



DIVERSITY IN PATIENT ENGAGEMENT LEARNING EXCHANGE

Linking Lessons Learned

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PATIENT ENGAGEMENT
LEARNING EXCHANGE

ÉCHANGE DE CONNAISSANCES
SUR LA DIVERSIFICATION DE
LA PARTICIPATION DU PATIENT

Canadian Foundation for **Healthcare Improvement**

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- British Columbia Patient Safety and Quality Council
- Canadian Partnership Against Cancer
- Canadian Patient Safety Institute - Patients for Patient Safety Canada

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INTRODUCTION

In 2019, the Canadian Foundation for Healthcare Improvement hosted a [Diversity in Patient Engagement Learning Exchange \(DLE\)](#) which brought together patient engagement leaders and patient partners from across Canada to consider diversity¹ in patient engagement methods. The objective was to collectively develop common principles to promote inclusion² in engagement initiatives.³

Researchers from the University of Manitoba Centre for Healthcare Innovation began the event by sharing their [Valuing all Voices Framework](#), which was developed through their work in patient engagement research. The framework embraces a health equity lens to engagement, considering elements such as trauma-informed care, intersectionality, and reflexivity. The key pillars are relationship building, trust, self-awareness, acceptance, communication and education.

As part of the DLE, six teams from health organizations were invited to share their work that was inclusive of many voices in the healthcare system. Using the Valuing All Voices Framework, we have reflected on what we learned from the teams and how the themes of the Framework may have applied in their work. Relationship building was a critical aim for each of the teams, made possible through the development of trust, self-awareness, understanding and acceptance, knowledge sharing, and education and communication. These elements are depicted in Figure 1, adapted from the original Valuing all Voices Framework and based on underlying principles of inclusive patient engagement.⁴



Figure 1.

How does the Valuing All Voices Framework apply in practice? We illustrate what these pillars look like in action and reflect on lessons taken from presenting organizations through case examples of two of the presentations. We highlight practical ways relationships are built and strengthened, and how a broad spectrum of experience and insights are welcomed into healthcare improvement and system change.

1 Diversity is about the individual. It is about the variety of unique dimensions, qualities and characteristics we all possess.
2 Inclusion is about the collective. It is about creating a culture that strives for equity and embraces, respects, accepts and values difference.
3 Diversity and inclusion are about capturing the uniqueness of the individual; creating an environment that values and respects individuals for their talents, skills and abilities to the benefit of the collective. Source: Canadian Centre for Diversity and Inclusion, accessed March 16, 2020 at: <https://ccdi.ca/our-story/diversity-defined/>.
4 Shimmin et al. (2017). Moving toward a more inclusive patient and public involvement in health research paradigm: the incorporation of trauma-informed intersectional analysis. *BMC Health Services Research*, 17: 539.

CASE STUDIES

Case #1: Involving People Who Use Drugs in Co-Designing Health Services

The Challenge

Ginetta Salvalaggio, a clinician-researcher refers to using “a square peg in a round hole” analogy to describe the problem the Inner City Health and Wellness Program (Edmonton, Alberta) sought to address as they recognized how often the care they provided failed to meet the needs of people struggling with substance use. This misalignment continued as service delivery and improvements were designed using administrative data that was not representative of the people being served. Attempts to address the specific health issues of patients led to worsened conditions because of a failure to understand and account for the broader reality of substance use in treatment plans.

“Before we started ARCH, we would see patients like Jack who had pneumonia but also a severe substance use problem. We would treat his pneumonia, but get frustrated when Jack went into withdrawal, used drugs in the hospital or left hospital before he finished his treatment and then came back sicker and needing even more help.”

– [ARCH implementation manual](#)

Understanding patients’ needs and the social complexity and intersectionality in which they lived was paramount in order to identify unmet needs and work together with patients to consider ways to address them. A combination of evidence-informed medicine and best practices in addiction treatment was needed together to address the social determinants of health. What resulted was the development of the Addiction Recovery and Community Health (ARCH) care model, developed by strengthening relationships with patients at risk and ultimately improving care and health outcomes.

The Clear Path Forward: Build Relationships

The Inner City Health and Wellness Program team believed that connecting with people who use drugs to understand when and why they come to hospital would reveal the insights required to tailor supports and provide the right care, at the right time, to people who all too often eluded the benefits of standard acute care processes.

Stronger connections with community partners, such as those provided by community liaison Shanell Twan, were also critical to the success and sustainability of the ARCH model. Through these relationships, resources could then be mobilized and brought together at the point of care, thereby addressing medical issues beyond acute care and gaps or barriers to care within the health and social service systems.

Importantly, relationships with all stakeholders have been maintained through a common sense of purpose that is nurtured and celebrated through recognition of individual efforts and collective success. Such relationships were built over time through the fostering of trust, self-reflecting, and gaining greater self-awareness and acceptance of others.

Trust

Lack of trust in a system not set up to address the needs of people was a primary concern addressed in the early days of ARCH implementation. There was misalignment between services and needs that was perpetuated by administrative data used for planning that was not representative of the people being served. Trust in the healthcare system was compromised over time with perpetual pilot projects that did not sustain change. Any gains in understanding patient needs was not shared between service providers, which led to persistent problems and frustrations, as well as weakened patient and provider engagement.

The team was guided by a set of principles with trust as a core value. These principles articulated what others could expect of them, and to offer honesty and transparency in their work. These principles also outlined how they would take direction based on needs of the community; use a harm reduction approach; broaden the definition of health to reflect community goals and outcomes; and research that would be action-oriented and accessible.

Self-Awareness and Acceptance

Providers needed to humbly acknowledge that care was suboptimal. They sought to recognize their own bias and assumptions, particularly related to patients' non-adherence with clinician-created care plans, and to understand the impacts of social determinants of health and past trauma on patient outcomes. Providers realized they needed to unlearn their own preconceptions and learn from others' experiences in order to deliver culturally competent, relationship-based care.

“My aim is to demonstrate genuine compassion and empathy, along with a non-judgmental attitude. [...] Each of these interactions is an important opportunity to connect with a patient, possibly laying the groundwork for other changes.”

– Corinne, Addictions Counsellor

Knowing change was necessary did not necessarily make change easy to implement. Resistance to change was met with opportunities for transparent and authentic interactions, shifting hospital culture towards becoming more accepting and emotionally safe for patients as well as staff.

Communication and Education

The development of the ARCH model exemplifies a commitment to listen early and often to stakeholders in order to deeply understand their experiences and perspectives. Through roundtable discussions, surveys, interviews and the creation of a Community Advisory Group, input and collaboration with patients, health and social service providers, as well as community stakeholders (i.e. police, government and academics), were systematically sought to provide clarity about the needs of the community, as well as potential barriers to providing good care.

Moreover, by taking the time to understand and address staff concerns via team or individual meetings and daily huddles, self-care was modelled, workloads were properly managed and adequate funding was secured to enable the team to grow as needs were revealed and activities increased. Having access to professional development, onsite resources and a central gathering place encouraged staff to exchange knowledge with each other, building their collective expertise and confidence that they are serving patients to the best of their ability. Education has also been extended to patients through Peer Support Workers who help patients gain access to hospital resources and act as a bridge between patients and staff. Specific resources included [Nothing About Us Without Us](#) and [Peerology](#) and [ARCH Implementation Manual](#).

- “What we hear from patients?:
- Involve more than one of us;
 - Steadfast, committed champions;
 - Invest time in our relationship;
 - Visit us, in our space;
 - Follow-through to build trust;
 - Leverage existing resources;
 - Use plain language;
 - Give time to come together and celebrate;
 - Recognize our investment.”

– Shanell, Community Liaison

What Changed and With What Impact?

Care is tailored to patients’ needs so they can feel safe and respected, rather than alone, judged, or misunderstood. Patients are given choices to address a range of health issues. Resources are mobilized to help patients meet their goals and help staff handle the complexity of care. As a result, this relationship-based collaborative approach encourages patients to take their own steps to improve their health and well-being.

“I used to think of myself as a BIC lighter. When people are done with me, they toss me away. You’re only useful a certain period of time. I don’t feel that way anymore.”

– Steven, patient

Case #2: Building Healthier Communities through Community Health Teams

The Challenge

Lisa Sutherland, Community Health Team Lead asks the question: “how do we support people to be well, live well and stay well?” as she describes the core functions and focus of the Community Health Teams that serve the greater Halifax area of the Nova Scotia Health Authority. She references key resources that have been developed to guide engagement with clients and families, decision-making and quality improvement. This is a clear sign of the awareness and recognition that the answers to her question need to come from the people accessing health and wellness services. A key issue has been to engage communities that experience greater barriers to accessing care, have higher needs and therefore can be more challenging to reach.

Relationship Building: “A Foundational Element of Community Health Teams”

The Community Health Team programs and services were developed based on what was learned during community conversations. The community conversations sought to actively listen to and gain insight, including strengths and needs, from each community. To understand the needs of those populations harder to reach, targeted approaches to engage specific groups were employed. The engagement process for three such groups (i.e. high-risk youth, newcomers and people who are hard-of-hearing) was outlined during the DLE. Community Health Teams drew from the strength of the strong relationships built with community partners to support their engagement and relationship building. Importantly, for Community Health Teams, engagement is not seen as a separate activity, but rather as a core function of the fabric of how staff work. They seek to address the question “how do we live engagement every day?”.

Trust

The Nova Scotia Community Health Teams recognized that relationship building required a foundation of trust. As such, the teams worked with partners trusted by the priority populations and planned engagement in spaces that were considered “safe” by the community – physical spaces where community members met –but also psychologically safe spaces where they felt they would be listened to and heard. Moreover, engagement processes ensured they were guided by and co-developed with community members and partners who had insight and experience with these specific populations in order to facilitate, establish and maintain trust, and to foster a deeper understanding to enable a “whole person approach” to care.

Self-Awareness

Understanding the challenges and barriers present for people accessing health services, healthcare providers needed to reflect on their own bias and assumptions that potentially perpetuated these barriers. Providers recognized the need for humility in order to change and improve care. Individual team members were pushed to reflect on their roles and the impact they have on peoples’ healthcare journeys. Community members became integral members of these multi-disciplinary community health teams.

Acceptance

Community Health Teams have come to know and accept that change is constant, both in terms of emerging needs within the community, and in how health services are organized. This team also spoke of acceptance that things do not always go as planned, and the need to stay attentive and make changes when feedback from the community warrants it.

“I really sense an openness to change [...] I think there’s such an adaptability with that [the people in the teams] aren’t afraid to try something, and they’re not afraid to say, no, that program didn’t work, we’re going to switch to something different. So I love that.”

– Community Health Team Partner

Communication and Education

Each Community Health Team member is trained in community engagement and have support and tools to make this work possible, enabling team responsiveness to engagement needs (e.g. the provision of interpretation, meals, and proper timing and location of meetings) and health needs (e.g. workshops on nutrition and parenting based on identified need). Community Health Team members were encouraged to raise and challenge assumptions about how things should be done based on frequent and ongoing communication with community members. Community Health Team members also receive training to apply a broader lens that is inclusive of the determinants of health and diversity that recognizes intersectionality and trauma-informed care, as well as client-driven behaviour change.

What Changes and With What Impact?

Reducing barriers to wellness programs and supports has provided community members with access to the information and services needed to be and stay well. They have reported that feelings of isolation and unfamiliarity with the health system have been replaced with a strong sense of belonging and networking, as well as confidence about who and what is there to support them.

I felt proud to be part of this happening. It was a door that was opening in the province of Nova Scotia.

– Joanne, mother of David, Community Health Team Client

Team members appreciate that the effort, time and space they take to engage meaningfully is recognized as essential to the quality of their clinical and/or administrative work. Engagement, and the ability to engage effectively, were found to contribute to their job satisfaction. Likewise, community partners were pleased to be involved in a community care delivery model that was truly community-driven, with flexibility about how things could be done.

Finally, the Nova Scotian Community Health Team model recognizes the fundamental importance of involving community members as true members of the teams, which requires training and support for people to take on different roles, developing different capacities to re-design based on community priorities.

CONCLUSION

These examples and others highlight the critical importance of patient engagement that builds stronger relationships that respect and reflect greater diversity. Relationships are strengthened through an intentional process to understand and reflect upon who we are, our bias and assumptions that influence how we behave, and how we relate. This process, once initiated, reveals how our experiences and perspectives are shaped by many intersecting forces and beliefs. And it requires us to open our minds, hearts and wills to the possibilities that emerge through an ever-deepening understanding of ourselves, and our collective capacity for relationship-based care.