



# FACING forward

IDENTIFYING RESEARCH PRIORITIES  
THROUGH PHA EXPERIENCE



“ We are humans—  
*not abstracts.* ”

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# EXECUTIVE summary



**What I have to offer is valuable to others.**

**PHA Priority  
Setting  
Participant**

OHTN is committed to Impact-focused research, defined as research relevant to the lives of people living with and at-risk of HIV that will have a measurable impact on their lives. In November 2014, OHTN partnered with the Ontario AIDS Network (OAN) Positive Leadership Development Institute (PLDI) to gather input from people living with HIV (PHAs) from across the province about their research priorities. The planning team was led by PHAs and facilitation was provided by PHA facilitators from PLDI and OHTN peer associates. Eighty-seven PHAs participated: 62 males and 25 females.

Rather than fitting PHA lived experience into research jargon, context and structure, participants were encouraged to share personal reflections about the questions most important to them. These were explored more deeply to identify research considerations, PHA nuances and personal impact in their lives. The day emphasized creating an actionable priority list producing the following seven priorities:



## MENTAL HEALTH

Participants wanted research to better understand:

- The impact of HIV and long-term ARV use on cognition and mental wellness
- Effects of social factors (stigma, housing instability, unemployment) that shape the lives of many people living with HIV on mental health



## ACCESS

This priority combines access to quality health care and also reliable information for health decision-making. Participants proposed solutions to access challenges that could be investigated and explored through research including:

- Knowledge sharing between PHA peers about improving quality of life
- Investigations of why people stop taking medications (leave the treatment cascade)
- Means of improving accessibility and readability of medical information
- Improved access to specific services (rehab, complementary medicines, treatments) both geographically and for priority populations
- The use of technology (Skype, telemedicine, webinars) to improve access



## AGING

In this area, participants urged research attention with a holistic perspective towards:

- Understanding and monitoring the changing demographics of HIV
- Co-morbidities and inflammaging – Why conditions, such as cognitive decline or heart disease, occur earlier in PHAs, how they could be prevented; the impact of different ARVs
- An examination of health outcomes for senior PHAs comparing various demographic identifiers such as urban/rural, ethnicity, sexual orientation etc.
- The issues behind new diagnoses in seniors
- Appropriate care (long-term care, home care) and resources for elderly PHAs



## CLINICAL

Participants concerns about clinical care largely focused on concerns around the long-term use of antiretroviral (ARV) medications and associated side effects pressing for more attention to:

- Long-term studies evaluating side effects of ARVs considering gender, age and ethnicity
- Medical interventions to address the physical effects of treatments and HIV on the body
- The links between ARVs and co-morbidities (eg. heart disease)
- Comparisons of the availability of clinical services for PHAs across the province



## HOLISTIC & COMPLEMENTARY CARE

Many PHAs have an interest in complementary care and desire information about the usefulness (and cost effectiveness) of such treatments. PHAs wanted:

- Information that clarifies the role of alternative therapies in living with HIV, in addressing treatment side effects and in improving overall health
- An inclusive environmental scan of rehabilitation services and supports
- An examination of how access and cost factors affect the use of complementary care



## POVERTY

Many participants talked about feeling trapped in poverty by the costs of treatments and the disability associated with HIV infection. They urged research and advocacy to explore:

- The potential costs/benefits of universal access to HIV medications (including ODSP impact)
- A better understanding of episodic disability and the impact on financial stability
- Assessment of ODSP/CCP/OW rates and ways of supporting transitions between programs
- Cost/benefits assessments of existing programs for PHAs (health, social service, justice)
- The economics of affordable housing and its impact on adherence, health and PHA income



## CRIMINALIZATION

PHAs discussed the impact of criminalization (and related stigma) on their health and well-being. They proposed research to understand how the criminalization of HIV non-disclosure influences:

- Behavior change (Does it make the world a safer place?)
- The willingness of PHAs to disclose their status and to access treatment
- Decisions to get tested amongst those at-risk

Meeting participants urged considerations of three themes when implementing research, and ultimately programs, in the topic areas above:

1. **Capacity Building:** Building the capabilities of individual PHAs and communities.
2. **Stigma:** Addressing biases based on both HIV status and other factors (such as drug use history or ethnicity) and the way that this stigma limit people's willingness to use services.
3. **Engagement/Peer Support:** PHAs have tremendous lived knowledge that can be shared.

Throughout the meeting, participants shared intensely personal and powerful reflections and expressed deep appreciation for the opportunity to genuinely and meaningfully speak and be heard on such important questions. The priorities and the context provided by attendees will be used to inform the OHTN's new strategic plan, and to guide funding decisions and the programs of Applied Research Chairs.

# SETTING THE stage



The Ontario HIV Treatment Network (OHTN) is committed to the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MEPA). Our voice, leadership and involvement as people living with HIV/AIDS (PHAs) have been an integral part of OHTN research and other initiatives, such as the OHTN Cohort Study since the OHTN was established. In 2013, the OHTN reinforced the importance of this relationship by making people living with HIV a priority for the OHTN's Impact-Focused Research Program and targeting research dollars to address our priorities.

In 2014, the OHTN partnered with the Ontario AIDS Network (OAN) Positive Leadership Development Institute (PLDI) to sponsor a PHA Research Priority Setting meeting. The day-long session was held immediately following the OHTN's Back to Basic Conference, which was designed specifically to engage people living with HIV in the basic science of how the virus affects the immune system and the work being done to understand the virus and develop a vaccine or cure.

More than 100 people living with HIV registered for the session and 87 participated: 62 males and 25 females. Participants came from across the province.

The event was the start of a concrete, intentional process of reaching out and asking people living with HIV to contribute in meaningful ways to setting research priorities that will have the greatest impact on their lives. Expected outcomes from the meeting include:

- contributing to the language and priorities of calls for proposals
- highlighting research gaps that may require targeted calls and outreach to address priorities and gaps
- identifying priorities and needs that may be addressed by other OHTN programs and needs, such as its capacity building programs with AIDS service organizations, clinics and health care providers.

**23**

Eastern  
Ontario

**34**

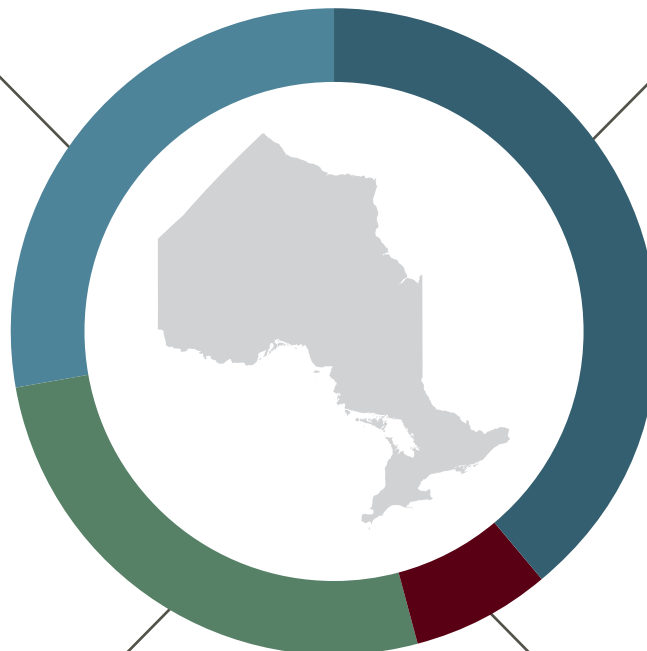
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**24**

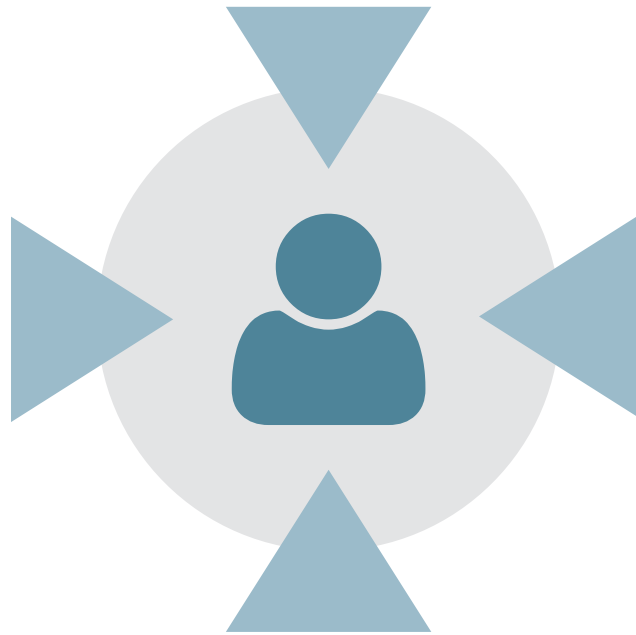
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Ontario



# USING A PHA-CENTRED approach



There were three critical and intentional elements to the approach taken in developing and coordinating the event:

1. Consistent with GIPA/MEPA, **the event was shaped by PHAs, had PHA involvement and leadership, and was structured from a PHA perspective.** The planning team was led by PHAs representing the OHTN, OAN PLDI and meeting facilitators. Small group table exercises were led by PHA facilitators from PLDI and OHTN peer research associates. Throughout the day, participants commented on how appreciative they were of this intentional ‘walking the talk’ and the resulting impact on the energy and overall event experience.
2. **The event used a holistic, PHA-centred approach.** To ensure the discussion was meaningful and led to priorities relevant to the lived experience of PHAs, the day was structured from our perspective. The exercises and facilitated discussions began from the perspective of identifying what would improve our health and wellbeing as PHAs. Event facilitators intentionally modified categories from the Gay Men’s Sexual Health Alliance (GMSH) Engagement Wheel and encouraged

participants to reflect on their whole lived experience including: self-worth, connection with others, medical/clinical care and health, complementary and other community/health services, and contribution towards self and others. These perspectives were then further explored in the context of what we would like to understand more fully as well as the nuances of the PHA experience. This process meant that the language was about our lives and not about research. Rather than fitting PHA lived experience into research jargon, context and structure, the focus was the reverse. This was a unique, powerful process that to our knowledge has not been undertaken elsewhere in Canada.

3. **The event adopted a strengths-based focus.** Using a strength-based approach to guide questions and facilitation helped focus attention and energy on solutions, strengths, growth and possibilities. A strengths-based approach supported the sharing of stories that acknowledged significant challenges; it also supported the exploration of possibilities. For research to have impact in the lives of PHAs, it must be informed by a strengths-based perspective.

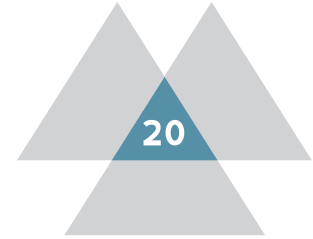
# IDENTIFYING priorities



1. Discussions throughout the day focused on identifying a set of priorities. First, participants were asked to identify three priorities on their own using a worksheet.



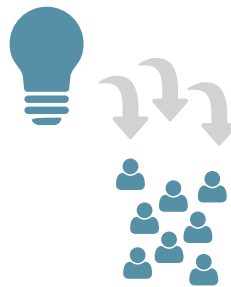
2. They then shared their priorities with others at their table, consolidating them, identifying common themes and selecting the top three priorities for each table.



3. Facilitators then consolidated these 30 priorities into a list of 20 (see below).



4. All 20 were deemed to be important...



5. ...and will continue to inform research and the broader needs of people living with HIV/AIDS.



6. To identify the top 7 priorities (blue in the list below), facilitators used an informal, anonymous, electronic voting process.



## TOP RESEARCH PRIORITIES FOR PHAs

- |   |   |
|---|---|
| <p><b>A.</b> Access: identify &amp; evaluate process for PHA sharing of tips &amp; tricks</p> <p><b>B.</b> Access: identify system gaps for diverse identities</p> <p><b>C.</b> Access: KTE &amp; PHAs</p> <p><b>D.</b> Burnout: how to avoid/deal with</p> <p><b>E.</b> Aging: increase epi data related to diverse identities</p> <p><b>F.</b> Aging: increase clinical knowledge</p> <p><b>G.</b> Aging: long-term care</p> <p><b>H.</b> Clinical: ARV side effects for diverse identities</p> <p><b>I.</b> Clinical: understanding &amp; addressing visible signs of HIV on the body</p> <p><b>J.</b> Alt/com therapy: knowledge, evidence and comparative impact</p> | <p><b>K.</b> Poverty: identifying &amp; understanding impact on holistic health</p> <p><b>L.</b> Mental health: understanding life-long impact &amp; PHA experience</p> <p><b>M.</b> Housing: evidence of holistic impact</p> <p><b>N.</b> Capacity building: create measures &amp; evidence</p> <p><b>O.</b> System integration to maximize long term health</p> <p><b>P.</b> Criminalization: identify &amp; evaluate impact on Tx cascade</p> <p><b>Q.</b> Engagement: impact long term involvement in sector</p> <p><b>R.</b> Peer support: evidence, guidelines</p> <p><b>S.</b> Accreditation, employment, retention &amp; transition spectrum</p> <p><b>T.</b> Stigma: health outcomes (external and internalized)</p> |
|---|---|





# EXPLORING THE TOP 7 priorities



The next few pages discuss the top 7 priorities in more detail. Each table provided notes from Its discussion. In addition, 39—or almost half the PHAs in attendance—completed and chose to share their worksheet identifying their personal priorities for health and wellbeing through incredibly powerful stories and statements. Wherever possible, comments in the report are in participants' own words.



## MENTAL HEALTH

**Specific to understanding life-long impact & PHA experience**

### Considerations

1. Access to services is not 'fair' or accessible in all areas (rural/urban and regions)
2. Self-stigma
3. Acknowledging the barriers and how to find help safely
4. Establish self-management and learning about self-care
5. Stress/anxiety related to sex with partners that have a different HIV status than us (impact on one's mental health)

### What can we better understand?

1. HIV (particularly long-term) and medication impact on cognition and mental wellness
2. Effects of stigma on one's mental health
3. Impact on behaviour, adherence, stable housing
4. Does HIV trigger mental health issues or does mental health bring us to HIV?
5. Unemployment and other social determinants of health and its impact on PHA's mental health

### Impact

1. More proactive involvement in your own healthcare
2. More services to address mental health issues
3. Increase in training for first responders (including ASOs)
4. Greater access to services and treatment
5. Appropriate support (non-judgmental)

### Nuances of PHA Experience

1. Prevalence and interconnectedness of mental/emotional issues (anxiety, PTSD, depression, suicidal thoughts, addictions, cognitive disorders)
2. Need continual follow-up and check-in to help reinforce the attitudinal changes and behavioural changes needed
3. Find a therapist that works in a modality that directly addresses the root causes and implications of the issues being faced
4. Deal with the trauma of losing the opportunity to have children
5. Counselling services should be provided for grief and loss



**I can choose to walk 'firmly' forward and focus on the rainbow rather than the rain.**

**Due to disconnect and isolation, I feel I am not contributing or growing. I feel washed-up, finished, waiting for death, with nothing to offer others.**

**Increased emotional issues due to declining mental health: I have a feeling of having been diminished because of being a PHA.**

**Keep me focused on the "wholeness and potential" of my life rather than the "diminished or restricted" aspects of my life because of my HIV+ status.**





## ACCESS

**KTE & knowledge sharing for PHAs; system gaps for diverse identities of PHAs (including age)**

### Considerations

1. How can we use research as a mechanism that captures the tools, techniques and tricks that PHAs use that allow us to LIVE with a better quality of life? The knowledge is in the room. Create space for the knowledge to be heard and shared and then captured and disseminated to all.
2. Why do these interactions (events) between PHAs, science and government not happen more often and how is this information returned back into the community?
3. How can we improve communication between doctors/health care organizations and patients both scientifically and in layman terms?
4. How is science answering the questions of PHAs from our angle and in the appropriate terminology?
5. Speed up invasive testing and screening processes required for poz folks.
6. Need for more doctors/specialists could be improved by increased use of Skype technology, student doctors, retaining practicing doctors and nurse practitioners.
7. How/what is the impact of national HIV medication (drug) programs?
8. What is the impact on HIV health in an emergency (i.e. access to essential services/support, travel reimbursement)?

### What can we better understand?

1. Need to examine factors behind why people stop medications or drop out at any stage
2. Community-based research on different groups in the cascade (qualitative interviews and focus groups)

### Impact

1. Access to rehabilitation services such as occupational therapy, physiotherapy as well as naturopathic doctors and complementary therapies to help offset adverse side effects of medications (HIV meds) and living long-term with HIV.
2. Easier access to medication to the ACB community.
3. Improved communication, engagement & KTE with PHA
  - Physician's notes easy to read and understand
  - Ready and accessible information regarding the outcome of all research
  - Accessible in all formats of communication (printouts, video, webinars)

### Nuances of PHA Experience

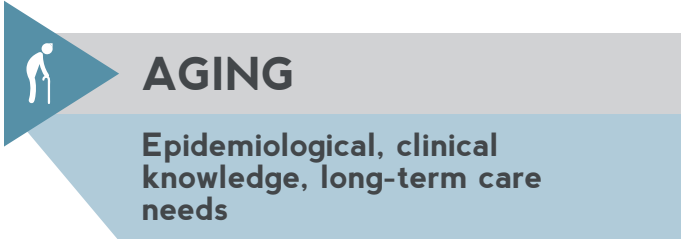
1. History of substance use equals no access to pain management or anti-anxiety medication
2. Treatment medication. If employed, I would need to pay over \$25,000 in drug costs
3. Better, more anonymized, LESS HASSLE! access to STI screening and treatment for PLHIV especially syphilis - with NO judgment
4. Treatment cascade seems to be the new language. Demand it be brought to housing and homelessness table
5. Safe, viable, community living free of stigma. Affordable retirement communities
6. Full choice at end of life to minimize suffering yet protect PHAs from misuse or abuse at end of life
7. More training on HIV sensitivity/violence against women in both sectors
8. Find religious institutions that nurture the soul without damnation
9. Supporting the lower rated HIV+ people. Like to see more programs to clients and services such as more groups for heterosexuals are needed
10. ASO staff should receive training on power sharing and an anti-oppressive framework



**We are humans – not abstracts. We are people not numbers! We are humans not lab rats!**

**I want generic meds and PrEP options for my partner (PrEP for HIV prevention). She doesn't like condoms. I agree. However, I don't want to put her ever in danger.**





## Considerations

1. Affordability, choices (short-term, long-term, homecare etc), safety
2. End of life (with dignity – all choices free from judgment)
3. Community, health care, emotional and municipal accountability
4. Minimal policies, guidelines or education exist for health care providers
5. Proactive vs reactive
6. Holistic view/lens of care
7. Peer involvement/networking/support consistently
8. HIV/AIDS assisted/senior/long-term care centres understanding stigma and confidentiality (safe, inclusive, culturally appropriate)
9. Educating other residents of care facilities and families/partners (affected)

## What can we better understand?

1. How many people over the age of 50 with HIV will there be in 2017?
2. Inflammation and aging – ‘inflammaging’
3. A research study with a holistic lens (mental, emotional, physical and social) broken down into priority populations (rural/city, demographics etc.) looking at long-term care for long term survivors and paying attention to the specifics and financial implications for data collection.
  - Research on long-term survivors and being exhausted from pill burden
  - Co-infections/co-morbidities
  - Data on rural seniors vs city seniors living with HIV
4. Can we prevent issues like CVD/diabetes/HAND with approaches like PrEP?
5. Is there a bigger issue behind newly diagnosed seniors?
6. Compare life timeline (health events for PHAs vs non-PHAs) and explore the effects of medications during these different life/age events

## Impact

1. Stable housing means stable people
2. Aging well with HIV
3. Protocols, policies, health care team education
4. Advanced construction of facilities/staff and tax dollars
5. Evidence-based and informed programs
6. ‘Aging in place’ organizations/establishments

## Nuances of PHA Experience

1. Stigma and care marginalization (i.e. over compensated universal precautions)
2. Importance of being able to stay within our own communities as we age
3. Financial stability of aging PHAs. We never expected to live long enough to retire!
4. Scared of the unknown (systems, future care, new discrimination)
5. Co-morbidities
6. Chronological care plan because we age sooner
7. Compounded cognitive disabilities
8. Neuropathy and energy
9. Are/how are we connecting older PHAs with younger/newly diagnosed PHAs?
10. What are the current parameters around defining “long-term survivors” – years of age, years of diagnosis, years of infection, years on ART?
11. Aging & self-care: To think & live outside HIV/AIDS
12. When using social networking/on line for meeting, end up feeling beaten up, depressed, unworthy - others dismissing you due to age, rejection due to HIV



**Are they prepared for us?!**

**I will not be forced into the closet again!**

**I am dealing with end of life issues and issues of my spirituality/soul on a daily basis.**

**I want to create improving life with older age - learning how to reconnect with self and set new goals.**

**As I age I get tired and neuropathy is more difficult – help please.**



## CLINICAL

**ARV side effects for diverse identities & long-term use, visible signs of HIV on the body**

### Considerations

1. Demanding medical interventions to fix the physical signs and body changes caused by HIV or HIV medication - not dismissed because it is seen as cosmetic surgery
2. Continue to make more useable (less impact on the lived life of person taking medication)
3. Identifying tests for better analysis and understanding of symptoms of drugs (e.g. side effects, pain, mental health, invisible symptoms)
4. There is a slowing down by the scientists in wanting/ needing to further investigate a cure or even take a closer look at current findings (e.g. the depo-provera allegations)
5. What research is being done to investigate the mental and physical changes caused by medications in women?
6. Manufacturing of women-specific ARVs to help address side effects that impact women more.

### What can we better understand?

1. Compare communities across the province (ASO services, interdisciplinary care, medical services, student doctor services, alternative health services, points of access, technology)
2. iMeasuring, evaluating and better understanding side effects of ARVs across gender, age and ethnic groups (including those that are not understood or recognized currently)
3. What (if any) is the correlation of ART and increased/ decreased libido?
4. What changes have physicians and providers observed with HIV poz people over time?
5. What is the awareness of health physicians around HIV and mental/emotional health?
6. Is there research being done with older woman and peri-menopausal and menopausal? Are there any changes in CD4 or viral load or other body systems?
7. If we know that certain HIV meds cause co-morbidities such as diabetes/HIV/CVD, would PrEP or proactive medications be effective in preventing these co-morbidities?

### Impact

1. Improved self esteem
2. Less stigma
3. More enjoyment outside the AIDS aquarium
4. Reduction of medication on the body
5. Less side effects (tolerable)
6. Effective pain management
7. Adherence to health plan
8. Informed treatment decisions from both sides

### Nuances of PHA Experience

1. The complexity of our issues cannot be covered in the 10-minute doctor's visit so interconnected problems are not caught earlier.
2. Problem of clinic-based practices: different doctor each time and lack of continuity.
3. Debilitation (physical and neurological problems), which will never improve, due to toxicity of earlier generation of drugs (often dismissed or knowledge doesn't exist with health care providers)
4. A history of substance use shouldn't be used as a reason to block certain classes of prescriptions from PHA (i.e. benzodiazepines)
5. Adherence - Work with supports to create a toolkit. Create organic support communities
6. More openness/inclusion of differing points of view around HIV treatment strategies
7. Admit they do not know instead of throwing stuff at us to keep us quiet and the line moving
8. Invisible symptoms but real pain



**I confront daily disabilities and handicaps due to HIV+ antiretroviral meds that have ravaged my body.**

**We are more than medicated people – this snowballs to so many social determinants of health.**

**My counts are good and liver is normal but ALWAYS TIRED. Very important to not just tell me numbers are okay because something isn't right!**

**Non-conformity to certain prescribed methods does not mean quackery/ stupidity – and poz people should not be shamed for their views.**



## HOLISTIC & COMPLEMENTARY CARE

Knowledge, evidence, comparative impact, interaction of alternative therapies; integrated holistic care (body, mind, spirit)

### Considerations

1. Create spaces where alternative/natural forms of HIV treatment can be shared and explored without stigma, shaming, judgment (with healthcare providers and community)
2. HIV treatment is critical AND who supports my broader health and wellness when I need it

### What can we better understand?

1. Conduct an environmental scan of current programs that provide access to rehabilitation services and support in the non-profit and public health sectors
2. Measure the benefits of naturopathic/alternative treatments in improving overall health, complications of living with HIV and side effects of HIV treatments
3. How does access and cost factor into impact?
4. Evidence-based information about when/how alternate therapies co-affect medications

### Impact

1. Better integration of sexual health including harm reduction
2. Better health outcomes for those living with HIV
3. Information that clarifies and gets rid of confusing conclusions about benefits of alternative therapies
4. If conclusions led to evidence showing better outcomes, there could be interventions created that would increase access of HIV+ people to alternative therapies
5. Government funded program to support proven holistic therapeutic health approach/option including nutritional component

### Nuances of PHA Experience

1. We are looking at our ailments and wondering: is this happening because of my HIV or because of the HIV drugs I take or because of aging? Or is there something else going on for me?
2. Wanting to make 'whole person health' a financial priority
3. Being more able to maintain a balanced life and good self-care
4. Helping to build the capacity of PHAs to understand the healing potential of our brains/mechanisms

5. Creating a space within medical/treatment spaces where I can explore and safely discuss with my healthcare provider alternative/natural forms of treatment
6. Self and supportive care – nutrition/diet, exercise, HIV rehabilitation network, writing, art therapy, etc
7. Convincing the MOHLTC that alternative therapies can save money when balanced against ODB savings



**Researchers have a tendency to compartmentalize our health (into such things as CD4 count, viral load etc.) without looking at us as holistic human beings.**

**My physical health depresses me because I feel like every facet of my life is tied to my weight gain.**







## POVERTY

**Accreditation, employment, retention & transition spectrum; identifying and understanding impact on holistic health**

### Considerations

1. Poverty impacts EVERYTHING!
2. HIV has physical and mental impacts that affect the ability to earn while also requiring additional expenses (particularly medication costs and deductibles which impact housing, nutrition, isolation, etc.)
3. Need higher ODSP/ CPP/OW rates and greater flexibility during transitions with ODSP/ CPP/OW
4. Documented graduation of OAN or other acknowledged training programs for PHA
5. Support to move from volunteerism to employment if desired
6. Uncertainty with employment (core funded permanent vs contract positions)

### What can we better understand?

1. Demonstrating cost/benefit for health care, social services and justice systems
2. Greater understanding of episodic disabilities and impact on financial stability
3. How provision of universally accessible HIV medications might impact who goes onto ODSP (often motivated by access to medication) and a cost analysis of this
4. What is the economic viability to provide more affordable/safe housing and its impact on mental health, income, adherence to medication?

### Impact

1. Validation of experience, accountabilities, sequences
2. Greater involvement and meaningful engagement
3. Increased accommodations for learning
4. Streamlining overlapping = shared funding (positively)
5. Accessibility to job postings and to both part-time and full-time jobs
6. Transferable skills
7. Living with dignity

### Nuances of PHA Experience

1. Accommodation needs (sick time, medical appointments, episodic)
2. Income vs medication - How many had to go on disability or can't go back to work to be able to afford their medication?
3. HIV can complicate other costly health needs such as dental and vision care
4. Intersection of HIV and poverty/financial insecurity has significant and complicated impact on HIV and overall health
5. Evidence and choice to access supplements (vitamins and probiotics are not covered)
6. ODSP keeps us in a cycle of poverty – demanding that we be destitute before we can access help means positive people will never escape the cycle of poverty. Making more money means that you can/will be thrown out of ODSP and made to pay for expensive meds which in turn makes the money you earn obsolete
7. Training/education programs needed but also recognize training fatigue (same messages, overlapping 'name game' of programming)

“

**I want to be able to reach for those high paying jobs.**

”



## CRIMINALIZATION

Identify and evaluate impact on treatment cascade

### Considerations

1. The social context of criminalization impacts overall health and wellness for PHAs.
2. Honesty with doctors means potential vulnerability to criminalization and judgment.
3. Increases stigma and reduces likelihood for people to take steps to improve their health.
4. Removes responsibility from HIV- individuals to protect themselves and take responsibility for their decisions.

### What can we better understand?

1. Does criminalization impact/change behaviour?
2. Does criminalization impact/increase disclosure?
3. Does criminalization make the world a safer place?
4. How does criminalization for non-disclosure impact people's decisions to get tested for HIV and their access to care/treatment?

### Impact

1. Decrease shame/blame
2. Increase self-responsibility for own sex acts
3. Increase of knowledge related to magnetic couples (sero-divergent)
4. Increase willingness to test, access care and remain on treatment
5. Respect for the accused PHA's privacy
6. Fair treatment of PHAs

### Nuances of PHA Experience

1. Prevention for HIV criminalization (sexual relations)
  - Discovering the sexual side of non-disclosure
2. How do I inform my doctor of my sexual health decision process using language that protects me from court subpoenas?
3. Changing the law to ensure responsibility for protection rests on all parties and not just PHA

“

I feel scared of further isolation and rejection, so I am very selective about disclosure.

I have to “edit” my conversations according to whom I am speaking, which causes more stress and emotional exhaustion.

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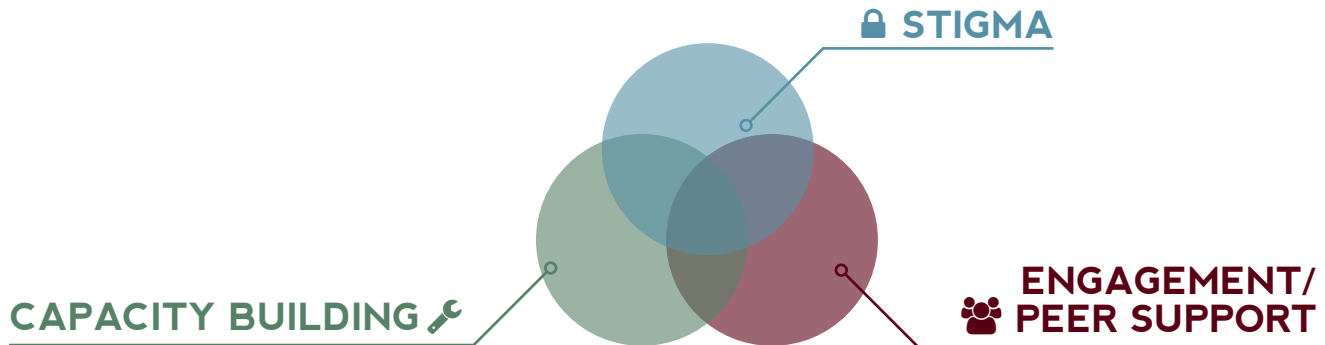


“ Health care,  
*not sick care.* ”

# KEY themes



There were three themes that were relevant and discussed across many or all of the identified priorities.



## Capacity Building

There was overarching emphasis and recognition that building individual capacity increases a sense of self-worth and well-being and improves overall health. Participants also discussed broadly and passionately that capacity building is a significant contributing factor to employment.

For some, employment was clearly an end goal impacting financial stability, health, wellbeing and sense of worth. For others, capacity building was important from the perspective of developing broader transferable skills (with no current, specific employment goal), reducing social isolation as well as personal growth and development.

Research can assist in communicating how capacity building impacts community health and HIV transmission using appropriate and evidence informed messages.

## Stigma

Stigma has a powerful and sometimes debilitating effect on those of us living with HIV and our communities. It is something that PHAs must engage in everyday including internalized stigma.

Discussions highlighted the vast range of stigma and experiences. Generally, participants focused on three areas: stigma experienced from health care providers; self-stigma (internalized HIV negativity); and stigma related to another part of our individual identity, which is compounded by HIV (including shaming of sexual preferences and behaviours).

Internalized HIV negativity was a somewhat new term that identified and consolidated very powerfully, the issues and impact of self-stigma such as:

- Assuming rejection before it happens
- Affecting relationships in many ways (including but not limited to sero-divergent)
- Feeling solely responsible for preventing physical transmission
- Recognition that it gets worse in isolation
- Real or perceived judgment
- Feeling defeated and 'dirty'.

Important responses and actions to address stigma were identified including creating anti-stigma campaigns that include increased peer engagement and positive PHA profiles as well as research on stigma.

“

**Don't settle for less than I'm worth.**

**Only have family doctor and does not know my status – unable to disclose – small town stigma.**

**I am alone and have difficulty finding gay men who understand HIV and want to know me better or have a relationship.**

”

## Engagement/Peer Support 🐾

Not surprisingly, GIPA/MEPA was an overarching theme in the identified priorities and seen as critical to overall health and wellbeing for PHAs.

Participants noted that GIPA/MEPA might look different for diverse communities and lived experiences (including the exploration of defining peer engagement for IDU communities separate from HIV status) as well as the complicated role of boundaries and support required for PHAs engaged in work as an employed health care provider.

There were also very honest and emotional conversations about self-care and boundaries in the context of being able and supported to take a break and say no to requests – particularly when there was a sense of no one else being available to step in.

Comments and highlights of the importance of PHA engagement included the following:

- a. Feelings of being capable, acknowledged, respected, validated, having self-worth
- b. Gives knowledge, meaning and hope
- c. Eliminates barriers – open lines of communication – eliminate ‘othering’ (them vs us)
- d. Recognition of Ontario Accord – Walk the talk!
- e. Express our Passion!
- f. Bonding and sharing our stories and compassion
- g. Breakdown the misconception of disability
- h. Eliminate stigma
- i. Personal growth
- j. Efficient use of resources
- k. Erase the gap between PHA and caregiver
- l. Accountability, trust and commitment

“

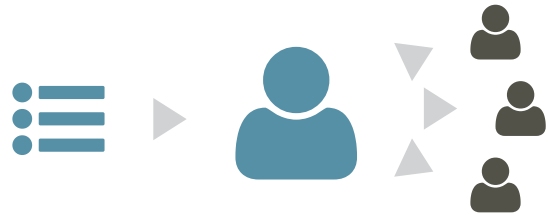
**I want to be a community member.  
I don't want a stack of certificates.**

**We feel used, abused and used up  
beyond burnout.**

**As a professional, I can get disconnected.  
We need to eliminate the ‘othering’ of  
PHA workers.**

”

Two possible actions emerging from the discussions included the need to:



### Develop ‘guidelines’ for the most effective use of peer support.

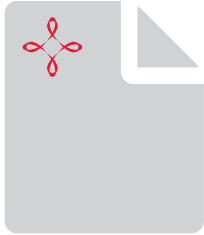
Guidelines for peer engagement would include defining the terms/expectations, setting parameters, creating transparent measures, developing policy documents and providing training. Participants agreed that provincial guidelines would contribute to support, commitment and accountability for ASOs and other community organizations engaging in peer programs and GIPA/MIPA activities.



### Conduct a needs assessment on a formal Peer Navigator/Advocate role in Ontario.

One model for Peer Navigator programming exists in Vancouver and a few ASOs in Ontario have programs, but they exist in isolation and all are different. Participants found the potential for a Peer Navigator program to link PHAs to various systems of care and increase retention in care exciting. They noted that it would be important to review how peer navigator programs create a sense of expertise and authority required in the role thus eliminating the risk of the role being looked down upon as ‘just a PHA’.

## NEXT steps



The priorities identified during the PHA-led consultation are being used to inform the OHTN's new strategic plan and to guide research calls and agency priorities. They will also be shared with the OHTN Applied Research Chairs to inform their research programs.



The OHTN also plans to consult more widely with people living with HIV in Ontario who were not able to attend the meeting so we can understand the issues and priorities more clearly and expand them if necessary.



**Note:** We know that issues related specifically to gay men, gay men's sexual health and recreational drug use have been raised in other PHA discussions but they did not arise as specific, separate priorities through this event. It will be important to ensure these and other existing and emerging priorities continue to be effectively explored, understood and addressed.

# conclusion



Participants were incredibly appreciative of the opportunity to have a separate, specific targeted opportunity as PHAs to share lived experience and contribute to PHA research priorities. There needs to be an ongoing, evolving and meaningful opportunity for PHAs to fully engage with research and to have this voice and impact.

They shared inspiring, intimate and incredibly powerful stories throughout the priority setting process. The focus on identifying what further research and exploration could improve overall PHA health and wellbeing resulted in passionate stories of frustrations and challenges but also of resilience, engagement, care and support. Below are a few of their personal desires, commitments, stories and reflections:



# appendices



## APPENDIX A: MEETING AGENDA

### OHTN PHA Research Priority Setting Meeting

*Facilitators: Darien Taylor & Murray Jose-Boerbridge*

8:30-9:00 AM	BREAKFAST
9:00-10:15 AM	Welcome – Introductions, Goals & Objectives Darien Taylor & Murray Jose-Boerbridge
10:15-10:35 AM	Overview of Research Needs & Gaps: Clinical Colin Kovacs
10:35 - 10:50 AM	BREAK
10:50 - 11:10 AM	Overview of Research Needs & Gaps: Epidemiology Mark Gilbert
11:10 - 11:30 AM	Overview of Research Needs & Gaps: Social Science & Health Services/Systems Sean Rourke
11:30 AM – 12:15 PM	Identifying PHA Research Priorities Facilitated Discussion
12:15-1:00 PM	LUNCH
1:00 – 1:15 PM	Personal PHA Research Perspective Lynne Cioppa
1:15 – 2:00 PM	Discussing the PHA Perspective Facilitated Discussion
2:00 – 2:15 PM	Personal PHA Research Perspective James Watson
2:15- 2:30 PM	BREAK
2:30 – 3:00 PM	Identifying Impact Facilitated Discussion
3:00 – 3:15 PM	Personal PHA Research Perspective Francisco Ibanez Carrasco
3:15 – 3:45 PM	Ranking PHA Research Priorities Electronic Voting Machines
3:45 - 4:30 PM	Final Discussion Darien Taylor & Murray Jose-Boerbridge

## APPENDIX B: WORKSHEET EXERCISES

### **EXERCISE #1 – Personal & Group Table Exercise**

WHAT WOULD YOU LIKE TO SEE MORE FULLY EXPLORED THROUGH RESEARCH IN THE CONTEXT OF BETTER HEALTH AND WELLBEING?

What are three things that, if changed, would most improve your health and wellbeing as a person with HIV?

Think about the whole person including:

- Self-worth
- Connection with others
- Medical/clinical care and health
- Complementary and other community/health services
- Contribution towards self and others (volunteering, employment, etc.)
- Desires, goals, dreams

### **EXERCISE #2 – Table Exercise**

WHAT IS IT ABOUT THE PHA PERSPECTIVE THAT YOU WANT TO HELP OTHERS BETTER UNDERSTAND RELATED TO YOUR HEALTH AND WELLBEING?

What are three things that would improve PHA's health and wellbeing?

What are some considerations on this topic that are specific to the PHA experience?

### **EXERCISE #3 – Table Exercise**

WHAT IMPACTS/CHANGES WOULD YOU EXPECT IF RESEARCH SUCCESSFULLY LED TO IMPROVED UNDERSTANDING, SUPPORT AND/OR RESOURCES FOR THIS TOPIC?

What order should these issues be worked on in the next 5-8 years?

Any other considerations or opportunities (i.e. another region or country has just completed some work on this topic or a new funding call is expected that might apply to this topic)?

## APPENDIX C: MEETING FACILITATORS

### **Darien Taylor**

With over twenty years of service, Darien Taylor has a rich history with the HIV movement in Canada and is well-known among its members for embodying wisdom, compassion, reliability and persuasiveness. As one of the first Canadian women to openly acknowledge her HIV status, she has been an outspoken advocate on women's issues, as well as a formidable treatment activist and educator. Darien has played a key role in improving policies and care for people living with HIV, in both community agencies and as an internal advocate within government, having worked for the AIDS Bureau, the AIDS Community Action Program and the AIDS Committee of Toronto, as well as having served on the board of the Toronto People with AIDS Foundation.

### **Murray Jose-Boerbridge**

As an HIV positive man for over 23 yrs, Murray is passionate about his work within the HIV community and opportunities for CBR to contribute to exciting and powerful impacts on the lives of PHAs. Murray has worked with four AIDS Service Organizations in Ontario including his current position as Executive Director with PWA as well as being a Founding Co-Chair of the Ontario HIV Treatment Network. Murray's direct participation in CBR has included Co-Investigator roles with studies including: Employment Change & Health Outcomes (ECHO); Impact of Food Security on Health Outcomes in PHAs Across Canada; and HIV Non-Disclosure and the Criminal Law: Establishing Policy Options for Ontario. In recent years, Murray has begun providing private facilitation and consulting support in the HIV and health communities which has provided further rewarding experiences to contribute, grow and support.

### **Table Facilitators:**

Kevin Borden, Joseph Babcock, Andre Ceranto, Jasmine Cotnam, Marisol Desbiens, Tara Jewal, Marvelous Muchenje, Martin McIntosh, Chris White, Bridget Young

