PICTURING PARTICIPATION

EXPLORING ENGAGEMENT IN HIV SERVICE PROVISION, PROGRAMMING AND CARE

"I love seeing the candle not lit, but there's times when I like to see the candle lit, because I know that person isn't suffering anymore" — CASEY HOUSE CLIENT

This report is dedicated to all those we have lost in this project, in our families, and in our communities.

PROJECT DESCRIPTION

PICTURING PARTICIPATION is a community-based participatory research project that uses photography and other creative mediums to reflect on the meanings of engagement in the HIV sector. We are a team of community members, researchers, and service providers that partnered with three local organizations to do this work.

The principles *Nothing About Us, Without Us* and the *Greater Involvement of People Living with HIV/AIDS* stress the importance of meaningful inclusion of those living with, and most impacted by, HIV in all aspects of the HIV response. We wanted to document how these principles were being understood and operationalized in diverse community settings: a youth-led HIV prevention and harm reduction program, an AIDS service organization, and a community-based HIV hospital.

Over a period of 10 months, we held 20 interactive workshops (and 17 interviews) with 36 clients, participants, peer workers, volunteers (with lived experience) and staff members at three organizations. We gave everyone a camera and asked them to take pictures that answered the question: *what does engagement mean to you?*

Together, we visually represented, discussed, and analyzed how we understood engagement, and what it looks like in practice at three different sites. Engagement was broadly defined – from participating in programs; to influencing decision-making (within an organization, a program, or in one's care); to co-leading programs or services.

We organized our key findings into seven themes identified here:

| REFLECTING ON JOURNEY | HONOURING RELATIONSHIPS | ACCESSIBILITY AND SUPPORT | ADVOCACY, PEER LEADERSHIP & SOCIAL JUSTICE | DIVERSITY AND DIFFERENCE | GRIEF, LOSS AND REMEMBRANCE | NON-PARTICIPATION |

This report has been designed to help communities think more deeply about how to support and foster diverse forms of engagement for HIV programs and community-based organizations. We share representative photographs and quotes to help illustrate themes and inspire conversation.

Names in report were chosen by participants; many are pseudonyms.

SITES

Casey House is Canada's first and only stand-alone hospital for people living with HIV/AIDS. Casey House opened its doors to clients in 1988 in a house on Huntley street. In the Spring of 2017, Casey House moved into a modern new facility and expanded its services. Casey House continues to provide a continuum of care to those living with HIV. It offers 14-sub acute care beds, a day health program, and community outreach for people living with HIV.

Empower – a program at Parkdale Queen West Community Health Centre (PQWCHC), is a youth-led HIV prevention, sexual health and harm reduction program that uses the arts to train diverse youth to develop and deliver educational workshops in their own communities. As a partnership between PQWCHC and Gendering Adolescent AIDS Prevention (New College, University of Toronto) Empower was in operation from 2010-2016, and complemented other agency programs such as harm reduction supply distribution, HCV programming for people who use drugs, and street and party outreach.

Toronto People With AIDS Foundation (PWA) is the largest direct support service provider for people living with HIV/AIDS in Canada serving men, transmen, transwomen and women living with HIV/AIDS in Toronto. Its mission is to engage people living with HIV/AIDS in enhancing their health and well-being through practical and therapeutic support services and broader social change, and to inspire them to live into their dreams and discoveries. Founded by people living with HIV, PWA has a long-standing history of engaging people living with HIV/AIDS in all facets of the organization, including its volunteer program which includes over 100 volunteers who give their time and expertise each week.

REFLECTING ON JOURNEY

What's your story? How did you arrive here? Many participants depicted journeys, growth, and transitions in their photographs and narratives. In some cases, they were evoking literal migrations across continents, or across cities travelling to organizations. In others, they were referencing metaphorical roads towards healing, acceptance or personal growth. Participants also reflected on organizational change. For some, personal transformation was connected to, and intersected with, organizational change.

Although journey was important at all sites, what this looked like at each organization was very different. At Empower, participants captured images of plants and flowers in many stages (seeding, growing, blooming and decaying) to symbolize growth. They recounted how systemic barriers inhibited them from reaching their full potential, and spoke evocatively to the importance of inclusive spaces where they could bring their whole selves to the table. At PWA, participants photographed paths, and reflected on how PWA has helped them along in reaching their goals and dreams. At Casey House, participants referenced the construction of the new facility as a metaphor for re-building hope around health, and their desire to 'give back.' Transitioning from an AIDS hospice to a small community-based hospital, Casey House is now a place where people try to get well, be comfortable, or stabilize their health.

> " I chose, you know, to take a different path when I was diagnosed with HIV. … I am not going to let HIV [stop] me from fulfilling my dreams. … You can see it's here and it's up to us. You know, which way do we wanna walk? "
>
> **— PWA VOLUNTEER**

> " It's living, it's not dying. You walk through the door — it's open space again. It's a new beginning over there. "
>
> **— CASEY HOUSE CLIENT**

> " I found my voice … I feel that's growth, finding your voice or reclaiming your voice. … I think that the more you give yourself permission to shine, the more you give others permission to do that as well. "
>
> **— EMPOWER PARTICIPANT**

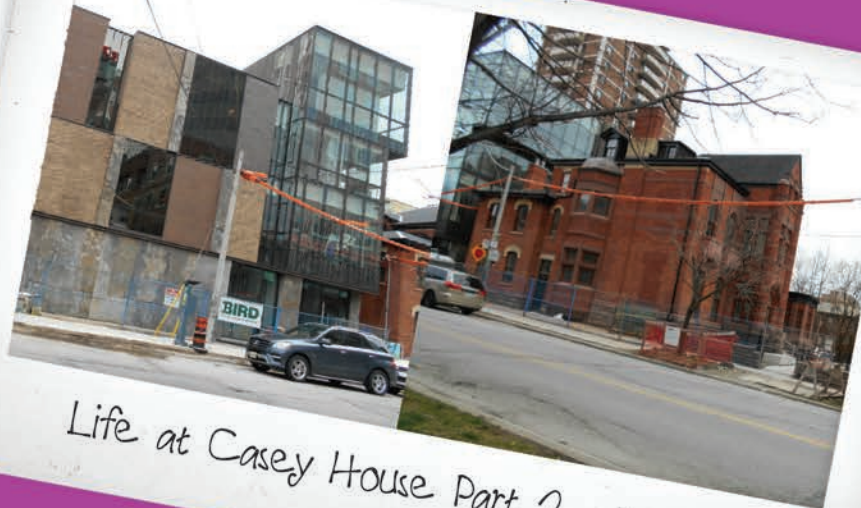Open Road, Open Dialogue — Andra

Isolation — Alberto

My Journey Starts Here — Graham

Journey Back — Khalil

Life at Casey House Part 2 — Rosy

QUESTIONS TO CONSIDER:

1) In our project, peoples' motivations for engaging in programs or decision-making was often connected to personal or organizational journey. How might leveraging the metaphor of journey help your organization engage community members in decisions about organizations, in peer-led programs, or their care?

2) Many participants spoke about their organization's journey to intentionally become more inclusive to broader communities living with, and affected by, HIV. What's your organizational story? How do you share it? Do communities have the resources and power within your agency to intentionally shape it? How do the personal journeys of community members you serve influence the services and programs you provide?

For more photos and narratives (by theme), please visit:

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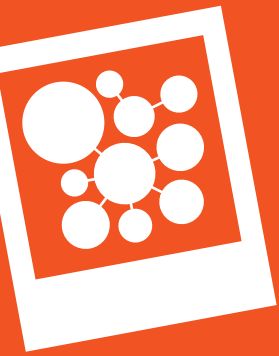
HONOURING RELATIONSHIPS

In our project, participants spoke about many different types of relationships (e.g., with oneself, with others, with HIV and Harm Reduction organizations, and with the land). Participants felt that their personal relationships with other volunteers, peer workers, participants, clients, or staff directly contributed to cultivating a sense of community and belonging at their respective agencies. These interpersonal connections laid the foundations for them to be able to work together collaboratively on larger projects, deliver peer-led services, or work on personal health goals.

Many participants drew on visual metaphors of the environment as a site to reflect on relationships within organizational or communal ecosystems. For some, however, the connection to land was more material; in these instances, participants reflected on the history of this land, and our responsibilities as either settlers or members of Indigenous communities.

"We can hit roadblocks and we can hit traffic jams…it's sort of communicating through those so that we aren't compromising what we've built and where we're going. But learning how to sort through that so that we can stay engaged with each other."

— CASEY HOUSE STAFF MEMBER

"No, I am not weird, I'm not wrong, it's not me, it's their discomfort. And to be able to go somewhere to that community that embraces you for who you are. I love that, and I feel like that's definitely what Empower did to me … It really unleashed me to be who I want and be happy with that."
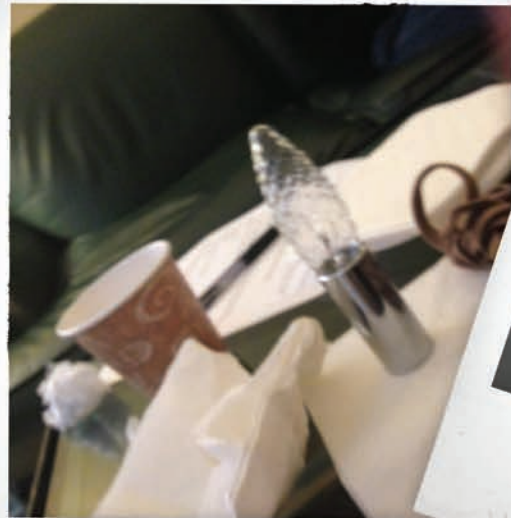
— EMPOWER PARTICIPANT

"A lot of community clients here and residents, we're like, we just click. Some of us have been here for so long that you know it's like 'oh good we're in the house with you.' … There is one girl that I've known since I was 16 …and I am 35 this year. We met when we were young at other agencies when we first both became positive. And years later, we're back at Casey House."

— CASEY HOUSE CLIENT
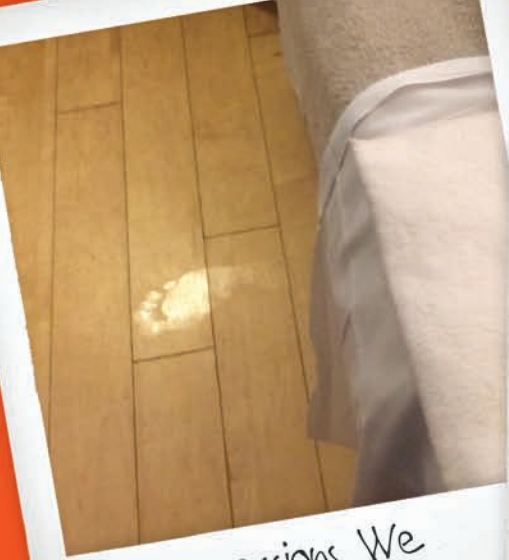
The Impressions We Leave Behind - Shona

Speak the Language - Robert

Untitled - Joanne

Surrounded - Michelle

Bee - Andrew

QUESTIONS TO CONSIDER:

1) Our participants continually taught us that it's the people who make the organization. How do you nurture and maintain relationships, when engaging people with lived experience in program and policy change?

2) What strategies does your organization or program have for centering different kinds of relationships (e.g., with oneself, with others, with other organizations, and with the land) in the work that you do?

3) Sometimes relationships and programs come to an end. Given that peer worker, volunteer and staff turnover is inevitable, how does your organization make sure that folks are supported through these transitions?

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ACCESSIBILITY AND SUPPORT

Experiences of people living with HIV and impacted by HIV are vast, complex, and wide-ranging. Identifying barriers to access and developing adequate supports for community members to meaningfully engage in decision-making or peer-led programming requires a close attention to organizational context, and the unique mental, physical, and emotional needs of community members.

Accessibility and support meant many different things to participants at each of our organizational sites. Under this umbrella, participants discussed:

- the ways they took care of each other as a community (i.e., informal support networks)
- organizational supports (i.e., trainings, events for volunteers)
- understandings of "safe" space
- opportunities for creativity as a form of support (i.e., art-making for different learning needs)
- access to agency services (i.e., medical, community programs, harm reduction)
- ideas of community-responsive programming (i.e., culturally-specific programs, spaces for youth 'aging out')
- barriers to engagement (i.e., fluctuating health levels, mental health, systemic issues)
- specific access needs (i.e., transit fare, food, pronouns, accessible/gender-neutral washrooms).

> " I see PWA as a tree with roots. And, the brightest is the diversity of people who access services here and also the volunteers that come here. PWA is a place where everybody when they come here, they feel it's a safe space to be for them. It's like a home for them. "
>
> **— PWA PEER WORKER**

> " So, when I think of the barriers and limitations, I see holistically. For me the missing wheel can be that intersectional component. Sometimes we look at youth only... Look at one experience that could be happening, and not considering the many factors that influence our lives. "
>
> **— EMPOWER MENTOR**

> " Some people can't go home and talk about how they're feeling because people don't know about their status. … So, I think being around people who are going through similar things [as] you are — that's important. "
>
> **— CASEY HOUSE CLIENT**

> " Trust is important because you don't want to feel like you have to lie about stuff. "
>
> **— EMPOWER PARTICIPANT**

Untitled - Amanda

Untitled - Brenda

Safe Space - Dakarayi

All You Get - Lydia

Untitled - Keeky

QUESTIONS TO CONSIDER:

1) To access programs at your organization, what are community members' specific support and access needs? Consider physical, social and structural barriers.

2) What supports do community members need to *adequately* and *meaningfully* contribute to decision-making or peer leadership in your organization or program? How willing and flexible is your organization to share power associated with the planning and delivery of peer-led programs and services?

3) What strategies do you use to build trust within your organization? Do community members trust that you will take their feedback seriously? Do they feel "safe" enough to provide feedback on programs and policies, without fear that it will jeopardize their access to services or opportunities?

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PEER LEADERSHIP, ADVOCACY, AND SOCIAL JUSTICE

Principles like *Nothing About Us Without Us* and *GIPA (the Greater Involvement of People Living with HIV)* have been central to the HIV response since the early 80's. From influencing program and policy design, to leading programs and services, participants spoke to the importance of being meaningfully engaged in their respective organizations. For some participants, they also saw their participation in this project as a form of advocacy.

While participants at all organizations saw their lived experience as expertise, how participants saw their role in influencing social change was significantly impacted by the contexts of the organization and the possibilities therein. For example, participants in Empower, a youth-led HIV prevention and harm reduction peer education project, saw clear parallels between their identities and experiences, systemic injustice, and their work as youth leaders in the broader community. In contrast, participants at Casey House and PWA - service-oriented organizations - saw advocacy and peer leadership as something that happened more internally (i.e., how to improve services), and in some cases, around broader anti-stigma efforts outside of the agency.

> " [It] reminded me of community, the way we need to be connected to one another. We can mobilize in ways that we might not be able to on our own. "
>
> **— EMPOWER COORDINATOR**

> " I took this photo as advocacy - to show my face, to make a difference. "
>
> **—PWA PEER WORKER**

> " I mean I can volunteer at church or anything else like that, but this place is important to me. … Right now we want to be in charge in a group. … And it is important to keep myself busy and focused. … We need each other. … My thing is to always talk about peers helping peers. "
>
> **— CASEY HOUSE CLIENT** (ON THE IMPORTANCE OF PEER PROGRAMMING)

> " We've had different volunteers come here …. we're just the latest cohort of volunteers, I am sure people have heard in this agency, 'wait for us, they are just picking up the baton'. "
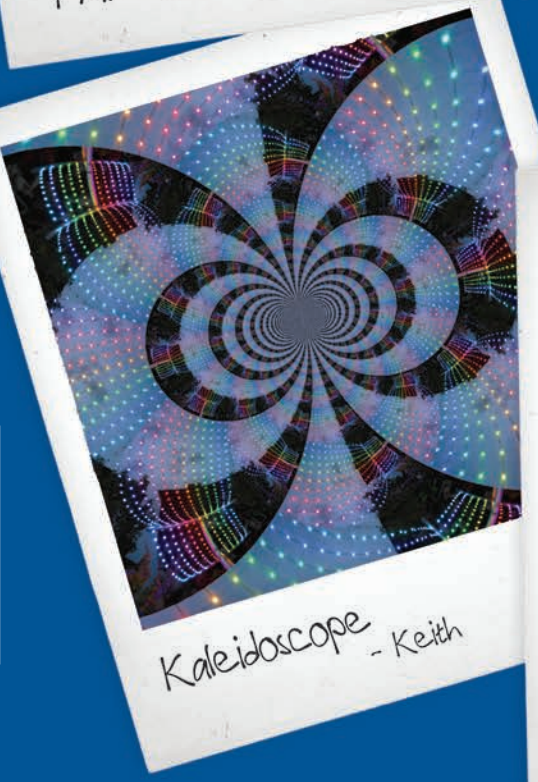>
> **— PWA PEER WORKER AND VOLUNTEER** (ON THE HISTORY OF GIPA AND THE HIV MOVEMENT)

engaging VOLUNTEERS

I Am a Volunteer – Yvette

Weapons of hope – Chantal

Kaleidoscope – Keith

Untitled – Kamilah

OMG Stonewall – DKO

QUESTIONS TO CONSIDER:

1) How do you define a "peer"? Some participants rejected the idea of peer based only on a singular identity marker like HIV status or age, and encouraged us to think about other intersectional factors (e.g., race, sexual orientation, gender identity, drug use experience, mental and physical health, housing).

2) Participants had a wide range of reasons for wanting to be involved in leading programs and services. These reasons ranged from peer leadership as ways to: advocate; connect with others; give back and stay busy; gain skills/experience; and deliver community-responsive programs. What opportunities for peer leadership exist within your organization? Do they correspond with peoples' desires for being involved and co-leading programs or services, or consulting on decisions?

3) What opportunities for advocacy and social justice exist within your organization? Who is your organization accountable to? Funders, or the community you serve? If you are limited by funding restrictions, are there ways to partner with external groups or projects to create opportunities for people to mobilize on issues of importance?

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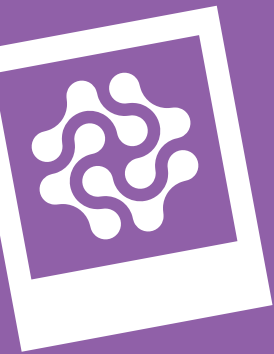
WORKING TOGETHER:
DIVERSITY AND DIFFERENCE

Honouring the differences that make up our communities is vitally important. In the sites we worked with (an ASO, a community-based HIV hospital, and a youth-led HIV prevention program), participants came from many different communities, and held intersecting identities associated with their gender, race, indigeneity, sexuality, ability, immigration experience, class, drug use experience, and health status. Participants spoke about what it meant to listen and learn from people who were not like them; to work across difference without erasing it; and to work in solidarity with each other and their communities.

"There is a perception that PWA is a white gay men's organization and I really, really bristle at that because I've been in this movement for really long time. … It pisses me off because there were women of color in this organization when it was being founded. There were straight men … there were lesbians. … You know to disappear all these people from our movement…."

— PWA VOLUNTEER

"Like now we are going to have the Pride. … I am not gay, I am not a man, but I get involved. …So me being out there as a coloured woman, an African … And [I want] to remove that notion that …. these activities are only for the Black people... Say like during the Black History month, only the Black people are there -- No, we don't do that."

— PWA PEER WORKER AND VOLUNTEER

"So when I think of some of the feedback we get from our clients there's that young substance user … And there is the older 50 years old, HIV 'seen all my friends dying' and they struggle to figure out how to share this space. But there's actually an opportunity to figure out how to share this space and leverage one another's kind of wisdom that they bring to the table."

— CASEY HOUSE STAFF MEMBER

"Is it ambitious to imagine youth programming that is all-encompassing of everything that we are? I think so, because I think by virtue of being all the different ways we come into programming, I think we're already fragmented in many ways. I don't think that programming can necessarily solve that but, maybe can alleviate it."

— EMPOWER MENTOR

Unity - "Bill Nye"

Stolen Land
We Now Stand - Rainbow

Diaspora Out of Focus
- Tumaini

Chair Mountain - Karen

Rainbow Purse
- Two Bite Brownie

QUESTIONS TO CONSIDER:

1) How is diversity reflected within your organizational structures? How are the communities you serve reflected in decision-making roles in your organization?

2) How do organizations create spaces where we can work across differences without erasing them? What programmatic spaces or activities have you intentionally created within your organization for allyship and solidarity?

3) To be culturally-relevant and responsive to community needs, HIV and Harm Reduction programs are often designed for specific communities. As our participants taught us, this can unintentionally serve to fragment people's identities. How does your organization continue to build community-tailored programs and services while also recognizing people's many intersecting identities?

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GRIEF, LOSS AND REMEMBRANCE

Loss and grief were dominant themes throughout the research. Many participants spoke about: experiences of losing loved ones; facing personal mortality; and loss on a societal scale through the AIDS or overdose epidemics. Participants also shared their feelings of grief, sadness and frustration as a result of dealing with ongoing systemic oppression, or programming spaces that didn't allow them to show up with all facets of their identity. Loss, however, was not always considered negative. Many participants spoke to the importance of hope and new beginnings in the face of loss.

> " I rushed all the burials, I rushed them and I thought I can escape by making my own film for them. I was in my own denial, not grieving. … I don't think I have grieved yet still for my cousin since she passed away. … It's the lifestyle of growing up in the hood…. What do I do? Like how do I control the situation? …. [This] could have been prevented by more cash, accessibility to drive to these communities to talk more suicide prevention, all of that. "
>
> **— EMPOWER PARTICIPANT**

> " Knowing how… the epidemic has consciously changed somebody, how strong the impact may be on them, you know? … He said that, 'I see the rooms where my friends died'. He said, 'you know instead, I look across the street and I see life, I see hope and I see forward movement… memories and feelings associated with these walls'. "
>
> **— CASEY HOUSE STAFF MEMBER**

> " Darkness is where you can regenerate first. And the first stage of grief, you have to go through to get to the second stage when you are marginalized or when you're first infected … It's OK to isolate a little bit. "
>
> **— PWA VOLUNTEER**

Untitled - Robert

Untitled - Marc

Untitled - Mama Ou

Untitled - Sunshine

#Hope - Michael

QUESTIONS TO CONSIDER:

1) How has the HIV or overdose epidemic affected individuals (peer workers, participants/clients, staff, etc.) in your organization over time?

2) As our participants reminded us, loss sometimes creates rooms for (re-) generative possibilities. What strategies does your organization have for supporting community members and staff during times of loss?

3) Loss takes many forms. How might your organization consider larger systems of oppression (racism, transphobia, stigma against drug users, etc.) when thinking about loss?

For more photos and narratives (by theme), please visit:

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NON-PARTICIPATION:

Sometimes people don't want to, or can't participate. Participants told us about: choosing to actively *not* participate as a form of self-determination; taking distance to heal or attend to one's physical or mental health needs; and the dangers of burn out. For many community members actively involved in peer leadership roles, they must carry multiple burdens, such as working with limited resources while also dealing with personal exhaustion and the weight of structural barriers. For others, just getting up and out the door when dealing with physical and mental health can be a large struggle.

> " In terms of my own position as a trans woman, and also a woman of colour, there are so many rich stories, rich narratives that aren't told …. Sometimes I feel burnt out because I feel like a lot of pressure is on me, to deal with issues that have existed longer than I have. "
>
> — EMPOWER PARTICIPANT

> " Just you know [the bench] was kind of away from the building, away from the nurses wherever anybody who was just trying to help. At that time, you are like 'ha, I just wanna get away'. "
>
> — CASEY HOUSE CLIENT

> " Sometimes people need to be left alone to really determine things for themselves and develop an understanding of what their needs are before being around other folks, so like that's a way of supporting a person, by giving them some space. Fall back. "
>
> — EMPOWER MENTOR

> " We rely on you, but do we not rely on you individually. "
>
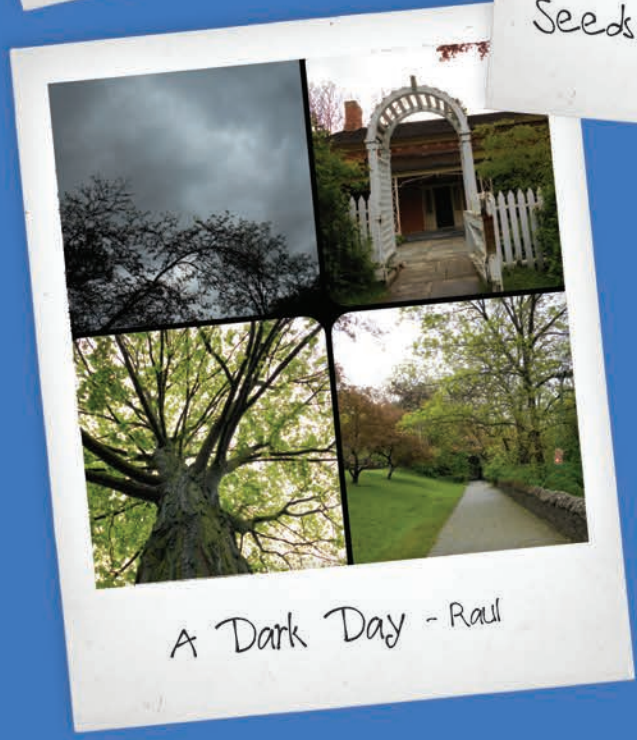> — PWA VOLUNTEER (ON THE IMPORTANCE OF TAKING BREAKS OR TIME AWAY)

The Different Types of Plants - Josh

Seeds of Our Labour — Buttercup

Orchids - Chris

A Dark Day - Raul

Growth - Lydia

QUESTIONS TO CONSIDER:

1) Community engagement models often focus on levels of active participation. How might your organization reframe the ways it looks at non-participation? Are there ways to create more fluid entry and exit points for meaningful participation to accommodate people's interests, and/or mental and physical health needs?

2) For many communities, self-care must go beyond having a hot bath or cup of tea. Given the weight of structural barriers and systemic oppression, how do organizations better support peer workers and volunteers who may experience symptoms of burn out?

3) How might the idea of non-participation help us center principles of autonomy and self-determination in peer-led programs? Or lead to more sustainable, equitable, and accessible programs or services?

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"By dreaming every day, dreaming with our hands, dreaming with our minds . . . Things are just starting."

— PWA VOLUNTEER

We believe that the HIV and Harm Reduction movement cannot exist without the insight, passion, and care of people living with and affected by these issues at the forefront. Whether your organization involves young people affected by HIV in larger prevention efforts, or people who use drugs in specific support services at AIDS Service Organizations, engaging community members must be done in ways that are **meaningful, sustainable** and **feasible**. We must not only dream it, but we must also do it.

RECOMMENDATIONS

1. Engagement has many different definitions. Organizational contexts and people's roles within them will shape how people understand engagement. Work with community members to define what engagement means at your organization, or within your program.

2. Consider the role of personal and organizational journey when designing peer-led programs, and spaces for individuals to consult on organizational change.

3. Honour relationships to self, to others, to your organization, and to the land. These relationships will form the backbone of your work together.

4. Ask community members what accessibility supports they need in order to be able to meaningfully consult on decisions and programs in your organization. In addition to tangible supports (transportation fare, connections to services, food, etc.), this may include support mechanisms to create inclusive programs across gender, race, sexuality, age, class, Indigeneity, drug use experience, and health status.

5. We arrive at organizations with different identities and experiences. These experiences are often linked to the privileges and oppressions we encounter in the world. Consider what it means to work across these differences in your work together.

6. Sometimes, participation can feel tokenistic. Create transparent and accountable dialogue and procedures around how peoples' input, decisions, and labour are being taken up and respected in your organization or program.

7. Reflect on the designation 'peer.' What does this mean within your organization? Consider who this label includes and excludes.

8. Create spaces for dialogue about the impact of loss and grief on community members and staff in your agency.

9. Consider whose voices are not at the table. Reflect on why this might be and where necessary, take action to address it.

10. Respect the importance of lived experience – in program and policy design; in peer-led initiatives and services; and in decisions affecting personal care. This may mean challenging deeply engrained organizational values.

11. Take careful note when people are not participating. This may provide valuable insight about how you consult people on important decisions, design inclusive peer-led programs or service delivery, and attend structurally to burn out.

12. Opening up decision-making processes to communities most affected by issues may change organizational plans, priorities or outcomes. Trust in this process – your organization or program will benefit in the long-run.
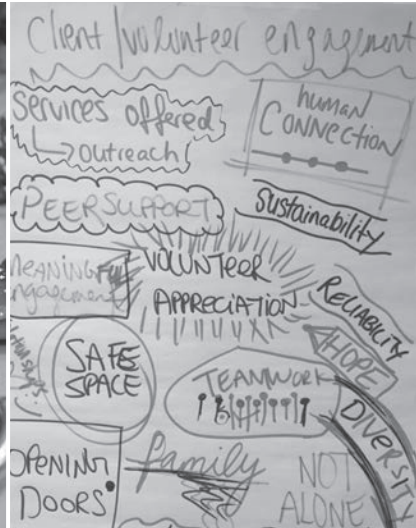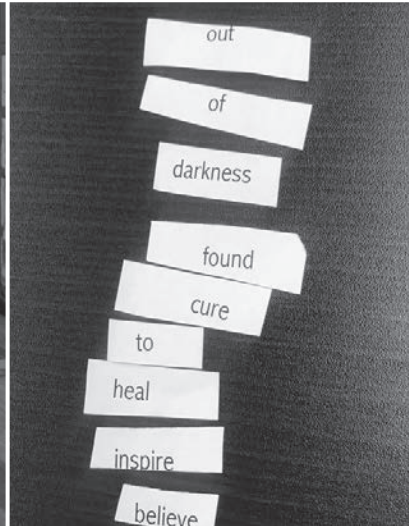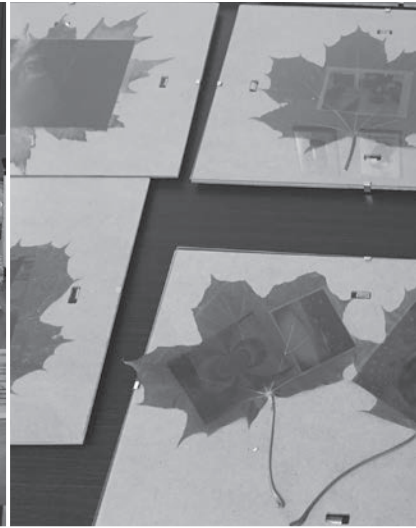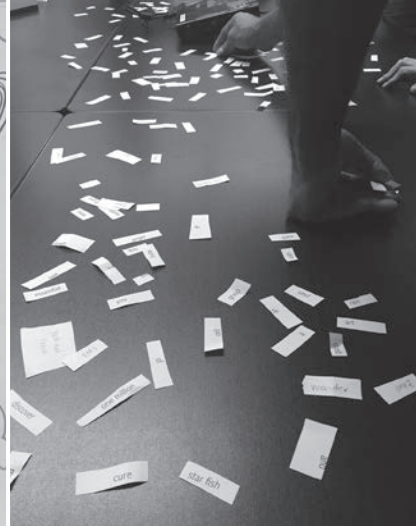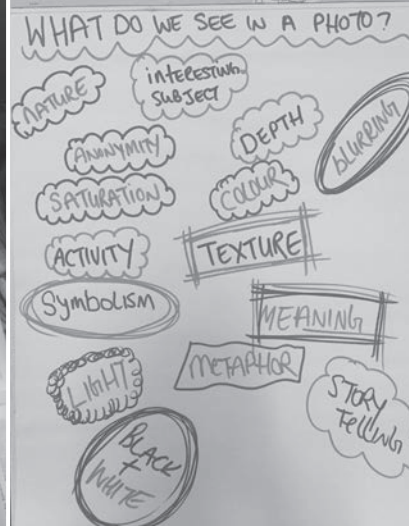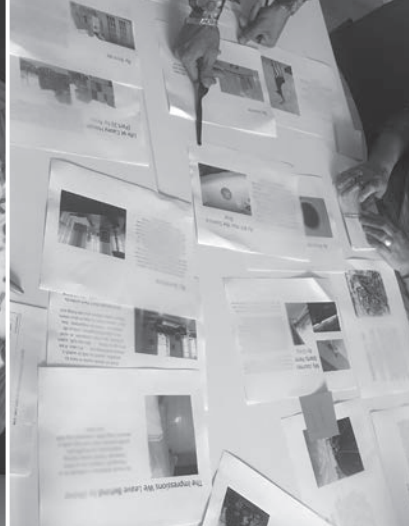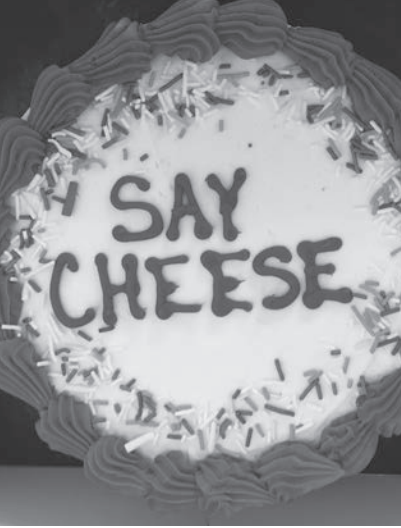
ACKNOWLEDGEMENTS

Our workshops took place in Toronto (from the Mohawk word Tkaronto). This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, this meeting place is still home to many Indigenous people from across Turtle Island, and we are grateful to have an opportunity to build relationships on, and with this land – including with many individuals in our project.

A warm thank you to all the participants who: contributed to our project, and helped us learn and grow; and to all the co-investigators, and research assistants who supported the project. A special thank you to community report working group members, and staff at the three sites who provided such a warm welcome.

Bridging the Gap - Buttercup
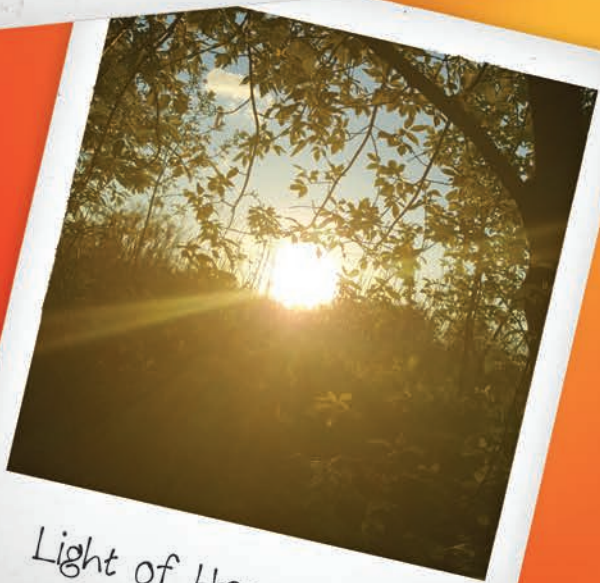
Light of Hope - Nick