

Sharing Space Community of Practice

January 12, 2021

Land Acknowledgement from Sherri Pooyak

Introduction - PAN and AHA Centre and overview inspiration for today's event and plan for today.

Background:

Making it Work project brought some of the team together. We've been discussing the challenges we've had doing research in COVID together, and wondering if others were experiencing the same issues. We thought we'd invite people from across the country to share and learn from each other.

PAN and the AHA Centre do not 'own' this space, we are working together to create space for community to share insights and create space for others to come to talk about struggles we're having. We can work together to problem solve ...

We wanted to create space to provide an unstructured space for us to chat about things.

Building the Agenda:

- Shari Margolese – interested in talking about:
 - the CANCURE project and issues around study recruitment and
 - cannabis studies as well.
- Sharlene Webkingad: project Helping Elders where they live- using an adapted version of Photo Voice. Doesn't want to take away from the experience of in-person sharing circles. Anyone working with older people ... and working in community with low broadband etc. (this is her Masters work)
- Shohan Illsley: have people have experience with keeping relationships strong with Zoom. Trying to figure out how to do that in virtual world – do we stop trying and wait for in-person to resume.
- Renee Masching: promoting a survey ... but the uptake has not been what we've hoped. (COVID and Pre-COVID) would love in put re: survey uptake.

Mentimeter exercises (Joanna will have data collected)

Presentation from Sherri Pooyak (AHA Centre/CAAN)

Weaving our Wisdoms – several team members present CIHR Operating grant (2018 to present)

- Began with a conversation around how Indigenous People living with HIV talk about wanting to learn more about culture and where they're from (people across Canada – not just people on the Prairies or on the Coast)
- Met in BC, but team and participants are from coast-to-coast-to-coast.
- Research Question: how to use land to optimize wholistic health for people living with HIV.
- We wish to honour a team member who passed and honour them in the work of the project.
- www.weavingourwisdoms.com to learn more about the project.
- Building our Bundles: met twice as a team to think about what the study would look like. Also- answer the question: what does land-based research mean (moved away from this term to use: being on the land).
- The team travelled to the Heiltsuk Nation outside of Bella Bella, BC to hold meetings, experience the work that was being done there, and learn about Heiltsuk culture.
- In Bella Bella, we planned for a National gathering that occurred in Saskatchewan, 2019. Hosted a 5-day gathering in Saskatoon. Day 1, people arrived, day 2: ceremony; Day 2 data collection (waneskeuin) Day 3: data collection interviews etc. Day 4: ceremony.
- The project was moving along, and then COVID hit. Publications on AHA's website, presented at CAHR 2019.
- The biggest part of the work was developing the concept of an HIV Older. Being called an HIV Older, where people living with the illness long term can pass along their knowledge with newly diagnosed people – providing support, access to care etc. We hope to move this concept more ...
- Activities we offered: teamaking; weaving etc
- What worked well:
 - Held gathering before COVID
 - Participants were new to research and new to CAAN; from all over the country. We were able to create an experience that was positive.
 - Participants continue to be engaged – direct call participants, hosted zoom meetings to generate more ideas re: how to continue to connect.
 - One participant mentioned it was “the best time of his life” - very powerful. You hope that participants will have a good experience – but it was amazing to hear this and how this was a good experience.

What's been tricky:

- About to do analysis and this is challenging to figure out. We've spent the better part of a year seeing and waiting, but it's time to sort out how to do this.
- We're still struggling with our term: being on the land – how do we understand it and need ot sort this because it will help to guide our conversations with participants re: what their understand is.
- Year 3 we're supposed to have a National Gathering in person, but now we have to figure out how to do this virtually. Internet connections are an issue as well

Artwork for project done by Lisa Boivin

Q& A:

Comment from the chat: "Sounds like COVID burnout is starting to set in"

1) Shari Margolese: have a wellness project working on. The funding was for an in-person meeting and had to re-organize things. NOTE: people are looking for things to do and feeling disconnected so advised that it's good to offer things for people to do. The team wanted as many people with HIV to attend as possible. Broke things down for community – did small training and did online focus groups and talked about wellness for their community. Have presentations coming up. Reached out to key knowledge holders who are working on wellness projects to speak. Still using Zoom but are incorporating traditional things into the talks. The biggest challenge was getting funders to agree to changes. Turning out to be richer than they thought at first – getting people to facilitate the training and also we were able to include more people than originally planned. WoW was lucky to have that original time together. Analysis work – having smaller teams to work on certain themes might be the way to go.

Question: how have things changed- def of land based, for example?

Answer: it has been easier because being away from Prairies (which is home) you were always thinking about being at home and on the land there. Having to conceptualize being on the land, and so for some of us it was more difficult. Going to Bella Bella helped to figure this out. At Qua Lodge, we only had internet for 2 hours a day, so we were forced to be present where we were. Thought that we had a good definition, but at Wise Practices, we were challenged re: the term we were using ... and so we decided the term 'being on the land' was more representative of what we were talking about. Any time we present, we try to include pictures that show what being in a place is like.

Stephanie responding to Sherri: on Coast Salish Territory. Was working on a project w/ Indigenous women on DTES when COVID hit, they experienced a lot of the same issues re: not reliable internet and computers. What they did was get people connected with computers and tablets and phones for people. Continued to do ceremony through devices. They didn't stop the research, but it was affected by internet fatigue etc. Could the WoW organize regional ceremony in each space? Try to do more fun kinds of things – have a drumming circle, for example.

Comment from Kimberly in the chat: We hooked our elders up with iPads and they are now zoom experts. They phone me and tell me "we need to zoom". It's not ideal and we do miss the face to face. We had some of our RA's reverse mentor them on the tech

Sherri: at our last team meeting, we were trying to engage our Elders better ... we asked project Elders to participate in an on-line team meeting and they were able to be included that way. We're in the process of trying to sort out how to engage people in a good way moving forward. We need to keep the relationships strong. Reallocating project funds away from travel to giving people what they need- art projects or something like that to help when having to be on screen.

Comment from Kelsey in the chat: Thank you all for sharing. We've also bought iPads/laptops, as well as data sticks for folks without access (this is in Vancouver). Have also had food delivered to everyone ahead of meetings (like pizza nights) and then for local folks hand delivering handmade gifts (jams and things), for zoom tea time/relationship building.

Comment from Renee in the chat: Hi there, I am happy to ask our friends here to share our survey for one last push at survey recruitment. Here is the link:

https://survey.ca1.qualtrics.com/jfe/form/SV_cZaJgA0japce06N

“The GIPA Homefire: Understanding IPHA Leadership towards a Wholistic Response to STBBIs”

Are you interested in taking part in a research study focusing on the strengths, benefits, and needs of Indigenous people living with HIV in leadership roles in community?

Who can participate in this research study? You must:

- Self-identify as an Indigenous person (First Nations, Métis, or Inuk)
- Self-identify as an Indigenous person living with HIV
- Be over the age of 18 years
- Have taken on a leadership role in community
- Be able to read and write in English

What will participating in the research study involve?

- Completing an online survey that will ask about your own lived experiences with taking on leadership roles

as an Indigenous person living with HIV. Participants will receive a \$50 honorarium for their participation.

I am renee.at.caan on Facebook and I will post there and on CAAN's FB page too. :-) Our website is under construction still

Comment from Jennifer in the chat: I recently heard from a colleague who was having a difficult time engaging an Elder. They contacted someone who could visit the Elder in person and get them set up with the technology and show them how to use it. Since then, engagement has been seamless.

Shari's cannabis project – it's an app project and people are enjoying the use of the apps to collect data. Project is probably easy to recruit for because it's cannabis use, but people are enjoying their involvement in the research. This is a pilot project. It's actively being used and testing feasibility. It's on Metric Wire (can enroll in studies with them).

The other project – on the steering committee for CANCure project. They want to get information out of people and that's been a challenge. A part of the project is an end of life project – collecting info re: people's feeling around donating tissue after they have passed etc. So the team may have to put this one aside for a while because people are having a tough enough time. How would we best approach this difficult topic during COVID.

Renee MASHinh. grew up outside of community and when we talk about tissue, we are also talking about how to respectfully collect tissue etc. - what are the respectful ways to collect and then return the samples. This could be a whole community of practice conversation.

Janice – we could include it as a bigger conversation in this group in future.

This would help because this is an area of research that needs more community input.

Renee posted a link to survey – please share

Next meeting: Feb 16, 9 AM – 10:30 AM Pacific

Sharlene: given up the idea where it has to be face-to-face. Trying to learn more re: Elders using tech. If there's any other ways to help support their involvement, please share – providing food prior to sessions, giving iPads etc. ... but in order to stop delaying the project, need to get creative. So, if there are ways to do research using pictures etc. Please get in touch: swebkamigad@laurentian.ca

Another project decided to prepare their favourite dish – participants sat down and ate together on Zoom prior to the meeting.

Renee in the chat: Sharlene, look up the project Visioning Health - Dr Tracey Prentice and Doris Peltier have presented at a lot of different conferences. they used a modified Photo Voice over FB to bring together a group of Women

Sherri- part of a project where PI and research assistant sent tea to participants and the other PI sent cookies to participants. We did this with the AHA Centre and designated the time as tea time – suggestion for us to bring our favorite cups and share stories about the cups. We wanted to use that time to get to know each other. Why is this your favorite cup? Led to convo re: who we were and what that meant ... good way to use connections. One of our Elders who is not good with tech. One of our co-workers called and got her grandson to help her connect. We call her ahead of time to help set up. When working with Elders, iPads work better ... the Mentorship Networks and NIEAHRS have grad stipends to help with research.

Liz in the chat: And fabric art like knitting while participating can help – tactile

Janice has received ideas re: how to make meetings better next time ... please reach out and send ideas and notes. We're open!

In February we can talk about what's next – how often we meet going forward, etc.