

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



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.



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. ”

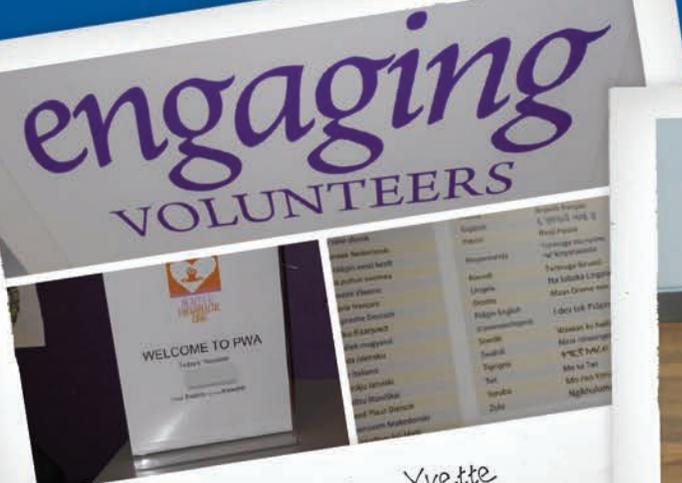
–**PWA PEER WORKER**

“ 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'. ”

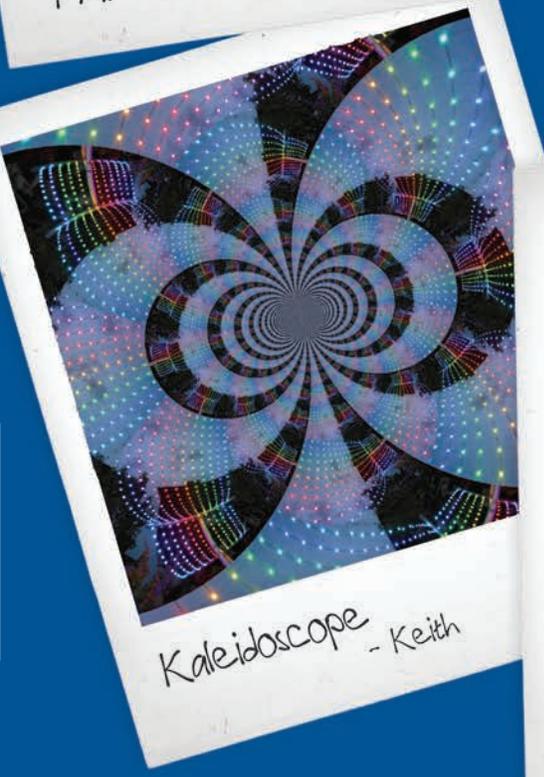
– **PWA PEER WORKER AND VOLUNTEER (ON THE HISTORY OF GIPA AND THE HIV MOVEMENT)**



I Am a Volunteer - Yvette



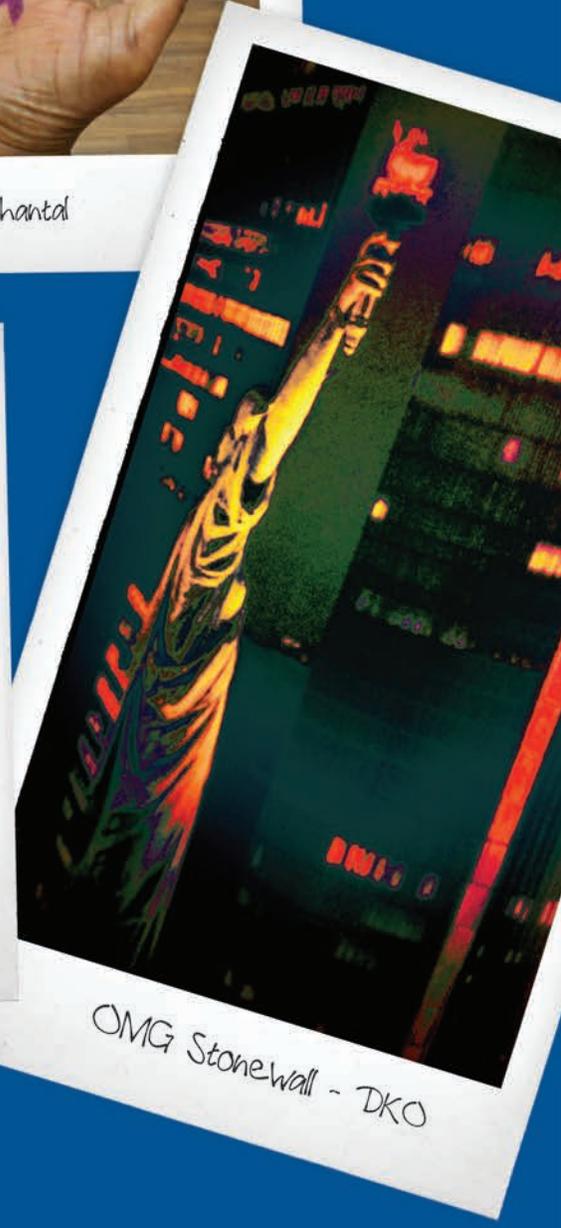
Weapons of hope - Chantal



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?

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

<https://pictureparticipation.wixsite.com/gallery>



Peer Leadership, Advocacy
and Social Justice

Stolen Land We now Stand - Rainbow



I'm a transgender woman who stands next to my community of brothers and sisters. It is important to be mindful of our stolen land we walk on every morning, and how our children, brothers and sisters fight everyday for accessible food medical services, income and food to feed our loved ones. Healing from our nature - water and trees. When we lose a part of a nature or land, we lose our loved ones impacted from HIV/AIDS. How can we work as a community of mixed races, genders, orientations, and religions to decrease barriers towards our stolen land and protect our loved ones? There is no "i" in "team", but there is us in community. We are all born different and struggle through multiple barriers with the stolen land we live on. Let's always be mindful, stand high and remember who is impacted by what was once here but now stolen from us.

Seeds of our Labor

- Buttercup



As an advocate that is committed to raising awareness to issues that impact marginalized youth; my understanding of engagement would be incomplete if I didn't think about the people who are actively working towards social change. I thought about some of the personal challenges. Like a rose that is so beautiful and vibrant in the beginning. As time progresses, without proper care and without being grounded, it wilts. The wilting resonates with my feelings of being burnt out; feelings of distress and agony that often comes along with doing this community work and challenging social norms. Ideally we need sustainable supports so folks do not become burnt out and can continue to work progressively in HIV prevention, sexual health and harm reduction programs.

Bridging Gaps

- Buttercup



As I thought about engagement and what that may look like in the future, I became consumed by thoughts of the gaps and disparities that currently exist. I thought about the different people involved in creating programs and services and who the programs were created to support. Also how we can improve our understanding of community engagement by creating opportunities for those impacted most; hence allowing their active participation in various forms of the programs development, particularly in HIV prevention, sexual health, and harm reduction programs. With this approach, the grass may literally be "greener on the other side".

All You Get

- Lydia



A bike without a wheel.

Locked- to a post.

A mostly usable bike... a metaphor for ways we attempt to help youth, without actually considering the barriers they face or the support that they need.

Without considering that youth have different access needs that cannot be solved by a single blanket solution.

Do we ever ask first? Or do we just assume that we know what is best because we hold the decision making power.

How can we know what is really needed?
How can we involve youth in more meaningful decision making?

The importance of being welcoming to Indigenous youth in harm reduction and HIV programs - Keeky



I decided to take this picture because it looks like it's in a forest. The reason I took this picture is to represent the importance of reaching out to Indigenous youth and I know technically Indigenous people have respected nature and lived out in nature.

How this is related to youth engagement , HIV and Harm Reduction : I know that a long time ago Indigenous communities of Turtle Island didn't frown upon sex work or drug use.

The Indigenous communities traditionally believed it's important to be respectful and accepting of everyone but we live in a society where sex work, drug use and people living with HIV gets frowned upon because of white supremacy, colonialism and the right wing neo-conservative mindset.

Untitled

- Kamilah



Where I am right now in life has changed my feelings towards how I feel about youth engagement. I took this photo because the way that these pillars and these poles were standing up and being connected to one another with a rope reminded me of community, the way we need to be connected to one another, and that when we are connected to one another we can mobilize in ways that we might not be able to on our own and it can serve to facilitate a larger movement in ways in which an individual movement cannot. And that's gotta be from the ground up - why I took the photo from this angle. Not top-down authority bullshit. At the same time, the station is empty, and that's how I feel towards being engaged now as a young person. I feel like there are resources around but I am feeling unsure how to use them, or know how to get through my personal shit (depression, lack of confidence) to actually use the resources. The way the train is just about to come in to the station - I feel like I am always just barely catching things, moving by the seat of my pants. I'm just kind of looking at this space and trying to figure out where I belong and how to move through all these pillars, poles, how to climb the ropes in between them. It's complicated. Even when the resources are around. Sometimes you need the extra help just to start a process of using them.

Gatekeeper

- DKO



Peer engagement.

As a gatekeeper, you lead the way, and show people how to open the door.

The skills and values learned during capacity building at the Positive Leadership Development Institute (PLDI); the Ethno-racial Treatment Support Network (ETSN); and Turning to One Another (TTOA) show us how to be an effective leader while giving back to the community.



OMG Stonewall

- DKO

Nothing About Us Without Us. How we formed the beginnings, how GIPA/MIPA was created

Ontario Accord **M**eaningful Engagement of People living with HIV (MEPA)/ADIS and the

Greater Involvement of People living with HIV/AIDS (GIPA)

= OMG

Untitled

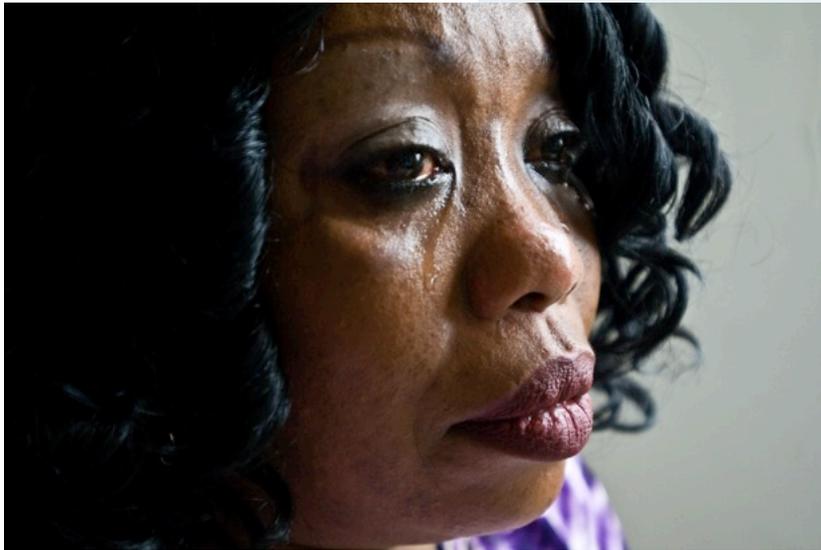
- Joanne



Our organization should be a reflection of the people it serves, this is at the foundation or roots of our philosophy. Engagement can be challenging and as we work together, it may be 'muddy' but the joy comes working through those muddy times and light at the end causing the reflection.

Million Tears of Life

- Chantal



Millions Tears of life because of stigma & discrimination I faced during genocide 1994 in Rwanda as victim of rape and survivor of HIV.

I was walking like a dead body, but after I found PWA as a 'family for everybody' I came to ask their HAND in emotional, mental, physical, and spiritual support. From that time, I became a normal human being and started to help other women and girls who are HIV positive to get out of isolation, stigma, and discrimination and make a better life.

This photo was initially taken as part of a project that aimed to fight violence against women.

Weapons of Destiny

- Chantal



As PWA family TREE I am strong. I stopped crying and started a new life moving forward.

I have become an activist, an advocate for others - people living with HIV/AIDS without discrimination of age, education, gender, sex orientation and religion. Raising my voice in defense of the social justice of peoples living with HIV/AIDS and those who are vulnerable.

This is my idea now.

I am a Volunteer

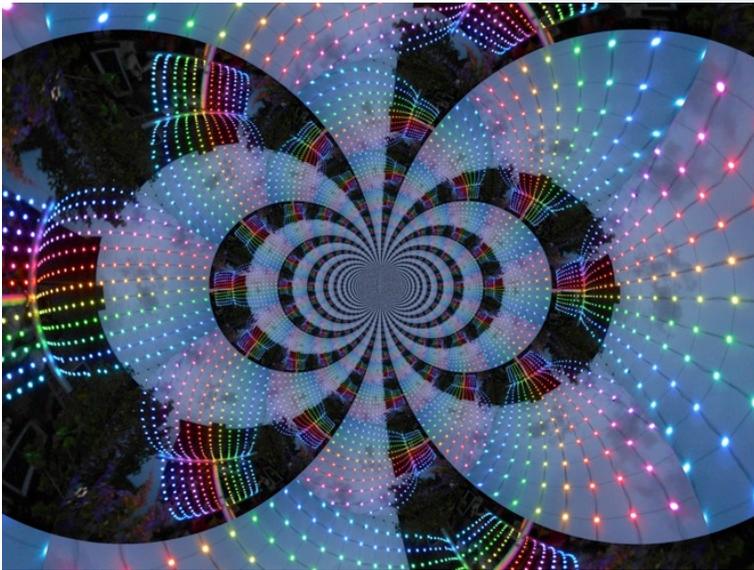
- Yvette

As a volunteer I learn and use valuable new skills and, most importantly, use those skills to do things that matter. At PWA, I am part of the team that provides consistent services with lasting impact through interpersonal relationship with peers and volunteers through MIPA principle. Like most of the volunteers and staff. I speak more than one common and popular languages. I am proud to be part of PWA an agency that accommodates diversity in many ways including language use. I am always ready and looking forward to the day I volunteer at the Therapeutic Clinic. Through GIPA principle its an honor to display my name as the Volunteer on duty to serve even as I wear the badge as well.



Kaleidoscope

- Keith



Volunteer engagement is about building and maintaining connections within the ASO community and extends to communities outside the barriers of ASO's.

Untitled

- Keith



Volunteer engagement is about fighting stigma and helping newly diagnosed find a clear path to resources, information and connecting people to supports within the community.

Untitled

- Yvette



Taking the time to recognize volunteers is crucial to PWA for their dedication and service ; I received a free theatre ticket “For Colored Girls...Ntozake Shange.” A reflection of myself in the photo makes me identify with the pain and joy in the stories. I am happy to be part of a volunteer team that is recognized in every way.

“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.

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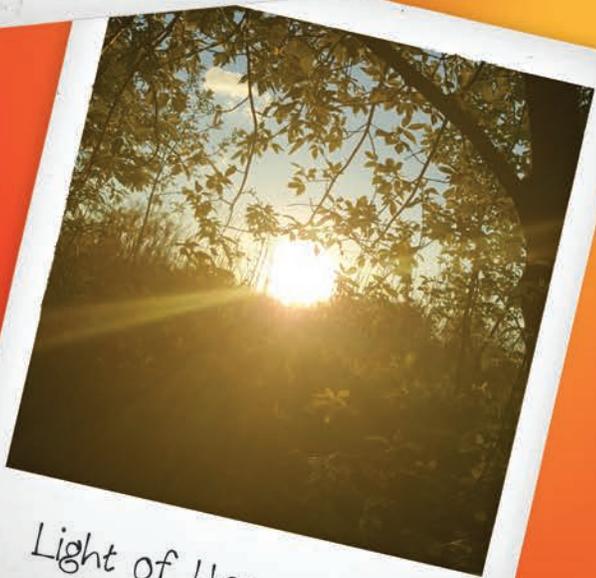
Sarah Switzer; Sarah Flicker; Soo Chan Caruosone; Alex McClelland; Tatiana Ferguson; Neil Herelle; Derek Yee; Shelby Kennedy; Bahlelisiwe Luhlanga; Kamilah Apong; Amber Corrdick; Charlene Grant Stuart; Anne Marie DiCenso; Karen de Prinse; Adrian Guta; Suzanne Paddock; Carol Strike. (2017). *Picturing Participation: Exploring Engagement in HIV Service Provision, Programming and Care*. [Community Report]. Toronto.

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Bridging the Gap - Buttercup



Light of Hope - Nick

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