

Action Hepatitis Canada

Ontario HCV Elimination Meeting

November 25-26, 2019 | YWCA Toronto

Action Hepatitis Canada is a pan-Canadian coalition of 65 member organizations. Our mission and mandate is to **provide community accountability on Canada's commitment to eliminate viral hepatitis as a public health threat by 2030.**

This was the first face-to-face meeting of Action Hepatitis Canada members since the launch of the **CanHepC [Blueprint to inform hepatitis C elimination efforts in Canada](#)**, in May 2019. The Blueprint is a document developed for policy-makers, program planners and service providers. It compiles expert recommendations to inform actions and strategies for eliminating hepatitis C.

AHC participated in the writing of the Blueprint, along with many other HCV stakeholders including community organizations, through an 18-month writing and national consultation process led by CanHepC.

With much of the work of advocating for **HCV elimination moving to the provincial/territorial level of government**, the AHC Steering Committee and CanHepC agreed on the need to have provincial-level community dialogue about what the recommendations mean in each province, given the diversity of contexts across the country.

Based on the large proportion of Canada's burden of HCV that lies in Ontario and the number of member organizations that AHC has in Ontario, it was agreed that Ontario would be the province in which to try out this type of gathering. The learnings from this meeting would then inform our engagement efforts in other provinces.

MEETING OBJECTIVES

- Gather insights from our regional membership on what specific barriers networks and organizations are facing as part of the provincial hepatitis C response, and which handful of recommendations from the Elimination Blueprint you feel will have the biggest impact from a community perspective.
- Gather stories to help move from the abstract to real-life examples of these recommendations being effective in a Canadian context to aid our advocacy efforts.

This information would feed into the creation of a **summary briefing for provincial health policy makers**, which could then be used by the AHC coalition members in Ontario as an **advocacy tool**.

MEETING PREPARATION PROCESS

The AHC Ontario Meeting Planning Committee sent invitations to AHC Ontario member groups and Steering Committee members. AHC is composed of member organizations working with different communities in different parts of the province who have joined the coalition, so additional effort was

made beyond our current membership to ensure representation of these priority populations and people of lived/living experience. Invitations were also sent to CanHepC and VIRCAN.

The Blueprint was sent out ahead of time, along with summaries, with the expectation that participants would come familiar with and ready to discuss the various recommendations made in the Blueprint and which ones would have the biggest impact in Ontario, if implemented.

Meeting Notes

(provided by the facilitator, include a summary of proceedings and also the consolidated notes from the Day 2 working groups)

LIST OF PARTICIPANTS

Aara Amey Ayer	AIDS Cmte of York Region
Aaron Vanderhoff	VIRCAN, Toronto
Dr. Beth Rubenstein	Kingston Street Health Centre
Bill Atlookan	Elevate NWO, Thunder Bay
Camelia Capraru	VIRCAN, Toronto
Christine Francis	Gilbert Centre, Barrie
Denise Baldwin	South Riverdale CHC, Toronto
Dominica Andersen	Réseau ACCESS, Sudbury
Fozia Tanveer	CATIE, Toronto
Holly Gauvin	Elevate NWO, Thunder Bay
Jennifer Broad	Toronto Community Hep C Program
Dr. Jordan Feld	CanHepC
Kate Mason	Toronto Community Hep C Program
Lindsay Jennings	PASAN, Toronto
Lisa Toner	Réseau ACCESS, Sudbury
Matthew Frederick	AIDS Cmte North Bay
Phillip Banks	Gay Mens Sexual Health, Toronto
Ross Wallace	Santis Health, Toronto
Shelly Archibald	Sioux Lookout First Nations Health Authority

Action Hepatitis Canada Steering Committee Members

Gerard Yetman	AIDS Committee of Newfoundland and Labrador (AHC Chair)
Colin Green	Gilbert Centre, Barrie (AHC Vice-Chair)
Laurence Mersilian	CAPAHC, Quebec (AHC Secretariat and Treasurer)
Emily Jones	Blood Ties Four Directions, Yukon
Janet Butler-McPhee	Canadian HIV/AIDS Legal Network, Toronto
Kari Hackett	Positive Living Fraser Valley, BC
Lesley Gallagher	Canadian Association of Hepatology Nurses, BC/SK
Melisa Dickie	CATIE, Toronto
Jennifer van Gennip	AHC Administrator, Barrie
Scott Black	Facilitator, Ottawa

PRESENTATIONS

Following an agenda review and go-round, two presentations were delivered to begin the day:

Blueprint to Inform Hepatitis C Elimination Strategies in Canada: Converting the Blueprint to an Action Plan

Delivered by Dr. Jordan Feld, this presentation was organized according to the three pillars of Prevention, Testing and Diagnosis, and Care and Treatment. Dr. Feld identified the following needs:

Prevention:

- Centralized tracking of NSP and OAT provision to assess adequacy of coverage
- Expansion of NSP & OAT in provincial prisons
- Expansion of HCV teams

Testing and Diagnosis:

- Birth cohort test – more to come
- Reflex HCV RNA on all positive Ab samples – standard in US!
- Acceptance of POC tests as positive Ab result by Public Health
- Formal approval of DBS testing for AB + RNA or RNA alone – broader access
- Funding for POC tests in relevant settings – e.g. HCV teams, prisons
- Allow for self-referral after positive HCV RNA test

Care and Treatment:

- Allow self-referral after diagnosis (or at least by PHO RN!)
- Removal of requirement for 2 x HCV RNA > 6m apart
- Allow treatment of acute HCV
- Add retreatment to LU codes
- Expand HCV ECHO or similar programs to enable non-specialists to treat – promote NP, PCP treatment, consider pharmacy treatment
- Provide treatment start or linkage upon release in prisons
- Allow inpatient treatment – psychiatric hospitals, long-term care facilities (currently not approved by ODB)
- Track all treatment starts and outcome in the province

DAA Prescribing Trends in Ontario

The second presentation was delivered by pharmacist Mina Tadrous, and focused on statistical findings of prescribing trends in Ontario (Specialists vs. GPs, urban vs. rural, etc.).

COMMUNITY PERSPECTIVES

Following the presentations and associated questions, each participant was given the opportunity to make general comments, as well as more specific comments in the following areas:

- What's working well
- What has to change
- Barriers
- Gaps

- Concerns

Participants from the LGBTQ community raised the issue that they face challenges around stigma. People may not be out with their physician, thus may be reluctant to engage in discussions about Hep C. The only help to date has come from the HIV sector, but asking the HIV community to take on Hep C without additional resources is not appropriate. Some physicians are reluctant to take on HIV and Hep C patients. Homophobia remains an issue.

A Quebec participant commented that services in urban areas and in correctional institutions are working well. However, here too physicians do not want to treat Hep C patients, and avoid contact with PWIDs.

In Toronto, a community advocacy program has reached large numbers of people. The Toronto Hep C Program has also been doing RNA testing on those who use supervised injection sites (SIS). People are coming to health centres, and engaging. Regarding testing, the six-month wait is a barrier, broader policy changes are needed.

A participant from Sudbury raised challenges with infectious disease specialists who will not treat, and even control access of GPs to patients. Housing and homelessness are huge issues in this community. Hep C is one priority of many for this population, they have major issues to deal with, such as shelter, food, income. Distance to supervised consumption services is a barrier. Long drives are necessary.

Outreach for testing in Sudbury has been very effective, but treatment is not as good. Trends are positive, with 54 currently on treatment. Thanks to the tireless efforts of the local team, they have achieved wonderful results in spite of the lack of stable housing. When serving priority populations we must keep in mind the other challenges they face, in addition to Hep C.

Incentives are working in Thunder Bay as well. At this point they have contacted the “easy people”; from this point onward it’s a grind, a game of inches to engage with the rest. In addition to Hep C people are infected with HIV, tuberculosis, and AIDS.

In a promising pilot project for HIV testing in Thunder Bay, they have asked for both HIV and Hep C testing. Three pharmacists have been recruited, each with physicians attached to them, who are willing to do HIV and Hep C work. There is a strong need for a mobile treatment option, such as a van, with a nurse, and a link to a doctor via telemedicine for curbside treatment. Until this option is available there will continue to be a gap, a barrier.

A participant from the immigrant community emphasized that rates of Hep C among immigrants are double the national average. Re barriers and gaps, testing is a huge issue in the immigrant population. Diagnosis takes a long time, so the disease advances. Currently it can take up to 10 years after arrival in Canada for diagnosis.

Age-based testing is a great way to diagnose many, but especially immigrants and newcomers, as it is non-stigmatizing. Many don’t have access to primary health care; no family doctors, no specialized programs. There is no program that focuses on immigrants and newcomers. As a result they must advocate for themselves, go to their family doctors (if they have one), get themselves tested, and referred to a specialist. For those who do not know the system and don’t have a job, it is difficult. By the time they get treatment, it may be too late.

A program designed specifically for immigrants and newcomers is desperately needed, as is a more community-based pathway to care. They are a relatively stable population compared to some others, so once treated, results will be good.

An Indigenous participant underlined that systemic racism is a huge barrier for Indigenous people. Changing this is beyond the scope of this event, but it's an important factor in Hep C prevention, testing and treatment. Sometimes Indigenous people don't have the courage to speak up to their doctors. We must involve Indigenous communities in decision making, and increase testing in Indigenous communities.

A participant with lived experience emphasized that building trust with priority populations is critical, as is peer support. The hard work is just starting, and it will take time to develop relationships and leverage networks.

Prevention efforts in York Region are stymied by unnecessary procedures that further stigmatize priority populations. Public Health in York Region provides harm reduction equipment, but require frontline workers to negotiate MOUs with each agency. The EDs of these agencies sometimes do not respond in a timely manner, resulting in delays of up to two years. Once MOUs are signed and a request is made for equipment, frontline workers are required to place it in a black bag, visit the agency, then meet with clients off-property. This is highly inappropriate. Harm reduction services should be offered on site.

A participant providing services to reserves in northeastern Ontario commented that leadership decides whether outside professionals can work in their communities. A lot of time is spent on education. Not all communities have harm reduction services, but there is access to clients. Nineteen of 31 communities have nursing stations. It is complicated to engage, must build relationships. There is only one funded position in the entire region.

These Indigenous communities have a very different relationship with Health Canada, which does a lot of work on reserve. Hep C patients are heavily stigmatized, so flying people out is a good method. Each community is different. Some have clean water, some do not; some are rich, some poor. When patients self-refer, they may not gain access to services. Also once a referral is made, the patient is not discharged. Clients should be able to decide when they want to be discharged. There is a lot of staff turnover due to burnout and other causes, constant education is necessary, and there are not enough resources. Colonialism is a living reality.

Commenting on the situation in and around Barrie, a participant from that community mentioned that substance use is not being addressed either on or off reserve. Very few programs are in place, thus engaging with priority populations is a difficult. A lot of education re harm reduction needs to be done. In Barrie there is also a clear need for a safe injection site, but some Indigenous and other organizations "don't want to touch" that topic.

Indigenous participants as well as participants serving Indigenous communities expressed reservations with proceeding due to the fact that the drafting of the CanHepC Blueprint document, which "is already written", did not include full consultation with rural and urban Ontario Indigenous communities.

BREAKOUT AND FULL GROUP DISCUSSIONS

Following the Community Perspectives discussion, participants were numbered off into groups to begin the process of distilling the more than 60 Recommendations and Good Practices in the Blueprint into six priority recommendations. They then heard from Ross Wallace of Santis Health, the policy expert tasked with translating the results of this event into a policy brief for distribution to Government of Ontario policy makers. Ross suggested people consider the following as they reviewed the Blueprint content:

In terms of what should be done in the province of Ontario regarding Hep C prevention, testing and diagnosis, and treatment and care:

- What is the easiest?
- What is the cheapest?
- What is the fastest?
- What is the most simple?
- Time Considerations:
 - What can be done in 3-6 months?
 - What can be done in a few years?

Participants settled into their groups, with Ross' considerations, as well as key points from the two presentations, provided on screen for reference. The balance of the day was spent in small group and full group discussion.

During a core group debrief following the conclusion of Day One, it was decided that based on progress thus far, identifying six priority recommendations might not be possible. Day Two goals were revised to include 3-5 overarching themes, with 2-4 recommendations for each theme.

Throughout Day Two, participants worked in small and full groups to meet the revised goals. As the end of the day approached, it became clear that the revised goals would not be met, but it was also acknowledged that much useful information had been collected, and could be passed on to Ross for further work. People commented further that the event had been an excellent opportunity for networking and information sharing.

As Day Two drew to a close several participants returned to the issue of lack of consultation with certain priority groups. There was an intense and productive discussion about the process leading to the creation of the CanHepC Blueprint, as well as the involvement of participants who were incarcerated, African, Caribbean and Black, and Indigenous in this AHC event. AHC Steering Committee members expressed regret at the perceived or actual flaws in both, and asked for the help of the membership to find a path forward that recognizes the tension between the urgency of the situation and the need for meaningful consultation. One recommendation was to have the draft brief endorsed by the Chiefs of Ontario, but is there a way to receive endorsement for the Blueprint from a pan-Canadian Indigenous group that will allow us to move the Blueprint forward as a tool, in a good way in all provinces? And what is AHC's role in receiving endorsement from priority populations on a Blueprint that is not ours?

This final discussion concluded with the general sense that while much had been accomplished at this event, there was work to be done re: consultation if Indigenous and other communities were to endorse any recommendations.

A commitment was made by the AHC Steering Committee to follow up with participants via email with this report for review and comment, and with a proposed path forward for Indigenous consultation.

In closing, several participants reiterated that “this time has not been wasted”, and pointed out that they now had a clear idea of “what AHC is and what they do”. Others thanked the organizers for “bringing us together”, and commented that the event has been “useful”. Finally, some participants mentioned that they now understood the importance of participating in AHC initiatives, and would encourage others to become AHC members.

EVALUATIONS

In total, 8 post-event evaluations were received.

Participants commented that the most valuable aspects of the meeting were:

- Opportunity to connect with other Hep C providers and discuss what is working well and what is broken.
- Increased feeling of connection to both the work and the membership of AHC.
- Hearing strategies used by other teams across the country that aren’t specific to Ontario.
- Learning how to turn challenges into policy recommendations.
- Opportunity to provide input.
- Discussion along participants.
- Dr. Feld’s presentation.

Suggestions for areas for improvement for next time included:

- Expand to 3 days to allow more time for debriefing, context, discussion.
- Discussion earlier about whether priority populations feel the Blueprint represents their experiences and a joint decision about how to move forward.
- Be mindful of the use of the term priority populations.
- Reaching out to priority populations beforehand to outline the process and mitigate concerns ahead of time.
- Better and more fulsome representation for all the priority populations.

Some participants also noted:

- An appreciation for the flexibility to explore the tough issues that came up on Day 2.

CONSOLIDATED NOTES

Following are the consolidated notes from all groups as of the end of Day Two. These notes are the result of considerable effort by participants, and will be the basis for the policy brief to be drafted by Santis and distributed to participants for comment. The AHC Steering Committee would like to thank all participants for their contributions.

Group One

Theme: Delivering 24/7 365 care (Hep C is not a 9-5 disease)

Recommendations:

Prevention/Treatment

1. Create satellite sites/drop in centres that could be run out of the homes of peer supporters. (option for safe disposal, access to harm reduction equipment)
2. Increase access to sharps containers in public spaces (washrooms, parks, etc.)
3. Fund clinics to keep hours open later (1-2 x per week)
4. Better coordinate and integrate health services and social supports (Sudbury CMHA shelter no longer admits HCV team)
5. Change corrections and detox release schedule to avoid weekends, stick to 9-5.
6. Health Bus: Create mobile wound clinics with harm reduction supplies, food, warming supplies, etc. and with predictable hours (change program delivery model such that Hep C teams can also deliver wound care (SOS Van, Thunder Bay))

Group Two

1. Priority Populations:
 - a. Expand Ontario's priority populations to include all PPs listed in Blueprint (with Ontario data to support)
2. Pass Bill 6, The Correctional Services Transformation Act, and implement the recommendations of the Expert Advisory Committee on Health Care Transformation in Corrections (and coroner's inquest recommendations)
3. Testing
 - a. Reflex confirmatory (RNA) testing to simplify testing process
 - b. Get rid of 6 months chronicity testing (delay)
 - c. Funding of simpler POC testing
 - d. One-time universal testing prompt, regardless of risk factors
4. Treatment
 - a. Create a system to track and share treatment starts provincially, so we can track our progress
 - b. Alleviate waitlists into treatment and care (by incentivizing treaters and/or expanding who can prescribe. Put doctors on salary?)
5. Data
 - a. Track death by HCV and overdose accurately provincially, so we can track our progress
 - b. Centralized tracking of NSP and OAT provision (to tie to rates of new infections)

Group Three

Testing

Challenge: Only ½ of all people living with HCV in Canada (need Ontario data) are aware of their infections

Recommendations:

1. Increase testing in the cohort population (1945-75)
2. Approve and fund POCT
3. Approve and fund Reflex testing
4. Increase peer delivered testing (volunteer or paid (baseline minimum wage), offer different points of entry and flexible policy, opps for advancement)
5. Testing awareness campaigns
6. Offer HCV anonymous testing

Prevention

Challenge: 85% of all new HCV cases are found in PWUD in Canada

Recommendations:

1. Education: Stigma awareness campaign
2. OHRDP requires program review and evaluation to provide broader access to safe supplies with access models developed by community
3. The cap on the number of CTS' must be increased to meet the needs determined by community
4. Corrections:
 - a. Establish needle exchange programs/OPS in provincial jails
 - b. Improve access to OAT in provincial jails

Treatment

Challenge: Only 7% of all people with HCV are cured (2016 data)

Recommendations:

1. Eliminate the 6-month waiting period to start treatment
2. Expand the scope of practice for HCV treatment to GPs and NPs
3. Increase education initiatives for health care professionals regarding new HCV treatment
4. Develop HCV curriculum for medical and nursing schools
5. Develop and deliver community education initiatives on HCV treatment and cure, harm reduction
6. Increase the number of HCV care teams (multidisciplinary models)

Priority Groups

Challenge: Not all priority populations are included in the populations identified in the Blueprint

Recommendations:

1. Specific strategies for priority groups

2. Increase data gathering and treatment linkages to priority populations
3. Duty to consult to identify priority populations, i.e. ACB community

Group Four

Overarching context piece for policy audience:

- What is hepatitis C
 - Most burdensome infectious disease globally and in Ontario (viral hepatitis combined)
 - Only infectious viral infection with a CURE
- Burden of disease
- International guidelines and WHO commitments, introduce blueprint,
- In Canada and in Ontario

Priority Populations

Challenge

People who are members of priority populations are often excluded from mainstream health services, and face high-levels of stigma, discrimination and other obstacles that make it difficult for them to utilize and access health care.

Recommendations:

Create specific focus and targets for each of the priority populations identified in the Blueprint in Ontario's Action Plan

1. Develop with meaningful consultation from people with lived experience, and community, research and clinical stakeholders with each priority population
2. Ensure adequate funding and transparent disbursement of funding dedicated for each priority population stream
3. Develop an accountability plan to measure progress in reaching targets

Challenge:

Hepatitis C is one of the most burdensome yet curable infectious diseases in Canada, preventable waste of resources. Nearly half of people living with HCV in Ontario are unaware of their status and have not been diagnosed and linked to care and cure.

Recommendations:

1. Implement one-time universal opt-out testing among the 1945-1975 age cohort
2. Offer and scale-up of routine screening and testing to people at ongoing risk increase diagnosis among priority populations
3. Introduce reflex testing in Ontario (following Alberta and BC models)
4. Streamline and broaden approvals for POC and DBS with PHO

Challenge:

Untreated HCV related liver disease will inevitably lead to a range of systemic health problems, progressive liver damage, decrease quality of life, increased transmission and increased health care costs.

1. Removal of Ontario's mandatory second positive HCV RNA test which is unique to Ontario and a barrier to treatment initiation (creating an unnecessary wait time and loss to follow-up)
2. Scale up of capacity building and education among service providers on hepatitis C testing, treatment and cure
 - Address discrepancies and dispel circulating myths among service provider knowledge
 - Cost-effectiveness
 - Treatment efficacy and simplicity and tolerability (over 95%)
 - Stigma
 - Treatment efficacy among PWID
 - Service providers should not be basing treatment initiation based on concerns with reinfection among PWID
3. Build upon and coordinate with existing provincial capacity building platforms (ECHO, HepCNet, CATIE)

Challenge:

The highest incidence and prevalence of HCV are found among PWID in Canada; two-thirds have evidence of current or past HCV infection, and 85% of new HCV infections occur among PWID. Criminalization, unstable housing, poverty, stigma and lack of transportation create barriers to services for PWID, and more broadly PWUD, and incarceration increases their risk of HCV and reduces access to equitable health care. Rural and remote communities face additional barriers to accessing prevention, testing and treatment services.

Recommendations:

1. Expand and build on CTS model increasing sites for broader access across the province and formally integrating HCV Teams and hepatitis C services within this model;
2. Integrate task shifting and the engagement of people with lived experience in co-design;
3. Expanding harm reduction models and innovative programming approaches (including safer supply models)
4. Develop and implement a rights-based services pathway inclusive of community-based service organizations and clinical services for provincial prisons that ensures continuity of care (intake and release planning)
5. Scale up of harm reduction programming including NSP and OAT in provincial prisons