

N'GINAAJIWIMI

“The essence of who we are is beautiful”

CHIWOS Aboriginal Advisory Board - Prioritizing the Health Needs of Positive Aboriginal Women (CAAB-PAW):

A Special Report on PAW Research and HIV-Related Health Concerns



The Canadian Aboriginal AIDS Network - CAAN

Étude sur la santé sexuelle et reproductive
des femmes vivant avec le VIH
au Canada
Canadian HIV Women's Sexual and
Reproductive Health Cohort Study



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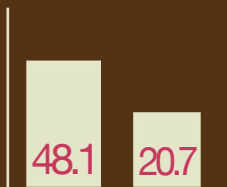
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INTRODUCTION

PAW in Canada – Inequitable health status, policies and services

Aboriginal women represent 48.1% of HIV-positive test reports known to be among Aboriginal people living in Canada in contrast to 20.7% in non-Aboriginal women.



It is well known that in Canada Aboriginal women living with HIV face issues that stem from the intergenerational impacts of oppression, colonization and residential schools, such as **gender-based power imbalances, violence, poverty, racism, and other determinants of health** which often impact their lives more heavily than HIV itself.²⁻⁴ These issues, along with invalidating encounters within the healthcare system contribute to the decline of their health status.² Existing policies fail to address the multiple burdens experienced by Aboriginal women, and the systemic under-appreciation of their lived experiences results in poor assessments of their health needs.

In 2010, during the preparation of the Environments of Nurturing Safety (EONS): Aboriginal Women in Canada Five Year Strategy on HIV and AIDS, Ms. Kecia Larkin, an Aboriginal HIV Activist and at the time the Voices of Women (VOW) co-Chair living in British Columbia, coined the term PAW – Positive Aboriginal Women – which imparts a dual meaning to “being positive” and breaking down a first barrier in how Aboriginal women impacted by this epidemic would like to be portrayed by using a strength-based approach. For the remainder of this document, PAW will be used as the term for Aboriginal women living with HIV.⁵

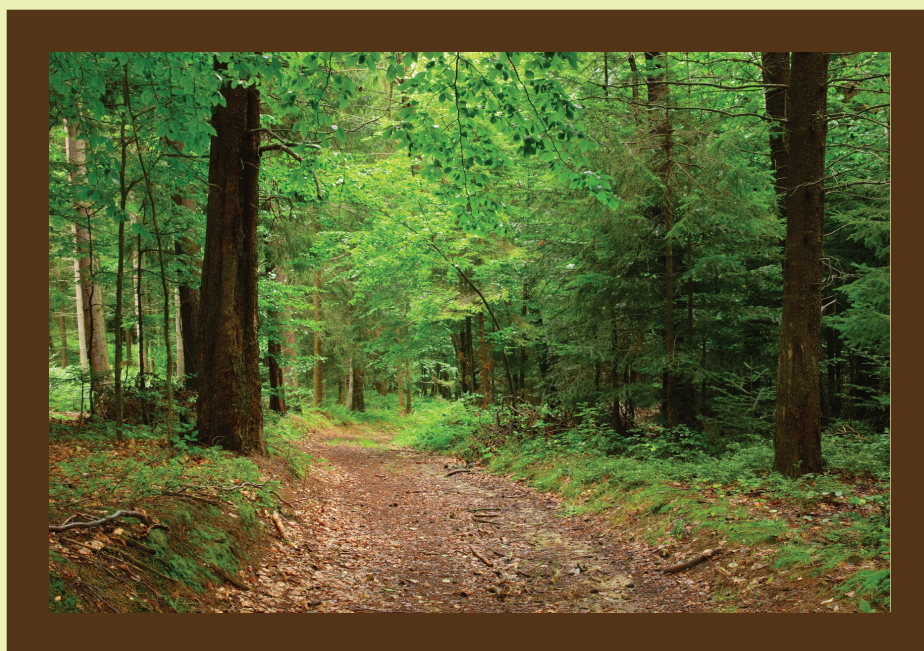
PAW (Positive Aboriginal Women):
Aboriginal women living with HIV.

CHIWOS & PAW

The epidemiology, management and response to HIV in women has not been well-described, but it is predicted that across Canada, antiretroviral use, which is correlated with better clinical outcomes, varies greatly from region to region. While the use of these services is predicted to be lowest in rural areas and among younger and Aboriginal women, higher use of women-centered HIV and AIDS related health services correlates with better health outcomes. The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study, also known as **CHIWOS**, is a 5-year national prospective cohort study that was funded in 2011 by the Canadian Institutes of Health Research. CHIWOS aims to assess the proportion, distribution and pattern of women-centered HIV and AIDS service use, and the effect of such use on reproductive, sexual, mental and women’s general health. By listening to the voices of women, CHIWOS has defined women-centered HIV and AIDS care as care, which supports women living with HIV to achieve the best health and well-being as defined by the women themselves. This type of care recognizes and addresses women’s unique health and social concerns and acknowledges that they are connected. Because this care is driven by women’s diverse experiences, women-centered care is flexible, and takes the different needs of women into consideration. CHIWOS aims to measure the access and quality of these services with HIV-positive women, service providers, and researchers through a national longitudinal interview-administrated survey. The survey is carried out using Community-based Research (CBR) principles and the Meaningful Involvement of Women and Girls Living with HIV (MIWA) principles with Peer Research Associates (PRA) on laptops every 18 months. In this initial phase of CHIWOS, the planned recruitment is 1355 HIV-positive women and is limited to the provinces of Ontario, Québec and British Columbia.

CAAB-PAW REPORT

While CHIWOS' sampling frame has been designed to target hard-to-reach women in Ontario, Québec and British Columbia, it was felt by the investigators and corroborated by Key Opinion Leaders on the topic of HIV and Aboriginal Women that a specific plan should be developed for the recruitment of PAW. In April 2011, Dr. Loutfy, the CHIWOS Nominated Principal Investigator heard Ms. Doris Peltier, the Canadian Aboriginal AIDS Network (CAAN) Aboriginal Women and Leadership Coordinator and APHA Liaison speak on the newly drafted EONS. Doris' talk and words moved Mona who saw similarities in the Vision of EONS and CHIWOS. Mona approached Doris about considering working with CHIWOS to bring an Aboriginal perspective.



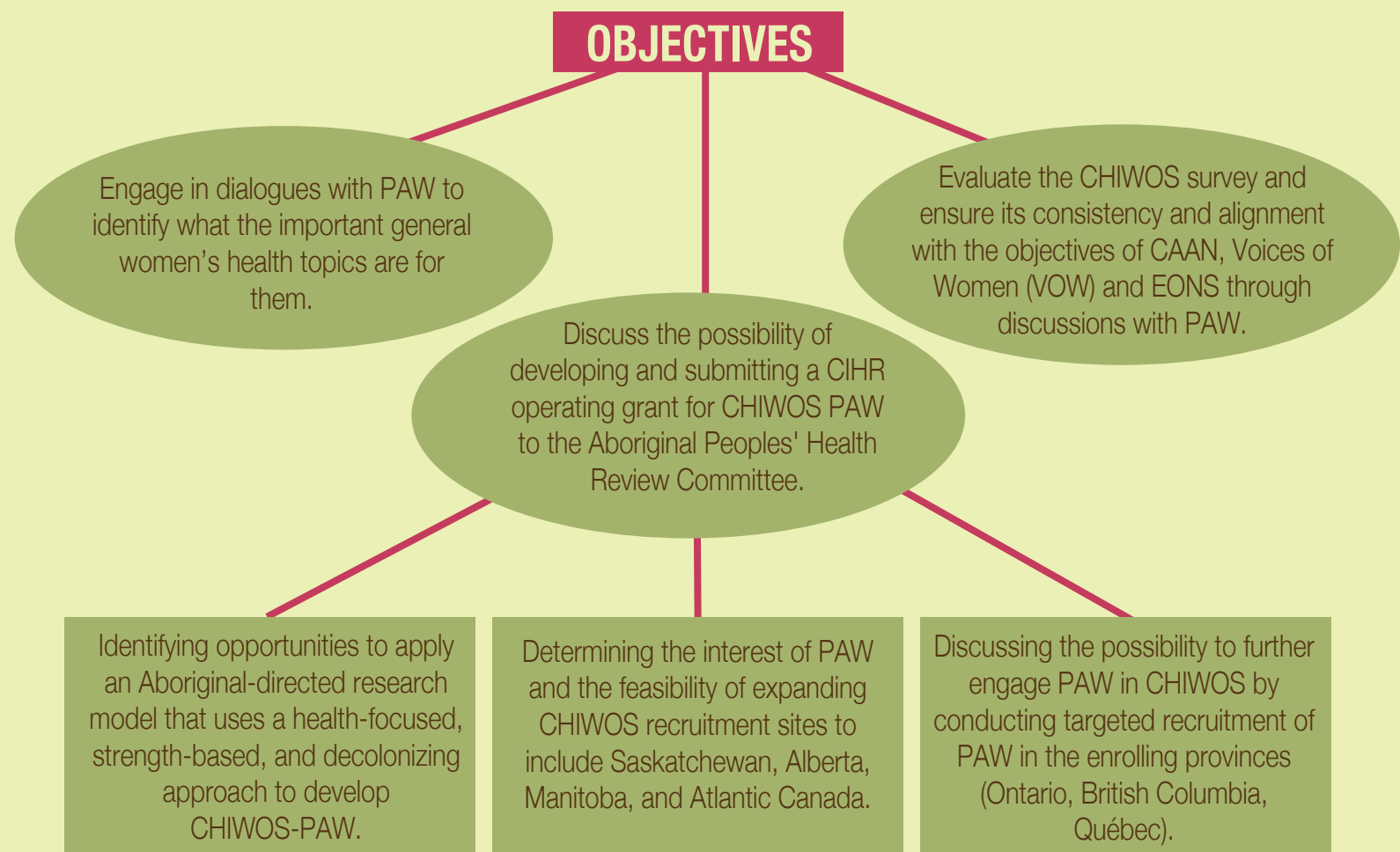
Group-Specific Advisory Boards to CHIWOS: CAAB-PAW

The CHIWOS Aboriginal Advisory Board: Prioritizing the Health Needs of Positive Aboriginal Women (CAAB-PAW) was created in 2012 when Leaders in the Aboriginal community responded to CHIWOS' invitation for partnership and collaboration to ensure their voice and needs were being addressed in CHIWOS. A membership was made with Ms. Doris Peltier and Dr. Anita Benoit as co-Chairs and Terms of Reference for the CAAB-PAW were drafted. CAAB-PAW was the first Group-Specific Advisory Board in CHIWOS. The goals of CHIWOS Group-Specific Advisory Boards are to address study issues pertinent to specific key population groups disproportionately affected by HIV in Canada while recognizing women's multiple and overlapping identities, issues and concerns. The CAAB-PAW was formed; through the CAAB-PAW, training for Researchers and Coordinators specific to Aboriginal communities and issues, which was held at CAHR 2012 in Montreal and a CIHR Planning Grant was received enabling the retreat meeting in September 2012.

CAAB-PAW CIHR PLANNING GRANT MEETING

What:

The objectives of the CAAB-PAW Planning Grant retreat were to:



When

The CAAB-PAW in-person Planning Grant retreat was held over two days, September 6 and 7, 2012, and there was a follow up in-person meeting on September 18, 2013.

Who

The Team was composed of PAW from British Columbia, Saskatchewan, Manitoba, Ontario and Quebec, Aboriginal and allied researchers, service providers (i.e. physicians, community research consultants, and support service providers) and a Spiritual Teacher.

Why

The aim of the Planning Grant meeting was to carry out integrated knowledge translation and CBR and have multi-directional engagement, discussions, and teachings to provide a forum for PAW and researchers to learn and share information about Aboriginal women's health research questions and needs.

Results

Since the Planning Grant meeting, the CAAB-PAW membership was finalized and the terms of reference were completed and approved, with the understanding that both these documents are fluid and can be changed as required. Also, the CHIWOS national survey development was finalized and implemented under the review and guidance of CAAB-PAW. The next steps are the release of this report and the submission of a CAAB-PAW CIHR Operating Grant. Please find on the subsequent pages a summary of the presentations and discussion from the September 2012 CAAB-PAW retreat meeting.

A DANGEROUS STORY:

Historic Portrayal of Aboriginal Women in Canada

presented by Doris Peltier

It is important to consider how Aboriginal people have been historically portrayed when doing research on Aboriginal communities. Historically, Aboriginal women have been portrayed in a negative manner and a pathogenic model of Aboriginal women in medical research has been instituted. This historical portrayal of Aboriginal women and the pathogenic model is a “dangerous story” for Positive Aboriginal Women (PAW); and the negative language of research keeps PAW diminished. Aboriginal

people have an oral culture where stories are very important and lived stories are sacred. There will be a shift in how Aboriginal people move forward in research and PAW will be part of this shift. PAW are stepping away from identities as HIV-positive women to a dual meaning about being “positive” and HIV-positive, hence, Positive Aboriginal Women.

One of the purposes of this meeting was to join in a new movement, led by PAW activist Doris Peltier, to decolonize how

Aboriginal women are engaged in research. In honour of Ms. Peltier’s work throughout Canada, we have named this report N’ginaajiwimi. When translated into English, this Anishnabe word means, “The essence of who we are is beautiful.” This phrase has a much deeper meaning when considered from an indigenous mindset, and as a title, it is intricately connected to Ms. Peltier’s message.

N’ginaajiwimi: The essence of who we are is beautiful.

REGIONAL REPORTS:

Current issues for PAW in Canada

During the two day meeting, retreat participants, including PAW and the Aboriginal AIDS Service Organization, provided an overview of the status of the epidemiology of HIV and HIV care and the main issues faced by PAW living in their region. These reports were subjective and should be viewed as the opinion and experience of meeting participants.

BRITISH COLUMBIA (BC)

Poverty continues to be the number one concern for PAW in BC. Addictions are compounded by poverty and many PAW have lost their lives to drugs and alcohol.. In addition, many PAW in BC have come through the foster care system or are residential school survivors, and many have lost their own children to foster care because of poverty and addictions. Furthermore, housing is not affordable in BC, which compounds these women's challenges – it is an uphill battle with social workers.

Two-spirited PAW have created their own special, safe place because of the violence they have experienced in areas where they previously accessed services; it is important for them to find a safe space due to the discrimination they continue to face in the community. More research is needed to understand the unique issues for Aboriginal, two-spirited women, and there is a need to find out why they need a safe space. It is important for two-spirited people to do this work and ensure they feel comfortable.


PAW in northern BC continue to face discrimination and are stigmatized in the mainstream healthcare system. These women want health and social services that are safe and non-judgmental. In northern BC, PAW seem to be predominantly young women, many of who are current drug users. In addition, issues related to transitioning from youth to adulthood, and screening and prevention services, e.g. pap smears, oral hygiene/care, diet, etc., are important to them. This is in contrast to PAW on Vancouver Island who have an average age of 55+ years



SASKATCHEWAN

Members of the Women and HIV Research Program at Women's College Hospital were in Saskatchewan in early 2012 as part of the National HIV Pregnancy Planning Guidelines dissemination; this was groundbreaking for the Saskatchewan Aboriginal community, as PAW continue to face stigma and discrimination in the healthcare system.

Many PAW are mistreated because they are also former injection drug users. In addition, there are a lot of challenges in Saskatchewan's judicial and correctional facilities, which are "breeding grounds" for HIV and Hepatitis C co-infection. In these facilities, there is a lack of awareness and education of HIV and HCV co-infection, so it is important to start to build relationships with those working in them to develop a strategy for HIV prevention and care. Although many PAW in the community have experienced trauma, residential schools and colonization, barriers exist to work with elders to address these issues. A strategic response is needed, especially in the school system and board.



There is a strong desire to use arts-based approaches in Saskatchewan communities, since art, e.g. painting, photography, drum making, singing songs, Pow wows, dance, etc, is a powerful way to connect with all people and experience healing. . There is also an opportunity to develop a peer-to-peer mentorship program, but there can be flaws in such programs as it is imperative to ensure GIPA and MIWA principles. It is challenging to be a role model or PAW leader in the community due to the difficulties in finding a safe space for a support group and the long road ahead in creating safe spaces for PAW in Saskatchewan. Maintaining confidentiality while being out on the front lines, fighting for the community's needs, is also a challenge, particularly with disclosure.

As increasing numbers of PAW become mothers in Saskatchewan, there is also mounting concern about how to optimize care during and after pregnancy. Negative encounters with child protection agencies have led many pregnant PAW in Saskatchewan to go 'underground' to avoid healthcare providers who are not trusted medically and are often seen as the referral mechanism to child protection services. This fear and mistrust is believed to have contributed to seven perinatally HIV-infected infants born in Saskatchewan between 2005 and 2007, accounting for almost one quarter of all positive births in Canada in that time frame (Saskatchewan Ministry of Health, 2010). There have been efforts to encourage collaboration between child protection agencies and healthcare providers to improve the care, services, and supports offered to PAW during pregnancy; these efforts will also ensure that measures are in place to support PAW in parenting their children, thus reducing the fear of apprehension. It is excellent new that no infants were infected in 2008 or 2011, with only one infant being infected in 2009 and 2010 (Saskatchewan Ministry of Health, 2012).

What about the men? What about sero-discordant couples? We cannot forget about our partners and our men. There are many opportunities to train, engage, and give a person a voice. We need to talk about reproduction and sexual violence, but there continues to be a lack of educational/ training opportunities in Saskatchewan. More research is needed so that we can bridge the gap with the elders – we need to partner with our elders, but also think critically about what is a role model? Who is a leader? Who are the helpers? What are our roles in the community? There is exciting work happening with the Aboriginal Youth Council on HIV/AIDS. We must remember that two-spirited people who have strong medicine should be welcomed beside us and can contribute greatly to the circle. It remains difficult to engage reserves; the response is "that problem is not here," which is a barrier to addressing the issues relevant to PAW.

SASKATCHEWAN (cont'd)

An exciting opportunity exists with child and family services and obstetricians for PAW who need help. The Regina Qu'appelle Health Region is looking to fund a facility to accommodate women who are struggling with addictions or have child and family services involvement or history. They will house them in a home set-up with programming, support and rehabilitation, with the goal to keep women and their children together and provide opportunities for continued bonding and change. There is much work to be done, and child and family service workers need to be educated as they do not consider the bonding process with baby in post partum. At the time the child is apprehended (in early post partum), HIV-positive mothers' hope "goes out the door," they feel ostracized and turn to their addiction. PAW in Saskatchewan continue to and enable them to have full awareness of their treatment, as they are the experts in their own lives. Layered trauma, e.g. sexual abuse, racism and other forms of discrimination, must be considered when delivering services to PAW.

MANITOBA

Businesses have closed and there are no safe spaces for PAW in Manitoba – the bottom line is that “Manitoba sucks.” PAW continue to live in fear of being found out about their HIV status, and often, they do not want to disclose their status to their partners (e.g. will use condoms profusely). Community members are not engaged because they are street-involved, therefore they have no credibility in the eyes of service providers and policy makers. For PAW in Manitoba, there is no where to go for services except for Health Sciences Centre and Nine Circles. Sunshine House received funding from the homelessness initiative, but it does not offer a program specifically for women, and resources have been cut back at Nine Circles.



Each reserve is given \$5,000 per year for HIV education; however, that money is allocated to other resources. Often this money goes towards providing HIV education for one day per year, which is not making a big impact in the community (specifically Winnipeg). The chiefs must be addressed, since many are in denial about the HIV epidemic. Safe spaces are needed for Aboriginal people living with HIV/AIDS (APHAs) to be loud and proud and talk; we must start with small towns that are willing to listen and follow with a provincial strategy.

Solvent use is an issue in Manitoba, but it is rarely discussed in the community and no one seems to be listening. Keith Fowke at the University of Manitoba is studying this problem (with Courtney Bell, Métis student). There is a provincial conference about HIV/AIDS every fall in Manitoba, but only 20 APHAs attend because the meeting is too scientific and is not respectful or welcoming of the community.

ONTARIO

HIV services and clinical care are very integrated in Toronto. Disclosure of HIV status, stigma, discrimination and fear of being “outed,” however, continue to be a challenge for PAW across Ontario. There are a number of mainstream and Aboriginal services that PAW can access in Toronto (and Ontario) if services and support are needed. It is important for safe spaces to be created and strengthened in order for PAW to share and feel comfortable disclosing their status. Aboriginal clients in Toronto also find it difficult to access dental care, as dentists do not take clients who are on ODSP because they “don’t want to be bothered with the billing.”

One agency with limited resources is Anishnabe Health in Toronto, which doesn’t offer harm reduction programs, point-of-care testing, HIV care or women’s programming. Anishnawbe Health offers anonymous HIV testing and the person’s name does not appear on a chart/medical form; however, people are not “anonymous” in the waiting room, which is a barrier to accessing testing.

Authorization to possess medical marijuana is a challenge for PAW in Ontario, especially for women who have been involved with child protection services or are street-involved [surveillance by City Police and Children’s Aid Societies (CAS) workers]. In addition, many doctors in Ontario do not support or sign application forms for medicinal marijuana.

Another current issue in Toronto that front-line service providers are seeing is the inclusion of a veterinary de-worming agent in crack. Many clients are not aware of this nor do they have the information to recognize side effects.

Fear of disclosure of HIV continues to be an issue for PAW. This fear is causing many women to go underground, and as a result, they are not accessing the testing and care services they need. In addition, the screening processes to access a physician are seen as a barrier to care. The question of how to engage PAW in care and treatment was raised.

PAW in Toronto continue to be challenged through involvement with CAS; they feel that CAS does not understand what HIV means and HIV is automatically seen as a death sentence. PAW fear being “found out” as having HIV (and possibly other addictions), since it may cause Native Child and Family Services to get involved and possibly apprehend their child. PAW are afraid of experiencing HIV-related stigma and discrimination, and feel they are being “watched” by CAS. The Bear clan was referenced whereby PAW are “mother bears” who want nothing else but to protect their children. The fact that CAS are stand-alone and not centralized in

Ontario (i.e. Catholic, Jewish, Native) is seen as a barrier to engaging CAS in policy development; they have not been responsive to historical outreach attempts.

HIV care and education on reserves in Ontario is limited. There are limited harm reduction resources on reserves and often PAW are not lucky enough to live close to a town that receives methadone, which reduces the risk of HIV transmission. Even though “methadone buses” to neighbouring communities are available, they inadvertently cause women to disclose their HIV status and often women cannot bring back methadone carries to their communities. A summit was hosted in March 2012 by a regional group (including on-reserve officials, APHAs, two-spirited people of the First Nations, and Oahas) to discuss jurisdictional barriers and challenges. A number of PAW from reserves attended. The group aims to create a seamless connection of support and care between urban and on-reserve communities, such as ensuring that APHAs transitioning on and off reserve have access to mediations and are able to easily search for a doctor. There is also an opportunity to do more work in the prison system, but it is a challenge to get HIV education and prevention resources into prisons. It is not the goal to “disguise” these resources when visiting with PAW who are incarcerated, since the resources would be viewed as contraband. There is also an opportunity to do more work in the prison system, but it is a challenge to get HIV education and prevention resources into prisons. It is not the goal to “disguise” these resources when visiting with PAW who are incarcerated, since the resources would be viewed as contraband.



QUEBEC

Aside from the Native Women's Shelter (seen as a "beacon on the hill" for PAW), there isn't an Aboriginal AIDS service organization (AASO) or safe space for PAW in Montreal. Women go to the Native Women's Shelter because of poverty and homelessness and are able to access healthcare at this centre. An infectious disease specialist goes to the clinic once a week and women can have a Pap test done at the shelter; this service is important because APHAs are not accessing any mainstream services.

As heard in the Visioning Health project, Inuit women do not disclose their HIV status to their children. They put on a "game face," but are often very fragile. Women are still dying in Montreal - not from AIDS, but from addiction-related complications and illnesses, and the fact that they are not linked to care. There are non-compliance issues with APHAs using highly active anti-retroviral therapy. In addition, a lot of paperwork is required to access the therapy in Quebec (through Indian Affairs) and there is no advocacy and little assistance to navigate this "red tape."

Although there is a provincial HIV/AIDS strategy (based out of Quebec City), it is ineffective and there is a need to scale-up AASOs in Quebec to ensure PAW have a safe space. Language is a barrier for many APHAs who speak French or native languages. Religion is a barrier to APHAs accessing care; traditional and cultural practices are limited in northern Quebec communities because of indoctrination with Catholicism.

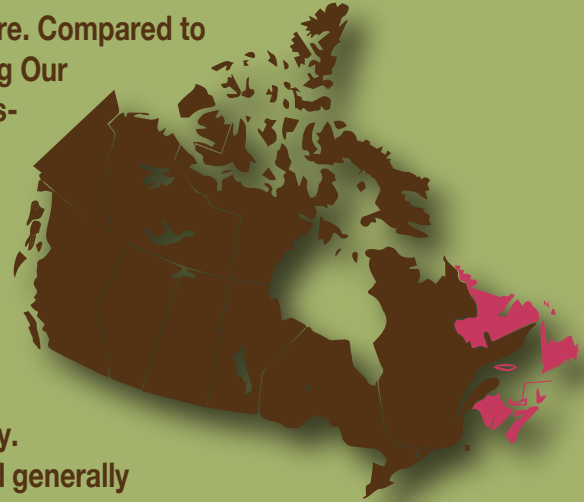
For those women who live in northern/remote communities in Quebec, remote access and significant travel to access treatment and specialists are significant barriers to care.



ATLANTIC REGION

(there were no PAW representatives from the region so, Renée Masching, a former staff member of Healing Our Nations offered comments based on her experiences)

APHAs in the Atlantic region have to travel long periods of time to access care. Compared to other regions, the Atlantic AASOs have quite a bit of political support. Healing Our Nations is based in Halifax, Nova Scotia, and serves Nova Scotia, New Brunswick, PEI and Newfoundland. Healing Our Nations works in partnership with the Labrador Friendship Centre HIV/AIDS Project, as well as communities in Labrador. Funded through a collective agreement by all of the chiefs in the region, Healing Our Nations's board includes members of the tribal councils in the region, professionals providing treatment programs, elders, and two APHAs. This board represents organizations with decision making "clout" in the community and was first established in 1993. Another interesting aspect of the region is the influence of the Catholic Church in the territory. Health staff and church representatives have worked hard to collaborate and generally the church is well respected in the community.



There is limited provincial funding in the region and organizations depend upon federal project funds and fundraising. The AIDS Coalition of Nova Scotia, for instance, needs to fundraise about 40 per cent of its operating costs. Intravenous drug use continues to be a problem in the Atlantic region, but affiliations between harm reduction organizations and (A)ASOs have resulted in innovative and effective programs. The Tommy Sexton Centre in Newfoundland has implemented an innovative program combining harm reduction and housing services.

CRITICAL PATH TO PAW RESEARCH:

Building Blocks

Each point below represents an important building block for PAW in Canada, supporting the next step to move forward and shift the research landscape.*

1998

Introduction to Ownership, Control and Access (OCAP™) for research with First Nations individuals.

2003

Aboriginal Strategy on HIV/AIDS in Canada is drafted/ released.

2006

Report entitled Making It Our Way: A Community Mobilization Tool Kit was published by CAAN.

2007

-CAAN Board established Voices of Women (VOW) Standing Committee.
-Commitment by CAAN to hold an Aboriginal Women's Gathering.

2009

- Aboriginal Strategy on HIV/AIDS in Canada II (ASHAC II) is released.
- As a commitment to report back to research participants first and recognize their contribution this important work, the research report "Our Search for Safe Spaces" is released to the community. This report came out of the sexual violence study and highlights the "dark road" PAW have experienced and the "underbelly" of Aboriginal communities. The research team discussed what to do after publication and to "book end" the study with something positive, i.e. Visioning Health.

2011

The Women's Bundle was created in 2011 in light of LaVerne's passing, and it is a lifelong commitment. The community has welcomed the bundle, which has already started mending disrupted relationships and supporting the shift in the research landscape.

1997

Canadian Aboriginal AIDS Network (CAAN) is established.

2001

Resolution at the CAAN Annual General Meeting to consider and put on the agenda women's issues.

2004

- Report entitled HIV/AIDS and Aboriginal Women, Children and Families was published.
- Shift in research principles to include "Possession" in OCAP™ for research with First Nations persons.
- Aboriginal women living with HIV/AIDS (AWHAs) request sexual violence study led by Drs. Charlotte Reading and Kevin Barlow.
- Report entitled Aboriginal Women Living With HIV/AIDS: Care Treatment and Support Issues was published by CAAN.

2008

- CAAN VOW resolution urging national five-year strategy for AWHAs.
- National Aboriginal Women's Gathering held in Toronto.
- AWHA Leader hired by CAAN (Ms. Doris Peltier).
- The Visioning Health project – a strengths-based, women-centred, culturally-grounded, arts-informed and community-based participatory research project – is funded.

2010

- CAAN develops a PAW-licy statement to entrench the creation of safe spaces in organizations and community groups
- The Environments of Nurturing Safety (EONS) strategy, created by VOW, is released on World AIDS Day. This day is significant as it also marks the day the Aboriginal community lost an important leader and advocate, LaVerne Monette.

2012

- Visioning Health presented at the Indigenous Pre-Conference event of the International AIDS Conference (AIDS 2012), as well as the main conference, with a lodge built and set-up in the front lobby of the hotel hosting the event.
- A workshop on "Creating Safe Spaces for Women Living with HIV: Utilizing an Indigenous Sharing Circle Model" for POZ Women was led by Doris Peltier at the International AIDS Conference (AIDS 2012).

*This timeline was captured by the author and editors to the best of their ability, but some dates may have been slightly missed.

TIMELINE LINKING CHIWOS TO THE CRITICAL PATH

2011

Dr. Mona Loutfy hears Ms. Doris Peltier present on EONS at the 2011 Gathering of Spirits Conference in Toronto, prior to the 10th Canadian Association of HIV Researchers (CAHR) Conference, and is moved and inspired.

Dr. Loutfy approaches Ms. Peltier about working together and actualizing some of the points of EONS.

2012

Ms. Doris Peltier, Ms. Kecia Larkin, and Ms. Renée Masching approach Dr. Loutfy regarding forming an Aboriginal advisory board for CHIWOS.

CHIWOS Aboriginal Advisory Board – Prioritizing the Health Needs of Positive Aboriginal Women (CAAB-PAW) is formed and established.

CAAB-PAW submits a CIHR Planning Grant, which is awarded and the meeting is held in September 2012.

2013

Aboriginal Women's Research Initiative is formed and established to support PAW in the role of Aboriginal community research consultants.

The “Visioning Health” Project

Presented by Doris Peltier and Tracey Prentice
on behalf of all PAW involved

The Visioning Health project arose out of recognition of the “startling lack of culturally-informed, gender-specific HIV care, treatment and support for Aboriginal women and girls” (CAAN, 2004), the predominance of deficit-models and illness-based research and little research on what it means to be “healthy” in the context of living with HIV/AIDS for Aboriginal women.

The goals of Visioning Health were to:

1. Engage with PAW in arts-informed research that would create new knowledge and knowledge products that were strengths-based, culturally-relevant and gender-specific.
2. Create an opportunity for PAW to tell their own stories of health (not illness), culture and gender

GUIDING PRINCIPLE

The way researchers acquire knowledge in indigenous communities may be as critical for eliminating health disparities as the actual knowledge that is gained about a particular health problem (Cochrane et al. 2008, p.22)



The process of doing the research was the most important aspect of this project; if the research was done well, it was known that appropriate results would then follow. Meaningful engagement of PAW throughout all aspects of the project was crucial; it was important that participants must want to be there (i.e. that the research is fun, engaging, safe and respectful) and that participants be involved in knowledge translation and exchange and beyond.

The Road to Meaningful Engagement: Creating Safety

Research in Visioning Health was viewed as ceremony (S. Wilson) and critical indigenous, decolonizing methodologies and transformational paradigms were important foundations for the research. The decolonizing methodology embraced four R's: respect, reciprocity, relationality,

and reflexivity. Furthermore, there was mutual responsibility amongst all team members and participants for long-term engagement. It was very important that the team stayed true to the project principles and there were numerous occasions for discussion and debriefing. The project was considered to be “women-centered,” or as one participant expressed, “shaped like a woman.” Throughout the project, safe and supportive environments were created for PAW; these environments were non-judgmental, flexible, responsive, incorporated principles of harm reduction, created opportunities for sharing (sharing circles), offered fair compensation to participants (including childcare or welcomed children) and also fun. A Traditional Knowledge Keeper was involved to ensure tradition and ceremonies were incorporated in the research, and by creating a safe and supportive environment, this person was essential to the success of the project.

Data Collection

Data collection evolved into a “strategy” and was not simply data collection “methods;” data collection needed to be methodologically sound, but also flexible and responsive enough to respond to the unique needs of each community. As a result, two PhotoVoice and one Drum Making workshop were held and each group participated in three research sharing circles. At the end of the data collection strategy, all participants were brought together in a participatory analysis session. All photos were reviewed and major themes to move ahead with were decided on by the group.

Lessons Learned Through Visioning Health

A number of lessons were learned through the Visioning Health project, including:

- o The research will be harder than you think it will be.
- o The research is more rewarding than you think it will be.
- o The research will take longer than you think it will!
- o Never underestimate the importance of ‘safety’ in research.
- o Partnerships are essential to success and like all relationships, they need nurturing.
- o “I want to be strong like you”: peer research assistants, peer support, peer mentoring and role modeling are very important aspects of research with PAW.
- o Meaningful engagement of PAW in research may lead to better health.
- o Women know what they need – just ask them! Give them time and support so that PAW can share what they know.
- o If you haven’t been changed by the research, you haven’t done it right!

WHEN WOMEN PICK UP THEIR BUNDLES: Redefining how we do research

“When the women begin to pick up their [medicine] bundles our nations will begin to heal.”

A paradigm is a way of thinking about something, a body of knowledge, a theoretical framework; a paradigm shift will enable a redefinition of how research is done with and about PAW in Canada.

Using decolonizing methodologies is a way to shift the paradigm of research with and about PAW in Canada. Indigenous languages and methodologies have a different world view and meaning; these methodologies, however, need to be supported on both sides of the “fence,” that is, by both PAW and research allies (Aboriginal and non-Aboriginal). “Two-eyed seeing” may be necessary to ensure this support on both sides of the fence whereby PAW straddle and resources/information are used from both worlds to shift the paradigm and drive the PAW research agenda forward. Ideas may be merged and people may need to be brought together (e.g. through a “think tank”) so to not work in silos.

This photograph represents an excellent example of this paradigm shift, where the results of a research study were presented at an international conference as a form of Indigenous knowledge translation and exchange. Here, the Visioning Health project displayed the participant’s and community researcher’s photographs and words in a Lodge in the lobby of the host hotel in Washington D.C. during the 2012 Indigenous Pre-conference to AIDS2012, the International AIDS Conference hosted by the International AIDS Society.



When the women begin to pick up their bundles our nations will begin to heal: this statement is inclusive of everyone; everyone has a vision of health in their heart, the layers just need to be peeled back to uncover that vision. We cannot forget our men; we cannot heal alone without them. We also always include our children, as well as our extended family, even our chosen family, and are always looking to take care of our community. The path to healing will result in the telling of a different and positive story of PAW.

Also at the 2012 International AIDS Conference in Washington, D.C., PAW from Canada facilitated a “Creating Safe Spaces” workshop. There is still much work to be done on creating safe spaces for PAW in Canada, even though a “PAW-licy” has been adopted in principal to create safe spaces in every region in Canada. There is need to ensure there is always safety within a circle. The Women’s Medicine Bundles are helpful to support this safety, but there are still pieces that need to be addressed.

OPPORTUNITIES FOR PAW RESEARCH THROUGH CHIWOS

National Phase Study Design

CHIWOS is a five-year, multi-site, prospective cohort study that is rolling out in Ontario, Québec and British Columbia. HIV-positive women will be recruited via word of mouth, at clinics, AIDS Service Organizations, shelters and other locations. The aim is to enrol 350 HIV-positive women per province in Québec and British Columbia and 665 HIV-positive women in Ontario. The national survey instrument, written with input from community stakeholders, was refined through a Formative Phase and survey development process. Recruitment for participants began in fall 2013. For the remaining portion of the five year study, participants will be recruited and enrolled, and be asked to attend a baseline in-person meeting as well as in-person meetings at 18 month intervals. All enrolled participants will meet one-on-one with a PRA to complete the survey introduced in an electronic format.

CHIWOS Study Goals

Among HIV-positive women:

- o To assess barriers to and facilitators of women-centered HIV and AIDS services use.
- o To assess the impact of such patterns of use on sexual, reproductive, mental and women's health outcomes

CHIWOS Hypothesis

Usage of women-centered services will a) be lower among more marginalized and stigmatized communities, and b) be shown to correlate with improved sexual, reproductive, mental and women's health outcomes.

CHIWOS Guiding Frameworks

CHIWOS is grounded in the following theoretical constructs:

- o **Critical Feminism**
- o **Anti-Oppression, Intersectionality, and Social Justice:** improving people's lives through policies and programming
- o **Social Determinants of Health**
- o **GIPA (Greater Involvement of People living with HIV and AIDS) & MIWA (Meaningful Involvement of Women living with HIV and AIDS)**
- o **Community-Based Research (CBR):** Women living with HIV are recognized as equal partners in all stages of the project (GIPA). Partnerships are formed from the beginning and on an ongoing basis to drive the study goals and design, and to disseminate or put into practice the results of the research as best seen by women living with HIV.

GIPA/MIWA

The principles of GIPA and MIWA are ensured through the following activities:

- o Women living with HIV are recognized as equal partners in all stages of the project.
- o All contributions and experiences are respected and valued; women living with HIV are recognized as experts in their own lives.
- o The research is practiced with intent to foster self-determination and agency in the community.
- o There is no tokenism.

Operationalizing CBR & MIWA in CHIWOS

The principles of CBR and MIWA are operationalized through the following activities:

- o Women living with HIV from each province are represented on the national management team, national steering committee, and other working groups.
- o Community advisory boards exist in each province.
- o CHIWOS has embraced a unique definition of “community” to mean anyone who has an interest in women and HIV.
- o PRAs were hired as partners to guide the study and facilitate the focus groups during the formative phase. PRAs will also engage HIV-positive women in the roll-out of the national survey instrument and conduct more than 99 per cent of the interviews.
- o The development of the vision, mission and mandate of CHIWOS was facilitated by women living with HIV.
- o Women living with HIV were integral in developing the questionnaire and methods.

More on the Group-Specific Advisory Boards to CHIWOS

Understanding and incorporating the lived experiences of women living with HIV in the research process are pivotal to CHIWOS. Therefore, CHIWOS has established a group-specific advisory board request procedure that will provide a forum for specific communities of women to address study issues such as survey development, recruitment, and knowledge transfer and exchange strategies. The goals of group-specific advisory boards in CHIWOS are to address study issues pertinent to specific groups while recognizing women’s multiple and overlapping identities, issues and concerns. CAAB-PAW was the first group-specific advisory board for CHIWOS and was welcomed by the CHIWOS team for partnership and collaboration to ensure that the voices of PAW and their needs were being addressed in CHIWOS.

OPPORTUNITIES FOR COLLABORATION: CAAB-PAW CIHR Planning Grant

PAW, CHIWOS researchers, service providers and other academics gathered in person to enter into dialogues concerning health issues relevant to PAW. The Planning Grant meeting led to new partnerships in Aboriginal women's health research and has provided the opportunity to develop priority health research questions by and for PAW. The meeting confirmed the necessity of expanding CHIWOS into other projects to develop arms focused solely on the health service concerns of PAW. CHIWOS PAW data collected within each province will give a regional picture of epidemiological, clinical and access-to-care differences. These differences will impact regional and national evidence-based diagnosis, prevention, care and treatment, and will support policies and programmatic interventions to improve the overall health of PAW in Canada.

OUTCOMES OF THE CAAB-PAW PLANNING GRANT MEETING

After the two-day in-person meeting on September 6 and 7, 2012, and at the follow-up meeting held on September 18, 2012, CAAB-PAW made the following decisions:

1. Finalize CAAB-PAW membership.

CAAB-PAW members agreed to seek PAWs from across Canada to reflect the diversity and generations of Aboriginal women on a 15-member board. CAAB-PAW will focus on requesting that women possessing specific skills and expertise be part of its board. A fuller description of CAAB-PAW's composition is described in its terms of reference.

2. Finalize the CAAB-PAW terms of reference.

The terms of reference will be considered a living document, as will other CAAB-PAW documents. It was decided that an iterative and incremental process was the optimal model for working with Aboriginal women to better meet and accommodate the women's needs and responsibilities, as well as to establish a working relationship that creates space for growth by all CAAB-PAW members.

3. Discussion of CHIWOS PAW objectives.

- a. Identification of PAW's health topics and research questions (see page 4 "Current issues for PAW in Canada.")
- b. Identification of other provinces to include in CHIWOS.

The expansion of CHIWOS to include other provinces and target PAW was deemed important, but the immediate focus was to engage Saskatchewan and Manitoba by applying for a grant to conduct a pilot study of the formative phase of CHIWOS.

- c. Discussion of proposed study to submit for the CIHR Community-Based Research (CBR) Operating Grant (see proceeding reports for further details).

Financial Support: The grant would support a formative phase consisting of focus groups and establishing community-advisory boards. Part-time research coordinators would be hired to work in the provinces, similar to other research coordinators working in the provinces already part of CHIWOS. PRAs will also be hired and trained. CAAB-PAW members emphasized the importance of engaging and properly compensating elders and spiritual teachers in the focus groups and community-advisory boards and also indicated that it was important to create accessible funds to acquire medicines and other supplies for Aboriginal ceremonies.

Priority Topics: The original topic chosen for the focus groups in CHIWOS would not necessarily be the same as in the formative phase for Saskatchewan and Manitoba. Further discussion on the actual topic was required and the "Current issues for PAW in Canada" on page 4 will serve as a starting point to identify potential discussion topics for the formative phase.

Formative phase research process: The formative phase will include a quantitative and qualitative component. In brief, steps of the formative phase will include the launch of CHIWOS in Saskatchewan and Manitoba with Elders, Spiritual Teachers, and ceremonies. The second step will be to conduct the focus groups. The focus group meetings will include the completion of the survey, survey feedback session, and discussions on topics of interest, with the inclusion of a culturally appropriate arts-based component. Furthermore, the research process of the formative phase will be evaluated for its consistency and alignment with CAAN VOW and EONS.

Community engagement: CAAB-PAW members strongly expressed the necessity of engaging Aboriginal stakeholders at All Nations Hope and Nine Circles. However, when this is not possible due to other commitments and being overburdened, CAAB-PAW must work to ensure their connectedness and/or awareness of the project.

Training: A training model for PRAs already developed for CHIWOS will be adapted for better use by Aboriginal PRAs and research coordinators. The national CHIWOS survey contains sensitive topics that may act as triggers to survey respondents; since caring is a multi-level process, it has been recommended that PRAs, Elders and Spiritual Teachers may require additional training in providing support and direction on how to access support resources in their respective regions (i.e. local service providers, counsellors, etc.).

4. Identify opportunities to hire PAW for continued engagement and relationship building.

PAW would be hired as peer research associates for facilitating focus groups and administering the survey in Saskatchewan and Manitoba. Currently, CHIWOS has hired PAWs as PRAs for peer-administration of the survey in British Columbia and Ontario. Additionally, PAW PRAs in Saskatchewan and Manitoba have been identified and are currently engaged in various initiatives of the Women & HIV Research Program, which houses CHIWOS, the Aboriginal Women's Research Initiative, the Interdisciplinary HIV Pregnancy Research Group, and the Aboriginal Women's Stress Study.

5. Identifying and applying for funding opportunities.

- o CIHR Operating Grant.
- o CIHR CBR Operating Grant (see above description in 3c).
- o CIHR CBR Catalyst Grant. Discuss how to implement CHIWOS in the Prairies.
- o Intervention Grant. CAAB-PAW members agreed to support the development of a plan for a regional intervention to be implemented in Saskatchewan and Manitoba, with Ms. Krista Shore and Dr. Mona Loutfy as the principal applicants. The topics of interest in the grant have been selected from a section of the "Current issues for PAW in Canada". This is currently under development.

NEXT STEPS

1. A follow-up meeting was held on September 18, 2012, during the CAAN annual general meeting at the Courtyard Marriott, Toronto, Ontario (see proceedings report for further details and the outcomes section of this report).
2. A CIHR Grant application will be submitted.
3. Finalization of the plan to bring CHIWOS to Manitoba and Saskatchewan. This work will be part of a future Operating Grant.
4. The following Planning Grant objectives were not met:
 - a. A decision was made to concentrate CHIWOS to Manitoba and Saskatchewan. This impacts the objectives of the Planning Grants as CHIWOS will not move forward into Alberta and Atlantic and Northern Canada.
5. It was reiterated that although CHIWOS is currently concentrating on the infrastructure and systems in Ontario, Quebec and British Columbia, there is an opportunity for the CAAB-PAW to:
 - a. Guide the CHIWOS National Survey development, finalization and implementation;
 - b. Determine who could represent PAW on the CAAB-PAW from a statistical analyst, quantitative researcher perspective.
6. The CAAB-PAW terms of reference will be completed and approved after the membership has been finalized.

CLOSING

The CAAB-PAW CIHR Planning Grant meeting was successful in identifying HIV-related issues of concern to PAW in attendance and discussing the plan for a CHIWOS grant specifically addressing the issues and needs of PAW – CHIWOS PAW. The plan will be to apply for a CIHR Operating Grant for CHIWOS PAW, which will also allow for the expansion of CHIWOS to include Saskatchewan and Manitoba and to carry out research that incorporates Aboriginal traditions in a culturally appropriate manner.

REFERENCES

1. Public Health Agency of Canada (2010). Population Specific HIV/AIDS Status Report – Aboriginal Peoples.
2. Barlow et al. (2008). Relational Care – A Guide to Health Care and Support for Aboriginal People Living with HIV/AIDS. Canadian Aboriginal AIDS Network, Final Report.
3. DeGagne M. (2007). Toward and Aboriginal paradigm of healing: addressing the legacy of residential schools. *Australas Psychiatry*, 15 (Suppl 1):S49-S53.
4. Smith D. et al. (2005). Turning around the intergenerational impact of residential schools on Aboriginal people: implications for health policy and practice. *Can J Nurs Res*, 37, 38-60.
5. Environments of Nurturing Safety (EONS) Aboriginal Women In Canada – Five Year Strategy on HIV and AIDS (2010 – 2015). Canadian Aboriginal AIDS Network Voices of Women Standing Committee (CAAN VOW). Report Revised 2011.
6. Saskatchewan Ministry of Health. (2010). Saskatchewan’s HIV Strategy, 2010-2014.
7. Saskatchewan Ministry of Health. (2012). HIV and AIDS in Saskatchewan, 2011.
8. Manitoba Health. Statistical Update: HIV and AIDS. Report to December 31, 2009.
9. Government of Alberta. Final Report – HIV and AIDS in Alberta. 2010
10. Nova Scotia Advisory Council on the Status of Women. Gender-Based Analysis. February 2005 version.
11. Public Health Agency of Canada. HIV and AIDS in Canada. Surveillance Report to December 31, 2009.