ECHO+: Improving access to hepatitis C care within Indigenous communities in Alberta, Canada

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ABSTRACT

BACKGROUND: Indigenous populations experience higher rates of hepatitis C virus (HCV) infections in Canada. The Extension for Community Health Outcomes+ (ECHO+) telehealth model was implemented in Alberta to support HCV screening and treatment, using Zoom technology to support Indigenous patient access to specialist care closer to home. Our goal was to expand this program to more Indigenous communities in Alberta, using various Indigenous-led or co-designed methods. METHODS: The ECHO+ team implemented a Two-Eyed Seeing framework, incorporating Indigenous wholistic approaches alongside Western treatment. This approach works with principles of respect, reciprocity, and relationality. The ECHO+ team identified Indigenous-specific challenges, including access to liver specialist care, HCV awareness, stigma, barriers to screening and lack of culturally relevant approaches. RESULTS: Access to HCV care via this program significantly increased HCV antiviral use in the past 5 years. Key lessons learned include Indigenous-led relationship building and development of project outputs in response to community needs influences impact and increases relevant changes increasing access to HCV care. Implementation of ECHO+ was carried out through biweekly telehealth sessions, problem solving in partnership with Indigenous communities, increased HCV awareness, and flexibility resulting from the impacts of COVID-19. CONCLUSION: Improving Indigenous patient lives and reducing inequity requires supporting local primary health care providers to create and sustain integrated HCV prevention, diagnosis, treatment, and support services within a culturally safe and reciprocal model. ECHO+ uses telehealth and culturally appropriate methodology and interventions alongside multiple stakeholder collaborations to improve health outcomes for HCV.

KEYWORDS: health intervention; hepatitis C virus; Indigenous; telehealth, therapy

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HEPATITIS C BURDEN OF DISEASE IN CANADA

Hepatitis C virus (HCV) infection represents a major public health burden in Canada, leading to more life-years lost than any other infectious disease, including HIV (1). The Public Health Agency of Canada (PHAC) identified an overall reported rate of 33.6 cases of HCV per 100,000 people in 2018, an estimated 317,000 cases nationally (2,3). Indigenous populations within Canada (consisting of First Nations, Métis, and Inuit Peoples) experience HCV incidence rates two to five times higher than non-Indigenous Canadians, a gap that has widened over time (3–11).

The Canadian Network on Hepatitis C developed a Blueprint to Inform Hepatitis C Elimination Efforts in Canada, a strategy to meet the World Health Organization’s goal of HCV elimination by 2030 (2). The strategy identified Indigenous Peoples as one of five priority populations for dedicated focus and activities. Furthermore, the Pan-Canadian Framework for Action acknowledged sexually transmitted and blood-borne infections (STBBIs), including HCV, disproportionately affect certain populations due to the complex interplay between social determinants of health, stigma, and discrimination (3). Although the impacts of HCV are felt in all age and ethnic groups, several populations (including Indigenous Peoples) may encounter an increased risk of HCV transmission compounded by low levels of engagement in seeking screening and treatment.

The Canadian province of Alberta has a hidden and rising burden of STBBIs within Indigenous populations (4,5,11). The HCV prevalence rate is four times higher for First Nations compared to all Albertans (11). A lack of access to culturally safe and appropriate prevention, screening and treatment services is a root cause of inequitable and avoidable HCV burden. Important changes to HCV screening and treatment in the last 5 years include increased safety profiles of HCV medications (>96% cure rate with 8–12 weeks of treatment) and the elimination of liver fibrosis testing before treatment approval. These HCV treatment changes increased access to treatment, but engagement with Indigenous communities through active communication and collaboration were key to health promotion and development of treatment solutions that met local needs.

Alberta Health Services (AHS), the provincial health service provider) consists of five zones: South, Calgary, Central, Edmonton, and North Zones. Provincial data showed an increase in hepatitis C incidence over 1000% in the South Zone between 2015 and 2018 (Figure 1), which motivated multi-disciplinary collaborations to identify and reduce HCV treatment barriers (5).

The number of distinct eligible claimants in Alberta who utilized HCV-related non-insured health benefits (NIHB) medication benefits increased for the past 7 years (Figure 2) (12). Increased HCV treatment from 2015 onward may reflect improved awareness of HCV, increased access to HCV medication, screening, and treatment, particularly
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through the Extension for Community Health Outcomes (ECHO) telehealth outreach model in Alberta described in the following section. One key data limitation is the exclusion of Métis, non-Status First Nations, and/or Inuit individuals; therefore, the total number of Indigenous Peoples treated for HCV is likely underrepresented. Jurisdictional complexity between federal and provincial health departments and challenges to identifying the full burden of HCV. Regardless, treatment options and policy changes over the past 7 years have reduced barriers to treatment. Within this context in 2015, the ECHO program was adopted in Alberta to increase equitable access to screening and treatment of HCV, especially in remote and Indigenous communities.

DEVELOPMENT OF ECHO AS AN INTERVENTION

Developed at the University of New Mexico in Albuquerque, New Mexico, USA, the ECHO model increased access to HCV care for remote and underserved populations by using telehealth technologies to connect to specialist care alongside training and support of primary care providers in effectively caring for individuals with HCV (13). Implementation of a “hub-and-spoke” model where a “hub” was connected remotely via telehealth to primary care practitioners and the health care team at “spokes,” or communities, to provide clinician education and support HCV patients with a connection to specialist care (13). The model proved to be highly successful, showing similar high cure rates in remote ECHO sites managed by generalist physicians or nurse practitioners compared to control groups treated at urban academic centres (13–17).

The ECHO hub-and-spoke model was adopted in Alberta for screening and treatment of HCV in 2015. The central hub (Calgary Viral Hepatitis Clinic) enhanced access to HCV care in remote and Indigenous communities through 20 family physicians and nurse-practitioner or nurse-directed spokes (17).

Since its inception in Alberta, there has been a need for a tailored expansion of ECHO into additional spoke communities, specifically for Indigenous populations. The health inequities experienced by Indigenous populations result in increased rates of HCV and STBBIs due to limitations in primary health care access (eg, transportation barriers) (4,5,7,17). Jurisdictional complexities between federal and provincial health services experienced by Indigenous people result in a lack of awareness related to HCV screening and treatment. The stigma associated with STBBIs negatively impacts screening rates within Indigenous populations, and the adverse reactions to historical HCV treatment remain key deterrents to seeking treatment. Discrimination and lack of culturally relevant care are experienced by Indigenous people that could be partially addressed through the expansion of the ECHO approach in a culturally
appropriate manner (5,9,11). Two years of grant funding was secured from Alberta Innovates to spread the ECHO model into more Indigenous communities in Alberta and to scale the provision of services beyond HCV to include more STBBIs. The evolution of the Alberta HCV ECHO into ECHO+ occurred in 2018.

**EXPANSION TO ECHO+**

Alberta’s ECHO+ Project expanded the hub-and-spoke model with a targeted focus on collaborating with Indigenous communities. The predominantly Indigenous ECHO+ team co-designed a culturally relevant program based on relationality and respect with Indigenous communities. A key development of ECHO+ was leveraging successful models of engagement and supportive team structures developed by the Alberta Cancer Prevention Legacy Fund (ACPLF) to ensure services were co-designed to be locally accessible, culturally safe, and appropriate. Specific elements of the engagement model included the introduction of Community Prevention Practitioners (CPPs), whose responsibilities included strengthening relationships with Indigenous communities in an approach that balanced Indigenous and Western ways of knowing.

The ECHO+ project has three main objectives aimed at maximizing impact and benefit to Indigenous communities: (1) Tailor and implement the ECHO+ model in an effort to reduce inequities in the identification and treatment of HCV and other STBBIs in Indigenous and remote communities; (2) Identify priorities of Indigenous community partners to support the development of strategies, resources, and interventions that incorporate Indigenous oral knowledge and Western written evidence into the development of an expanded ECHO+ model; and (3) Rigorously test and evaluate the impact of spread and scaling the ECHO+ model to Indigenous communities using a mixed-methods approach.

**METHODS**

In 2003, the federal government formed the Truth and Reconciliation Commission of Canada (TRC), focused on reconciliation and healing with Indigenous Peoples. The TRC final report included 94 Calls to Action, including accountability and investment in relationship building by listening with an open and reciprocal mindset to community-voiced issues, with the goal of creating positive change to health care barriers (18). The TRC espoused the use of the “Five R’s” design: Respect, Relevance, Reciprocity, Responsibility, and Relationship. The ECHO+ project implemented the Five R’s design as core principles working within a Two-Eyed Seeing approach (Figure 3) (18–20).

Relationship is not only the basis of effective and impactful project design but also a necessity in recognizing the rich cultural beliefs, concepts, ceremonies, and practices relevant to community health and wellness (20–22). Respect means living this relationship in all interactions with a “good heart,” modelling honesty while humbly guaranteeing good motives and actions toward all stakeholders or participant partner communities involved in the program. ECHO+ incorporated these values with the Two-Eyed Seeing perspective by including and respecting the perspectives from “both eyes” in knowledge building, design, and approach, thus creating a shared collaboration process (23,24). Acknowledging First Nation and Métis worldviews honouring resilience, relationship, and healing is important (25). ECHO+ embodies this perspective by combining community-specific feedback and direction with scientific approaches while maintaining a focus on the Five R’s to build a circular, iterative model expanding hepatitis C awareness and treatment within communities (Figure 3) (21,22).

A community-directed approach to implementation and expansion increased relevance to meet local community needs and simultaneously provided HCV practitioner education. In turn, the practitioners providing care to Indigenous communities undertook an iterative process of sharing wholistic perspectives on health in a spirit of reciprocity with the ECHO+ team. Willie Ermine terms this approach *The Ethical Space of Engagement*, reflecting the intent to examine diversity between Western and Indigenous approaches to develop respectful engagement and collaboration (26).

The ECHO+ project originated in collaboration, focused on building a project team with strengths in community engagement, relationship building, and Indigenous roots, alongside professional strengths and experience in hepatitis C care, to incorporate the Two-Eyed Seeing and Five R’s into daily action impacting health access. Co-design of this expanded scale and spread project included multiple partners showcasing the strengths of collaboration and shared expertise toward a mutual goal.

Equally important in project integration was the incorporation of best practices from Indigenous
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Research methodologies. One First Nation methodology integrated into the ECHO+ expansion was the inclusion of OCAP principles: Ownership, Control, Access, and Possession. Implementing a project with OCAP compliance protects Indigenous community information, data, and knowledge shared with the ECHO+ team (27). The project team implemented the principles of OCAP in design, data collection, and reporting.

Active engagement with Indigenous participants has been integral to the ECHO+ project, with an annual ECHO+ conference as a key activity. For example, focus groups were held in 2019 with Indigenous participants to guide and give permission for the proposal development. Accountability to established relationships resulted in a World Café approach to seeking Indigenous stakeholder feedback in the areas of health promotion material development around hepatitis C, approaches to inform Indigenous community leadership, STBBI stigma, and identifying areas for targeted expansion. This co-design approach through broad provincial engagements (ie, ECHO+ conference) has informed the activities of the project team.

**ECHO+ IMPLEMENTATION**

The implementation of ECHO+ is highly adaptable based on available community resources and priorities, which allowed Indigenous communities to customize the program. The ECHO+ team provided a menu of options based on the capacity and needs of the community (Figure 4). The iterative process may begin at any location in the “Circle of ECHO+ Supports for Communities”; however, a common approach has been to start with “introductions, conversations and options.” The CPPs have a range of options to initiate a relationship with Indigenous communities, such as introductions from colleagues, ongoing relationships, health care connections, or referrals from individuals previously connected to ECHO. CPPs facilitate community HCV awareness sessions to

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Figure 3: The Five Rs design supporting the Two-Eyed Seeing framework in community approaches to hepatitis C care

*The five core principles work as the foundational hub (inner circle). The work streams (outermost arrows) reflect the five categories of funding requirements. Western written evidence, combined with community-directed priorities, oral knowledge, and the Indigenous perspective of wellness (slices of the circle), create a circular iterative model to expand hepatitis C awareness and treatment within communities.*
provide education and awareness support of the ECHO+ opportunity while listening and learning about local context from community stakeholders related to barriers in accessing hepatitis C care.

Building relationships with Indigenous community health care teams provides an opportunity to share a *Welcome Package* signifying agreement to implement ECHO+. CPPs continue building relationships with the completion of a Community Capacity Assessment in partnership with Indigenous communities. The capacity assessment content included health staff available in the Indigenous community, access to lab services, available HCV screening options, linkage to HCV education options, and established treatment and follow-up processes. The capacity form served multiple purposes of increasing rapport, documenting available local health services, and ultimately tailoring the implementation of ECHO+ to best meet the unique needs of each Indigenous community. The impact of the ECHO+ model is customizable as an approach to support communities in identifying and actioning priority health outcomes.

The ongoing relationship between the CPPs and the Indigenous community contacts provides a feedback mechanism ensuring the ECHO+ implementation is meeting community needs. Adaptations and requests for additional information have been a key success, tailoring the available knowledge tools and health system processes to best meet the evolving needs of Indigenous communities. Activities and outputs created have been documented to inform the evaluation of the overall effectiveness of the ECHO+ model.

**RESULTS**

Adapting the Project ECHO model from New Mexico and implementing it in a Canadian context with Indigenous populations has generated key knowledge about the implementation of population health interventions within Indigenous research methods. An expected result of ECHO+ implementation has been a high degree of responsiveness to the unique needs of each Indigenous community. Responding to identified needs led
to hiring a second CPP specifically focused on the Northern areas of Alberta. The ECHO+ Project Team has also been responsive to the needs of Indigenous communities through the creation of practical resources. Specific requests have included a monthly newsletter, a step-by-step guide to inform the preparation of a patient case for presentation at an ECHO+ Zoom session, and simple culturally relevant awareness resources (e.g., a culturally appropriate “HCV fact versus myth” booklet).

An education package was developed and distributed to support communities in joining the ECHO+ program with minimal demands on their already overtasked resources. This package includes an ECHO+ program brochure, a menu of options to support community efforts, an updated and streamlined fillable-field case presentation form, a step-by-step guide on how to prepare a case for the Zoom session, a list of hepatitis C awareness resources, and a “Dear Colleague” professional letter of invitation to ECHO+. A community acknowledgement letter outlining the roles and responsibilities for program participation was also developed to ensure community leadership and health care team members were appropriately informed about all aspects of the ECHO+ program. Finally, the case report form for discussion at the biweekly sessions was greatly simplified to reflect unavailability or challenges related to accessing lab and blood testing (28). For example, the requirement for lab results calculating Fibrosis-4 (FIB-4) and aspartate aminotransferase to platelet ratio index (APRI) scores was dropped, and the only required test remains a positive HCV-RNA PCR result.

The ECHO+ Project Team received many requests to address the stigma associated with HCV and/or STBBIs to increase screening capabilities. The third annual ECHO+ conference held in Calgary in October 2019 included a World Café session, where one station was dedicated to discussing approaches for the reduction of stigma in a culturally competent manner. Participants identified a shift in language from “Hepatitis C Virus” to “Liver Health” as a safe method to communicate health promotion materials. We shifted language in ECHO+ pamphlets to say, “Hepatitis C can happen to anyone” instead of accusatory statements such as, “Do YOU have HCV?” as well as using the term “screening” versus “testing,” as more neutral and less stigmatizing. Another approach facilitated the development of a “Myth vs Fact” booklet specific to HCV as a simple culturally relevant tool for increasing awareness, per community request.

Another community-requested approach to destigmatizing HCV screening and treatment has been through sharing lived experiences of individuals who have completed HCV treatment and have been cured. The ECHO+ team met with Indigenous Knowledge Holders and several Indigenous individuals with Lived Experience who shared their experience in written and video format to support increased awareness and treatment support. These stories were shared via the monthly ECHO+ newsletter, presentations at the ECHO+ annual conferences, self-portraits to illustrate “I am not the face of HCV” from a strength-based perspective, and video storytelling in partnership with ECHO+ Advisory Committee members to inform additional grant funding. Relationship building and interaction with the community Knowledge Holders facilitated the sharing story and wellness strategies, incorporating traditional healing ceremonies, plants, and practices.

The ECHO+ Project Team has supported treatment initiation by wayfinding complex policy environments across multiple jurisdictions. For example, discussions with Indigenous communities identified limitations of nursing scope of practices within federal policy. The issue was brought forward at the monthly ECHO+ Advisory Committee meeting, where the Indigenous Services Canada representative was able to clarify the policy interpretation and remove a perceived barrier. A province-wide update was sent to First Nations in Alberta to clarify the scope of practice policy. Another example has been the reduction of HCV-RNA PCR test denials from the provincial virology lab that had been frustrating front-line practitioners. The ECHO+ Project Team connected with AHS Public Health Virology Lab leadership to raise these concerns and clarified the lab requisition process.

The expectation of ongoing discussions and the flexibility to develop materials to fill information gaps has served to build trust in the accessibility and appropriateness of the ECHO+ program. Implementing a rigid, linear model based on Western approaches would have been ineffective in expanding ECHO+ for Indigenous communities. Working in partnership with an understanding between Indigenous, municipal, provincial, and federal stakeholders is a key element of success with the ECHO+ project, even as the project team made significant adaptations in response to the pandemic.
COVID-19 IMPACT
The COVID-19 pandemic created challenges and barriers impacting community engagement and program facilitation (28). These opportunities are ideally designed to be held in person, and the program envisioned a robust travel schedule for HCV awareness and ECHO promotion; however, in response to COVID-19 social distancing, virtual presentations using Zoom technology were provided as a meaningful alternative. For example, the annual ECHO+ Conference was shifted to a Zoom format in 2020, and the project team pivoted to providing education sessions remotely using Zoom. Regional engagement and training meetings were cancelled due to provincial COVID-19 travel restrictions. Alongside budget reallocation, travel restrictions and decreased capacity in community health centres due to staffing shifts or redeployment for pandemic response rendered prevention and awareness programming non-existent. The pandemic changed the ECHO+ project expansion from building relationships in the Indigenous communities directly to shifting connections and relationships from a distance electronically. Innovative pandemic response incorporated the expansion of the biweekly case conferences to include infectious disease experts to address questions about the COVID-19 virus and pandemic-related issues. This modification has proven to be popular and helpful to communities.

The impact on the ECHO+ project was two-fold: the health care providers in Indigenous communities prioritized the COVID-19 response, and the project team was hindered in the expansion of a non-pandemic program. For example, scheduled community gatherings that would have brought together families to provide liver health education and seek input on implementing ECHO+ in their community were postponed, moved to virtual sessions, or cancelled altogether. An overall impact on patient screening efforts also occurred.

The risk mitigation approach acknowledges federal fiduciary responsibility, Indigenous sovereignty over health, and a role for the provincial health services to contribute inclusively.

DISCUSSION
The original ECHO HCV program played a significant role in expanding direct-acting antiviral (DAA) treatment starts in Alberta Indigenous communities. ECHO+ builds on this to expand the number of Indigenous communities and thus improve HCV access to care in this underserved population. Thus, an investment of time and energy into screening can identify comorbidities and facilitate a cure, lowering the overall burden of disease in a supported environment and alleviating some of the pressures on the upstream federal and provincial health systems. Downstream impacts include linking community health staff to remote specialist services, which has been an identified gap (ie, “Whom do I call if my patient has an HCV confirmed test result?”).

High levels of engagement with Indigenous communities have strengthened the co-design approach to meet local needs. The ECHO+ Project Team daily connects with Indigenous communities and interfaces with provincial AHS as well as federal Indigenous Services Canada (ISC) to improve the availability of culturally appropriate HCV treatment. Creating an Indigenous-adapted ECHO+ model for Alberta that respects Indigenous sovereignty, provides AHS staff with an intervention to improve care, and ensures appropriate linkages with provincial and federal services has required a robust and reciprocal approach to co-design.

ECHO+ was developed with a strong foundation of engagement and co-designed with Indigenous communities, and iteratively has been adapted due to COVID. Relationship-building activities that were impacted included “road trips” facilitating face-to-face introductions, community leadership meetings, community awareness presentations, participation in ceremonies, and shared meals with community members. These relationships with various community members are vital for continuity, given the high rate of community leadership transitions and clinic staff turnover. Moving the project to a Zoom-based distance approach was not the preferred method; however, Indigenous partners involved in ECHO+ have understood and remain committed by necessity to prevent the spread of COVID-19.

Conclusion
Public health and primary care provider knowledge gaps—as well as policies that restrict DAA prescribing to a select group of specialists practising in larger urban centres—create health inequities, especially for Indigenous communities. Forcing individuals from remote communities to travel to urban centres for diagnosis and treatment amplifies the inequity. Reducing this inequity requires supporting local primary health care providers
to create and sustain integrated HCV prevention, diagnosis, treatment, and support services.

Once identified, hepatitis C is easily curable with oral antivirals. Improving the lives of patients unaware of the damage HCV is causing to their bodies was a key reason the ECHO model was started in Alberta in 2015. Evolving the provision of services and welcoming additional Indigenous communities into the hub-and-spoke model was the basis for ECHO+ in 2018. The ECHO+ program thus utilizes telehealth and a culturally appropriate methodology with multiple partners to improve the patient experience and health outcomes for hepatitis C and STBBI for Indigenous Peoples in Alberta. Navigating jurisdictional boundaries and barriers between federally funded nurses, AHS practitioners, and regulated health professionals funded by Indigenous communities is a unique element of this work. Efforts to eradicate HCV among Indigenous Peoples have been hampered but not stopped by a pandemic. The sustainability of the telehealth approach will occur after the grant funding ends based on the outputs developed to support adaptable, community-identified implementation that varies across the province.

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