

Looking ahead: our “Letter of Intent” (LOI)

Thinking beyond the “life” of the CPPN’s current contribution agreement with the Public Health Agency of Canada’s Community Action Fund (which terminates on March 31, 2022), we did submit a comprehensive “Letter of Intent” (LOI) to seek funding for fiscal years 2022-2023 through to 2026-2027. The following excerpts from the LOI highlight the salient points of our proposal.

THE CHALLENGE WE WILL ADDRESS

While data (estimates) are nearly three years old, the CPPN recognizes that new HIV infections continue to occur despite prevention efforts and improved prevention technologies. According to the [Public Health Agency of Canada](#), there were 62,050 people living with HIV in Canada in 2018 and, in the same year, more than 2,000 new HIV infections were identified. We also know that as many as 8,000 individuals are living with HIV but are unaware of their sero-status.

In terms of HIV co-infection (specifically, hepatitis C), based upon estimates published by the [World Health Organization](#), we know that up to 15% of people living with HIV worldwide are also affected by hepatitis C infection. Extrapolating for Canadian context, this estimate suggests that HIV co-infection affects as many as 9,000 Canadians.

While the CPPN does not purport to represent all people living with HIV or HIV co-infection in Canada (i.e., current membership is far-less than 62,000 individuals), its raison-d’être is to work with and seek advice and guidance from as many people living with HIV and HIV co-infection as possible. The CPPN’s mission and mandate and, indeed, its activities are developed and delivered with, by and for people living with HIV and HIV co-infection.

Though difficult to quantify, it concerns most of CPPN’s members that the meaningful engagement of people living with HIV and HIV co-infection is trending toward (or has notable potential for trending toward) tokenism. The CPPN certainly agrees with the conclusion drawn in a paper published by [“Project PEER”](#): *“Currently, there are no common standards or frameworks/guidelines on how to operationalize GIPA/MEPA in either an organisational or research team context.”*

In formally incorporating, the CPPN answered the call of people living with HIV first articulated in 1993. It was that long ago that people living with HIV identified a need for a national network that would ensure their meaningful engagement despite the absence of common standards, frameworks, or guidelines that define meaningful engagement at local levels.

In fact, it was - and remains - the vision of the CPPN's earliest members that the CPPN is and should be best-situated to define for themselves what meaningful engagement is and ought to be. The CPPN's members represent unequivocal expertise by virtue of their lived and living experiences that should never be tokenized, but too often feels like it is.

The **central tenet** of this project (Letter of Intent) is to reassert and underscore that understanding and adopting a set of principles which place true value on the meaningful engagement of people living with HIV and HIV co-infection lacks credibility and does not instill confidence for people living with HIV and HIV co-infection if/when these 'principles' are not the product of the people for whom they are intended.

OUR PROPOSED APPROACH

While the CPPN is a virtual network that was not designed to reply upon a conventional bricks and mortar" approach to its operational framework, it was and will always be the CPPN's commitment to facilitate face-to-face opportunities for people living with HIV and HIV co-infection designed to ensure meaningful interactions and peer-driven support, capacity-building, and camaraderie.

The arrival, persistence, and impact of the COVID-19 pandemic has undoubtedly made it impossible to fully meet this commitment safely and of its intent. The CPPN has and will continue to adapt its functional approach to meaningful engagement through ongoing virtual opportunities. At the same time, the CPPN is optimistic that effective public health interventions in the near- medium-terms will put COVID-19 and its social distancing requirements behind us.

Therefore, the proposal outlined within this LOI anticipates an approach that takes various forms over five years: virtual Webinars, workshops, seminars, and regional and national policy dialogues and roundtable meetings; and, when it is 'safe' from a public health and safety perspective, face-to-face skill-building fora and priority-setting/needs assessment members' meetings.

Activities will include (but may not necessarily be limited to):

- Establishment of working groups that represent the diversity of the CPPN's members (as illustrated above) and are composed of peers who will:
 - Work together to identify their needs and priorities.

- Develop initiatives that build individual and collective skills and capacity to represent their needs and priorities with confidence and credibility.
 - Actively participate in the design and delivery of workshops, seminars, and ongoing priority-setting consultations.
 - Be instrumental in the ongoing performance measurement and evaluation activities that will guide the CPPN.
 - Be meaningfully engaged in activities that are designed to issue “calls to action” for service providers, educators, policymakers, and politicians, and one another as peers.
- Probative and retrospective examination (and celebration) of life as a long-term survivor and as people who are aging with HIV and HIV co-infection.
 - Collaboration with peers and service-providers to focus on the quality of life of people living with HIV to define and articulate Canada’s “4th 90” in the domestic and global response to HIV.
 - Facilitation of CPPN members’ meaningful engagement in knowledge development and skills-building opportunities offered by local-, regional-, and national-level service providers and decision-making bodies (e.g., Communicating effectively on issues related to criminal law reform).
 - Development and delivery of national “campaigns” designed to:
 - Raise (and evolve) general awareness of and sensitivity to the real-time issues faced by people living with HIV and HIV co-infection, including (but not limited to) social determinants of health and related disparities, systemic barriers to accessing care and community-based services, the importance of access to prevention technologies, and the need for national pharma care.
 - Combat the stigma and discrimination that too many people living with HIV and HIV co-infection continue to experience in their everyday lives and articulate strategies that protect people living with HIV and HIV co-infection from the real and potential consequences of the discrimination we experience - personally and collectively.
 - Continue to support and enhance messaging that underscores and highlights scientific and community-based advances which contribute to our quality of life (e.g., Undetectable = Untransmittable).

- Address and raise awareness to issues related to gender-identification and gender disparities which people living with HIV and HIV coinfection continue to experience in programs and services - locally, regionally, and nationally.
 - Promote testing and the ongoing development of testing technologies in effort to identify those who are unaware of their sero-status and, ultimately, facilitate processes which guide them to treatment and care.
- Facilitation of regular/ongoing opportunities for people living with HIV and HIV co-infection to engage with one another interactively and meaningfully for peer support, to:
 - Help minimize feelings of isolation.
 - Address “survivor guilt”.
 - Support one another's efforts to identify, enhance, and sustain personal strategies which are designed to safeguard our individual and collective health, wellness, and quality of life.
 - While preliminary and included here as output examples (over five years), initiatives/project activities will include (but are not necessarily limited to):
 - A jointly hosted initiative with the Canadian HIV/AIDS Legal Network focused on understanding criminal law related to non-disclosure and building the skills necessary to speak publicly on the subject, to participate in public policy dialogue, and to contribute to position statements which underscore the need for criminal law reform.
 - A jointly hosted knowledge development initiative which serves to “define” quality of life for people living with HIV in Canada and then to design a Canadian-based approach/action plan as the “4th 90” in the domestic and global response to HIV.
 - Regionally focused round-table meetings intended to monitor local trends (e.g., epidemiology, emerging issues, co-morbidities and syndemic conditions, etc.) and to develop peer-driven action plans to address/combat systemic barriers to care and services, to promote and encourage testing, and to tackle regionally specific health disparities and sources of stigma.
 - Policy dialogues that probe for practical and ethical considerations and policy and programmatic recommendations related to testing and diagnosis, care, and support services (outside of the medical model), emerging prevention, testing, and treatment technologies, surveillance, and data collection, etc.

- Development and delivery of national “campaigns” to enhance general awareness and sensitivity to the lived and living experiences of people living with HIV and HIV co-infection.
 - “Love Positive Women”
 - Aging
 - Anti-stigma
 - Anti-racism
 - Anti-sexism

- Hosting and/or co-hosting workshops focused on determinants of health (beyond the diseases-specific paradigm) to identify and understand health and social issues which affect our well-being and quality of life; navigating “systems”; learning how to be effective advocates for our own needs.
- Developing peer-based approaches to social marketing and social media focused on learning how we can and should work together to develop and deliver social marketing campaigns that are relevant to our “real-time/real-space” needs and priorities; how can we work together to effectively put social media to work for us and with us?
- Developing strategies to build and sustain effective partnerships: understanding how and why we need to develop and foster effective partnerships (with each other, with our communities, with our allies, with funding agencies, with governments, etc.); identifying our partnership successes and challenges to-date; building strategies focused on building and maintaining future partnerships and collaborative relationships.
- Hosting and/or co-hosting roundtable meetings to identify and develop population- and/or issue-specific position and solidarity statements and related action plans (e.g., “Black Live Matter”, engaging Indigenous Peoples and acknowledging Indigenous lands).
- Collaborating with regional networks to promote and foster the “Positive Leadership Development Program”.
- Publishing the CPPN’s quarterly newsletter “Interconnected”.

The activities described above are deliberately ambitious and the CPPN is confident that realizing evolving progress to their inherent intent over five years is possible because (and only if) they are each identified by people living with HIV and HIV co-infection and will be designed, delivered, and monitored by CPPN members. The Community Action

Fund sets out to ensure that funded efforts reach key populations, are evidence-based (both quantitative and qualitative in scope), that maximize the potential benefit for as many people living with HIV and HIV co-infection as is reasonably possible, and that squarely address the stigma that disproportionately affects us. The CPPN maintains that the activities proposed herein meet, and may exceed, the objectives of the Fund. Moreover, perhaps, the federal government’s health portfolios each have integral roles and mandates to protect and promote the health and wellness of Canadians. At the true core of the CPPN’s proposed activities is the same “marching order”... health promotion, care and support for people living with HIV and HIV co-infection.

HOW (WHY) IS THE CPPN BEST SUITED TO UNDERTAKE THIS WORK?

The project proposed in this LOI is “Greater and More Meaningful Peer Engagement and Mentorship”. The CPPN recognizes and acknowledges that there are many local, regional, and national allies and service organizations in Canada who/which all focus their full-time efforts in the interest of the health, well-being, and quality of life of people living with HIV and HIV co-infection in Canada. Furthermore, as noted earlier, the CPPN values the relationships it sustains now and will foster in the future with all of them. And, undoubtedly, the CPPN can, does, and will continue to learn much from all the experts that these allies and organizations represent.

Notwithstanding these truths, the CPPN IS the only national independent network OF, BY, and FOR people living with HIV and HIV co-infection. As such, its very existence is the product of the efforts and activism of people living with HIV and HIV co-infection from across Canada. And, indeed, the CPPN’s ongoing existence and its viability and credibility going forward does and must rely on the advice, guidance, and meaningful engagement of people living with HIV and HIV co-infection.

Since this project is wholly focused on enhancing and fostering greater and more meaningful peer engagement and mentorship, by design and default the CPPN is the best-suited organization in place in this country to represent our needs and to assert our health, wellness, and quality of life priorities. Why? Because we live those needs and priorities every single day. Why? Because, when it really boils down, the CPPN is the only organization in Canada that represents an individual and collective archive of lived experience and the only “real-time” repository of living experience and expertise that must be central to the domestic response to HIV and HIV co-infection, now and always.

Who better to reach out to peers who do not realize that they are peers (i.e., people who are unaware of their sero-status) with respect to the myriad stressors associated with testing, diagnosis, and acceptance of a positive diagnosis than a person who has lived through it?

Who better to reach out to peers - young and old, long-term survivors and newly diagnosed - to help navigate the complex nature of health and social services; to the care and treatment cascade; to local-level services; to understand the broader implications of public policy and public policy imperatives that a person who is living through it now and every single day?

Who better to realize the greater and more meaningful peer engagement and mentorship with, by, of, and for people living with HIV and HIV co-infection? Who better than the members of the CPPN (with and alongside its allies and community-based ‘partners’)?

WHAT IS OUR PROPOSED INVESTMENT IN THE CPPN OVER 5 YEARS?

The level of funding we outlined in our LOI represented a total of **\$2,006,769** over 5 years:

Year One:	\$376,450	Year Two:	\$388,711
Year Three:	\$402,258	Year Four:	\$410,102
Year Five:	\$386,808		

This sum represents significantly more than the CPPN received through its first five (funded) years. However, central to the heart of our proposal is an **unwavering commitment to (truly) meaningful engagement and greater involvement of people living with HIV and HIV co-infection**. While, to some folks, \$2 million+ over five years is a lot of money. However, in our LOI we stressed the importance of recognizing the expertise that people with lived/living experience and compensating them for that experience and expertise. Hence, **nearly 60% of the total budget proposed is committed to direct payments to CPPN members**.