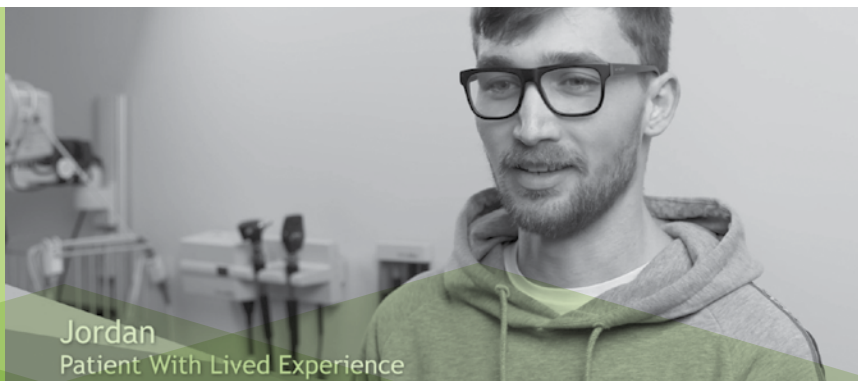


## Spotlight: Meaningful Engagement of Individuals with Lived Experience



Jordan  
Patient With Lived Experience

### Background

The opioid crisis in Alberta is more widespread than people think with the effects not being unique to any one group of people. For those who have been directly impacted, by their own experiences of opioid use/misuse, their lives are often permanently changed. The added ripple effects leave a lasting impression on family, friends, care providers and entire communities. People in need of help, depend on primary care, hospital-based care, addiction and mental health services, and community and social services and yet individuals with opioid use disorder (OUD) are often not receiving the help they need. Experiences of being stigmatized and judged, a lack of appropriate, available and accessible services, and not knowing what services are available or how to access them are just a few of the challenges people fighting OUD face. In addition, the unrealistic expectation that people in a compromised state of health should be able to navigate a complex system, add to their challenges accessing the care.

### Engaging Individuals with Lived Experience (IWLE) in a Meaningful Way

Valuing the insights, wisdom, and skills that can only be found in the lived experience is an important part of any practice. Research supports extending engagement of IWLE beyond “tokenism” and story-telling, towards deeper collaborative relationships; seeing them as true partners in the decision making stages of developing strategies to address the opioid crisis.<sup>1,2</sup>



As part of this work, the AHS Engagement and Patient Experience Program and the Primary Health Care Opioid Response Initiative (PHC ORI) Patient Engagement Working Group, developed and launched Engaging Individuals with Lived Experience: A Framework<sup>3</sup> in June 2018. The framework reflected a commitment to engaging IWLE in a proactive, patient-centered, and meaningful way; free of judgement and bias at various levels of the health care system throughout the 2-year PHC ORI project.

In order to better understand the experiences and value brought to the work through the meaningful engagement of IWLE, four individuals with lived experience who were involved in different levels of the project participated in a 1-hour individual interview. The team members who lead the engagement process were also interviewed.

<sup>1</sup>Dardess, P., Dokken, D. L., Abraham, M. R., Johnson, B. H., Hoy, L., & Hoy, S. (2018). *Partnering with patients and families to strengthen approaches to the opioid epidemic*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

<sup>2</sup>International Association for Public Participation Canada. *Public Participation Spectrum*. Available from: [http://c.yimcdn.com/sites/www.iap2.org/resource/resmgr/foundations\\_course/IAP2\\_P2\\_Spectrum\\_FINAL.pdf](http://c.yimcdn.com/sites/www.iap2.org/resource/resmgr/foundations_course/IAP2_P2_Spectrum_FINAL.pdf)

<sup>3</sup>Engagement of Individuals with Lived Experience: A Framework. Available from: <https://act.albertadoctors.org/file/engaging-lived-experience-framework.pdf#search=Engagement%20of%20Individuals%20with%20lived%20experience%20framework>

## Spotlight: Meaningful Engagement of Individuals with Lived Experience

### What was found?

While some teams struggled to find a way to meaningfully engage IWLE in their work without it seeming tokenistic, other teams at the provincial, zone and clinic level had very successful and significant experiences. At all levels of engagement, IWLE were responsible for ensuring the patient perspective and voice was represented to ensure activities reflected the true needs of individuals with OUD. The persons who were involved represented individuals with diverse circumstances that lead to their OUD and as such, were able to provide examples of how circumstances do not necessarily fall into a “one-size fits all” strategy to tackling opioids. Their stories put an everyday face to OUD and challenged the stereotypes normally associated with substance misuse. What all the IWLE did share, however, was a passionate commitment to influencing changes that would “prevent others from having to go through the same discomfort and tragedy.”

The following are a few examples of meaningful engagement at different levels of the system that took place during this project. At higher levels of engagement, the major role of the IWLE was to ensure the work that was progressing was patient-centered, meaning the patient voice was represented and meeting the needs of patients remained a focal point of the decision-making process. In addition, at the provincial level one individual was involved in the development of training tools and resources. Notably, the individual was not just asked to share his story but also included in pilot testing the training which helped the team address tensions arising in response to some of the content. Having the IWLE present, not only validated their work but he was also able to offer the additional context around why the content was included, providing the presentation with the credibility needed to push controversial but necessary conversations. At the zone level, IWLE took on the role of educators and advocates, providing feedback and support in the creation of pathways and materials to enhance the understanding of the patient experience and perspective for health care professionals and their teams. At the clinic level, an IWLE was invited to work as a patient advisor to assist the clinic in making improvements to their practices and processes providing opioid related care. The insights shared from their lived experience informed several

practice changes at the clinic level, such as the process involved with urine drug screening and clinic level stigma training.

*“Even the stigma that [the IWLE] experienced in our own clinic, we might not have been fully aware or even at least to the degree that we are aware now, without her involvement.”* (Family physician)

### The Immeasurable Impacts of Engaging IWLE in the PHC ORI Project

#### **Finding Meaning and Purpose in Life’s Challenges:**

IWLE and their teams had genuine feelings that the contributions of IWLE helped by offering a unique perspective. Contributing to this work allowed IWLE to turn their negative experiences into something positive, giving purpose and meaning to the challenges they faced. While speaking as a single individuals, IWLE were often sharing the voices and experiences of their peers. For an individual in active recovery, managing multiple health issues, coping with chronic pain issues and/or managing a complex history of trauma, engaging in this kind of work provided them with something to look forward to and focus on as part of her recovery.

*“All those kind of experiences together, which I would have thought was those were my weak spots...but being in there talking about them and seeing others ask questions and dive into it more...my struggles are of value.”* (Working group member, zone level)

*“No drug has ever given me a better high than being able to work with these doctors and work with [individuals I sponsor] and help everybody.”* (Patient advisor, clinic level)

**Reduced Stigma and Discrimination:** Stereotypical perceptions of individuals with OUD were challenged by engaging IWLE who have a diverse set of circumstances, skills, educational backgrounds and medical histories that do not fit the typical stereotypes. For those that grew familiar with IWLE working on their teams, the level of trust and communication that developed should reduce the incidences of stigma and discrimination among those physicians and team members, especially where training was paired with their work.

## Spotlight: Meaningful Engagement of Individuals with Lived Experience

**Renewed Hope in the System:** Involving IWLE in the PHC ORI work provided them with an opportunity to see a different side of health care professionals and the health care system. Where some IWLE may have experienced stigma and judgement in the past, working alongside teams and seeing an authentic desire to make a difference for individuals with substance use issues inspired hope for that person where it may have been lost. In turn, all the IWLE that were engaged, are connected to a network in the community of organizations, programs and individuals with whom sharing what they learn about this project helps bring hope to others who may still be struggling to find some.

**Personal and Professional Growth:** Teams genuinely felt their experience working with IWLE was very rewarding, offering them opportunities to grow both personally and professionally, suggesting there is a mutual benefit to more purposeful engagement of IWLE. Representatives at the provincial level felt that with each success engaging IWLE, they are developing their professional capacity to engage IWLE in the planning of their work at earlier stages of each project. For IWLE, the confidence and experience they gained from learning how to voice their opinion and work as equals with health care professionals has led to further career related opportunities.

*“It became a very honest and therapeutic relationship for both of us, as lived experience, that we had gone through together.”* (Family physician)

### Practices That Created a Positive Engagement Experience

Although individuals engaging IWLE in their work were not familiar with the Engaging Individuals with Lived Experience: A Framework (2018), they were nonetheless implementing practices that supported positive experiences.

Building a safe and secure environment with good communication, mutual respect and consideration were foundational elements achieved through the following practices discussed by IWLE and their teams:

- Where possible, sharing back with IWLE how their contributions have informed the work or final products they have been involved in developing.
- Feeling that their opinions and perspectives were heard, valued and equitable to those of the healthcare professionals they worked with.
- Having a reliable and trusted point person to connect with to de-brief with after meetings, clarify things they do not understand, discuss their needs with and express their frustrations to
- IWLE seemed to be engaged in roles that suited their experience and background making the expectations, roles and responsibilities manageable and enjoyable.
- IWLE appreciated the genuine empathy and understanding and ability to work flexibly when personal circumstances would come up
- Being offered genuine and authentic, non-judgmental encouragement and kindness.

*“We tried to really wrap him in a feeling of safeness and security and really support him more than, you know if we were [working with] someone else.”* (Working group member, provincial level)

### Lessons Learned for Improving the Engagement of IWLE in Future Work

**Discussing Roles and Responsibilities to Confirm it is a Good Fit:** IWLE stated at times, expectations, roles and responsibilities were not always clearly laid out, leaving them to rely on their ability to navigate “the unknown” and speak up for themselves. Being provided with an adequate project background and training was something IWLE felt would have improved their experience. Even for IWLE who have a great deal of experience volunteering in different capacities, teams are best to remember, that these people are “visitors of the system”; one that is complex and daunting at times. Others who may be new to filling these kinds of roles may need more background and training to ensure they do not feel overwhelmed and to maximize their comfort to contribute in a meaningful way.

## Spotlight: Meaningful Engagement of Individuals with Lived Experience

---

**Focusing on the Positive Experiences with the Healthcare System:** Teams sometimes struggled with balancing tensions between being true to the experience of the IWLE and needing to “soften” some of the stories to prevent “demonizing” primary care and sensationalizing the negative aspects of OUD. Looking for and focusing on the positive experiences that helped the IWLE out of their darkest place, helped teams locate the focal point of their work, and helped identify system strengths to build on.

**Finding Opportunities to Work Differently at Higher Levels of the System:** Working at lower levels of the system, it is easier for IWLE to see the impact of their involvement, but at higher levels of the system, IWLE can feel like decisions are already made and question the value of their involvement. For those who want to engage IWLE, the group may need to make a commitment to engage in discussions that respects and values all opinions. Engaging IWLE earlier on in the project will also help to support IWLE in being truly engaged in the planning and decision making process.

**More inclusive and timely involvement of IWLE:** One IWLE recognized that he was just one voice and recommended the inclusion of others who are more disproportionately affected by the opioid crisis. Teams

also indicated that they had to go back and re-work some of the resources they developed because there were changes that needed to be made once the IWLE started working with them. Again, engaging IWLE early on in project planning phase can also increase project efficiency.

*“I think it would be very important for somebody with a different perspective, especially a First Nations perspective, to be a part of these {PHC ORI activities} and offer that perspective.” (Individual with lived experience)*

**Staying Mindful of the Ongoing and Daily Challenges of OUD:** It is important to keep in mind when working with individuals with OUD that stress is a potential “trigger.” Establishing open and honest communication will support both sides having realistic and reasonable expectations which, is important when addressing the challenges and complexities of system level change. Regular “check-ins” will also support manageable workloads that are respectful of IWLEs circumstances and time.