Developing a National Action Plan to Advance the Sexual and Reproductive Health and Rights of Women Living with HIV in Canada

Summary of the CAHR 2018 Ancillary Event Discussion
27th Canadian Association for HIV Research (CAHR) Conference 2018

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November 7, 2018

Executive Summary

The collaborating partners for the *Canadian Webinar Series on Implementing the WHO Guideline on Sexual and Reproductive Health and Rights of Women Living with HIV* hosted an ancillary event at the 2018 Canadian Association for HIV Research (CAHR) conference: *Developing a National Action Plan to Advance the Sexual and Reproductive Health and Rights of Women Living with HIV.* This event brought together nearly 100 policy-makers, community workers, social workers, clinicians, students, and researchers from across Canada to discuss policy, programming, and research considerations that will lay the foundation for a national action plan to advance the sexual and reproductive health and rights (SRHR) of women living with HIV (WLWH).

Outlined below are **summaries**, **key messages**, and **detailed discussion notes** from each of the four discussion topics: (1) Trauma- and Violence-Aware Care/Practice; (2) Supporting Safer HIV Disclosure; (3) Reproductive Health, Rights, and Justice; and (4) Resilience, Self-efficacy, and Peer Support. The circulation of these discussion notes is part of an ongoing process of soliciting feedback from a wide community of stakeholders. Input and insights offered will inform the development of a national action plan to support, enhance, and strengthen the sexual and reproductive health and rights of women living with HIV. **We welcome you to join the conversation by offering your recommendations on key priorities, gaps, and next steps!**

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Links to recorded webinars and other webinar resources can be found at:
http://www.chiwos.ca/webinars/
Please see Appendix C for additional webinar information.

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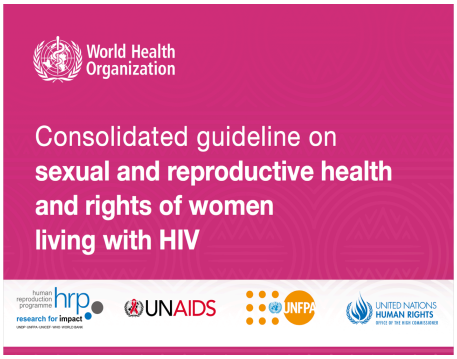
The Canadian Webinar Series on Implementing the WHO Guidelines on Sexual and Reproductive Health and Rights for Women Living with HIV: An Overview

Purpose

This document presents a summary of the small group discussions facilitated at the 2018 Canadian Association for HIV Research conference (CAHR) ancillary event: *Developing a National Action Plan to Advance the Sexual and Reproductive Health and Rights of Women Living with HIV.* Outlined below are **summaries**, **key messages**, and **detailed discussion notes** from each of the four discussion topics: (1) Trauma- and Violence-Aware Practice; (2) Supporting Safer HIV Disclosure; (3) Reproductive Health, Rights, and Justice; and (4) Resilience, Self-efficacy, and Peer Support.

Background

In February 2017, the World Health Organization (WHO) released the *Global consolidated guideline on sexual and reproductive health and rights of women living with HIV*[1]. The values and perspectives of women living with HIV (WLWH) were centered in the development of these global guidelines, which place women, gender equality, and human rights at the forefront of the evidence-based recommendations and best practices that the guideline describes.



As a response to this guideline, the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) partnered with five leading women and HIV organizations in Canada, including the Canadian Aboriginal AIDS Network (CAAN), Women's Health in Women's Hands Community Health Centre, the Canadian Positive People's Network (CPPN), the Oak Tree Clinic at BC Women's Hospital, the WHO Department of Reproductive Health and Research and Implementing Best Practices (IBP) Initiative, to develop and host a multi-phase **Canadian webinar series on the sexual and reproductive health and rights of women living with HIV**[2]. The series brings together the voices and perspectives of WLWH,

[1]The Consolidated Guideline can be viewed at: http://apps.who.int/iris/bitstream/handle/10665/254885/9789241549998-eng.pdf;jsessionid=7104DCEC2BC20D1F9762561790BD680B?sequence=1

[2] Webinar recordings and materials can be accessed at: http://www.chiwos.ca/webinars/?doing_wp_cron=1537195392.3729050159454345703125&lang=en

front-line community workers, researchers, clinicians, and policy makers to share key considerations and to identify gaps in research and service.

To date, the webinar series has hosted four webinars: i.) Trauma- and Violence-Aware Care/Practice; ii.) Supporting Safer HIV Disclosure; iii.) Reproductive Health, Rights, and Justice; and iv.) Resilience, Self-efficacy, and Peer Support. The webinars, which are based upon key WHO recommendations relevant to the Canadian context, highlight the needs, perspectives, and priorities of WLWH.

Objectives of the Canadian Webinar Series were to:

i. Share WHO recommendations and best practices;
ii. Define constraining and enabling environments shaping Canadian WLWH's SRHR;
iii. Outline work being done in Canada and disseminate Canadian research and best practices;
iv. Showcase the importance of community-academic partnerships and meaningful involvement of WLWH

Building on the successful delivery of four interactive webinars, the collaborating partners for the *Canadian Webinar Series* hosted an in-person ancillary event at the 2018 Canadian Association for HIV Research (CAHR) conference, which brought together key stakeholders to discuss policy, programming, and research considerations and outcomes towards laying the foundation of a national action plan to advance the sexual and reproductive health and rights (SRHR) of WLWH in Canada.

Figure 1. Elder Valerie Nicholson welcomes participants the CAHR 2018 ancillary event: Developing a National Action Plan to Advance the SRHR of WLWH and recognizes unceded territories on which participants

Approximately 100 people attended the event, with over 70 participating in small-group discussions. Represented among attendees were WLWH, clinicians, service providers, researchers, policy-makers, community advocates, and funders.

Objectives of the Ancillary event were to:

i. Learn from WLWH, as they share their lived experience and priorities regarding sexual and reproductive health and rights;
ii. Discuss connections between research and policy/programming initiatives in Canada related to the sexual and reproductive health and rights of WLWH;
iii. Engage in inter-sectoral World Café Style discussions regarding key action items to advance the sexual and reproductive health and rights of WLWH in Canada;
iv. Strategize next steps and key considerations in the development of a national action plan to advance the SRHR of WLWH.

This document summarizes the themes, recommendations, and opportunities identified during facilitated, small group discussions on the four webinar topics:

i. Trauma- and Violence-Aware Care/Practice;
ii. Supporting Safer Disclosure;
iii. Reproductive Health, Rights, and Justice;
iv. Resilience, Self-efficacy, and Peer Support.

Each group was asked to discuss opportunities and challenges to addressing the particular topic, and to provide key messages to be relayed in the national action plan. Through the course of these discussions, **several key themes were identified as important across all four discussion groups.**

In addition, each small discussion group identified key messages that were specific to their discussion topic. These key messages are outlined below by webinar topic, alongside brief discussion summaries and detailed discussion notes.

Figure 2. Dr. Manjulaa Narasimhan, World Health Organization, provides overview of Consolidated Guideline

Key Themes Across All Discussion Groups:

i. WLWH must be involved throughout the process of developing a national action plan
ii. Efforts of inclusion must attend to the diversity of women's individual needs, experiences, and identities, and meet women where they are at
iii. Additional support and attention are needed for the extended network of WLWH, including:
    a. Supporting mothers living with HIV as parents
    b. Supporting children with parents living with HIV
iv. Efforts must critically consider the language and terminologies (both formal and informal) used to discuss sexual and reproductive health and rights of women living with HIV, ensuring use of careful, intentional, and non-stigmatizing language:
    a. Failing to do so risks (re)producing language and guidance that is limiting, universalizing, and or otherwise insufficiently inclusive of the diversity of women's experience
v. Work must be grounded within an anti-oppressive framework[3], including acknowledgement of systemic, institutional, and lateral violence[4]
vi. Critical need for improved Knowledge Translation & Exchange (KTE) initiatives:
    a. All stakeholders require access to up-to-date information to enable the autonomy, choice, and informed decision-making of WLWH
    b. WLWH deserve to know their rights and the resources and supports available to them
    c. Need to identify key messages that can be utilized for diverse audiences and through diverse mediums
    d. KTE efforts must be adaptive and responsive to the needs of target audiences

Next Steps

The participation and engagement at this ancillary event demonstrated strong enthusiasm and commitment of stakeholders to developing a National Action Plan on Sexual and Reproductive Health and Rights of Women Living with HIV. Key priorities and recommendations identified during the webinars, this event, and subsequent discussions will be used to inform the development of a national action plan to support, enhance, and strengthen the rights and health of women living with HIV.

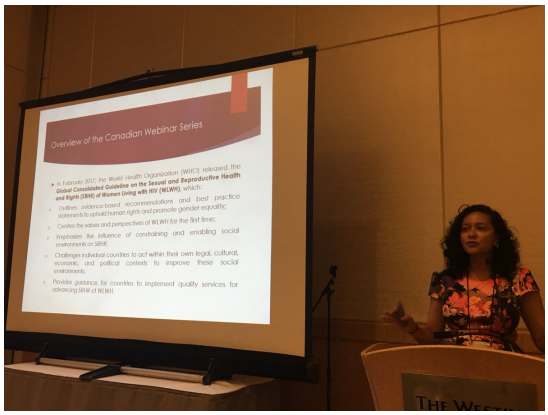


Figure 3.Dr. Angela Kaida, Simon Fraser University, presents an overview of the Canadian Webinar Series

[3] We define anti-oppressive framework as an approach that actively challenges the systems of oppression in which we operate and critically analyzes our own roles within these systems.
[4]Lateral violence can be defined as violence against one's peers rather than one's adversaries, which results from and is rooted in systemic cycles of abuse and oppression trauma, racism, and discrimination. This definition of lateral violence is described in more detail in the following report, released by The Native Women's Coalition of Canada: https://www.nwac.ca/wp-content/uploads/2015/05/2011-Aboriginal-Lateral-Violence.pdf

1. Additional questions informed by these discussions will be circulated to a broader community of stakeholders via a Google Form in order to gather diverse feedback and input into the development of the national action plan.

2. The collaborating partners for the *Canadian Webinar Series* will pursue two additional webinars based off of topics identified from webinar participants and community priorities. Suggested webinar topics include: sexual satisfaction, pleasure, and intimacy; HIV and aging; and an exploration of what 'undetectable equals untransmittable' means for WLWH.

3. Key priorities and recommendations identified within the webinars and through in-person and online discussions will be used to inform the development of a national action plan to support, enhance, and strengthen the rights and health of women living with HIV.

4. Consistent with global priorities identified and explored at the Sexual and Reproductive Health and Rights Pre-conference for *AIDS 2018,* the national action plan will support integrated and innovative approaches to supporting SRHR of WLWH and catalyze multi-level action to advance SRHR. The SRHR Pre-conference offers a unique opportunity to develop a national action plan which integrates pressing global priorities into a Canadian response and to demonstrate global leadership in support of SRHR of WLWH. [5]

5. Utilize additional opportunities to share our development process and gather feedback on the national action plan, including *Women Deliver* 2019, which will be held in Vancouver, BC in June 2019.

Summaries, key messages, and detailed notes from discussions facilitated at the 2018 CAHR ancillary event are outlined below. These discussions will provide a framework for the developing national action plan, and we welcome your feedback and insight into key priorities, gaps, and next steps.

[5] The Sexual and Reproductive Health and Rights Pre-Conference agenda and roadmap can be viewed at: https://www.ippf.org/static/docs/preconference/SRHR_2018-Pre-Conference-Roadmap-FINAL.pdf

Discussion Group:

Trauma- and Violence-Aware Care/Practice

Co-leads: Valerie Nicholson (Simon Fraser University, Canadian Aboriginal AIDS Network, Positive Living BC), Dr. Neora Pick (Oak Tree Clinic, University of British Columbia), and Jay MacGillivray (Positive Pregnancy Program)

Participants: n=24

Summary of Discussion

Several key themes emerged from the discussions among the Trauma- and Violence- Aware Care/Practice group which will inform a national action plan to advance the sexual and reproductive health and rights of WLWH. The group defined "trauma- and violence-aware care/practice" (TVAC/P) as a strengths-based framework that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment.

First and foremost, a key theme was that **language matters, and is a reflection of attitude**. The use of the term "trauma-aware" instead of "trauma-informed" suggests humility in that a care provider is not an expert in trauma or one person's trauma, but can still practice such care. The term "trauma- and violence-aware practice" (TVAP) is recommended because "care" denotes that the care provider holds power and may be considered patronizing. When delivering TVAP, it is essential to unpack and critically assess the language that we use.

Next, TVAP can be practiced by all and in every interaction. It can be achieved by being kind, genuine and open; and by listening, and showing care and humanity. Care providers can provide TVAP by demonstrating self-reflexivity and humility (clinical, personal, cultural humility). Care must be approached by understanding women's unique experiences of trauma, and applying individualized responses instead of universal ones. Rather than interventions, women want tools, information, and support. Ultimately, women should lead; their agency and power should be prioritized and their decisions respected.

TVAP must be supported through policy that is integrated at all levels, including the medical system, legal system, and social services. Within the medical system, this can be done by integrating TVAP into medical school training, improving continuity of care, providing woman-centred care, and transforming the medical system structure to allow physicians to

spend more time with their patients. TVAP within the legal system would adequately support women, women's freedom from violence, and women as parents (i.e. every effort should be made to keep children with their mothers). Finally, service providers must work in collaboration and leverage opportunities to communicate information to improve the continuum of care and provide TVAP across settings.

Key Messages to be relayed in National Action Plan:

i. Language is important, as it shapes and reflects implicit bias and judgment
ii. Families must be kept together: Women often separated from their children. Every effort should be made to support women as parents, and this should be reflected in policy.
iii. Must be able to reinforce/encourage trauma-aware practice through policy
    a. Ex. Funding dependent on providing trauma-aware care
iv. Trauma-aware practice requires clinical humility, personal humility, cultural humility, kindness, genuineness, and taking/making the time
v. Improved continuity of care important
vi. Provision of woman-centered care
vii. Recognize that providers may have, themselves, experienced trauma; may experience re-traumatization and vicarious trauma through practice
viii. Trauma- and Violence-Aware Practice must be integrated into medical school training
ix. Trauma- and Violence-Aware Practice depends on equity in care; provided without judgment or discrimination

Detailed Discussion Notes

Key priorities for national action plan:

- Need to better address the needs of im/migrant populations through improved continuity of care, leverage opportunities to communicate information regarding continuum of care
    - Example provided: trauma-aware practice for migrating and refugee women in the European Union provides more seamless care and allows care to be provided across spheres and settings
- Service providers must be working in collaboration; need for greater integration both horizontally and vertically

Unpack and critically assess language:

- Language is a reflection of attitude
- Trauma-aware *practice* rather than *care* because the term 'care' is patronizing.

> *It's about power: Who has it, who doesn't have it, and how to change that. Having the cultural humility to acknowledge the way I've been trained likely may or may not work with the person sitting in front of me.*

- Language simplifies, fails to capture difference and diversity in experience.
- Trauma-aware or trauma-informed? A provider is not 'informed' after one training. Trauma-*aware* practice must be integrated at all levels and in meaningful ways. For this, education is essential.
- Awareness of and sensitivity to the words used is important:
  - Ex: triggers on the street are guns. The term "activators" shows greater sensitivity to the context and better captures the process
- Practice cultural humility:
  - be aware of demographics of practice, personal, and professional commitment to Indigenous cultural awareness
  - know the geopolitical and gendered realities of patient caseload
  - apply awareness of social determinants of health to practice and to system racism

> *I did not want 'trauma informed care', I wanted support. I didn't want 'interventions', I wanted tools and information.*

<u>Define trauma-aware practice:</u>

- "Trauma-Aware": 'awareness' needs to be defined. **It is necessary to go beyond awareness to *understanding* the lived experience of trauma.**
  - "From an Indigenous woman's perspective, all our lives we have been living in trauma, so it is normal. I didn't want to tell the nurse because I didn't want to scare her. The provider could not handle it. Those of us who have had the privilege to not have this experience, really go and try to educate yourself: *What is it like to go to sleep listening to someone else getting beat?"*
  - Important to approach each woman with an **understanding of her particular experience**

- Approaches used should not be universal, but rather individualized: providers must have the humility to be wrong, to want to learn. Asking questions is fundamental.
- This is achieved by ***being kind, genuine and open, listening, showing care and humanity.***
  - Providers to practice and demonstrate self-reflexivity
  - "Approach with humanity. When I see my family doctor, I feel love. She's not there to provide love, but that is what I feel. My old doctor wouldn't even look me in the eye… So basic humanity goes far. "
  - Important to bring kindness to work: "recognize the anger and amp up the love, amp up the kindness, recognize that there is trauma there"
  - Trauma-aware practice is about providing a service, space, environment. Women already know everything they need to heal, and I (the service provider) can walk behind, beside, or wherever they are.

Figure 4. Jay MacGillivray (left), Positive Pregnancy Programme and Mina Kazemi (right) Women's College Hospital facilitate small group discussion.

- Hire people with lived experience, but how do we then support those workers? Must address the need to support women and the providers.
- Support for healthcare provider important as they themselves may have experienced trauma and can be re-traumatized through their work.
- Care that is not truly trauma-aware has the potential to re-traumatize
- Trauma-aware practice must be supported through policy.
  - Ex. In the U.S. funding is dependent upon offering trauma-informed programming. This must be implemented in Canada as well.
- Trauma- and violence-aware practice should be incorporated into all areas of care - not just HIV care – and to all trainings (eg. Training for nurses, doctors, nurse-practitioners, midwives, dentists, massage therapists, and any other professional whose practice could be enhanced by TVAC)
- medical school, residency, and other professional trainings.

- Choice and empowerment are important: Women should lead, their agency and power should be supported, their decisions respected. Choices and safety are created by cultivated self-determination and agency. This keeps the relationship between women and care providers intact.
- Women are experts and should be equal partners in decisions regarding their health; providers be aware of power dynamics inherent to the medical system that reproduce power imbalances between providers and women

Service providers must work to support women's power

- The legal system does not adequately support women, or women's freedom from violence. Support for women as parents is essential, and at all levels policy should protect this.
- Physicians also need *time* to spend with women, yet this is not widely supported by the structure of the medical system (elaborate why for people who may not know – ie. Because physicians are expected to see a certain number of patients a day, otherwise they don't get paid).

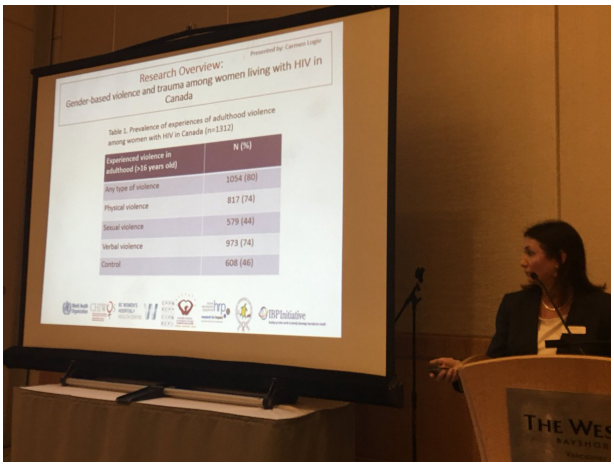


Figure 5. Dr. Neora Pick, Oak Tree Clinic, provides an overview of Trauma and Violence Aware Care webinar

Discussion Group:

Supporting Safer HIV Disclosure

Co-leads: Jasmine Cotnam (Women's College Hospital, Canadian Aboriginal AIDS Network, Ontario HIV Treatment Network, CHIWOS) and Wangari Tharao (Women's Health in Women's Hands Community Health Centre)

Participants: n=15

Summary of Discussion

Several key themes emerged from the discussions of the Safer HIV Disclosure group, which could inform a national action plan to advance the sexual and reproductive health and rights of WLWH. Participants acknowledged that language is very important and that we must talk about '*safer*' disclosure rather than 'safe' disclosure, as disclosure cannot be guaranteed to be entirely safe. However, this is not to say that we cannot advocate and promote safer sociopolitical and legal environments that would support safer disclosure. As part of this, participants discussed the need to rethink the use of the word '**disclosure'**, which is heavily tied to the law and to the criminalization of non-disclosure.

Participants further underlined the importance of peer support as integral to promoting safer disclosure. The group discussed the need for organizations to meaningfully support WLWH who are in peer support roles through stable and equitable employment opportunities.

Culturally appropriate strategies were also identified as necessary to promoting safer disclosure among different communities of WLWH. Among Indigenous communities, it was expressed that there was a need to include Elders as peers to support WLWH. When discussing safer disclosure it was outlined that there is need to have Indigenous women's voices and experience at the forefront, given the legal climate of HIV non-disclosure and child welfare in this community.

A safer disclosure environment is not feasible if we do not address intersectional stigma – defined as the manifestation and lived experience of discrimination towards groups of people with multiple social identities. Safer disclosure must be supported through policy that is integrated at all levels including the medical, legal, and social services, as well as main

stream media. Disclosure doesn't solely impact an individual; but impacts entire families and communities.

Key Messages to be relayed in National Action Plan:

i. Integrate social networks and peer systems
ii. Structural changes are needed
iii. Support for peers who work with WLWH important
iv. Address stigma at all levels of society
    a. And target different places/levels with different, culturally appropriate strategies. Strategies must be adaptive and responsive.
v. Provide process for responding to current and emerging issues
    a. Templates for responding to media articles
    b. Strategies for advocating to broader society
vi. Language shift is essential:
    a. Change/rethink 'disclosure', as this term is closely tied to the legal system
vii. Support *all* people

Detailed Discussion Notes

- **Indigenous women's voices need to be heard and listened to rather than tokenized and excluded**

Identify opportunities:

- Ontario Toolkit: Women's Health in Women's Hands
    - Collectively developed, peer leadership
    - Organizations picking up this toolkit must include peers
    - Considers implications in family, social networks, etc.
    - Gives support to the person to make a plan/prepare to consider safety
    - Define safety: different for everyone
- Calgary Peer Group

Support safer disclosure for families:

- **Disclosure doesn't just impact the individual person, impacts the whole family.** How do we support children whose parents are living with HIV? How can we address the safety of children with parents living with HIV in towns with high HIV stigma?
    - Education within the school system important, although this misses other networks
    - Some youth say "I was just saying what I am, not who I am."
    - Women who do not have access to social supports may disclose to children for support. Need family-centered programs that reach these children and youth.
    - Children/youth may want to share but doing so discloses their parents' status

- Organizations can make space for youth to have someone to talk to
- Offer opportunities for youth to meet and share together

  - Some recommend not disclosing until child is old enough to understand the implications
  - Elders and grandmothers to be on the frontline to take the knowledge back

<u>Critically assess language and terminology:</u>

- Language matters: **"disclose" is a legal term; disclose is a sharing that can't be taken back; creates fear**

Figure 6. Wangari Tharao, Women's Health in Women's Hands, facilitates discussion

<u>Integrate support for safer disclosure across disciplines:</u>

- Advocacy groups, etc. involved in disclosure have heavy energy/defence response.
  - Should support women whether they choose to disclose or not (and make this clear to people who might need support)
- Contextual approach shifts the burden from women.
  - Need to reach communities "outside"
  - Geography comes into play as well – many toolkits developed within and for urban settings but cannot be implemented in rural setting because lack of resources, etc.
- Safer disclosure should be embedded in systems at various levels.
  - Ex: moving to new place and woman was made to sign documents saying she would disclose. This does *not* support safer disclosure
  - Systemic support for women to disclose when, how, and to whom

'Safer' disclosure rather than 'safe' disclosure recognizes that disclosure cannot ever be guaranteed to be entirely safe, yet conditions and environments to support safety are essential

Discussion Group:

Reproductive Health, Rights, and Justice

Co-leads: Margarite Sanchez (Viva Women, Southern Gulf Islands AIDS Society, CHIWOS), Dr. Deborah Money (University of British Columbia), and Dr. Angela Kaida (Simon Fraser University)

Participants: n=19

Summary of Discussion

Key messages in the Action Plan need to center and highlight the voices of WLWH, with a clear understanding of how allies can support an intersectional message to reach key decision makers in government, policy, and healthcare without losing the voices of women. Key messages need to be tailored to the different stakeholders at different 'levels' in order to educate and resonate with a diverse audience, use appropriate and inclusive language – and include solutions. Social media is a great way to reach various audiences, inform public decisions, and engage youth.

One immediate area for concentration is mandating comprehensive training for service providers (ie. Medical professionals and social workers), including: collaborative KTE events to push out the recently updated 2018 pregnancy planning guidelines for WLWH; increase reach of webinars by providing continuing medical education credits; address the 'soft skills' in healthcare, and disarm the privilege between healthcare providers and WLWH by using language that is not stigmatizing, shaming, or judgemental: instead teach healthcare providers to ask the individual what SRHR looks like for them, and listen to what they need.

Secondly, availability of care does not necessarily equate to accessibility to care. Women need access to care across their reproductive lifespan, including safe abortion, contraception, and prenatal care regardless of geographic areas, economic status, etc. Women and the general public need to have access to updated scientific information, which needs to be accurate, impactful, and actionable. Women must be informed about their reproductive rights – often, which is also seen in CHIWOS, there is a lack of information or women experience a gap in understanding their rights. Further, choices must be supported in a meaningful way – women must have the necessities required to act on those choices.

A peer model has been identified as useful, however the point was raised that we need to be conscientious about the load that we are expecting women and peers to take; where do allies come in to provide services? Peers need proper compensation and recognition for their work.

Women Deliver 2019 identified as a goal to disseminate a national action plan, through an opportunity to insert HIV into the meeting and mobilize local, national, global community.

<u>Key messages to be relayed in the National Action Plan</u>:

i. Community empowerment forums for WLWH are needed to support knowledge regarding their sexual and reproductive rights
ii. This work is inherently political. We need to engage at a political level, including involvement during elections
iii. Utilize CHIWOS data to build an evidence base and find ways of layering messaging for different audiences
iv. Women Deliver 2019 is an opportunity to disseminate messaging about reproductive health, rights, and justice among women living with HIV
v. Need to address gaps in access to contraception, including conversations about a national pharmacare plan
vi. Promote education: layer messaging in order to reach audiences beyond healthcare
    a. Offer solutions: access to abortion and contraception
    b. Advocate for national pharmacare
    c. Acting as an example at the local level
vii. Implementation of the pregnancy planning guidelines
viii. HIV across the lifespan
ix. Use social media: it's is free, available, and accessible

Detailed Discussion Notes

<u>Key priorities for national action plan:</u>

- Action plan must be built on the voices of women in Canada
    - We want to reach beyond WLWH without losing the voices of WLWH
        - Allyship essential
- Women must not feel like vectors of disease.
    - Example: U=U campaign
        - Should push for inclusion of **reproductive rights** in U=U
    - Spreading message that it is safe to have babies. Stigma against WLWH having children is still strong despite body of scientific evidence and campaigns
- Soft skills in healthcare shifted:
    - Feeling of authority/stigmatizing and shaming WLWH
    - Institutions allow/perpetuate
    - Know the individual: ask women what SRHR look like for *them*

- Disarm privilege among HCP and women W/O HIV
- No judgment, no assumptions, listen: what do you need

Opportunities:

- Pregnancy planning guideline: need widespread implementation through collaboration
- Informed care, including **access to *information* and care** (safe abortion, contraception, prenatal care) should be available and accessible across Canada
  - Access limited in rural and remote communities
- CHIWOS has wealth of information regarding what women want and need
  - Begin by targeting those issues that will be the easiest to tackle
  - Need to know what information we're missing with regard to women's unmet needs around HIV and pregnancy, planning, postpartum, breastfeeding
  - Address physical and emotional difficulty that can be associated with *not* breast feeding
  - WLWLH want and need to know transmission risk via breastfeeding; greater attention to this is needed in the context of U=U, including further research.
- Better and enforced training for medical professionals and social workers
  - Increase spread of webinars by providing CME credits
- In spreading messages all levels must be involved: women, community, care providers, fertility clinics, policy makers
- **Key messages:**
  - For women: U=U; knowing rights; access to most recent scientific info
  - Providers: safe and healthy pregnancy
  - Policy
  - Public: challenge stigma and discrimination
  - Information must be impactful and actionable
- Tailor message to different stakeholders in order to educate diverse audience: WLWH, public, providers, policy makers
    - Example: U=U in schools

Figure 7. Margarite Sanchez, CHIWOS and Rebecca Gormley, CHIWOS facilitate small group discussions

Disseminate key messages:

- Develop and disseminate 3 brief messages that are short, dramatic, and can be spread through multiple sources to reach politicians and other decision makers
    - Include solutions to be picked up by politicians (access to contraception, endorse new national pharma program)
    - Message must be co-written with WLWH
    - KTE that is versatile, memorable, and comprehensive

- Repeats facts
- Co-written with WLWH
- Broader social media presence
- Gendered presentation of U=U
- Opportunity to speak up with own thoughts, wishes, and desires
- Sex is important

  - All make a commitment to spread messages on social media; establish productive partnerships to help spread the message
    - Example: Yummie Mommy club has resources on how to use social media most effectively
  - Must pursue new avenues to reach young people
  - Need brief 1-pager directed at policy makers that includes personal stories

Figure 8. Facilitator, Muluba Habanyama introduces participants to small group discussion exercises

Women must be informed about their reproductive rights: "a voice and a choice"

  - Use peer model to provide info to women
  - Lack of information a barrier
  - Must know their rights and their choices
  - Choices must be supported in a meaningful way; must have the necessities required to act on those choices

- **Be political and intersectional**
  - Involve MPs and decision-makers
  - Learn from other groups who have developed effective campaigns and have policy influence
  - Language: don't isolate women who can't become undetectable
  - Repercussions: need safety
- Women Deliver 2019 an important deadline by which we can develop and disseminate action plan
  - Insert HIV theme into meeting
  - Mobilize local, national, global community
  - Call for topics: women and HIV

Discussion Group:

Resilience, Self-efficacy, and Peer Support

Co-leads: Tracey Conway (Canadian Positive People Network, Women's College Research Institute), Brittany Cameron (PARN), Brenda Gagnier (Ontario HIV Treatment Network, CHIOWS), & Dr. Carmen Logie (University of Toronto)

Participants: n=13

Summary of Discussion

Several key themes emerged from initial discussions of how best to integrate and cultivate resilience, self-efficacy, and peer support within the development of a national action plan to advance the sexual and reproductive health and rights of WLWH.

Discussions underscored a need to revision, re-centre, and recommit to the meaningful engagement of WLWH, and the importance of having leadership from WLWH at *every stage* in the development of a national action plan. It was suggested that best practices be established for working with peers, which should explicitly address the need for sustainable, long-term employment that offers opportunities for upward mobility, education, and equal pay. Suggested directions for further training and education included leadership training, media training, and training in grant-writing. Further, participants outlined the importance of meeting women where they are in order to cultivate such opportunities for leadership and capacity-building.

As part of this discussion, key barriers to inclusion were identified (e.g. the need to more effectively reach young women and women who are geographically isolated). Participants highlighted gaps in policy and programming that currently impact WLWH. Particular attention was given to the closure of women-specific ASOs and the need for collective advocacy to re-instate women-specific programs and services. In addition, participants noted a need to strengthen community-academic partnerships by centering women's voices and offering opportunities for women to gain experience in academic writing and research – this commitment should be built into grant applications to ensure adequate resource allocation. Finally, participants recognized a need to build stronger allyships with supporters in order to cultivate greater understanding of women's experiences and a need to better

leverage KTE opportunities in order to ensure that up-to-date information is widely available.

Key messages to be relayed in the National Action Plan:

i. *Money matters!*
   a. Adequate compensation for peers is essential
   b. Funding for women-specific services is important
ii. Use of an intersectional lens and attention to gender imbalances
iii. Develop toolkit for working with women and in women's care
   a. To facilitate implementation
   b. To inform allies
iv. Leverage opportunities that already exist
   a. Example: CPPN is already funded, is free, is live and running. Utilize this to build the NAP
   b. Example: Turning to One Another and Positive Leadership Development Institute have made headway in establishing peer-leadership. This is something to build off of
   c. Example: Utilize established organizations to reach other communities
v. Raise awareness, recommit, revision, and re-centre MEWA
   a. Nothing about us without us
   b. Maintain involvement of WLWH in the process moving forward

Detailed Discussion Notes

Identify key opportunities:

- Closures of services for women (Voices and PWN) have left a gap
  - Women newly diagnose don't have the opportunity to connect due to these closures
  - Need greater advocacy to political groups to understand the importance and value of women-specific ASOs
- Need a *national* women's voice
  - Identify partnerships to promote women's issues, voices, and organizations supporting GIPA/MEWA principles
  - Women's caucus at regional and national level
  - At the local level, as well, must ensure that there's a platform for women; that women have a space and a platform at all levels

Figure 9. Tracey Conway, Canadian Positive People's Network, describes meaningful engagement of women living with HIV as a foundational principle of the webinar series.

- Women must be represented in a meaningful way
- **Intersectional approach must be foundational**
- *Document* key principles for doing women's work at all levels – local, provincial, national

Provide adequate compensation and opportunities for peers:

- **Equal pay for peers.** This particularly important because it is often women, people living with HIV, and the line of work is less paid
  - Establish best practices for working with peers and implementing peer programs
  - Currently little/no upward mobility for peer researchers. Projects are not sustainable or long-term. Offers only tenuous employment
    - Funding projects 'hand-to-mouth'

> *We need longer term, more sustainable employment for peers that offers upward mobility, opportunities for further education, and skill-building.*

  - Funding should be dependent upon equal pay for peers
    - Ex in funding applications can say honoraria will be provided but this is not enforced, there is no established minimum
  - Example: TTOA developed best practices for peers
- **Socioeconomic inequity prevents people's voices from being heard, prevents people from accessing services**
- Capacity-building and skills-building is essential to meaningful engagement
  - Through leadership training
  - Could be general and issue specific
  - Example: Media training, grant writing, self-management of HIV, disclosure
  - Meeting people where they are and involving them in a way that simultaneously increases their capacity
    - Example: CAHR scholarships priority given to WLWH w/ academic background? **Need opportunities for women to build this knowledge and experience!**
  - Mentorship and fair compensation for that mentorship important
  - Refresh, renew, revisit and recommit to GIPA/MEWA
    - **Meaningful representation, inclusion, engagement:** WLWH in positions of power, in decision-making positions
    - GIPA/MEWA not widely understood outside of 'us'

> *Women's voices are powerful, and this should be reinforced*

Key barriers:

- Voices of WLWH are seldom included in academic publications

- Give equal/greater importance to the voices of WLWH compared to researchers
- Offer experience in writing, research, publications
- Build this inclusion into funding

- Need for improved KTE: we have the research evidence, but how do we get it to the public?
  - **Women must have access to the most up-to-date information**
- Need for strengthened community-academic partnerships
- Work offered to peers is tenuous with little upward mobility
- Must provide full benefits equal to other employees. This gap is experienced not just for peer workers but for everyone working in the trauma field.
- **Current Gaps:**
- Geography: access to healthcare especially limited for those who are geographically isolated (including mental health supports, HIV care, substance use, etc.)
  - Peer mentorship more available in urban areas
    - How can we better engage WLWH who are living in more remote communities?
- Age: young women often treated differently, not engaged.
  - young women excluded from process of peer mentorship/leadership
  - Leaves young women with this gap between pediatric care and then being well established in the field of women peer support
  - Some considerations are going to be more relevant for younger age groups, as well
  - Acknowledge that women (including young women!) are experts in their own lives
  - Sometimes when they are involved they aren't heard, their experiences are not valued or validated

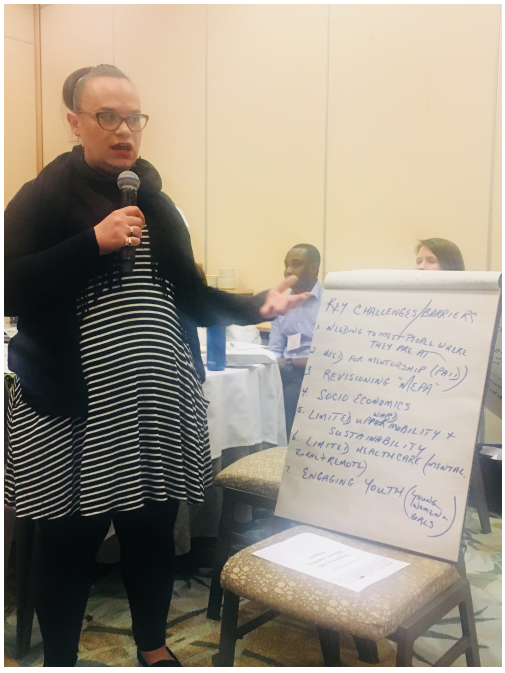


Figure 10. Brittany Cameron, Co-lead, describes key messages

> *We need support for young women as they move out of pediatric care, because "as a kid you're treated like a child, but when you turn 16 you're treated like a 'risk'"*

- Build allyship: What does it take to build effective allyships?
  - Education and understanding of experiences

- Essential to build understanding
  - Example: Men living with HIV may not face same challenges around penalization w/ threat of child apprehension
- Inadequate compensation for WLWH
  - Need adequate pay, opportunities for advancement
  - Provide full benefits equal to other employees. This is an important gap not just for peer work, but for everyone working in the trauma field.
    - Need access to mental health care
    - Essential component of supporting the supporter
    - People have wide variety of lived experiences. Must adequately support them in a way that ensures their ongoing employment and involvement.
      - Example: WLWH who may have experience with mental health, addiction may continue to face these during their work. Need support to do so

<u>Identify additional voices, stakeholders, and perspectives:</u>

- Youth, adolescents, young women and girls
- LGBTQ2+ people

APPENDIX A: Discussion questions

World Café Questions: CAHR 2018
Trauma- and Violence-Aware Practice
Co-Leads: Valerie Nicholson, Dr. Neora Pick, & Jay MacGillivray
Coordinator: Mina Kazemi

We define "**trauma and violence aware care" or "practice"** (TVAC/P) as *a **strengths-based** framework that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes **physical, psychological**, and **emotional safety** for both providers and survivors, and that creates opportunities for survivors to rebuild **a sense of control** and **empowerment***[2]

1. Brief Icebreaker/Introductions

2. What are the key opportunities for implementing TVAC/P (across the policy, programming, and research domains)?

3. What are the key barriers for implementing TVAC/P (across the policy, programming, and research domains)?

4. What is needed to implement TVAC/P in the Canadian context.
    a. What is already being done in Canada (i.e. key strengths)? What is missing?
    b. What language should be used? (i.e. word choice)
    c. Are there additional stakeholders, resources, information, voices that we need to include in this discussion?

5. What are the key messages we want to relay in the national action plan?

[2] K Hopper, E., L Bassuk, E., & Olivet, J. (2010). Shelter from the storm: Trauma-informed care in homelessness services settings. *The Open Health Services and Policy Journal*, *3*(1).

World Café Questions: CAHR 2018
Supporting Safer HIV Disclosure
Co-Leads: Wangari Tharao and Jasmine Cotnam
Coordinator: Sandra Godoy

We believe **that supporting safer HIV disclosure** requires a woman-centered approach that respects the autonomy and dignity of people living with HIV and allows their reality and sentiments to inform and determine how a disclosure action plan will develop.

1. Brief Icebreaker/Introductions
2. What are some key opportunities to support safe HIV disclosure for women living with HIV in Canada?
    a. Who are leading these initiatives, what are some actions or recommendation to help build on these opportunities in the short-term/long-term?
    b. What else can we do to support safer HIV disclosure?
3. What are the key barriers that woman living with HIV face in disclosing their HIV status?
    a. What underlying societal or social mechanisms are constraining women to actualize disclosure goals?
    b. What policy, programming, and research action plans are required to mediate the identified barriers? What actions can help mediate these mechanisms?
4. What work is being done in Canada to support women living with HIV to disclose their HIV status?
    a. Who is involved in this work?
    b. What changes have you seen over time? What needs to be improved?
5. How can we promote safe HIV disclosure across Canada?
    a. Whose voices are we missing at this table and how can we support this gap?
6. What are the key messages we want to relay in the national action plan?
    a. Review any recommendations you have proposed and identify who should be responsible for moving them forward, highlighting responsibilities for service providers, researchers, policy makers, and women living with HIV and their communities.

World Café Questions: CAHR 2018
Reproductive Health, Rights, and Justice
Co-leads: Margarite Sanchez, Dr. Deborah Money, Dr. Angela Kaida
Coordinator: Becky Gormley

"The **reproductive justice framework** – the right to have children, not have children, and to parent the children we have in safe and healthy environments – is based on the human right to make personal decisions about one's life, and the obligations of government and society to ensure that the conditions are suitable for implementing those decisions. The RJ framework represents a shift from advocating for control of our bodies to a broader analysis of racial, economic, cultural, and structural constraints on our power. Reproductive Justice addresses the social reality of inequality, specifically, the inequality of opportunities that we have to control our reproductive destiny. Our options for making choices have to be safe, affordable and accessible".
~ Definition provided by webinar presenter Krista Williams of the Native Youth Sexual Health Network
~ Language of 'Reproductive Justice' was coined in 1994 by the *Women of African Descent for Reproductive Justice (WADRJ)*

1. Brief Icebreaker/Introductions

2. What are the key opportunities to support the reproductive rights, health, and justice for women living with HIV in Canada?
    a. Across policy, programming, and research domains?

3. What are the key barriers to action on reproductive health, rights, and justice?
    a. Across policy, programming, and research domains?
    b. Consider a spectrum from individual-level to broader social and structural mechanisms.

4. What is needed for action on reproductive health, rights, and justice in Canada?
    a. What is already being done in Canada (i.e. key strengths)? What is missing? What can be strengthened?
    b. Who are the key players involved in this work?
    c. Who/what are the additional stakeholders, resources, information, voices that need to be included in this discussion?

5. What are the key messages we want to relay in the national action plan?

World Café Questions: CAHR 2018
Resilience, Self-Efficacy, and Peer Support
Co-leads: Tracey Conway, Brittany Cameron, Brenda Gagnier, & Dr. Carmen Logie
Coordinator: Sarah Watt

We believe that the meaningful inclusion of women living with HIV (MIWA) is essential to women's autonomy, resilience, and self-efficacy. In line with this, we are committed to cultivating the leadership of WLWH through opportunities for mentorship, capacity-building, and peer support.

1. Brief Icebreaker/Introduction

2. What are the key opportunities for action to support resilience, self-efficacy, and peer support among women living with HIV in Canada?

3. What are the key challenges or barriers to action that should be addressed in the national action plan to support peer support, resilience, and self-efficacy among women living with HIV?
    a. What are the most prominent gaps in policy, programming, and research within your province/community with regard to cultivating resilience, self-efficacy, and peer support?

4. What is needed to better support resilience, self-efficacy, and peer support?
    a. What work is already being done in Canada?
    b. What is missing?
    c. Are there additional stakeholders, resources, information, or voices that we need to include in this discussion?

5. What are the key messages we want to relay in the national action plan with regard to peer support, resilience, and self-efficacy?

APPENDIX B: Developing a National Action Plan to Advance the Sexual and Reproductive Health and Rights of Women Living with HIV Agenda

Developing a National Action Plan to Advance the Sexual and Reproductive Health and Rights of Women Living with HIV in Canada

Thursday, April 26th, 2018 || 12:30-4:00PM || Salon 3, Stanley Park Ballroom

MEETING AGENDA

Time	Topic	Speakers
1:00-1:05	**Welcome** Opening Remarks, Traditional Opening and Recognition of the Territory	Elder Valerie Nicholson
	Opening Panel	Facilitated by Muluba Habanyama, Canadian Positive People Network
1:05-1:15	Overview of the Canadian Webinar Series on Supporting the SRHR of WLWH and purpose of the ancillary event	Dr. Angela Kaida, SFU, Chair of Webinar Series
1:15-1:25	Introduction and overview of WHO Consolidated Guidelines: Update on Canada's role in piloting guidelines, update on countries implementing these guidelines	Dr. Manjulaa Narasimhan, World Health Organization, Department of Reproductive Health and Rights
1:25-1:35	Importance of centering women's voices and lived experience in SRHR of WLWH	Tracey Conway, Canadian Positive People Network
1:35-2:05	**Webinar Highlights** ❖ Trauma and Violence Aware Care ❖ Supporting Safe HIV Disclosure ❖ Reproductive Health, Rights, and Justice ❖ Resilience, Self-Efficacy, and Peer Support	Valerie Nicholson, Jay MacGillivray, & Dr. Neora Pick Jasmine Cotnam & Wangari Tharao Margarite Sanchez, Dr. Angela Kaida, & Dr. Deborah Money Tracey Conway, Brittany Cameron, Brenda Gagnier, & Dr. Carmen Logie
2:05-2:15	**Introduction to Small Group Discussion Exercise**	Muluba Habanyama
2:15-3:15	**World Café Style Small Group Discussions across the four webinar topics** ❖ Trauma and Violence Aware Care ❖ Supporting Safe HIV Disclosure ❖ Reproductive Health, Rights, and Justice ❖ Resilience, Self-Efficacy, and Peer Support	Everyone
3:15-3:45	**Large Group Discussion & Feedback**	Facilitated by Muluba Habanyama
3:45-3:55	**Next Steps and Wrap-Up**	Collaborating partners
3:55-4:00	**Elder Closing**	Elder Valerie Nicholson

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APPENDIX C: Canadian Webinar Series Dates and Links

Trauma- and Violence-Aware Care/Practice	
Date	September 13, 2017
Presenters	Valerie Nicholson, Positive Living BC, Red Roads HV/AIDS Network, AIDS Vancouver, Canadian Aboriginal AIDS Network, and CTN's Prevention and Vulnerable Populations Working Group,
	Dr. Angela Kaida, Simon Fraser University, Webinar Series Chair
	Dr. Manjulaa Narasimhan, World Health Organization
	Dr. Carmen Logie, University of Toronto
	Dr. Neora Pick, Oak Tree Clinic
	Dr. Jesleen Rana, Family physician
	Jay MacGillvary, Positive Pregnancy Programme
	Tracey Conway, Canadian Positive People Network
	Wangari Tharao, Women's Health in Women's Hands Community Health Centre
Webinar Link	https://register.gotowebinar.com/recording/4217250904891321862
Supporting Safer HIV Disclosure	
Date	November 16, 2017
Presenters	Kerrigan Johnson, Women's College Research Initiative
	Dr. Mona Loutfy, Women's College Hospital, Women's College Research Institute, University of Toronto
	Dr. Manjulaa Narasimhan, World Health Organization
	Dr. Angela Kaida, Simon Fraser University, Webinar Series Chair
	Valerie Nicholson, Positive Living BC, Red Roads HV/AIDS Network, AIDS Vancouver, Canadian Aboriginal AIDS Network, and CTN's Prevention and Vulnerable Populations Working Group
	Jasmine Cotnam, Women's College Hospital, Canadian Aboriginal AIDS Network, Ontario HIV Treatment Network
	Marvelous Muchenje, Women's Health in Women's Hands Community Health Centre
	Sandra Godoy, Women's Health in Women's Hands Community Health Centre
Webinar Link	https://www.youtube.com/watch?v=leAlj4pP7HU&feature=youtu.be
Reproductive Health, Rights, and Justice	
Date	January 24, 2018
	Dr. Deborah Money, University of British Columbia
	Elder Valerie Nicholson, Positive Living BC, Red Roads HV/AIDS Network, AIDS Vancouver, Canadian Aboriginal AIDS Network, and CTN's Prevention and Vulnerable Populations Working Group
	Dr. Manjulaa Narasimhan, World Health Organization
	Krysta Williams, Native Youth Sexual Health Network

	Brittany Cameron, Turning to One Another Network, North American Board of the International Community of Women Living with HIV, Canadian #UequalsU Steering Committee, Pacific AIDS Resource Network
	Dr. Angela Kaida, Simon Fraser University, Webinar Series Chair
	Dr. Saara Greene, McMaster University
	Frederique Chabot, Action Canada for Sexual Health and Rights
Webinar Link	https://www.youtube.com/watch?v=rhhrFTxspq4&feature=youtu.be
Resilience, Self-efficacy, and Peer Support	
Date	March 9, 2018
Presenters	Tracey Conway, Canadian Positive People Network
	Kerrigan Johnson, Women's College Research Initiative
	Dr. Manjulaa Narasimhan, World Health Organization
	Allyson Ion, McMaster University
	Dr. Carmen Logie, University of Toronto
	Doris Peltier, Visioning Health II, Canadian Aboriginal AIDS Network, Canadian HIV Women's Sexual and Reproductive Health Cohort Study, Waakebiness-Bryce Institute for Indigenous Health, CIHR Canadian HIV Trials Network
Webinar Link	https://register.gotowebinar.com/recording/4217250904891321862