



# STORIES OF LIVED EXPERIENCE (SoLE) - MARCH 11, 2020 REPORT

## SUMMARY

On March 11, 2020, 58 people from all parts of the province gathered in Surrey for the Pacific AIDS Network (PAN) Event entitled “Stories of Lived Experience” (SoLE). The program spanned from learning about leadership, to hearing from those with lived experience of HIV and/or hepatitis C, and then participating in group consultation that will inform the work of the [PHSA Collective Impact Network \(CIN\)](#) in the coming years. The event was greatly appreciated by participants and there is a desire for this to happen again.

## BACKGROUND

In the summer of 2019, in collaboration with Friends for Life (FFL) PAN began to envision and plan two peer gatherings on consecutive days to allow for the best possible attendance. The first event would be a celebratory coming-together of peers from the [Friends for Life Women’s Wellness and Leadership Project](#) - designed to support women on their own path to health and wellness – and the second would be PAN’s SoLE event.

The aim of SoLE were to take people with lived experience of HIV and/or lived experience of hepatitis C into an exciting new space for community building, in line with [PAN’s mission and approaches](#); and to bring together peers to talk about leadership in all aspects of life, as well as the issues that arise from their lived experiences, both honouring differences and discovering similarities. For those who have attended the people living with HIV Forum at PAN Fall Conferences in years past, this would be a step beyond: a place to welcome those with different lived experiences to learn and support each other in health and growth. There would also be peer storytelling, a chance to understand, inform and get involved with PAN’s work in the future. In the final session, there would be a chance to meaningfully engage in the future planning of the CIN, and to offer their expertise for future work too.

These events were made possible by the generous support of the PHSA.

## INTRODUCTION

Two days before the event, concerns started to be raised about COVID-19, and PAN contacted the PHSA and Fraser Health for their recommendations. In response, we ramped up our communication about hygiene, sickness and physical greeting before and during the event. We also altered the food service and hygiene arrangements with the hotel. At that time, we were advised to go ahead – a situation that would change a week later.

So, on March 10, SoLE took place at the Civic Hotel on the unceded traditional territory of the Semiahmoo, Katzie Kwikwetlem, Kwantlen, Qayqayt and Tsawwassen First Nations. Fifty (50) peers and 8 PAN staff attended the event. Elder Shane Pointe, a knowledge keeper with the FNHA, opened and closed the day for us, and one of the attendees spoke into the importance of such events from her perspective.

## PROGRAM HIGHLIGHTS

### Session 1 – Recognizing the leader in everyone

The day began with PAN’s PLDI Manager, Marc Seguin, talking about “What is Leadership and should I be here?” He emphasized that lived experience has value, and that everyone is a leader, and that Leadership Development is

actually Self-Development. It is not about information or techniques, but about liberating the leader within. Leadership is being as well as doing, and so should be internal and reflective. It starts from self-worth, self-care, and can show up in your family, close relationships and with your peers (before it impacts workplace and community). It is important to build a good foundation before you can help out. Leadership is also Community Building, and there is wisdom in the room so now there is an opportunity to learn and support each other in health and growth.

Afterwards, the room broke into small groups, to think about and share on two questions:

- “Why is your LIVED EXPERIENCE so important? (What does it look like?)” – Themes that came up were: Engagement, Knowledge Transfer, Empowerment, Peer work, helping the next generation.
- “How is your LIVED EXPERIENCE a challenge? (How have you overcome that?)” – Common themes here included Stigma, Disclosure, Addictions, Rejection, Mental Health, Communicating with Professionals, Resiliency.

This time of personal self-reflection, discussion and feedback, set the scene for the sessions to come.

### **Session 2 - Learning from each other**

This session revolved around storytelling by people living with HIV and with lived experience of hepatitis C. Four peers spoke from the heart to the audience of lived experience peers, telling different but powerful stories of successes and challenges. In the evaluation, from the respondents (n=27), 77.8% rated it ‘excellent’, the rest ‘good’, making this session the most high rated. Participants expressed their appreciation of the sessions by sharing the following comments:

*Hearing from the panel of different people experience and how I was able to relate to a lot of them, in ways that I didn't even know.*

*First hand stories of how PWLE are demonstrating leadership in challenging stigma in their lives and communities.*

*That living with HIV is manageable as demonstrated by panel members.*

### **Session 3 – Highlighting PAN’s work and opportunities to lead**

PAN engages peers in its work in numerous ways every year, but not everyone is aware of this. So, this session was designed as an engaging way to highlight and promote some of these areas – as well as opportunities to get involved. Each of the following was presented as an IGNITE talk by [PAN Staff](#) that was followed by a question and answer time:

- Marc Seguin on [Positive Leadership Development Institute \(PLDI\)](#)
- Janice Duddy on [Community-Based Research and Evaluation](#)
- J. Evin Jones on [Advocacy, Action and Policy change](#)
- Simon Goff on [Collective Impact Network](#)
- Monte Strong on [Hepatitis C Leadership Project](#) (HCLP)

### **Session 4 – Lived Experience specific breakouts**

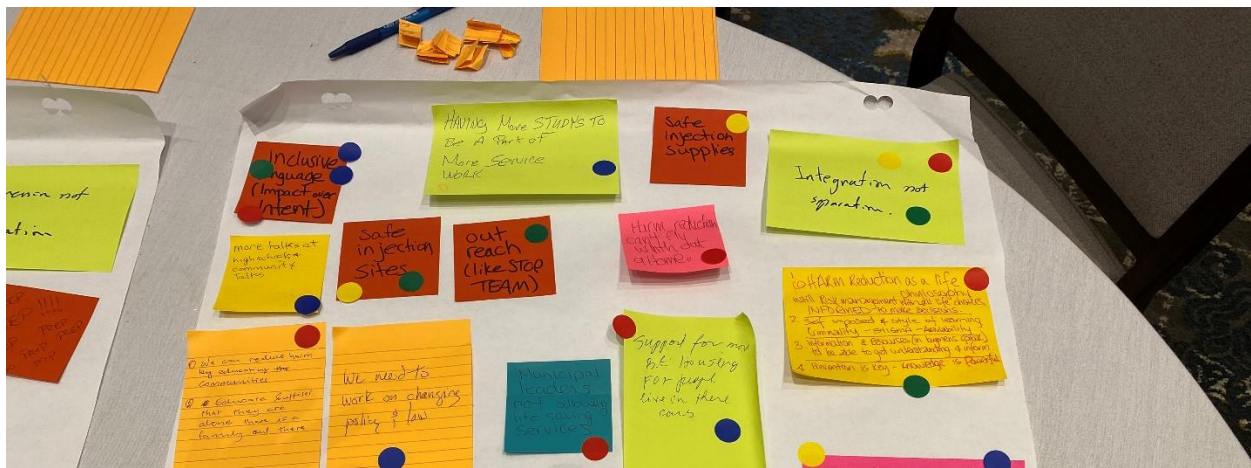
In the last main session of the day, we wanted to engage the voices of the peers in a meaningful way to inform PAN’s work, its collaborations and projects moving forwards. This time, we decided to let the room self-select into two breakout sessions that flowed from the last two talks in Session 3: one feeding back into the future work of CIN; and the other - to the work of the HCLP.

#### 4A – Collective Impact Network

Simon Goff, PAN’s Collective Impact Network Coordinator, discussed the agreed upon priorities of the [Collective Impact Network](#). Importantly, he stated that this is a great opportunity at this particular time to feedback ideas and advice to this network, because it is just about to start its next stage of planning, implementation and funding. In the session, the group had the opportunity to brainstorm the following questions about the four (of five) CIN priorities (the exception was hep C equity, which was addressed at another concurrent breakout): **How can we achieve this? What are the barriers? What has worked well in your experience? What other ideas to you have?**

After collecting and scribing their thoughts on sticky notes at each priority ‘table’, participants could add comments and/or their colored stickers (as approval/likes). Finally, peers had the opportunity to put their name in the (SoLE) circle, to be added to a roster of peers willing to be contacted for future involvement.

PAN committed to taking this work (and data) to the CIN in May, and to report back to attendees.



From the 225 (raw) sticky notes, here are some that gained the most traction/agreement with other peers (right column), ordered under each priority:

##### 1. INCREASING PEER ENGAGEMENT

Have paid peers working in Frontline clinics and hospitals How can we achieve this? Specific training to produce skilled peers example scope of practice active listening change process. Barriers - Funding from Health Authorities What has worked in your experience? Development of Peer Navigation	7
More training towards jobs	6
Encouraging others w HIV to go to leadership courses and to be leaders	6

##### 2. INCREASING RURAL EQUITY

CIN partners might create a one stop pot of funding that is administered by pan to foster the FN rural relationships and or conduit for research conduct.	6
Barriers - technology, not all have cell service, internet, not all have computers; transportation, Prince George to burns Lake bus, only twice a week	5

Letters to the Minister of Health to achieve what we need	5
Aging population and pill burden increase, how do we support the rural?	5

### 3. HARM REDUCTION

Job trainings.	4
Inclusive language impact over intent.	3
Integration, not separation.	3
No shame in accessing harm reduction materials.	3
Safe smoking kits.	3
Provide Naloxone training everyone can benefit can save their lives in their community.	3
What are the areas of progress on the 90-90-90 - by 2020 we should have met that goal to end aids by 2030, where are we not on track and why.	3

### 4. STIGMA REDUCTION

From the people of African descent, by paid programs for Education Fund programs for stigma reduction - barriers for us, funds to educate. As per our community, nothing, nothing has worked. We keep losing community when they learn you are one living with HIV.	13
More programs for seniors, living with HIV.	9
Connect with more people with lived experience	9

#### 4B - People with lived experience (PWLE) of hep C

Created specifically for people with lived experience of hepatitis C, session 4B was titled, “Campfire Cafés”. It was designed to serve two purposes. First, to be an interactive focus group that would yield lived experience input for PAN’s Hepatitis C Leadership Project needs assessment and also for the Collective Impact Network’s hepatitis C workgroup. Second, the session was to provide an opportunity for lived experience of hepatitis C to share stories and experience with one another in terms of successes and challenges as individuals and local communities.

The format of Campfire Cafés was to have four sets of questions posted around the room where the group would spend a few minutes at each station and generate answers as a group through discussion. Then, participants were given a written survey that contained the same questions for them to answer as individuals and from their own perspective. The results of the survey were then tabulated and results were shared after the event.

Of the attendees of SoLE with lived experience of hepatitis C, approximately 30% attended session 4B – Campfire Cafés. The other 70% of the attendees either joined the HIV-focused session 4A or had left the event early in order to make travel connections back home.

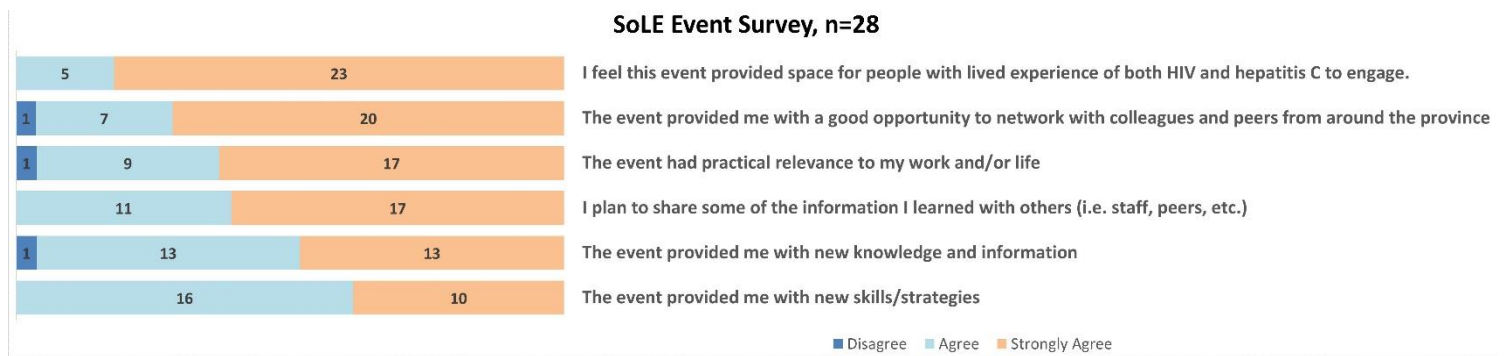
The lived experience of hepatitis C session attendees felt the information and focus group exercise was neither too easy nor too difficult (i.e. just about right). Four people indicated they really enjoyed the session, and two people indicated ‘somewhat fun’. Some comments on how the session could be improved included, “more time”, “more face to face meetings w/ the facilitator & group of PWLE”, “more people to get ideas from and updated info to

communities”, “more people with ideas”, “have it when you have more brain energy earlier in the day. Framed really well”.

The session was designed and executed by the Hepatitis C Leadership Project Coordinator, Monte Strong. Upon reflection of what could be improved for a similar, future session, one of the ideas was for a coordinator to contact each SoLE participant with lived experience of hepatitis C before the event to personally invite them to the session. This would also provide an opportunity to gather input on what individuals would like to get out of the session.

### EVALUATION HIGHLIGHTS

Following the event, all attendees were asked to complete a PAN survey. Overall, respondents were either very satisfied 71.4% (n=20), or satisfied 28.6% (n=8) with SoLE. The following chart represents how respondents agreed with specific outcomes from the event.



When asked to reflect about the main takeaways from the event, participants provided the following reflections:

*Thinking about the importance of face to face events particularly for PWLE and how as a sector we should think about collaborating to ensure those opportunities can continue.*

*I live in a Province with strong warriors and dedicated leaders, and there are places that I can get involved and learn more and gain work skills and be a valuable asset.*

*There is a devoted community and individuals passionate for the pursuit of social justice for those people living with HIV and Hep C. Everyone there is ready to for paid work.*

### CONCLUSION

SoLE was a very successful event, and there is a call to continue to gather peers together. We will take the work done at SoLE forward to impact and inspire the CIN work and other PAN projects. The voice and engagement of peers is both valuable and essential, and we will continue to advocate for peers to be [properly compensated](#) for their work in all aspects of our sector.