

Anishinaabek Cervical Cancer Screening Study

Community Update Report 2015



Thunder Bay Regional **Research Institute**







www.accssfn.com



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Executive Summary

Despite a dramatic drop in cervical cancer deaths since the advent of the Pap test, Canada's First Nations women remain vulnerable to the disease and are 2 to 20 times more likely to develop cervical cancer than the general Canadian population.

Why rates remain high among First Nations women is a question the Anishinaabek Cervical Cancer Screening Study (ACCSS) wants to answer. The study is led by cancer biologist Ingeborg Zehbe, who has assembled an inter-disciplinary team of collaborators.

The study's long-term goals are

- to see if the use of self-sampling would increase levels of participation in screening, and
- to engage directly with First Nations women about how to develop and implement sustainable and culturally acceptable screening programs in their communities to increase screening and reduce cervical cancer rates in those communities.

Following a pilot study, ACCSS expanded to include 10 First Nations communities, conducting 16 interviews with health care providers in these communities, held sharing circle focus groups (76 women in total) and conducted a controlled trial to determine if women prefer selfsampling over Pap testing.

The interviews and sharing circles confirmed that there are many

significant barriers to screening for First Nations women. These include the shortage and high turnover of appropriate health care providers, geographic and transportation barriers, education and socioeconomic inequalities, the colonial legacy, and the lack of an automatic system to contact eligible women for cervical screening known as a 'recall system'.

The controlled trial indicated that cervical screening by self-sampling for HPV was preferred over Pap testing. Twice as many women participated in self-sampling compared to Pap testing. HPV analysis indicated that 20% of the women who did self-screening were carrying high-risk types of HPV.

Overall, less than 25% of eligible women accepted the offer of screening. One of the over-arching themes from both the interviews and sharing circles was the need for more education. Suggestions from the women included:

- Starting education early to inform about sexual health
- Creating a 'screening culture' based on women's well-being known as "pimatisiwin" from the Ojibwe language
- Reducing the stigma associated with HPV by creating awareness that it is very common
- Including men in the dialogue

ACCSS Milestones April 2009 - October 2015

April – Decemb 2009 L	er Spring 2010	October 2010	Winter 2010 & Spring 2011	Spring 2011	Summer 2011	January 2012	Spring & Summer 2012	October 2012	January to April 2013	April 2013 I
Pilot study with 49 women in communit	visits 1 with the	Introduction of larger study at All Chiefs' Meeting	Ratification of research agreements with the partner communities	Meet and greet visits to introduce the study to health directors	Interviews with 16 health care providers conducted in the partner communities	Obtained funding for larger study from the Canadian Institutes of Health Research (CIHR) for 3 years	Eight focus group sharing circles with community women (altogether 76 women)	Workshop with community delegates to develop educational strategies specific to each community	Hiring of a community based research assistant (CBRA) in each community	Start of the screening trial

Conclusions

First Nations women experience significant health inequalities in cancer screening that are, based on our research, less influenced by personal risk behaviors and more by broader societal forces.

Health care providers need to be made aware of the unique 'structural barriers' faced by First Nations women to avoid the perception that they are disinterested in their health.

Jurisdictional divisions between on-reserve (First Nations community) and off-reserve (mainstream community) providers result in a lack of access to health information by community-based First Nations workers and impede the development of a locally controlled, First Nations recallbased screening system.

Need policy changes to improve patient data sharing between on-reserve and off-reserve providers

Need new policies to support innovative screening approaches like self-sampling for HPV

On October 27 and 28, 2015, a Community Update Gathering was held in Thunder Bay to present current findings.

trial



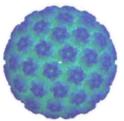
Partner Communities

Animbiigoo Zaagi'igan Anishinaabek* Biinjitiwaabik Zaaging Anishinaabek Bingwi Neyaashi Anishinaabek* Fort William First Nation Kiashke Zaaging Anishinaabek Long Lake #58 First Nation Pays Plat First Nation Pic Mobert First Nation Red Rock Indian Band Whitesand First Nation *Band members do not live on land base (reserve)

Spring, Summer, Fall 2013	September 2013	Winter 2013 & Spring 2014	June 2014	July 2014	August 2014	August 2014	September 2014	July 2015	October 2015
Educational workshops in each partner community to create awareness for the screening	ACCSS reflection meeting with health directors	Follow-up community visits to present findings from focus groups and interviews	Reflection meeting with CBRAs	Wool felting focus group: Arts- integrated approach	Health fair in Whitesand First Nation	End of screening trial	Ongoing analyses of qualitative and quantitative data by the ACCSS team	Cancer Prevention Fair in Whitesand First Nation	Community update gathering to present ACCSS findings

Cervical Cancer

Cervical cancer is one of the most common cancer types in women worldwide and is primarily caused by high-risk strains of the human papillomavirus (HPV).¹ It can be prevented with regular screening and follow-up treatment. The Pap(anicolaou) test introduced in the 1950s can identify abnormal cells in a woman's cervix, which may be indicative of a precursor lesion or cancer. Use of Pap tests has led to an 83% drop in cervical cancer deaths in Canada between 1952 and 2006.² An alternative way to screen for cervical cancer is testing for high-risk HPV. National media coverage has emphasized Canada's role as a pioneer in cervical cancer screening and an exemplar of early detection through regular Pap tests. However, the media did not report the elevated risk of cervical cancer incidence and mortality among vulnerable populations in Canada, leaving the impression that the improvement included all groups of Canadian women. Indigenous women in Canada are 2 to 20 times more likely to get cervical cancer.³⁻⁵



Human Papillomavirus

Rasmol image by Jean-Yves Sgro ©2004. Unpublished blue version ICTV 8th report images at virology.wisc.edu/ virusworld

In Canada, First Nations women are 2 to 20 times more likely to develop cervical cancer

Why are cervical cancer rates higher among First Nations women?

One possible reason is that First Nations women have less access to or are uncomfortable getting Pap tests due to the invasive nature of this test. Would First Nations women be more likely to participate in cervical screening if the method were self-sampling?

This was the question asked by Dr. Ingeborg Zehbe in a pilot study in the Fort William First Nation in 2009. The study found self-sampling for HPV testing was overwhelmingly the preferred option, embraced by 87% of the First Nations women participating.⁶

ACCSS – the Anishinaabek Cervical Cancer Screening Study

The results of the pilot study were presented at the Northern Superior All Chief's Meeting in the fall of 2010. Stemming from this presentation, research agreements were reached with 10 First Nations communities in the Robinson Superior Treaty region of northwest Ontario. This was the start of the Anishinaabek Cervical Cancer Screening Study (ACCSS).

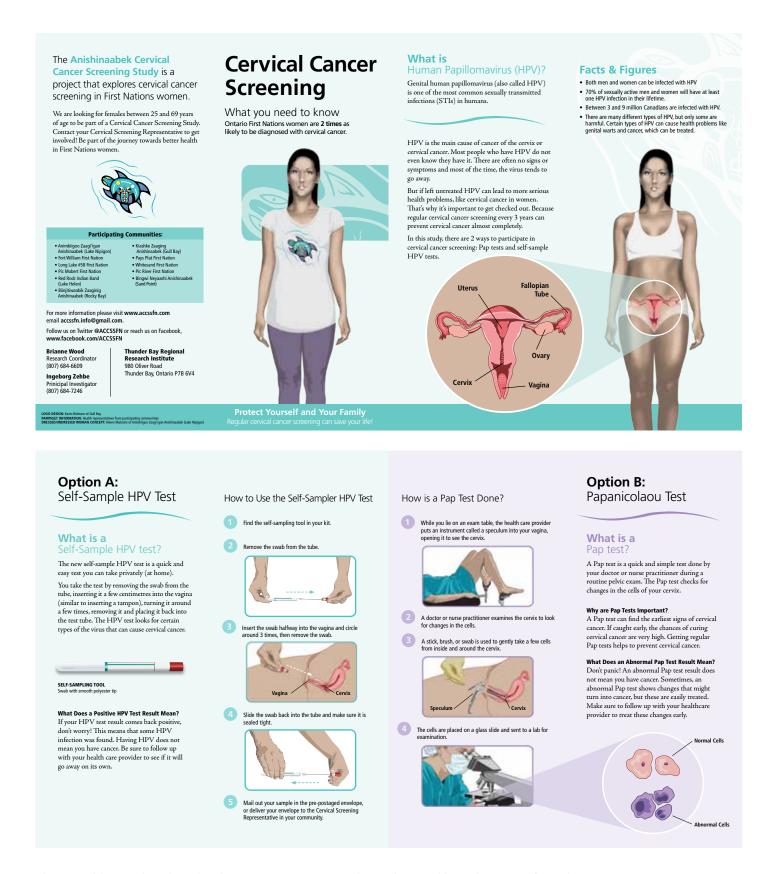
The community leadership encouraged the research team members to:

• Attend community events to build a better relationship with local women

- Present at annual health fairs and cultural celebrations to raise awareness about the study and cervical cancer prevention in general
- Develop a clearly outlined process for HPV testing that was to remain blinded at the community level to give optimum privacy to participants
- Draft research agreements that could be tailored to the needs of the respective communities

Once the research agreements were in place, the communities and

research team worked together to design a research plan. This included obtaining qualitative information via individual interviews and sharing circles and collecting quantitative data via questionnaires and offers of cervical screening. Two methods were to be compared: the standardof-care Pap test and HPV testing with the women taking their own sample (self-sampling).



The pamphlet used to describe the ACCSS screening trial was designed based on input from the communities and the concept of the woman dressed on the cover/and undressed on the inside pages was contributed by Aileen Malcolm of Animbiigoo Zaagi'igan Anishinaabek. In this way the pamphlet was designed to respect First Nations women's sense of privacy about the body and to make the pamphlets culturally acceptable for display in public spaces such as community and health centres.

Ethical Space

To ensure the study was conducted in collaboration with the partner communities -- embracing the principles of partnership, shared control, mutual benefit and respect -the study team borrowed the concept of **ethical space** developed by First Nations scholar, Willie Ermine⁷ which involves an ongoing dialogue and collaboration between the study team and the partner communities.⁸

Public Health Research Approaches

Ethical Space Dialogue Aboriginal Holistic Health Approaches

Invitation to dialogue with 10 communities during Meet and Greets

Development of research agreements

Invitation to dialogue with leaders at all regional Chiefs' Meeting

> Formal dialogue with one community and pilot research

> Informal dialogue on First Nations women's experience with cervical cancer screening in one community

This included:8

- Informal dialogue with health care providers in one community providing input for study design
- A pilot study in that community, the success of which led to the larger study
- Dialogue at the All Chiefs Meeting providing input for development of the large scale screening study - ACCSS
- Collaborative development of research agreements
- Invitations from the 10 First Nations communities to discuss the proposed research during community visits ("Meet and Greet")

During the "Meet and Greet" sessions, community partners made the following suggestions about the design of the study:⁸

- Raise community and health care provider awareness of HPV infection, transmission, vaccines, and testing
- Develop culturally based prevention approaches for sexually transmitted infections
- Explore HPV prevention in traditional teachings provided by Elders to young girls
- Include questions provided by community partners in the screening trial questionnaire.

- Address HPV in the context of First Nations health services, health budgets and medical transportation, and the impact of the residential schools experiences on HPV infection, and cervical cancer screening
- Protect the confidentiality and privacy of participating women

At each stage of the study, the ACCSS team attempted to include community leaders, health professionals and community women in shaping the research approach.

Community Engagement

Community steering committee:

We formed the community steering community (CSC) with one representative from each community (e.g. health director and/or band council member: Fort William First Nation: Karen Bannon; Whitesand First Nation: Angela Nodin; Bingwi Neyaashi Anishinaabek: Edna Hodgkinson; Pays Plat First Nation: Debbie Bouchard; Pic Mobert First Nation: Carol Rowland; Biinjitiwaabik Zaaging Anishinaabek: Robin Thompson; Red Rock Indian Band: Lucille Lesperance: Long Lake #58 First Nation: Judy Desmoulin; Kiashke Zaaging Anishinaabek: Gwendolyn King; Animbiigoo Zaagi'igan Anishinaabek: Lynda Lynch. The CSC ensured that the ACCSS was on track and provided guidance on cultural safety and feedback from their communities. Teleconferences were conducted every couple of months between the research co-ordinator (Brianne Wood), the principal investigator (Ingeborg Zehbe) and the CSC.

Publication steering committee:

The publication steering committee (PSC) was composed of at least two

ad hoc members from any of the participating communities recruited for each manuscript to be submitted for publication. All scientific, peerreviewed publications were submitted to the PSC and the community leadership prior to submission to academic journals. In some cases community members contributed to the writing of articles and were listed as co-authors.

Community-based research assistants:

The CSC recruited local, and whenever possible, First Nations communitybased research assistants (CBRAs) to implement the ACCSS screening trial in their community. CBRAs acted as a liaison between the ACCSS team in Thunder Bay and their community during the time of the trial.

The CBRAs were critical to the success of the project. They created awareness for HPV and its relation to cervical cancer by organizing and hosting community events, distributing pamphlets, participating in health fairs and Well Women Clinics as well as by communicating directly with women in their communities. They had regular update meetings with the research team and helped to shape the research design based on input from the communities.

They explained that infection with high risk types of HPV could lead to cervical cancer. They suggested that participating in screening was part of 'pimatisiwin' or living the good healthy life and part of each woman's wellbeing. They let women know that cervical cancer was treatable if caught early.

Sharing this information was meaningful in providing women with reason to participate in screening. The CBRAs also followed up with individual appointments to work through the informed consent, the baseline and follow-up questionnaires and the offer of cervical screening.

The ACCSS project has provided some insight into reasons for the currently low levels of cervical screening of First Nations women. The CBRAs have played a significant role in collecting data that can be used to inform changes to policy and regulation and in this way have been part of the first step towards improving health care practices in their communities.

Congratulations and Miigwetch!

The Community-Based Research Assistants Gathering on February 19, 2013

From left to right: Belinda McWatch (Pic Mobert First Nation), Juanita Hardy (Biinjitiwaabik Zaaging Anishinaabek), Katrina Fisher (Pic River First Nation), Kyla Morrisseau (Animbiigoo Zaagi'igan Anishinaabek), Melissa Sitch (Pays Plat First Nation), Lisa Bishop (Fort William First Nation), Candace Robert (Red Rock Indian Band), Rose Antonasic (Bingwi Neyaashi Anishinaabek), Carol Samuelson (Kiashke Zaaging Anishinaabek), Brianne Wood (research co-ordinatior, TBRRI), Michelle Ossibens (Long Lake #58 First Nation).

Missing: Carla Shawayhamaisch, Tuesday Recollet, Yvonne Banning, Marissa Thompson, Vanessa Bouchard, Ashley Laframboise, Marie McWatch and Melissa Oskinegish





ACCSS Findings

Qualitative information was gathered from interviews and focus group sharing circles:⁹⁻¹⁴

Interviews with health care providers (12 of 16 were community members)

Topics: Effective ways to reach First Nations women with screening information and strategies to motivate them to participate

Focus group sharing circles (8 groups, total of 76 women)

Topics: Cancer in general, cervical cancer screening in particular

Question: Why women do or do not participate in cervical screening?

Shortage of appropriate health care providers:⁹

- Not all health care providers are trained to do Pap tests
- High turnover of physicians
- Women are shy and need someone familiar they can trust
- Preference for female health care
 providers

Transportation barriers:⁹

Most communities have access to a medical transportation van, which can take people to larger centres so they can access health services that aren't available in their community. However, there are many other factors to consider:

- Women do not want to take a whole day off work just for a Pap test
- The medical van often doesn't have room for mothers to bring children
- It can take up to 3 hours to get to an appointment and then you have to wait until the van is scheduled to go back
- There may be other costs associated with the trip
- It's not possible to bring an escort which may be needed for older and very young women who require moral support

Education and socioeconomic inequalities: ^{10,12,14}

The lack of appropriate health education was recognized as the biggest factor leading to women not participating in screening. Community members with lack of understanding of why cervical screening is performed will be unlikely to subject themselves to a Pap test.

"We know that cervical cancer is 100% preventable, and I know because I read stats and see statistics that Aboriginal women are the number one on the list for dying from this. So I think maybe "Education is the biggest thing"

Have a cancer survivor speak:

"Maybe a person that already went through it, like you know, I had cervical cancer and obviously beat it, you know, maybe something like that type of speaker".⁶ reinforcing that message, that this is 100% preventable"

Not only was there a lack of understanding regarding the preventable nature of the disease, but some women were also unaware of how to access health services. or had reduced comfort level in navigating the health services system. In some cases women were unaware of the link between HPV and cervical cancer. There was also the issue of HPV being considered a sexually transmitted infection and the associated shame. This, along with the lack of privacy and confidentiality within a small community prevented some women from choosing to be screened. These women were likely unaware of how prevalent HPV is in the general population. Many women were unaware that men could be infected with HPV and pass it on to their partners. In the pilot study it was found that 84% of participants were unaware that men can also be infected with and transmit HPV. In order to improve general awareness of HPV and cervical cancer the following strategies could be used:

Education could be provided through already existing programs and should be respectful (culturally appropriate), start early in schools and be ongoing.

Educational approaches could be tailored to the specific needs of different generations (e.g. teens and Elders) and should include males and females since both can contract and transmit HPV.

Education needs to include specific knowledge about HPV including: that transmission occurs through sexual contact, that most people will have some strains at some point in their lives with no illness, and that only some strains are high risk and only women who have persistent infections with high risk strains of HPV are at risk of cervical cancer.

Generational effects:⁹

Older women may not attend screening because they feel intimidated due to language and cultural barriers. Other reasons we heard were that they were in monogamous relationships, or they were no longer sexually active. Some women also said that they fear leaving the community. They were concerned that if something was found during a Pap test it would mean they would have to stay in the hospital, away from their community.⁹

"That history, that went on there that really still has such an impact! We think that we've made things user friendly, and to us it is, but to others, to them, it isn't, you know. For some of the older generation, they may not necessarily have been through mainstream education, and they don't know what questions to ask, and, they are, just very intimidated by it, and so they just avoid [mainstream health care] altogether."

"It seems that the older that they are, the more they keep to themselves and they think that automatically cancer just means you're going to die so they don't try to get the help that they can ... most of the older ones are not trying to help themselves and they feel that it would be selfish of them to put the burden onto someone else."

Colonial legacy:9,13

Colonial legacy has had negative implications for Indigenous women's sexual health. Government assimilation policies, such as the residential school system, have destabilized First Nations traditional gender roles, reduced women's status in their communities and disrupted the transmission of culture and knowledge between generations. Direct or indirect experiences with the Residential School system have led to:

- Mistrust of mainstream Canadian institutions in general
- Loss of traditional roles of women as family health educators, caregivers, and advocates
- Negative body image, shame, shyness about sexuality
- Loss of traditional First Nations view of the body

"As we were growing up as kids, we had ... a housecoat that was almost at the floor, you know, covering our ankles. ... Your body was always covered ... I honestly, I don't think that's so much cover was part of the [First Nations] tradition, [instead] I think a lot [of] it came from the abuse from the residential schools."

Building trust is essential for First Nations women because of the past Canadian residential school system with its physical, sexual and emotional abuse by teachers and institutional authorities. As one health care provider pointed out: "They have been sexually abused, too, and I know like, in the past residential schools, that kind of thing, those people are just not comfortable because of their experiences in the past I will be here for a long time and whenever you need to see me, to come see me, so that even just that little thing and then when they do come I do see them, hopefully that trust builds up and I think that's a big piece with the First Nations."

Also, control over health services continues to be managed by federal authorities leaving communities and individuals feeling excluded from decisions about their own health and wellbeing. To empower First Nations women to take control of their wellbeing new policies need to:

Improve cultural sensitivity in health care practices,

Adopt self-sampling to ensure women's privacy and control of the screening process,

Reaffirm women's traditional caregiving and teaching role, and

Enhance mother-daughter communication.

No systems in place to initiate screening or to follow-up:^{9,11}

Canadian guidelines for cervical screening (2015) recommend that women who are 21 and older, and have ever been sexually active, are screened every 2-3 years. Currently, only British Columbia. Manitoba and Nova Scotia have recall-based screening systems where a cancer registry identifies and invites eligible women for screening. Other provinces have 'opportunistic' screening which relies on either health care providers to invite their patients to be screened or on women themselves to request a Pap test. This approach has not been fully successful in getting First Nations women to be screened. Many women are unaware of why they should get tested and even though health care providers can suggest Pap tests if women come in for other issues, this will not reach all women. Also, the lack of agreements for patient data sharing between on- and off- reserve health care providers means that a communitybased reminder system is currently not possible. These issues could be addressed by implementing:

policies for the sharing of patient data between on- and off-reserve health care providers and

a community-based recall system so that women will be regularly reminded about screening.

All above quotes were obtained during the interviews and focus group sharing circles.

Quantitative Analysis -Cervical Screening by HPV Self-Sampling or Pap Tests¹⁵

The 10 partner communities participated in an exploratory, randomized controlled trial comparing the uptake of self-sampling for HPV with that of Pap testing. All women who chose to participate in the study were asked to fill out a questionnaire and were offered cervical screening. The study pamphlet (page 4) was designed by members of the communities in collaboration with the research team and then used as an aid to describe the techniques to participants.

- The communities were randomly assigned to Arm A (Intervention group) or Arm B (Control group)
- In Arm A communities, women were offered screening by HPV selfsampling first and those who did not get screened by this method were later offered screening by Pap test
- In Arm B communities, women were offered screening by Pap test first and those who did not get screened by this method were later offered screening by HPV self-sampling
- The alternate type of screening was offered 1-2 months after the initial type
- Less than 25% eligible women participated in screening (filling out a questionnaire and getting screened)
- Some women filled out the questionnaire, but chose not to participate in screening

Approximately twice as many women participated in cervical screening when self-sampling was offered One in five women tested positive for high-risk HPV types from self-sampling

Screening Results:15

- Approximately twice as many women participated in cervical screening when self-sampling was offered:
- When women who declined the first offer were offered the alternate test a few months later, no woman who refused the self-sample wanted to do a Pap test instead, but 6 women who had refused the Pap test originally were willing to do a self-sample
- DNA analysis was used to determine the presence of HPV in the self-sample
- DNA analysis was also able to identify which types of HPV were present in the self-sample
- One in five women (19 % of the selfcollected samples) tested positive for high-risk HPV types
- 96 % (78 of 81) of self-sampling tests were of adequate quality for DNA analysis

Questionnaire responses:¹⁵

The majority of screening trial participants were between 25 and 50 years old and over 60% of the women had completed high school or beyond. Although 58% of women were employed, 27% stated that they had concerns for food security. Most women rated their health between "Good" to "Excellent", but almost half of the women said their health was negatively impacted as a result of first-hand or familial encounters with residential schooling.

The psychosocial scores which provide an indication of stress levels in the participants, did not differ between the two arms of the study. This confirms that the increased uptake of self-sampling was not due to differences of psychosocial factors between the two arms.

Only 20% of eligible women participated and the majority of these women were already taking care of their health, with approximately twothirds of them reporting that they had a Pap test in the 3 years prior to the study. These findings indicate that further work needs to be done to develop strategies to engage and involve the "hard to reach" women.



The ACCSS Champion: "Making our own HPV Balls"



Theresa Morrisseau hadn't really thought much about cancer in the first 59 years of her life. Growing up in Biinjitiwaabik Zaaging Anishinaabek in an Ojibwe speaking home, health resources and education were scarce. If she was sick, she'd go see a doctor in nearby Beardmore; she didn't pay it much mind. "I'm a very stubborn person," the now 60-year-old mother of three and grandmother of nine, an Elder of Biinjitiwaabik Zaaging Anishinaabek, says matter of factly. "I don't go to the doctor because I have a sore leg. There's got to be something seriously wrong with me, the leg is falling off, before I go see a doctor. I don't want to waste anybody's time. Seeing a doctor is not a priority." But she has a daughter-in-law who might be just as stubborn. Kyla Morrisseau is involved with the ACCSS as a research assistant in her own community and bugged her mother-in-law to join in until she finally relented. What she learned about the incidence of cervical cancer among Indigenous women and the importance of screening was a revelation.

So, when a lump formed on her chest, she went and checked it out. It has since been treated and is in remission. She's not sure she would be alive today if she hadn't acted when she did. She has friends who passed away. They were not so lucky. Theresa has become an advocate of women in her community, and women in general, getting information and educating themselves about the possibilities of getting cancer and the actions they can take to prevent it or detect it early enough. Her interest started when she attended the ACCSS-sponsored arts-integrated workshop on HPV and cervical cancer.

First Nations women are less likely to seek out medical care until it's absolutely necessary. Growing up, Theresa didn't have easy access to health resources or information. There was no doctor or public nurse in the community. The subject didn't get talked about in the home. In the numerous more remote communities in northwest Ontario the situation was probably even worse. "There was nobody to say I'm working on health

issues," she recalls. "No one to say what the consequences of not getting these tests done are. No one to give the relevant information." Going off reserve to get even limited access to healthcare wasn't particularly appealing either. Residents have had enough bad experiences that they avoided interactions with anything that smacked of the non-Indigenous world. So it would have to be a fairly serious situation to go. "We saw the government as the bad guy," she says. "So you kind of stayed away from the whole deal . . . we would go if we had to, but otherwise no." Addressing these structural barriers and ways in service delivery-factors like remote geography, transportation issues and lack of adequate health resources on reserves - as well as cultural barriers stemming from the legacy of colonialism following contact with Europeans that face First Nations women like Theresa even today, is the goal of the ACCSS.

Dr. Zehbe realized after conducting some focus groups that a traditional approach to education wasn't going to work. So the goal became to find innovative educational tools to promote the screening that would see greater participation. The ACCSS study is designed to address that. In thinking about how to get the message of the importance of screening across effectively, she ended up consulting Dr. Pauline Sameshima, the Canada Research Chair in Arts Integrated Studies at Lakehead University, who is now part of the ACCSS team. Dr. Zehbe had integrated art into the ACCSS already to design the study pamphlet with the community women and a local artist from Kiashke Zaaging Anishinaabek (Mr. Kevin Belmore) designing the study symbol—a turtle (www.accssfn.com).

Dr. Sameshima came up with wool felting of styrofoam balls representing HPV—work that would be done during the education sessions in an attempt to increase dialogue and communication. This was tried as a pilot in one of the 10 partner communities and the aim was for



the participants to metaphorically take charge of their own wellbeing by creating their own design through felting the HPV balls, she said. At the outset, there are two sides researchers on one side, community participants listening to them on the other. Then the balls come out, the felting begins, even as a power point plays informing the participants about cervical cancer and screening, and everyone comes together in the circle as they work with questions and discussion flowing between the researchers and community members. The line between the researchers and community members disappears as each works on their ball, chatting as they do. "The difference in the amount of back and forth dialogue between the time people were felting and the time we didn't use felting, was phenomenal," said Dr. Sameshima. "At the end of the felting, when all the balls were out, there was a real sense of common ground. We probably all have the virus in us, it's dangerous for some, not dangerous for others, but as a group we can all care for one another."

Theresa's involvement in the study prompted her to take control of her health. Armed with the information she received at the felting session, Theresa sought medical attention when she had a persistent sore rib. It was attributed to a recent fall she had, was likely broken and only time would heal it. That sounded reasonable, so she went home. determined to live through the pain in the meantime. But after two weeks without the pain subsiding, she realized something had to be wrong. In the past, said her daughter-in-law Kyla, she would have just continued to suffer. But with the awareness the cancer information had created, she returned to get checked out again. Testing discovered she had cancer, which could cause bones to break. Her treatment was successful and now she says she's fit enough to take on her interviewer in a race. But she knows what fate awaited her if she hadn't been on top of her own health and eager to get tested. As an

outcome of the felting session, some of the other women participating who had not previously been screened went and got screened. And a roomful of women are now ambassadors for screening, talking about their experience with their friends and neighbours. "The ladies go home, like I do, and talk about it," she said. "They have a cup of tea, sharing what I went through. That cascading effect in the wake of the workshop is an important part of the project, says Dr. Zehbe. "The evolution is just beginning," said Theresa. "This is just a start."

Special Report by Mr. Chisholm Pothier from the Thunder Bay Health Sciences Centre (revised and adapted for the current report)



Pam Wakewich, Pauline Sameshima, Elder Theresa Morrisseau, Kyla Morrisseau and Dr. Ingeborg Zehbe

Implications for Practice and Policy^{9,10}

The results obtained from HPV testing are more sensitive and give an earlier warning of the possibility of developing cervical cancer than the currently used Pap testing. Sample analysis can provide detailed information about the strains of HPV present. Since HPV vaccination, testing, and surveillance programs will be integrated into the Ontario Cervical Screening Program over the next few years, now is the time to suggest a cervical screening program tailored to meet the needs of First Nations women.

The prospect of including the novel and non-invasive screening approach, namely, HPV self-sampling, was received positively because it is consistent with First Nations teachings on personal responsibility for caring for your body. As such, it has the potential to further empower women to collect their own samples in privacy, giving them control over how and when they participate in screening.

Suggestions:

- Create new policies to support innovative screening approaches like self-sampling
- Make policy changes in the area of patient data sharing between onreserve (First Nations community) and off-reserve (mainstream community) providers
- Continue working to ensure implementation of self-screening programs within the First Nations communities in the study
- Share ACCSS results and encourage similar programs in First Nations communities across Canada
- Integrate services with the "Screen for Life" mobile coach (Cancer Care Ontario) to reach more of the women aged 50 and higher
- Support the development and implementation of novel appropriate educational strategies

- Investigate the use of arts-integrated education which shows promise as a technique for reaching First Nations women who may not participate otherwise
- Integrate HPV education with already existing programs (e.g. moon time girls and wilderness boys as well as playgroups and bingos)
- Continue to train women from the community to partake in the research in a variety of capacities, for example, as program coordinators, research assistants and co-authors on publications





ACCSS Community Update Gathering dinner

The ACCSS Community Update Gathering: Sharing the findings and so much more

On October 27th and 28th 2015, two representatives from each of the participating First Nations communities as well as stakeholders from Cancer Care Ontario (CCO) and the Society of Obstetricians and Gynecologists of Canada (SOGC) were invited to come to Thunder Bay for the ACCSS Community Update Gathering. There were approximately 40 participants in attendance also including the ACCSS team members Drs. Anne Burchell, Brenda Magajna, Pauline Sameshima, Pamela Wakewich and Ingeborg Zehbe as well as the Kiashke Zaaging Anishinaabek artist Kevin Belmore who had created the ACCSS turtle logo and graduate student and artist Matthew O'Reilly to paint his impressions of the gathering. The ACCSS team was very honoured to welcome Dr. Angeline Letendre and Elder Theresa Morrisseau.

The goals of the gathering were to share and report back the ACCSS findings, to invite feedback and guidance from the partner communities regarding educational approaches that had been used and to invite input for the next steps of the ACCSS project. The event began with an informal dinner prepared by a local Indigenous caterer consisting of moose meat stew, fried pickerel and fresh greens where participants shared stories and reconnected. The evening was capped with a lovely performance by the Medicine Wheel Spirit Singers from the Fort William First Nation, singing songs in the Ojibwe language about health and empowerment.

The next day began with a blessing by Elder Theresa Morrisseau. Her beautiful spirit set the tone for the day. Dr. Sameshima had prepared a basket of turtle insignia "talismans". As the basket was passed around, each member chose a small talisman and spoke. The group was arranged in a sharing circle and each member communicated what they hoped to gain from the day. A common goal was to gain information that could be brought back and disseminated in their communities such as ways to empower Anishinaabek women to care for their own health and understand the benefit of cervical screening. There was consensus in the group that such

a sharing circle was a valuable way to discuss and learn from each other.

After the opening circle, Dr. Zehbe provided an informal overview of the ACCSS project, the history and the results with comments from Lakehead University study collaborators Drs. Wakewich and Sameshima each of whom emphasized the importance of relationship building and creating trust in the communities. Kyla Morrisseau and Luanne Maki shared their experiences as Community Based Research Assistants with the ACCSS. Kyla noted that women found selfsampling empowering since it gave them control and was less invasive than Pap screening. Luanne pointed out that even getting 3 more women to do screening was a success, and that creating awareness was an ongoing process.

The invited guest of honour, Dr. Angeline Letendre [lead scientist of the Community Research Stream for Cancer Prevention and Screening, including Health Promotion with the ACPLF at Alberta Health Services], who had given a talk to the university community on Tuesday afternoon prior to the gathering entitled "Alberta First Nations: Scratching the Surface in Support of Two-Way Translations & Cancer Research" also presented a summary of her work during the gathering: "Stories of survival among aboriginal people with cancer: scratching the surface in support of two-way translations to give voice to communities". The similarities faced by First Nations people in Alberta and those in northwest Ontario were striking: the lack of trust and avoidance of mainstream medicine, the issues of poverty and food security, and the racism encountered while navigating the health system. Also similar were the immediate concerns of women who were diagnosed with cancer: How will I support my family if I can't work? Who will look after my children while I can't? How will I cover costs associated with leaving the community?

In the afternoon, the group was divided into three smaller groups to discuss one of three focus questions in a World Café style. Each group began with one question. Ideas were copied to chart paper and after 20 minutes the groups switched allowing the next group to build on what the first group had contributed. In this way focus groups explored the feedback from community members about the project: (i) what worked and what could have been better, (ii) best approaches to deliver cancer prevention education that is holistic and culturally appropriate, and (iii) desired future directions based on what would be considered project success.

Community members acknowledged the "persistence" of the research team and their ability to adapt to the needs of each community as these were important to the success of the project. The importance of relationship building and trust was a common theme. The need for more consistent communication between the researchers and the community was also noted. Researcher's visits and screening need to be done with regularity.

Common suggestions for education included, providing information to all ages and both males and females, using visuals to explain more complex concepts, using a variety of tools like videos, stories of cancer survivors, and games, keeping information sessions short and understandable, sharing information in person and including the sharing of a meal, using a traditional retreat-based approach, sharing information during Elder's Circles, being respectful of all perspectives, focusing on messages of hope by sharing stories of cancer survivors, including humour and generally focusing on well-being "pimatisiwin" and healthy lifestyles.

The best indication that the ACCSS project has been successful would be higher rates of cervical screening among First Nations women based on improved trust of the health care system and knowledge of how to access services. Different approaches to health care are needed and the political will to respond and fund alternatives like self-sampling for HPV would be another measure of success. Also, changing the attitude toward HPV and cancer, so that people are more comfortable speaking about these topics more freely would be a meaningful accomplishment. After the World Café style focus groups, Dr. Zehbe's undergraduate biology student Robert Strachan provided comic relief and an important educational message in his presentation 'HPV in Males'—sharing the fact that HPV-related cancers in men are on the rise. One of the next research team's goals is to implement HPV awareness programming for First Nations men.

Dr. Angeline Letendre, Beatrice Twance-Hynes, Kyla Morrisseau, Dr. Pam Wakewich, Kevin Belmore, Jacqueline Gagnon, Debbie Bouchard, dinner, Lauren Beach, Jennifer Fawcett, Tarja Heiskanen, Elder Theresa Morrisseau



The ACCSS team also engaged a young artist/Master's student in the Department of Education, Lakehead University-Matthew O'Reilly. Matthew was tasked with painting his impressions during the gathering. Dr. Sameshima had only briefly discussed the project with Matthew so that he could maintain an outsider's perspective-knowing about the ACCSS is one thing and being active in it another. He was aware that he would meet a heterogeneous audience of community members, researchers, stake holders and facilitating staff as well as different gender, ages, cultures—all creating 'space'. Matthew did not want to appropriate anything Indigenous, as a non-Indigenous artist, but rather tell the story as he heard it from the participants, using his own style as an artist. He wanted to do something unique capturing the day with an abstract rather than objective/ scientific approach. He was aware of the emotions in the gathering room and worked from different layersone on top of each other as the day unfolded. Matthew wanted to create a visual metaphor, spontaneous, an element of chance and away from reference pictures, a new framework just for this project and just for this gathering.



Commissioned artwork by MSc student and artist, Matthew O'Reilly

Overall, there was significant support for the ACCSS to be continued as well as gratitude expressed for Dr. Zehbe's commitment to keeping the communities engaged in a meaningful way. Participants were eager to bring the messages of the day back to their communities and looked forward to future meetings. The day ended with a blessing by Elder Theresa Morrisseau. Community visits to get input from the communities for the next steps of the ACCSS were scheduled for early December 2015. The journey continues. A separate report about this dynamic gathering is in progress.



Future Directions

THe ACCSS project has worked over the last 6 years to develop trusting relationships with members of the partnering First Nations communities. The research team, CBRAs and project staff have strived to create awareness of the role high-risk strains of HPV, if left unchecked, play in leading to cervical cancer. In turn, the women in the communities have shared their stories, described barriers to screening, and proposed strategies to increase screening uptake.

The arts-integrated approach to HPV education:¹⁶

One of the strongest messages from the communities was the need for alternate approaches to education.

With the goal of finding innovative educational tools to promote screening that would see greater participation, Drs Pauline Sameshima & Ingeborg Zehbe organized a wool felting workshop to test out as a pilot in one of the 10 partner communities. In the summer of 2014, participants created their own HPV balls with wool felt while a power point about HPV and cervical cancer played in the background. "The difference in the amount of back and forth dialogue between the time people were felting and the time we didn't use felting was phenomenal." The success of this workshop indicates that such artsintegrated research should be pursued further and communities that we have heard from are interested in more sessions of this nature.

Most importantly, the ACCSS team strongly encourages input from the partner communities and will conduct focus groups to inquire about feasible educational approaches, e.g. using various types of arts-integrated education or other potential activities and strategies.

Extending our reach: HPV awareness for men, older women and girls:

The ACCSS project facilitated involvement of 25 to 59 year old women. It became clear during the research that there was a need to create specific educational programming geared to older women as well as specific attention to girls and teens. Future work will involve community members in the design and implementation of programming designed to reach these groups.

Another theme that came out of the research was the need for HPV education for men. Many women were surprized to learn that men could be carriers and spread the virus. It was suggested that most men are also likely unaware of this. Given that the rate of HPV-related head and neck cancers in men is on the rise and that HPV has been linked to anal and penile cancers, it will be meaningful to promote HPV awareness in First Nations men.

The ACCSS project is working towards creating sustainable cervical screening programs in First Nations communities. Specific educational strategies need to be developed to reach younger women, older women and men

Anishinaabek Cervical Cancer Screening Study - Community Update Report 2015

The Research Team

We are an interdisciplinary team spanning areas such as cancer biology, virology, sociology & women's studies, epidemiology and public health, artsintegrated education and philosophy. Drs. Zehbe & Maar conducted the field work during the qualitative phase. Dr. Zehbe and Ms Brianne Wood conducted the field work during the quantitative phase (screening trial) of the ACCSS. The following list includes both current and former members.

Dr. Ingeborg Zehbe, Senior Scientist, Thunder Bay Regional Research Institute (TBRRI), TBRRI/Lakehead University Research Chair, cross appointment in Clinical Sciences at the Northern Ontario School of Medicine (NOSM) (principal investigator)

Dr. Pamela Wakewich, Director of the Centre for Rural and Northern Health Research Lakehead (CRaNHR), Professor of Sociology and Women's Studies, Lakehead University; cross appointment in Human Sciences at the NOSM (co-investigator) **Dr. Pauline Sameshima**, Canada Research Chair in Arts-Integrated Studies and Education Specialist, Department of Education, Lakehead University (co-investigator)

Dr. Julian Little, Epidemiologist, Canada Research Chair in Human Genome Epidemiology, University of Ottawa (coinvestigator).

Dr. Ann Burchell, Epidemiologist, Ontario HIV Treatment Network, Dalla Lana School of Public Health, University of Toronto (co-investigator)

Dr. Alberto Severini, Virologist, Chief of the Viral Exanthemata and STD Section at the National Microbiology Laboratory, Public Health Agency of Canada, and Assistant Professor in the Department of Microbiology, University of Manitoba (co-investigator)

Dr. Gina Ogilvie, Public Health Epidemiologist, British Columbia Centre for Disease Control, University of British Columbia (co-investigator)

Dr. Nicholas Escott, Pathologist and Colposcopist at the Thunder Bay Regional Health Sciences Centre, cross appointment at the Clinical Sciences at the NOSM, Cervical Screening Lead for the Northwest Ontario Local Health Integration Network (collaborator)

Mr. Lee Sieswerda, Public Health Epidemiologist at the Thunder Bay District Health Unit (collaborator)

Dr. Richard Maundrell, Ethical Philosopher, Associate Professor, Department of Philosophy, Lakehead University (collaborator)

Dr. Brenda Magajna, Post-doctoral fellow at Lakehead University/TBRRI (ACCSS coordinator)

Dr. Marion Maar, Associate Professor, Medical Anthropologist, Human Sciences at the NOSM (previous coinvestigator)

Ms Brianne Wood, (previous ACCSS coordinator), Epidemiologist, PhD Candidate at the University of Ottawa

Dr. Helle Moeller, (previous ACCSS coordinator), Medical Anthropologist, Associate Professor, Department of Health Sciences at Lakehead University



ACCSS Team Meeting on August 18th, 2015. From the left: Richard Maundrell, Pam Wakewich, Brenda Magajna, Ingeborg Zehbe, Jennifer Fawcett, Pauline Sameshima, Nicholas Escott. Missing: Gina Ogilvie, Alberto Severini and Lee Sieswerda.

More Information

General publications:

- 1 zur Hausen, H. (2000). Papillomaviruses causing cancer: Evasion from host-cell control in early events in carcinogenesis. Journal of the National Cancer Institute, 92, 690-698. doi:10.1093/ jnci/92.9.690.
- 2 Dickinson, J.A. Stankiewicz, A., Popadiuk, C., Pogany, L., Onysko, J., & Miller, A.B. (2012). Reduced cervical cancer incidence and mortality in Canada: National data from 1932 to 2006. BMC Public Health, 12, 992. doi:10.1186/1471-2458-12-992.
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- 5 Colquhoun, A., Jiang, Z., Math, M., Maiangowi, G., Ashbury, F., & Chen Yetal. (2010). An investigation of cancer incidence in a First Nations community in Alberta, Canada, 1995–2006. Chronic Diseases in Canada, 30(4), 135-40. doi:10.3402/ ijch.v72i0.19743.

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- 8 Zehbe, I., Maar, M., Nahwegahbow, A. J., Berst, K. M., & Pintar, J. (2012). Ethical space for a sensitive research topic: engaging First Nations women in the development of culturally safe human papillomavirus screening. Journal of Aboriginal Health, 8(1), 41.
- 9 Maar, M., Burchell, A., Little, J., Ogilvie, G., Severini, A., Yang, J. M., & Zehbe, I. (2013). A qualitative study of provider perspectives of structural barriers to cervical cancer screening among First Nations women. Women's Health Issues: Official Publication of the Jacobs Institute of Women's Health, 23(5), e319-e325. doi:10.1016/j.whi.2013.06.005.
- 10 Maar, M., Wakewich, P., Wood, B., Severini, A., Little, J., Burchell, A.N., Ogilvie, G., & Zehbe, I. (2014). Strategies for increasing cervical cancer screening amongst First Nations communities in Northwest Ontario, Canada. Health Care for Women International, 1-18, doi: 10.1080/07399332.2014.959168.
- 11 Wood, B., Burchell, A. N., Escott, N., Little, J., Maar, M., Ogilvie, G., Severini, A., Bishop, L., Morriseau, K., & Zehbe, I. (2014). Using community engagement to inform and implement a community-randomized controlled trial in the Anishinaabek Cervical Cancer Screening Study. Frontiers in Oncology, 427. doi:10.3389/fonc.2014.00027.
- 12 Zehbe, I., Wood, B., Wakewich, P., Maar, M., Escott, N., Jumah, N., Little, J., and on behalf of the ACCSS group. (2015) Teaching tools to engage Anishinaabek First Nations women in cervical cancer screening: Report of an educational workshop. Health Education Journal, 1-12, doi: 10.1177/0017896915580446.

- 13 Wakewich, P., Wood, B., Davey, C., Laframboise, A., Zehbe, I., and on behalf of the ACCSS group. (2015) Colonial legacy and the experience of First Nations women in cervical cancer screening: A Canadian multicommunity study. Critical Public Health, doi.org/10.1080/09581596.20 15.1067671.
- 14 Zehbe, I., Wakewich P., Wood B., Sameshima P., Banning Y., & Little J. Engaging Canadian First Nations women through education (Manuscript submitted for publication).
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- 16 Sameshima, P., Slingerland, D., Wakewich, P., Morrisseau, K. & Zehbe, I. (2015) Growing Wellbeing through Community Participatory Arts: The Anishinaabek Cervical Cancer Screening Study (ACCSS). The Palgrave Handbook of Global Arts EducationSection V - Health, wellbeing and arts education. Edited by Georgina Barton and Margarete Baguley (Manuscript accepted for publication).

*Except Ermine (2007)

Already published ACCSS manuscripts can be accessed at www.accssfn.com or by contacting Ingeborg Zehbe at zehbei@tbh.net

ACCSS Conference Presentations

Zehbe, I. & Maar, M. Culturally safe HPV screening in First Nations women in northern Ontario. Circumpolar Health Conference, Fairbanks, US, August 9, 2011.

Zehbe, I., Maar, M. Ethical space for a sensitive research topic: engaging First Nations women in the development of culturally sensitive HPV screening. 27th International Papillomavirus Conference, Berlin, Germany, September 20, 2011.

Maar, M., & Zehbe, I. Provider perspectives of community-based recruitment strategies to increase Aboriginal women's participation in cervical screening in Ontario, Canada. 28th International Papillomavirus Conference, Puerto Rico, December 4, 2012.

Wakewich, P., Wood, B. & Zehbe, I. Decolonizing Indigenous female bodies and health through culturally sensitive education and self-sampling for HPV testing: a Canadian multicommunity study. The Body, Public Health and Social Theory Conference. Copenhagen, Denmark, April 2013.

Sameshima, P., Wakewich, P., Wood, B., & Zehbe, I. Engaging Canadian Anishinaabek First Nations Women in Cervical Cancer Screening: Integrating the Arts in Community Education and Data Collection. The World Alliance for Arts Education Global Summit, Griffith University, Brisbane, Australia. November 27, 2014,

Sameshima, P. Arts Integrated Research, Parallaxic Praxis, Antiphona, and Arts in Community Education. Guest Lecture and Workshop, Hunter Building HB14, Callaghan Campus, University of Newcastle, Australia, December 1, 2014. Sameshima, P. Arts Integrated Research, Parallaxic Praxis, Antiphona, and Arts in Community Education. Guest Lecture, Education Building A35 Room 408, University of Sydney, Australia, December 2, 2014.

Sameshima, P., Slingerland, D., Wakewich, P., Wood, B., & Zehbe, I. Learning through felting. Provoking Curriculum Studies Conference. University of British Columbia, Vancouver, BC, Canada, February 20-21, 2015,

Sameshima, P., Slingerland, D., Wakewich, P., & Zebhe, I. Bridging the arts, sciences, and social sciences in cervical cancer screening education in Northwest Ontario: Highlights from the ACCSS Project. Poster presentation at Research and Innovation Research Week. Lakehead University, Thunder Bay, Ontario, March 6, 2015.

Sameshima, P., Slingerland, D., Wakewich, P., & Zehbe, I. (2015, April 10). Needle felting viruses as pedagogy. Feminisms at the Lakehead 2015, Lakehead University. Gender Issues Centre and Department of Women's Studies, April 10, 2015.

Sameshima, P., Wakewich, P., & Zehbe, I. Growing wellness: Ekphrasic renderings from a First Nations Women cervical cancer screening study. 5th International Symposium on Poetic Inquiry. Vancouver, BC, October 8-10, 2015.

Notes

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The turtle logo for the Anishinaabek Cervical Cancer Screening was designed by

Mr. Kevin Belmore from Kiashke Zaaging Anishinaabek

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