engagement at the client level every day. In American Sign Language, David and Joanne shared their experience working directly with the team to minimize barriers to improve accessibility to health services. When initially engaging with the team, sign language interpretation for the Deaf was not available, which significantly limited David's ability to actively participate in programming. The Community Health Team collaboratively worked with David, Joanne, community partners and NSHA Interpretation Services to secure interpretation services on an ongoing basis. As a result, Community Health Team's wellness and healthy lifestyle programs were accessible to David and to all members of the Deaf and hard of hearing community. Not only did this collaborative effort result in positive health changes for David, but it also allowed system change as interpretation services for the Deaf and hard of hearing was subsequently accessible for any service offered by the NSHA. Joanne and David emphasized that this change would not have happened if the team had not been so willing to listen and work together: there was a willingness by the Community Health Team to learn, be flexible and open to new ways to ensure needs were met.

KNOWLEDGE SHARING AND WHAT'S NEXT

Carol Fancott and Angela Morin, CFHI, closed the day by revisiting the three questions that had been posed to participants at the beginning of the day and offering their reflections on the learnings that had been shared over the course of the evening reception and the day of presentations. They emphasized the importance of creating a brave and safe space to have these conversations as the group considered what the next steps are. Reflections from participants included:

- There is a vast array of meaningful work being done across provinces that are not always shared due to provincial healthcare silos. The human connection created by the event has helped to break down these silos to allow sharing.
- The conversation around patient engagement has shifted over the past decade, moving from the need to do more, to considering what we do and how we do it.
- Stories are a catalyst for change and for learning.
- The structures are not always in place for successful and equitable engagement, and work is needed to overcome this through our actions.
- The importance of building relationships and trust will foster co-development and enable more voices to be heard.

Identifying the level of individual commitment in the room, Carol Fancott asked participants to reflect on not only their commitment to learning, but their commitment to bringing this learning into action, and what the next steps might be. Participants raised further thoughts and considerations, indicating there were numerous actions that could be taken:

- Further organizational partnering
- Return to communities to affirm that there is someone listening, and returning to patient and community groups to share learnings, and to ensure equality and moving beyond tokenism in representation
- Consider how information about the event and the initiatives are being shared, and how information can be shared in a non-traditional/non-colonial way
- Promote capacity building through sharing and collaboration amongst organizations and provinces
- Facilitate understanding that engagement can happen in various ways

All learnings were shared with an emphasis on the importance of being authentic and relational in engagement. In particular, participants expressed a desire to share the learnings and to create a space to continue the conversation that was had, and to reconvene in another in person event.

CFHI and partner organizations closed the day with the commitment to continue to collaborate, work together, and to create space to have these conversations.

Next steps included synthesizing and sharing the learnings from the presentations and discussions. The steering committee will reconvene at a later date to consider next steps.

EVALUATION

An evaluation of the Learning Exchange was conducted, with 42 participants completing the evaluation survey at the time of the event. Participants learned about new engagement approaches that can lead to improvements for diverse patient populations and about how others across the country are participating in and improving engagement activities. Participants also stated that they had an increased understanding of the complexities of engaging with diverse populations and what was needed to advance the work, as well as an increased capacity to understand and advocate for various methods of engagement.

All participants found the networking opportunities provided by the learning exchange valuable and identified the event as a valuable learning opportunity.

Leaving the learning exchange, participants indicated they planned to apply their learnings to their engagement work in the following ways:

- Engaging in conversations with their organizations and teams to work to put learnings into practice
- Being intentional in increasing awareness and understanding different and diverse perspectives
- Giving consideration into creating diversity in patient populations that are being engaged, and evaluate representation in comparison to these populations

Overall, participants were highly satisfied with the event, and indicated lengthening the event, and creating more time for case studies, facilitated discussions and sharing of lived experience as possible ways to improve.

SUMMARY OF EVENT

The Diversity in Patient Engagement Learning Exchange highlighted six engagement initiatives from across the country to learn from organizations that had engaged with diverse patient/ community populations to support improvements in care, service delivery, and system level change. Participants engaged in meaningful conversations and expressed a desire to collaborate and continue this work at both individual and organization levels.

Throughout the learning exchange, the following overall themes emerged:

- The importance of a foundation of relationship and trust in engagement with diverse populations
- The importance of flexibility and meeting people where they are at in their healthcare journey
- Being both willing to learn and unlearn about engagement, and being flexible with engagement methodologies
- The desire to continue the conversation and sharing of wise practices

APPENDIX A: STEERING COMMITTEE MEMBERS & SUPPORTING ORGANIZATIONS

STEERING COMMITTEE MEMBERS

| STEERING COMMITTEE MEMBER | AFFILIATED ORGANIZATION |
|---------------------------|--|
| Amy Lang | Health Quality Ontario |
| Lucie Allard | Patient Partner |
| Jean Beckett | Patient Partner |
| Jenny Gilbert | Health Quality Ontario |
| Jocelyn Watson | Saskatchewan Health Quality Council |
| Caroline Beck | Saskatchewan Health Quality Council |
| Kristina Watkins | Health Quality Council of Alberta |
| Len Auger | Patient Partner |
| Jake Jennings | Alberta Health Services |
| Ioana Popescu | Canadian Patient Safety Institute |
| Teresa Bissenden | British Columbia Patient Safety & Quality Council |
| Carol Stathers | British Columbia Patient Safety & Quality Council |
| Alison Dennis | Patient Partner |
| Audrey L'Espérance | Centre of Excellence on Partnership with Patients and the Public |
| Anila Sunnak | Canadian Partnership Against Cancer |
| Vinesha Ramasamy | Patient Partner |
| Angela Morin | Canadian Foundation for Healthcare Improvement |
| Carol Fancott | Canadian Foundation for Healthcare Improvement |
| Jessie Checkley | Canadian Foundation for Healthcare Improvement |

SUPPORTING ORGANIZATIONS

British Columbia Patient Safety and Quality Council³

Canadian Partnership Against Cancer³

Canadian Patient Safety Institute³

Centre of Excellence on Partnerships with Patients and the Public

Health Quality Council of Alberta

Health Quality Ontario

Saskatchewan Health Quality Council

³ Also a supporting organization.

APPENDIX B: ABBREVIATED AGENDA

The recordings of the Diversity and Learning Exchange sessions can be found on the CFHI website here. An abbreviated agenda is provided below and the full Diversity in Patient Engagement Learning Exchange Agenda can be found here.

Abbreviated Agenda

| MARCH 4, 2019 |
|---|
| <p>KEYNOTE</p> <p>Valuing All Voices: Developing a Trauma-Informed, Intersectional Framework for Patient and Public Engagement in Health Research</p> <p><i>George & Fay Yee Centre for Healthcare Innovation</i></p> |
| MARCH 5, 2019 |
| <p>CASE STUDY: PROVINCIAL INITIATIVES</p> <p>The Equity in the Engagement Framework, <i>Cancer Care Ontario and Rainbow Health</i></p> |
| <p>CASE STUDY: PROVINCIAL INITIATIVES</p> <p>Parent Collaboration and Adolescent Consultation - Developing a Clinical Practice Guideline for Empowerment for Young People 6 to 21 Years of Age with Intellectual Disabilities, <i>L'Institut national d'excellence en santé et en services sociaux</i></p> |
| <p>CASE STUDY: MENTAL HEALTH</p> <p>Adult Addictions Advisory Committee, <i>Saskatchewan Health Authority</i></p> |
| <p>CASE STUDY: MENTAL HEALTH</p> <p>Youth Mental Health Coalition, <i>Parkland Alberta</i></p> |
| <p>CASE STUDY: FROM THE COMMUNITY</p> <p>Involving People Who Use Drugs in Co-Designing Health Services, <i>Edmonton Inner City Health</i></p> |
| <p>CASE STUDY: FROM THE COMMUNITY</p> <p>Community Health Teams – Building Healthier Communities, <i>Nova Scotia Health Authority</i></p> |