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# Teaching tools to engage Anishinaabek First Nations women in cervical cancer screening: Report of an educational workshop

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## Abstract

**Objective:** To explore educational strategies for engaging First Nations women in Canada to attend cervical cancer screening.

**Design:** Within a participatory action research framework, semi-structured interviews with health-care providers in First Nations communities revealed that education about the value of screening is perceived as being a key factor to promote cervical cancer screening.

**Setting:** To obtain feedback from workshop informants, a 1-day educational workshop was held to identify appropriate educational intervention strategies, which would be applied in a forthcoming randomised controlled cervical screening trial.

**Methods:** Common discussion and discussion groups, which were facilitated by a First Nations workshop moderator and a note taker.

**Results:** This workshop helped to strengthen the ethical space dialogue with the First Nations communities with whom the study team had established research partnerships. The workshop atmosphere was relaxed and the invited informants decided that an educational health promotion event for community women needed to be held prior to inviting them to the cervical screening trial. Such an event would provide an opportunity to communicate the importance of attending regular cervical screening allowing women to make informed decisions about screening participation. Complementary promotional items, including an eye-catching pamphlet and storytelling, were also suggested.

**Conclusion:** The key messages from the events and promotional items can help to de-stigmatise women who develop a type of cancer that is caused by a sexually transmitted virus that affects both men and women. Developing and implementing positive health education that respectfully depicts female bodies, sexuality and health behaviours through a First Nations lens is strongly warranted.

## Keywords

Canada, cervical cancer screening, educational strategies, First Nations women

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## Background

Since the introduction of cervical cancer screening with the Papanicolaou (Pap) smear, rates of cervical cancer incidence and mortality have been declining in countries where this test, in combination with follow-up management support, is used in screening programmes. One of the earliest cervical cancer screening programmes started in British Columbia, Canada, in 1949 (Anderson et al., 1988). Overall, in Canada, between 1955 and 1974, the crude incidence of cervical cancer declined from 28.4 per 100,000 women aged 20 years or older to 8.6 per 100,000 (Canadian Task Force, 1976). Nevertheless, cervical cancer remains the third most common cancer among Canadian women aged 29–40 years (Public Health Agency of Canada [PHAC], 2002).

Compared to the general population in Canada, First Nations women have lower rates of screening and follow-up (reviewed in Vasilevska et al., 2012). Consequently, their incidence and mortality of cervical cancer is considerably higher than that of the general Canadian population (Colquhoun et al., 2010; Corriveau, 1999; Marrett and Chaudhry, 2003; Nishri et al., 2015; Young et al., 2000). Among the First Nations and Inuit in Canada, three key areas have been identified that influence women's willingness to access cervical cancer screening programmes. First, women want more information about how Pap tests are performed and why they were necessary (Cerigo et al., 2012; Deschamps et al., 1992; Hislop et al., 1996; O'Brien et al., 2009; Steven et al., 2004). The information provided often focuses on a diagnosis of cervical cancer, where women fear and hence act as a deterrent to screening (Black, 2009; O'Brien et al., 2009). Also, the women were concerned about not hearing any screening results from their health-care provider, good or bad (Deschamps et al., 1992). Second, a trust or support-based relationship between the woman and her health-care provider was identified as critical due to the history of marginalisation of Canada's Indigenous peoples in encounters with institutions and the intimate nature of the examination (Black, 2009; Deschamps et al., 1992; Hislop et al., 1996). Emotions such as embarrassment, shyness and shame are frequently associated with Pap test experiences (Cerigo et al., 2012; Deschamps et al., 1992; O'Brien et al., 2009; Steven et al., 2004) and may prevent many women from getting screened. Such feelings were exacerbated with either a male health-care provider or with a high turnover of health-care providers (Calam et al., 1999; Cerigo et al., 2012; O'Brien et al., 2009; Steven et al., 2004). The confidentiality of clinical encounters involving cervical cancer screening was of significant concern to the women studied (Black, 2009; Calam et al., 1999; Steven et al., 2004). Third, a tension between traditional worldviews and Western medicine, in terms of ideas about the body and privacy, has been described (O'Brien et al., 2009). The Western concept of preventive medicine is not well understood in the traditional Indigenous framework, where a more holistic approach to health and the promotion of well-being for self and community is more acceptable (Hislop et al., 1996; O'Brien et al., 2009; The Saint Elizabeth First Nations, Inuit and Metis Program, 2012).

Demographic, psychosocial factors and knowledge about the disease are all influential in deciding whether or not a woman is screened for cervical cancer (Gillam, 1991). Educational strategies as positive stimuli aimed at increasing uptake of cervical cancer screening are widely described in the literature. The largest body of evidence pertains to underserved communities in the USA and in particular Latina women (Bullock and McGraw, 2006; Giarratano et al., 2005; Hunter, 2005; Kepka et al., 2011; Luque et al., 2011; Rudolph et al., 1993; Suarez et al., 1993), Southeast Asian immigrants (Mock et al., 2007; Nguyen et al., 2006; Rudolph et al., 1993; Suarez et al., 1993; Taylor et al., 2002) as well as Black women (Bullock and McGraw, 2006; Cates et al., 2011; Giarratano et al., 2005; Wetzell et al., 2007; Yancey et al., 1995) with low literacy, limited knowledge of English or low rates of medical insurance. In contrast, there are limited data on educational strategies targeting Indigenous communities specifically. Such data largely are

derived from studies in American Indian, Alaskan Native and Native Hawaiian communities from the USA (Chrisman et al., 1999; Christopher et al., 2008; Dignan et al., 1996, 1998; Kulukulualani et al., 2008; Pardini, 1996; Strickland et al., 1999) and Aboriginal communities in Australia (Bethune and Lewis, 2009; Read and Bateson, 2009; Reath and Usherwood, 1998). These studies have primarily made use of participatory action research (PAR) to identify the most effective message and means of delivering that message (Bethune and Lewis, 2009; Chrisman et al., 1999; Christopher et al., 2008; Kulukulualani et al., 2008; Strickland et al., 1999). In some studies, lay health workers from the community have educated women (Dignan et al., 1996, 1998; Pardini, 1996; Read and Bateson, 2009; Reath and Usherwood, 1998). Favourable short-term outcomes were obtained in all studies with regard to either increased understanding of the importance of cervical cancer screening or increased rates of cervical cancer screening in the women studied, respectively. However, long-term outcomes (i.e. continued screening and follow-up appointments by the woman after the study period has ended) have not been reported. Two studies have identified the critical need for education in cervical cancer screening among First Nations women in Canada (Black, 2009; Hislop et al., 1996), but to date, only one study has emphasised a need for education based on the principles of PAR specifically targeting this high-risk group (Morgan and Wabie, 2012).

Our ongoing cervical cancer screening study (Wood et al., 2014) fills this gap by using a mixed-methods approach in which First Nations women from Northwest Ontario, Canada, are actively engaged in cervical cancer screening. We postulate that increased screening uptake and follow-up of positive results would reduce the higher cervical cancer burden in First Nations women (Colquhoun et al., 2010; Corriveau, 1999; Marrett and Chaudhry, 2003; Nishri et al., 2015; Young et al., 2000). On the basis of qualitative research, for example, via interviews with health-care providers (Maar et al., 2013, 2014), we concluded that education about cervical cancer screening is a key feature to engage the women in the subsequent quantitative part of the project, a two-arm community-randomised controlled cervical screening trial. We responded to this finding by hosting a workshop for the interviewees to explore potential educational strategies prior to initiating the trial.

## Methods

### *Partner communities and study design*

The interdisciplinary study team with expertise in cancer biology, virology, epidemiology, medical anthropology, sociology and public health developed a PAR project in collaboration with 11 Ojibwa and Oji-Cree First Nations – Anishinaabek<sup>1</sup> – communities in Northwest Ontario, Canada, to promote cervical cancer screening in this population. The study team borrowed the concept of *ethical space* developed by First Nations scholar Ermine (1995, 2007), which involves an ongoing dialogue and collaboration between the study team and its First Nations partner communities. The process was started by the principal investigator (I.Z.) as a pilot study involving one First Nations community in May 2009 (Zehbe et al., 2011) and eventually led to the current larger study, which began in August 2011 (Zehbe et al., 2012). Formal research agreements were ratified between the political leadership of each participating First Nations community with the principal investigator and the sponsoring institution (the Thunder Bay Regional Research Institute). This mixed-methods project consists of a qualitative part with interviews and focus groups and a quantitative part with a two-arm, community-randomised controlled screening trial (ISRCTN84617261) as described in detail elsewhere (Maar et al., 2013, 2014; Wood et al., 2014). This study was approved by the Lakehead University Research Ethics Board (#038 11-12/ROMEO #1462079).

### *Continuing the ethical space process*

During informal 'Make Contact' visits with the communities' health directors and staff in spring 2010, the ethical space between partner communities and study team was substantiated through intensive dialogues and negotiations about research design, research questions, methods and planning for knowledge mobilisation (Zehbe et al., 2012). Originally, the study team did not intend to offer formal education as part of the screening trial to be conducted in the partner communities. Nevertheless, after interviewing community health-care professionals, the study team concluded that education about the benefits of cervical screening was crucial to move forward with the trial (Maar et al., 2013, 2014). In particular, the comment of one interviewee, conveying a desire to be *engaged* with the study process, sparked the idea of a special focus group – in the form of an Educational Workshop:

... it would be good to get the information through that focus group ... how best can we disseminate, how could we pull off a project, how could we best engage the community, is that, is that still part of your research?

In response to the above request, the study team hosted an educational workshop in October 2012 to discuss educational strategies to be implemented for the upcoming screening trial. This workshop focused on the benefits of cervical screening and on human papillomavirus (HPV), the main trigger of cervical cancer. Representatives from each participating community, who were previously engaged with the study through 'Make Contact' visits (Zehbe et al., 2012) and/or interviewed by the research team (Maar et al., 2013, 2014), were invited to elaborate on the concept of an educational intervention in the project.

### *Workshop participants*

Overall, 24 people participated in the workshop: 13 First Nations female attendees from the partner communities who held positions reflecting health, wellness or social work; 1 female workshop moderator; 1 White female research coordinator; 3 White female and 2 White male members of the study team; 2 First Nations women elders advising the study team; 1 First Nations male elder in charge of the smudging ceremony and the closing prayer; and 1 White female note taker, whose notes formed the basis for the quotes in the 'Results' section.

## **Results**

### *Setting and initiation of the workshop*

Held in a local cultural community hall, the day was more about the dialogue and interaction between the workshop attendees than a meeting structure based on a rigid agenda. We began with a traditional Anishinaabek smudging ceremony with the purpose of purification of the mind, body and spirit. The male elder led the smudge with meeting attendees and helped to create a welcoming and open environment for the meeting's proceedings. The workshop was facilitated by a female First Nations researcher from a Northeast Ontario reserve who affirmed that everyone who was invited to this meeting consented to discussing effective methods of cervical screening education. Her role was to guide the workshop participants (i.e. both the attendees from the First Nations partner communities and the study team members) through the day, so that all participants stayed at the same level. Having completed the fieldwork for the qualitative part of the project, findings from the interviews (Maar et al., 2013, 2014) were presented to the participants with a planned

brainstorming session scheduled for the afternoon. Possible reasons why First Nations women may not be adequately screened for cervical cancer were presented as lack of a recall system and transportation, socioeconomic inequalities, generational effects, colonial legacy, a shortage of appropriate health-care providers and, most importantly, lack of health education.

One of the participating community attendees commented on the impact of *colonialism* on First Nations women's sexuality as a barrier for cervical screening. Historically, First Nations women were highly respected for their roles as Givers of Life and for providing for their family. Resulting from the arrival of settlers to North America, First Nations women are considered inherently 'less worthy' than men and are managed and shamed by the 'powerful' men. This patriarchal portrayal of First Nations women has altered how women perceive themselves, their bodies, their health and their sexuality. Consequently, First Nations women may feel shameful, embarrassed or unworthy of cervical cancer screening:

Colonialism has affected how women view themselves sexually. We come from a society where women have a lot to say and receive a lot of respect. A paternalistic governing system does not respect women the same. Catholicism has influence – the priest dictates the role of women. Women who are married in a church are perceived higher than those not married in a church.

Another community attendee elaborated on the study team's point about availability of appropriate health-care providers and also commented on language barriers and health literacy among First Nations communities:

In my community, there are language barriers, with elders and speaking in layman's terms. How do you talk about cancer, how do you talk about cancer screening, how do you explain to Elders how to get screening?

She went on to stress that health-care providers must be able to communicate about cancer and cancer screening with different generations, in particular with elders, using a vocabulary and language that they understand. Without trust or open communication with their health-care provider, First Nations women may avoid the health-care system altogether.

### *Educational strategies*

When addressing community plans for HPV and cervical screening education, the meeting focus shifted from presentations led by the study team to a collaborative request from the community attendees about implementing the discussions from the meeting. Community attendees were split into four smaller groups to identify educational strategies to promote cervical cancer screening in their respective communities. The groups then presented their education work plan ideas in a plenary session. Meeting attendees brainstormed 'plans of action' for different teaching tools for potential use during the trial: educational sessions, promotional items, pamphlet or poster and storytelling or video.

Regarding educational sessions, the suggested approaches likened to successful programmes already in place in the communities: in the form of 'Lunch & learn' workshops or games like Bingo to inform eligible women (aged 25–69 years) about the forthcoming cervical cancer screening trial. These focused events would be reinforced with study promotion at existing community events such as Christmas parades, Valentine's or Mother's Day. Establishing a presence within the community was emphasised as a crucial way to gain trust of community members and to reach a wide audience with cervical screening education. To reach demographic groups beyond our trial cohort

and on a more long-term basis to sustain a screening culture, school demonstrations and attending elders' activities were also emphasised.

Branding the study was suggested as an important component for consistent community presence and engagement. By creating familiar images or messaging with logos and slogans, community representatives thought the study would create more cervical screening awareness and form a comfortable environment for discussion surrounding cervical cancer. Promotional material such as T-shirts, pens and buttons should be consistent in its message and capture the attention of different generations. Depicting First Nations women themes was deemed necessary to keep the attention of all audiences as mentioned by a community attendee:

... (T)o use an Aboriginal person ... whether they're in their regalia or not or just an Elder with their handkerchief on their head you know, it's, to see someone of their own and especially to have someone share their story about it.

One of the female elders – a previous cancer care worker – led the poster and pamphlet design group, and she presented the concept of a dressed First Nations woman on the front of the pamphlet and the woman undressed on the inside, with the reproductive organs labelled. She described that this idea of the dressed to undressed woman speaks to and respects the more conservative aspects of First Nations female culture and privacy. Also, by depicting a First Nations woman in the graphics, meeting attendees agreed that the material seems more relatable and appealing to a First Nations audience.

The other female elder suggested creating a contemporary version of a story that personally resonated with them, which could then be used to convey messages for health promotion. Described as the legend of Moessa (also known as Windigo in some First Nations communities), this story involves a personification of a threat to the community, which community attendees suggested could represent HPV or cervical cancer. The giant, Moessa, is perceived to be a threat, and the community must work harmoniously to combat this danger. The participant mentioned that most of the communities have their own variation of this story, but a modern twist on the storytelling method was essential for reaching the audience. A video that could be distributed to the different health centres and promoted on social media was suggested as a modern and feasible vehicle for communicating this story. The participant thought the Moessa story could be adapted to a short film while maintaining a traditional storytelling format. The story would also demonstrate how modern tools, such as HPV self-sampling, could be combined with traditional teachings, such as, Moessa and 'Grandmother Moon', to promote healthy behaviours.

After a detailed discussion of the educational strategies, the community attendees concluded that the study team offers educational workshops two months prior to invitation into the trial and reinforce these messages with print media leading into the trial.

### *Wrapping up the workshop*

Workshop participants specified action points and next steps for the project. Following the dialogue throughout the day, clear objectives and timelines were identified and agreed upon in that community attendees after the workshop (1) help the study team develop their educational material, (2) plan and prepare a health promotion event that was specific to their community needs and preferences and (3) provide a budget for the planned educational event.

The community attendees agreed to form a Community Steering Committee (CSC) to continue as community-based consultants for the remainder of the project, informing the educational strategies and the execution of the screening trial. They indicated that the parallel involvement of them

as primary care providers was particularly important in this project to encourage cooperation and to set the stage for translating the results of the study into practice. In addition, and as communicated previously during Meet and Greet visits, the study team confirmed the hiring of community-based research assistants (one in each community and paid through funding obtained by the study team) to take over most of the local responsibilities related to the forthcoming screening trial. The study team also committed to communicating a summary of the educational workshop discussions and the resulting tasks. The male elder performed a final prayer to close the meeting.

The majority of community attendees handed in evaluation forms about the day's events. They consisted of seven Likert scale questions and three open fields where the participants could communicate 'improvements', 'value' and 'suggestions' of the workshop. The feedback was ultimately positive: 'networking' was the outstanding remark as several responders commented that this communication was 'the most valuable' part of the workshop for them. The community attendees appreciated the opportunity to meet and brainstorm with their colleagues from different communities. The interactive tone of the day resonated well with all workshop attendees. The collaborative nature of PAR is an important ingredient for successful completion of the project. In particular, maintaining the flow of information and keeping an open dialogue was seen as highly valued by the community attendees. This workshop promoted the continuity and iterative nature of the educational process to health professionals and community members and was instrumental in shaping the trial design. In the meantime, the trial has been largely facilitated by the community-based research assistants, hired and supervised by B.W., as described in detail elsewhere (Wood et al., 2014).

### *Epilogue: creating a study name, a logo and a community-specific pamphlet*

After the workshop, the dialogue continued through teleconferences. The study team and the community attendees agreed upon a study name and logo to be included in the pamphlet and other promotional material. The study is now called the Anishinaabek Cervical Cancer Screening Study (ACCSS). A brand in the form of a unique, identifying symbol that speaks about the study's target, and Anishinaabek culture was also created. With the community attendees' input and the study team's idea to use a turtle – the Anishinaabek symbol of beginning with an analogy of good health for women – a local Anishinaabek artist was commissioned to provide a custom painting following the workshop, which upon obtaining copyright has been used for the production of promotional items such as T-shirts and letterheads (ACCSS, 2014).

For designing the study pamphlet, the study team had compiled a portfolio of relevant cervical cancer educational media already in use worldwide: posters, brochures, fact sheets and videos from Canada, the USA, Latin America, Australia and Asia. A preselected sample of these materials, which the study team had chosen due to their concise messaging and their culturally appropriate imagery and creative promotional strategy, was on display during the educational workshop (Alberta Health Services, 2011a, 2011b, 2011c, n.d.; Cervical Screening NSW, 2013a, 2013b, 2013c, 2013d; Government of Nunavut, Department of Health and Social Services, 2013; National Aboriginal Health Organization, 2009). Both parties agreed that the pamphlet should help to inform about cervical cancer screening facets in the particular context of First Nations women in Northwest Ontario – the benefits of cervical screening and the methods currently available for it as well as the fact that cervical cancer is related to an HPV infection and that both genders can contract this infection. Based on the discussions during and after the workshop, the trial pamphlet design was finalised and professionally designed by a local company using the turtle logo as central theme (ACCSS, 2014).



## Discussion

In this article, we have presented the outcome of an educational workshop held to receive guidance from health-care professionals representing the First Nations communities with whom the study team has partnered to conduct a project to engage First Nations women in cervical cancer screening. In particular, the study team was seeking feedback about culturally appropriate educational strategies to promote its forthcoming cervical screening trial. This work is unique since it is the first to address special educational needs to engage in cervical cancer screening using a PAR approach and, in particular, a vulnerable target population – First Nations women in a rural Canadian environment. The workshop was a successful continuation of ethical space, an approach that has formed the frame for the described project since it began 5 years ago (Zehbe et al., 2011, 2012). It was important to have this face-to-face interaction between the representatives from each partner community and the study team to find the best possible solution in a friendly, welcoming and trustworthy environment such as the one used for this meeting. It is noteworthy that the networking itself was something that the community attendees valued and saw as reaffirming the PAR process employed for this project (Wood et al., 2014). The pamphlet that resulted from discussions during and after the workshop has been carefully designed to capture all the items that are essential for a successful educational tool: First Nations women are more susceptible to cervical cancer; this type of cancer can be prevented by regular screening (either cytology or HPV testing); both men and women can be infected with HPV, the major cause of cervical cancer; the concept of the dressed and undressed First Nations woman of the pamphlet is culturally appropriate since it stems from the idea of a woman elder with many years of experience in cancer care who is also considerate of both cultures (ACCSS, 2014). While other studies have reported on educational material tailored for Indigenous populations in Canada (Alberta Health Services, 2011a, 2011b, 2011c, n.d.; Cervical Screening NSW, 2013a, 2013b, 2013c, 2013d; Government of Nunavut, Department of Health and Social Services, 2013; National Aboriginal Health Organization, 2009), there has been no long-term evaluation. In contrast, our goal is to continue with the project even after the trial is completed. We intend to refine and extend our educational tools with ongoing input from the trial participants and collaborations with experts in integrative arts and in knowledge mobilisation. The ultimate goal is to create a sustainable screening culture where women are encouraged to make informed decisions regarding their health. When debriefing shortly after the workshop, the study team concluded that the event successfully promoted a positive venue to widen the circle of ethical space shared between the partner communities and the study team. Interestingly, through the interaction between community attendees and the study team, the topics of colonial legacy and paternalistic values that diminish the pre-colonial, matricentric (Indigenous) society stood out as key themes. Positive health education through the development and use of educational materials, which present First Nations values, female bodies and sexuality in a culturally sensitive and respectful manner, is strongly warranted.

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ACCSS group: The Anishinaabek Cervical Cancer Screening Study (ACCSS) team members in alphabetical order: Alberto Severini, Ann Burchell, Gina Ogilvie, Ian Graham, Ingeborg Zehbe, Julian Little, Marion Maar, Nicholas Escott, Pamela Wakewich and Pauline Sameshima.

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## Note

1. The term Anishinaabek is an autonym (<http://en.wikipedia.org/wiki/Endonym>) often used by the Odawa, Ojibwa (<http://en.wikipedia.org/wiki/Odawa>) and Algonquin ([http://en.wikipedia.org/wiki/Algonquin\\_people](http://en.wikipedia.org/wiki/Algonquin_people)) First Nations ([http://en.wikipedia.org/wiki/First\\_Nations](http://en.wikipedia.org/wiki/First_Nations)) in Ontario (<http://en.wikipedia.org/wiki/Ontario>), Canada, who speak closely related *Anishinaabemowin*-Anishinaabek languages ([http://en.wikipedia.org/wiki/Anishinaabe\\_language](http://en.wikipedia.org/wiki/Anishinaabe_language)) of the Algonquian language family ([http://en.wikipedia.org/wiki/Algonquian\\_languages](http://en.wikipedia.org/wiki/Algonquian_languages)).

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