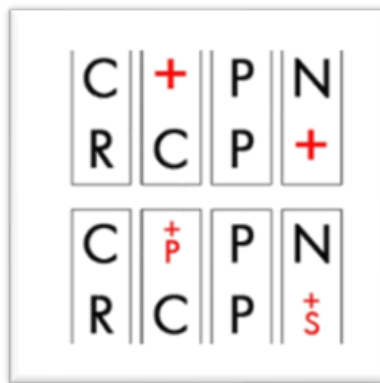


MID-TERM EVALUATION REPORT

Canadian Positive People Network

"Revolutions begin when people perceived as 'the problem' gain the power to redefine the problem."

1718-HQ-000760



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Report to:

Ewa Pyman, Senior Advisor, Program Delivery (2020-06-30)



PROJECT PROFILE

The Canadian Positive People Network (CPPN) is the only national network for people living with HIV and HIV co-infections in Canada. Committed to actively and effectively contributing to Canada's ongoing response to HIV, hepatitis C and other sexually transmitted and blood-borne infections, CPPN members represent an invaluable perspective of lived experience that informs and builds concrete actions essential to this response.

The CPPN remains committed to the inclusion of people with lived/living experience in all aspects of its work, present and future. Through this project, people living with HIV and co-infections across the country could actively participate in peer-led interventions that deliberately focus on addressing stigma and discrimination, systemic barriers to prevention, diagnosis, and treatment services, and on public policy reform.

With the support of this project funding, CPPN activities encourage engagement; collaboration and partnership with other sectors with the express aim of reducing the many existing systemic barriers face-to-face by people living with or at significant risk of HIV, hepatitis C and related STBBIs, with the specific objective of targeting improving the social determinants of health, and the well-being and quality of life of individuals and communities.

Objectives and activities

The CPPN is working towards a single SMART goal: "By 2022, the Canadian HIV-Positive Network(CHN)will have delivered 100 interventions (i.e., engagement measures) to 180 people living with HIV/or co-infections (hepatitis C, STBBIs) across Canada to: strengthen capacity, self-confidence and credibility by 20%, and increase by 20% the number of participants who report having applied the new capacity in local, regional and national interventions (i.e., mobilization actions)."

Work to achieve this goal is supported by four instrumental objectives:

1. Serve with, for and on behalf of HIV-positive people and/or HIV co-infections across Canada, in ongoing collaboration with CHN collaborators and stakeholders in the national response to HIV and HIV co-infections (e.g., hepatitis C and/or related sexually transmitted and blood-borne infections).
2. Develop and promote the innovative and inclusive roles of members in supporting the growth and effective evolution of Canada's national response to HIV and HIV co-infections, maintaining an acute awareness of the ever-changing landscape, and remaining vigilant to ensure that the presence of the CPPN in Canada and in its practical evidence-based activities and interventions is relevant and meaningful to collaborators and CPPN stakeholders.
3. Be relevant and responsive agents of change, based on the recognition and respect of the CPPN's privileged place as an independent national network of people living with HIV and/or co-infections in Canada, by and for them: serve as an informed and credible catalyst for change and change of course, asking difficult questions if and when the survey is appropriate, protect and promote a



response to HIV and HIV co-infections that is relevant and responsive to changing needs and priorities, and that is timely.

4. Contribute to Canada's national response to HIV and HIV co-infections by engaging CPPN collaborators and stakeholders in a meaningful, multidisciplinary, multi-sectoral and multi-jurisdictional manner that is motivated and rooted by people with lived and living experience, and with conscious and empathetic sensitivity and needs awareness, priorities and the myriad of syndemic health issues that affect their well-being and quality of life in "real time/real space".

From April 2017 to March 31, 2020, CPPN activities were undertaken through actions in three specific areas of focus and engagement: (1) knowledge development, translation, and exchange; (2) communications, media, and social marketing; and (3) enabling environments and engagement. Inclusive and meaningful engagement with people living with HIV and with HIV co-infections has been used to facilitate the development or improvement of the skills and capacities of CPPN members to:

- Understand and discuss policies and practices as well as the impact and implications on the well-being and quality of life of people living with HIV and co-infections.
- Contribute effectively to the development and interventions for the development and implementation of policies and practices.
- Challenge assumptions that contribute to or perpetuate stigma and discrimination, and that influence change in knowledge, attitudes, and behaviours.
- Establishing and affirming that people living with HIV and co-infections are credible authorities in the development, interpretation, and implementation of evidence-based action, and to promote the importance of GIPA/MEPA/MEWA: **our lived experience is expertise!**
- Make meaningful and effective contributions to Canada's global commitments and targets.
- Speak with confidence and credit as experts and advocates about the impact and implications of evidence on policy and practice with a wide range of audiences (e.g., peers, community representatives, politicians and policymakers, media, members of the public, etc.).

From April 2017 to March 2018, the activities approved for the first year focused on establishing the composition and governance structure of the network and setting short-, medium- and long-term priorities. In fact, prior to the final approval of the contribution agreement with the CPPN, a comprehensive consultation tool had been developed and was ready for implementation and data collection.

The priority-setting initiative and e-consultation engaged and engaged 131 CPPN members, 188 Canadian non-governmental organizations (or their representatives) and 110 stakeholder organizations. Open invitations were also posted on Twitter and Facebook, generating more than 4,000 impressions, and reaching 1,700 people, respectively. Response rates were notable: 33% of respondents were members of the CPPN, 80% responded individually, and 22% participated as representatives of an organization or group.

The consultation tool was designed, implemented, and analyzed by CPPN members, included 136 questions, and was intended to gather information and obtain ideas, advice, and recommendations on:

- Individual demographic information,



- Organizational profiles,
- Experience with HIV, hepatitis B and C and other sexually transmitted and blood-borne infections (STBBIs),
- The mission, vision, critical pathways, and pillars of activity of the CPPN, as well as its goals and objectives, and
- The form and function of the CPPN.

This ambitious initiative has not been without its limits. Some participants acknowledged that the comprehensive nature of the consultation tool was important, but others suggested that it was so comprehensive (complex) that it isolated or marginalized potential respondents. In addition, the potential scope in terms of invitations to participate was limited in that respondents were not asked to self-identify as members of a specific priority population.

The most relevant conclusions drawn from respondent feedback are summarized as follows:

- Neither the original CPPN mission statement nor the proposed (revised) statement presented in the consultation tool resonated with most respondents. More than 50% of all respondents indicated that considerable effort should be made to avoid implying that the CPPN is assuming a role or responsibility for more than it should or is reasonable. In short, more than half of the respondents suggested that THE CPPN develop its mission statement based on the feedback provided throughout this consultation exercise.
- To a slightly higher degree, so is the organization's long-term vision. Fifty-four percent of respondents who provided advice agreed that the vision statement should be rewritten to be more concise, clearer, and reasonable with respect to the long-term role of the CPPN and the potential impact in Canada's response to HIV and HIV co-infections.
- Examining four specific objectives focused on ongoing engagement, innovation, and growth (with a particular focus on practical, evidence-based activities and interventions), the CPPN as a relevant and accountable agent of change, and engaging with key collaborators and stakeholders, found that more than 60% of all respondents agreed that the proposed events were realistic. However, several respondents cautioned that the targets, as presented, may be considered high and/or overly optimistic; and this significant effort must focus on simplified language and what is realistic and possible.
- Similarly, when asked to comment on three broad objectives of the CPPN focused on national credibility and its representative role, community engagement and its role in building individual and organizational capacity, trust and credible authority, more than 70% of all respondents agreed that, while the objectives are realistic, the CPPN must be very clear about its independent role, be aware of the work of others to ensure that efforts are not duplicated unnecessarily, and must remain flexible and responsive to needs at the local level with a clear understanding of current issues and priorities.
- In general, interviewees agreed that the CPPN needs to revisit the critical avenues it proposes to ensure a much more realistic and less ambitious approach in the future.

The level of detail in this report related to this activity alone is intentional as the "Setting Priorities" initiative was the most comprehensive and informative engagement work that THE CPPN undertook in its first year as a funding recipient. Particular attention to this activity also underscores the extent to which CPPN has worked to



protect the GIPA/MEPA/MEWA principles on behalf of its members and other people living with HIV and co-infections across Canada. The results of this work also represent the fundamental and fundamental considerations that CPPN members expect to guide the future and ongoing work of their national network.

In its first year, CPPN engaged 10% of its members in an in-person event in Toronto that undertook a gap analysis and needs assessment that recognized the importance of adopting lived experience as an essential piece of expert evidence that should guide Canada's response to HIV and HIV co-infections. This was a validation exercise that aimed to gain additional wisdom and insight in terms of what the CPPN's work needs to focus on in the future.

The Toronto gathering paved the way for a capacity development retreat in Montreal (March 2018) that mobilized more than thirty people. Members of the CPPN and the governance team, people living with HIV and co-infections in the greater Montreal area who were not yet members, as well as key representatives of the community of organizations that offer HIV and HIV co-infection services in Quebec were present. The meeting served to further validate the findings of the priority setting, but it also resulted in the establishment of the formalized CPPN bylaws, a charter of commitment, a competency building and operational guidance manual for current and future members of the CPPN governance team, and draft mandate documents for the CPPN Board of Directors, Executive Committee, Governance Committee, Strategic and Operational Planning Committee and Financial Management Committee.

Following significant efforts to engage and consult with CPPN members in preparation for the Public Health Agency of Canada's STBBI Roundtable in February 2018, two members of the CPPN governance team attended the roundtable, providing recommendations outlining the points that any action taken by the federal government in the development, the implementation and evaluation of the government's STBBI Framework must recognize and value the fact that lived experience represents unequivocal expertise and should not be overlooked.

With respect to tangible community resource products, CPPN collaborated with its members and community representatives across Canada to develop and distribute a "Community Resource Directory." CPPN also established its virtual and social media presence by launching its website, Twitter, and Facebook accounts in the first year. While data were not collected to highlight the success of these online platforms in terms of engaging people living with HIV and with HIV co-infections in particular, the comparative data reflects a gradual growth in reach.

Platform	Year ended 2018-03-31	Year ended 2019-03-31	Year ended 2020-03-31
Site Web			
- Total number of visits	1 245	1 432	No data were collected (See limits)
- Total number of page views	3 330	3 830	
- Unique visitors	896	1 030	
Twitter			
- Total number of subscribers	30	719	No data were collected (See limits)
- Re-Tweets	130	63	
- Total likes	162	186	
Facebook			
- Likes	118	136	No data were collected



- Comments	80	92	(See limits)
- Shared Total	456	524	

In the first and second years, although specific figures were not considered, CPPN members across the country actively and meaningfully participated in local, regional, and national activities commemorating World Hepatitis Day, the International Day for the Elimination of Violence against Women, the International Day of the World's Indigenous Peoples and World AIDS Day. Similar opportunities were realized in the third year but making them possible for CPPN members across the country was impeded, as noted in the limitations section of this report.

The focus on community collaboration and partnerships facilitated the active and meaningful participation of CPPN members in several skills building, capacity development, and knowledge development and exchange events during the first and second years, as outlined below.

« **AIDS 2018** »

Although not funded by the CPPN contribution agreement, several CPPN members participated in the development of Canada's presence at AIDS 2018 in Amsterdam, the Netherlands. Over 15% of CSPC members attended the full conference and pre-conference programs, including a pre-conference skills building event focused on Undetectable = Untransmittable (U=U).

The Executive Director of the CPPN was invited to attend a breakfast hosted by Canada's federal Minister of Health to represent the interests of the CPPN related to Canada's official position on U=U. In the end, the Minister took to the podium to officially announce Canada's support for the U=U campaign.

CATIE Forum - November 2017 - Transforming our practice: new knowledge, new strategies

In the months leading up to CATIE's 2017 Annual Forum in Toronto, a small number of CPPN members, including the Executive Director, were members of CATIE's National Advisory Committee responsible for programming the Forum. Just over 35% of CPPN members, supported externally, attended the Forum to build capacity and share knowledge focused on:

- Concrete actions to address HIV, HCV and other STBBIs in Canada.
- New science of HIV treatment and prevention and real-world practice: achieving our 90-90-90 goals.
- What it will take: Eliminate HCV by 2030.
- Harness innovative technologies and testing approaches to reach undiagnosed HIV and HCV.
- The Changing Landscape of Hepatitis C: Responding to the Changing Realities and Needs of Those Affected.
- Increase access to PrEP – gay, bi, and other men who have sex with men, and beyond.
- Addressing Factors and Barriers: The Role of Harm Reduction in Addressing Hepatitis C and HIV among People Who Use Drugs.
- Dried Blood Stain Testing: A New Community-Based Approach to Screening and Linking Hepatitis C and V IH.
- Peer navigation in HIV.
- HIV Stigma Index: Influencing programs and practice.
- HIV stigma through the prism of "Undetectable = Untransmittable".



- Approaches to changing the narrative of HIV communications in the era of the new science of HIV prevention and treatment.
- Advise clients on the risk of perinatal transmission of HIV in the context of U=U.
- Supervised consumption services.
- Access to hepatitis C treatment: Expand and diversify HCV treatment models.
- Structural stigma and the achievement of our HIV and hepatitis C goals.
- Multi-level approaches to improving mental health outcomes in Canada's African, Caribbean, and Black communities.
- Hepatitis C testing and linkage to care among Canadian immigrants and newcomers.
- The Mental Health Challenge: Developing mental health services as part of an effective combination HIV prevention response.
- Indigenization of harm reduction.
- The role of the HIV and hepatitis C response in the overdose crisis.

Canadian Association for Health Research, Annual Conference (Vancouver)

The participation of several CPPN members was provided directly and/or facilitated externally to:

- Participate fully in the work of the conference.
- Co-host the pre-conference sub-conference session, "25 Years of Meaningful Participation of HIV-Positive People: Community Action in Research."
- Co-facilitate the pre-conference sub-session, "Developing a National Action Plan to Advance the Sexual and Reproductive Health and Rights of Women Living with HIV in Canada."

HIV is not a crime training academy III (June 2018)

Following the successful participation of CPPN members in the "HIV is Not a Crime Training Academy" in Huntsville, Alabama (May 2016), CPPN members were sponsored and several other CPPN members participated in the Third HIV Training Academy is not a Crime Training Academy in Indianapolis, in Indiana, to build capacity and share learning focused on:

- Develop relevant and current leadership skills for an effective and intersectional criminalization movement.
- Criminal justice issues and advocacy strategies relevant to disproportionately criminalized communities.
- Advocates of resources, tools, and skills must succeed in developing and implementing a state-level campaign to repeal or modernize criminalization laws.

In conjunction with the CPPN priority-setting initiative, it was planned that **the regional Symposium would** validate the initial findings and then further explore problems, gaps and needs that are more related to the realities on the ground. Although the completion of the symposia in the five regions of British Columbia and Yukon, the Prairies and Northwest Territories, Ontario and Nunavut, Quebec, and Atlantic Canada was expected by the end of the second year, several factors intervened that prevented the completion of the full plan. These factors will be described in detail in the limitations section of this report. Highly productive sessions were held prior to the fiscal year ended March 31, 2019: the first in Vancouver in April 2018 and the second in Halifax in June 2018).



Regional Symposium: British Columbia and Yukon Territory, April 21, 2018

The CNPS partnered with the Positive Living Society of British Columbia to host this (first) regional symposium of CPPN members from British Columbia and Yukon. Twenty-nine people living with HIV and co-infections participated, representing just under 14% of all CPPN members at the time. While the program was designed to support the validation and development of the CPPN priority-setting initiative, it also included capacity development and knowledge sharing activities that focused on three topics of particular relevance to the region and to CPPN members across the country: (1) U=U with a focus on women and girls; (2) drug use and the opioid crisis, both regionally and across Canada; and (3) HIV and criminal law, in matters of HIV disclosure.

The deliberations summarized in the post-symposium report show that CPPN members in the region strongly believe that:

- The CPPN should be ready and willing to intensify its advocacy efforts: it should raise members' concerns about the funding process (and its shortcomings) with PHAC officials; he should be ready to stand in solidarity with the community in the calls to action where funding considerations are reviewed by PHAC officials and the Minister of Health; and the CPPN should stand in solidarity with local, regional and national organizations calling on the federal government to restore "core funding" for funding recipients at all levels.
- The CPPN should, as soon as possible, organize a national (virtual) roundtable focused on HIV and motherhood, and people who identify as men should be encouraged to participate.
- MEMBERS OF THE CANADIAN COALITION TO REFORM HIV CRIMINALIZATION (CTHRC) CPPN members should ensure that CTHRC's forward-thinking efforts and discussions focus on Canadian criminal law with respect to HIV and breastfeeding and/or breastfeeding.
- The CPPN should issue an explicit call to action that focuses on research related to HIV and mothers who breastfeed and breastfed.
- CPPN should make every effort to respect, honour and celebrate the community efforts and innovative work of British Columbia's community and academic activists who are leading the burden of treatment as prevention – an important precursor to the U=U movement and campaign.
- The CPPN should include in its long-term engagement plans the development and implementation of an advocacy program that supports and requires unequivocal attention and investment in research and treatment initiatives and the expanded/sustained provision of harm reduction supplies.
- The CPPN should ensure that its ongoing engagement efforts and initiatives include groups of drug users and include, support, and continue to encourage the active participation of people who use drugs.
- When developing and implementing its long-term engagement plans, the CPPN should remember and adopt the very fundamental principle captured by this quote from John McKnight, ***"Revolutions begin when people perceived as 'the problem' gain the power to redefine the problem."***
- The CHN must stand in solidarity with those most directly affected by HIV criminalization and must continue and strengthen its advocacy role with CHRC.
- "The CPPN must be insistent and present" in criminal law reform efforts, putting pressure on provinces and territories to develop and implement scientific guidelines for prosecutions.
- The CPPN should, as soon as possible, develop and implement education and social marketing initiatives that are evidence-based, linked to the U=U campaign and highlighted by lived experience.



- The CPPN, with and independent of CTHRC (where appropriate), should identify and foster meaningful partnership opportunities with local, regional, and national organizations to help advance a science-based, lived and living agenda to promote criminalization reform.
- The CPPN, in collaboration with CTHRC and local, regional, and national partners, should identify "other criminal law issues that are related to HIV but may not be directly related to non-disclosure." (E.g., HIV and child custody and safety laws.)
- The CPPN should explore opportunities to develop and implement "storytelling" initiatives in which individual experiences with HIV and criminal law are presented in efforts to "expose the injustice" of Canada's current criminal law enforcement – particularly with respect to the experiences of HIV-positive women.
- The CPPN, in collaboration with CTHRC, should convene a sub-committee or working group to explore HIV criminalization and its impact on African, Caribbean, and Black communities in Canada.

Nearly 100% of symposium participants completed the evaluation form. Anecdotally, all participants indicated that their level of knowledge and personal confidence in their ability to effectively share this knowledge with their peers increased because of the Symposium's deliberations. Participants also made it noticeably clear that the Priority Setting initiative is and will continue to be of critical importance to the ongoing work of the CPPN and the evolution of credibility. Data collected through the evaluation form were reviewed; the specific limitations on their analysis and reporting will be described in detail in the limitations section of this report.

Regional Symposium: Atlantic Canada (all four provinces), June 23-24, 2018

CPPN partnered with the Atlantic Interdisciplinary Research Network to plan and facilitate the second regional symposium for CPPN members from New Brunswick, Nova Scotia, Newfoundland and Labrador and Prince Edward Island. Thirty-seven people living with HIV and co-infections (more than 17% of all CPPN members at the time) gathered in Halifax for two days of rich deliberation. The approach of this symposium was slightly different from that of the BC-Yukon meeting in that the first day program was dedicated to the areas of interest of the CPPN, and the agenda for the second day facilitated the time and space for participants to delve deeper into HIV research and HIV co-infections in Canada (in general) and in the Atlantic region in more detail.

The CPPN-specific agenda, such as the Vancouver meeting, was organized to facilitate the further validation and development of the "Setting Priorities" initiative. Time was also allocated for capacity building and capacity development sessions focusing on: (1) U=U; (2) the opioid crisis in Canada (in general) and in the Atlantic region (in particular); and (3) HIV and criminal law reform. While the second day was designed to inform the Atlantic Interdisciplinary Research Network, the day's discussions (by all accounts) resonated with CPPN members and inspired several members to dedicate their ongoing contributions to the region's research efforts as experts in HIV and HIV co-infections based on their lived experience.

Based on the discussions that followed the event with members of the CPPN leadership team, there should be no doubt that the Atlantic meeting unfolded in a particularly different (and challenging) manner from the Vancouver experience. In fact, a member of the management team described the rally as a show that completely derailed for reasons that were not obvious or easy to explain. Nevertheless, although anecdotally once again, when discussions focused on the ongoing work, relevance, and credibility of the CPPN, most participants expressed their conviction that with focused efforts and ongoing consultation and dialogue, "the



future of the CPPN is bright." Specific limitations related to meeting discussions and post-event evaluation and analysis will be highlighted in the limitations section of this report.

At the heart of this report and the growth and relevance of the CPPN in its first three years is a description of the valuable partnerships and collaborative opportunities that CPPN members have been offered by many community organizations that have done remarkable work in Canada's response to HIV and HIV co-infections. These partnerships are summarized below. It is important to note that several HIV-positive people and with HIV co-infections, virtually from their CPRN membership, have been significantly engaged in each initiative included here. In addition, there is little doubt that CPPN members have benefited significantly from the outputs and the deliberations that have resulted from them. However, as the CPPN was not the lead organization for these interventions, impact data was not collected or analyzed with respect to the relationships between the opportunities and the "SMART" objective of the CPPN. Given this reality, valuable lessons learned will be outlined in the Lessons Learned section of this report.

Collaborative partnerships that involved and engaged several CPPN members from across the country during the first three years of the CPPN included:

Documenting Lessons Learned: Canadian Aboriginal AIDS Network Advisory Committee

Joining forty-five global partners and several Canadian organizations working to improve and monitor the response to HIV and HIV co-infection with respect to Indigenous peoples, CHN members had the opportunity to participate in critical discussions focused on national and international best and promising practices and approaches that demonstrate results towards achieving global HIV reduction goals, tuberculosis, and hepatitis C. It will provide an opportunity for Indigenous peoples, researchers, and policy makers to develop recommendations to strengthen and harmonize monitoring and evaluation systems to track outcomes across the continuum of care. This project is also expected to support Canada's commitment to address the disproportionate impact of HIV, TB, and hepatitis C in Indigenous communities and guide Canada's efforts to move towards global targets related to HIV, TB, and hepatitis C by 2030.

Canadian Coalition for HIV Criminalization Reform

Under the leadership of the Canadian HIV/AIDS Legal Network, CPPN members joined representatives from the national (and local) HIV and legal communities to contribute to ongoing deliberations and policy development recommendations focused on why Canada's federal and provincial HIV laws (particularly HIV disclosure) are outdated and require immediate reform.

Canadian HIV Stigma Index Steering Committee

As part of CPPN's ongoing contributions to HIV research in Canada, members joined with research experts from across Canada to participate in and contribute to the development of the HIV Stigma Index, a research and community-building tool used in more than ninety countries around the world that is designed (and evolving) to gather information on people's experiences. HIV-positive people related to stigma, discrimination, and human rights.

Transforming our practice: new knowledge, new strategies: CATIE National Advisory Committee

This opportunity for partnership and engagement for CPPN members was described earlier in this report. One highlight that has not yet been considered, however, is that the Executive Director of the CPPN was invited to



present, on behalf of the CPRN members, the importance of adopting the "GIPA/MEPA/MEWA" principles in all aspects of Canada's response to HIV and HIV co-infections in a keynote address to the plenary.

AIDS 2018: Canadian Society for International Health National Advisory Committee

CPPN's commitment to AIDS 2018 was described earlier in this report. However, one element that has not yet been captured is that the Executive Director of the CPPN was invited to join several of his HIV-positive peers (also members of the CPPN) to contribute to the production of a "Personal Stories" video that was presented at the Canada Pavilion in Amsterdam.

Operation CHIWOS

Several CPPN members were engaged by representatives of the Sexual and Reproductive Health of Women Living with HIV in Canada Cohort Study to make significant contributions to the study grant application and highlights of the related Research Ethics Board application for approval and its supporting documents.

Reaching the Undiagnosed in Canada: Action Plan – Pragmatic Leadership and Implementation Strategies

Several CPPN members joined a national advisory committee comprised of a multidisciplinary group of representatives from REACH, St. Michael's Hospital, and many national and regional organizations to help develop a national action plan focused on:

- Citizen engagement.
- Canada's diagnostic landscape and barriers to testing implementation and "scaling."
- Barriers and opportunities for the implementation of point-of-care testing technologies.
- The regulatory testing review and approval process in Canada.
- National leaders and partnerships with laboratory systems; and
- Creation of a Canadian Working Group on Testing and Testing Leadership in Canada.

HIV and Life Insurance: National Advisory Committee to Achieve

CPPN members joined a highly specialized and multidisciplinary group of community, private sector and academic representatives from Canada and international jurisdictions to:

- Foster dialogue between insurance providers, community organizations and HIV-positive people on life insurance issues.
- Identify insurance issues and opportunities that impact HIV-positive people.
- Identify current practices and potential future strategies to address these issues.

This work was inspired by the little-known or understood reality that some life insurance companies and/or policyholders adopted policy changes that HIV should be considered a chronic, manageable disease that would no longer be included in companies' disqualifying prerequisite lists. Because the policy change was so discreet, CPPN members were consulted prior to this dialogue to identify and isolate the issues and issues that were most on the minds of HIV-positive people in Canada.

Canada's 4th 90: Gilead National Advisory Committee

CPPN members, at the invitation of Gilead (a multinational pharmaceutical company), engaged with representatives of Canadian community organizations, private sector stakeholders and the Canadian HIV research community to develop a strategy paper that explores the notion (and recommends related actions) that "there is a growing belief that 90-90-90 is not about optimizing care for people living with HIV." To truly



meet all the needs of HIV-positive people, we also need to pursue a fourth "90", where 90% of HIV-positive people also have a good health-related quality of life.

Ending the Epidemic: Canadian Treatment Action Council Advisory Committee/Working Group

The Canadian Treatment Action Council brought together a small group of HIV-positive people (CPPN members) to collaborate on a peer-centred, community-based plan to "end the epidemic," including an opinion piece that highlighted "why we are not winning the war on HIV." This work included a focus on: (1) improving testing (innovative technologies, developing a culture of frequent testing, meeting people "where they are"); (2) move from a disease model to a sexual health model; (3) provide instant referrals to prevention, treatment, and support services; and (4) innovative ways to combat stigma.

HIV Disclosure in the Workplace: University of Winnipeg Advisory Committee/Working Group

The University of Winnipeg established an advisory committee or working group that included CPPN members from representatives from the Nine Circles Community Health Centre, the Toronto HIV/AIDS Network, and Realize deliberated and developed a manuscript entitled "Supporting Choices about HIV Disclosure in the Workplace: A Cross-Canada Survey of Current Strategies". This work was highlighted by a representative from the University of Winnipeg in conjunction with a CPPN member at the Canadian Association for HIV/AIDS Research conference in Vancouver.

Canadian HIV Trials Network Community Advisory Committee

CPPN representatives were invited by the Canadian HIV Trials Network Community Advisory Committee to contribute to the review and selection of recruits and/or candidates for the Committee, all of whom are HIV-positive individuals and many of whom are CPPN members.

The "Seeking Help" project

THE CPPN was invited to support and develop a partnership relationship with the Seeking Help project: a space where service providers can engage with each other on issues related to addiction and mental health. This work is evolving.

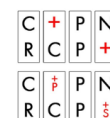
The 15k Challenge

CPPN members actively participated in a dialogue focused on operationalizing the women-centred model of HIV care from the perspective of HIV-positive women and their caregivers. The objective of this initiative, and the specific area of focus for comments and advice from CPPN members, was twofold:

- To determine whether the BCSC model addresses the unique needs and barriers that HIV-positive women face in accessing health care in Ontario by introducing our BCSC model to HIV-positive women and health care providers (HCPs) who provide care to HIV-positive women.
- Develop an action plan to ensure the feasibility and adoption of the WCHC model by seeking input from HIV-positive women and health professionals in Ontario through focus groups.

Pan-Canadian Framework for Action: Reducing the Health Impact of Sexually Transmitted and Blood-Borne Infections in Canada by 2030

The Public Health Agency of Canada invited two representatives from the CPPN governance team to participate in a national roundtable that would help: (1) update progress for stakeholders in developing a pan-Canadian framework; and (2) identify concrete priority actions arising from the Framework in areas of common interest



for the implementation of the Framework. CPR members were consulted (electronically) in the preparation of this roundtable and provided valuable information and recommendations that effectively contributed to discussions focused on key elements of the Roundtable agenda:

- Horizontal enabling factors.
- Targets and data.
- Comprehensive sexual health education.
- Reduction of stigma.
- Prevention.
- Access to testing and treatment.
- Integration; and
- Financing.

Priority Populations and/or Target Audiences

Project Reach

SMART Objective	Output	2017-2018 Geographic reach of the activity	2017-2018 No. of Individuals Reached	2018-2019 Geographic reach of the activity	2018-2019 No. of Individuals Reached	2019-2020 Geographic reach of the activity	2019-2020 No. of Individuals Reached
By 2022, the Canadian Positive People Network (CPPN) will have delivered one hundred Interventions (i.e., engagement actions) to 180 people living with HIV and/or HIV co-infections (Hepatitis C, STBBIs) across Canada to: <ul style="list-style-type: none"> • strengthen capacity in, self-confidence, and credibility by 20%, and • Twenty percent of participants will report having applied the new skills in local, regional, and national interventions (i.e., engagement actions) 	Engagement interventions which support: <ol style="list-style-type: none"> 1. Knowledge development, translation, and exchange, 2. Communications, media, and social marketing, and 3. Supportive environments and mobilization. 	National	150	National	212	National	206

Age Breakdown of the Priority Population Reached

Year	19 and under	20-29	30-39	40-49	50-59	60+	Unknown
2017-2018	0	7	25	32	48	38	
2018-2019	0	10	35	45	68	54	
2019-2020	0	9	35	43	65	54	



Gender Identity/Gender Expression of the Priority Population Reached

Year	No. of Females	No. of Males	No. of Trans Males	No. of Trans Females	No. of Other	Gender Identity/ Expression Unknown
2017-2018	49	88			13	
2018-2019	69	125			18	
2019-2020	66	122			18	

Specific Groups of Indigenous People Reached

Year	No. of First Nations Individuals	No. of Inuit Individuals	No. of Métis Individuals	Unknown
2017-2018	8			
2018-2019	11	2	5	
2019-2020	10	2	5	

Referrals to Testing and/or Treatment

Year	Number of individuals referred to treatment	Number of individuals referred to STBBI testing services	Unknown
2017-2018	Not applicable; the CPPN does not make treatment or testing referrals.		
2018-2019			
2019-2020			

By design, the CPPN activities and engagement are inclusive and representative of a broader population of people who bring to bear lived/living experience that is not exclusive to HIV, and who are more centrally entrenched in a truly integrated public and social health response that is comprehensive and informed by people and their peers on the ground.

Project Resources

The CPPN's Contribution Agreement under the Community Action Fund, initially, stipulated approval for the total expenditure of \$901,677. The following detail highlights the planned vs. actual expenditures year-over-year from April 2017 to March 2020. Specific challenges related to the CPPN's workplan and the related impact on its budget for year three are described in the limitations section of this report.

Budget category	Fiscal Year Ended 2018-03-31			Fiscal Year Ended 2019-03-31		
	Planned Expenditures (\$)	Actual Expenditures (\$)	Variance (\$)	Planned Expenditures (\$)	Actual Expenditures (\$)	Variance (\$)
Personnel	63,093	58,520	(4,573)	65,096	59,730	(5,366)

Travel	63,285	38,176	(25,109)	75,126	52,685	(22,441)
Materials	4,668	5,894	1,226	5,669	3,516	(2,153)
Equipment	300	0	(300)	305	0	(305)
Rent/Utilities	70	0	(70)	71	0	(71)
Evaluation	12,000	0	(12,000)	14,000	12,000	(2,000)
Other	6,824	4,078	(2,746)	7,501	17,026	9,525
TOTAL	150,239	106,169	(44,070)	167,768	144,957	(22,811)

For Fiscal Year ended 2018-03-31, the total variance, as pertains to funding planned, received, and expended under the terms of the CPPN Contribution Agreement is linked directly to the late arrival of funding. While the Contribution Agreement was approved and the project’s official start-date was April 1, 2017, the payment was not received until after project activities and related spending had commenced. More specifically, some of the under-spending was due to time-constraints and operational challenges associated with executing some of the planned activities. For example, the travel budget for the year was under-spent because it was deemed fiscally irresponsible to convene planned face-to-face gatherings of CPPN members later than originally anticipated because travel-related costs have risen significantly since the costing for such gatherings was first estimated. The CPPN Program Consultant and the representative from the Public Health Agency of Canada’s Centre for Grants and Contributions were apprised of the CPPN’s determinations and agreed with recommendations to postpone and/or cancel some of the planned activities.

For Fiscal Year ended 2019-03-31, explanation of the budget variances is more complex in that planned activities and related expenditures were notably interrupted by a governance and operational crisis that negatively impacted the CPPN’s organizational structure and impeded its ability to effectively conduct its planned activities. A full and detailed explanation of related challenges and effect on the CPPN to realize the full potential of its approved workplan, is included in the limitations section of this report.

Except for one paid (contractual) representative, the CPPN Executive Director, the project is entirely driven by the effort and dedication of people living with HIV and HIV co-infections who volunteered their time AND their expertise (and will continue to do so) to:

- Articulate the CPPN’s foundational “raison-d-être” and translate the thoughts and feelings of people living with HIV and HIV co-infections from across Canada to establish the CPPN as a relevant, credible, and meaningful national network (in the beginning, with or without funding).
- Establish the CPPN’s original governance structure and the required “corporate” documents and declarations that paved the way for its official incorporation as a viable not-for-profit entity in Canada.
- Recruit members and maintain an uncompromising commitment to each that the CPPN was, is, and will remain an independent national network of, by and for people living with HIV and HIV co-infections in Canada... even if/when this sometimes meant (and will continue to mean) taking unyielding (but not always popular) advocacy positions that could jeopardize its federal funding.
- Develop the CPPN’s workplan and associated budgets and then (successfully) negotiate their value and importance to the Public Health Agency of Canada, and to a broad and diverse range of individuals and community-based organizations and related stakeholders for whom/which Canada’s response to HIV and HIV co-infections is central to their individual and collective contributions.



- Influence, foster, and champion meaningful debate and dialogue to shape public health policy which respects and safeguards the expertise that is represented by the lived/living experience of people living with HIV and HIV co-infections at “the centre of the circle” as it relates to affecting positive change and innovative evolution that positively impacts the health, wellbeing, and quality of life for all people living with HIV and HIV co-infections in Canada (whether individuals are members of the CPPN or not).

While members of the CPPN leadership team and members of standing or ad-hoc committees, past and present, signed an understanding that a minimum of ten hours per month of volunteer time would be required, it has been difficult to quantify the total number of hours that these volunteers have truly invested.

The current leadership team of the CPPN agrees that the inability to capture specific data which place a numeric value on the number of hours that volunteers contribute is a shortcoming that requires resolution going forward. It is addressed in the lessons learned section of this report.

Project Involvement of People Living with HIV/AIDS, Hepatitis C and other STBBI

As Canada’s only national, independent network of, by and for people living with HIV and HIV co-infection, the CPPN is a living reminder that many people who survived the earliest days of HIV/AIDS are still living despite the odds and, therefore, have unequivocal expertise and invaluable insight that can and must guide the ongoing response to HIV in Canada and around the globe.

By design and, the CPPN engagement is inclusive and representative of a broader population of people who bring to bear lived/living experience that is not exclusive to HIV, and who are more centrally entrenched in a truly integrated public and social health response that is comprehensive and informed by people and their peers on the ground.

KEY INDICATORS OF PERFORMANCE

SMART Objective	Indicator	Year	Total Number of Participants	Total number of Respondents	Pre-Intervention Result	Post-Intervention Result	Result (%)
By 2022, the Canadian Positive People Network (CPPN) will have delivered one hundred Interventions (i.e., engagement actions) to 180 people living with HIV and/or HIV co-infections (Hepatitis C, STBBIs) across Canada to:	Strengthen the capacity, self-confidence, and credibility of 180 people living with HIV and HIV co-infections across Canada to be actively and meaningfully engaged in Canada’s response to HIV and HIV co-infections] by 20%.						
	Ensure that, Ensure that, ff 180 people living with HIV and HIV co-infections in Canada who participate in the CPPN’s engagement opportunities/activities, 20% of participants report having applied the new skills in local, regional, and						

	national interventions (i.e., engagement actions).	<p>subject to their own performance measures for approved activities contained in their respectively funded workplans.</p> <p>If this is a failing rather than an invaluable lesson and directive for future management and leadership, the CPPN current governance team accepts full responsibility.</p> <p>This narrative is necessary in the spirit of full transparency, as even in those activities for which mandatory indicator data were collected and analyzed, the evidence to support this assertion is either missing from the files or should come under scrutiny for its credibility given the significant governance and organizational crisis that served to immobilize the CPPN mid-way through its second year.</p>
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In past and future efforts to monitor and measure the CPPN performance against the mandatory indicators, the following overarching outcomes underpin all the CPPN’s engagement activities with its members and with people living with HIV and HIV co-infections from across Canada:

1. Increased Capacity (skills, competencies, and abilities) to prevent infection and improve health outcomes (CAF Outcome-3)

By initiating and supporting meaningful engagement opportunities with and by people living with HIV and HIV co-infection, both individual and community capacity is strengthened and facilitates making informed, healthy decisions related to prevention, diagnosis, care, treatment, and support. This enhanced capacity also supports the CPPN’s capacity to readily identify gaps, needs, and priorities, and to identify and/or address policy and programmatic barriers and challenges. It is anticipated that people living with HIV and/or HIV co-infection will be confident as credible experts in their own lives and empowered to make meaningful contributions in ways which affect their health, well-being, and quality of life, and have a positive impact on Canada's response to HIV and HIV co-infection.

2. Enhanced Application of Knowledge in community-based interventions (CAF Outcome-4)

Increased individual and community capacity (skills competencies and abilities) contributes to a supportive environment in which people living with HIV and HIV co-infection have enhanced capacity to mobilize, as credible experts in their own lives, to improve access to programs and services (health, social and support services), and to apply their knowledge more-readily in community-based activities and/or best/promising practices.

3. Improved Access to health, social and support services (CAF Outcome-6)

The CPPN's meaningful engagement opportunities with and by people living with HIV and HIV co-infection facilitates the identification, development, and/or implementation of concrete actions and activities to address priority issues both independently and in partnership/collaboration with allies, community-based organizations, and other relevant/key stakeholders.

METHODOLOGY

The CPPN data collection processes and analysis methodology plans were clear in its intended approach and as related (specifically) to each of its planned and approved engagement activities/interventions. Excepting a few activities that were intentionally designed as foundational in nature (i.e., operationally focused on the CPPN’s form, function, and structure), execution of the CPPN’s engagement activities/interventions was intended, in all cases, to contribute in quantifiably measurable ways. to the realization of the improved/increased capacity,



confidence, and credibility of CPPN member and people living with HIV and HIV co-infections in Canada in terms of their individual and collective contributions to Canada’s response to HIV and HIV co-infections as experts in that response by virtue of their lived/living experience – if not because of their professional and/or academic credentials. The performance measurement intent and data collection methodology attached to each of the CPPN planned activities included but was not limited to:

- One-on-one interviews,
- Key informants focus groups,
- Consultative surveys and questionnaires,
- Pre- and Post-intervention feedback (evaluations), and
- An “open invitation” for ongoing feedback, advice, and recommendations.

It was and is the intent of the CPPN to gather data which measure and reflect their organizational relevance, credibility, and value relative to the members’ contributions to the Canadian response to HIV and HIV co-infections. This includes perspectives of external individuals, community-based partners and allies, other stakeholders engaged in Canada’s response, and multi-level governmental agencies. Interviews, surveys, and evaluations of the CPPN performance when it or its members serve as advisors/collaborators for activities that the CPPN is not identified as the convenor is and will be particularly important.

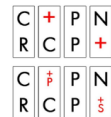
The approach/methodology described was successfully implemented during the first three years of the CPPN activities. Regrettably, the evidence to support this assertion is primarily anecdotal due to the challenges noted and the limitations described in the limitations section of this report.

Administrative and demographic data were gathered and analyzed on participants joining CPPN. This data was compiled on Excel spreadsheets and Survey Monkey platforms. Tables were used for simple quantitative analysis (frequencies, cross-tabulations etc.). Output level data were tabulated, analyzed, and rolled up using simple analysis (#s, frequencies) and summarized data will be made available for the CAF Annual Report. Sex and Gender-based analysis was undertaken using the demographic data and project administrative information.

Data Collection Methods and Analysis

Where formalized data collection and analysis occurred and can be supported by documented evidence, every opportunity to reflect upon and assess the CPPN performance was limited to people living with HIV and HIV co-infections. This assertion does not suggest that people who do not live with HIV or HIV co-infections cannot make valuable contributions to the ongoing assessment of the CPPN performance. However, the CPPN is Canada’s only national, independent network of, by and for people living with HIV and HIV co-infections in Canada and, as such, its primary focus is on service and accountability to people living with HIV and HIV co-infections. So, by design and by default, all data collection and analysis efforts were and will be undertaken by CPPN members and never exclusive to members of the CPPN’s governance team.

Despite the success of the CPPN’s first two years, unequivocally supported from an anecdotal perspective, evidentiary support for that success by way of documented data collection initiatives and analyses is only marginally possible due to the challenges and limitations described in the appropriate section of this report. It is critical to note that the current governance team of the CPPN and the designated representatives of the



Public Health Agency of Canada responsible for the CPPN Contribution Agreement are aligned in terms of the difficult realities that the CPPN has faced. We all acknowledge that the CPPN is accountable to report effectively and with credibility, supported by documented evidence related to the CPPN’s performance and the efficacy of its engagement interventions with members as well as on their behalf

Limitations and Constraints

The limitations and constraints described herein are not exclusive to evaluating the CPPN’s mid—term progress. Rather, it must be noted that significant governance and operational challenges which emerged during the CPPN’s second year (and continued for most of its third year) created an uncertain future for the CPPN in terms of its viability to the end of its current Contribution Agreement and beyond. These challenges adversely affected the CPPN’s ability to fulfill its planned activities, the organization’s credibility within the Canadian community of organizations which serve people living with HIV and HIV co-infections in Canada, and, indeed, the trust, confidence, and faith held in the CPPN by its members. In fact, while the CPPN was experiencing notable growth in year two (i.e., membership registration increased by 50% from year one to year two), but its governance and operational ‘crises prompted the membership withdrawals of four people living with HIV and HIV co-infections and the expulsion of two members due to behaviours that contravened the CPPN’s values and guiding principles. True that these numbers only represent a 3% reduction (approximately) in the CPPN’s membership, losing any member because of a loss of confidence in the CPPN’s relevance is cause for concern and expedient mitigation.