



First nations people's perspectives on barriers and supports for enhancing HPV vaccination: Foundations for sustainable, community-driven strategies

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HIGHLIGHTS

- A trauma-informed lens is key to cervical cancer prevention in First Nations.
- Colonization's disruption of family & community ties drives health disparities.
- Ruptured intergenerational ties undermine community capacity for prevention.
- Community-based prevention requires reconciliation with healthcare providers.
- Increased uptake of HPV vaccination requires community engagement.

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ABSTRACT

Objective. In Canada, Indigenous people have higher human papillomavirus (HPV) infection rates, lower screening rates for cervical cancer, and higher rates of invasive cancer, leading to worse cervical cancer-related outcomes than observed in non-Indigenous Canadian women. Lingering harms from European colonization drive these health inequities and create public health challenges. Policy guidance is needed to optimize HPV vaccination rates and, thereby, decrease the burden of HPV-related illness, including high-morbidity surgical procedures and chemo-radiotherapy. The Enhancing HPV Vaccination In First Nations Populations in Alberta (EHVINA) project focuses on First Nations, a diverse subset of recognized Indigenous people in Canada, and seeks to increase HPV vaccination among girls and boys living in First Nation communities.

Methods. Developing an effective strategy requires partnership with affected communities to better understand knowledge and perceptions about cancer, healthcare, and the HPV vaccine. A 2017 community gathering was convened to engage First Nations community members, health directors, and health services researchers in dialogue around unique barriers and supports to HPV vaccination in Alberta. Voices of community Elders, parents, health directors, and cancer survivors ($n = 24$) are presented as qualitative evidence to help inform intervention design.

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Results. Key findings from discussions indicate barriers to HPV vaccination include resource constraints and service infrastructure gaps, historical mistrust in healthcare systems, impacts of changing modes of communication, and community sensitivities regarding sexual health promotion. Supports were identified as strengthened inter-generational relationships in communities.

Conclusions and Future Direction. Ongoing dialogue and co-development of community-based strategies to increase HPV vaccine uptake are required. The identification of possible barriers to HPV vaccination in a Canadian Indigenous population contributes to limited global literature on this subject and may inform researchers and policy makers who work with Indigenous populations in other regions.

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Indigenous communities across Canada experience a significant burden of disease associated with the human papillomavirus (HPV). Higher rates of infection compared to the non-Indigenous population [1–5] are complicated by lower cervical cancer screening rates [6], increased burden of disease [7,8], and related hospitalization [9]. In 2010, the rate of cervical cancer among First Nations women was around double the rate among all women in Alberta (15.4 vs. 8 per 100,000, respectively [10, 11]), while data from Ontario indicate that survival after cervical cancer diagnosis is lower among Indigenous women [12]. This parallels cancer burden more broadly, which in Alberta in the past decade has reached as high as 20 times the incidence compared to non-Indigenous populations [4]; with recent reports indicating cervical cancer among First Nations and Inuit women in the province is 2.3 times higher than among non-First Nations and Inuit counterparts [5]. While data on HPV vaccine uptake among Indigenous people is lacking (e.g., [13]) and while the impact of vaccination according to variability in rates of uptake remains speculative [14], there is evidence to suggest that vaccination is lower in Indigenous populations [15]. These data suggest that there may be barriers to care at distinct levels of prevention and treatment, driving disparity in cervical health outcomes for Indigenous people. Policy guidance that addresses health inequities is urgently needed to optimize HPV vaccination rates, thereby decreasing HPV-related illness and its sequelae, including colposcopic/surgical procedures and chemo-radiotherapy.

Developing an effective strategy to increase HPV vaccine uptake requires partnership with Indigenous communities, as well as recognition of their diversity and unique determinants of health. In particular, what do affected communities know about HPV and its health impacts? How (and how well) have healthcare providers and systems reached this diverse population for sexual health promotion? And, what insights might communities have for improving preventative care? This article addresses such questions, focusing on a specific Canadian Indigenous population, First Nations (FN) people within the province of Alberta. FNs are not only descendants of the original inhabitants of North America, but as nations form administrative units and function with official status recognized by the federal government. The stakeholders in this project included primarily Elders from FN communities; FNs encompass a population of approximately 118,000 people in Alberta, representing 14% of FN people in Canada [16]. Elders are individuals recognized in distinct ways by their communities as having accumulated knowledge and skills with which they mentor and/or lead others for the benefit of their culture and communities [17]. Their perspectives were gathered at an event that took place in 2017 to inform the EHVINA initiative, a university, health services, and First Nations partnership aimed at Enhancing HPV Vaccination In First Nations Populations in Alberta.

The current study contributes to a larger EHVINA project goal of identifying and validating known barriers and supports to HPV vaccination among FN people in Alberta. The EHVINA study also aims to establish baseline HPV vaccination rates among people living in FN communities in Alberta, as existing data are fragmented. Many FN communities in Alberta have been allocated at least one ‘reserve’ (i.e. a geographic area designated for use by a FN).¹ While the Alberta provincial

government tracks childhood vaccine uptake off-reserve [18], only recently have the provincial government and some FNs (i.e., 3–4 of 48 FNs in the province, which encompass a total of 140 reserves communities) begun to link it to data on vaccines delivered to populations on reserve (see **Box 1: HPV Vaccination in Alberta**). Findings reported here will contribute evidence around barriers and supports to HPV vaccination identified by community members, helping to inform the development of evidence-based, theory-informed, and context-sensitive/population-based intervention strategies [19–21]. Findings may also provide relevant information for jurisdictions in other geographic regions with large Indigenous populations. The upstream, community-oriented social determinants approach employed here is aligned with recent findings by the Truth and Reconciliation Commission (TRC) of Canada, specifically Call to Action number 18 of 94, which states that “the health of Aboriginal peoples is [recognized as] a direct result of previous Canadian government policies” [22]. Among Canadian government policies that affect Indigenous health is the residential schools system that, for most of the twentieth century, forcibly removed Indigenous children from their homes and communities with the intent of assimilation [23].

1. Methods

In order to ensure EHVINA's alignment with community experiences and perspectives on cervical cancer, in June 2017 the team brought together partnered FN knowledge holders and the research team. Insights learned from FN community members who attended the gathering (i.e., Elders, health directors) form qualitative data shared here. The narrative and exploratory nature of findings are relevant to health services and

Box 1 HPV Vaccination in Alberta.

Vaccines preventing HPV infection have demonstrated long-term effectiveness and acceptable safety profiles (2), also preventing other cancers, namely HPV-associated vulvar, vaginal, penile, anal, and oropharyngeal (i.e., mouth and throat) forms (3). In Alberta, the Gardasil vaccine has been provided by the province through a school-based program to grade 5 girls since 2008 and boys since 2014, with a catch-up for un-vaccinated peers in grade 9. Health Canada, which is the federal department responsible for food inspection, pharmaceutical patent review, as well as public and FN health provision, funds the vaccine to FN children living on reserve. National HPV vaccination strategies have reduced the incidence of associated sexual infections, such as genital warts, but at lower rates in Indigenous populations (76% versus 87%, respectively) (7; 8). This is related, at least in part, to decreased likelihood that on-reserve children will be vaccinated. As cervical cancer is a recognized problem in FN communities, designing and implementing effective intervention strategies to increase HPV vaccination rates is critical to addressing this disparity.

¹ From the Canadian Department of Justice: <http://laws-lois.justice.gc.ca/eng/acts/l-5/page-1.html?txthl=tract+lands+land#s-2>.

policy research [24], particularly for generating new hypotheses around barriers and supports to vaccination, framing context for critical appraisal [25] of existing best practices and identifying needed changes within healthcare delivery [26].

The event was preceded by a 2015 partnership development meeting that focused on establishing an advisory relationship with key Elders. In June 2017, FN Elders and health directors who were invited to participate were from 6 partnered communities; these were identified and mobilized by the Alberta First Nations Information Governance Centre (AFNIGC), an EHVINA project co-lead. The AFNIGC is mandated by Alberta FN people, through their elected Chiefs, to create safe ethical space for FN data [27], where communities have greater control over who has access to their data for research purposes. The organization works with FN people to promote data sovereignty and advocates for sustainable and transformative research. The 2017 gathering brought together knowledge holders from communities in all three of Alberta's Treaty territories (6, 7, and 8) and from Blackfoot, Stoney, Dene/Sarcee, and Cree cultural backgrounds.²

1.1. Recruitment

Recruitment to the one-day event involved invitations to FN Elders, health service directors and community leaders across 48 FN communities in Alberta with connections to the AFNIGC; these connections were established principally through a recent cancer prevention initiative. AFNIGC community liaisons advised participants of the research team's intentions for inviting them to this gathering, prior to arrival. All consenting participants ($n = 24$), whose voices are included here, self-identified as Indigenous (unless otherwise specified); and originated from Cree, Dene/Sarcee, Stoney Nakoda, and Blackfoot cultural backgrounds. Only three were men, with the majority indicating that they were grandparents. Out-of-town attendees were compensated for travel and accommodation; breakfast and lunch were provided to all. An information package about the event was provided to participants, and voluntary, informed consent was sought from each.

1.2. Data collection & stewardship

The gathering took place on FN land, at the Grey Eagle Resort on the Tsuut'ina First Nation adjacent to Calgary. It began with an opening prayer, followed by an address by the Operations Manager of the AFNIGC. Three presentations by health service providers followed—one by a gynecologic oncologist who treats patients with cervical abnormalities, one by a pediatrician who advises families about HPV vaccination, and one by a FN nurse with experience delivering the HPV vaccine on reserve—to inform participants about existing research regarding cervical cancer screening and prevention. Each presentation was followed by a brief discussion, in which participants were invited to speak and ask questions. Participants were then separated into two groups with approximately twelve participants in each, and participated in three rounds of 'sharing circles', addressing sequential questions that had been developed with guidance from the team's Elder Advisors. Sharing circles are a comparable method to qualitative focus groups, though they differ in the inclusion of strategies to honour values common in many Indigenous contexts, such as diminishing hierarchy by allowing all participants the opportunity to speak in clockwise or counter-clockwise order for as long as they wish without interruption [28]. Sharing circles are considered safe spaces in which to share knowledge, such

as through stories, that address spiritual and emotional aspects of daily life, in addition to mental and physical well being [29]. The process of exchanging information in small groups facilitated a strengths-based, realist approach to eliciting stories about drivers of HPV infection in FNs and opportunities for enhanced prevention. The three sharing circle rounds focused on:

- 1) What may have contributed to a higher burden of HPV and cervical cancer in FN Peoples?
- 2) How have FN communities been supported or not supported/hindered in preventing cervical cancer?
- 3) How is information about the HPV vaccine and ways to prevent cervical cancer delivered and shared within FN communities?

Research assistants sat outside two simultaneous sharing circles transcribing all contributions verbatim. The research assistants also took note when occasional statements were made in Indigenous languages and then translated by the FN facilitators into English; whenever a participant requested that his or her words not be recorded, transcription ceased. All transcripts were saved directly to USB keys, deleted from computers, and immediately transferred to the AFNIGC, who maintained stewardship of the data to ensure ethical access by research team members and collaborative analysis.

1.3. Analysis

Transcripts were independently coded in three rounds in NVivo 10 software by two researchers, including an AFNIGC research associate with a bachelor's in biomedical sciences (CH) and a PhD-trained social scientist (RH). An Indigenous PhD-trained nursing scholar (AL) and a gynecologic oncologist (GN) joined in meetings to facilitate agreement on coding and relevance for practitioner audiences. A phenomenological thematic analysis was employed [30], with initial coding for emergent themes informing discussion and review of data until agreement was reached on a framework for systematic coding. Decolonizing [31] and post-colonial theory guided analysis [32], prioritizing FN voices throughout the research process, emphasizing practice-oriented impact, and affirming a trauma-informed attention [33] for how colonization shapes health and healthcare experiences [34]. A first round of analysis produced three prominent themes for deepened consideration, elaborated in sections below as: 1) the need for a trauma-informed lens (see Box 2: Trauma-Informed Lens), 2) the role of family and community ties, and 3) adapting to a changing information landscape. Subsequent analysis focused on identifying supports and barriers to HPV

Box 2 Trauma-informed lens.

The notion of a **trauma-informed approach** is borrowed here from healthcare literature (1) on skills that support services for individuals and groups having endured significant adversities. A trauma-informed approach is not itself meant to be therapeutic, but orients teams (in this case researchers) to awareness of trauma, its impacts on mental health, substance use, and coping strategies, as well as the importance of collaboration, consent, trust, and safety. As an analytical lens, it draws attention to the prevalence and legacy of historical and cumulative adversities within Indigenous settings as social drivers of negative health outcomes. The AFNIGC's partnership on the EHVINA initiative enhances capacity to apply this lens, by highlighting FN perspectives on their own resilience in the face of trauma, shifting focus away from deficits alone, while not shying away from addressing challenging evidence.

² Treaties between the Government of Canada (or the British Crown) and Aboriginal (increasingly referred to as Indigenous) people are solemn, legal agreements that set out promises, obligations and benefits for both parties. In recent centuries, treaties defined, among other things, respective rights of Aboriginal people and governments to use and enjoy lands that Aboriginal people traditionally occupied. From Indigenous & Northern Affairs Canada: <http://www.aadnc-aandc.gc.ca/eng/1100100032291/1100100032292>.

vaccination by contextualizing these within processes of colonization and social change; identifying impacts on screening, prevention, and treatment; and proposing solutions for enhanced community-driven prevention.

1.4. Ethics approval

Two health research ethics protocols were followed: the Canadian national *Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans* [35] and the Ownership, Control, Access and Possession (OCAP®) principles framework adopted by the First Nations Information Governance Centre in Canada [36]. The Health Research Ethics Board of Alberta Cancer Committee (HREBA—CC) granted ethics approval and work was executed with AFNIGC guidance and partnership.

2. Results

The themes below contextualize the impact of colonization and social change on women's health, including impacts on screening, prevention, and treatment practices, as well as possibilities for enhancing community-driven prevention.

2.1. Cancer & HPV experiences

Awareness of cancer and its burden was high among this group, with many in the sharing circles reporting they had lost family members to cervical, breast, or stomach cancers. Some participants were familiar with the disease's capacity to progress: "Once they corrected the cervical cancer you would end up with cancer somewhere else" (SC2). Despite a sense of growing incidence, participants described cancer as having an isolating effect on individuals, being difficult to talk about, and sometimes requiring great sacrifice for gruelling treatment. It took time for one family to realize that it was "not just happening to them, it's the whole community" (SC1). A sense of increasing cancer prevalence emerged in stories about how Elders used to describe it and about memories of first encounters. Loss of function due to demanding treatment regimens also emerged. Cancer was seen to impact more than physical health, but also a spiritual struggle; several survivors attributed their wellness to family love and support.

Explanations for the causes of cancer and experiences with treatment were predominantly inflected with doubt and mistrust of influences external to communities: "It must be the pesticides that are being sprayed on our cultivated land...You can see our area and there is a layer of dust in spring and harvest" (SC1). Cancer was also likened to the emergence of other epidemics (e.g., diabetes), both well documented through modern science and perceived by FN communities and people themselves. A connection was also made with disruption of community relationships caused by the residential school system, and further disruption with recent litigation seen to have "Opened a whole can of worms; when all the illness and substance abuse went on a skyrocket" (SC2). In both sharing circles, participants argued that residential school litigation broke students' capacity for intimacy throughout their lives, playing out in self-destructive coping strategies (e.g., substance dependence, early sexualization) and increased risk of victimization. Speaking of a sister in the end-stage of cervical cancer, one middle-aged participant attributed the illness to chronic sexual abuse: "There were a couple times she had STIs [sexually transmitted infections] and didn't really know, may have been HPV or may have been another" (SC2). Recognizing a complex sequence of risks that may heighten vulnerability, the participant ensured that her daughter received the HPV vaccine at school, wishing only that it had been available sooner.

Table 1 illustrates the inter-related nature of perspectives shared on cancer, HPV, and causes. The right-hand column summarizes the analytical lens applied in order to link contextual factors to prevention, screening, and treatment practices, and key messages for improved prevention.

2.2. Trauma-informed lens

The first speaker in one circle began by describing the breakdown of intimacy brought on by residential schools. She was responding directly to the question of what may contribute to higher burden of HPV and cervical cancer among FN people: "Our people are starving for affection, support, respect and love." (SC2). Such needs are an effect of disrupted relationships resulting from the Canadian government's efforts to forcibly remove children from their families and communities throughout the twentieth century, and the resulting loss of traditional practices like family involvement in preparing for and arranging marriage. Residential school survivors in the circles recalled nuns repeatedly reminding them that sex was bad: "The nuns make sure to remind you no matter what you do, you're going to hell" (SC2). Residential schools were also described as having suppressed talk about sex and the communication of important knowledge about sexual organs: "We were taught to be quiet about our private parts...a lot of sexual abuse went on, and spiritual, physical, you name it" (SC2). Participants noted that such admonishment made it hard later in life to feel as though they could talk about sexual health with children and grandchildren, even though grandmothers and grandfathers of earlier generations were remembered as being open with their granddaughters and grandsons (respectively) about caring for their bodies. One mother described overcoming the awkwardness with her then adolescent daughter by insisting that the daughter use condoms. In the end, "She got an STI because she was taken advantage of" (SC2) by someone other than her partner. The mother connected her daughter's exposure to loss of identity and heavy drinking at parties in her community. She also attributed heavy alcohol consumption among some sectors to unresolved grief among residential school survivors; lowered inhibitions brought on by alcohol, and illicit drug use were seen by several other speakers to have become normalized among younger generations, who "see the suffering of their parents and grandparents, and they are running to the substance abuse" (SC1).

One speaker brought these lingering effects of residential schools together by describing a shift in her society from monogamous relationships to relaxed sexual boundaries, noting that with her own daughters she "didn't lay down the law like our parents did" (SC1). Recalling his time as an elected community leader a decade earlier, another participant explained that many in leadership positions are aware of these processes, as statistics indicate that more and more youth are entering the criminal justice system and correctional institutions, as well as many young women who are not completing their secondary education due to adolescent pregnancies. He observed that such statistics reflect disrupted connections between partners, between Elders and youth, as well as with nature and spirituality: "We are not islands, we need to be connected to people and that is what is missing" (SC2). Colonization and the multi-generational impacts of trauma further undermined connectedness at a community level, with "poor housing, overcrowding, and addictions" (SC2) common in some reserves. Alluding to chronic underfunding of on-reserve services by federal agencies, one speaker noted that in some communities "Three or four families live in one home, and that is hard for the children, for positive living" (SC1). Another argued that, in such contexts, health promotion is less of a priority when "Our priority is food, our next fix, how are we going to feed our children" (SC1). In both circles, speakers expressed compassion for younger generations today: "It was a lot easier in my time because we would go to ceremonies...but today, our grandchildren are exposed to drugs, alcohol, everything" (SC2).

Tracing the impacts of such processes does not immediately lead one to HPV or cervical cancer. One participant explained that it was only in the 1990s that community members appreciated how substance misuse—especially during pregnancy—may lead to negative health outcomes among youth. She described how, as an early childhood educator, she learned from physicians and others about fetal alcohol spectrum disorder (FASD). In her view, that was the first impetus, together with

Table 1
Analysis grounded by cancer & HPV experiences.

Quotes	Emergent themes	Prominent themes
<p>“People back then were healthy... They were always on the move and they were healthy. They had to move because they were hungry. They had to find their food from sunset to sundown... No one had big stomachs like this back then. They were fit. I remember a few of the Elders were telling me this, if they saw someone with a big stomach they were surprised and it was not acceptable... It looks like the man is pregnant... And the first time I heard of cancer was when my grandmother had cancer and she was older but not really that old, early 50s...It was worse back then... Horse team, dog team, and that was the mode of travel... In order to get [to the nearest hospital], the dog team or horses took maybe a day. I remember a plane landing there and I didn't know what was wrong and they told me she had cancer. So she got taken [away]. I remember she came back once to visit for maybe a day or two and then they take her back, and after that she passed on, and they didn't bring her body back. They buried her at St. Albert.”</p>	<p>-Traditional activities, diet</p> <p>-Isolation</p> <p>-Loss & disconnection</p>	<p>Trauma-informed lens</p> <p>Crosscutting barriers & supports</p>
<p>“I am learning a lot in these workshops. My mother died of stomach cancer, my sister of stomach cancer. I had 5 girls, and 4 of them went through breast cancer. My oldest daughter, her cancer spread. When they were younger I made sure they all got their needles. But, you know, I have never had a workshop like this. If I get a cold, I can fight it off. When I got those needles, I was told I was able to fight the sicknesses; it won't kill you—that is what I was told. This is really good for my grandchildren; I will take this message home to my family. I have two nurses in my family, they probably know about it, but this is a really good thing I am still learning...[speaking in Cree] “I was worried the white people would not take care of us, but they have so far [group laughs]. We need to talk to young ladies about how to take care of themselves.”</p>	<p>-Family</p> <p>-Resources & structural supports</p> <p>-Parents & grandparents</p> <p>-Mistrust in healthcare providers</p> <p>-Role of Elders</p> <p>-Communication</p>	<p>Family & community</p>
<p>“Somewhere down the line we have to meet somewhere, we have to come to an agreement of Western ways and Native ways. It doesn't have to be [about] making money. The pharmaceuticals, the doctors, it's all about money. But from the Native people, we are humble and compassionate people, because we work from here [points to heart]. That's why we're still here, we didn't have any doctors. We have healers, we have traditional leaders. But slowly people are turning away from the traditional leaders, to science, to evolution, to atheists...But the young people are slowly coming back to the traditional. In Western society, they don't have a cure. There are early stages, but sometimes it's too late. We use lots of prayers, we use lots of ceremonies. Spirituality grows over the years. We need to meet the grandfathers at least half-way. You can't just carry people who don't believe. That's why we're given a mind and body. Just start to move a little bit...that's a start. This Elder had said that these times are coming, but he only came back [from cancer treatment] with an illness, that stuff comes with sickness, prayer is the only thing that is going to cure you. I'm not trying to tell you how to live your life, but you have to believe, you have to start somewhere. The science is good, but don't stray too far. Because maybe one day you will mix that [up] and that's your belief. The spiritual life, it will just be a memory. That was not long ago back then.”</p>	<p>-Youth</p> <p>-Traditional knowledge & spirituality</p> <p>-Values</p> <p>-New influences</p> <p>-Identity loss</p> <p>-Fear, anger</p>	<p>Changing information landscape</p>
<p>“One of the girls I used to visit got cervical cancer. She is very angry, she will not talk to me even though I give her support. She was told 3 years ago that she should get the tests and she didn't because she had problems for a long time.”</p>	<p>-Community</p> <p>-Inappropriate care</p> <p>-Parents/children (family)</p>	
<p>“We never see a doctor. The health department has to get a hold of us, the ones that are never home. There are a lot of us in the community... We hear suddenly of these workshops and information centres in the community. We wanted to go but we had other commitments so needed others to go. My niece, she died about 3 years ago because she had cancer. They brought her to Edmonton, they started her on chemo...left her kids at home.</p>		

the emergence of HIV, to frame a community health strategy to reduce blackout drinking and to educate community members about the risks associated with uncommitted sexual relationships. One such consequence [of these changes in behaviour has been an increase in Indigenous children apprehended by the child welfare system, “It's sad to say that lots of babies have been taken because their mothers were on opium, and the mothers are in treatment and are so sorry” (SC2). Those in the child welfare system were described as having few supports to learn anything about their own bodies, let alone to have anyone following up whether they receive the HPV vaccine within school-based programs. One grandmother found the situation of foster children particularly troubling, noting that their extended separation from family and community seems to increase likelihood for risk-taking behaviour (e.g., heavy drinking, illicit drug use, reduced inhibitions): “A lot of those kids when they come back to the reserve they are very angry, there are a lot of things that happened [to them] that we don't know about” (SC2). One speaker, who had recently completed a Master's in community health on Indigenous women's experiences with HIV and pregnancy summarized four factors contributing to greater HIV burden in FN **Box 2** (see **Box 3**): shame, stigma, fear, and early sexualization.

Key messages generated by applying a trauma-informed lens to the sharing circles highlight that many of the negative factors contributing to HPV infection are not cultural, but result from the accumulated effects of colonization. Therefore, the burden of HPV in FN people is rooted, at least in part, in efforts by people across the lifespan to cope with the violent disruption of family and community connectedness, as well as connection to land and spirituality. This burden is manifested not only in risk-taking behaviour, but also in avoidance of wider health systems:

“I think First Nations don't get checked when they are supposed to, to be honest. They just wait until it is too late to help them” (SC2). Many of the Elders in attendance welcomed new information about the health of their communities and prevention strategies, hoping to play a greater role in preparing children for the world they will live in. The Elders emphasized the importance of their own involvement in prevention, as individuals who “know our culture, know our people” (SC1).

Box 3
Stigma, Shame, Fear & Early Sexualization from Tina Nash, MSc.

There is internalized shame and guilt. Guilt is: “I made a mistake.” Shame is: “I am a mistake.” Generations of carrying that shame and being exposed to that shame has exposed us to these situations such as promiscuous relationships and sexual violence and not taking a stand against those things. Stigma of what people think of [women], internal stigma about what we think of ourselves, and then the layered stigma of being a woman, and then an Indigenous woman, and then stigma of being an Indigenous woman with an STI. The fear comes from not knowing the outcome of HPV or cervical cancer and what may happen to me. The early sexualization, I see this in my children, I see them watching music videos and women being sexualized and they are not honoured as being the creators of life, and the same with video games. The early sexualization sets them up to be in unhealthy relationships.

2.3. Family & community

Many of the Elders emphasized that health education within Indigenous contexts is anchored in the love and care for children. For one speaker, this affection involves *“hugging your children and telling them ‘I love you’, you don’t say goodbye to anyone”* (SC2). Coming from a communal society, another participant observed that today many struggle *“to fit into an individualistic society, and we don’t fit”* (SC1). The legislated prohibition of ceremony throughout the early half of the twentieth century was seen to have affected this intergenerational sharing; in earlier generations, girls and boys would learn from Elders through ceremonies about sexuality and respect for their bodies. A younger speaker recalled learning in an off-reserve high school what she had already learned within her community at 10 years old. She valued her early exposure to sexual health education from her Elders, especially exposure within her Indigenous language—which she believed strengthened the sense of commitment to one another and the weight of the message conveyed. Another participant related the role of traditional teachings about respect, honour, and truth that connect youth to older generations—at the heart of which it was noted—are healthy relationships built on mutual trust.

Family and community were observed as supportive of knowledge and education. One elderly couple had taken it upon themselves to visit families in their communities to convey what they had learned in events such as this gathering: *“[My husband] goes and sits with the men and teaches them; for me, I can go out and explain things to the mothers and the children, and out of respect...he’s getting that message across [in his sweat lodge ceremonies with men]”* (SC1). The involvement of men was considered key to several speakers, in transmitting messages of respecting women’s bodies, and in regaining and celebrating the role of all parents as community educators and leaders. These speakers also emphasized that effective prevention depends on building trust, which requires spreading the word orally, and being prepared to sit with people to answer their questions. Several speakers cautioned that some families avoid facing hard truths about sexual and community health. While lack of education may play a role, speakers observed guilt as well in avoidance of health providers: *“If I’m drinking and drugging, then I’m going to feel guilty about taking my children to the clinic to help them live a healthier life”* (SC2). Here, the challenge was not just in encouraging the dissemination of scientific knowledge, but in building relationships: *“We need to talk to our people in a way they understand, no disrespect to any organization, but people don’t look at that material [brochures], it’s obvious that the way we deliver that message has to be different”* (SC1). She had started her own initiative, providing workshops at the health centre to get messages across about sexual health. She focused on sharing knowledge within the general community population, to reduce stigma reinforced by attendance at a clinic.

Several speakers reflected on their experiences with HPV vaccination specifically, highlighting gaps in strategies that depended on written materials alone to raise confidence in the vaccine. One mother explained that when her daughter was due for it, *“The health centre sent out a notification and a consent form, and they listed the benefits and risks...and I paid more attention to the risks, and I decided not to allow her to be vaccinated, because as a parent I needed to do what was best for my children”* (SC1). After the morning presentations at the gathering, she concluded that her health centre had not engaged in sufficient education or follow-up. Also, given that she was new to her community, she had concerns about trust and confidentiality, which she felt might have influenced her decision not to have her daughter vaccinated.

Other participants experienced more support, though invariably from within the community and among youth themselves. Participants described children as educators of one another: *“There are anti-bullying programs...and there are cultural programs; some kids are brave and some are afraid of getting immunized, but all the children support each other”* (SC2). This supportive environment among youth receiving the vaccine was encouraged in some communities by celebrating the event of

vaccination itself, with a meal and acknowledging the support that youth provided to one another. Nevertheless, some speakers were disappointed to learn after the fact that their grandchild had been vaccinated, sensing that they had lost an opportunity to discuss with the youth issues related to sexual intercourse, to foster the kind of openness between generations believed to be protective of health. These participants believed that health providers or teachers could provide some education, but that *“The best teachers are your parents”* (SC2), as long as parents (and grandparents) are equipped with information. One [grandparent?] felt that there was no support extended to these: *“This is the first time I have heard about HPV”* (SC1). Meanwhile, others could appreciate that it might be difficult from a school’s perspective to educate in detail all families about HPV, but these speakers proposed that school-based programs alone were not entirely effective, and instead require outreach to older generations as well, *“to get the word out”* (SC2).

In proposing recommendations for improved prevention, participants noted that not all FNs are the same: *“Every community has their own personality”* (SC1). Many were described as fighting among themselves over religion, between traditional practices versus Catholicism versus born-again Christianity. Religious difference led to caution that messaging about sexual health be non-denominational, and that any strategy that connects to traditional practices also recognize that some people are no longer traditional. At the same time, the integration of Indigenous languages in messaging was considered by speakers young and old to be empowering. Indeed, a message in a traditional language could call one to attention even if one did not speak it. The importance of verbal forms of education was among the strongest themes, underscoring that prevention without relationships would be unlikely to improve HPV vaccine uptake or related health outcomes.

2.4. Changing information landscape

Earlier generations were seen to not have had as much access to healthcare as youth today, *“These young people are lucky to get these different resources...it’s scary when you think about it, you didn’t think about [the health risk] before, because you didn’t know anything about it”* (SC1). Becoming informed felt empowering to several grandmothers, who recalled their own grandmothers teaching them how to take care of their bodies. They still desired new information, to better understand and teach anatomy and to share accurate information about viruses from a traditional approach.

New possibilities for knowledge sharing were not without problems, as several speakers expressed concern that young people today are too open about their bodies and even immodest on social media. Such platforms (e.g., Facebook) perplexed some Elders, who were surprised that youth could share private information so publicly, but at the same time feel awkward when a grandparent tries to talk to them about sexual protection. Television commercials advertising prescription drugs for improved sexual performance were another unwelcome influence. One troubled grandmother considered publicity of this sort to convey a message that sex is only about one’s own pleasure, and not about relationships and respect. Describing how her children and grandchildren gather every Sunday evening for dinners, she explained that she regularly takes these gatherings as opportunities to convey counter-messages of her own.

Even those with access to contemporary resources for health promotion had questions that often went unanswered. One health director who was herself FN had not approved the HPV vaccine for her own daughter, believing at the time that vaccines are perhaps *“not natural, that they are more chemicals given by the government to hurt us”* (SC1). This perspective highlights mistrust in health systems even among Indigenous providers, some who may feel that health promotion is just impersonal and un-invested in one’s actual health, where *“doctors just throw stuff at us, so many papers [brochures]”* (SC2).

Frustration with health provider dependence on written materials to educate community members echoed the importance of oral transmission of knowledge in FNs. Proposing a shift toward oral forms of health promotion, each sharing circle wound up proposing the possibility of enhancing prevention via short educational videos. The idea grew with discussion, with speakers envisioning videos that feature different Elders speaking using traditional languages, as well as English, and sharing accurate and respectful illustrations of the body. The videos could be a mechanism to equip parents and grandparents with information for educating youth, while also embedding traditional knowledge and language to catch people's attention. The idea was particularly appealing in these circles given the perceived mobility of videos, as these could be passed around on DVDs and posted on the Internet. The technology was also seen as adaptable for diverse populations within communities (e.g., Two-Spirit, Elders, youth) with unique perspectives on HPV and its impacts.

Locating opportunities for mobilizing supports and addressing barriers to HPV vaccination in FNs, Table 2 is a first step in the EHVINA initiative's efforts to map community perspectives onto evidence-based, theory-informed, and context-sensitive intervention strategies.

2.5. Limitations

This was not a population-based cohort, as members from only 6 partnered FN communities attended, while representation of Elders and health directors from each was uneven and predominantly women. Though unaddressed here, the EHVINA team aims to fill a gap in quantitative information about actual HPV vaccine uptake in FN communities in Alberta. Additionally, the absence of youth voices was noted at the gathering, which occurred during school hours.

Table 2
Emerging barriers & supports to HPV vaccination in FN communities.

Scale	Barriers to HPV vaccination	Supports for HPV vaccination
Services	Under-funding of on-reserve services Limited sexual education, primarily text-based Widespread avoidance of health & social services Child welfare separation from community & associated adversities; lack of follow-up	Sexual health education often comes late Guidance of service appropriateness by Elders Verbal modes of knowledge transmission Equipping parents & grandparents with information to support outreach
Community	Repressed sexuality from residential schools Reduced Elder involvement in education Disrupted relationships to nature & spirituality Poverty Denominational tensions between religious faiths	Involvement or mentorship of family in choosing & respecting partners Grandparent support Indigenous language (strengthens commitment) Audio-visual technologies
Family	Broken family relationships/loss of connectedness Move away from monogamous relationships Over-crowding, hunger	Love, care & trust extended openly to children
Individual	Negative coping strategies for life adversities Substance misuses & reduced inhibitions Increased victimization (e.g., sexual assault) Early sexual experiences Social & popular media that reduces boundaries/privacy (e.g., Facebook)	Meaningful relationships (with parents, Elders, mentors, peers, land, Indigenous language, etc.)

3. Discussion

The voices shared here highlight a need to address healing from colonization's disruption of family and community connections, where traditional ties between youth, their parents, and grandparents may offer possibilities for enhanced HPV vaccine uptake. The involvement of men emerges as an important component for communities in regaining control over sexual health promotion. School-based programs appear not to tap into the resource of inter-generational educators within communities who, by way of inter-personal outreach and in audio-visual media, could complement written materials. Some authors here observe a recent shift in the United States to anchor HPV vaccine education in cancer prevention, which may be a means of broaching sexual education despite sensitivities and lingering traumas around sexual abuse in some FNs. Nevertheless, future efforts to develop materials, curricula, and community champions through the EHVINA initiative must continue culturally-competent and safe engagement to test impact in diverse FN contexts and ensure that messages about vaccines and the diseases that they prevent are locally appropriate.

The tendency of Western research is to compartmentalize knowledge and information which may be related to 'ownership' of knowledge and information. This approach toward knowledge and knowledge generation becomes apparent by analyzing the structure of health organizations, healthcare programming and service delivery and even healthcare provider disciplines, such as oncology. Wilson [37], a First Nations researcher and scholar states that research with Indigenous peoples must be able to capture the interconnectedness of people to each other, the environment, the past and future, as well as the spirit world. Wilson further explains that the way Indigenous people experience the world is inherently complex, managing Indigenous interconnectedness while living in the dominant culture; therefore, research with Indigenous peoples must counter the dominant academic practice of fragmenting, simplifying and decontextualizing knowledge. These perspectives toward knowledge and knowledge generation are viewed as disrespectful or without honour for Indigenous ways of being. In analyzing the information shared by FN participants during this event, the interconnectedness and relationships that emerged indicate a need for further exploration from within these contexts, such as the knowledge contained within traditional teachings and the exercise of traditional health and wellness practice and beliefs.

For healthcare systems, future research must address how acceptance of childhood vaccines may be enhanced in a respectful, trauma-informed fashion among diverse underserved populations. An unexpected insight from the gathering in this respect is the historical openness of FN Elders toward sexual health education and a desire to take up their roles as teachers and carriers of this knowledge, which has been repressed through European colonization. The call for greater Elder involvement falls outside existing public health practice, and highlights the need to evaluate the effectiveness of current strategies (e.g., pamphlet-based education) and whether these might actually reduce rates of vaccination. Insights from this gathering may challenge best practices in current programs, but are vital to optimizing HPV vaccination and improved health outcomes.

Conflict of interest

RAB discloses having received speaking fees from Three Rivers Area Health Education Centre for HPV vaccine-related presentations to healthcare providers.

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