BMJ open accessible medical research

Feasibility of self-sampling and human papillomavirus testing for cervical cancer screening in First Nation women from Northwest Ontario, Canada: a pilot study

Ingeborg Zehbe,[1] Helle Moeller,[1] Alberto Severini,[2] Bruce Weaver,[3] Nicholas Escott,[4] Crystal Bell,[5] Sandra Crawford,[5] Diane Bannon,[5] Natalie Paavola[5]

▸ Prepublication history for this paper is available online. To view these files please visit the journal online (http://bmjopen.bmj.com).

Received 3 December 2010
Accepted 1 February 2011

This final article is available for use under the terms of the Creative Commons Attribution Non-Commercial 2.0 Licence; see http://bmjopen.bmj.com

[1]Thunder Bay Regional Research Institute, Thunder Bay, Ontario, Canada
[2]National Microbiology Laboratory, Health Canada, Winnipeg, Manitoba, Canada
[3]Northern School of Medicine, West Campus, Thunder Bay, Ontario, Canada
[4]Thunder Bay Regional Health Sciences Centre, Thunder Bay, Ontario, Canada
[5]Dilico Family Health Team, Thunder Bay, Ontario, Canada

Correspondence to
Dr Ingeborg Zehbe;
zehbei@tbh.net

ABSTRACT

Background: The incidence of cervical cancer is up to sixfold higher among First Nation women in Canada than in the general population. This is probably due to lower participation rates in cervical cancer prevention programmes.

Objective: To raise screening participation in this underserved population by launching an alternative approach to (Pap)anicolaou testing in a clinic—namely, vaginal self-sampling followed by human papillomavirus (HPV) diagnostics.

Methods: Good relationships were established with a First Nation community of the Northern Superior region in Northwest Ontario, and then 49 community women, aged 25–59, were recruited, who provided a vaginal self-sample and answered a questionnaire. Frequency distributions and cross-tabulations were used to summarise the data. Associations between categorical variables were assessed using the χ^2 test of association, or the Goodman–Kruskal γ if both variables had ordered categories. Self-collected samples were tested for integrity and HPV using optimised molecular biological methods.

Results: The majority of participants (87.2%) were amenable to future HPV screening by self-sampling. This finding was independent of age, educational level and a previous history of abnormal Pap tests. Interestingly, the preferred way to learn about sexual health remained through interaction with healthcare professionals. As defined by the presence of a housekeeping gene, self-sample integrity was high (96%). Using polymerase chain reaction-based Luminex typing, the overall HPV positivity was 28.6% (ie, with either a low- or high-risk type) and 16.3% were infected with a high-risk type such as HPV16.

Conclusion: In this pilot study of First Nation women, self-sampling and HPV testing was well received and self-sample quality was excellent. A larger survey to be conducted in other Northern Superior communities in Northwest Ontario will determine whether this approach could become a viable screening strategy for First Nation women.

ARTICLE SUMMARY

Article focus

- Independent international studies have shown that self-sampling for cervical screening is safe and equally reliable as sampling by a health professional.
- Self-sampling has been reported to increase screening compliance for women who have never or not regularly been screened.
- To date, self-sampling has not been studied in First Nation (aboriginal) women in Canada, an underserved population in whom cervical cancer is up to six times higher than in the general population.

Key messages

- First Nation women participating in this pilot study were amenable to self-collection and 87.2% reported that this alternative screening approach would probably increase their screening participation.
- The preferred way to learn about sexual health is through healthcare professionals.
- Self-sample integrity was high (96%) as defined by the presence of a housekeeping gene. Using polymerase chain reaction-based Luminex typing, 28.6% of the participating women were HPV-positive (ie, with either a low- or high-risk type) and 16.3% were infected with a high-risk type such as HPV16.

Strengths and limitations of this study

- Good relations with the largest First Nation community in Northwest Ontario have been established and our pilot study forms a basis for promoting cervical cancer screening in other First Nation communities in that region.
- A larger study is needed to validate our findings and to achieve good statistical power.

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

INTRODUCTION

Cervical cancer is among the top three cancers affecting women world wide[1] and the third most common cancer in Canada among women aged 20–49.[2] Aboriginal populations appear to be particularly affected by this disease. In Canada, cervical cancer is up to sixfold higher in First Nation women than in the general population in the Northwest Territories,[3] Manitoba[4] and Ontario.[5] Similarly, aboriginal women from Australia and the USA have a higher cervical cancer prevalence than the general population in those countries.[6 7]

Most women who develop cervical cancer have been infrequently or never screened,[8] yet such screening is crucial for early detection of precancerous lesions. Accessing health information and preventive medical services can be challenging for First Nation women[9 10]—their communities are generally rural and remote, transportation is a limiting factor and culturally appropriate, on-site health and educational services may be inadequate. These challenges (as well as the lack of an electronic database to identify seldom or never screened Ontario women) probably contribute to irregular participation of First Nation women in cervical screening in comparison with other Canadian women.[4 11 12]

Lack of accessible or appropriate screening facilities could be overcome by offering a screening test based on self-collection. Indeed, the Canadian National Aboriginal Health Organization suggested that HPV testing based on self-sampling may be a good alternative to (Pap)anicolaou testing to increase participation among First Nation women.[13] In addition, a comprehensive review by the International Agency for Research on Cancer Working Group concluded that human papillomavirus (HPV) testing is a justifiable strategy for cervical cancer prevention.[14] Self-collection of vaginal samples for HPV testing has been investigated as a potential cervical screening method in several populations, with good uptake (reviewed by Stewart *et al*[15] and by Huynh *et al*[16]and references therein[17–20]). Two Swedish studies found that, among women who had not been screened for more than 6 years, 32–58% participated in self-sampling.[18 19] Similar findings have been obtained in a recent Canadian study, suggesting that Caucasian women who do not participate in cervical cancer screening programmes may be willing to provide a self-collected specimen instead.[17] Furthermore, self-collection has been observed to be as reliable as sampling carried out by a doctor for the detection of high-risk HPV associated with an increased risk of cervical cancer.[21]

A study on cervical cancer screening uptake based on self-sampling and HPV testing among First Nation women has never been conducted in Ontario. Before beginning a large investigation in 10 Northern Superior communities in Northwest Ontario (box 1), we conducted a pilot study with 49 First Nation women in the largest of these communities. Our approach was based on convenient self-sampling and sensitive HPV testing, rather than (Pap)anicolaou screening. To assess the feasibility of this alternative method we used a questionnaire in which demographics and cervical cancer knowledge, self-sampling and sexual health were investigated. Sample adequacy and HPV testing methods were also evaluated.

Box 1 Participating Northern Superior communities in alphabetical order

- Fort William First Nation
- Gull Bay First Nation
- Lake Nipigon First Nation
- Long Lake No 58 First Nation
- Pays Plat First Nation
- Pic River First Nation
- Pic Mobert First Nation
- Red Rock First Nation (Lake Helen)
- Rocky Bay First Nation
- Whitesand First Nation

METHODS

Participating First Nation community

Fort William First Nation (FWFN), the community that participated in our pilot study, is situated near Thunder Bay on the northern shore of Lake Superior in Northwest Ontario, Canada. FWFN was created in 1853, as a result of the 1850 Robinson-Superior Treaty. With a total of 1798 individuals registered, of whom 832 live on-reserve, FWFN is the largest of the Northern Superior communities (box 1). The mean population of all communities is 313 (range 70–832). We chose these communities for our investigation since they are part of one strategic region of the Anishinabek Nation inhabiting the northern shore of Lake Superior from Pigeon River to Batchawana Bay. They are under the healthcare portfolio held by the Regional Grand Chief in FWFN.

Approvals

After a meeting with the band council a research agreement, identifying potential benefits for the participants' community, data ownership and plans for dissemination and publication of the results, was signed in September 2009 by FWFN Grand Chief Peter Collins. The agreement adhered to guidelines formulated by the First Nations Information Governance Committee through ownership, control, access and possession.[22] The study was also approved by the local research ethics board of Thunder Bay Regional Health Sciences Centre (TBRHSC REB#2009125). The on-site Dilico family health team (DFHT) agreed to recruit participants and provide feedback about the study approach.

Participant recruitment

A DFHT nurse practitioner (project nurse) served as primary contact for the participating women. To enrol approximately 50 volunteers, recruitment and

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

information dissemination was carried out between 16 November and 18 December, 2009 through a community meeting with an information poster; flyers posted in public places within the community; flyers sent to all community households through the weekly Band newsletter and flyers distributed at parenting workshop nights through the Band office and DFHT staff. Women were not approached individually. All participants automatically took part in incentive draws for five, CAD$100 grocery certificates.

Participant eligibility

Eligibility for our pilot study required that participants: were female; self-reported First Nation ethnicity; registered in FWFN; were aged 25–59 years and had a command of the English language. For safety reasons, women who knew they were pregnant or menstruating were excluded. Women were enrolled from age 25 rather than age 30 because Canadian First Nation women exhibit earlier onset of cervical cancer than the general population[4] and HPV testing is recommended at an earlier age.[23]

Protocol

Eligible women who wanted to participate in the pilot study contacted DFHT staff. The research nurse provided information orally and through the informed consent form, which was explained to, and signed by, the volunteer before taking a self-sample. After taking the self sample, the questionnaire was answered, numbered and sent to the research team in a sealed envelope. Participants could choose whether or not they wanted their test results sent to their healthcare provider (HCP) or to their homes, or to both.

Self-sampling

The project nurse provided each participant with a sterile, plain polyester Dacron swab[15] and transportation tube (Copan Diagnostics Sterile Plain Swab; licensed in Canada by Inverness Medical: #552C). Swabs were sent at ambient temperature in the transportation tube to the National Microbiology Laboratory in Winnipeg. For confidentiality, HPV test results were blinded to the project nurse (sent in individually sealed envelopes, each identifiable by the participant's number). This ensured that members of the research team did not have access to the names of the participants, and the project nurse, to individual test results.

Self-sampled DNA testing

DNA from self-samples was purified using Roche MagnaPure (automated, magnetic bead-based DNA extraction; Roche, Mississauga, Canada), validated specifically for HPV genotyping. Sample integrity was assayed by amplifying the housekeeping gene β-globin by PCR, as described previously.[24]

HPV testing was done by Hybrid Capture II (HCII), based on an antibody capturing RNA:DNA hybrids.[24] HCII generically detects the 13 most common high-risk HPV types (16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59 and 68) at a viral load that best correlates with cervical dysplasia. For specific typing, our in-house Luminex technology,[25] based on nested PCR amplification,[26] was concomitantly used on all 49 participant samples The Luminex method is less expensive than comparable commercial tests and has been successfully used previously.[27]

Reporting of results

Only samples that were positive for high-risk HPV were reported to the participants as "Your sample is positive with a high-risk HPV" followed by the corresponding HPV type with which they were infected. Cases testing negative for high-risk, but positive for low-risk HPV, were reported to the participants as "Your sample is negative for high-risk HPV". When communicating HPV test results to the participating women, it was emphasised that this study was not a substitute for their biennial Pap test. Women who tested positive for a high-risk HPV type were requested to contact their family doctor or the local colposcopy clinic at the Thunder Bay Regional Health Sciences Centre. The research team provided names and contact information of the principal investigator (IZ) and the colposcopist (NE).

Statistical analyses

All analyses were carried out using PASW (formerly SPSS), version 18.0. Data obtained from the questionnaires were examined by frequency distributions and cross-tabulations. Associations between primary questions (general, self-sampling and sexual health) and secondary questions (age, education and abnormal Pap history) were assessed with the Goodman–Kruskal γ (when both variables were ordinal) or Pearson's χ^2 test ($p \leq 0.05$ was considered significant). For 2×2 tables with any expected counts <5, we used the 'N−1' χ^2 test.[28]

RESULTS

The questionnaire (Appendix) was divided into three sections: general questions (including participants' demographics—table 1), questions about self-sampling and questions about sexual health—that is, HPV and cervical cancer (table 2).

General questions

All participants reported having had previous Pap tests, with 67.3% (33/49) screened at least biennially. Fifty-one per cent (25/49) of participants reported a previous abnormal Pap test; this statistic is almost 10-fold higher than that generally seen in Ontario women.[2] Participants with previous abnormal Pap tests reported that they had undergone (52%, 13/25) or were undergoing (36%, 9/25) treatment. Participants without regular Pap tests (32.7%, 16/49) reported a hiatus of up to 20 years. Regular participation in Pap screening was associated with a higher level of education ($p=0.035$) but not with age or previous history of abnormal Pap tests. Willingness to self-sample was not associated with previous level of participation in cervical screening. Four participants

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

Table 1 Demographics of pilot study participants (n=49, unless otherwise indicated)

Metric	Number	Percentage
Ethnicity		
First Nation	47	96.0
Metis	2	4.0
Age range*		
25–39	27	56.2
40–49	12	25.0
50–59	9	18.8
Education†		
University undergraduate	23	48.9
College	12	25.5
High school or lower	12	25.5
Smoker		
At some point	45	91.8
Tampon user	45	91.8

*Only 48 participants responded to the age question.
†Only 47 participants responded to the education question.

were unsure about whether they had received HPV vaccine (Gardasil); everyone else reported that they had not.

Self-sampling questions

As shown in the Appendix, questions 11 and 12 each had nine ordinal response options, ranging from 1=easy/comfortable to 9=difficult/uncomfortable. For analysis, both questions were recorded such that 1–3 became 'easy/comfortable', 4–6 'mid-range' and 7–9 'difficult/uncomfortable'. For acceptability of self-sampling, 77.1% (37/48) found self-sampling easy, 6.3% (3/48) were mid-range, 16.7% (8/48) found it difficult and one did not answer (question 11). Likewise, 61.7% (29/47) participants experienced comfort with self-sampling, 23.4% (11/47) were mid-range, 14.9% (7/47) were uncomfortable and two did not answer (question 12). Thus the majority of participants found self-sampling easy and were comfortable with using it. Consequently, 87.2% (41/47) indicated willingness to participate in self-sampling screening in the future; 8.5% (4/47) did not know if they would participate more regularly; 4.2% (2/47) answered no; and two did not answer (question 13). Sixty-seven per cent (32/48) preferred self-sampling rather than an HCP taking the sample; 18.8% (9/48) had no preference, while 14.6% (7/48) preferred an HCP to take their sample (question 14). For cross-tabulations of questions 11–14 with age, educational level or a previous history of abnormal Pap tests, no statistical significance was achieved in any case.

Sexual health questions

Educational methods

We received 133 suggestions from the 49 participants about the best way to provide education about sexual health (question 15). The preferred way to learn about sexual health was through interaction with an HCP: 35% (47/133). This was followed by the use of audiovisual material—that is, watching a DVD or looking at a poster: 31.6% (42/133). Learning "on my own" and "together with my partner" were the least attractive options: 9.8% (13/133) and 7.5% (10/133), respectively.

Cervical cancer and HPV: knowledge, attitude and behaviour

Participants' knowledge about cervical cancer and HPV was scored as follows, with each of two questions having five possible correct answers (questions 16 and 17; 19 and 20): 1/5 correct=some knowledge; 2/5 correct=fair knowledge; 3/5 correct=good knowledge and 4 or 5 correct=very good knowledge. Importantly, 87.8% (43/49) had knowledge ranging from "some to very good" and about half of the participants had "good or very good" knowledge about cervical cancer. For HPV biology, 69.4% (34/49) of participants had knowledge ranging from "some to very good" and about half of the participants had "good or very good" knowledge. Awareness about cervical cancer and HPV biology was not significantly associated with age, educational level or a history of abnormal Pap tests. Most participants (83.7%; 41/49) were not aware that both men and women can contract HPV infection. Information about cervical

Table 2 Self-sampling and sexual health questions of pilot study participants

Self-sampling	Sexual health
87.2% willing to participate in self-sampling in the future	Educational methods: 35% prefer learning through HCP 31.6% want to use audiovisual material 9.8% want to learn on their own
67% prefer self-sampling to HCP sampling	7.5% want to learn with their partner
77.1% found self-sampling easy and 61.7% found it comfortable	Knowledge, attitude and behaviour: 87.8% have some to very good knowledge about cervical cancer 69.4% have some to very good knowledge about HPV 83.7% did not know that both men and women can be HPV-infected
	Relevance and comprehension of questions: 74% found questions important 69% found questions easy

HCP, healthcare provider.

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

cancer and HPV was mainly obtained from an HCP—65.9% (29/44) and five participants did not answer the question or know about cervical cancer and HPV.

Relevance and comprehension of questions

As shown in the Appendix, questions 22 and 23 had nine ordinal response options ranging from 1=important/easy to 9=not important/difficult. For analysis, these questions were recorded such that 1–3 became 'important/easy', 4–6 'mid-range' and 7–9 'not important/difficult'. Seventy-three per cent of participants (36/49) found the questions important, 6.1% (3/49) were mid-range and 20.4% (10/49) found them unimportant. Sixty-nine per cent (34/49) found the questions easy, 14.3 (7/49) were mid-range and 16.3% (8/49) found them difficult. Thus the majority of participants found the questions that they were asked to answer in the questionnaire both easy and important. The importance of the questions and ease of answering them were positively related ($p<0.001$). Comfort was also related to ease of answering and importance: those who felt most comfortable with self-sampling perceived the questions to be easier ($p=0.000$) and more important ($p=0.001$). However, no statistical significance was reached when both questions were cross-tabulated with age, education or abnormal Pap test history.

HPV testing and typing

Integrity of the self-sampled DNA was high, with 47/49 (96%) testing positive for the β-globin housekeeping gene. Overall, HPV prevalence was 28.6% (14/49); this is within the 10–30% range found in the Canadian adult population (Society of Obstetricians and Gynecologists, Ottawa, Canada).

HPV typing indicated the prevalence of all HPV types (oncogenic and non-oncogenic) in our participants. The detected high-risk HPVs (n=8) included types 16, 35, 52 and 58, which all belong to the phylogenetically related species A9 (HPV 16, 31, 33, 34, 35, 52 and 58).[29] Interestingly, only one case was positive for HPV 39, a member of the other high-risk species, A7 (HPV 18, 26, 30, 39, 45, 51, 53, 56 and 59).[29] Several women (n=6) were positive for low-risk types 13, 54, 83, 89 and 90, which belong to the species A9[29] or to other low-risk groups.[30] Of eight positive cases with high-risk HPV examined using Luminex, only four cases were positive using the less sensitive HCII method. No association was found between testing positive for high-risk HPV and a previous history of abnormal Pap tests.

DISCUSSION

This initiated investigation examines HPV testing based on self-sampling in First Nation women in Ontario for the first time. Our pilot study relied on HPV-specific DNA assays of vaginal swabs provided by participants to a blinded nurse volunteer, complemented with participant feedback via a detailed questionnaire (Appendix). The participants in this pilot study were positively inclined towards self-sampling, preferring self-sampling over HCP sampling. If it becomes clear that self-sampling is an acceptable screening strategy for First Nation women in other Northwest Ontario communities, offering self sampling might be a significant alternative for the recruitment of First Nation women for cervical cancer screening. Some women (14.7%) reported discomfort with self-sampling in our pilot study, yet surprisingly there was no association between discomfort and preference for HCP sampling.

The majority of our study participants had at least some knowledge of cervical cancer and HPV. This acute awareness could be attributable to the patient demographics in our small sample size: they reported higher formal educational levels than those of average First Nation women[31] and several participating women were local health centre employees. An unexpected finding was the low awareness that HPV can infect both men and women.

Although self-sampling was widely embraced, our participants still preferred receiving information about sexual health from an HCP and/or using audiovisual material; self-study and learning with a partner were much less popular. Indeed, most participants obtained HPV knowledge through an HCP, confirming the important role of this professional group in First Nations' health education.

A reliable cervical cancer screening programme has to use state of the art technology. Our study used the most common, 'best practice' self-sampling device described in several Canadian studies—the Dacron swab.[15] The use of vaginal tampons[32] is not recommended because DNA extraction from tampons is time consuming and inefficient (Dr Alberto Severini, unpublished results). Two available tools can be used for cervical screening: the Pap test,[33] with its high specificity but low sensitivity (detecting only 50% of high-grade cervical lesions), and the highly sensitive (close to 100%) HPV tests.[11 34 35] As a primary screening tool, HPV testing can lead to increased detection of high-grade cervical lesions and allow larger screening intervals than the Pap test,[33–37] probably resulting in lower costs and higher screening participation. Furthermore, HPV testing can be conveniently performed on self-collected samples, which further reduces HCP hours and costs. Consequently, our approach included HPV testing and typing.

Self-sample integrity in our study was found to be excellent and at least similar to, or even better than, that found in other studies.[23] The overall HPV prevalence of 28.6% (and 16.3% for high-risk types) was within the upper range of the overall Canadian population.[2] Interestingly, typing revealed almost exclusively HPV types phylogenetically like type 16, but not type 18. Similar findings were reported recently in a study involving aboriginal women from a Northern Plain American Indian reservation outpatient clinic.[38] Of note, our more sensitive in-house Luminex technique detected twice as many positive cases

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

of high-risk HPV as did HCII because HCII was developed to detect only clinically relevant cases whereas the Luminex technique detects latent HPV infections.

Limitations

Despite the small sample size of our pilot study, similar studies among Caucasian populations in Canada and elsewhere are in agreement with our findings.[15–20] Our study population differs from that which might be expected in First Nation communities, which renders generalisation difficult. The high participation in regular Pap screening may be connected to a higher level of education in our participants than among most Canadian First Nation women. Indeed, we found a positive, statistically significant association between higher education and participation in cancer screening. On the other hand, participants who did not have regular Pap screening reported intervals of up to 20 years. Self-reported rates have to be considered cautiously because of over-reporting. Indeed discrepancies between self-reporting and medical charts have been published by several independent studies[39] with concordance rates between 65% and 89%. Our participants also had easy access to the collaborating health centre in FWFN, which advocates Pap tests for First Nation women and may explain the rather high reported rate of previous Pap tests. The situation differs for members of the other Northern Superior communities who are required to travel to larger cities like Thunder Bay for their health needs (Lee Sieswerda, epidemiologist, Public Health Unit Thunder Bay, personal communication).

CONCLUSIONS AND FUTURE DIRECTIONS

Our findings indicate that HPV testing based on self-sampling is feasible among First Nation women in Ontario. The majority of women agreed that self-sampling would be the preferred way of taking the sample. We are aware, however, that the women who took part in this pilot study reported having had cytology at least once and that accessing unscreened First Nation women is challenging, a factor that will be dealt with in our larger study. A high sample quality and HPV prevalence, comparable to that of the general Canadian population, was obtained in this pilot study. Based on the success of this pilot study, we will conduct a larger-scale study of cervical cancer screening in 10 Northern Superior communities in Northwest Ontario. In view of the demographics in the communities we will be able to recruit more than 800 women. Owing to over-rated self-reporting when assessing the screening history,[39] a chart review of previous Pap screening will be performed. A key question to be answered in the larger study will be how best to reach and provide sexual health education to underscreened women. We will also ask participating women to explicitly rate their discomfort by comparing HCP sampling with self-sampling.

Acknowledgements The authors thank the following for their assistance with this project: the women who volunteered in this study; the Fort William First Nation community and Band Council headed by Chief Peter Collins; individuals with an advisory role: Lee Sieswerda, Carrianne Agawa, Gerry Martin, Alison McMullen, Tony Jocko, Tarja Heiskanen and Cindy Sinnott. We further thank Vanessa Goleski for assisting with HPV testing and typing.

Funding The Northern Health Fund provided financial support for this pilot project.

Competing interests There are no industry relationship with the present study.

Patient consent The research nurse provided information orally and through the informed consent form, which was explained to, and signed by, the volunteer before taking a self-sample.

Ethics approval Ethics approval was provided by Thunder Bay Regional Health Sciences Centre.

Contributors IZ designed and conducted most of the study and took the lead in performing the statistical analyses together with BW and in writing the manuscript. HM assisted substantially in these activities and NE assisted with study design and writing up the manuscript. AS performed HPV testing and typing. CB, SC, DB and NP provided input to the study design and instructed volunteers about sample taking and filling out the questionnaire. All authors provided input into writing the manuscript.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Technical appendix, statistical code, and dataset available from the corresponding author at zehbei@tbh.net. Consent was not obtained but the presented data are anonymised and risk of identification is low also because questionnaires were coded and researchers had no access to the names of the participants.

REFERENCES

1. Saslow D, Castle PE, Cox JT, *et al*. American Cancer Society Guideline for human papillomavirus (HPV) vaccine use to prevent cervical cancer and its precursors. *CA Cancer J Clin* 2000;57:7–28.
2. Health Canada. *Cervical Cancer Screening in Canada: 1998 Surveillance Report* http://www.phac-aspc.gc.ca/publicat/ccsic-dccuac/index-eng.php 2002.
3. Corriveau A. Cancer incidence and mortality in the NWT 1991 to 1996. *Epi-North* 1997;9:5.
4. Young TK, Kliewer E, Blanchard J, *et al*. Monitoring disease burden and preventative behavior with data linkage: cervical cancer among aboriginal people in Manitoba, Canada. *Am J Public Health* 2000;90:1466–8.
5. Marrett LD, Chaudhry M. Cancer incidence and mortality in Ontario First Nations, 1968–1991 (Canada). *Cancer Causes Control* 2003;14:259–68.
6. Dignan M, Sharp P, Blinson K, *et al*. Development of a cervical cancer education program for native American women in North Carolina. *J Cancer Educ* 1995;9:235–42.
7. Reath J, Carey M. Breast and cervical cancer in indigenous women-overcoming barriers to early detection. *Aust Fam Physician* 2008;37:178–82.
8. Spence AR, Goggin P, Franco EL. Process of care failures in invasive cervical cancer: systematic review and meta-analysis. *Prev Med* 2007;45:93–106.
9. Moeller H. Tales about tuberculosis and colonization: the socio-cultural experience of tuberculosis in Nunavut. *Alaska Med* 2007;49:179–83.
10. Moeller H. Current tales about tuberculosis and colonialism in Nunavut. *J Aboriginal Health* 2010;5:1.
11. Healey SM, Aronson KJ, Mao Y, *et al*. Oncogenic human papillomavirus infection and cervical lesions in aboriginal women of Nunavut, Canada. *Sex Transm Dis* 2001;28:694–700.
12. Clarke HF, Joseph R, Deschamps M, *et al*. Reducing cervical cancer among First Nation women. *Can Nurse* 1998;94:36–41.
13. First Nations Centre. *Cancer of the Cervix in North American Indian Women*. Ottawa: First Nations Centre at the National Aboriginal Health Organization2006.
14. International Agency for Research on Cancer (IARC); World Health Organization. *IARC Confirms Efficacy of Cervix Cancer Screening for Women 25–65 in Reducing Mortality. Press Release No.: 151. IARC Cervix Cancer Screening Meeting* 2004. http://www.iarc.fr/pageroot/PRELEASES/pr151a.html (accessed 12 May 2004).
15. Stewart DE, Gagliardi A, Johnston M, *et al*. HPV Self-collection Guidelines Panel. Self-collected samples for testing of oncogenic

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

human papillomavirus: a systematic review. *J Obstet Gynaecol Can* 2007;29:817–28.
16. Huynh J, Howard M, Lytwyn A. Self-collection for vaginal human papillomavirus testing: systematic review of studies asking women their perceptions. *J Low Genit Tract Dis* 2010;14:356–62.
17. Ogilvie G, Krajden M, Maginley J, *et al*. Feasibility of self-collection of specimens for human papillomavirus testing in hard-to-reach women. *CMAJ* 2007;177:480–3.
18. Stenvall H, Wikström I, Wilander E. High prevalence of oncogenic human papillomavirus in women not attending organized cytological screening. *Acta Derm Venereol* 2007;87:243–5.
19. Wikstrom I, Stenvall H, Wilander E. Attidudes to self-sampling of vaginal smear for human papillomavirus analysis among women not attending organized cytological screening. *Acta Obstet Gynecol Scand* 2007;86:720–5.
20. Sanner K, Wikström I, Strand A, *et al*. Self-sampling of the vaginal fluid at home combined with high-risk HPV testing. *Br J Cancer* 2009;101:871–4.
21. Moscicki AB, Widdice L, Ma Y, *et al*. Comparison of natural histories of human papillomavirus (HPV) detected by clinician- and self-sampling. *Int J Cancer* 2010;127:1882–92.
22. http://www.naho.ca/firstnations/english/documents/FNC-OCAP_001.pdf.
23. Bhatla N, Lalit D, Rajkumar AP, *et al*. Can human papillomavirus DNA testing of self-collected vaginal samples compare with physician-collected cervical samples and cytology for cervical cancer screening in developing countries? *Cancer Epidemiol* 2009;33:446–50.
24. Zehbe I, Wilander E. Nonisotopic ELISA-based detection of human papillomavirus-amplified DNA. *Mod Pathol* 1997;10:188–91.
25. Goleski V, Severini A, Dawood M, *et al*. Luminex based assay for multiplexed genotyping of 45 mucosal human papillomavirus types. *Int J Antimicrob Agents* 2009;34(Suppl 2):17–18.
26. Gravitt PE, Peyton CL, Alessi TQ, *et al*. Improved amplification of genital human papillomaviruses. *J Clin Microbiol* 2000;38:357–61.
27. Antonishyn NA, Horsman GB, Kelln RA, *et al*. Distribution of Human Papillomavirus Types Among Patients at a Colposcopy Referral Clinic in Saskatchewan, Canada. *Arch Pathol Lab Med* 2007;132:54–60.
28. Campbell I. Chi-squared and Fisher-Irwin tests of two-by-two tables with small sample recommendations. *Stat Med* 2007;26:3661–75.
29. de Villiers EM, Fauquet C, Broker TR, *et al*. Classification of papillomaviruses. *Virology* 2004;324:17–27.
30. Terai M, Burk RD. Identification and characterization of 3 novel genital human papillomaviruses by overlapping polymerase chain reaction: candHPV89, candHPV90, and candHPV91. *J Infect Dis* 2002;185:1794–7.
31. Statistics Canada (2006a). *Aboriginal Identity (8), Age Groups (8), Area of Residence (6), Sex (3) and Selected Demographic, Cultural, Labour Force, Educational and Income Characteristics (233), for the Total Population of Canada, Provinces and Territories, 2006 Census - 20% Sample Data*. http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/tbt/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=0&GK=0&GRP=1&PID=97446&PRID=0&PTYPE=88971, 97154&S=0&SHOWALL=0&SUB=0&Temporal=2006&THEME=73&VID=0&VNAMEE=&VNAMEF= (accessed 18 Oct 2010).
32. Coutlée F, Hankins C, Lapointe N. Comparison between vaginal tampon and cervicovaginal lavage specimen collection for detection of human papillomavirus DNA by the polymerase chain reaction. The Canadian Women's HIV Study Group. *J Med Virol* 1997;51:42–7.
33. Leinonen M, Nieminen P, Kotaniemi-Talonen L, *et al*. Age-specific evaluation of primary human papillomavirus screening vs conventional cytology in a randomized setting. *J Natl Cancer Inst* 2009;101:1612–23.
34. Tota J, Mahmud SM, Ferenczy A, *et al*. Promising strategies for cervical cancer screening in the post-human papillomavirus vaccination era. *Sex Health* 2010;7:376–82.
35. Kitchener HC, Almonte M, Gilham C, *et al*; ARTISTIC Trial Study Group. ARTISTIC: a randomised trial of human papillomavirus (HPV) testing in primary cervical screening. *Health Technol Assess* 2009;13:1–150iii–iv.
36. Mayrand MH, Franco EL. Integrating novel primary- and secondary-prevention strategies: the next challenge for cervical cancer control. *Future Oncol* 2010;6:1725–33.
37. Ratnam S, Franco EL, Ferenczy A. Human papillomavirus testing for primary screening of cervical cancer precursors. *Cancer Epidemiol Biomarkers Prev* 2000;9:945–51.
38. Bell MC, Schmidt-Grimminger D, Patrick S, *et al*. There is a high prevalence of human papillomavirus infection in American Indian women of the Northern Plains. *Gynecol Oncol* 2007;107:236–41.
39. Howard M, Agarwal G, Lytwyn A. Accuracy of self-reports of Pap and mammography screening compared to medical record: a meta-analysis. *Cancer Causes Control* 2009;20:1–13.

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

APPENDIX

Part I: General questions

1) What is your age?
- ☐ 25-39
- ☐ 40-49
- ☐ 50-59
- ☐ No answer

2) Do you consider yourself:
- ☐ First Nation
- ☐ Métis
- ☐ Other (please specify)
- ☐ Do not know
- ☐ No answer

3) Highest level of formal schooling achieved:
- ☐ Less than High School graduate
- ☐ High School graduate
- ☐ College degree
- ☐ University degree, please specify
- ☐ Other, please specify
- ☐ No answer

4) Have you ever smoked?
- ☐ Yes
- ☐ No
- ☐ No answer

5) Is cervical cancer screening valuable?
- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ No answer

6) Have you had Gardasil vaccination?
- ☐ Yes
- ☐ No

7) Have you ever had a Pap test?
- ☐ I have Pap tests regularly (about every 2 years)
- ☐ I have had Pap tests, but not regularly
- ☐ I have never had a Pap test taken
- ☐ Do not know
- ☐ No answer

8) If you have had Pap tests before: Have you ever had an abnormal Pap test?
- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ No answer

9) If you had an abnormal Pap test before which statement best describes your present situation?
- ☐ I have been treated
- ☐ I am still being followed by my doctor
- ☐ I decided not to have treatment or further follow-up
- ☐ Do not know
- ☐ No answer

10) Have you ever used tampons?
- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ No answer

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

Part II: Questions about self-sampling

11) When taking your own sample today, did you find this easy or difficult? Please, answer on a scale from 1 to 9.

☺ ☹

Easy _____ Difficult

1 2 3 4 5 6 7 8 9

☐ Do not know
☐ No answer

12) When taking your own sample today, did you feel comfortable or uncomfortable? Please, answer on a scale from 1 to 9.

☺ ☹

Comfortable _____ Uncomfortable

1 2 3 4 5 6 7 8 9

☐ Do not know
☐ No answer

13) Assuming that self-sampling and sampling by a physician/nurse practitioner are equally good for testing what would you prefer in a future screening program?

☐ Self-sampling (at home or at Health Centre)
☐ Sample taken by a physician/nurse practitioner
☐ Does not matter
☐ Do not know
☐ No answer

14) If you have the option of using self-sampling, is it more likely that you would regularly participate in future cervical cancer screening?

☐ Yes
☐ No
☐ Do not know
☐ No answer

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

Part III: Questions about sexual health: HPV and cervical cancer

15) What is the best way for you to receive information about sexual health? (Check all that apply)

- ☐ Watching a DVD where pictures are shown and explanations are given orally at the same time
- ☐ Looking at a poster where things are described with pictures and text
- ☐ Directly interacting with a Health Care Provider to whom I can ask questions after having read a pamphlet
- ☐ Directly interacting with a health care provider who uses a life size model of the female reproductive tract so things can be demonstrated and we can talk about what we see
- ☐ On my own
- ☐ Together with my partner
- ☐ In a small group with other women I know
- ☐ None of the above
- ☐ Other suggestions:
- ☐ Do not know
- ☐ No answer

16) What do you know about cervical cancer? (Check all that apply)

- ☐ A form of cancer that affects middle-aged women the most
- ☐ A form of cancer that affects younger women the most
- ☐ A form of cancer that affects the lower genital tract of women
- ☐ Persistent infection with some types of HPV causes cervical cancer
- ☐ Cervical cancer is the second most common cancer in women worldwide
- ☐ Only women who have ever been sexually active may develop cervical cancer
- ☐ Both women who are and women who have ever been sexually active may develop cervical cancer
- ☐ Do not know
- ☐ No answer

17) What do you know about prevention of cervical cancer? (Check all that apply)

- ☐ Regular screening can almost entirely prevent me from getting it
- ☐ I can get a Pap test done
- ☐ I can get an HPV test done
- ☐ I would get HPV vaccine
- ☐ I am not in danger of getting cervical cancer if I use birth control pills
- ☐ I am not in danger of getting cervical cancer if my partner uses condoms during sexual activity
- ☐ Do not know
- ☐ No answer

18) Where did you obtain your knowledge about cervical cancer? (Check all that apply)

- ☐ By reading the information provided for this study
- ☐ Through a health care provider
- ☐ Through the newspaper/magazines
- ☐ Through television
- ☐ Through the internet
- ☐ Through friends/ relatives
- ☐ Other, please specify:
- ☐ Do not know
- ☐ No answer

19) What do you know about HPV? (Check all that apply)

- ☐ HPV is a common sexually transmitted virus
- ☐ Many HPV types exist and some of them cause cervical cancer
- ☐ Rates of HPV infection are highest in women between the ages of 20 and 30
- ☐ Not all HPV infections lead to cervical cancer but all cervical cancers are most likely caused by HPV infections that do not go away
- ☐ If I have HPV I can get medication to treat it
- ☐ Both men and women can get HPV
- ☐ Only women can get HPV
- ☐ A positive HPV test is generally accompanied by pain and fever
- ☐ A positive HPV test is generally not accompanied by any symptoms
- ☐ Other, please specify:
- ☐ Do not know
- ☐ No answer

20) What do you know about prevention of HPV? (Check all that apply)

- ☐ Using a condom when having intercourse can decrease the likelihood of getting HPV
- ☐ Using a condom also helps to avoid other sexually transmitted diseases such as HIV, Chlamydia and fungus
- ☐ If I never have intercourse I will not get HPV
- ☐ By having only one or few partners I can decrease the likelihood of getting HPV
- ☐ By having only one or few partners I will not get HPV
- ☐ Using birth control pills will prevent me from getting HPV
- ☐ The HPV vaccine is given to girls in grade 8
- ☐ The HPV vaccine is given to girls and boys in grade 8
- ☐ Other, please specify:
- ☐ Do not know
- ☐ No answer

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.

21) Where did you obtain your knowledge about HPV? (Check all that apply)

- ☐ By reading the information provided for this study
- ☐ Through a health care provider
- ☐ Through the newspaper/magazines
- ☐ Through television
- ☐ Through the internet
- ☐ Through friends
- ☐ Through relatives
- ☐ Through parents
- ☐ Other, please specify:
- ☐ Do not know
- ☐ No answer

22) What did you think about the importance of the questions we were asking you? Please, answer on a scale from 1 to 9.

☺ ☹

Important _____ Not important

1 2 3 4 5 6 7 8 9

- ☐ Do not know
- ☐ No answer

23) Did you find that the questions were easy or difficult to answer? Please, answer on a scale from 1 to 9.

☺ ☹

Easy _____ Difficult

1 2 3 4 5 6 7 8 9

- ☐ Do not know
- ☐ No answer

Your participation is appreciated. Thank you for your time.

The Research Team

BMJ Open: first published as 10.1136/bmjopen-2010-000030 on 26 February 2011. Downloaded from http://bmjopen.bmj.com/ on April 17, 2024 by guest. Protected by copyright.