OUR NETWORK:

A DETAILED DESCRIPTION OF

WHO WE ARE AND WHAT WE THINK

A report which details what we learned from our 2020 “Membership Demographics Initiative”

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OUR NETWORK: A DETAILED DESCRIPTION OF WHO WE ARE

Last year, we asked CPPN members to renew or reaffirm their membership and took the opportunity to explore, in detail, who we are, where we come from, how we identify and what we think. We undertook this "demographic" initiative in two parts: 1) the membership renewal survey and 2) a comprehensive follow-up survey. All participants who responded were paid for their submissions ($25 for each survey completed and submitted). The pages that follow share the "image" that has emerged.

HOW OLD ARE WE AND HOW LONG HAVE WE BEEN POSITIVE?

The average age of CPPN members is 51 years. The youngest member is 28 years old, and the eldest member is 79 years old.

The table below illustrates the age range of all CPPN members:

Age range	Number of CPPN members (n = 99)
20 to 30 years	2
31 to 40 years	15
41 to 50 years	19
51 to 61 years	38
61 to 70 years	17
70+ years	5

We analyzed the data to understand how long our HIV-positive members have been living with HIV. The results may not be surprising given that we know that people who were living with HIV in the early years of the epidemic are still alive (despite the odds at that time) and are likely to live for years to come. To summarize:

- Of all CPPN members who responded (n=99), those aged 41-50 years represent the broadest range of “years positive”:
    - 10% have been living with HIV for 5 years or less.
    - 29 % have been HIV-positive for between 6 and 10 years.
    - 48% have been living with HIV for between 11 to 20 years.
    - 32% have been living with HIV for between 21 and 30 years. And,
    - 10% have been HIV-positive for more than 30 years.
- The youngest member who responded was 29 years old and has been living with HIV for 5 years.
- The eldest member who responded was 80 years old and has been HIV-positive for 21 years.

Click **HERE** to see the complete data table and a graphic representation of the numbers.

HOW DO WE IDENTIFY OUR GENDER?

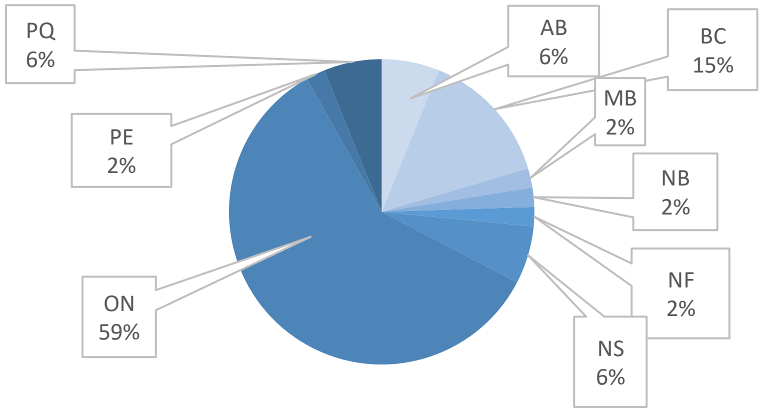
Members were asked to identify their gender. The question was open, in part because we wanted to build a "drop-down" list (for future member registrations) that was built by our members. Of those members who responded (n=98):

- Most members, regardless of age, identify as female (26.00%) or male/cisgender male (60.20%).
    - The mean age of members who identify as female is 47 years.
    - The mean age of members who identify as male/cisgender male is 54 years.
    - The mean age of members who identify as non-binary is 37 years.

Click **HERE** to see the complete data table and a graphic representation of the numbers.

WHERE DO WE LIVE?

As the graph below clearly illustrates, most CPPN members live in Ontario and British Columbia (59% and 15% respectively).



WHERE WERE WE BORN; HOW DO WE IDENTIFY WITH OUR RACE OR ETHNICITY?

From the beginning, we knew that the CPPN was represented by members from across the country. However, before launching this specific initiative, we really did not know how diverse we are. So, we asked the members; here is what we know now:

- Of members who responded (n=91), 82% reported that they were born in Canada while 18% were foreign-born.
- For those members who were foreign-born, their arrivals to Canada were as early as 1953 and as recently as 2016.

Click **HERE** to see when our foreign-born members arrived, and where they arrived from.

Members were also asked how they identified their race or ethnicity. As we mentioned earlier, the question was open because we wanted to establish a "drop-down" list (for future member registrations) that was built by our members. Here is a summary:

- Of all members (of all age groups), an average of 74% identify as Caucasian.
- 15% of those between the ages of 31 and 40 years identify as Black.
- 11% of members who responded and are aged between 41 and 50 years identify as South Asian.

- While the majority (61%) of members who are aged between 51 and 60 years identify as Caucasian, this age group represents the most ethnically diverse among all members.it is within this age group Members between the ages of 51 and 60 years represent the most ethnically diverse, including 6% who identify as First Nations, and 3% who identify as Algonquin/Métis.

Click **HERE** to see the complete data table.

HOW DO WE IDENTIFY OUR SEXUALITY?

Again, with an open-ended question, so that our future drop-down list would be established by CPPN members, we asked how people identify their sexuality. Here is what we learned:

Of all CPPN members (n=99) – all ages and racial/ethnic identities:

- **50%** of the members who responded identified as **gay** and **one** member identified as **"200 gay".**
- **25%** of the members who responded identified as **straight.**

Click **HERE** to see the complete data table, represented by age group and how members identify their sexuality AND to see what we learned about how all members who responded identity with their sexuality together with how they identify with the ethnicity.

WHAT ABOUT OUR RELATIONSHIPS?

As we entered this initiative and knowing what we knew about long-term survivors and their general feelings of isolation (or, at least, had a sense), we asked members to answer a few questions about long-term relationships. We also wanted to know how CPPN members ‘measured’ their HIV status and viral load against their desire for a long-term relationship or their existing long-term relationship. It should be noted here that at least one member was offended by this set of questions. In fact, this member included in the response: **"Are you setting up a dating service for poz people?"** This member expressed concern that asking questions about the state of the relationship was unethical – UNLESS it served a purpose.

There was/is a goal! Because we know (and continually learn) how long-term survivors "cope" with the fact that they are living longer than they were ever supposed to, we also understand and recognize that many long-term survivors struggle with feelings of isolation and "survivor guilt." And many of those who are not engaged in long-term relationships wonder if they will be engaged again. In addition, we know that some people who have just been diagnosed – despite the "road we have travelled" – fear that a long-term relationship will never again be possible.

As part of this initiative, we surveyed members' feelings (and concerns) about long-term relationships because we want to understand how and why feelings of isolation – especially among long-term survivors – affect quality of life. And most importantly, we want to understand how the CPPN, as a national network that exists with, by and for HIV-positive people and with HIV co-infections can/should focus some programmatic energy and financial investments to address these very real concerns.

Ethical concerns expressed and acknowledged, here is what we learned (n = 59):

- CPPN members who are currently in a long-term relationship represent **44%** of the total membership. The tables and/or charts that follow provide specific details gleaned from all data sources. The following, though, is a summary of findings.
  - The mean age of members who are currently in a long-term relationship is 56 years.
    - The youngest is 37 years old; the eldest is 74 years old.
  - Most (64%) of respondents self-identify as female. Those who self-identify as male represent 42% of those who responded.
  - Most respondents self-identify as gay (42%). Those who self-identify as straight represent 25% of those who responded.
  - The largest number of respondents self-identify as Caucasian.
  - Most who responded that they are IN a long-term relationship (14%) are aged between 51 and 60 years.
  - Most who responded that they are NOT in a long-term relationship (25%) are also aged between 51 and 60 years.

Click **HERE** to see data tables and graphic representations related to long-term relationship status and age (age group).

We asked members to indicate the degree of importance they place on long-term relationships, whether they are currently engaged in one or not.

- Of those who indicated that they are in a long-term relationship (n=23), 48% of respondents indicated that a long-term relationship is **very important**.

Of those who indicated that they are NOT in a long-term relationship (n=33), 21% of respondents indicated that a long-term relationship is **very important**; while 36% of respondents reported that they are **neutral** on the question. **Two respondents** indicated that a long-term relationship is **not at all important** to them.

Click **HERE** to see the complete data table and a graphic representation of the importance of long-term relationships by age group.

Long-term relationship importance: in members' own words

"It is not important as it is a personal choice to be in a long-term relationship. I am independent and self-sufficient, but I have a partner who complements me and, ultimately, our whole."
"I focus on my work and activism. If I end up in a relationship, great... If not... great!"
"We believe our continued relationship of mutual reliance and trust has contributed immeasurably to our combined health, longevity, and contentment (32 years and counting)!"
"I just find it easier to not be in a long-term relationship at this point in my life. Although, I'm sure I wouldn't resist one if the right person came along."
"I'm neutral because sex and romance do not appeal to me in any shape or form, but a relationship is still important, but not somewhat or very important. However, there might come a day when I change my mind - either going left or right. But for now, I am neutral."
"Loaded question! I have been in 2 relationships which both ended bad. Now, dating with HIV in a rural area can be difficult and when you reach the part about talking about HIV, there is still STIGMA around HIV and no matter how much education, you can't change their minds (in my experience)."
"Loneliness is huge in our HIV community. It is important to have someone in your life. Most people are abandoned by their loved ones, and you end up dying alone."
"Most of my life was constructed on the concepts of "endless love", monogamy, and long-term commitment - hopefully lasting a lifetime. My romantic pursuits were a disaster. After my last relationship - a marriage - imploded in 2011, I have proceeded

with extreme caution. As I have aged, so too have my priorities. I do not want to be in a long-term relationship for the sake of being in one. I have accepted that a long-term relationship may simply not be in my future. Ergo, I am completely neutral - and most of all, comfortable - on the topic. If it happens, it happens; if it does not, it doesn't."

"Safer to be single, less stress."

HOW OPEN ARE WE ABOUT OUR SERO-STATUS?

We often hear that many people living with HIV will not entertain the notion of a long-term relationship UNLESS with another HIV-positive person while others have no reservations whatsoever engaging in a long-term relationship (or short-term relationships) regardless of their partner's (or partners') sero-status. This is especially true for many since the science is unequivocal that **Undetectable = Untransmittable (U=U).**

We have also heard that there are mixed feelings among people living with HIV with respect to how open they are (or might be) about their sero-status. While some folks suggest that it is less-a-concern because HIV has "normalized" over the years and that there is not as much stigma surrounding HIV infection as there was in the early days. Others, sometimes, emphatically disagree. For many, stigma is as prominent or more so than in years past, and for many, openness about their sero-status is not an option (or an option with extreme caution).

We wanted to quantify how CPPN members consider all of this. So, we asked, **"If you are in a long-term relationship, is your partner also living with HIV and/or HIV co-infections?"**

- Fifty-six (56) members responded to this question.
    - 11% of respondents indicated that their long-term partner is also HIV-positive.
    - 34% of respondents shared that their long-term partner is NOT living with HIV.
    - 52% of respondents indicated that the question was not applicable to them.

We also asked members to indicate the importance of shared sero-status in their long-term relationship AND whether their viral load influences how they think about and/or engage in sexual activity. This is what we learned.

If you are engaged in or looking to be in a long-term relationship, how important is it to you that your partner is HIV-positive and/or living with HIV co-infections? (n=50)

Very important	Somewhat important	Neutral	Not very important	Not at all important
10%	10%	30%	4%	46%

If applicable to you, does sustaining an undetectable HIV viral load influence how you think about and/or engage in sexual activity?

Yes, it does, and it is…

Very important	Somewhat important	Neutral	Not very important	Not at all important
8%	10%	31%	5%	46%

No, it does not, and it is…

Very important	Somewhat important	Neutral	Not very important	Not at all important
11%	--	33%	--	56%

I am not sure, and it is…

Very important	Somewhat important	Neutral	Not very important	Not at all important
50%	50%	--	--	--

We believed that quantifying this information was important, but we also probed for members' sentiments in term of why they made the choices they did in effort to better understand their motivation. In their own words, this is a sampling of what they told us:

Importance of shared sero-status	
Very important	"People are ignorant about how HIV is transmitted. I feel comfortable dating someone of my status. Lack of knowledge is huge and stigma and discrimination, especially in our African community." "It is essential in that the person should be someone who is engaged in care and treatment and has an undetectable viral load. Or, if someone has a detectable viral load, preventative measures should be used (condoms) to prevent HIV transmission"
Somewhat important	"Life is easier, sex life is easier with a zero-concordant partner."

	"Makes it easier to want to get to know someone if they share HIV status."
Neutral	"As long as they accept me for who I am and we take the precautions required, it really does not matter as long as you are both being safe." "Again, can be go either way, because if the person was positive would be (I feel) easy because they already know about living with HIV but could be difficult because there could be a struggle with comparison between the two people."
Not very important	"It doesn't bother me either way as long as both people understand and accept the precautions and risks that can be involved." "I do not base my relationship on what disease the person has...."
Not at all important	"I would want someone to love me for who I am not what I have and would feel the same way about the person I'm with." "The question is whether my partner is educated about HIV. If he is, then HIV status becomes a non-issue."

Does viral load influence sexual engagement?	
Yes, it does	"There is a burden of responsibility, and consequences for disclosure or lack of disclosure. That burden is too high when one's viral load is detectable. That burden is lessened significantly when one's viral load is undetectable." "I feel much better knowing that I cannot pass on the virus, even though it has become so manageable. Being on the sweet side of undetectable gives me a layer of emotional and (in some jurisdictions) legal protection as well and that can only be a good thing, given how changeable and vindictive some folks can be. Undetectable is also a really good stigma buster."
No, it does not	"Because... 1) I do not have sex or have not had sex since 2008 and as of now, do not wish to have sex, and 2) an undetectable viral load isn't something that I can always reach."

	“I do not think that I can transmit the virus regardless of being undetectable. I have been assured by infectious disease experts that it is highly unlikely that women transmit the virus to men through sex. In their words "It simply does not work that way."
I am not sure	“I find that difficult to answer; mostly, I don't even think of undetectability, as I have been undetectable for many years; I don't link it at all to sexual activity, although if I didn't have it, I might. I just don't know.”

We wanted to quantify (and qualify) the degree of openness CPPN members are comfortable with when thinking about/engaging with various “populations.” To summarize salient points:

- By and large, most CPPN members are **always** open about their sero-status regardless of who they are interacting with.
- Thirteen (13) members indicated that they are open with members of their extended family, but with care and caution.
- Six (6) members are **never** open about their sero-status with members of their extended family, and five members are **never** open with their employer.

Click **HERE** to see the complete data table.

Finally, we asked members to share why they are open OR why they are not necessarily open. We also asked how members felt that the CPPN programs/services could help make is easier for people living with HIV to be more comfortable with disclosing their sero-status (if appropriate). Members’ reasons for being open or not are wide-ranging. But clearly, most members feel that being open about their sero-status should be much easier than it is.

With respect to the CPPN’s role (or potential role) in affecting change in terms of comfortability of members AND in terms of influencing public opinion and/or systemic barriers which make it difficult to be open about sero-status, clearly members feel strongly that the CPPN should be engaged in earnest.

In their own words, the table below highlights what some of the members who responded shared with us.

Engagement - Open or not... why?	**Engagement - CPPN's role re. openness**
“Personally, I find it is important to share my status with people that are a big part of my life for me to live without fear of someone	“I think providing Workshops on Disclosure for the many different relationships I/we have. For example, Children, Parents, Friends, Work colleagues whichever is applicable

finding out from some other source, it allows me to be me and not feel as though I'm keeping a "secret"	- as I personally feel all of these relationships are unique in how/when & why we disclose.”
“I think that being open should be easier than it is for all of us. I am comfortable because I am "secure in my skin" and I know that I am a responsible citizen. I have never been anything but open about my HIV status. Still, I do remember being fired from a job because of my status. It was a long time ago... but it should never, ever happen!”	“Absolutely! If the CPPN can play a part in eliminating the barriers - the stigma and discrimination - associated with our sero-status, the time is now... the time was a long time ago!”
“Self-disclosure, like in "coming out" opens the doors to true authenticity of self. I did not experience any barriers in disclosing my HIV status to the above-noted groups. I have, however, experienced continuing hardships in the "coming out" of my psychiatric diagnosis of bipolar disorder ii.”	“I think that scenarios provide an excellent way to demonstrate the variations of response. Through guide or booklet, CPPN could tackle the concept of barriers through illustrations of a variety of scenarios. In all cases, I feel that counselling should be encouraged, and mentors could become options to a ensure a more direct path to a healthier, emotional self.”
“This is a complicated question, but I will attempt to answer it. I am not out to immediate and extended kin/family and am out to three friends, who found out by mistake, and not because I went out of my way to tell them and am out to two other friends who I did tell. I am out at work - my boss and colleagues know I am HIV-positive but that is because I work for an ASO and so, there is ease and familiarity in that. If I worked elsewhere - a non-ASO company or agency, I would not be so open. I am out in the ASO sector, more so as a frontline worker who just happens to be HIV-positive. But I do not advertise this. People usually assumes it when they see or hear of me at exclusive events for poz folks. I never proclaim that I am poz on any of my social media pages: FB, Instagram, Twitter, LinkedIn, etc. I will post events and what-not from the ASO sector and the agency I work for, but my relatives and most friends who are not poz will see those as a frontline worker doing their part. There are barriers to my being out to especially my family/extended family because I am not sure how they would react. Stigma is still a huge barrier in most communities and in South Asian communities it is no different. And stigma can open a lot more barriers, not only for myself but also for my family. That is the thing that keeps me from	“I'm not sure if it should only be the CPPN, but the CPPN could start it and it would be followed by all the large govt agencies like the Public Health Agency of Canada! A campaign to address HIV stigma and how it might impact folks who have or are thinking about coming out to their family/relatives/friends, etc. It could be a poster campaign, and then maybe even a public service announcement on TV - hit people constantly, consistently, until they start getting it inside their heads that HIV can happen to ANYONE, and not just a small population of gay men (yes, many folks still think this). The campaign needs to be direct, edgy, and impactful. It needs to reach people of all ages but done differently for each population. It cannot be one size fits all kind of thing. I really wish we could do that. I mean there are campaigns about new HIV meds, and they are good and paint poz folks as regular, everyday people, but still, these commercials do not make much of a difference in the lives of those who are HIV-negative. And, no, scare tactics about the fear of getting it are not what I had in mind. Maybe a post-counselling scene between a person who just finds out they are poz and their doctor, who explains to them that they can still have the kind of life they had before the poz diagnosis or the kind of life they dream of with HIV. There is nothing

telling them. It is more because of how it might affect them and their worlds. The other side of this is that it is a health condition and so, I treat it like other health conditions, I keep it private between myself and my healthcare providers. So, there is no need to tell my family and friends. Of course, I have told the folks who may have been interested in sleeping with me, but as soon as I told them, they would lose interest. I do not make HIV the only thing that's part of my life. I am many different things (and people), and HIV is one of the things that is part of me."	wrong with being poz. Yes, people still die from AIDS and/or other conditions that are worsened because of the HIV. But such is life. Life is death and death is life. **There Is Nothing Wrong With Being Poz**. There is something that is WRONG with society if it thinks that and acts as if there is something morally wrong with people living with HIV. The campaign must address this particular wrong."

HOW DO WE FEEL ABOUT MEANINGFUL ENGAGEMENT?

We have heard many anecdotes whereby people living with HIV are concerned, alarmed, angry, disenchanted – the adjectives are many – because the importance of their meaningful engagement in all things that affect their health, wellness, and quality of life is nothing more than a principle for too many decision-makers and, in some cases, service providers. We know that there is much effort underway locally, regionally, provincially, and nationally which, if effective, will crystallize (finally) how unwavering the commitment to meaningful engagement MUST be. People living with HIV and HIV co-infections are no longer willing to be tokenized. Their lived experience – particularly that of the growing community of long-term survivors and those aging with HIV – represents unqualified expertise and that expertise is relevant and cannot be understated or under-valued. But… these are anecdotes and we wanted to dig a bit deeper into how CPPN members feel about meaningful engagement.

Firstly, we wanted to understand **how** members define (for themselves) what meaningful engagement is and what it means to them (what it looks like; what we need to do to ensure that it is truly meaningful). While the table below includes specific comments made by some respondents (n=57), the data gleaned made it clear that CPPN members feel that meaningful engagement is:

- Respect for diversity and diversity of opinions – absent egos.
- Sharing information and ensuring that the information is relevant and expressed in language that is easy to understand.
- Ensuring that **every voice** is heard and that **every voice** (opinion) is respected without judgement.
- Inclusivity and diversity.

- Mentorship.
- Routine, automatic; free from bias; free from judgement.

What meaningful engagement is – in members' own words

"Meaningful engagement to me means being active in any capacity of the HIV/AIDS movement of awareness. It can be as simple as being out to all and sundry in your life; this promotes a sense of tolerance towards HIV positive people. Of course, work with various groups and agencies is laudable but being open about who and what you are does far better than that of all the do-gooders out there."

"We need to work harder to ensure that we are hearing the voices of diverse people living with HIV. We need to work on why we are not getting the involvement of diverse voices. Meaningful engagement to me means being involved at every stage/phase of the work. And that our work is valued, particularly financially."

"Meaningful engagement, to me, is personally defined as pertaining to my participating in something that helps bring acceptance and understanding to others living with HIV, the community and the organizations. I want to be heard, acknowledged, and have my story be relevant. Rural issues are different that urban issues for many reasons. Therefore, I find it difficult on a national platform that is focused more, and understandably so, on higher populated areas. It's hard to be a leaf in a forest."

"First of all, I would put priority to people that have opinions that have been shut out by the massive Ego's of the few. Members that have caused trouble at conferences and at the CPPN should be told that everyone's opinion is valid. meaningful engagement to me would mean perhaps a mini conference without the massive Ego's of people whose voices are yet to be heard and then a declaration of thoughts moving forward time to let the new have a little bit of a voice."

We asked members to share with us whether they feel meaningfully engaged as people living with HIV and/or HIV co-infection in their community and why (or why not).

- Of those who responded (n=58), **60%** indicated that they do feel meaningfully engaged, while **12%** were unsure.

Why do CPPN members feel that they are meaningfully engaged in their community (or why not)?
This is (in part) what we learned (in members' own words).

"Part of my role in the community is to facilitate HIV health promotional education workshops in the community, shelters, and outreach in festivals and community events, creating HIV awareness and encouraging community members to get tested.

Reaching out to these communities also gives me an opportunity to disclose my status, and by doing that people tend to listen more and understand HIV and risks of having HIV."

"I have been learning and volunteering since my diagnosis 10 years ago. Since I am not part of the LGBTQS2 community, I do not think people in the Community think I know or understand about stigma and discrimination. I really do not think they listen to me. Our Agency is more based with Shift (Sex Workers who are not positive) and Addictions Harm Reduction for people who are not positive. Others at the Agency who are positive do not feel save to discuss their status because there are others there that make it clear that they are not positive. There is one Agency in Calgary (HIV Community Link) and there are more than a dozen Agencies for Addictions in Calgary. PLWHIV should be the only people allowed in HIV Community Link otherwise the Agency is breaking confidentiality. PLWHIV at HIV Community Link were not involved with the changes to allow SHIFT and Harm Reduction Addicts who are not Positive into the Agency. I believe that there should be a client or someone living with on the Board."

"I am not meaningfully engaged at the moment as there are too many members of the community who do not understand my message and therefore assume it is negative."

"While I make no bones about my status including in job interviews, the gay population of my town is very small and closeted. There is little chance to get out and meet other people be they positive or negative, COVID has not helped the situation as the monthly mixers are no longer in existence."

"Not currently, but it fluctuates. My focus has needed to be elsewhere lately."

"The secrecy of being HIV-positive prevents me from engaging with the public."

"It would be more meaningful with a regional representative who can report on issues from the region."

We went a step further and asked members how meaningfully engaged they feel **as CPPN members** and why (or why not).

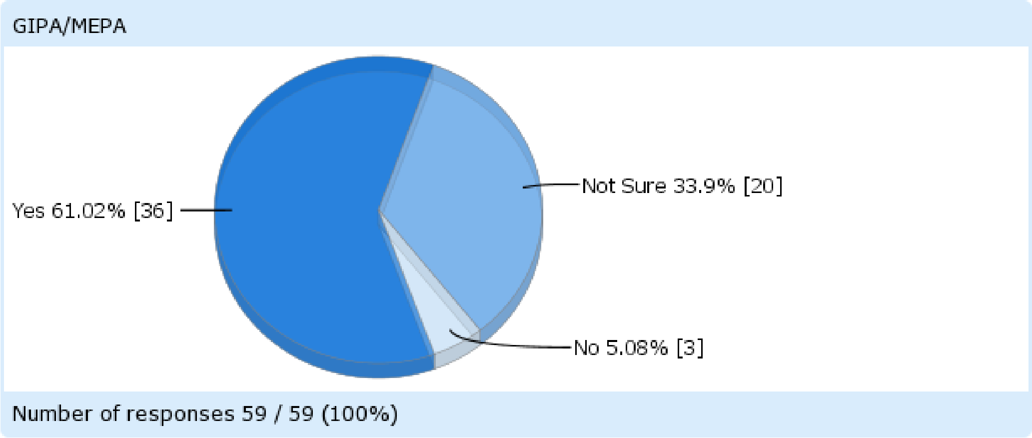
- Of those who responded (n=58), 47% indicated that they **do** feel meaningfully engaged as a member of the CPPN.
- 19% of respondents shared that they **do not** feel meaningfully engaged as a CPPN member.
- And, of **considerable concern**, 35% of respondents are **unsure** if they feel meaningfully engaged as a CPPN member.

Based on the comments respondents offered in response to the why/why not question, it is and should be clear that the CPPN has much to do to improve its outreach with members AND to ensure that ALL members understand what the CPPN is and what it is doing, and to encourage (and incentivize) more active engagement of members more routinely.

Why do CPPN members feel that they are meaningfully engaged as members of the CPPN
(Or why not)?
This is (in part) what we learned (in members' own words).

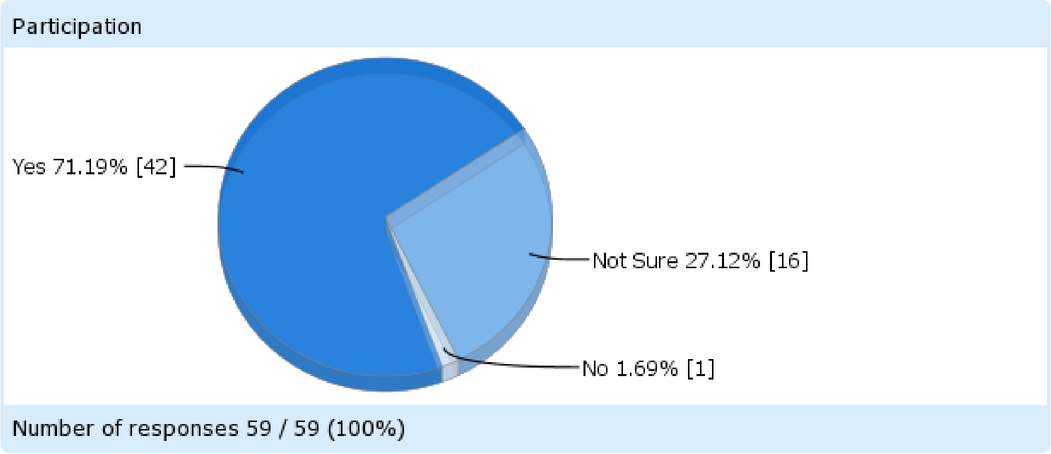
"It's been an incredibly tough road in some respects. I know that I am not respected by some of my peers, but I also know that I am accepted, supported, and meaningfully engaged by the majority of my CPPN peers."
"[The] CPPN has been dominated by a few people with enormous egos and their need to dominate every aspect of HIV and conferences the person with a meek voice is simply shut out. You are wondering why people are leaving the CPPN perhaps the over 60's white male need to take a step back and let younger people in. But when members come across people talking about how wealthy they and HIV not any impact on having their live it begs belief that anyone can relate to that sort of snob attitude that seems to be dominating the whole conversation. Yet I still in the past was motivated to do things as I thought other voices should be heard and should not be about getting awards and flaunting it."
"Not yet. I have attended only one CPPN event in Vancouver - which I fully enjoyed- but I have not connected much outside of that other than receiving the emails from CPPN. I like the idea of CPPN. All my affiliations are with grassroots organizations."
"So far, I am enthused by the CPPN's professionalism - with respect to the consistency of the messaging and branding!! I like the frequency and relevance of the CPPN's communications. The quality of the writing and materials is outstanding! I am engaged."
"My initial exposure to the CPPN was undermined by confusion and emotional personalities. I recognize that these challenges may be rooted in trauma from stigma and the challenges of activism.... but it was bewildering, stressful, and unpleasant. I'm open to further opportunities to engage, but I would want to tread carefully...."
"I have been a member for a few years now but don't feel like I've contributed anything. I do not know what the CPPN's policies are. I want to be meaningfully engaged."

Because we know that there is much interest in taking stock of the "GIPA/MEPA" principles in terms of their practical applications, we asked CPPN members, **"IF the CPPN proposed an initiative that would have us "revisit/re-define" the "GIPA/MEPA" principles, would you agree that this would be a valuable exercise?** "While not unanimous, of those who responded (n=59), most agree that this would be a valuable exercise.



We went one step further and asked CPPN members if they would actively participate in a "revisit/re-define" initiative if/when the CPPN initiated such an exercise.

- Of those who responded (n=59), most indicated that they would actively participate.



WHAT DOES OUR NETWORK MEAN TO US?

Without doubt, the CPPN – as Canada's only independent, national Network which exists with, by, and for people living with HIV and HIV co-infections – has experienced notable challenges in recent times. Issues of members' trust in the CPPN and, indeed, concerns about the credibility and viability of the CPPN as a national Network that is effective, representative, and meaningful to people living with HIV and HIV co-infection have been prominent. Without focus on the historical governance and/or operational issues that emerged, we wanted to know what the Network means to members **now**, and what it could/should mean going **forward**.

So, we asked, **"In this moment, what does "Canada's only national, independent Network of, by, and for people living with HIV and/or HIV co-infections" mean to you?"** We learned that:

- By and large, and despite historical challenges and missteps, clearly, most CPPN members have continued faith in and hope for the CPPN as the only national, independent Network which exists with, by, and for people living with HIV.
- Notwithstanding the apparent confidence in the CPPN, that confidence is not immune to some skepticism or "suspicion." Sentiments expressed by respondents (n=56) suggest that there is much to do before the community of people living with HIV and/or HIV co-infections understand or believe in the value and/or relevance of the CPPN going forward.

In their own words (in part), the table below includes what CPPN members shared with us.

What the CPPN – as a national Network – means to its members right now

"The CPPN means that there is a chance to change the way people look at HIV. We have a great opportunity as a National Organization to effectively reach persons across the country with a variety of topics and issues of importance."
"Right now, in large part because of past crises, this is an aspiration more than it is a reality. So much work is needed to restore/foster trust, confidence, and involvement of the HIV and HIV co-infections community."
"I think the original mandate of the organization has changed to satisfy the funders and others so the status of the organization for tax benefits we have to get back to the roots to a national gathering of members who wish to attend and work for what is right without fear."
"Well, first, it means a great deal to me. There's power in that. Presently, I am not sure what that power could/should look like because we are at the early stages of the network. However, I feel there is enormous potential for CPPN to bring about

real change in terms of HIV stigma and discrimination, HIV criminalization, our interpersonal relationships especially with HIV-neg folks, impacting young people and the education system, taking part in decision-making and policymaking at the local, provincial, and federal levels, and more.

But there are some missing pieces: namely, BIPOC (Black, Indigenous, People of Colour) visibility and engagement and Trans and Nonbinary visibility and engagement. Why not have a Diversity, Inclusion, and Integration Committee that would make it its raison d'être to reach, invite, welcome, include, and integrate people from these populations?

Also, there is a provincial independent network of, by, and for Asian, West Asian, South Asian, and Middle Eastern people living with HIV and/or HIV co-infections called the Ontario Positive Asians+ Network (OPA+). We should try to reach out to them and maybe ask them to consider being part of CPPN."

"It will mean more to me as the CPPN develops policy positions and ensures its members are sitting at tables where those CPPN developed positions that ensure rights and reduce stigma are able to be heard."

"As a peer who has been involved in many capacities in the HIV community, I feel like this is the right place and time for me to join this network. I have been a strong believer from the beginning and for us by us and I feel like CPPN shares a lot of my values. I'd love to be a part of anything that changes things for the better and create programs that help my peers."

To go one step further, we also asked, **"What SHOULD Canada's only national, independent Network of, by, and for people living with HIV and/or HIV co-infections" mean to all of us going forward? Why? How do we get there together?"** The respondents' comments make it clear that the CPPN needs to:

- Understand and perpetuate its role (and its obligation) to be inclusive and open to diversity (of opinions, of self-identity, of lived experiences, etc.).
- Improve its approach to sharing responsibility with its members to interpret public policy and to affect change to public policy if/when it fails to reflect the real-time realities faced by people living with HIV and/or HIV co-infections IN real time.
- Do more to encourage, support, and engage with members in action-oriented activities AND be ever-vigilant of the value of members' time and expertise. "Sharing information is simply not enough."

In their own words (in part), the table below includes what CPPN members shared with us.

What the CPPN – as a national Network – SHOULD be going forward
“Boils down to empowering the membership to engage one another and our allies (and educating and confronting and challenging those outside the community when required - especially around issues like stigma). One step at a time with slow and steady growth and organizational development.”
“It should lead to words like leadership; caring; advocacy; community; knowledge; education. We need to know right from the outset what is do-able and what is not. Communicate that and you will stop people from expecting too much.”
“I follow the motto often that teamwork makes the dream work. Together I feel that we can make positive change and outcomes for each other. These are unprecedented times and the way we support each other and offer services has had to change and evolve. Together I feel that we can figure out ways to support each other in these crazy times and beyond.”
“It means that we are a group unified in a cause. We share a common goal, the universal understanding of HIV and HIV co-infections. As to how we get there together, that is what the CPPN is there for, to find and figure our way through the labyrinths not just of red tape, but of the mind and cultural differences which are endemic to the HIV/AIDS cause.”
“Nothing mutually beneficial thrives without combined mutual support, effort and involvement. Human nature will take anything freely offered. Having those who benefit also taking a role, big or small in scope, increases pride in community success and appreciation of reward. Once more, the model I have at hand is Positive Living. Yes, benefit was extended to all HIV+ members but such benefits materialized through the effort of hundreds of volunteers. That base of volunteerism was maintained by meaningful, measurable appreciation.”
“Should mean something to all of us going forward. I think we could learn how to look out for one another; how to argue without losing ourselves in the argument and always keeping respect between one another; how to think of each person and ourselves as people other than just our race, gender, sexuality, age, and other identities; they have their places in our lives, but there are other things that give each of us our unique shine; I want us to celebrate that, and at the same time, acknowledge that all of us may be ignorant, privileged in some way, and/or harbouring some subconscious or conscious animosity or fear towards 'the other'. We must know how to be vulnerable and uncomfortable with our feelings and/or past experiences that may have significantly affected us (and we may not be aware of this) and our relationships with other people. We need to heal or to be on our healing journey.”

WHAT ARE OUR THOUGHTS CONCERNING “QUALITY OF LIFE” ISSUES?

Today, most (but certainly not all!) people living with HIV and/or HIV co-infections have access to care and treatment that is far-superior to what was offered years ago. More and more people living with HIV are living with undetectable viral load; an increasing number of people living with hepatitis C are achieving viral clearance having experienced treatments-of-late that are far more tolerable than earlier protocols. And we know that there are earnest efforts afoot – domestically and globally – which insist on concerted emphasis on addressing “quality of life” issues – especially since people who expected to die years ago are living longer and who are faced with health issues that present significantly greater concern than their sero-status.

So, we asked CPPN members, **“How do you define "Quality of Life"? Your response can focus on your own quality of life with HIV and/or HIV co-infections. Your response can focus on quality of life (with or without HIV and/or HIV co-infections), or your response can be a broad mix of both. The bottom line... what does quality of life mean to you and why?”** Reflecting the sentiments of ALL who responded (n=57), the table below represents what CPPN expressed.

Quality of Life: what does it mean? Why?

“Quality of life for me is being engaged and involved in my Medical care. Having access to participate in a number of different programs not only with my ASO but also with any other organization for HIV/HIV coinfections Having Food & Housing security I think all the necessities to stay healthy and live my best life.”
“Quality of life is the basis by which we recognize our health versus or being. If simply existing day to day is insufficient, then quality of life is not there. Quality of life demands that we engage not only others but ourselves as well. Keeping our minds agile as we age is as important as keeping our bodies as active as our medical conditions and age will allow. I am a survivor of 38 years. Because of having been on some of the earliest medication regimes, there are illnesses I will take to the grave with me because of HIV. That and the fact that I am aging at an accelerated rate mean quality of life is very important to me. If I remain engaged with life in general, then I remain to have a quality of life that can be enjoyed.”
“In no particular order: It means self direction and freedom from intimidation. It means access to the wherewithal to take care of one's physical needs. It means access to learning, to find interests and direction in life. It means being able to pursue the above as well as whatever love (or sex) one desires (consent permitting, of course) without fear of existential threats from others. It also means access to a community of one's peers. Other things too, probably. But that is already lots to be getting on with. Oh, cats, lots of them. And more Christmas cake, right now.”

"As racialized woman living with HIV, I face multiple challenges such as racism, stigma, and discrimination, where I have to fight and advocate for my community members to address these issues. As a black woman in employment settings, I must work hard to prove myself. Racism, HIV stigma and discrimination affect diverse people living with HIV in my community. To achieve a satisfactory quality of life while faced with intersecting challenges is very difficult. These challenges increase the risk of stress, anxiety, isolation, opportunistic infections (, diabetes, blood pressure etc..) and dealing with anti -retroviral side effects. All these issues compromise the physical, mental health and well being of people living with HIV."

"Quality of life is:- having a roof that I can afford to live under- having food on my table- living free from fear of judgement for who I am, how I live, or what I live with (e.g., HIV)- having a healthy sex-life; being free of intimacy fears or reservations- loving and being loved - unconditionally!"

"I envision a world where all people living with HIV are treated with dignity caring and compassion. Our quality of life depends on this. Access to treatment and care. Access to information and resources. Ensuring basic needs are met."

"That I am living my best life, despite HIV co-morbidities and stigma. That I have the tools to be able to advocate for myself and others to overcome the stigma we live with. That I and others can be truly listened to about what it is like to live with HIV. My quality of life has truly diminished since becoming infected as I do not have the life that I might have had if I had not been infected. Illness, stigma, co-morbidities have all contributed to this diminished quality of life. Everyone thinks that this is a chronic illness that is manageable. Our quality of life couldn't be further from the truth."

"Quality of life means EVERY BASIC NECESSITY is secure without fear from one month to the next. From a personal level, I would like the possibility of being gainfully employed when I feel able to be a reliable employee without the bureaucracy associated with returning to a disability income and those other secure basics."

"Living happily and in reasonably good health."

"A supportive family (however defined), activities (paid or otherwise) that provide enjoyment and/or a sense of purpose, and as much health as can be attained! Resources (financial and otherwise - but ESPECIALLY financial) that allow PLHA to live as healthfully as is possible. About 80 of the support work we do with our long-term / high-needs PLHA clients is about resources! Inadequate housing, inadequate budget for special diets, inadequate health supports beyond the core HIV-specific, inadequate opportunities (including resources) for social engagement, inadequate infrastructure to address the complex and interconnected HEALTH challenges (physical, mental, spiritual, communal, etc.) of living long-term with HIV."

"Quality of life means being freedom, wealth, health, housing, a job, a car and food to sustain myself. As I approach the end of my life, I realize my entire life was wasted. My full potential went unfulfilled."

"Quality of life, hmmm not sure how to answer this one. Like I said, I am healthy, happy, I have support, I have pension, so I am not struggling. It is as limited as ODSP but there is not the threat of being cut off if I do something wrong or the government makes cuts. So holistically I know I am better off than many people and I am grateful for that. I worked hard over the years to be where I am today."

“Quality of life means having the opportunity to be your authentic self, without barriers (financially, socially, emotionally). While each of us has individual and unique needs to reach authenticity, it does come back to ensure that the basics for survival are intact and that any dream can be your dream. Sadly, this is not the case for everyone due to discrimination (employment, family, etc.). Ensuring a network of people to support each other, to act as mentors to each other, might be one direction CPPN can go to give the opportunity to membership to live as full a life as possible, potentially obtained through the learned experience of others.”

“Quality of life means helping people live their lives in their own way... whatever that looks like to the individual. QUALITY is often diminished by BARRIERS, so if we can remove BARRIERS, we can open a whole bunch of doors for people.”

“My quality of life means to me, not hiding my HIV from anyone, My loving family, and most of all my hubby .”

“So, the quality of life means to me that a person has lived out their fullest life before they passed. Looking back on all of their flaws, and achievements that they have been through their life and then share it with others as well as learn from others”

“To live a normal life, just like everyone else!”

“To be alive is the most quality of life anyone can ask for”

“Quality of life to me means having a place to live that I love; eating good food, being able to take care of myself and animals; being able to have what I need to be comfortable. Of course, I 'd like a few extras, like cannabis but I do not need a lot to be happy. Attending conferences on a scholarship has been a wonderful bonus for me. They became the vacations I could never afford.”

“Quality of life is my general well-being in society. However, showing stigma against me and others who are HIV+ creates negativity and people shut themself off from the world and or life that has or can be created by CPPN for them. But my quality of life is deemed by a provincial social service system that if family or friends send me money deposited to my bank account the government takes it back off the next check which means I received no benefit from the extra cash, I must have it send to another individual or have the family send me a gift card instead. I survive on a weekend welfare system that gives me $634 a month of which $311 is from the CPP they forced me to apply for at 60 $333 from social services as they deduct the CPP the money includes from welfare a $40 bonus for the food they do not tell you about you have to ask then they are obligated to give it to you after the Dr. verifies each year you are HIV, doing it each year is demeaning to ask the Dr. to comply with the request. CPP Disability denies you using lawyers to prove your case wrong and uses item that is over 5 years old against to make their decision so they do not have to pay you yet there are others with HIV still alive who get it from the '80s and work under the table. I cannot work anymore; I fall and need some specific (Cane/walker/ other aids are now being assessed) aids to live my life in my own home. The inept action by the CPP Disability and the federal government to take a truly honest look makes me ineligible for disability it makes life not worth living even after a second try to obtain the benefits because of the low income.”

“Having a safe house-free of mold & pests. Having a connection to nature/community/work... being a contributing member of society... being able to properly feed/clothe myself & partner... helping those that are less fortunate than myself. (Homeless etc.) We are all human beings, with 1 world(earth=home) we are all related (1 race=human). We are ALL connected.”

“Quality of life is being able to live healthy, happy, safely, and openly for all.”

“On a practical level, quality of life might mean we have money in the bank and with this money, we can afford the necessities of life. It could mean (and this is still practical) we have a good job (you don't hate this job, but it's also not the be-all and end-all of your life) that pays the bills, pays the rent or mortgage, pays the debt load, etc., and maybe has a bit more to use for emergencies, for family, or for people who you don't have any relationship with but you want to help in some way. Or, on another level - practical, functional, humanistic, etc. - quality of life could signify good health or reasonable health of your loved ones and yourself; that your health care providers understand you, listen to you, and make recommendations based on your needs; your health care providers care about you as a person and guide you towards optimal health. Or quality of life could mean we have got all the above covered, and then some. That 'some' could be anything we want it to be. It could be one thing or a few things. The one thing could be that one person. The one thing could be that one home. The one thing could be that one picture perfect painting we did. Or it is being near the ONE - the higher plain, the universe, gods and goddesses, the God. We could have a good quality of life one minute. The next minute, it is not so good because we have changed course. We want or wish for change, for something else that might bring a new reality. The possibilities are infinite. I like to think that that is what quality of life means. It means no matter how life has affected us with all the social determinants, inequities, and such, if we are of sound mind, the potential in every heart, mind, and soul is endless. If we are not of sound mind and/or we do not have bodily integrity, our potential is only as great as what our handler thinks of us, unless there is some way we can tap into our mind, body, and spirit and gain hold of that which is limitless. Thank you for reading all of this! I think I may have meandered away from the main points of each question, but I thank you for giving me the space to do just that!”

“Quality of life to me is about a happy and healthy life. This involves engagement, respect, love, (self and from others), a healthy and happy environment that is safe, secure, warm, and dry. It involves a healthy diet and hygiene. And finally, it would be nice if it included the love of a domestic partner.”

“Quality of life over quantity of life was my mantra from day one of my diagnosis in 1996 and remains to this day. I have made the choice of being my own captain and take charge of my health care. This has opened an avenue with my health care providers which can be very interesting at times but has worked well for me. I have been lucky to have great people around me. Choosing quality is very easy, choosing quantity is impossible. Any depression or down time I have had over the years was not due to HIV but rather the passing of friends, family and peers.”

“The bottom line is we need to have networks that benefit us Health, mind, body, spirit. we need to start listening to others with the same beliefs and reject the way things were. We need to stand together and fight for what is right not only HIV but as we have seen new viruses emerging at a time when conservatives are cutting services. For CPPN we need to reject the EGO and embrace ALL of us.”

“It means adding a 4th 90 or similar that covers QOL. That QOL can be defined by a combination of clinical health outcomes, successful aging and intersection with social determinants of health such as housing, income security, food security, support, mental and sexual health, mobility, mastery etc.”

“Quality of live means to me, being able to access medications, access to HIV Specialist and GP. To be able to have a place to live, have an income, to have access to education, to have the infrastructure and service within the community I live in. To have personal security within the community I live in and to have the transport to be able to participate within the community I live in.”

“All depends, some focus on material needs others spiritual as long as a person feels their life is functional, connected to others, and that there is hope life has quality.”

“Quality of life means a healthy balance of self-confidence and self-awareness of your body and mind's reaction to its immediate environment. A supportive human connection, stability, access to food shelter and medical support and the ability to look after yourself, mentally and physically. Having a good quality of life means having the opportunity to see that better thigs are possible and not to take things you have for granted. Life is short and we need to be the best person we can be. Be kind to each other and not get filled up with negative and destructive feelings and thoughts.”

“Quality of Life means, to me, the ability to make independent choices about values, mission in life and activities. HIV is part of my life, so my quality of life will include living a healthy life with HIV. But that is not all. When you cannot make decisions about your activities based on your values and mission, your Quality of Live will suffer. Example: having to work at a job that does not satisfy you, but you must make a living means poverty (or, not having the money you feel you need and or want to make the choices you want to make) is affecting your quality of life. Having Quality of Life means you can find and achieve the balance that will satisfy your economic, physical, emotional, and spiritual needs/wants in a way that brings you satisfaction and contentment. If you have Quality of Life, you are mostly happy and satisfied with the circumstances of how you live, day-to-day.”

“To live a life like you would have had without HIV and/or HIV co-infections. A life without stigma and a life where the lawmakers are not deciding what you can or can not legally do. A life where employers whether legally or not can discriminate against you. The only thing holding me back is the anxiety I've been dealing with, so aside from that, my own quality of life is ok.”

“Quality of life means an overall sense of well-being and includes happiness and satisfaction.”

“To be as healthy as possible is important, in order to be able to enjoy pleasures in life/love... to be financially secure, in order to afford the extras/luxuries... to have decent, honest persons in your comfort zone”

“Quality of life means: access to medical care without concern about potential stigma and discrimination being able to pursue research without being bashed and silenced within the HIV community more resources and focus on women living with HIV as our experiences are unique asking those who signed on to the consensus statement to decriminalize HIV to in turn sign on and support the consensus statement by ICW and other organizations (The Well Project) who are moving forward with promoting women living with HIV, breastfeeding and u=u. Why are they not supporting women living with HIV who choose to breastfeed? Which research studies in Canada for and by women living with HIV have not signed on to the consensus statement around breastfeeding? Not sure what they are waiting for as this is a direct show of support. I think the consensus statement on HIV and criminalization had 180 signatures. How many signatures did the consensus statement on breastfeeding receive so far? Ten? Five? None from the Canadian research teams. More focus on prevention for women is most helpful as paying attention to the situation after the fact is indeed - after the fact and not as useful. There is a huge gap between a woman before contracting HIV and a woman who is living with HIV and leaves one wondering what happened. This is an example of quality of life. Not doing research repeated for the sake of research and funding would improve the lives of people living with HIV. For example - why do we need another costly research study on stigma and HIV when there are endless sources of information available on this topic already? It is well documented and what we need now to improve our quality of life is some action. By action I mean, as mentioned before, a strong and solid marketing campaign, public service campaigns, interventions and training for hospital staff and other persons involved in working with people who are living with HIV.

Interventions that educate and enlighten the public would be a more useful way of improving the quality of life for people living with HIV rather than dwelling on the "dysfunctions" of our community, dysfunctions that are examined and amplified and only serve to reassure the public that indeed those people living with HIV are an unstable group. An improvement to my quality of life would be when I am no longer asked to be part of a research study that serves no purpose and reiterates what we already know. Not having women as tokens would be an improvement to the quality of our lives. Women need more active roles and to be heard as our voice is deemed unimportant in this group that is predominated by men. Giving women living with HIV funds directly to initiate their own research on topics they identify as important would improve the quality of our lives. Why do we need a team of "experts" to tell us all about disclosure of our HIV or intimacy? If women worked independently in gathering our own data and creating resources, we would have no need for "expert" outside advice that is so often self serving for the researchers whereby women living with HIV gain nothing. Nothing about us without us needs to be more than a slogan thrown around to justify others speaking about us without us."

"To me it means living your best life.... encompassing emotional and physical well being."

"It's the "fourth 90". We talk a lot about "ending the epidemic" (the other three 90s) but it is important to remember that short of a cure, the epidemic will not end for those of us with HIV. Which is why focusing on the quality of life of those of us living with HIV is very important,"

"To be healthy mentally, emotionally, spiritually and physically and able to enjoy life."

"Meaning engages in employment. Financial security. Access to healthcare. A real community of happy people who do not focus every living minute on a virus or disease or obsessed with CD4+."

"Quality of life means how my life when I'm content and not wanting for anything feels. Being happy and at peace with myself being healthy and pain free. Doing what I love and being around friends and family and living stress free."

"Quality of life is a blend of everything. Mental, physical, spiritual, it is all connected. Quality of life is how you live, where you live, your relationships, your family, friendships. Your neighbours and more. When all these things are in harmony we have good quality of life, when the different pieces are out of alignment it starts affecting that harmony. Working together we can help build a better quality of life."

"My Quality of life depends on trust of my doctors/pharmacists; trust in myself-to be able to work meaningfully; having friends that I can count on; having someone to share and experience life with; knowing that I am doing my best and being my best self."

"It means levelling the playing field to ensure that people living with HIV are not lacking the Social Determinants of Health. It means resolving income disparities, providing secure housing and access to nonjudgmental health care that is seamless, integrated and provides triage for mental health care and addictions services as required. It requires supporting and creating equal space for people from racialized communities and working together towards health and social policies that are anti-racist."

"Quality of life for me means to get quality, non-judgmental health care from our health care system. To be able to participate/be heard in what programming the local Agencies provide. It would be nice if more PLWHIV would step up and start running these Agencies. I just want to love myself fully and completely, so that when stigma comes my way, I can handle it without getting emotional or putting myself down. I really want to educate the common population to the myths about HIV and give them the facts to help stop transmission, get people on meds and be compliant. We really should be going into the High Schools heck all schools to let people know that HIV is everyone's disease (Addiction, Age, Gender, Race, Religion, Sexual Orientation) I don't know how else we are going to get to stop transmission without major education about HIV to the public."

"Grandchildren, gardening, art, activism, love. Quality of life is having the good mental and physical health to enjoy family, friends, and nature. It is having the ability to participate in activities that are fulfilling and rewarding. And sometimes quality of life is just breathing ...."

"Quality of life means being healthy (body and mind); active; independent; having strong connections to family, friends and community; living in a comfortable home; never having to worry about money; and having access to great healthcare and culture. Those elements combined contribute to feeling grounded and living life with a purpose."

"My quality of life means the degree to which I am meaningfully engaged, supported and supportive to others in my community- it is beyond just existing in, or working in, or living in but rather THRIVING in my community. The ability to fully be "me" in my community allows for my best quality of life."

"Quality of life for me means being able to live without barriers, much the same as with other chronic health issues. You should not have to change your life (other than things associated with medical problems). You should be able to continue to grow as an individual. Your life goals should not have to change. And especially having a part in the discussions when we are part of policy debates about our community."

"Quality of Life to me is about the structural and social determinants of health, connection to our families and communities, to find out what our roles and responsibilities are on this earth walk. " You have to understand me to help me""

"After reviewing some explanations of Quality of Life online, I would agree with the definition that QOL is the measurement or perception of health, comfort, and enjoyment of life and life's events, both on individual and group levels. In the context of living with HIV and/or HIV co-infections, quality of life would mean:

- ensuring that people living with HIV have access to high standards of health care, regardless of location. That level of care, and outcomes, should be comparable to the levels attained for other major areas of healthcare, such as cancers, diabetes, and heart disease.
- ensuring that people living with HIV are not impeded financially from achieving goals that are attainable to the general population, such as having secure housing, mobility, food security, security in old age, etc.
- ensuring that people living with HIV feel secure in their communities, at their workplaces, in medical settings, in pursing relationships, free of stigma and misinformation.
- ensuring that the needs of people living with HIV are discussed and addressed by politicians, in the media, in educational settings.
- recognizing the emotional burden that HIV carries, and that people living with HIV should be prioritized in receiving mental health supports to lessen that burden."

“Quality of life means a safe secure place to live, enough food, and enough money to live day to day. These are the same needs that have been the case since the onset of HIV/AIDS.”

“Being able to laugh again.”

“For me quality of life means living your best life. It means that your life and the way you are living it is “good quality.” It is important for me to find ways that I can view myself as living my best life. This means physically, mentally, and emotionally. My well-being and how are use my time is very important to me.”

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