



Feast Centre for  
Indigenous STBBI Research

**A Feast Centre Conversation, Hep C in Indigenous Communities: Hearing the Full Story**

**(00:15 – 03:02) Renee Masching:**

So welcome now to the recording. Wonderful to have... to have this documented for the records. And, to have a welcome to our conversation series about hepatitis C. So, we began with a quick introduction and overview of the conversation series and had a beautiful opening with kokum Gayle, I'd like to acknowledge that I'm calling in from the territory of the Mi'kmaq Nation. And of course, as I look across the screen and recognize names and look forward to meeting more people through our conversation. I know that we're coming in from from sea to sea to sea. And so want to acknowledge that... that we're coming together across this country called Canada. Hopefully, the reach of this conversation series may even be beyond the borders of what is now called Canada. And that we're mindful that, in this beautiful territory where we live and work and play, that we have responsibilities to... to honour the traditional holders of the territories and to respectfully consider how we leave this space for those who will come out. In the context of the Feast series and this conversation, we really value your participation and your support of events such as this. We welcome you following us on Facebook, on Instagram, and we use Eventbrite as well to host our future events. The Feast Centre has a host of resources that are open to the public. So please make sure to also visit us at [feastcentre.mcmaster.ca](http://feastcentre.mcmaster.ca) My name is Renee Masching, and I have the honour of helping to facilitate the session today. My bloodlines are from Six Nations of the Grand River. I'm also Irish descent. I was adopted as an infant and raised in a family of Eastern and Western European descent. My father's a first-generation Canadian, and I bring all of that context to the way that I walk and work and play in this world. I work with CAAN Communities Alliances and Networks, as Research Impact Leader. And I'm the co-director of the Feast Centre with Doctor Randy Jackson. For today's conversation, each of our presenters will do a short presentation and then I will have the chance to moderate a conversation between the 3 of them. We'll then open the floor to questions from the audience. Really encourage you to write your questions in the chat box. We're going to be watching that and we'll do our best to address the questions during the question and answer period of the... that's planned at the end of the event. Also, appreciate that, everybody's got their mics on mute. Thank you very much. If you want to react or raise a hand, that's wonderful as well. We'll be monitoring for that. I would like to encourage each of our panelists to introduce themselves because you are amazing and fantastic and wonderful people who I have the privilege of getting to know already. So, I think it's best that you get to say who you are on your own terms. So, Kacheena, may I introduce... invite you to introduce yourself first?

**(03:02 – 04:33) Kacheena Naytowhow:**

Okay tanis miyo kisikaw, It's a beautiful day to have a conversation. You know, and to be here today in front of all you wonderful people. Thank you for having me. Thank you for having me on this panel. Truly appreciate, you know, all the voices and everybody here. Gayle, your words were just, you know, so many lessons you gave in the... in, you know, when you explained what you said, it's, you know, it's beautiful to be Indigenous and I appreciate our teachings, where we come from and our culture. So my name is Kacheena Naytowhow. My father comes from Sturgeon Lake First Nation, and my mom comes from Cowessess First Nation. So I'm full plains Cree. I'm from Treaty 6 and Treaty 4 territory. But I like to say as I live, work, and play on the original lands of the Cree, So to Dakota, Nakoda, Lakota, Anishinaabe, the homeland nation of the Metis. You know, I respect... I pay respects to the ancestors of my land, and I reaffirm my relationship with them as I'm here. You know? So I... that's my lineage, my background, my educational background. I have a master's in business administration. I specialize in Indigenous leadership and business, and I got that from my parents. It's just to go all the way to honour that treaty right that we have, you know, to go all the way and honour my ancestors. I have 20 years of experience working with Indigenous communities, right from being a camp worker to building financial statements, to doing strategy, and now being able to work with CanHepC on their Indigenous process and being able to have these wonderful conversations. Thank you for having me.

**(04:34 – 04:39) Renee Masching:**

Oh, wonderful. Thank you so much. Marina, can I invite you to introduce yourself, please?

**(04:40 – 06:39) Marina Klein:**

Yes. First of all, thanks so much, Renee and Will and all the other speakers that are here for such an honour and privilege to be here among you and and take part in this conversation, which I think is one that's very close to my heart. I'm coming to you from Tiohtia:ke Montreal, which we know is the unceded territory of the Kanien'keha:ka First Nations as well as a number of other Indigenous groups have traditionally come to meet on these lands. And I've... if you want to I think it's only fair that I also share my background, which is typical of a newcomer to this land, which is that very mixed, originally actually born in New York City, of parents who come from French Canadian origin, but also Eastern European and Ukrainian, origin. So a real mix. And, I think I grew up in a environment that was quite different from most, I think, in a sort of a commune in the seventies in Montreal, which gave me a real appreciation for differences among people, the need to recognize diversity and take... and I think it's really what inspired me to go along the path that I did, which was ultimately into medicine, and to care for people who are living with HIV and hepatitis c. And I'm privileged to have led the Canadian co-infection cohort study, which is a cohort now that's going on for almost going into its 16th year, which has recruited participants from right across the country, from all walks of life, who've really generously participated in sharing with us their stories, their data, their blood, their treatment histories, and has really allowed us to get a vision of what's happening in this country. And, hopefully, I can bring some of that to the conversation today.

**(06:40 – 06:47) Renee Masching:**

Beautiful. Thank you so much. I don't think I knew you grew up on a commune. It's good to learn something new.

**(06:47 – 06:49) Marina Klein**

Something I give out in meetings.

**(06:51 – 07:11) Renee Masching:**

It's definitely part of the context of, of working and partnering in Indigenous communities. It's good to know that relationship building part's important. Gayle, can I ask you to introduce yourself? And then if you'd like to carry on and share your story with us today as you as you feel good, that would be wonderful. Thank you.

**(07:11 – 26:44) Gayle Pruden:**

Okay. Well, as I was introduced as Kokum Gayle Pruden, I do enjoy that name because so many of these younger generation that I'm meeting across Canada are turning to me as their Kokum and being a 2-spirited... being in this 2 spirited Kokum role is so important to me because I speak a lot at conferences, and, usually, I ask the people at the conference what they want me to talk about, and I'll do that. But then I always ask for a bit of time at the end where I can say what's on my... what's in my heart and what I need to say as supporting the very young generation. They're so tender, 2-spirited that are coming up as trans. So I am originally from, treaty 2, but I live in the biggest reserve in Canada in treaty 1, Winnipeg, Manitoba. But for me, I miss my home when I leave my home, and I don't see the violence that everybody sees on the news because it's really broadcasted in such a crazy way for them. Like, they've never broadcast anything nice about Winnipeg. There's a lot of nice things that happen here. Otherwise, I wouldn't be sitting here talking if it was the murder capital. And I'm always out in public. And I was raised on a reserve, called Little Saskatchewan. It is in Manitoba. It's not in Saskatchewan. I don't know why they called it Little Saskatchewan, but that's where I was raised in Manitoba. And my treaty is in the next reserve called Fairford. That's where my dad is from, so I'm treaty from there. And I was raised by my, my grandmother, my grandfather, my great grandfather. And there was no residential school, but there was no Catholic church. So being raised there, I'm so grateful that I... the knowledge that I carried today, I didn't know what my grandmother was doing at the time being raised in that traditional way, but allowing us to follow her is the things that she did, and made no sense back then. But now as I get older, everything is just so bursting with this beautiful knowledge that she left for us. I mean, I'm the oldest of 5, and... but my siblings are passing me. They're older than I am. I don't know what's going on. I'm still out there dancing up a storm, dancing jingle dress. I've been dancing jingle well over 20 years. I think that's what's keeping me so up to date with my with my strength to go on. And they're all gray haired and crippling up, and it's, oh my god. Come on. I'm quite I'm quite busy all the time, and I love what I do. So I, for my job, I, I've been with CAAN. Actually, I don't... I'm always putting CAAN up in the air because if it wasn't for CAAN, I wouldn't be able to speak the way I do today as being a public speaker because... Doris Peltier was the one who dragged me into Canada's Canadian Aboriginal Alliance Network. And when she used to drag me off to these conferences, I used to, like, hiding in a corner. Don't look at me. Pretend I'm not here. Don't even say my name. Oh my goodness. I was so nervous back when I was in this tiny, tight little shell that I didn't want anybody to know I existed. But I didn't know at that time how important it is that today I speak for the 2-spirit, and I fight every way

for the 2-spirit, especially the young trans that are out there. I'll do anything because I'm at that age already. Like, my skin is like an old crocodile, so you can hit throw whatever you want at me and just bounces right off. It doesn't bother me one bit as long as I'm there speaking for the 2-spirit, the younger generation of the trans. They belong. Creator's the one who gifted us to be here. I don't know why society is so harsh on accepting people for who they are. They should be, like, taking care of the homelessness or the drug activity that's going on. And instead of, like, attacking the young 2-spirit that wanna live and I always say that being 2-spirit, that's a gift, a very special gift that's given to you by Creator. It's up to the family to nurture and also protect this 2-spirit to be who they wanna be. Let them live. There's a reason for them being put here on Mother Earth, and we're not any better than anybody else either. We're all equal in Creator's eyes because that's the way I was raised. My grandmother always told us, as siblings [Anishinaabemowin] So he told us all, don't ever try not proud of yourself or in front of anybody. Creator sees everything you do. A really good reminder for us all that anything that we carry or do, creator sees. We can fool people, so we think, but we can never fool Creator. Creator watches everything we do. So I guess that's a little bit of what I can talk about myself. So down to talking to what I experienced with this Hep C, which I think almost took my life back in the day where I had to struggle. I had to fight loss to stay alive. And even though I look healthy now, then, at that time, I was like, you could see you could actually see the bones through my skin. That's how harsh the medication was. I had no hair. If it wasn't for my late mother, I wouldn't be here because she is the one who really, really forced me to eat and drink, and I just wasn't up for that because that treatment that I took was so, so harsh. It was ripping my my insides apart, my spirit, everything all so down, and I wouldn't walk. I didn't wanna go in public. I didn't wanna be seen. It was horrible. And even being in a hospital where I felt I was really killed all the time, ignored, and being disrespected, I just didn't wanna live. I didn't have the fight in me because of the treatment that I had in, laying in the emergency where because I was never used to being called sir, him, and that really hurt, especially when I couldn't defend myself or say anything. I was so sick that I couldn't even talk from this Hep C. And it was the liver that really... that attacked me was the liver. And I don't know. Just simply that, you know, being for being who I am as an Anishinaabe and trans, I think that took a big part in the medication part, especially in an emergency. Like, I was in that what do you call that? The intensive care unit. I remember being in there, but I also went into a coma. And maybe I can share a little bit about what saved my life with that part of being in a coma was, because I danced jingle, I had told a friend about my jingle dresses, and I don't know why. So many people do not have faith in your dress. So, you know, when we dance this jingle dress, there's a spirit in this dress. We're only the helper. We're carrying this dress. We wear it, but we have nothing to do with that healing. It's in that dress itself where we get the healing from. As for myself, I pray for myself when I wear this dress, then I pray for everybody else. And that's just the way I've been taught through older older women that I dance with from Treaty 3 where they always remind me to humble myself. And even though it was brought up to be humble, still, you need that reminder. Level yourself off with Creator and Mother Earth. So I shared that story with a friend of how... I said so many jingle dress dancers always come up to me giving me tobacco, giving me sweet grass, whatever gift they want, to pray for their loved one that's in a hospital or having a hard time with their health. I said, why don't they just, like, you know... they don't need to wear the dress. They can maybe wrap it up in some kind of, blanket of some sort, smudge it, pray for it, then go take it towards needed by this person that's ill or needs that healing from the dress. So what she remembered that story was, I was in a coma... because my family was

ready to unplug me, at that point where I was in a coma for so long. And, my friend didn't... wasn't ready to give up on me. And then she remembered that story, so she went to my place and got the jingle dress. And when you are in a coma, you do already travel lots. I did travel. I've seen so much that... a lot of beautiful places I've seen, but also a lot of terrible places that I've seen. The real horrible, terrible places, I did not wanna remember. I remember them, but I just don't wanna think about them because they were ugly. But the beautiful places that I've seen and been was taken, so I just loved that. I was able to travel in that way. So it's true. When people are in a coma, they do travel. They are there. They can hear you. So my friend, went and got my jingle dress, and I could hear the jingles really far away, I remember hearing them, and I was just so excited and happy. I was trying to go towards them, but then they start fading away. I remember that so clearly, and I hear the voices. This is when she had brought that jingle dress to me because she said, I wasn't ready to give up on you, and I needed to save you in some way that I can. I remembered your story when I got your jingle dress. I put it by your bed when you were not ICU, and then she said I left the room crying. And I came back about 5, 10 minutes ready to put your address and take it away, take it back and but then I looked at you because your... my eyes were covered in Vaseline or whatever. She said I could see movement. I was so happy when I seen that movement, she said, and I started screaming for the doctors and nurses. She's coming back, and that's what it took. And then that's when I came out of that coma. I fought so hard to get out of there. But during that time of fighting is when I was facing so much... oh, I don't even know what I don't even know how to label the treatment that I got in there. It was terrible. And one thing that I remember that I'd like to share is what happened is that they wanted me to pee, and they were making me wear this adapter or whatever it's called that you pee through. And I couldn't pee, and they were getting mad at me because I couldn't pee. And I kept telling them I was able to talk already at that point. I'd kept telling them, give me a warm cloth, and I'll put it on my private give me something warm to drink, and I'll pee. They wouldn't do it. They wouldn't listen. So I started yelling in there, and my language, Ojibwe, kept saying [Anishinaabemowin]. Does anybody understand me? Please come here. Because in the next bed, I remember somebody was laying in there. All they would do is just moan a little bit. Everybody would come running up to them. Do you need morphine? Do you need to have painkillers? And here, I was laying in my bed half dead. They wouldn't even listen to me. They would just ignore me, and I was in so much excruciating pain. But, finally, there was a health care aide that walked by, and she understood my language. And then I asked her, I said, can you please go and get me a warm cloth and something hot to drink? I said, I know I'll be able to pee. And even her, she said, I'm not allowed to do that because I don't work here. But she said, you know what? I'll do it for you. I'll sneak it. So she did. She went and got a warm pot, warm... hot tea, I think she brought. I drank that night and I peed. But the nurses were so mean that she came in there yelling at me. It's about time you're pissed. We've been waiting for so long. She ripped that adapter out, and I just fainted. That was that. It was so horrific. I remember that pain because that... that's your private part, and that was horrific. Like, why the hell would they do that, something like that? And even though I tried to complain, they denied it. They denied it right through. And so when the doctor came, I gave him shit also about I said I was treated so horrific here. It's treated so bad. I said if your mother was here. I said, would you let her lay in her shit for 4 days like I did? I said, you know what? That's terrible. It's horrible. Nobody wanted to clean me. He just stamped his book down. He said, I don't have to listen to this. He walked out, and that was supposed to be my doctor. But I was so angry because, like, where was all the health care? Why didn't they take care of me the way they did

everybody else? Why was I being treated like I was nobody? So when I when I came out of it, like, I fought hard. I kept exercising because I knew I had to get my blood flow going in order to get out of there. I just wanted to leave so bad. And at one point too, I even, stole a spoon and tried to shove that down my throat, so I stopped breathing. I didn't wanna live anymore. And this is the hospital. This is where you're supposed to be encouraged to live, fight to live. There was none of that. I felt none of that. I just felt like I was in the way. So, anyways, I kept fighting. I kept exercising. I finally... finally, I came out of there, and the doctor came up to me when I was leaving, says, you know, I need to give you a hug. You're the first one who's ever danced out of this ward. There's 2 ways to leave from here. Either you're half dead or you're dead, and you're dancing out. So I truly believe in our cultural ways that our medicines work and our address. So with the treatment that got me there, it was so awful. It was like radiation or..., yeah, I guess, like, called radiation where because it was so harsh, the first treatments that came out. And I'm talking the eighties when I had my Hep C. And I went to the first treatment. Like I said, it took all my... took all my weight away. I just had bones sticking through my face, through my arms. Like, there was a baggy skin covering my bones. That's all it was with no hair. And, it worked, and then I was getting my health back, and I got the Hep C back again. So there was 3 different kind of treatments that I took throughout the years, and finally, I just didn't wanna do it anymore. So I just rather, you know I don't have the fight. I'm just gonna go. But then the doctor Kaida, who had given me a call and said, we've been monitoring you. So knowing that you wanna live, we're gonna try this pill that just came out on you. And that's what finally got rid of it. Well, I it's still... I still have it, but it's undetectable. And through all those years of going through what I went through, I knew that because I had liver cirrhosis that... the doctor told me that cancer will set in one day. So it did, and there's a tumor in my liver. But I carry on. That's not a priority to me. It's just there. It's something that Creator will take away for me. So I don't take any Western medicines. I rely on our traditional medicines, and they don't even know what stage that cancer is in that tumour because they can't probe; if they do, it'll just spread, and I'm gone. And they can't operate it because I'll bleed to death and I'm gone. So I'm just, like, really stuck with what it is that they've given me. I do not claim this tumour. I never do. It's there, but it doesn't matter. It's not gonna it's not gonna stay with me. I know I'm gonna beat it. So with this traditional medicine, here's what I really rely on that's keeping me alive. And not only that, every sacred item that Creator has given me, I turn to every one of them, and I respect each and everything that Creator has given me. I have my bundle. I have my dresses. I have ceremony. Everything, you name it, I'm there. I do it. And I pray and I pray for myself, but not only for myself, but all our people. So, *Miigwech!*

**(26:47 – 27:30) Renee Masching:**

Thank you so much, Gayle, and thank you for fighting. Thank you for being here and for sharing. That was so personal and, yeah, I can't even imagine. So, so thankful that you're here with us today. And this is the important reason for this conversation, to learn more about and understand the context of hepatitis C. And so, we really, wanted to bring together many voices and perspectives. So, Marina, turning to you to help to kind of give us a foundation and understanding what this, this virus is that, that has impacted so many people in so many ways. Thank you. Over to you.

**(27:31 – 37:37) Marina Klein:**

Thanks, Renee. And thanks, Gayle, for sharing that. It's very, very powerful and, disturbing because I think some of these things are clearly still happening, and we'll get probably to talk more about that

later in the conversation. But I was just gonna start by, giving an overview of hepatitis c. Maybe it's a bit basic at some levels, but, happy to answer other questions that are more detailed later on. But I think there's some important features about hepatitis c. It's a virus, and it's a virus that actually only infects humans. So, that makes it possible in theory if we could get... find everybody, offer them treatment, treat everyone, and cure them all, that we could actually eliminate this from the human population. But, you know, focusing on treatment, and I think Gayle's story is really about that. It's far too simplistic because it's not... it's just a tool, but it's in this piece of a whole bunch of other things that are going on. And so, that's, I think, gonna be the focus of we're gonna talk about later in terms of how we can better address that. But in short, hepatitis c attacks liver cells, and causes liver damage. And it's spread most efficiently from blood to blood. So it goes hand in hand often with a lot of other viruses that are passed the same way, such as HIV in particular. And early on, we saw people would get infected with this virus by being exposed to blood, either through blood transfusions or through medical procedures before we knew about this virus, what it was, how to screen for it, and how to eliminate it from the medical practice. But there's still countries in the world where people are being infected today because of bad medical practices and reuse of needles, for example, in medical settings. But in Canada, it's mostly currently being transmitted through injection drug use, but also, by sharing equipment that's used to prepare drugs prior to injecting them or snorting. So sharing equipment is one of the other ways that people are less familiar, but can also lead to, being exposed to the virus. Sexual transmission is also, possible, particularly, among men who have sex with men. So it's both the question of numbers of partners potentially, but also the context in which, sex is occurring sometimes in the context of drug use. And mother to child transmission is also possible. Much less than we see with HIV, but it does occur and particularly does occur in women who are also infected with HIV. So mothers need to know that they're have the virus because we can address it before they become pregnant. Most people who get infected with hepatitis c go on to develop chronic illness, and this causes various symptoms. I think the most severe symptoms are those that relate to how the virus damages the liver over time and causes scarring in the liver, which then can lead to cirrhosis, which is where the liver is really so scarred that it can't make its normal function. And this is what can lead to cancer as well as Gayle has told us about. But it also is associated with a lot of other symptoms that people, don't really recognize. And I think early on, they say it's asymptomatic most of the time. But a lot of people, if you talk to them, they may say, no, there's, you know, they find they're tired all the time or difficulty concentrating, sort of brain fog, like we see with lots of viruses. It also can have effects on the the neurologic system. So you can have pain, you know, neurochronic pains, cardiovascular disease, so heart disease, diabetes. So it has a lot of other knock on effects. So it's in a virus that although it affects the liver, is important elsewhere. About 20 to 25 percent of people can actually cure the virus on their own after they get infected, and these are called spontaneous clearances, and that's great. And in fact, there's... the... what causes that is not clearly known. There's probably some, genetic factors from... host factors, that is their immune systems differ. Maybe the virus also differs. And in fact, spontaneous clearance may incur more frequently amongst Indigenous peoples, it's been observed. So that's a good news side of things. But the bad news side of things is that even if people clear the virus, they can get infected again because it's... once you... it's like even if you've been exposed to the virus, you don't get immune to the virus. And that's why we've had so much trouble developing a vaccine against hepatitis c because if you it's not enough just to have immunity. You have to have, like, your cells able to get rid of the virus from the system. So

that... we're still struggling to get a vaccine, and probably will do so for many, many years to come. So... and it also means why it's sometimes difficult to diagnose somebody because you can have an antibody in your blood that tells you you've been exposed to the virus, but it doesn't tell you if the virus is still around. And so you need to have 2 steps to get a diagnosis. 1 is antibody step, and then the second step is the the PCR test or the RNA test. And that tells you if the virus is in the blood. And so because of those two steps, often what happens is somebody gets tested, they think they have hepatitis, and then they never get the second test. And then they don't know if they need treatment. And there's a big gap, and then, you know, people go on and do whatever else they do in their life, and then they don't like, get picked up again till much later, and they may have already developed some damage because of that virus that's going on. So it's really important to try to reduce that time between, you know, make a more efficient diagnosis to give people the opportunity to get to treatment. Because now fortunately, good treatments exist. Unlike the terrible interferon Ribavirin based treatments that Gayle unfortunately had to have at the beginning which really made people sick, and didn't actually even work that well, now it's almost as simple as taking an antibiotic. The treatments that exist, which are called direct acting antivirals, are 1 to 3 pills a day for 8 weeks or 12 weeks, and they have really few side effects and cure more than 95% of people. So it's like it's pretty miraculous in terms of developing a treatment, and it's really the first chronic viral infection that we have in humans that can be cured. So it's pretty, pretty amazing. And when you get cured, you actually... liver, which is a really remarkable organ, has a capacity to regenerate, rebuild, and can get healthy again. Not entirely healthy again, but much of the liver can, you know... so you can reduce the the scarring, reduce the risk of cirrhosis progressing, reduce the risk of cancer even. And so, really, it should be simple. It's like a no brainer. Everyone should be treated, but we know that it's not that simple. Right? So, you know, first, it costs a lot of money, these treatments. So at the beginning, we really restricted them to who was sickest and who should get them first. Now they've become available right across the country here, not everywhere in the world, but they're still expensive, but the governments are largely paying for them. Though in some provinces, there's still co payments, which can be a, you know, important barrier. But there's also this holdover of, like, the old treatments, and also people not feeling... either doctors not feeling somebody is worth being treated or people not feeling they're worth being treated because they're so expensive. I think it's something that we don't talk about a lot, but it's really important. And then I already mentioned the diagnose... you know, the issue about diagnosis, the 2 stages. Then they have to link someone to get to the treatments, and then they have to take the treatments every day. So there's many steps in the process, and we've been doing this in the old way always. Come to the specialized clinic, fit into our hours from, you know, 8 to 4, navigate the system that doesn't actually make it easy for you. And so a lot of work that, you know, we've been doing now is really to try to reduce those steps to simplify, simplify, simplify, meet people where they're at, because the treatment is simple. So we need to change our approach to getting it to people. And I think the other two points I'll make before closing is that we can't forget about prevention, because, like I said, there's no vaccine. And like I said, you can get infected more than once. So we really have to also think about reducing harms, reducing the harms of that are associated with with drug use exposure, empower people not to be put in a situation where they can get infected. Because if they don't have access to clean needles, then they have no choice. It's not like someone goes out to get infected. We need to make it, you know, and this is a particular problem, for example, in prisons or, in situations where, you know, there's real stigma around using drugs. We need to do we need to really move to do better on the prevention



side. And then finally, I think the point that Gayle raised so eloquently is that cure doesn't mean that Hep C is gone for a lot of people. So it's a... it's something we wanna achieve. It's a first step to making people feel and get better, but it's really only the beginning of the road to wellness and the road to recovery because a lot of things don't go away. The stigma of having been infected may stay. The physical damage that was done by the virus can endure. The risk for having cancer can be there. And that's the emotional side of and harm that occurred along the route to getting to that treatment. It doesn't just go away because the virus goes away. And I think we have to remember that when we, are engaging with people with hepatitis c. So I'll stop there because I know there's probably lots of other things that need to get said in this conversation and happy to come back to any of that if anyone has questions.

**(37:38 – 38:20) Renee Masching:**

Thank you so much. That was an amazing overview. And it really has been very exciting in joining in this work to learn more about hepatitis c and this idea that we, you know, we can actually cure a chronic viral infection. And so, of course, important work that we're doing in Canada is, in partnership with the CanHepc network, which is leading a response in Canada to hepatitis c, is the development of roadmaps that will help to implement an action plan for the elimination of hepatitis C as a public health threat. And, Kacheena, you're leading our work for a national Indigenous road map. So love to hear more about what you're doing and how you see the work progressing.

**(38:21 - 48:58) Kacheena Naytowhow:**

Thank you, Renee. My co panelist, you guys are amazing presenters. I just gotta say that, you know, following both of you is just a... is a hard thing. And coming into this conversation, I guess I'll just do it my own way. And how I would do it is just to have a conversation. To have a conversation and tell a little bit story about how I ended up, where I ended up. So finishing my master's, I finished my master's at Simon Fraser University this summer, and just entering it. And I was really thinking, you know, for me, I believe in Creator. I believe in the western world, the traditional world. I was blessed with both educations. My parents pushed me on both sides, you know, to be raised in ceremony, but also acknowledging that education, you know, is our new buffalo, and that's how we're gonna change perspectives for our people. And that's my goal, is to change perspective for our people in Canada so that we don't have to go through and have stories like Gayle. Like, those stories can end because that's not the only one I've heard, you know, of going through health care and encountering that kind of trauma. So coming into that and coming into the role that I've come into. So with CanHepC, I'm the national Indigenous platform coordinator. And how does that title scare me? You know, you hear national and you just you think so... It's across Canada, right, this big role that you have, you know, little person me, you know, in my culture, in my traditional ways, we're called oskâpewis We're just learning or, you know, we're in that learning stage. So to come in here, you know, I always wondered, what am I gonna do with all of the experience that I have? And the experience that I have is with Indigenous communities. So right from being raised in Indigenous communities to ceremony, to working with Indigenous communities, to studying them, to working with West Bank First Nations, so, you know, I have all of this experience, you know, and I'm so grateful that CanHepC chose me as their candidate. I'm coming in and learning about, you know, the hepatitis C virus and what the goal is with Canada. You know? So that it started with the World

Health Organization, and they're like, okay. We're gonna eliminate hepatitis c virus by 2030. And Canada's like, yes. Let's do this. We have all the tools available. You just heard from Marina. We have all the tools available, you know, that we can eliminate this, but it coming back, you know, so just creating the policy, the action plan. So Canada's like, yes, let's do this. So they created a blueprint, a Canada blueprint on how they're going to do this by 2030. So that was released in 2019 and it said, so this is what we're going to do is we're going to separate it out into regions. So we're gonna separate it up to British Columbia. We're gonna separate it out to the northern region, which is the The Yukon, and then Nunavut way up there. And then you have Quebec. We're gonna give them their own regional map. And then you have the Atlantic region. You have Ontario, who's already released their blueprint on how they're gonna reach their elimination goals of 2030. So they're the first ones out of the game right now with their road map. And then you have the prairie region. So you have all of these regions working on their road maps for elimination. They all have leads. They have partnerships. And so, like, the work that is progressing, it's coming together. We have doctors. They're such a good... CanHepC has such a good team you know, leaders and they're coming together. But not only that, they're a research organization. That's one thing that I appreciate so much is CanHepC is a research organization and a teaching one. You know? So combining that teaching, learning, new methods with the research that's there, that the data that is there already for Canada really creates strong quantitative and qualitative data for realistic goals, creating policies and actions plans because the information is there, whereas you're not outsourcing it. So CanHepC is just a really great leader in 454, the HCV elimination goal for 2030. And one thing I really appreciate about CanHepC is, you know, realizing so coming into it. So what they did is what Marina said is they established 5 priority populations that have the highest for HCV. So the first one is people who inject drugs, and then you have inmates, you have men who have sex with men. There's immigrants, newcomers that come from countries where there's high level of HCV and no testing coming in. And then you have Indigenous people. And so how my role evolved, is... so there's 634 nations, communities of Indigenous people in Canada. We are the fastest growing population here. And they predict by 2050, like, half of the population will be Indigenous people with some kind of Indigenous background. So thinking about that and thinking about these 5 priority populations, what they didn't realize is there's a lot of intersectionality of Indigenous people in these 5 priority populations. There's a high percentage in people who inject drugs and inmates and men who have sex with men, and then you have Indigenous people in their own. And they're like, okay. So how... CanHepC really took a look at it, and we had... we have the 2 leaders. So the national Indigenous co chairs, one is sitting right there leading the questions, Renee is one of them. That is my mentor right there. And then you have doctor Alexandra King. You know, these 2 ladies said, we need to look at this a different way. We need to acknowledge that Indigenous perspective in a different way. So, CanHepC was like, okay. How do we do this? So they created the national Indigenous people's roadmap. And so, like, the first thing they had to do was to hire a National Indigenous Platform Coordinator. So, and then they were telling me, we searched far and wide and, you know, coming in here. So I really, you know, coming in and I just started in December and coming in and learning about it. And for me, my goal has always been to change perspective for Indigenous people. And I come from... I live in the prairies. I come from the prairies, but I also come from 2 worlds. So I come from 2 worlds where there's a lot of blood trauma. So blood trauma is intergenerational trauma. I always remind people is, like, so I'm a 1st generation that's allowed to raise my kids. Like residential school just happened, and we have all of this trauma, all these cycles that come out of residential

schools, you know? So we can't look at eliminating HCV or, you know, hepatitis C virus in Indigenous communities from a disease perspective. That here's the tools, let's expect you to do it, you know. If anything, you have to look at it from a wellness perspective, and just understanding how Indigenous communities work. So So you think about Indigenous communities, and there's 634 of them, but in Indigenous communities, maybe 1 third of the population is there. The rest of them are in urban centers. Gayle said she's from one of the biggest reserves, which is Winnipeg. You know, you have Regina, you have Edmonton, you have Vancouver, you know, so you have these these Indigenous areas where they really need to have that perspective, that Indigenous perspective of HCV elimination. You know? So to come into it... and one thing that I'm grateful for here in Canada, so I have the National Indigenous Peoples Road map. I get to meet with each region, each region and provide support and provide guidance. They're... they wanna provide that Indigenous perspective in their roadmaps, but they're like, how do we do it? How do we do it? How do we include that? How do we connect with indigenous communities? And I was like, well, how how do you think you would? How would you like to do it? If you were to meet another organization, how would you introduce yourself? You know, I was like, so that's how you do it. So I provide support. I provide recommendations. I work with the team. I make sure it's connected, but at the same time, taking away from each one of them that there's inclusive of Elders and that wellness, you know. So Doctor Alexander King is what she says. We have to see it from a 2-eyed approach. You have to see it from the western. And like Gayle said too, you have to take in that Indigenous people. We have trauma. We have trauma and stigma coming from smallpox. Starting from smallpox, you know, half of our population was eliminated, You know? And then going into, like, the health care industry and being in hospitals and stuff like that, we have a huge fear of working in, you know, hospitals and clinics and cures and, you know, interferon. You know, one thing they don't realize about Indigenous people is word-of-mouth is huge. We don't have books. We don't have stories. We tell stories and it stays here in our recept... you know, in here. So when that interferon came out and people are they want to eliminate. They want health and wellness. And so that fear is there. And so being able to use this national Indigenous road map and work with communities to help eliminate that fear and that stigma, that's probably my biggest goal. My biggest goal is because, you know, I'm like, we look about this, like, Canada looks at it to reduce medical costs down the road. Right? That's why we're eliminating it. You know? Like, what what HCV does is, you know, millions and billions of dollars down the road if we don't take a look at it and cure it now. How I'm looking at it right now is if we don't get diagnosis, if we don't fill those gaps, we're gonna lose our Elders. I'm gonna lose my Elders. I'm gonna lose, you know, there's gonna be a lot of pain and that in our communities, you know, and so we were already healing from a lot of things. So being able to work as a National Indigenous Platform Coordinator with CanHepC and try to spread this good word and get it to the communities and create this roadmap and work with every region to make sure there's good Indigenous inclusivity. I feel like, you know, it's a wonderful... it's a wonderful goal I'm on and to be able to work with an organization that's so receptive. We wouldn't have got this 10 years ago. You know? But Indigenization is happening across Canada, you know, where it needs you know, the Indigenous conversation needs to be part of it now. We are the fastest growing population. So for CanHepC to go through it. And I'll tell you how receptive they are. As I just started in December and going out there, I presented at the annual meeting and, oh, it's really intimidating, you know, going out there and presenting to PhDs and researchers and doctors and, you know, they're doing all these wonderful, amazing, beautiful things, you know, and being out there and

presenting and for them to just be so humbled by what I had to say. Because I realized, like, I got a PhD too, but Indigenous experience. So being able to share that with the organization and have them so amazing on the path, you know, and to start this journey just makes me feel really good about changing perspective and working with the health care industry and changing it. It needs to change because, like, I don't wanna hear any more stories of well, you know, we shouldn't hear any more stories like Gayle's. There shouldn't be trauma stories like that. And sadly, you know, a lot of my family and a lot of my friends and that have similar stories to this day. So that's the work that I'm doing right now as in my role. Thank you guys for listening.

**(48:59 – 50:14) Renee Masching:**

Wow. Amazing. I love your energy, Kacheena. And I just want to note and acknowledge some of the comments that are coming in already just with profound appreciation, Kukum, and love from your grandchildren, love from many of the people who are here on the call, and an appreciation, Marina and Kacheena, both for your energy and for your presentations. And so, it's just, it's such a lovely space to come together. It means, you know, the gift of our virtual opportunities to connect. So I wanted to have a chance to have all of you interact a little bit, or we want to have a chance for you to interact together. So a question to all of you as panelists, maybe, Kokum, if you're there. I'm not sure your video is off which is a nice way to kinda have a break from seeing yourself online. But we want to talk a little bit more about that that thread of stigma. And think about, you know, both how does stigma impact access to treatment and think that maybe about as well, how have we been able to address stigma? Are there any other any success stories that we wanna share? I'll open that up to all of you. I see your mics are all silent. I've got all of our panelists. So, and if you wanna jump in for this. Excellent.

**(50:12 – 52:01) Gayle Pruden:**

Hi! Yeah. What I'd like to mention too is that, well, I guess I could say I was excited, but not excited because I went there when I was sick again. I went to Saint Boniface. It was my breathing this time. I couldn't, just happened recently where... because I had the, COVID and, you know, the after effect of breathing, my breathing, I got really scared that I couldn't stop coughing, and my breathing was just going out of whack. So I went to St. Boniface. And they have all my records there, like, because that's the only place I'll go to, St. Boniface Hospital, if anything happens health wise. So when I went there this time, I was in the room, and there was this trans that came to me, and she was taking such good care of me. I just loved that. I said, oh my god, it's about time! I said, no, I don't care about... I feel so safe that you're here, and I feel so wonderful to see, finally, our people working. I said there needs to be more more of us out here in the work field. I told her, and I said, thank you for coming to take care of me, and she was so wonderful. Like, it felt so... I don't know how to put it, but I was so happy. I wasn't happy that I was sick. I was fighting for my life again, but to see to see a trans employee there, that's so beautiful to see. And she was so wonderful. Like, I just thought I'd share that.

**(52:03 - 52:05) Renee Masching:**

Thank you. It's beautiful! Marina.

**(52:06 – 56:08) Marina Klein:**

Yeah. I was wanting to share a bit of, you know, a project that I was involved in a few years back now. But, you know, one of the things that we sort of started to realize really early on, in the DA in the treatment era where we have good drugs is that, the health... there were a lot of health disparities being experienced by the Indigenous participants in our cohort. And so together with Margo Pearce, who is a postdoc, a CTN postdoc with me, and who'd been working a lot with the Cedar Project, and Indigenous Elders from the Cedar Project and others. We got together to carry out a project where we did 45 interviews, with Indigenous people living with hepatitis c, and to listen to their stories and try to get their perceptions about... recommendations about how we could do better, how we could decolonize hepatitis c care. And it came in... out in the paper, so it's worth I can put it in the chat later. I think it's worth looking at if people are interested in it. But we really came... they came out with 3 themes, which I think are really important to share because a lot of it speaks to how can we address some of these experiences that that that Gayle has had. First of all, the first theme was that treatment providers really need to learn and come to understand and accept that colonization is a determinant of health and wellness, among hepatitis c and affected Indigenous peoples. And that this ongoing I think, Kacheena, you alluded to this about, you know, the ongoing impact of the residential school experience about losing children. This is still impacting every day, and until the treatment providers understand that and recognize it, they can't come meet people at their level at all. The second thing was having safe attitudes, that can create trust between people and the providers that are giving them care. And that opens up opportunities then for engagement and care. But until you have those safe spaces of safe attitudes and we even heard from providers in our... we also interviewed providers and sadly were shocked by some of the kind of pervasive attitudes that were there. And then I don't think they even really realized that they were saying what they're saying and how negative and impactful it could be. So we learned we learned from that. But the third thing, and I think was really, one where I we can probably take and try to really try to build on was that this concept of building strong circles of care that can have the greatest potential to engage people. And that circles are like circles. So there's it's the relations, people's relations. I think you you talked about this a lot, Gayle, how important your mother was in helping you to get well. So the support from trusted family and friends and connections, peers, to support all along the pathway to wellness from, you know, finding about a diagnosis, supporting someone when they get that diagnosis, and that's... to supporting adherence with treatment, encouraging people to come forward, to take treatment, to celebrate the successes that they have when they can get cured. Those things were really valued and really important. But also circles of, like, health and social services, and particularly the role of Indigenous-led organizations and Elders and, ceremony and sharing circles, talking circles, all of this so important in kind of encompassing the whole person because it's not just the treatment. And it came out over and over again from all the interviews, and I think that was for me... I learned so much through that project, and it's really sort of informed my thinking about what we need to do to collaborate and really co-design interventions with Indigenous partners so that we can really move forward to make a difference.

**(56:10 – 58:53) Kacheena Naytowhow:**

And just add on to that Marina. Like, I couldn't agree more when I was thinking about it. And I was like, so for Indigenous people, especially being in the hospitals and healthcare, like, you know, we need to humanize them again. I don't know when we didn't become human, when they... we were dehumanized, you know, and sometimes I feel like that's Canada's perception that they that they

threw out of us. In the media, you see all the statistics of Indigenous people as street workers, as you know, addictions, inmates, you know, the labels that they've created for Indigenous people. And not only that, but I can understand to some extent that, you know, working in the health care industry and working in hospitals, you know, and you have so many Indigenous populations or high Indigenous populations in the city struggling with blood trauma, struggling with addiction, struggling with these ones? So, you know, going into with these... these struggles, but then you have Canada saying, yes. Those are the bad people of Canada. Right? Dehumanizing us. Right? So I was like, how do we humanize what they should... you know, how healthcare looks at Indigenous people because we're treated very badly, you know? So thinking about that, I think about diversity, equity and inclusion, you know, and that's what's coming across Canada, you know. So if we can have Indigenous diversity and equity inclusion in the healthcare industries, and these are lunch and learns. These are going out to communities. They're learning about Indigenous healing models and methods, like creating that respect, understanding our culture, our people, you know, making us human again, that, you know, what Canada is representing and what with the people that are coming in with the trauma don't... isn't Indigenous culture and, you know, we're trying to heal our people too. And not only that, transfer of learning, thinking of transfer of learning and respect, like it would be nice if we could have it for, you know, the people working in the healthcare industry. Would you like to go to a sweat? Would you like to ceremony? Would you like to really understand our healing methods? You know, like, we're 2 sovereign nations. We need to come together, You know? But it's to respect our healing methods as well. You know? Like, because there's ways out there that they that medicine can't describe. There's miracles that happen in Indigenous communities, you know, that can't be described. So to go out there and to get... latch onto that medicine and understand it, I think, would really be good for them, You know? Or even to have, like, Indigenous healers on-site. You know? To have those Elders on-site, to have that ceremony, you know, like, to really combine and collaborate because I know that they're exhausted in the health care industry, especially after COVID. It's burnout. It's exhaustion. You know? So, like, being able to utilize other healing sources. You have naturopaths out there. You know? You have Indigenous healers out there. You know? Let's spread that out outside of Canada and really create good healing, you know, to eliminate that stigma. That's what I think.

**(58:55 – 1:03:00) Gayle Pruden:**

And the other thing the other thing I have asked also was when I was there, if there was any... it's kind of, like, to have a sharing circle happening because there's not only one person that's infected by this. And you know it'd be so great, if we were to sit together, people that are infected. So... because when I first found out, that was like... it was like my life was over. That's what I thought. And I had no support from nobody. I had no idea what I was getting into. So, like, you know, for people like that, people that are just finding out, to talk to other people that have been through it would be so important that, you know... a little bit more of a faithful like, you know, faith in medicines that are out there because they'll hear stories from people who have had it and what their journey was like. And so when I did ask at that time if there was any kind of, support system happening, they just throw it in my face. Why don't you do it yourself? I'm like, I'm not the one who's getting paid here. Hello? Do your job. Like, I think that would be so important to have a space like that where we can talk amongst each other, what their... our experiences have been through with the Hep C and allowing other people who are just newly diagnosed to come in and listen. And so they'll know at

least a little bit about how different our stories are, how different the journey is gonna be with fighting for your life to stay alive, especially when it comes to this hep c. And, I have been sitting, I... well, I did sit in front of panels a few times at the health science center where I felt like I was attacked by, like, you know, what I experienced there as trying to survive this hep c and also within that coma part. And what I noticed is that they brought in the nurses, the doctors, the health care field to come in and listen and listen to our stories. I think there was 3 of us trans people that were on there, and they had no questions. So I don't know... because I noticed that in general population... so even some people approach me, say they don't know how to talk to me. They don't wanna hurt my feelings. But I tell them, you know, you can... I'm an open book. You can ask me anything you want. It wouldn't bother me. You wanna know, I'll tell you if I do know the answer, but I don't have the answer for everything. And I don't know why we never got called back in to do more with these upcoming people that are gonna be saving lives to learn about who we really are as trans people and also about all these hep c and all the things that we've been through and experienced. So I think a lot more of that needs to happen. Even open up even cancer, maybe open up a space where have a sharing circle, an open sharing circle across Canada with people who've had that experience of what I've went through and also open it up for the ones that are newly newly diagnosed so they don't have to fear. Live in fear. We have no time to live in fear. We don't know how long we're here. I just thought I'd say that a little bit. *Miigwech*.

**(1:03:01 – 1:03:27) Renee Masching:**

Thank you. That's a very powerful place to, to jump from. I'm just... I'm mindful I have some... I have some more questions for you, but I also want to know if there are any questions from people who have signed on with us because time flies when you're talking with great people, and time is flying. So if anybody wanted to raise a hand or, or yep. Martin, thank you. Welcome to hear from you.

**(1:03:28 – 1:03:34) Martin Morberg:**

Hi. I'm wondering if I should turn my camera on.

**(1:03:34 – 1:03:36) Renee Masching:**

Whatever makes you happy. It'd be great. Yeah.

**(1:03:36 – 1:03:45) Martin Morberg:**

I guess I could show my face today. Hi, Kokum Gayle. I'm one of Gayle's...

**(1:03:45 – 1:03:48) Gayle Pruden:**

I love you, and I miss you!

**(1:03:49 – 1:07:43) Martin Morberg:**

And it's nice to see you too, Kacheena. I just wanna thank everyone, for sharing. I'm a person too that has lived experience, with hepatitis c. And, like, I remember how scary that was for me. And I have a question for Marina and then also, Kacheena. But I guess my question to Marina is that, like, I remember when I was diagnosed, it was a really scary time because the treatment was being made available. They were like, we're sorry. We understand that you're... you've tested positive, but there's not enough liver... or damage done to your liver yet. So you're gonna have to wait. And I

was... that's what really scared me. And so they're like, well, we're gonna keep an eye on it. The treatment is really expensive. We're talking about, like, thousands of dollars here. And so I had to go back every few months. And what they noticed was happening is that I was actually clearing the virus on my own. And so, I had some confirmatory tests, and I actually ended up having it come back, but wasn't exposed to hepatitis c again. It was the same instance. It was the same strain. Like, it was it was from the same experience. And so I remember being really highly stigmatized in the health care system about that because they couldn't understand why it would come back, and they really thought there was only one way that it can come back. And, like, I had been sober at that time for, like, maybe over 2 years. So there was no way that I could have been reinfected, with that. So with that being said, I think what happened was, they kept stalling and kept stalling, and they were doing fibre scans and just showing, like, oh, there's not enough damage done yet. But then I think pharmacare changed their rules, and they're like, anyone that's co-infected with HIV can receive the treatment. And then even then, it was gonna take months for me to receive that treatment. And the best thing that that doctor could do at the time was to refer me to one of the top doctors, here in Vancouver, doctor Mark Hull, and he gave me the treatment right away. I was, like, within a couple of weeks, I was taking the first pill, and I took the one pill a day for 12 weeks and was completely cleared. And so I guess my question for Marina is... what is that accessibility like today? Are people having a hard time, accessing that treatment? And, like, what sort of barriers would be in place? Because, you know, there's so many intersections that an Indigenous person can face when accessing health care alone, never mind accessing this life-saving treatment and then adhering to it for the required amount of time because it was really stressed to me at that time, the important of adherence every day. And then my question for Kacheena, who I believe is with CAAN. Lovely to see you. I just wanted to know, so I'm aware that CAAN has a leadership council of Indigenous people that have lived and living experience with Hep C. So my question for you is how is that council being engaged in CanHepC's work And are they, offering, like, any advisory support, on the hep c work happening with CAAN?

**(1:07:45 – 1:13:09) Marina Klein:**

Great. Thanks, Martin, for those questions. I mean, so you were experiencing that new diagnosis at a time when treatments were definitely in transition. And as I sort of alluded to when I gave the introduction about Hepatitis C, one of the the main reasons that treatment was actually restricted, the early... the direct acting antiviral system treatments were restricted was their cost initially. And that led to kind of uncomfortable situations because looking purely at a kind of cost-benefit reality, the payers, the provinces, and the federal government decided that, it makes more sense to treat people who have advanced liver disease because they're likely to get sick faster and cause, you know, and need health care sooner. And therefore, it makes a lot of sense to treat those people first. And nobody would argue with that in terms of on the personal level, that that makes sense. But there's a lot of people that didn't fall into that level who also would benefit from treatment for a variety of reasons. First of all, because who wants to run around with a virus that they know is causing damage to their liver and not be able to do anything about it when there is a good treatment out there that they know can cure them? And second, can't we prevent other people from getting infected by removing people... you know, removing infections from people who are carrying them even if they don't have any symptoms at the time? So there's lots of good reasons to treat everybody, but the finances initially didn't allow that. Over time, there's been negotiations with the 2



major pharmaceutical companies that are providing the treatments that we use most frequently today to... and we don't know, we're not even privy to what the real price that the payers are paying. The list price is still extraordinarily high. If you look at, in my province in Quebec, the list price is, about \$20,000 per month of treatment. So if you're on the 3 month treatment, 12 weeks, that's \$60,000. And if you're on the 8 week treatment, it's \$40,000. We think that the real price that's being paid is somewhere more in the 10 to \$12,000 range per treatment course, but that's still a lot. That that's like, we're talking about a medication that we know costs almost nothing to make. If you look at what's happened in the rest of the world where generics have come into being, so places like India and South Africa, they've got the... and Egypt have got the price down to as little as \$250 per treatment course. So that's... and that's still making a profit, the generics are still making a profit. So we know that that there's a huge money taking going on, with respect to the pharmaceutical companies. And that's a whole other battle that we've tried to wage at an international level, and we didn't make that much progress. But suffice it to say, currently, at least in Canada, access should be pretty good, but it varies from province to province. So this is why the road maps are being developed in provincial jurisdictions because the epidemiology differs a little bit in each province, but so does access to services and treatment. So in some provinces, it's 100% covered. It's covered for many Indigenous people will fall under the federal coverage, and it's covered 100% with no co-payment. In my province, it's covered like any other drug. But it still requires special access. So a doctor still has to do a special form to get the request approved and then reimbursed to take place. So some people will have to pay co-pay, which could be quite a lot of money. So it's 20% of the cost of the treatment. So you can do the calculation, but that's thousands of dollars. And... or their insurance doesn't... they have insurance, and their insurance only pays part of it. So it's not free. So that means that there's still a barrier. And there's also these these juris... these, administrative barriers, which means you have to get approved and you have to wait for that approval. That's really come down in many places. Like, Quebec, we can do it online, and it's done within minutes. It's done. So the same day, you could see someone and treat them. But that's not the case everywhere. So that's why, this is how, you know, when it's going happening. I'll... I'm gonna address the other question because I think Doris actually asked it, and it relates to something, Martin, you brought up is how can hepatitis c, kind of seem to disappear and then come back again without it being a reinfection? And that just speaks to the fact that we don't really understand, the full biology of this virus. It's... and we don't really monitor people early on in their infection well enough to know that that virus actually can go down below a level of maybe we can detect it, but then it can come back up because changes in the immune system happen or the virus happens. So it's totally consistent, your story, with a natural first infection that your body tried to fight off, but maybe was not able to fully control because of other aspects of your immune system. And we see this happening. We also see people clear their virus years after they have it for no reason. So... and we don't talk about those very much, but it does happen. So there's these these kind of things that we need to understand better, and maybe that'll help us understand how to make a vaccine. I think, Kachina, I think, I'll turn it to you. We had some questions for you.

**(1:13:09 – 1:14:35) Kacheena Naytowhow:**

And so just thinking about the Indigenous platform, so how so my role is with CanHepC, But, CAAN is one of the partners, Powassasquan and Wanska. Those are those are the partners that work with CanHepC. So I work at the University of Saskatchewan right now, and I was really... I was really

grateful and blessed to come into such a strong Indigenous platform. So they created Indigenous roadmap team structure with all of the partners. So you have the core planning group, which is... this is, like, probably that's like Sandy-Leo in there. There's Renee, Melissa. So you have the CAAN the CAAN partnerships in there, the Powassasquan the Wanska. You have the advisory committee, and then you have the ad hoc support and the researchers. And this is just for CanHepC. So then I really get to utilize... like that's where we met was at a CAAN conference. Right? Being able to come out there and go to All Nations Trust and have the conversations and get that with that experience so that I can bring it home to CanHepC, and it can work with the national Indigenous road map. So what Renee and and Alexandra and Carrielynn Lund... I can't Carrielynn Lund is a kokum of my heart that I just, you know, never knew that I had out there until I found her. Like, that woman just changed my perspective and my life. Right? And... as well as they send me out to Elders conferences here where I'll be speaking at the Elders conference. So like, all of this beautiful Indigenous support and that so that I can create a strong national Indigenous roadmap is amazing with all the partners.

**(1:14:37 – 1:15:23) Renee Masching:**

Brilliant. Thank you so much, Kacheena. And I've answered a couple of questions in the chat as well. And so, Martin, just offered that insight about CAAN Communities, Alliances, and Networks and CanHepC, the Canadian Hepatitis C... the Canadian Network on Hepatitis C, and put web links for both of those in the... in the chat. And and really important to make sure that we are bringing forward the voices of living experience. So, certainly, that's an influence, through contributions that we make to the CanHepC network. And I think it's, it's work that that CAAN, Communities, Alliance, and Networks really wants to elevate and continue to make sure that we're privileging the voice of lived experiences as a priority and clear voice in the work that we're doing.

**(1:15:23 – 1:15:30) Kacheena Naytowhow:**

And just add on to that, we do sharing circles of people with lived experience. So we really get that strong story, that intent and that emotion.

**(1:15:32 – 1:16:59) Renee Masching:**

Beautiful. Thank you. And, just, Layla, we're following up an email already, but, to acknowledge that, in the work that we're doing with the national road maps, that... and with the prairie road map as well, that there will be opportunities to connect. We absolutely hearing directly from from the front lines, from communities, from the people who are doing the work and who are concerned and interested in the work is... that makes it... that's what makes it worthwhile. So but the intention of the big especially with the national scope, is that we are... we're not reaching out directly to individual First Nations. So we'll make sure that connection happens as well. And time has flown. I think, I'm gonna thank on the recording. I'm going to thank all of us for and just, again, really want to echo, the feedback in the chat to say that this has just been a wonderful panel and what you've shared and opened and begun a conversation that, that we're really looking forward to continuing. And in the context of the Feast Centre For Indigenous STBBI Research, you know, this opportunity to really... to expand and understand the scope of what falls under the umbrella of STBBI is so critical for the way that we move forward. And, I have to say, it's always very exciting for the nerd in me that we come together as researchers, and I actually get excited about research. So thank you. Thank

you. Thank you so much. I'm gonna ask for us to have a closing prayer, but also that we'll turn off the recording, and so that we won't have that, that recorded.