Programming recommendations

The following recommendations highlight program-level approaches and mechanisms that are factors of success in the development of integrated models of care that are accessible, relevant and effective at addressing hepatitis C.

Programming recommendation #1: Develop community-specific and culturally safe programming

“Not only is indigeneity a risk factor, but it is also part of the solution.” – Meeting participant
“One of the things that concerns me is that ‘those’ populations are Aboriginal people. When you are speaking of and about ‘your’ populations it would be respectful to acknowledge that you do have Aboriginal people on your caseloads. That is the start of a dialogue with Aboriginal people in all of our communities.” – Meeting participant

Successful integrated program models are culturally relevant and safe. While the term cultural safety was first used by and for Indigenous peoples, the concept and its practical approach may apply to all cultures and communities. Moving the standard of care beyond that of cultural competence to that of ensuring cultural safety is a programmatic factor for success. Cultural safety transforms power imbalances in society and it advances progress toward self-determination and de-colonization.

Culturally safe programming begins with a recognition that Indigenous peoples and people from other cultural/ethnic/spiritual communities are accessing the services provided. Programs that invest in Indigenous-led models of care can produce culturally safe programming. Hiring and retaining an Indigenous workforce is critical. Indigenous peoples in Canada have developed a variety of culturally safe programs.

Programming recommendation #2: Ensure opportunities for clients to engage in programming as soon as they are ready

“Instead of just focusing on if someone is sick enough for hep C treatment, is there a window of opportunity that we need to take advantage of now, because now they are ready. Triage based on window of opportunity instead of how advanced the disease is.” – Meeting participant

When a client is ready to begin addressing their hepatitis C infection, it is important that programs respond and not turn individuals away. Although treatment may not be possible immediately, programs that have pre- and post-treatment elements can engage clients immediately and over time, which limits lost opportunities for engagement and treatment.

Immediate engagement is particularly important when working with marginalized or vulnerable service users for whom treatment and care readiness may be directly linked to specific moments-in-time: when lifestyle, emotional readiness, relative stability and other factors line up. When triaging and prioritizing services, it is essential to consider “windows of opportunity” or critical moments in time when a service user may be particularly well-positioned (i.e. personally ready) for treatment and care. For example, there is a “window of opportunity” to discuss hepatitis C testing and treatment when an individual begins to engage with a methadone maintenance program. In this example, hepatitis C treatment can be part of a broader stabilization plan; “treatment becomes part of engagement and stabilization, not the other way around where stabilization is required for treatment” (as one meeting participant explained).

Programming recommendation #3: Prioritize relationship building and develop trust and credibility with service users

“What works is building trust. If you always deliver what you say, trust will follow. This is a population that is given mixed messages and constantly not delivered upon. It’s impressive when you do. It’s shocking.” –
Meeting participant
“The physician is like a grandfather, the nurses are like aunts and others are like cousins. It’s hard to let go of the relationship.” – Meeting participant

A key success factor of integrated hepatitis C programs is the trust established with service users. People who face consistent hostility and discrimination from the mainstream are naturally reticent to trust healthcare and service providers. It is critical to provide non-judgemental and respectful services, to follow through on commitments, to offer flexible and appropriate hours and timely follow-up, and to deliver services with patience and flexibility. The term “being where someone is at” embodies an approach that is attentive to the priorities and realities of an individual, and it promotes trust and relationship building by making individuals feel understood and respected.

Programs that offer a familial atmosphere and that foster genuine relationships between service providers and clients garner stronger engagement and adherence to treatment and programming. For example, at the Centre Sida Amitié, patients are given a diploma at the end of their treatment and report a sense of family connection, using terms like aunt, uncle and cousin to describe service providers and clients.

**Programming recommendation #4: Ensure a commitment to harm reduction approaches in all aspects of integrated programming**

A harm reduction approach across the full continuum of hepatitis C care is critical to effectively offering services to people who use injection drugs. Harm reduction programs can include safe consumption sites, safe equipment distribution, safe-use education, overdose prevention interventions, and anti-stigma initiatives. Services like these reduce potential harms associated with drug use and provide a gateway to testing and other health-related services that can lead to treatment and care.

Criminalization of drug use makes people who use drugs more susceptible to adverse health issues and makes it difficult for people who use drugs to access mainstream health care services. A harm reduction approach includes providing services designed to create safe spaces and make health care more accessible. An integrated model should employ a harm reduction approach in its prevention, testing, treatment and care (including post-treatment care) programming.

**Centre Sida Amitié, St-Jérôme, Quebec**

A clinic that feels like a family: a low-threshold harm reduction approach

A harm reduction approach to treatment ensures that treatment is accessible to clients whether or not they have stable housing or are sober. Centre Sida Amitié, in St-Jérôme, Quebec, is a low-threshold organization for people who are street involved and use substances. The organizational commitment to harm reduction has facilitated successfully engaging service users, many of whom are transient youth who have successfully completed hepatitis C treatment regimens. Program staff have a relationship with service users, recognizing that in many cases, staff are the only significant relationships in service users’ lives.

**Programming recommendation #5: Develop trauma-informed and reconciliation-based approaches to crisis and conflict resolution**

“I’ve never fired a patient. It’s always just, so this can’t happen right now but you can come back to me tomorrow. Life is so stressful. Coping strategies are diverse. We are all humans.” – Meeting participant

A key success factor of integrated hepatitis C programs is their ability to anticipate and appropriately address conflict and crisis. Individuals who are living with, affected by, or at risk of hepatitis C may also be faced with managing a range of stressors, social exclusions and unmet needs on a daily basis. It is normal for misunderstandings and conflict to arise occasionally, considering the burden of stress and perhaps trauma some people may be dealing with. Programs that protect space within which misunderstandings and conflict may occur, and which have supportive conflict resolution mechanisms in place, particularly for individuals experiencing crisis, are more successful in terms of reach, retention and outcomes. The same success is not realized when individuals who are experiencing conflict or crisis are turned away.

Banning or excluding individuals from services because of conflict or behaviours is re-traumatizing and fuels issues of health inequity for highly underserved populations. Trauma-informed methods of engagement can prevent
conflict and inform reconciliation approaches. It is important to train staff in reconciliation, transformative justice, conflict resolution and trauma-informed approaches. Hiring staff that have strong capacity for and skills in relationship-building, empathy and trust-oriented practices is also critical.

Programming recommendation #6: Despite shortened treatment durations, ensure programs incorporate the full continuum of care

“We are not going to treat our way out of the epidemic. We talk about eradication, but we’re not going to be able to do it with just treatment so prevention strategies have to be scaled up side by side.” – Meeting participant

With shorter treatment times and better tolerated treatments, the role of supportive care in the context of hepatitis C is changing but certainly not going away. While individuals may no longer need to attend health centres for treatment and managing side effects is less of an issue than in the past, there will be a heightened need to support individuals’ treatment adherence. There will also be a continued need for prevention strategies, as well as post-clearance healthcare and support, including liver care, mental health support and ongoing services as needed. Indeed, although it may become easier to clear the virus, the challenge will be supporting individuals to remain clear of the virus and providing post-clearance health support.

Hepatitis C treatment is a gateway to engage individuals in services for other health-related and basic needs. Individuals from priority populations are likely to have other health-related and basic needs that are also important in terms of hepatitis C treatment outcomes, healthy living with hepatitis C and care.

Programming recommendation #7: Facilitate seamless access to services beyond the traditional hepatitis C continuum of care services

“Who wants to go and see a doctor if you haven’t showered in a week?” – Meeting participant

A key success factor for integrated hepatitis C services is seamless access to services and supports that are not hepatitis C specific. Individuals from priority populations may have other, more pressing health-related and basic needs, including (but not necessarily limited to) housing, income support, healthy food, peer support, psychosocial supports, legal support, employment assistance and language training. It is important to pay particular attention to the breadth of non-traditional health services and supports that are essential to a comprehensive hepatitis C program model.

Programming recommendation #8: Provide non-traditional incentives to service users

“Incentives save lives. You might not have to use incentives forever, but incentives can be a really good thing. It is not always something you hand over, it can be kindness, respect and gestures.” – Meeting participant

“We need to find ways to meaningfully engage the people most affected and sometimes compensation is a part of that. I hope this continues to be a part of the dialogue. I worry that this might be a piece that falls off the cliff.” – Meeting participant

Non-traditional incentives can make programs more appropriately suited to clients’ realities and needs. Any individual who engages in a healthcare program does so because he or she is incentivized to do so; often the incentive is to become healthier. For many individuals, long-term health is a less-pressing priority than are issues such as child care, employment, food security and/or access to drugs and equipment. Individuals grapple with competing priorities and, often, the asymptomatic nature and slow progression of hepatitis C means that clearing the virus is not a primary concern for individuals with multiple, more immediate needs. Non-traditional incentives beyond the simple health benefits can make programs more appropriate and suited to client needs and realities. Non-traditional incentives such as laundry facilities, snacks, gift cards, food boxes, honoraria and child care can make programs accessible and suited to the varied and more immediate needs of individuals.

Programming recommendation #9: Enhance meaningful service-user engagement

"It's worth believing in the by and for approach and sitting down with people as equals at the table and not simply taking individuals as nice personalities who look good in a report. Because yes, we include people, but in the end we didn't listen." - Meeting participant
Integrated hepatitis C program models are culturally situated and client-centred. Engaging service users in the planning, delivery and evaluation of programs and services is a key success factor in ensuring that they are relevant to the individuals for whom they are intended, and that they reflect the communities within which they are offered/provided. For example, having patient advisory boards that guide research, evaluation and program development is a useful strategy. The key to meaningful engagement of service users (peers) is transfer of real power and ownership and fundamental respect for the value of lived experience and its resulting individual expertise.

There is much to be learned from HIV principles such as the Greater Involvement of People Living with HIV (GIPA) and Meaningful Engagement of People Living with HIV (MEPA), as well as from the disability rights principle, Nothing About Us Without Us.

**Programming recommendation #10: Invest in peer programming**

“We would be absolutely nowhere without our peer programs and people with lived experience. It’s worth the work.” – Meeting participant

“Most of us don’t like being called peers. I myself am a community support worker. I receive the same training as other workers. The only difference is that I have walked the walk and they haven’t. We are treated as equals in our workspace so there is no problem. Our model works really well.” – Meeting participant

“I believe that the capacity to respond to this is actually within newcomer and immigrant communities because the clients have social work and medical degrees.” – Meeting participant

To design and deliver relevant, culturally safe and effective programming, it is important that individuals from priority populations are meaningfully engaged in the processes. The success of particular elements of programming hinges especially heavily on the input and guidance of people with lived experience. For example, having peers design and lead outreach strategies has proven extremely effective in terms of reaching and serving highly marginalized and underserved populations. Individuals who have experience and trust within particular communities can identify where, how and when to reach out. Indigenous patient navigators have been critical in bridging service users with the healthcare system in Indigenous communities.

**Programming recommendation #11: Enhance outreach and testing efforts with emphasis on underserved and marginalized populations**

Enhanced outreach and testing efforts are key success factors in reaching people and bringing them into care. Though there is no simple solution, a first step is to introduce a more robust role for hepatitis C screening into primary care and enhance targeted testing.

Hiring and engaging people who have relevant lived experience to design and deliver outreach and testing strategies for underserved and marginalized populations is an important approach. Individuals who identify with and have trust within particular communities are well positioned to plan where, how and when to reach out. For example, the Punjabi Community Health Services, a community health centre serving South Asian communities, engages retired “aunties” as peer navigators to connect the broader community to its health and social services.

**Programming recommendation #12: Identify, document and research hepatitis C programming approaches in the new era of hepatitis C treatment**

To continue improving hepatitis C programming, it is essential to identify, document and share new promising approaches and good practices that are in development in this new era of hepatitis C treatments. It is also important to leverage research opportunities to develop evidence-based policies, programs and interventions. In terms of fostering innovation, partnerships with researchers can be a strategy to support interventions that are unlikely to be funded by mainstream sources, at least initially prior to sufficient evidence to support funding.

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Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

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