

## ***Table of Contents***

<b>Introduction</b> .....	1
 <b>Section 1: Ethical CBR in the Aboriginal Community</b>	
Indigenizing research practices: Two Indigenous researchers share their experiences of incorporating Indigenous culture into research.....	3
<i>Anita C. Benoit and Doe O'Brien-Teengs</i>	
Community-directed research priorities for Indigenous peoples in Canada and hepatitis C: a scoping review.....	22
<i>Chris Macklin, Malcolm King, Alecia Kallos, Sharon Jinkerson-Brass, Sandra Laframboise, Renée Masching, Tracey Prentice, Alexandra King</i>	
Water Journey: methods for exploring the research priorities for Indigenous peoples in Canada and hepatitis C.....	44
<i>Chris Macklin, Malcolm King, Alecia Kallos, Sharon Jinkerson-Brass, Sandra Laframboise, Renée Masching, Tracey Prentice, Alexandra King</i>	
Water Journey: emerging themes for research priorities for Indigenous Peoples in Canada and hepatitis C.....	61
<i>Alecia Kallos, Chris Macklin, Malcolm King, Sharon Jinkerson-Brass, Sandra Laframboise, Renée Masching, Tracey Prentice, Alexandra King</i>	
 <b>Section 2: Dissemination of Results / Finding</b>	
Knowledge translation in Indigenous communities.....	81
<i>Randy Jackson and Renée Masching</i>	
 <b>Call for Papers</b> .....	 105

## **Water Journey: methods for exploring the research priorities for Indigenous peoples in Canada and hepatitis C**

*Chris Macklin<sup>1</sup>, Malcolm King<sup>2</sup>, Alecia Kallos<sup>3</sup>, Sharon Jinkerson-Brass<sup>4</sup>, Sandra Laframboise<sup>5</sup>, Renée Masching<sup>6</sup>, Tracey Prentice<sup>7</sup>, Alexandra King<sup>8</sup>*

<sup>1</sup> Chris Macklin is a Masters of Public Health candidate at Simon Fraser University.

<sup>2</sup> Malcolm King is a professor in the Faculty of Health Sciences at Simon Fraser University.

<sup>3</sup> Alecia Kallos is a Masters of Public Health graduate from Simon Fraser University.

<sup>4</sup> Sharon Jinkerson-Brass is an artist, community Elder and Aboriginal community liaison for the Pacific Association of First Nations Women.

<sup>5</sup> Sandra Laframboise is an Elder, Healer and community researcher with the Canadian Aboriginal AIDS Network and Dancing to Eagle Spirit Society.

<sup>6</sup> Renée Masching is the Director of Research and Policy at the Canadian Aboriginal AIDS Network.

<sup>7</sup> Tracey Prentice is a Community-Based Health Research and Evaluation Consultant with the Canadian Aboriginal AIDS Network.

<sup>8</sup> Alexandra King is a researcher and Internal Medicine Physician at the Lu'ma Medical Centre.

### **ACKNOWLEDGEMENTS**

Chris Macklin wishes to thank Alexandra King, Malcolm King and the *Water Journey* Community Steering Committee for their guidance and mentorship during the writing of this review.

The authors would also like to acknowledge and thank Trevor Stratton, Colleen Price, Carrielynn Lund, Patrick Brownlee and Leona Quewezance for their contributions to the *Water Journey* project and Justien Wood (from the *Nacho Nyak Dun* First Nation) for the design of the *Water Journey* logo.

Lastly, the *Water Journey* Research Team wishes to acknowledge the support from the Canadian Institutes of Health Research (CIHR) Institute of Aboriginal Peoples' Health, the CIHR Canadian HIV Trials Network (CTN) James Kreppner Post-doctoral Fellowship, the CanHepC Summer Studentship Program and the Canadian Aboriginal AIDS Network (CAAN).

### **CONTACT AUTHOR**

Alexandra King, Cameco Chair in Indigenous Health, University of Saskatchewan, Rm 5B42, Health Sciences Building, 107 Wiggins Rd. Saskatoon, SK, S7N 5E5;  
Email: [alexandra.king@usask.ca](mailto:alexandra.king@usask.ca)

## ABSTRACT

Indigenous peoples in Canada (First Nations, Inuit and Métis) bear a disproportionate disease burden for hepatitis C (HCV). This issue must be framed within the context of historical and ongoing trauma. Newly available and highly effective HCV therapeutics have transformed the treatment landscape. As such, there is a pressing need for Indigenous leadership in this area, as well as a need to develop programs, policies and a comprehensive HCV research agenda to realize health equity for Indigenous peoples.

Our team conducted four concurrent sharing circles (one male, two female and one two-spirit/gender-diverse) in which Indigenous people with diverse lived experience of HCV discussed their healing journeys and research priorities for HCV. Indigenous Elders guided the sharing circles, which were held as part of a wellness ceremony. The sharing circles were audio recorded, transcribed verbatim, and then the transcripts were analyzed qualitatively using a grounded theory-based approach. Next, themes and sub-themes were identified. The results were subsequently validated with other Indigenous communities, helping to build a comprehensive understanding of community-driven research and health priorities for HCV. From the sharing circle analysis, cross-cutting themes were identified, with both individual and system-level factors impacting peoples' life course with HCV. Ways forward that honour Indigenous knowledges and ways of knowing were also elucidated.

This project highlights the criticality of Indigenous leadership in setting HCV research priorities, programs and policies pertaining to First Nations, Inuit and Métis. Indigenous research methodologies and ways of knowing privilege community voice and lived experience. The methods discussed in this paper offer concrete, practical examples of strategies that may be employed for bringing Indigenous research principles to life – specifically within the area of HCV research, where an Indigenous worldview is clearly and urgently needed.

## INTRODUCTION:

### **Disproportionate impact of HCV among Indigenous peoples in Canada**

The Public Health Agency of Canada (PHAC) estimated that 332,500 Canadians (0.96% of the total population in Canada) were positive for hepatitis C (HCV) antibodies in 2011 (Trubnikov et al., 2014). The above figure includes those people who clear the hepatitis C virus spontaneously. Yet, uncertainty currently exists with respect to the actual prevalence of HCV in Canada - both in general and in terms of gender and ethnicity.

However, Indigenous peoples (First Nations, Inuit and Métis) are recognized as having a significantly increased HCV disease burden, especially among women (CATIE, 2015). For example, the *A-track* study (which examined HIV/HCV prevention, testing and care indicators in among Aboriginal people in Canada) also showed excess HCV burden amongst Indigenous peoples, with a combined self-reported lifetime HCV seropositivity of 41.6% (PHAC, 2012).

Furthermore, 36.3% of participants in the *I-track Phase 3* study (which monitored the prevalence of HIV/HCV and associated risk behaviours among people who inject drugs in Canada) were Indigenous (PHAC, 2012). Moreover, *I-track Phase 3* demonstrated the intersection of Indigeneity and gender. Specifically, 24.7% of the non-Indigenous HCV population were female, whereas 44.5% of the Indigenous HCV population were female – almost double. Similarly, in the Canadian HIV/HCV co-infection cohort, 13% of participants self-identified as Indigenous, with the highest Indigenous rate being found in British Columbia, at 33% (Klein et al., 2013). In this study, Indigenous women also faced increased prevalence of co-infection, at 52% versus 22% for non-Indigenous women (Klein et al., 2013). The disproportionate Indigenous HCV burden highlighted in the above three studies suggests the presence of multiple failure points within the HCV care/cure continuum, resulting in decreased rates of HCV screening, reduced healthcare access and utilization, and limited research inclusion/participation for Indigenous individuals and communities.

### **Colonization as a determinant of health inequity for Indigenous Peoples in Canada**

Residential schools and their legacy, the systematic erosion of culture through assimilation policies, and the loss of language and tradition have resulted in isolation, marginalization and poor coping mechanisms for many Indigenous peoples (King, Smith & Gracey, 2009). These factors are seen as providing part of the context that enabled HIV/AIDS to have such a disproportionate burden in Indigenous Canada (Barlow, 2009). Arguably, HCV would be the same. Their contribution has been through multiple mechanisms, including at the individual, family, community and societal levels (King, Smith & Gracey, 2009). Many survivors of residential schools and their families experience shame and deeply rooted mistrust and anger. This, in turn, contributes to the high-risk behaviours and substance misuse that place many First Nations, Métis and Inuit peoples at risk for blood-borne and sexually transmitted infections, such as HIV and HCV (Barlow, 2009).

### **New opportunities to address HCV need to reach Indigenous Peoples**

The HCV landscape is changing rapidly. The new therapies, direct-acting antivirals (DAAs), moving towards both pegylated-interferon-free and ribavirin-free regimens for most people, have substantially changed treatment (i.e. reduced side effects and shortened courses) while dramatically improving cure rates (i.e., 85-100%) (CATIE, 2005). However, the new DAAs entail substantial cost, estimated at \$60,000 to over \$100,000 per person for a full course of treatment (CATIE, 2015). The landscape is also changed by the integration and streamlining of the Public Health Agency of Canada's HIV/AIDS and hepatitis funding model (Arthur, 2013). This new delivery model will involve a strategic partnership network in which, given the epidemiology of HCV, entities that are knowledgeable of and focused on principles of Indigenous health will be even more critical (Arthur, 2013). Otherwise, there will be little assurance that the current HCV disparities among Indigenous peoples will not worsen.

### **The need for a decolonizing approach to HCV research**

*“We have been researched to death. It is now time to research ourselves back to life.”* (Brant Castellano, quoting an Indigenous Elder, 2004). The above statement reflects a firming resolve

amongst Indigenous peoples in Canada for Indigenous leadership and research approaches. Such desires reflect similar messages in New Zealand and Australia (Tuhiwai Smith, 1999; Wilson, 2008). The importance of a decolonizing approach to Indigenous health research – by us, for us – stems from the recognition that the health of Indigenous peoples in Canada has been *ascribed* since contact, with the effect of worsening health disparities (Dion Stout, 2012). Self-determination, including what is researched, how, and by whom, will allow us to *achieve* wellness (Dion Stout, 2012). It is therefore crucial that the strength of Indigenous research and decolonizing methodologies are brought to the field of HCV research in order to understand and address the needs of Indigenous peoples in Canada who are at-risk for, or living with, HCV.

## **PURPOSE**

The purpose of this article is to describe a framework of Indigenous research methodology designed to inform HCV research and practice for Indigenous peoples in Canada. This approach takes the form of a multifaceted community-based research program (titled “*Water Journey*”) which seeks to elucidate and explore culturally resonant ways in which to aid and support Indigenous peoples in Canada who have lived experience of HCV in their journeys of healing, wellness and self-empowerment. The knowledge and insight gained from this project is designed to inform the development of a national framework to guide research with and for First Nations, Inuit and Métis peoples who have been impacted by HCV. The *Water Journey* findings have also informed further exploratory and intervention studies, including peer navigation and land-based cultural retreats. First, we introduce the *Water Journey* project, and its conceptual underpinnings. Next, we describe the core components of the project. We then describe, in detail, the methodological steps related the sharing circle phase of the project. We close with a discussion of implications for research focused on HCV and Indigenous peoples in Canada.

This paper is the second in a three-part series of articles focused on the *Water Journey* project published in this edition of the CJACBR. The first article, a scoping review titled “*Community-directed research priorities for Indigenous peoples in Canada and hepatitis C*” (pages 22 – 42) synthesizes the existing body of scholarly literature focused on Indigenous peoples and HCV. The third paper, titled: “*Water Journey: emerging themes for research priorities for Indigenous peoples in Canada and hepatitis C*” (pages 61 – 79) presents findings on the analysis of a series of sharing circles conducted with Indigenous persons with lived HCV experience.

## **METHODOLOGY**

### **The journey begins...**

Water is the "life blood" of Mother Earth and is a unifying element for many Indigenous people in Canada. HCV is transmitted via blood. Sacred Water was chosen as a symbol for our project because our life begins in water and we require water to sustain our life and all living things on our planet. Water has nourished, cleansed and connected our people since time immemorial. In our logo, water holds our prayers for all people in the four sacred directions to come together to heal the wounds leading to and left by HCV.



*Figure 1: Water Journey Logo*

In the center of the logo is a medicine wheel, symbolizing a balance of physical, emotional, mental and spiritual health. Medicine wheel teachings are diverse, complex and layered, providing us with a vision of balance and wellness. This medicine wheel depicts earth (the Inukshuk), plant (corn), animal (salmon) and infinity for Métis, or alternatively, inter-tribal. Infinity is also a symbol for something limitless and enduring; we hold that same vision for healing.

Surrounding the wheel are four paddles. Paddling through water represents agency, resilience and strength for First Nations, Inuit and Métis living with HCV who are navigating their own healing journeys. The eastern paddle contains an infinity symbol, representing the Métis. It was decided to put it in the East because the Métis Settlements began in the East when the French Settlers first arrived. We honour the Métis and their diverse journeys on Turtle Island, from East to West.

In the south is corn, the senior of the three sisters that nourish our peoples. Sacred Corn has blessed many Nations with abundance for countless generations. Corn is also used as a sacred medicine to restore people from illness. Grandmothers kept precious corn seeds in their bundles to protect them from harm throughout the winter months. We pray our brothers and sisters who are suffering will feel this same protective force.

In the West is Salmon. Salmon returns home to give birth in the very place they were born right before they pass to the spirit world. Many of our people honour Salmon as our brothers and sisters. Salmon nourishes the riverbanks and also provides food for many creatures that live by

the ocean and the rivers. The Salmon People are resilient but will only return if they are respected. Respect is an important part of the journey of healing.

Within the northern paddle is an Inukshuk, symbolizing the Inuit. It is said that rocks are the first storytellers, that they were the first Nation here and that they have seen everything since the beginning of time. The flowers that surround the rock emulate the feminine energy in the world, bringing together another expression of balance. Surrounding the logo are waves to symbolize a river of wisdom that we navigate during our personal circle of life. We hold a vision that all of those who have been affected by HCV continue to find medicines that heal body, mind and spirit. We are all part of the sacred circle of life.

### **Theoretical perspective of the *Water Journey* project**

Key aspects of the *Water Journey* project are the integration of the concepts of Two-Eyed Seeing and Ethical Space. The concept of “Two-Eyed Seeing” was put forward by *Mi’kmaq* Elder Albert Marshall and is intended to describe a method to view the world with both Indigenous and Western perspectives (Hall et al., 2015). Specifically, this concept posits that we (as individuals, researchers and practitioners) must view the world with the strengths of both Indigenous and western ways of knowing in order to gain a more wholistic perspective of the world and our relationships (Hall et al., 2015).

Professor and Elder Willie Ermine expands upon the discussion of Two-Eyed Seeing with the concept of Ethical Space. Ermine suggests that most often, within the contemporary academic and organizational realm, western ways of knowing are held above Indigenous ways of knowing in a way where western knowledge is privileged as the highest standard of truth, and Indigenous knowledges are portrayed as “anecdotal”, and therefore inferior (Ermine, Sinclair & Jeffrey, 2004). This biased assumption has structurally facilitated the devaluing of Indigenous knowledges. Ermine proposes to reconcile this devaluing, these two ways of knowing must be utilized simultaneously and in a non-hierarchical way (Ermine, Sinclair & Jeffrey, 2004). Therefore, through the creation of Ethical Space, Indigenous and non-Indigenous worldviews can come together to illuminate more wholistic understandings of the world and health-related issues.

The aim of *Water Journey* is to conduct research on HCV among Indigenous peoples “in a good way” by combining and building on the strengths and expertise of lived experience, the knowledge of our Elders and the skills of Indigenous community and academic researchers. From an Indigenous worldview, research done “in a good way” is a sacred endeavor, grounded in ceremony, connected to ancestral wisdom, that supports community and leads to healing (Tuhiwai Smith, 1999; Wilson, 2008). Within the research, intentions and processes become as important as the knowledge acquired and, as such, the individual and the collective are both critical perspectives (Wilson, 2008).

### **Core components of the *Water Journey* project**

The goal of the *Water Journey* project is to better provide the Indigenous community with a voice with respect to an emerging program and research agenda that is informed by insights from

Indigenous peoples with lived HCV experience. *Water Journey* comprises seven core components: (1) a rapid review of the HCV literature employing an Indigenous lens; (2) a series of sharing circles with Indigenous peoples who have lived HCV experiences; (3) content and thematic analysis of the collective sharing circle discourse; (4) validation of research findings with diverse communities across Canada; (5) team-building, integrated knowledge translation and multi-directional capacity strengthening; (6) development of a larger community-based grant application for future research funding consideration; and (7) drafting of a comprehensive national research framework for Indigenous peoples in Canada and HCV.

The research activities of *Water Journey* align with strong recommendations from Indigenous researchers that Indigeneity needs to be considered central in understanding the disproportionate HCV burden in First Nations, Inuit and Métis peoples. Moreover, there is an established need for further research on the unique needs of Indigenous peoples in relation to HCV prevention, care, treatment and post-treatment support, as well as the criticality of Indigenous-led solutions (King, 2015). In considering relevant epidemiology, our research team is cognizant of the need to layer intersectionality, with inclusion of gender, incarceration, mental health and addictions, as well as other relevant frames.

*Water Journey* is guided by a strong and experienced Community Steering Committee made up of community, academic, student and peer researchers, Elders and Healers, advocates, allies and community members with lived HCV experience. Most members of the project team and Community Steering Committee are themselves Indigenous. This group has diverse experience revolving around Indigeneity, HCV and community-based health research. The Community Steering Committee met regularly with the research team, guiding research processes and vetting every part of the project.

### **Rapid literature review**

A rapid review of the literature, employing an Indigenous lens, was undertaken in May 2015 to explore and synthesize key themes from the scholarly literature related to HCV and Indigenous populations in Canada, and elsewhere in the world (Australia, New Zealand and the United States) which have similar colonization experiences. This scoping review helped identify research areas needing further elucidation and functioned to ground our future operating grant proposal in current knowledge. Using Arksey & O'Malley's (2005) framework, a systematic search strategy was employed. A preliminary search, based on terms provided by key informants, was conducted using relevant academic databases (e.g., Proquest, Web of Science, Scopus). A selection criteria was used to identify 37 relevant articles, which were then reviewed and coded using the qualitative data analysis software NVivo 10©. Key themes that were grounded in the existing literature emerged and were integrated into a document using a scoping review framework. Gaps were also identified and presented to both the research team and sharing circle participants for consideration.

Results of the review highlighted the importance of addressing intersectional HCV risk factors, such as injection drug use, gender and youth, and further exploring the many "silences" in the HCV data. Recommendations from the review included an increased focus on (1) involving

Indigenous peoples and communities in the process of deciding program and research priorities; (2) obtaining more comprehensive HCV data; (3) promoting cultural safety, culturally appropriate care and community-led research and (4) incorporating wise practices that are based on innovation, self-determination, integration of services, partnerships, wholism and traditional ways of knowing.

### **Sharing circles as a research tool**

On 15 July 2015, our research team conducted a series of sharing circles with Indigenous peoples who had lived experience of HCV. Ethics approval to conduct our sharing circle event was received from the Simon Fraser University Research Ethics Board in June 2015. The sharing circles were part of a larger HCV event for Indigenous peoples focused on healing and wellness. Sharing circle methodology is similar to focus groups, but imbued with Indigenous processes and philosophies (Lavallée, 2009). Sharing circles reflect our oral tradition and storytelling as teaching and sharing. The circle is also premised on continuity, interconnectedness, equality and respect (Lavallée, 2009). Furthermore, sharing circles facilitate a collective understanding of the rich diversity of the shared experiences and a community to advance an Indigenous research agenda forward (Rothe, Ozegovic & Carroll, 2009). This, in turn, promotes a wholistic approach of learning and healing whereby “all of the senses, coupled with openness to intuitive or spiritual insights, are required” (Brant-Castellano, 2000, p. 29).

For many generations, sharing circles have been used as communication tools by various Indigenous peoples and groups to discuss important issues within an egalitarian, supportive and non-confrontational setting (Rothe, Ozegovic & Carroll, 2009). Sharing circles reflect traditional Indigenous values of sharing, mutual support and respect for life experiences, and incorporate oral traditions and styles of interaction that are foundational to Indigenous culture (Lavallée, 2009). They are typically used to identify problems and derive solutions by providing culturally enriching environments that offer participants support, guidance and affirmation (Struthers et al., 2003). Furthermore, sharing circles can be used to teach culture and tradition, to promote and research health, and to provide spiritual counselling and healing to members of Indigenous communities (Rothe, Ozegovic & Carroll, 2009). Within the sharing circle, all aspects of an individual’s experience may be shared—physical, emotional, mental and spiritual, and permission is given to the facilitator to report on the discussions (Nabigon et al., 1999). Lastly, the utilization of sharing circle methodology as a strategy to research health issues within Indigenous populations can provide a greater richness of information in comparison to conventional interview techniques, while also providing a culturally safe research environment (Rothe, Ozegovic & Carroll, 2009).

### **Recruitment**

To be eligible to participate in a sharing circle, each participant had to be over the age of 19 and self-identify as First Nations, Métis and/or Inuit. An additional requirement was “lived experience of hepatitis C”, which the research team defined as either being positive for hepatitis C, having previously cleared or been cured of HCV, or having a close partner or relative affected by HCV.

Recruitment occurred through an extensive network of service providers, agencies and researchers locally in Vancouver and throughout Canada. In addition, promotional flyers and social media (e.g. Facebook) were utilized in the recruitment process. We also recruited participants from the *Aboriginal Persons Living with AIDS* (APHA) caucus during their event on 14 July 2015 at the *Canadian Aboriginal AIDS Network (CAAN) Skills Building, Annual General Meeting and Wise Practices V*. At this event, we circulated promotional flyers and had a registration form available where interested persons could discretely sign up to be contacted and screened to participate in the sharing circles. Study participants were asked to complete a brief questionnaire providing demographic information as well as justification for their selection into the study. For their participation in the sharing circles, participants were provided with an honorarium of \$50 to cover their expenses and compensate them for their time. Diverse lived experiences were sought so that, in addition to lived HCV experience, substance misuse/abuse, gender, incarceration, homelessness, HIV co-infection and other relevant dimensions would have voice.

### **Nesting the sharing circles within a larger context of culture and wellness**

In addition to the research component, our sharing circle event was part of a larger day of healing and wellness. The event began and ended with ceremony. We began with an opening prayer and blessing, followed by a smudging ceremony. Each participant was cleansed with cedar and welcomed into the circle.

Led by our project Elders, individual and community wellness activities were held throughout the event and included traditional singing, dancing and drumming. Our goal was that the sharing circle event would be an affirming, cleansing and empowering experience for all those who attended. Upon completion of the gendered sharing circles, all participants came together as a group in a final sharing circle to debrief. In this group sharing circle, participants then reflected upon and discussed any thoughts, ideas or experiences from the sharing circles which they found to be particularly resonant. Next, all participants were invited to make their own personal wellness bundles to take with them on their wellness journeys. The wellness bundles contained various traditional medicines, and the significance of the medicines was explained by the Elders. Finally, the sharing circle event concluded with a closing ceremony and prayer.

The last component of the event was the unveiling of a button blanket made by the *Water Journey* Elders. This activity also facilitated wellness, both at the individual level (through each participant signing a small cedar paddle to be sewn on the blanket) and collectively (through the blanket becoming a symbol of Indigenous strength, healing and resilience in regard to HCV). The button blanket is intended as a collaborative gift from the group to help de-stigmatize HCV and build acceptance, connections and healing in our communities.

### **Qualitative data collection through sharing circles**

Each participant was invited to attend the sharing circle (e.g. male, female or two-spirit/gender diverse) that they most identified with that day in terms of their self-determined gender identity. At the beginning of the event, tobacco was offered to each sharing circle participant, Elder and

research team member to honor their contribution to our research and thank them for their participation in the event.

This tobacco protocol served as a culturally appropriate approach to obtain informed consent from the sharing circle participants (Lavallée, 2009). All sharing circle participants were asked if they would accept tobacco for their participation. The significance of them accepting the tobacco bundle was explained. All participants accepted the tobacco. In addition, informed consent, as approved by the Simon Fraser University Research Ethics Board, was signed or verbally assented by all participants. Prior to commencement of the sharing circles, the purpose of the study, expectations on the part of the participants and sharing circle procedures were discussed as a group. All participants were encouraged to respect the confidentiality of their fellow sharing-circle members.

During planning meetings, guiding questions for the sharing circles were discussed and deliberated. Questions were narrowed and finalized collaboratively with the research team and the Community Steering Committee.

The following four questions assisted in guiding discourse within the sharing circles:

1. What is your experience of being an Indigenous person living with hepatitis C?
2. How have you lived, survived or thrived with this disease? What have you learned that you can share for the benefit of others?
3. How has your [male | female | two-spirit | transgender] Indigenous identity affected your healing journey?
4. As a [male | female | two-spirit | transgender] Indigenous person, have you encountered barriers in accessing treatment? Have you been able to navigate these barriers?

Our research team conducted four concurrent sharing circles: a men's sharing circle, two female sharing circles and a two-spirit sharing circle. We had a total of 32 participants. Following brief introductions by participants, the sharing circles were opened by an Indigenous Elder who was also responsible for guiding and supporting participants. Each sharing circle ran approximately 90 minutes in length and was audio recorded using a digital recorder.

A member of the research team was present within each sharing circle to memo, note-take and provide logistic support. The four questions listed above helped to guide the discourse within the sharing circles, however, discourse also flowed organically was relatively unstructured. Audio recordings from the four sharing circles were then transcribed verbatim by the research team. Each transcript was double checked for accuracy by the research team member who was present in the circle.

### **Analysis of sharing circle data**

Sharing circle transcripts were then imported into the qualitative data software NVivo 10© for coding and thematic analysis. Qualitative analysis was then performed on the sharing circle data using a Grounded Theory-based approach (Hutchinson, Johnson & Breckon, 2010). Using an

open coding method, the transcripts were analyzed through content analysis, focussing on systematically identifying relevant themes and sub-themes to gain a wholistic picture of the sharing circle discourse (Hutchinson, Johnson & Breckon, 2010). Within NVivo©, various themes related to HCV and the Indigenous lived experience of sharing circle participants were then systematically mapped out as “nodes”. Memoing functions within the software were employed to assist in identifying commonalities and connections between the data. Next, the codes were organized and collapsed, whereby over-arching themes and sub-themes emerged.

Two independent coders carried out the preliminary qualitative analysis, with one coder conducting the analysis of the men’s and two-spirit circles, and the second coder conducting the analysis of the two women’s circles. To increase confidence in the validity of the coding (after coding their assigned sharing circle transcripts) the two coders then compared their emergent codes and assessed for convergence and divergence. Upon comparative analysis, it was found that the emergent codes from both independent coders were similar, with many themes converging and showing relevance across all four circles.

### **An Indigenous approach to data validation**

Group meetings were held with the research team and Community Steering Group to collectively discuss and clarify the sharing circle themes and codes in relation to their applicability to HCV and Indigenous peoples. In addition, the themes were analyzed in relation to the themes that emerged from the project scoping review. The preliminary findings from the qualitative analysis of the sharing circles were then shared at two validation sessions across Canada (Manitoulin Island and Ottawa).

Participants at the validation sessions included Indigenous people living with HCV, as well as healthcare providers involved in HCV care. At these sessions, a brief presentation was given to the community which detailed the background of the *Water Journey* project and the preliminary emergent themes. A *Dotmocracy* exercise was then conducted with validation session participants. *Dotmocracy* is an established technique for collecting and recognizing levels of agreement on written statements among a large number of people (Better Evaluation, 2015). During the exercise, green, yellow and red dots were used by participants in the group to indicate their individual level of agreement to the various *Water Journey* themes which were presented on separate posters. The result of the distribution of the different colored dots gave a graph-like visual representation of the group’s collective opinion about each posted statement. Probing questions were employed to further elucidate why participants agreed or disagreed with the various themes.

Feedback from the validation sessions was then compiled and integrated with the preliminary themes from the sharing circle analyses. A document was then drafted which outlined six major cross-cutting themes which showed applicability to the combined lived experiences of the female, male and two-spirit participants of the sharing circles. Themes within the document were supported by de-identified quotes from sharing circle and validation session participants. The aim of the synthesis document was to distill the complex realities of the Indigenous women, men and two-spirit participants shared in the four circles into multiple, intertwined yet distinct themes

to come up with recommendations and research priorities. More detailed information on the findings of the sharing circles can be found in the accompanying article titled “Water Journey: emerging themes for research priorities for Indigenous Peoples in Canada and hepatitis C” (Kallós et al., 2017).

### **Integrated knowledge translation activities and community engagement**

Knowledge translation activities and engagement with diverse Indigenous communities were core components of *Water Journey* and were integrated both early and throughout the project. Specifically, results from the initial scoping review were shared with the Community Steering Committee and with the participants of the sharing circle event. This was done through a brief presentation while all event participants were seated in a large circle. During the presentation, all attendees were encouraged to share with the research team which of the scoping review themes resonated with them most. In addition, event participants were invited to ask any questions they may have had about the goals and activities of the *Water Journey* project. Finally, preliminary findings from the sharing circles were disseminated throughout our network and validated in several community sessions with diverse groups of Indigenous peoples.

Five journal articles will be published from *Water Journey*: a scoping review paper, this methodology document, a sharing circle thematic analysis document, a paper exploring (in more depth) the underlying context of and rationale for the selected research methodologies, as well as their contribution to Indigenous research methodologies, and, finally, a paper synthesizing the *Water Journey* results with literature related to Indigenous research paradigms and implications for HCV policy and practice.

Paramount in our approach was having *Water Journey* project Elders co-present project findings alongside members of the research team. Results from *Water Journey* have been presented orally at the local, national and international levels at both community and academic/scientific conferences, including a First Nations Health Authority/CATIE HIV & Hepatitis C Educators Conference (Vancouver, 2016), the 5<sup>th</sup> Canadian Symposium on Hepatitis C (Montreal, 2016) and the Canadian Aboriginal AIDS Network Skills Building Workshop (Montreal, 2016). Internationally, *Water Journey* was recently presented orally at the 2017 Lowitja Institute International Indigenous Health and Wellbeing Conference in Australia.

Moving forward, themes from the *Water Journey* project have laid the groundwork for a continuing research project titled *Connections with the Land*, which will examine the utility and impact of cultural wellness retreats as healing interventions for Indigenous people with lived HIV, HCV and co-infection experience. A CIHR Catalyst Grant for this project was successful in the summer 2016 competition. Lastly, ongoing knowledge translation activities will include the integration of the *Water Journey* themes and findings into a national research framework for Indigenous peoples in Canada and HCV.

## **DISCUSSION**

### **Implications regarding HCV research**

The approach to Indigenous research implicit in the *Water Journey* project has both immediate and far-reaching implications regarding HCV research. The landscape for HCV is dramatically changing, however, the newer, more effective therapies come at substantially increased financial costs. At the same time, funding integration and streamlining will mean HCV care will be delivered by more entities - not all of which are experienced with the unique needs of Indigenous peoples with respect to HCV. As such, increased involvement of Indigenous peoples in driving the HCV research agenda forward with the integration of Indigenous ways of knowing at all stages of the process are crucial for meaningful program and policy development.

Currently, in the field of Indigenous health research, the application of Indigenous ways of knowing and Indigenous research methodologies has an increasingly strong grounding. Yet, within the current body of scholarly knowledge, there is less clarity on the specific methods that might be used to realize these principles. To the best of our knowledge, *Water Journey* is the first project to integrate a series of Indigenous research methods and apply them specifically within the context of HCV. Further, it is the first project to use a decolonizing and community-based approach to elucidate and explore the lived experiences of Indigenous peoples in Canada who have been impacted by HCV. As such, we believe that the methodologies discussed in this paper offer concrete, practical examples of strategies that may be employed for bringing Indigenous research principles to life – specifically in the area of HCV research, where an Indigenous worldview is clearly and urgently needed.

## CONCLUSION

The *Water Journey* project seeks to research culturally resonant ways in which to aid and support Indigenous peoples in Canada who have lived experience of HCV in their healing journeys. Findings from our project underscore the urgent need for further exploration of the research priorities for HCV among Indigenous peoples. Furthermore, the analysis of the *Water Journey* sharing circles indicated that many Indigenous people want to actively participate in the process of deciding research priorities for HCV within their communities. More comprehensive information regarding the emergent findings from the *Water Journey* sharing circles, as well as recommendations for future research and programming directions, can be found in the accompanying paper, titled: “Water Journey: emerging themes for research priorities for Indigenous Peoples in Canada and hepatitis C” (Kallós et al., 2017).

The arrival of new HCV treatments presents huge opportunities to move forward; however, the need for the inclusion of Indigenous perspectives, as well as the integration of Indigenous knowledges and resiliency into HCV policy and practice, is evident. To close HCV disparities among our peoples, there is a need for more community-based research to develop programs and services that are designed *by* and *for* Indigenous individuals and communities. Moreover, to help us achieve these research goals, the development of new and relevant methodologies must integrate innovation, self-determination, wholism and our vibrant Indigenous culture. Ultimately, this is what the *Water Journey* project, and the national HCV research framework that it will inform, hopes to accomplish. Our journey continues.

## REFERENCES

- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32. Accessed at <http://eprints.whiterose.ac.uk/1618/1/Scopingstudies.pdf>
- Arthur, J. (2013). Future directions for HIV/AIDS and HCV community funding. Accessed at [http://www.cdnaids.ca/files.nsf/pages/phac\\_futuredirections\\_casforumagmjune2013/\\$file/PHAC\\_FutureDirections\\_CASForumAGMjune2013.pdf](http://www.cdnaids.ca/files.nsf/pages/phac_futuredirections_casforumagmjune2013/$file/PHAC_FutureDirections_CASForumAGMjune2013.pdf)
- Barlow, K. (2009). Residential schools, prisons, and HIV/AIDS among Aboriginal peoples in Canada: Exploring the connections. The Aboriginal Healing Foundation Research Series. Accessed at <http://www.ahf.ca/downloads/hivaids.pdf>
- Better Evaluation.org. (2015). Dotmocracy. Retrieved from: <http://betterevaluation.org/evaluation-options/Dotmocracy>
- Brant Castellano, M. (2000). Updating aboriginal traditions of knowledge. Indigenous knowledges in global contexts (pp. 21–36). Toronto, Canada: University of Toronto Press.
- Brant Castellano, M. (2004). Ethics of Aboriginal research. *Journal of Aboriginal Health* (Jan 2004).
- CATIE. (2015). Backgrounder: context for CATIE's national deliberative dialogue on integrated hepatitis C programming and services. Accessed at <http://www.catie.ca/pdf/background-context-dd2015-catie-en.pdf>
- Dion Stout, M. (2012). Ascribed Health and Wellness, *Atikowisimiýw-āyāwin*, to achieved health and wellness, *Kaskitamasowinmiýw-āyāwin*: Shifting the paradigm. *CJNR* 2012, Vol. 44 No 2, 11–14.
- Ermine, W., Sinclair, R., and Jeffrey, B. (2004). The ethics of research involving Indigenous peoples. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics. Accessed at [http://ahrnets.ca/files/2010/05/ethics\\_review\\_iphrc.pdf](http://ahrnets.ca/files/2010/05/ethics_review_iphrc.pdf)
- Hall, L., Dell, C. A., Fornssler, B., Hopkins, C., & Mushquash, C. (2015). Research as Cultural Renewal: Applying Two-Eyed Seeing in a Research Project about Cultural Interventions in First Nations Addictions Treatment. *The International Indigenous Policy Journal*, 6(2), 1–15. <http://doi.org/10.18584/iipj.2015.6.2.4>
- Hutchison, A. J., Johnston, L. H., & Breckon, J. D. (2010). Using QSR-NVivo to facilitate the development of a grounded theory project: an account of a worked example. *International*

*Journal of Social Research Methodology*, 13(4), 283–302.  
<http://doi.org/10.1080/13645570902996301>

Kallos, A., Macklin, C., King, M., Jinkerson-Brass, S., Laframboise, S., Masching, R., Prentice, T. & King, A. (2017). Water Journey: emerging themes for research priorities for Indigenous Peoples in Canada and hepatitis C. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*.

Klein, M. B., Rollet, K. C., Saeed, S., Cox, J., Potter, M., Cohen, J., & Walmsley, S. (2013). HIV and hepatitis C virus coinfection in Canada: Challenges and opportunities for reducing preventable morbidity and mortality. *HIV Medicine*, 14(1), 10–20. <http://doi.org/10.1111/j.1468-1293.2012.01028.x>

King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: the underlying causes of the health gap. *The Lancet*. 374, 76–85. Accessed at: <http://www.ncbi.nlm.nih.gov/pubmed/19577696>

King, A. (2015). First Nations, Inuit and Métis peoples and Hep C. Invited presentation to CATIE’s National Deliberative Dialogue on Integrated Hepatitis C (HCV) Programming and Services. (Toronto ON, 11-12 February 2015).

Lavallée, L. (2009). Practical application of an Indigenous research framework and two qualitative Indigenous research methods: sharing circles and Anishnaabe symbol-based reflection. *International Journal of Qualitative Methods*. 8(1). 21-40. Accessed at <http://www.homelesshub.ca/sites/default/files/i21yr5dn.pdf>

Nabigon, H., Hagey, R., Webster, S., & MacKay, R. (1999). The learning circle as a research method: The trickster and windigo in research. *Native Social Work Journal*, 2(1), 113–137. Public Health Agency of Canada. (2012). I-Track Overview and Reports. Accessed at <http://www.phacaspc.gc.ca/aids-sida/about/itrack-eng.php>

Public Health Agency of Canada (PHAC). (2012). Summary of key findings from A-track pilot survey. Accessed at: <http://www.phac-aspc.gc.ca/aids-sida/publication/reports/a-track/index-eng.php>

Rothe, J., Ozegovic, D., & Carroll, L. (2009). Innovation in qualitative interviews: “Sharing Circles” in a First Nations community. *Injury Prevention*. 15(5). 334-340.

Struthers, R., Schanche Hodge, F., Geishirt-Cantrell, B., & Lorelei, D. (2003). Participant experiences of talking circles on type 2 diabetes in two Northern Plains American Indian tribes. *Qualitative Health Research*. 13(8). Retrieved from: <http://qhr.sagepub.com.proxy.lib.sfu.ca/content/13/8/1094.full.pdf+html>

Trubnikov M, Yan P, Njihia J, Archibald C. (2014). Identifying and describing a cohort effect in the national database of reported cases of hepatitis C virus infection in Canada (1991-2010): an age-period-cohort analysis. *CMAJ Open*. 2014 Oct 1;2(4): E281-7.

Tuhiwai Smith, L. (1999). *Decolonizing methodologies: Research and Indigenous Peoples*. London and New York: Zed Books Ltd.

Wilson, S. (2008). *Research is ceremony*. Halifax NS: Fernwood.