

ALL MY RELATIONS: PATIENT ORIENTED RESEARCH FOR RECONCILIATION &  
EMPOWERMENT OF INDIGENOUS WOMEN'S EXPERIENCES WITH CERVICAL  
SCREENING

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## **Abstract**

Cervical cancer is caused by high risk strains of the Human Papillomavirus (HPV), but is preventable through vaccination and screening. In British Columbia (BC), cervical cancer occurs predominantly in under screened women, and First Nations women have a 92% higher rate of invasive cervical cancer than non-First Nations women. The current standard of care in the province screening is via the Pap test; Indigenous women experience complex barriers to accessing Pap testing, which has contributed to the higher rates of cervical cancer. CervixCheck North (CCN) is a project in partnership with Carrier Sekani Family Services (CSFS) that offers under screened First Nations women in 11 Northern BC First Nations communities the option to self-collect a sample to be tested for the presence of cancer-causing HPV. This thesis explores the ability of patient oriented research, in combination with Indigenous methodologies to conduct ethical research in First Nations communities, and offers a qualitative review and suggested improvements to CCN. Data was collected from 6 communities using focus groups and a survey, and analyzed using thematic analysis and network analysis. Eleven themes were selected from the transcript data at four levels of impacts to cervical screening, individual, community, health system, and research level, and vetted by community members in an iterative process. Theme convergence was found to occur at the community level, surrounding knowledge acquisition as a source of empowerment. In order to maximize the positive impacts of HPV self-collected projects, holistic health approaches must be taken that involve health education community events. Recruitment of the most vulnerable women is facilitated by offering various options for women to screen, and by hiring champions for the project who are trusted members of the community. For researchers, using both patient oriented methodologies and Indigenous methodologies functions to bridge the divide between Western and Indigenous ways of knowing within academia. At a policy level, the most impactful changes to the health care system that can function to improve Indigenous peoples' health must be informed by Indigenous voice, and meaningfully incorporated into existing health structures to truly achieve self-determination and reconciliation.

## **Lay Summary**

Cervical cancer is caused by the Human Papillomavirus (HPV), but is preventable through vaccination and screening. In British Columbia (BC), cervical cancer occurs predominantly in under screened women, and First Nations women have a 92% higher rate of cervical cancer than non-First Nations women. Screening in BC occurs via the Pap test, but Indigenous women experience complex barriers screening. CervixCheck North (CCN) is a project offering Northern BC First Nations women the option to self-screen for cervical cancer. This thesis uses patient oriented research and Indigenous methodologies to conduct a review of CCN. Data was collected using focus groups and surveys. To maximize the impacts of HPV self-collected projects, holistic health approaches incorporating community health education events must be taken, and community champions for the project should be hired. At a policy level, impactful changes to the health care system stem from Indigenous voice, and help to achieve reconciliation.

## **Preface**

This dissertation is original, unpublished, independent work by the author, M. Giovannoni.

The project described in Chapter 4 is a project in partnership with Carrier Sekani Family Services, and was covered by UBC Ethics Certificate number H19-00131. This project underwent harmonized review with the UNBC research ethics board, and the Carrier Sekani Family Services research ethics board.

The fieldwork reported in Chapter 4 was covered by UBC Ethics Certificate number H19-01299

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## List of Abbreviations

BCCDC:	British Columbia Center for Disease Control
CBPAR:	Community-based Participatory Action Research
CBRA:	Community-based Research Assistant
CCF:	CervixCheck Fraser
CCN:	CervixCheck North
CHR:	Community Health Representative
CIHR:	Canadian Institute for Health Research
CIN:	Cervical Intraepithelial Neoplasia
CSFS:	Carrier Sekani Family Services
DNA:	Deoxyribonucleic Acid
HISL:	High-grade squamous intraepithelial lesion
HPV:	Human Papillomavirus
LSIL:	Low-grade squamous intraepithelial lesion
MOA:	Medical Office Assistant
NBC:	Northern British Columbia
OCAP:	Ownership, control, access, possession
Pap:	Papanicolau
POR:	Patient-Oriented Research
RCT:	Randomized Controlled Trial
SCJ:	Squamocolumnar junction
STD:	Sexually Transmitted Disease
STI:	Sexually Transmitted Infection

## **Glossary**

Carrier Sekani Family Services: An organization offering health and wellness services to eleven Northern Interior BC First Nations communities

Indigenous: An inclusive term used to describe people who identify as First Nations, Métis or Inuit.

First Nations: Any of the groups of Indigenous people in Canada, with or without “Indian Status”, excluding Métis and Inuit people.

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To my friends ~ For sharing this experience with me, supporting me through the lows and celebrating with me through the highs

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To my love ~ for loving me forever and always, believing in me, and giving me the freedom to grow and make a difference in this world

*To all my relations*

## **Chapter 1: Introduction**

### **1.1 Positionality**

A critical and difficult step in my research journey has been to locate myself within my research, and to reflect on how my identity brought me to this project, and the affect that my identity has undoubtedly had on the outcomes of my research. According to Absolon and Willett, when locating oneself in research we are making a claim about our intentions for our research projects, and describing how our life stories have brought us to ask these questions (1). While objectivity is my goal, my research will undoubtedly be affected by my epistemology, or way of experiencing and understanding the world. Thereby, my experiences, beliefs, worldview and way of knowing the world become critical in identifying biases and assumptions I possess that could impact my research. I offer a brief introduction of myself as the storyteller, with the understanding that my position has affected why these words have been chosen for this paper, and for the reader of this thesis to understand the viewpoint from which this research has been written.

I was born in Edmonton, on the traditional territory of the Cree, Sauleaux, Niisitapi (Blackfoot), Métis, and Nakota Sioux people- although I was not aware of this, or the existence of traditional territory, until I reached post-secondary. My grandparents immigrated from Italy to Canada, making me a third-generation Italian settler in Canada. I was raised according to Western, Roman Catholic worldviews that taught that individuals must work hard in order to secure their happiness, hard workers would be rewarded in life, and those who did not work hard could never be successful. This worldview, coupled with my lack of exposure to the world outside of our particularly white suburb forced the development of a set of stereotypes surrounding non-white, non-middleclass people that lacked sympathy, and laid individual blame. When I reached university, I was able to leave the bubble of my upbringing and became more aware of my biases, and privilege.

During those four years, I discovered my passion for reproductive healthcare and feminism. Through my biology classes, I became mystified by the strength of women's bodies and fascinated by the intricacy of reproductive cycles, foetal development, and hormone cascades. My appreciation for women's strength became fortified through my gender studies classes, where I heard stories of the historical and ongoing fight for women's rights. This is also where I became acutely aware of my position of privilege in society, and how my whiteness, middle-classness and able-bodiedness have contributed to my success thus far, and will

continually benefit me through my life (2). I also gained an awareness of how society's insistence on normativity has negatively impacted me, as a member of an adoptive family. I worked, and am still working towards dismantling the stereotypes and assumptions I grew up with, and am humbled by my belief that I was born into this position of privilege because of both dumb luck, and the decisions of those who came before me. I have always been very uncomfortable with my privilege. One of the ways I have located to manage my guilt, is to dedicate myself to being an ally to marginalized people, and do my part to dismantle unequal power structures that hinder the pursuit of equity. I am particularly shaken by the inequality that permeates women's healthcare, which contributes to a lack of access to safe, judgement-free reproductive healthcare for all women. I felt the need to participate in a project that combined both my passion for reproductive healthcare with my urge to make a difference in the disparities in the health care system. That is what brought me to this project. It presented an opportunity for allyship with marginalized women in the pursuit of high-quality reproductive healthcare.

I present myself as a settler researcher who understands that I will bring a non-Indigenous lens to this important research. I do not have the same life experiences or worldview as an Indigenous researcher, and therefore I know that I cannot bring the same kind of analysis and contribution to self-determination that an Indigenous researcher would be able to. However, as Shawn Wilson advises, I have "checked my heart", and made certain that my heart's motives are good (3). As such, I commit to doing this research not only to receive a degree, but for the women in the communities that I have visited. I commit to listening to stories, suggestions and criticisms, and consistently learning and adapting my research in order to best serve the women that I am dedicated to working with.

## 1.2 Overview and Summary

The first chapter of this thesis offers a background review of the literature on the pathophysiology of cervical cancer, the virology of the Human Papillomavirus (HPV) and the current cervical screening options. It will situate the reader with prevalence rates of cervical cancer in Indigenous populations in BC, and background knowledge on how HPV self-collected screening is beginning to be implemented in various modalities and locations across Canada to reach under screened women.

The following chapter will ground my work in a theoretical framework. This framework serves as the foundation of all aspects of this research project, from the development of my research question, to the analysis of my data and finally the writing of this very thesis. This chapter will outline the social determinants of Indigenous health model, postcolonialism, the feminist theory of Intersectionality and finally, Indigenous feminisms as grounding theories. It will also offer an explanation as to why this framework is uniquely suitable to this research project.

Methodology is a central component to this thesis; the third chapter of this work will outline Indigenous research methodologies and patient oriented research (POR) methodologies. It will describe how Indigenous methodologies have empowered Indigenous researchers to decolonize the institutional research environment, and reclaim research from settler hands, to do work that matters to them and their communities. Further, it will describe the newly popularized methodology of POR, a methodology that seeks to involve patients on the research team, in order to do projects that matter to patients, and improve health outcomes. The shared tenets of the two methodologies will be highlighted, and the potential for these two methodologies to working work cohesively towards reconciliation when conducting health research with Indigenous communities will be emphasized.

The fourth chapter will outline the CervixCheck HPV self-collected HPV screening project and the CervixCheck North (CCN) branch of the project seeking to facilitate engagement in cervical screening for under screened Indigenous women in Northern British Columbia. It will describe the methods of the qualitative review of CCN, and highlight women's voices through survey and focus group data. The reader will gain an understanding of NBC First Nations women's experiences with cervical screening, and read their suggestions on how to improve community health. This section will also provide an example for how to conduct POR in Indigenous communities in order to inform improvements to research projects.

The final chapter offers suggestions at the programmatic and at the policy level for how to improve self-collected HPV interventions in First Nations communities, and make meaningful changes to the health system that prioritize a path to reconciliation with Indigenous people.

## 1.3 Background

### 1.3.1 Cervical Cancer and the Human Papillomavirus

Cervical cancer is among the deadliest cancers for women, worldwide (4). It is unique among cancers because of its singular known cause, persistent infection with HPV. In Canada, mortality rate from cervical cancer is lower than the global average due to aggressive screening programs (5). HPV is the most prevalent sexually transmitted infection in Canada, with 75-80% of all sexually active adults becoming infected at some point in their lives (4). It is transmitted through intimate touching, including oral, anal, vaginal and digital sex. Many HPV infections are symptomless, although the most common presentation of non-oncogenic (low-risk) strains of the virus is the presence of anogenital warts. Over 90% of HPV infections are cleared by the immune system without medical intervention, however, if they are not cleared, persistent oncogenic (high-risk) virus infection can lead to cancer (6). The virus is responsible for cancer of the cervix and for some cancers of the vulva, vagina, penis, anus, mouth, and oropharynx. At present, 130 HPV types have been identified, and are either classified as high or low risk, depending on their oncogenic capabilities (7). The types of HPV that are of importance to this thesis are the fourteen types of HPV that can cause cervical cancers and precancerous lesions of the cervix, types 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 66, 68 and 70. HPV types 16 and 18 are the most common strains of the virus, associated with cervical cancers, with type 16 accounting for 50-70% of all cervical cancer cases worldwide (6).

HPV infects squamocolumnar junction (SCJ) cells that sit between the squamous cells of the exocervix and the columnar cells of the endocervix, in an area known as the transformation zone (8). The cells of the transformation zone are in a continuous state of remodeling as old SCJ cells are replaced by new SCJ cells in a process called metaplasia. This continuous state of change makes the cells of the transformation zone uniquely vulnerable to HPV infection. After infection with an oncogenic HPV type, the cells can undergo cervical dysplasia. Dysplasia, or cervical intraepithelial neoplasia (CIN) causes SCJ metaplasia cells on the surface of the cervix to grow to irregularly (4). There are two grades of CIN currently recognized; low grade

squamous intraepithelial lesion (LSIL) or high grade squamous intraepithelial lesion (HSIL) (9). In BC, LSIL lesions are classified as CIN1, mild dysplasia caused by high and low risk HPV strains, and HSIL lesions are classified as CIN2, moderate, and CIN3, severe (6). Additional co-factors for cervical cancer include high parity, HIV infection, immunosuppression, oral contraceptive use and smoking for commercial tobacco (4).

Provincially, cervical cancer control is being addressed via vaccination programs, as well as screening using the Papanicolaou test (5). Pap testing technology has been a keystone in women's reproductive public health since its incorporation into BC health practice in the 1960's, and has succeeded in lowering the mortality rate from cervical cancer in Canada by 83% (5, 10). As of 2016, screening guidelines in BC recommend screening women using the Pap test every 3 years, from age 25 to age 69 (11). The Pap test is a highly effective method of testing, with a sensitivity of approximately 70%, and a specificity of approximately 95% (12). Furthermore, the HPV9 vaccine, which is currently being offered free of charge in-school to students of all genders in the 6<sup>th</sup> grade, can effectively protect against 90% of cases of cervical cancers, 80% of all cases of anal cancers and 90% of cases of genital warts (13). It is expected that the rate of cervical cancer in Canada will continue to drop as a result of the vaccination program. As of 2017 in BC, 63% of women are attending regular screening; however, a large percentage of eligible women either have not been screened over the past five years, or have never been screened (14). This can be especially impactful given that, in BC, approximately 200 women per year are diagnosed with cervical cancer, and on average, the majority of newly diagnosed cases of cervical cancer are in under or never screened women (15, 16). This is compounded by the fact that it is estimated that in 2019, 30.4% of Canadian women diagnosed with cervical cancer will die from the disease (17). Therefore, encouraging under screened women to participate in screening programs quite literally has the potential to save women's lives.

Since cervical dysplasia is treatable with early detection, there is an indirect correlation between engagement in screening programs and incident cases of cervical cancer (18). Women of low socioeconomic status, women in rural communities, immigrant women, and otherwise vulnerable populations of women are among those with the lowest engagement in screening programs (18). Rurality has been cited as a risk factor for cervical cancer because of the unique challenge of offering cervical cancer screening in rural communities (19). This was examined in a meta-synthesis reviewing thematic data from qualitative studies that examined the impact of HPV screening for cancer prevention among adult women living in rural communities, in high income countries. Researchers isolated 14 studies from after 2002 that related directly to rural

women's experiences with screening, and located two main themes influencing women's decision to access screening; first, their interactions with care providers, and second, their access to the health care system. During interactions with care providers, women were more likely to seek screening if the doctors exhibited patient-centered care, and had effective communication styles. For instance, women preferred doctors who gave concise and thorough information, made eye contact with them, responded to questions, and demonstrated cultural sensitivity. In contrast, it was found that screening can be hindered by existing social relationships between patients and their care providers, as a result of the smaller population of the rural community. Women avoided screening because of these existing social relationships, but also because of perceived stigmatization of rurality, mistrust of care providers and lack of culturally and linguistically accessible care. Further barriers are listed under the theme of healthcare access; structural and logistic barriers included a lack of care providers, funding and privacy in rural communities as inhibitors to screening. This meta-synthesis illustrates that the most effective way to screen women for cervical cancer is an approach that puts the patient at the forefront, is able to maintain women's privacy, and be delivered efficiently despite being in a rural or remote geographies (19).

As a result of colonialism, many Indigenous groups were stripped from their traditional lands and placed on reserves, deliberately farther away from city-centers, where access to care presents unique challenges (20). First Nations women in BC have a 92% higher rate of cervical cancer than non-First Nations women (15). Some contributing factors for cancer of the cervix being one of the most common cancers affecting First Nations women in Canada today include rurality, as almost half of First Nations women live on reserve in rural or remote communities, as well as the impact of higher prevalence of commercial tobacco use among First Nations women (15). Notably, a powerful societal level determinant for the discrepancy in rates of HPV and cervical cancer is the lack of culturally safe screening options, which has left Indigenous women chronically under screened (15, 21, 22). In fact, due in part to the lack of appropriate early detection methods, Indigenous women have been found to have Pap testing rates of only 50% compared to 85% for all ever-screened women (23). This is due to a number of complex barriers to Pap screening such as rural and remote geographies, lack of qualified care providers, lack of trusting relationships with care providers, concerns of confidentiality in small communities, fear of stigma surrounding HPV and intergenerational trauma rooted in Canada's dark colonial history (23). As a result, Indigenous women in Canada can have from 2 to 20 times the risk of cervical cancer depending on the province (24).

In order to better understand the screening experience for First Nations women, a 2013 study reviewed provider perspectives on structural barriers to cervical cancer screening for First Nations women in Ontario (24). In depth interviews with First Nations and non-First Nations care providers allowed researchers to identify ten unique barriers affecting women's ability to access regular screening, and subsequent follow-up. These included community level barriers like, a lack of qualified care providers to administer pap tests, a lack of care providers trained in cultural and linguistic customs of the community, a lack of transportation to medical clinics in larger city centers, a lack of health education in schools and clinics teaching women about cervical cancer and HPV, and a lack of recall systems to remind women to participate in screening. Personal barriers included the inability to take time off of work and inability find reliable childcare for the often-daylong trips to health centers to get screened. Finally, the barriers identified that were attributed to Canada's dark colonial history were found to be caused by the intergenerational effects of colonialism from the history of residential schools and Indian Hospitals; these caused increased rates of sexual abuse in First Nations communities, shame surrounding women's bodies, mistrust in healthcare providers, and finally, fear of leaving the community to receive screening.

Similar barriers were identified in a 2015, multi-community study of care provider and community member perspectives on cervical cancer screening (21). Individual interviews and focus group meetings identified colonialism as a central theme affecting women's cervical cancer screening experiences. Colonialism was cited as the root cause of negative body perception and negative experiences with government health services which were key barriers to screening. Participants also commented on the power of relationality between mothers and daughters, patients and health care providers and culture and education on ameliorating the cervical cancer screening experience for women. Finally, participants expressed hopefulness if the ability of self-collected HPV screening to increase women's autonomy over the screening experience, and empower women in their self-care.

### 1.3.2 Human Papillomavirus Testing and Self-Screening

As a result of the fact that HPV infection is necessary in all cases of cervical cancer the door has been opened to a new screening method, that does not rely on cell-based samples, as required by the Pap test. HPV screening uses a viral-based sample that detects the presence of HPV DNA in the cervico-vaginal environment (25). HPV self-testing has the potential to reduce the invasiveness and discomfort associated with pelvic exams because it simply requires the

collection of a sample of the cervico-vaginal fluid, usually using a dacron swab. DNA is extracted from the sample, amplified via polymerase chain reaction, and sequenced for the presence of specific high-risk HPV DNA. A summary of the studies included in this literature review regarding HPV testing, and self-collected HPV screening can be found in Appendix A. Studies have been conducted to compare the effectiveness of the HPV test with physician-collected samples to the conventional Pap test in their ability to detect cervical cancers and high grade cervical dysplasia (12). They found that the HPV test boasted a higher sensitivity of 94% [95% CI: 89-97] than the Pap test's sensitivity of 70% [95% CI: 57-80], and a slightly lower specificity of 90% [95% CI: 86-93] compared to the Pap test's specificity of 95% [95% CI: 92-97]. This evidence indicates that the HPV test will deliver fewer false negatives and a relatively equal number of false positives than the Pap test. Since the HPV test has a higher sensitivity and comparable specificity to the Pap test, HPV testing has the potential to be assessed as a primary screening option that could replace the Pap test.

The HPV FOCAL trial is a randomized control trial comparing the current standard practise of screening using liquid based cytology (LBC) Pap testing, where the sample is stored in a liquid media after collection, to the use of HPV testing with PCR as a method of primary screening for cervical cancer (25). Evidence from this study will be used in the near future to inform a shift to HPV testing for primary screening. The trial recruited 19009 women who had no history of HPV, cervical cancer or CIN in the last 5 years. Women were randomized into the intervention group, HPV testing, or the control group, LBC testing. At baseline, women received a pelvic exam where a physician either collected a cervical cell sample for use in LBC, or a vaginal swab for use in HPV PCR testing, depending on the group for which they were randomized; women in the intervention group with a negative HPV test result were rescreened at 48 months with co-testing, and negative women in the control group were rescreened at 24 months and 48 months using LBC and co-testing, respectively. The study found that the overall incidence of CIN and invasive cervical cancer were similar across randomization groups, indicating no significant difference in the two groups. It also found that the HPV testing identified significantly more CIN3+, and CIN2+ than the LBC test at baseline. At 48 months, there were significantly higher rates of CIN2+ and CIN3+ detected in the control group than in the intervention group. This result indicates that more cases of CIN were caught at an earlier stage using HPV PCR testing as the primary method of screening than the current standard of practice, LBC. Furthermore, this result indicates that many cases of CIN are being missed by using only LBC as the primary method of screening. These results suggest that HPV screening is

more effective at catching CIN2+ and CIN3+ than conventional cytological screening, and should be considered as a replacement for the Pap test. Since we know that HPV testing is a more effective test than the Pap test for primary cervical cancer screening, and since this test requires only a sample of the vaginal environment, unlike the Pap test that requires a cervical cell sample, it offers the unprecedented option for women to avoid an invasive pelvic exam, and to collect their own samples using a self-swab (26).

In order to ensure that women are receiving the same quality of care when given the option to self-collect as an alternative means of screening, the performance of HPV self-collected samples was compared to physician collected samples to trial for non-inferiority (27). A randomized control trial in the Netherlands was conducted to compare the accuracy of using physician collected samples to the accuracy of self-collected samples to detect CIN of grade 2 or 3 when testing for HPV using a PCR enzyme immunoassay. They invited 187473 under and regularly screened women to the study, and after randomization and exclusions, 7643 women were assigned to the self-collection arm and 6282 women were assigned to the control, physician collection arm. 569 women in the self-collection group, and 451 women in the clinician-collected group tested positive for HPV. These women received follow-up according to the national guidelines, but were also retested using the opposite collection method from which they were initially randomized. The sensitivity of self-sampling was found to be 92.9% [95% CI: 87.3-98.4] and for physician-sampling was found to be 96.4% [95% CI: 92.9-99.9], with a relative accuracy between the two of 0.96 [95% CI: 0.90-1.03]. The specificity of self-sampling was found to be 93.9% [95% CI: 93.4-94.5] and for physician-sampling was found to be 96.4% [95% CI: 93.6-94.8], with a relative accuracy between the two of 1.00 [95% CI: 0.99-1.01]. This evidence indicates that for a regular screening population, self-collected samples are not inferior to physician collected samples.

A meta-analysis investigating the accuracy of self-samples versus physician collected samples was conducted that reiterates the above finding (28). After reviewing 56 accuracy trials, it was found that self-collected samples were as accurate as physician collected samples when used in HPV testing using a PCR assay. The average relative sensitivity for the detection of CIN2+ was found to be 0.99 [95% CI: 0.97-1.02], and for CIN3+ was found to be 0.99 [95% CI: 0.96-1.02] indicating no significant difference in sensitivity between the two tests. The average relative specificity of detection of CIN2+ and CIN3+ was found to be 0.98 [95% CI: 0.97-0.99], pointing to self-collected screening having a slightly lower specificity than physician collected samples. This demonstrates that the overall effectiveness of self-collected samples for HPV

screening is comparable to physician collected samples. It should be noted that a shift towards self-collected HPV screening would result in women undergoing fewer pelvic exams. Although there is no evidence to support clinical benefits to annual pelvic exams for asymptomatic women, the American college of Obstetrics and Gynaecology recommends annual pelvic exams to potentially detect other cancers of the reproductive system, which are checked for visually during pelvic exams (29). Nevertheless, this evidence opens up the possibility of self-collected HPV screening to be an option not only for reaching under screened women, but perhaps as a method of primary screening.

In order to verify whether patients would be open to HPV self-collected screening, studies to assess the acceptability of self-screening as an alternative screening method with patients were conducted. A systematic review and meta-analysis was performed that included studies that measured the acceptability of cervicovaginal self-sampling among women who had participated in self-screening interventions (26). The study identified 37 studies including 18516 participants from countries across the world, that surveyed women about their experiences with self-sampling. Results indicated that, on average, 97% [95% CI: 95% - 98%] of women found self-collection acceptable, and that 87% [95% CI: 73% - 95%] of women would prefer to self-collect again if given the option. The reasons identified for a preference for self-sampling included ease of use, less embarrassment, and increased privacy and comfort. Shortcomings of self-collected sampling were also identified as being uncertain about sampling correctly, pain or discomfort with collection, anxiety, and discomfort with touching themselves. Although this study provides strong evidence for the use of self-sampling as a screening method that appeals to patients, it fails to differentiate between self-collected screening experiences of women who participate in regular Pap screening, and those who are under screened. Nevertheless, these results indicate a high acceptability for self-sampling as an alternative to clinician collected sampling, and highlight a self-collected sample's ability to circumvent barriers to screening such as embarrassment, and discomfort with pelvic exams.

In light of the complexities of delivering cervical cancer screening to rural and remote Indigenous communities, a pilot study was conducted examining the use of HPV self-sampling in a First Nations communities in Northwest Ontario (22). This study recruited 49 women aged 25-59 to participate in HPV self-collection, and to complete a survey regarding the acceptability of the test. The study found the method to be highly acceptable among the First Nations women with 77% expressing that the device was easy to use, 85.1% feeling little to no discomfort with screening and 87.2% expressing a willingness to participate in self-sampling as their preferred

method of cervical cancer screening in the future. The study was limited by its small sample size, and by its use of predetermined survey questions to assess the acceptability of the test instead of allowing women to express their experiences in a qualitative interview, talking circle or via an open questionnaire. Furthermore, all of the participants in this study had participated in Pap screening at some point in their lives. As a result, the study lacked the voices of women facing many of the common barriers to screening among First Nations women. Since the majority of cervical cancers occur in under and never screened Indigenous women, further research that prioritizes the participation of under screened women is required. Nevertheless, the study was strong in its ethical approach to research with Indigenous communities, as the researchers took time to develop relationships with the communities before conducting the study, and incorporated sexual health education for participants into their study protocol as to provide long-term benefits to its participants. The research from this study concluded that HPV self-sampling was an effective and acceptable means of reaching First Nations women, in rural communities, for cervical cancer screening. Additionally, it was able to inform a subsequent larger scale study.

The Anishinaabek Cervical Cancer Screening Study (ACCSS) was conducted to investigate the capacity of HPV self-screening to increase screening participation, comfort, and acceptability of cervical cancer screening among First Nations women in Northern Ontario (30, 31). The study took a mixed-methods approach, employing the use of both qualitative and quantitative components to assess the screening intervention. Community based participatory action research (CBPAR) informed the study. This included engaging with Chief and Council of the ten participating communities to have the study approved, hiring community-based research assistants (CBRA) in each community to maintain a close connection and build capacity, and frequent field trips to communities to build relationships between the communities and the study team. The quantitative portion of the study was a randomized controlled trial (RCT), where five communities were assigned to the experimental group, HPV self-collected screening, and five communities were assigned to the control group, Pap testing (31). In total, 834 eligible women from these ten communities were randomized, and baseline characteristics of both groups, determined through a questionnaire, were found to be similar across all points. During phase I of the study, the women in communities assigned to the intervention arm were first offered HPV self-screening, and women in the control arm were first offered Pap testing; during phase II, women were offered the opposite method of screening. Recruitment for participation in both screening modalities occurred between November 2013 and August 2014, at health events organized by the CBRAs. Using intention to treat analysis, the study found that women were

5.7% [CI: -11.6 to 34.0, p=0.628] more likely to participate in screening when initially offered self-collected HPV testing, than when initially offered Pap testing. Overall engagement in screening was lower than expected, and indicates that both screening interventions are missing many women. However, in communities where CBRAs were lay health workers, there was a higher level of participation, indicating that the trusting relationship between care providers and women plays a large part in engaging women in screening, regardless of screening method. This study was limited by the fact that out of all of the women who participated in the study, approximately 70% of participants had engaged in Pap screening previously within the past 3 years. This indicates that the intervention was failing to reach many of the under screened women, who make up the higher proportion of women with cervical cancer. Furthermore, by randomizing by community, the study may be biased by the differences in care delivery, level of remoteness, and unique history across the communities. Still, this RCT provides evidence that HPV self-collected testing has the potential to facilitate engagement in cervical cancer screening for First Nations women in Northern, remote communities.

The qualitative portion of the study was conducted from 2011 to 2012. It included in-depth interviews with care providers in each community, and focus group meetings with community members (30). Each community recruited one or two health care providers for the interview process, with 15 total care providers, some identifying as First Nations, participating in ten individual interviews. Additionally, ten focus groups were conducted, one in each community, where participants were recruited by community health managers. Participants were asked about their communities' experiences with cervical cancer and Pap testing, concerns about cancer, knowledge about cervical cancer screening, screening availability, and interest in HPV self-screening. The interviews and focus groups were recorded, transcribed and coded using open coding methods. Five main themes were selected following data analysis. The first theme related to cervical cancer screening practices in nearby communities, and highlights many of the barriers Northern Ontario First Nations women face to Pap screening. Participants commented on the irregularity of screening services, lack of provider flexibility, infrequency of doctor visits to their communities, lack of transportation and childcare to attend screening, lack of efficient follow up and concerns regarding the privacy of their results. The next theme centered around the physical comfort of both screening modalities, with participants commenting on how Pap tests are more painful than HPV self-sampling. Similarly, psychological comfort arose as a theme. Participants commented on the fact that Pap testing was embarrassing, regardless of the gender of the care provider, but that there were more uncomfortable around male care providers. Further, there was

mention of younger and older women being the hardest to reach for screening because of embarrassment and histories of trauma from residential schools, respectively. They also emphasized that HPV self-sampling would reduce this embarrassment and increase women's comfort with screening. The final theme was with respect to education, where participants described that women would be more willing to complete self-collection if the process was explained to them. They also voiced concerns about the sexually transmitted nature of HPV, surrounding women being blamed for spreading the sexually transmitted infection (STI). They worried that if there were cases of HPV in their communities, it would propagate negative stereotypes regarding Indigenous women having higher rates of STI than non-Indigenous women. Although this study is strong in that it includes the voices of First Nations and non-First Nations care providers and community members, similarly to the quantitative portion of this study, there is a lack of voice of under screened women. It is critical for research to also include voices of under screened women, and cater to their needs in order to increase screening among under screened women. Nevertheless, the themes that were reported during this study should be considered during the rollout of future self-collected HPV interventions in First Nations communities.

### 1.3.3 Human Papillomavirus Self-Screening for Under Screened Women

Under screened or never screened women represent 54% of the cases of invasive cervical cancers in BC (14). Therefore, they are a critical demographic for targeted screening programs in order to reduce the overall incidence of cervical cancer. The majority of women who are under screened are women living in remote and rural parts of the province, immigrant women, and Indigenous women (32). HPV screening kits provide a new method of reaching under screened women by overcoming geographical, linguistic and cultural barriers.

A meta-analysis was conducted to verify whether offering self-sampling for HPV would increase participation in cervical cancer screening programs, when compared to offering clinician collected sampling for HPV or Pap testing (28). This meta-analysis limited its analysis to only include studies that targeted populations of under or never screened women. It also stratified by recruitment strategy in order to verify what method of delivering self-collected kits demonstrates the greatest improvement in participation rates. The study reviewed 25 participation trials that used mail-to all, opt-in, door to door or community campaign recruitment strategies, and compared the participation rates to a control arm (physician collected sampling). The average participation in the mail-to-all strategy was 19.2% [95% CI: 15.7-23.0] for the self-

sampling arm, and 11.5% [95% CI: 8.3-15.1] for the control arm, demonstrating a 1.87 times higher relative participation rate in self-sampling. Similar results were found for door-to-door campaigns, with a 1.99 times higher relative participation rate for the door-to-door distribution of kits as opposed to the door-to-door offering of physician sampling. In opt-in strategies, self-sampling saw a lower participation rate of 7.8% [95% CI: 5.2-10.9] than the control arm's rate of 13.4% [95% CI: 10.2- 16.9]. However, community campaigns proved to be the best strategy for recruitment, with a striking 94.2% [95% CI: 83.0-99.9] participation rate, compared to 53.3% [95% CI: 10.5-93.2] participation in the control arm. In fact, community self-screening campaigns offered a 2.58 times higher rate of participation in screening than a community campaign to undergo physician collected screening. This evidence demonstrates that with mail-to, door-to-door or most notably, community campaign recruitment strategies, HPV self-collected testing can increase screening participation among under screened women.

The ability of women to self-collect samples to screen for cervical cancer invites the possibility of circumventing some of the barriers that Pap screening presents and making cervical cancer screening a more accessible service for women. Thus, it can facilitate an increase in screening participation. A systematic review was conducted of studies comparing participation in screening programs that offered women either an invitation letter to participate in Pap testing or a mailed HPV self-collection device (18). The authors reviewed 10 studies that occurred in developed countries, that targeted populations of under or never screened women. These studies offered either mailed or door-to-door self-collected HPV tests as the experimental group, and offered an invitation letter to participate in Pap screening as the appropriate standard of care control group. The meta-analysis found that the overall participation in screening increased by 200% when patients were offered the self-collected HPV test than when they were sent the Pap reminder letter. Further, all of the studies reported high specimen quality from the self-collection devices. The high quality of results as well as the high acceptability of HPV self-screening among women provides evidence for HPV self-collected screening programs to increase participation rates in cervical cancer screening among under screened women, which makes it an ideal option for screening women in rural or remote communities, or women with histories of sexual trauma or mistrust of the healthcare system (33).

A randomized controlled trial was conducted in Ontario to examine whether offering self-collected sampling for HPV to rural women would yield a higher uptake of cervical cancer screening and a higher satisfaction with screening than with an invitation letter to participate in Pap screening, or with opportunistic screening (34). The study recruited 818 women to

participate in the study, 335 women were randomized to complete the self-collected HPV test and acceptability questionnaire, 331 to the Pap invitation letter stream and 152 to the opportunistic Pap screening arm. In total, only 171 women received screening; in the self-screening arm, 70 completed the HPV test, and 37 opted for a Pap test. In the invitation letter arm, 51 underwent a Pap test, and in the control arm, 13 underwent opportunistic Pap testing. Women who were offered the self-collected HPV test were three times more likely to undergo screening than women who received no intervention. The acceptability questionnaire revealed that a mean acceptability score of 92.6%, and 90% of participants said they would use self-collection again in the future. Low levels of participation in all randomization arms limited this study. Furthermore, there was no way of determining whether women were regular screeners, or were under screened. Notwithstanding, the study was able to achieve 80% power and provide statistically significant results. This study demonstrates that in a rural setting, the HPV test using a self-collected sample is highly acceptable, and will increase screening rates among hard to reach women.

The self-collected HPV test has also been shown to have a high acceptability among under or never screened women. A literature review of studies examining the acceptability of the test, specifically among women who do not participate in regular Pap screening, found that women appreciated the comfort, convenience and privacy of the self-collected test when compared to a Pap test (32). Reasons for this high level of satisfaction include the comfort, privacy, convenience and low cost of self-screening. Educational interventions regarding HPV and cervical cancer were also found to be highly acceptable among under screened women. Areas of concern for patients were similar to those of regularly screened patients, and included fear of sampling incorrectly, concerns regarding fidelity in marriage and lack of funding for follow-up care as potential barriers to screening. Additionally, since does not require the same invasive pelvic exam that a Pap test requires, it is an appealing option for women who face embarrassment or mistrust of their healthcare provider as a barrier to screening, most notably when paired with comprehensive sexual health education.

There is a strong body of evidence supporting that HPV testing is a more accurate alternative to Pap testing for primary screening, and furthermore, that self-sampling can be as accurate as Pap testing for reaching under screened women. Also, it is known that the HPV test with a self-collected sample offers a barrier-reduced method for screening for cervical cancer, that has been able to improve the screening rates in rural communities and as well as First Nations communities. However, there lacks studies investigating First Nations patient partner

perspectives on self-collected HPV screening programs. Therefore, there is a gap in knowledge surrounding community-recommended approaches to delivering a self-collected HPV intervention. As a result, barriers to the self-sampling process for First Nations women in rural communities may still exist. Further research is required to understand the unique experience of self-screening using an HPV kit for First Nations women living in rural NBC communities. Projects must work with women in order to develop an efficient and culturally safe approach to launching an HPV self-screening program, that can inform a provincial scale up to all First Nations communities in rural NBC, and beyond.

## Chapter 2: Theoretical Framework

This theoretical framework has guided my research from its nascence. It has informed the data collection and analysis, the writing of this thesis, and will continue to be applied in future manuscripts. According to Margaret Kovach, if a researcher articulates their theoretical framework it allows them, as well as their readers, to understand better how they see the world, and what lens they have applied to the research presented (35). As a non-Indigenous woman engaging in a decolonizing approach to research, it was important for me to select a framework that challenged my position of power as a white settler, and allowed me to approach my research being aware of my biases and taking a strength-based perspective. I selected the social determinants of Indigenous health model to ensure that my understanding of health was free from individual blame, and targeted larger systems that affect health. The feminist theory of intersectionality also informed my work, as a way to understand how Indigenous women occupy a unique position in society, based on colonial hierarchical power structures that exist in Western society. Postcolonialism complemented this theory, as it provides the understanding that colonialism has and continues to affect Indigenous people in complex, entrenched manners. Finally, Indigenous feminist theories were also incorporated as theories written by Indigenous women that provide an understanding of how gender, and primarily colonialism, interact in a unique way to affect Indigenous women's lives. This chapter will offer an overview of these four theories.

### 2.1 Social Determinants of Indigenous Health Model

The social determinants of Indigenous health model provides a framework for the interpretation of the health disparities experienced by Indigenous people in Canada (36). The model acknowledges that the Indigenous definition of "health" offers a more holistic approach to health than Western medicine. Western medicine prioritizes physical health, while Indigenous understandings consider good health to be the harmony of physical, spiritual and emotional health (37). The model aims to reduce the individual responsibility placed on patients that the biomedical model presumptively applies, and to look broadly at the historical, social and institutional context of the patient in determining culpability for poor health. At the core of the model is the understanding that the legacy of colonialism and modern neo-colonialism are the root cause of the majority of health concerns affecting Indigenous people (20). In fact, it cites the fact that all social determinants affective Indigenous people's health, including geographic,

economic, historical, narrative, genealogical and structural determinants, interface in some way with colonialism. This model divides the determinants of health into three groups: proximal determinants, intermediate determinants and distal determinants (37).

The proximal determinants act on an individual level and include factors in health behaviours such as substance abuse, factors in the physical environment such as housing and working conditions and factors in the social environment such as early childhood experience, income, education, social support, employment and food security (36). In Indigenous populations, poor proximal determinants of health like high prevalence of cigarette smoking and overcrowding in houses contribute to the adverse health outcomes such as increased incidences of cancer, diabetes, suicide and domestic violence and increased rate infection transmission. However, it is critical to understand that all of these factors can be attributed to the dark legacy of colonialism (20). In Indigenous communities where a healthy social environment has been fostered through reconciliation and cultural revitalization, direct positive impacts on health have been observed including lower rates of depression, anxiety, and suicide, due to an increase in overall self-esteem (37). Though the proximal determinants of health offer an obvious, individual explanation for the higher prevalence of poor health outcomes in Indigenous communities, it is critical to cite colonialism as the overarching cause of ill health.

The intermediate determinants of health include overarching systems that affect the way Indigenous people are able to manage their lives. These include the health and education systems, labor markets, government and attachment to culture and the environment (20, 37). Health service delivery and education in Indigenous communities are often hindered by jurisdictional disputes, lack of funding, lack of cultural safety and lack of self-determination. Availability of health services on-reserve can impact access to care, including cervical cancer screening (24). In communities with high rates of education with integrated cultural and linguistic programs, there tends to be lower suicide rates, higher employment and improved overall health (37). Since environmental stewardship and ceremony have deep roots in traditional Indigenous way of life, communities that have the infrastructure to support interaction with the environment and the participation in cultural customs, such as Dakelh traditions of potlatch and smudging, also experience greater holistic health. Although the intermediate determinants are a less individual determinant of health, they are the result of colonialism, and subsequently, directly feed the proximal determinants of health's ability of impact individual health (20).

The final, most abstract, and arguably most impactful level of contribution to the social determinants of Indigenous health are the distal determinants. Colonialism, racism, social

exclusion and lack of self-determination represent the overarching systems of oppression that function to keep Indigenous people in a subjugated position, and inhibit the pursuit of holistic health (37). These political, ideological, historical and social foundations are the root of all other determinants, making them the primary reason for health inequalities (20). Historical trauma from Canada's dark colonial past has led to poor health outcomes in residential school and Indian hospital survivors and their families. In fact, a 2019 study connected suicidal thoughts and attempts in youth to families whose parents or grandparents had attended residential school (38). However, modern day policies rooted in racism such as the Indian Act continue to affect Indigenous people's health by controlling many aspects of life including the delivery of health and educational services, the access to healthy living conditions and freedom of control in communities (37). This racism at the bureaucratic level trickles down to impose conditions that promote ill health. Furthermore, racism in the form of stereotypes, racial micro-aggression and misconceptions about Indigenous people contribute to a sentiment of social exclusion. Racism is often experienced by Indigenous people when they are living off reserve, or when they are interacting with Western institutions, like the health care system. The possibility of experiencing racism, along with mistrust in the health care system due to colonial history impacts Indigenous women's comfort level with and experience of cervical screening. Social exclusion contributes greatly to the mental health crises many Indigenous communities are currently facing. Finally, the majority of Indigenous communities are deprived of the right to total self-determination, and as a result, the sentiment of "lack of control" has been found to be prevalent in many Indigenous communities. Notably, in communities with a higher degree of self-determination, there is a lower incidence of mental health problems and suicide (36). The distal determinants of health are grounded in colonialism and are the root contributor to Indigenous people's health. They must be addressed in order to change the management of systems and behaviours that directly affect Indigenous health. A determinants of health analysis is beneficial as it offers a well-rounded, total picture of health. It was selected for this study in order to prevent any judgement of the study participants by myself and other researchers should participants describe reasons they have or have not accessed screening or follow-up for cervical cancer. Particularly, framing the social determinants within an intersectional perspective can function to strengthen their impact on the understanding of marginalized persons' health.

## 2.2 Intersectionality

The theory of intersectionality is a tool for interpreting and untangling the interactions between interconnected systems of oppression and privilege (39). It details that people occupy a variety of social positions based on their gender, race, class, ability, sexuality, socio-economic status, etc.; within each of these dimensions of social life, they can either be in positions of privilege and power, or oppression (2, 40). Hankivsky writes that the way a person experiences the world is based on the unique intersections of the positions they occupy and their associated privilege (2). For example, in Canada, the norm by which all other group's value is measured is white settler culture. Therefore, an able-bodied, cisgender, affluent, white, male occupies a highly privileged position in society, however, if this same individual were disabled or poor, two less-valued position in society, they would simultaneously occupy positions of power because of their race and gender, and positions of oppression because of their ability and class. It is these complex relationships between social position that an understanding of intersectionality functions to clarify.

In addition, intersectionality requires that no one social category be given more importance than another (40). Rather, all categories should be considered together for their collective impact on that person's social position. The theory also forbids the essentialization of members of social categories; all members of social categories experience life based on the interconnectedness of their various social identities, and therefore assumptions regarding their social experience simply based on any one category is unacceptable. Similarly, since everyone's lived experience is different, their experience of privilege and oppression must be unique to them (2). It is critical to note that the relationship between identities is not additive; it is based on the shared experience of axes of oppression/ privilege. For example, a First Nations woman cannot navigate the world as either a woman, or a First Nations person, and their experience is not the sum of the experience of woman hood First Nationhood. They are simultaneously both, and together, these social positions create their social experience. This social experience is carried throughout all aspects of life, and its impact at the health level must be considered. For example, a First Nations woman will experience cervical screening uniquely, and might experience certain barriers to screening due to their position in society. It will also affect relationships to researchers visiting First Nations communities to engage with women, as researchers tend to occupy positions of power within society.

Finally, intersectionality requires those who are engaged with the theory to have a commitment to social justice underpinning their work. Researchers should commit to doing work

that reduced the inequalities people experience based on their social categories. When working within the theory of intersectionality, it is required that they reflect on their own positions of power and oppression, to understand how their social experience of the world may affect the way their studies are conducted, and their data are collected and analyzed (39). It is critical that as researchers are acting as the experts in their work, they are not working to reinforce systems of oppression. This commitment to social justice not only promotes research that will have longstanding positive impacts on the marginalized populations that are working with researchers, but also interrogates the systems of power that put people in undervalued social categories to begin with.

Although intersectionality provides a framework for relieving the essentialization of oppressed groups and promises to create a better understanding of individual experiences of oppression, it has been critiqued for over-dividing groups of people, for lacking a clear methodology for intersectional research and for claiming that the world is insurmountably complex (40, 41). Since intersectionality is focused on individual experiences of oppression, it can alienate the unifying power of shared experiences of oppression (41). This over-division can hinder the pursuit of common goals of marginalized groups by focusing efforts on categorizing people into the correct groups, rather than fostering a collective empathy to drive change. Additionally, since the theory of intersectionality is rather young, there is a lack of a clear methodology for researchers seeking to engage in “intersectional research” (40). As a result, researchers intending to adopt intersectional methods can inadvertently subject their participants to essentialization. Further, in some research settings there is a requirement to focus on a single social identity, and in these scenarios, researchers are left unsure of how to maintain an intersectional framework. Finally, there is the critique that since the experience of oppression and privilege can be subdivided into infinite combinations of identities with some privilege and some oppressions, that there is little hope for untangling the complexity of the structures that maintain these power relationships (41). This, causes feelings of futility in researchers and activists and can leave them feeling as though there is little hope for change. Although the theory of intersectionality suffers from the above shortcomings, it is able to offer a rounded understanding of the interconnectedness of social positions which have direct effects on the social determinants of health, and an individual’s experience of health. Given its strengths, I selected intersectional theory in order to allow me to better understand my position of power and privilege in society, and my study population’s experiences interacting with a Western health care system and researchers.

## 2.3 Postcolonialism

Postcolonial theory is grounded in the understanding that the history of colonialism, as well as ongoing neo-colonialism, continue to affect colonized people's ability to achieve equal opportunity and thrive in Western society (42). The theory acknowledges how the socially constructed concept of "race" has deeply permeated society, and created an artificial hierarchy of peoples that colonialism has exploited in order to subordinate Indigenous peoples and propel settlers into positions of power. It suggests that the colonization of bodies as well as the process of Othering are an explanation for the health disparities experienced by non-Western populations (43). This is in contrast to the racist, constructed misconception that poor health is because of the inherent inferiority of non-Western groups. Post-colonialism acknowledges that racialized populations experience other forms of oppression on the basis of gender, culture, ability and class, however, colonial racism is cited as the root cause of this inequality.

An understanding of postcolonialism is critical for researchers working with marginalized populations, including First Nations people (42). For First Nations people in Canada, the legacy of the Indian Act continues to regulate lives, limit the capacity for self-determination, and withhold access to land and funding for health care and education (44). It is because of the continuing legacy of colonization that First Nations people are disproportionately experiencing poverty, substance abuse, and health disparities. Research stemming from Western institutions seeking to investigate prevalent health issues in First Nations communities has left a shameful legacy of disrespect (45). Often in this research, data are analyzed through a Western lens, results perpetuate negative stereotypes about First Nations people, and participants are excluded from the results of the study as well as any recognition for their contribution to the body of literature. This research, conducted outside of the postcolonial framework, has led to a justifiably deep mistrust of research in First Nations communities. Postcolonial theory acknowledges and rejects the exploitative history of research in First Nations communities in the past (42). Research grounded in a postcolonial understanding emphasizes the use of voices that are generally undervalued, and on the margins of Western society to identify issues of importance to their communities. It requires researchers to develop a non-exploitative relationship that benefits both the people involved in the study and the researchers doing the project, while building capacity and empowering community partners with research-related skills. It states the social requirement of researchers to disseminate the research findings in a manner that acknowledges colonial histories and the context of the findings, with the goal of amending social attitudes and diminishing disparities.

Although postcolonialism is a theory that acknowledges both the historic and modern impacts of colonialism on marginalized groups, it has been subject to a variety of critiques (42). First of all, the word postcolonial itself has been criticized because it implies that society has moved past colonialism, and is currently in a period following colonialism. Regretfully, this is not the case, as Indigenous people in Canada and around the world are still experiencing the impacts of historical colonialism, and modern colonialism. For example, In Canada, this modern colonialism takes the form of discriminatory Indian Act legislation that limits Indigenous Peoples rights, and ongoing battles between Bands and industry to protect traditional territory from exploitation. When being applied to Indigenous communities, it has been critiqued as being a Eurocentric theoretical perspective forced into the lives of Indigenous peoples. Battiste, a Mi'kmaq scholar, writes that postcolonialism lacks the Indigenous voice that it claims to hold above all else (27). They argue that a Eurocentric theory could never conceptualize the complexity of the colonial experience and that a postcolonial Indigenous knowledge is more suitable for theorizing the colonial experience, because it considers an Indigenous worldview. Another critique of postcolonialism is that it polarized the colonizer versus colonized (28). By dividing people into a binary, there is masking of the complicated economic, social, political and relational structures that can both fetishize and demonize the "other" simultaneously. The experience of marginalized peoples is further at risk of being clouded in postcolonialism due to the essentialization of the experience of colonization. Oftentimes, it is assumed that colonized people experience the same set of oppressions equally; however, in reality, people's experiences with colonialism and oppression are unique and should not be assumed to be universal (25). Furthermore, postcolonialism received critiques from Indigenous women because the experience of colonialism is different for Indigenous women than it is for Indigenous men, therefore an intersectional feminist understanding of colonialism is critical when working with First Nations women. Notwithstanding its critiques, postcolonialism can be a valuable theoretical framework with which to situate research, provided its weaknesses are supplemented by other theories, including those covered in this chapter.

## 2.4 Indigenous Feminism

Feminism, specifically intersectional feminism, lends itself well to being coupled with postcolonialism (46). A feminist post-colonial approach acknowledges that we all occupy positions of privilege and oppression depending on our positions along various social axes such as race, sexuality, gender, socioeconomic status, ability, etc., and that for non-white people,

colonialism is the greatest source of oppression. This approach allows for strength to be derived from the shared experience of colonialism between Indigenous people, but also makes space for the unique manifestations of oppression within individual experience.

Feminism alone has been found to be alienating and irrelevant to many Indigenous scholars (47). In an Indigenous context, feminism alone is an insufficient framework to work within because it is, in and of itself, a white, colonial construct. When it is imposed on Indigenous people, it can be an act of colonialism. Furthermore, feminisms that support anti-man rhetoric directly go against the traditional gender-equality prevalent in many Indigenous cultures. In addition, Indigenous scholars have stated that anti-colonialism should be the main pursuit of social justice, because in a world without colonialism, there would be no injustices for Indigenous women. This is because of the legacy of traditional societies that existed pre-contact; many were organized matriarchically, held women in positions of great respect, and prioritized the needs of all members of society over self-interest. Therefore, women were not oppressed. Although the anti-colonialism portion of Indigenous feminism is core to the theory, advocating solely for decolonization in social justice activism also has its shortcomings.

A solely anti-colonial framework cannot fully encapsulate the experience of Indigenous womanhood in a postcolonial/modern colonial society, because women experience colonialism differently than men (47). For example, the high rate of sexual violence against Indigenous women is a problem experienced uniquely by women. It is oppression on the basis of both gender and race, which makes it unique to Indigenous women. It is because of patriarchy that women experience higher levels of sexual violence than men, and because of colonialism that Indigenous women experiences higher rates of sexual assault than non-Indigenous women. This is just one example of the unique space Indigenous women occupy, that requires a harmony between feminism and postcolonialism to fully understand.

An intersectional feminist lens that works cohesively with postcolonialism holds space for the unique social niche that Indigenous women navigate, and acknowledges that through anti-colonialism first, and feminism second, society can be changed so that it no longer marginalizes the voices of people who do not occupy positions of power. Using this theory to focus my research allows the focus of the project to be on decolonization and reconciliation, through the empowerment of the women in my study population.

## Chapter 3: Patient Oriented Research Meets Indigenous Methodology

The term methodology will be employed in this chapter to describe the underlying theories that determine how research will be conducted (3). A methodology provides a framework for how research questions will be asked and what methods will be used in order to answer those questions. Methods will refer to the procedures for knowledge acquisition that are informed by the research methodology. This section will describe Indigenous methodologies as well as POR methodologies, and their utility in conducting ethical, mutually beneficial, decolonizing health research with First Nations communities, in the pursuit of reconciliation.

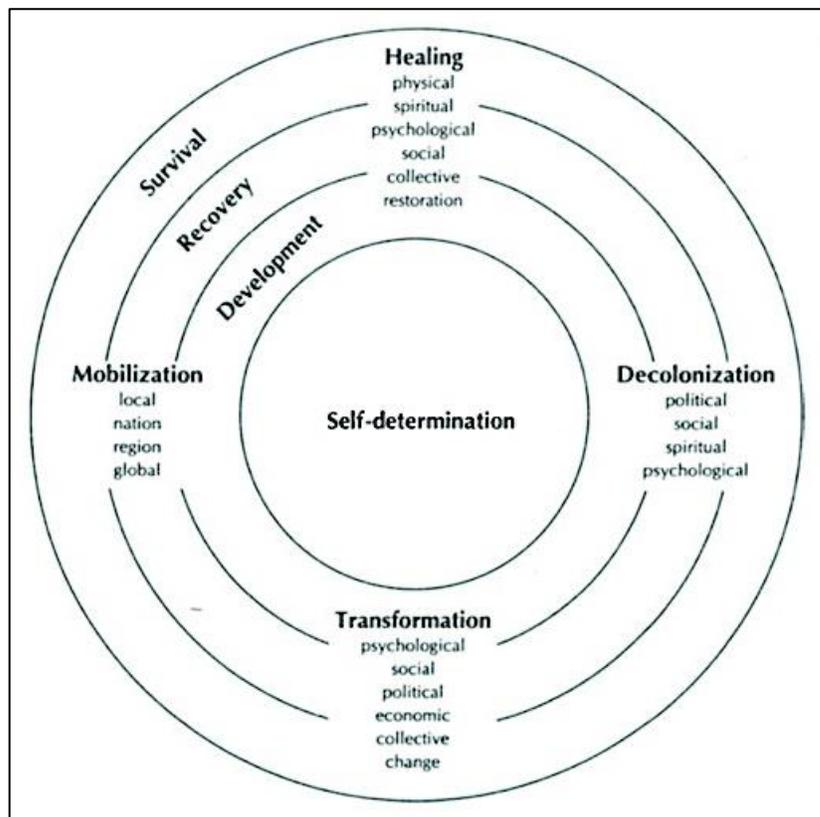
### 3.1 Indigenous Methodologies

Indigenous people have been the “subjects” of Western research since settlers first arrived in Canada; in fact, many say that they are the most researched people in the world (45). However, this research has not functioned to benefit Indigenous people in the way one might imagine. This is due to fundamental differences in epistemologies between Western people and Indigenous people (48). Western research methodologies, based on the epistemology of the individualistic pursuit of the truth through statistically valid data, have dismissed the value of Indigenous knowledge and ways of knowing in research. As a result, the use of Western methodologies on Indigenous people has functioned to further marginalize Indigenous people, and reinforce the systems of oppression that keep colonization and racism alive and well in Canada. Thus, there exists a justifiable deep cynicism and mistrust among Indigenous people with respect to research (45). Since research in its many forms is recognized cross-culturally as fundamental to the pursuit of knowledge and improvement, Indigenous academics have sought to outline a research methodology shaped by the struggle of living in a colonial society and focused on relationships that can function to reverse the damaging effects of colonialism, and facilitate moving forward to a better future (45, 49). Shawn Wilson writes of the need for a wholly Indigenous research paradigm that is not simply a Western methodology informed by Indigenous methods, but a paradigm built out of Indigenous ontology, epistemology and axiology (3). This has been described as the tribal epistemology (35). An Indigenous methodology is based on the fundamental belief that knowledge is relational, and needs to be shared with all of creation. Knowledge is created in relationship with others, and is to be shared amongst everyone. Although Indigenous research has always existed, it was first put into words by Maori scholar Linda Tuhiwai Smith, and employed in Australia as a guideline for the development of uniquely

Indigenous research methods, for research by and with Australian Indigenous people (45). The methodology has subsequently been taken up by Indigenous people around the world, as a means of conducting decolonizing research. They propose research methodologies that are based out of the unique worldview of their nations, that serve to prioritize their communities' knowledge, voice and sovereignty (49). Any research being conducted on traditional territories of Indigenous people, or in collaboration with Indigenous people must align with Indigenous methodologies. This will guarantee that the research is being conducted “for” Indigenous people rather than “on” Indigenous people and a respectful, reciprocal and relational interaction between participants and researchers is fostered.

Decolonizing methods require that research comply with the research agenda for Indigenous research (45). The agenda, as depicted in Figure 1, demands that research function to foster the survival of people, the recovery of culture and language, the development of individuals and communities, and the pursuit self-determination. Further, the agenda highlights processes that facilitate the achievement the above goals as healing, decolonization, transformation and mobilization.

**Figure 1:** The Indigenous Research Agenda (45)

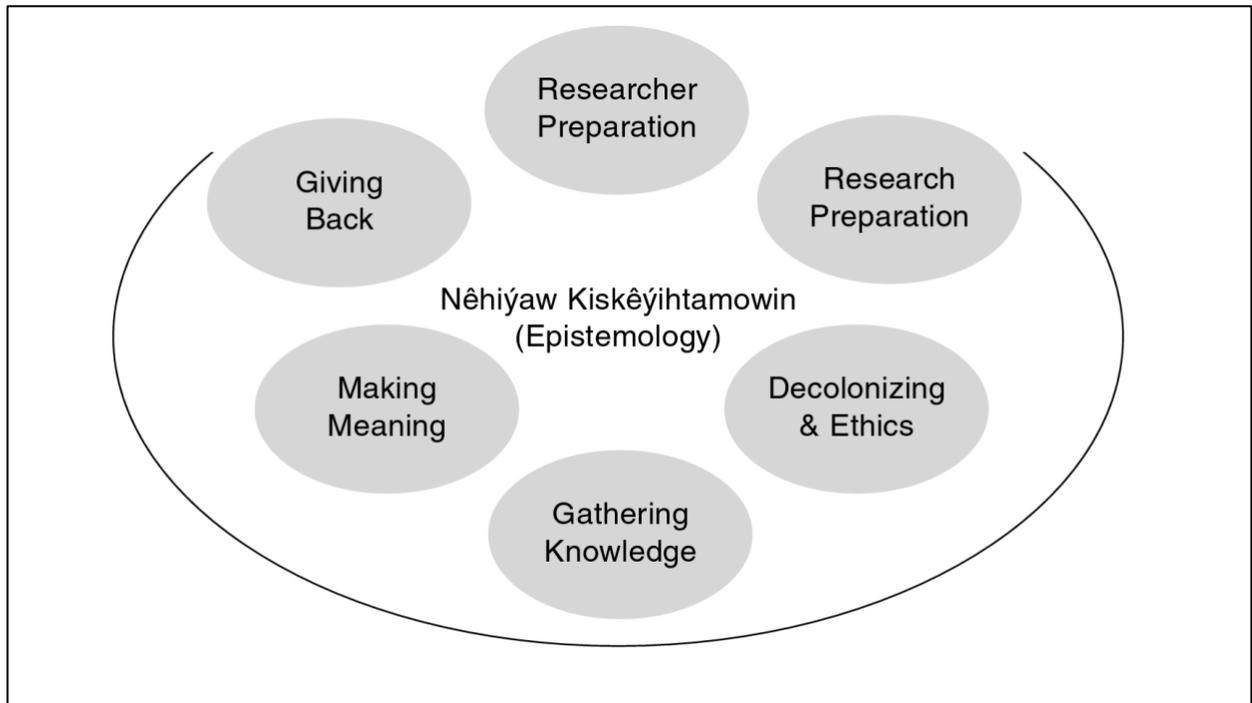


Building upon Smith's research agenda, six pillars to Indigenous research have been identified. Relationality, respect, responsibility, relevance, reciprocity and refusal are these key tenets (49). Wilson describes how researchers are in relation with themselves, their research participants, the land, the generations that came before them and those that will come after them, and the Creator (3). Their knowledge is shaped by these relationships and shared with these relationships, and therefore they are central to the research methodology (49). Not only do these relationships exist and impact the research, there is the strict expectation that they are honored through respect throughout the research journey. This requires considerations including ongoing consent and honesty to be prioritized by the researcher. Projects must be relevant to Indigenous communities, in order to ensure that they are focusing on a question that will further the Indigenous research agenda, and pursue the goal of self-determination (Figure 1). Responsibility refers to accountability the researcher has to the participants before, during and after their research. Researchers should enter into projects with a good heart, meaning that their intentions are to benefit the community and the people they are working with; their projects should leave the participants with long-term benefits that will leave positive ripples in the community long after the research has concluded (3). Many projects take up responsibility by compensating participants for their time spent on the project, through capacity building, where community members are taught tangible research skills that can facilitate their future development. Alternatively, the pillar of reciprocity allows for the researcher to also gain from the project. As all Indigenous research takes place in respectful relation with others, it is important that researchers and participants alike gain from the experience (49). Finally, refusal acknowledges the sovereignty of Indigenous people over their knowledge, and allows for participants and communities to refuse to share their knowledge or participate in any research that they do not wish to engage with. Following these seven guidelines will facilitate meaningful engagement with Indigenous research methodologies.

Another key component to an Indigenous methodology is for the research to position themselves within the research. A researcher's worldview is central to how they conduct, analyze and make meaning out of their research. Therefore, researchers must be reflexive on how their epistemology will impact their research. Outlining a theoretical framework can help researchers and readers of their work understand this worldview. Margaret Kovach outlines the theoretical framework she took as a Cree Saulteaux academic, and other Indigenous researchers could take, when following an Indigenous methodology (Figure 2) (35). Researchers must first gather tribal

knowledge that can inform their work, then illustrate the decolonizing aim of their research project. Then, researchers must prepare by learning cultural protocols of the people they will be working with, and developing a culturally safe research design. Finally, researchers must make meaning out of the knowledge that has been shared with them, and focus their understandings on giving back to the communities and people that they have worked with.

**Figure 2:** An Indigenous research (conceptual) framework with Nêhiyâw epistemology (35)



An Indigenous decolonizing methodology should be considered when conducting any research project with Inuit, First Nations or Metis people or on their traditional territories, as a way to reconcile the exploitative legacy of research, and work towards the creation of projects that are beneficial to everyone involved. It is however important to note that non-Indigenous researchers working within a Western institution cannot ever fully adhere to an Indigenous methodology (3). Indigenous methodologies are meant to be a guide for research to be done for Indigenous people by Indigenous people. Therefore, one may argue that non-Indigenous researchers, regardless of intention, are re-colonizing by using the methodology (49). Non-Indigenous researchers do not have an epistemology, or way of understanding the world and their experiences, that is rooted in Indigeneity. Since methodologies are informed by one's experiences of the world, and Indigenous methodologies are rooted in Indigenous ways on

knowing and Indigenous lived experiences, non-Indigenous researchers can never fully understand an Indigenous methodology, and therefore can never properly employ and Indigenous methodology. Furthermore, researchers are generally working under Western academic institutions that are grounded in Western axiology; as a result, research projects are bound by regulations set by the institution (3). Universities, and academic communities have historically used Indigenous people to gain notoriety through projects that are exploitative, devalue Indigenous knowledge and tradition, and provide no tangible benefits to communities, all while leaving academics with degrees, publications and notoriety (49). Also, the academic community struggles with acknowledging the value of spiritual knowledge acquisition, something that many Indigenous researchers have found to be key to their research methods. Thus, these projects can never be fully decolonizing, because they are working within an inherently colonial structure that historically, has caused a great deal of harm to Indigenous peoples.

I acknowledge that as a non-Indigenous researcher, I cannot adopt an Indigenous methodology. Notwithstanding the impossibility of employing a totally decolonizing methodology, I believe that it is possible for, and critical for non-Indigenous researchers to follow the teachings outlined within Indigenous methodologies. First Nations communities that are engaged in this research project have asked for this project to be available in their communities. I was invited into these communities, and “checked my heart” (3). They deserve to have the best possible care in their communities, and this review of the project is critical in ensuring that the best service is being offered to women. My goal in life is to facilitate the delivery of non-judgemental and safe reproductive healthcare for all women. Although I am a non-Indigenous researcher, I am dedicated to doing what I can to deconstruct systems of power and oppression impacting Indigenous people. I have done the work to learn the histories of the land, unlearned my assumptions and checked my biases, and built trust with the communities; as such, I am able to act as an ideal amplifier of women’s voices, in order to advocate for equitable, culturally safe, holistically healing care.

### 3.2 Patient Oriented Methodologies

Conventionally, health research projects are born out of the minds of the researcher with the intention of answering a question that they have about health care, outcomes or care delivery. However, oftentimes, researchers are not familiar with the experience of patienthood, and even well-intentioned projects can end up having little to no effect on patient outcomes and the patient experience. There is potential for this paradigm to be reversed by engaging patients in research.

This is defined as, “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—clinical care, organizational design and governance, and policy making—to improve health and health care” (50) According to the Canadian Institutes of Health Research, patient oriented research (POR) refers to the broad spectrum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes (51). This research paradigm places the expertise in the hands of patients to inform a research project from its nascence to its completion, and uses their lived experience to guide researchers to ask the right questions (52).

The four guiding principles to POR, as outlined in the Canadian Strategy for Patient Oriented Research (SPOR) are inclusiveness, support, mutual respect and co-building (51). POR should include a variety of patient perspectives in order to represent the diversity of the patient experience. In fact, it has been proposed that a good quality patient oriented research project takes a “half plus one” approach to determining the number of patient partners involved in the project, meaning the patient partners make up the majority of the research team (53). This research methodology views patient partners as equal members of the research team, and although they likely will not be involved in bench lab work, they can be meaningfully involved in other aspects of research including project design, feedback, feasibility and dissemination of research (54). Researchers must support patient partners by creating safe spaces for discussion and by appropriately compensating them for their contributions (51). Compensation must be provided to patient partners ahead of time for their time, travel, accommodations and other expenses that they may have during the period of research project (53). This can be a challenge, as institutions traditionally operate on a pay-then-refund basis, and therefore researchers must support their patient partners by advocating for cash advances for compensation. Appropriate compensation helps to acknowledgment of the value of all patient partners’ expertise and experiential knowledge. When engaging with a study population where financial security may be a barrier, it becomes even more important for partners to be paid fairly for their time and not expected to pay out of pocket for travel, food and other project-related expenses. Projects in partnership with Indigenous patient-partners should allocate funding to up-front payment of patient partners. In order to help to effectively secure funding for POR projects, patient partners should be involved as early as possible in discussion with health care decision makers, in order to find common ground in where their research priorities can align with those of policy makers, researchers (53).

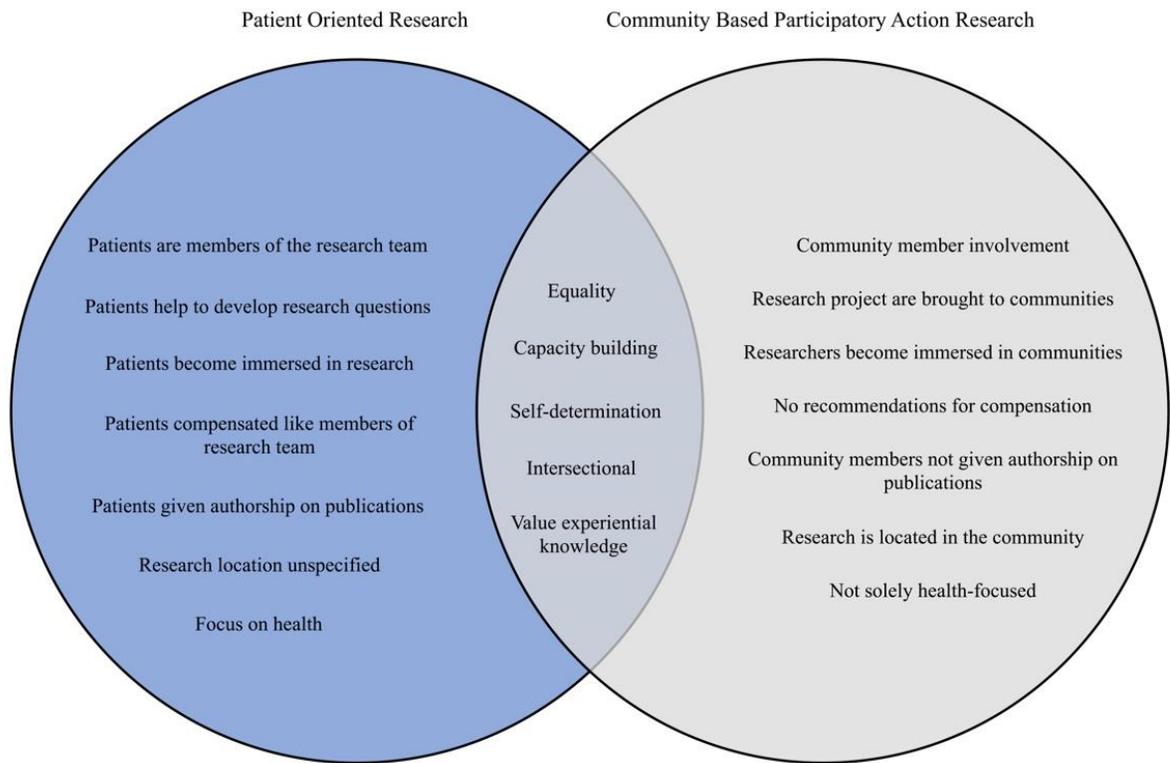
Patient oriented methodologies can be categorized based on the four levels of engagement that the patient partner may take on during the research project (55). The lowest level of commitment for patient partners starts at the level of consultants where their role is to provide feedback on research projects. When working with patient consultants, researchers can use focus groups or expert panels to gather patient input. A more engaged role for patient partners is at the level of “involvement”. At this level, patients are a part of the research project from beginning to end as advisors on the project. This requires patients to be given membership positions on research and advisory teams. Patient partners involved at the collaborator level are on equal levels to the rest of the research team. At this level they become research co-investigators and members of research steering committees. The most involved level for patient partners is at the level of research leads. These partners have the final decision-making power with respect to the research projects, and are often the principle investigators in studies. Although this is arguably the most “patient oriented” level of engagement for patients to be involved in research projects, barriers at the institutional level often prohibit anyone other than an institutionally-hired researcher to be a principal investigator on studies (53). For this reason, at the current time, the collaborator level is the most appropriate level of engagement for patient partners to participate meaningfully on research teams. Additionally, because self-determination is a critical piece in reconciliation with Indigenous people, POR in partnership with Indigenous people should seek to involve patients at the highest possible level on the research team (45).

Although the SPOR framework is relatively new, being published in 2018, projects that engaged patients as partners were being conducted before the development of the current SPOR framework (51). A systematic review of research projects involving patient engagement and using the principles outlined in the SPOR framework before it was formalized was conducted; it includes 55 studies where patients were involved as partners and the project had a goal that improved the health care system at either a systems, organizational or individual level. The review locates seven successful approaches to patient engagement in health research. These are, engaging patients at the earliest possible stage of the research project, clearly defining patient roles and responsibilities, providing training to partners to orient them in the field of research, providing support and encouragement throughout the project, ensuring mutual respect, ensuring trust and including an evaluation plan for engagement. The steps identified in the review are in line with the four guiding principles of Canada’s SPOR plan (51). The review also outlines shared characteristics of successful patient engagement opportunities in health research. Successful studies had a clear description of patient’s roles and levels of engagement in the

study, took the time and effort to create a trusting, long-term relationship between researchers and patient partners, used patient's input across all phases of the research project and ensures a respectful cross-communication between all research team members (52).

While POR is an emerging methodology just entering into popularity, its underlying framework has been around much longer under the name of community based participatory action research (CBPAR) (51). CBPAR is a research orientation that values the active involvement of community members in research, to answer questions that matter to the community. In health research, it seeks to even out the power imbalance between researcher and subject and acknowledges the importance of experiential knowledge. According to Minkler, CBPAR can be summarized as follows; it is participatory, it is a cooperative, equal process between researchers and community members, it is a co-learning experience that it aims to improve communities through capacity building and systems development, it empowers and promotes self-determination, it achieves balance between research and action, and it acknowledges the intersections of gender, race, class, ability, etc. CBPAR methodologies value the input of community members in much the same way POR values the input of patient-partners. Both methods seek to conduct research projects that matter to the people involved, and add diversity to the research team, while incorporating experiential knowledge, capacity building and equal collaboration. Critical differences between POR and CBPAR include that POR tends to be solely health focused, with patient partners becoming a part of research teams before the development of research questions, and paid and recognized in authorship as being equal to all (Figure 3). CBPAR can be trans-disciplinary, generally community-member involvement occurs after the research questions and methods have been developed, and it lacks provisions for payment or awarding of authorship for community members who participate in the projects. Nevertheless, since the methodologies share many commonalities, it can be concluded that the methodologies will share similar critiques.

**Figure 3:** Venn-diagram comparing Patient Oriented Research to Community Based Participatory Action Research



CBPAR has been critiqued as a methodology whose intention to do “good” falls short of the results it produces (51). While CBPAR claims to circumvent power imbalances between academic researchers and community members, and to conduct research projects that improve communities, projects claiming to use CBPAR put themselves at risk of not fulfilling these promises. In fact, unsuccessful project can function to further increase power imbalances between researchers and subjects. Furthermore, CBPAR projects are at risk of worsening power differentials because of the notion of having to overcome the “gap” between researcher and researched, in a self-fulfilling prophecy. The affirmation of the existence of difference between the two groups functions to validate the “otherness” of researchers and researched, rather than place the two on an equal level. Another critique of CBPAR is that with its ascent into popularity, researchers are describing projects as following a CBPAR methodology, when in reality, community members are involved at surface-level, in tokenistic roles. As a result, these projects function to maintain power imbalances, and take funding opportunities from projects that would have successfully implemented CBPAR techniques. CBPAR conducted with

vulnerable populations must be especially aware of power imbalances, as these populations are most often put in tokenistic roles and taken advantage of in research (50). Finally, there is a conflict of accountability in CBPAR, where researchers must remain accountable to both the communities they are working with, and the institutions they are affiliated with (51). As a result, there can be a lack of accountability to communities because researchers must adhere to institutional guidelines and regulations. Researchers engaging in POR should be attentive to the shortcomings of CBPAR and make provisions to avoid methods that may widen gaps in power and diminish researcher accountability to patient partners.

Similar critiques have arisen in analyses of the ethical implication of patient engagement in health research (50). Authors with experience conducting POR highlight the establishment of a shared vision, the process and method of engagement and the practical aspects of engagement as areas of POR where barriers to meaningful engagement may arise. For a research project to be a success, the research team should arrive at a shared vision of the project. This can be complicated in POR in patient partners are confused about the level of engagement they will be participating at. In addition, difficulty may arise in POR with the instrumentalization of government funding bodies when the funding body has objectives and rules that need to be followed that do not line up with the patient partner's objectives, the goals of the patient partner tend to be undermined. These barriers can often be circumvented with open communication early on in the research process, and with training for all team members on how to work on interdisciplinary teams.

A dramatic critique of POR builds on the idea of the instrumentalization of funding organizations, which are often government organizations, by claiming that the push for the popularization of POR by the CIHR may be because of its capacity to quell the concerns of dissatisfied patients (51). When patients are investing their energy into research projects, they are not concentrating on banding together to critique the health system as a whole. Instead, they are participating in research projects that allow them to feel as though they are making a difference and improving the health care system through their research. However, since it is generally government funding bodies that decide which projects get funded, the government gets to decide which projects are allowed to occur, and which cannot. Thus, POR becomes a means for the government to regain control over dissatisfied patients.

Researchers in the process of forming a POR team should be aware of who they are choosing to be on their teams (50). Patient partners should not be chosen because they agree with the researchers, rather they should be chosen because they offer a new perspective to the project.

Relationships with vulnerable populations of patient partners need to be clearly described, at the power imbalance between researcher and patient can be deepened, most notably if the researcher is also their clinician. Vulnerable patient partners need to be assured that their care will not be affected by their participation in research. This is especially applicable when working with First Nations women, as patient partners must feel confident that their involvement in research will not compromise their safety and autonomy, and that they are able to share their opinions with the project regardless of whether they are in agreement with the other researchers.

Finally, the practical aspects that may be challenging in patient engagement include things like compensation, scheduling and authorship. Patient partners should be compensated for the amount of time they put into a research project and for all associated expenses, their schedules should be accommodated for and respected. With respect to authorship, they should be given authorship in cases where they are involved in the conception or design of the work, drafting the work or revising it critically for important intellectual content, approving the final version, and agreeing to be accountable for all aspects of the work. As a way to remedy the exploitative history of research in First Nations communities, the principles of Ownership, Control, Access and Possession (OCAP) were created, as a means of protecting the intellectual property of Indigenous people engaging with research, and ensuring that this knowledge stays within communities for them to use how they wish (56). POR with First Nations people must acknowledge the contributions to the research that patient partners are making in a meaningful way, and follow the recommendations outlined by the OCAP principles.

Another consideration the formation of a POR team should be surrounding what kind of people generally come forward to be patient partners. Currently, there are no guidelines for how patient partners should be selected. Generally, the people that step forward as patient partners are confident people, who have the disposable time to participate in research, and feel as though their contributions can make a difference in research. Researchers should consider whether their patient partner's perspective is similar to the general patient population in their group of interest, and whether it is appropriate to have one person or a small group of people speaking on behalf of a huge patient population. The current system for POR makes no provisions for the perspectives of patients who would not have the personality type to volunteer themselves for research, or those are unavailable for research because of children, work or other commitments. Although more research is needed to clarify this aspect of POR, having a large and diverse group of patient partners can help to minimize this concern.

## **Chapter 4: Engendering Patient Oriented Indigenous Methodologies**

### **4.1 Background Project – CervixCheck North**

CervixCheck is a province-wide HPV self-screening project, targeting under screened women. There are two branches to the project, CervixCheck Fraser (CCF) and CervixCheck North (CCN). CCF is a project in partnership with health clinics in the Fraser Valley, geared towards immigrant women of Chinese or South Asian descent. Women are recruited to the project by posters or medical office assistants (MOA) at participating health clinics, and referred to the cervixcheck.com website where they request for a self-collection kit to be mailed to their homes. Women self-collect where and when they are most comfortable doing so, then mail the pre-paid postage kits to the British Columbia Centre for Disease Control (BCCDC) for testing. Follow-up occurs with their family doctors.

CCN is a large-scale cervical cancer-screening program offering self-collected HPV screening kits to under screened women in Indigenous communities in NBC. CCN has three branches, the Northwest project, which is in partnership with Métis Nation BC, the Northeast project, which is in partnership with the First Nations Health Authority, and the Northern Interior project, which is in partnership with Carrier Sekani Family Services (CSFS). The recruitment methods and advertisement strategies for both branches of the CervixCheck project were developed with the project's partners, in order to best suit the unique needs of each community in which it is being offered. The research project described in this thesis is a part of the project in partnership with CSFS, and for the purposes of this document, "CCN" will be used to describe the project partnership between CervixCheck and CSFS. CCN is grounded in a trusting relationship between the research team, the communities, and CSFS, an organization that provides health and wellness services to First Nations communities living in Carrier and Sekani traditional territories. Dr. Sheona Mitchell-Foster developed a partnership between CervixCheck and CSFS, working closely with Dr. Travis Holyk, the Executive Director, Research, Primary Care and Strategic Services for CSFS. Through this relationship, the project underwent approval by chief and council of 11 communities serviced by CSFS. Extensive community engagement for CCN has allowed participating communities to become heavily engaged with the project, community members to build relationships with study team members, and relevant stakeholders to have a voice in how the program would be delivered in their local health centres. CCN is currently offering HPV self-collected screening in the community health centres of Nadleh Whut'en, Takla Lake, Stellat'en, Yekooche, Burns Lake Band, Wet'suwet'en Band and Saik'uz First Nation and at the Southside health and Wellness Clinic which services the communities of

Cheslatta, Nee Tahi Buhn and Skin Tyee First Nation. Women are recruited to this study by recommendation of the community health nurses at their regular appointments, or on community health days. In Stellat'en, a generic invitation letter was sent out to each household informing them of the service available at the health centre. Also, at some communities, on community health days, the CCN team is invited to the community to host an information booth promoting the program. Nevertheless, the majority of recruitment to the project occurs through opportunistic screening. Women who are eager to participate are encouraged to self-collect in the clinic and return their samples to the community health nurse, who then ships the sample to the BCCDC to undergo testing. Results are received by the patient's CSFS family physician, who is then in charge of that patient's follow-up care. As of February 2020, 34 women from participating communities have been recruited to the project. At its conclusion, the intervention is expected to reach approximately 150 women in Northern Interior BC. The primary outcome of interest for CCN is the uptake rate of HPV self-screening, with secondary outcomes including HPV and CIN1/2+ prevalence, proportion of patients receiving their result and attending follow-up, and differences between subgroups of interest (age, Indigenous status, HIV status, community).

## 4.2 Methods

The purpose of this CCN sub-project was to illustrate how POR approaches can effectively be taken up in Indigenous communities. The goal was to outline how to ethically conduct relevant POR in an Indigenous community, in order to improve health interventions. In this particular case, the intention was to use POR to make CCN a valuable intervention not only by screening under screened women, but revealing patient-determined improvements and modifications to the project in order to inform scale-up. Using a patient oriented approach, this project reveals the complicated and unique experience of cervical cancer screening for women living in rural First Nations communities, identifies the objectives that the communities would like to achieve during and after the CCN project, and brings to light how patient oriented research can be employed to improve the pilot project. Further, the project identifies a synergy between Indigenous methodologies and patient oriented research methodologies as an invaluable tool for the development of community-based research projects, and the pursuit of reconciliation.

A qualitative approach, informed by Indigenous methodologies was used for this study (35). Before the commencement of the project, I, as the researcher, worked to understand what brought me to this project and what were my motivations for undertaking his work. I also sought

to understand how my worldview, along with past history, present and future self may impact my interpretations of the research. Finally, I learned about the history of the land that I would be working on and of the Dakelh people who live on the land, in order to ensure the maintenance of cultural safety throughout the project.

Focus group meetings were used to gather qualitative data, followed by a semi-structured survey to gather quantitative background data that was used to situate the qualitative thematic data. The use of the focus group aligned with Indigenous methodologies and patient oriented methodologies because it accommodates oral traditions, favours the importance of patient voice and relationship with community, and allows patient partners to have control over what topics are discussed in most depth (45, 51). However, the use of the survey was also critical as it ensured that questions pivotal to the success of the project were answered during the study, and that participants were able to confidentially answer the questions that they did not want to discuss in front of other focus group participants. The results from the focus group and survey were combined after data collection was complete.

The questions for the initial focus group and survey were based on extensive literature review, and both expert and patient opinion. It was ultimately put together by Dr. Mitchell-Foster, Dakelh physician Dr. Aldred, Dr. Holyk, patient-partner Marion Erickson, and I (Appendix B, C). Marion is a Dakelh woman from Nak'azdli, and a health researcher with lived experience navigating the colonial health care system in the context of cervical cancer screening and follow-up. Marion had worked with both Dr. Mitchell-Foster and I on past projects, and was eager to team up to be a part of this project. Their cultural expertise and experiential knowledge were instrumental in the creation of the focus group script and survey. The community meeting materials were informed by three themes that the study team wished to cover during this research project (Table 1). These themes were, Indigenous women's health & cervical cancer screening, HPV self-collected screening (CervixCheck North), and patient participation in research. Sub-themes for CCN included stigma surrounding STI screening versus cancer screening, partner influences on screening, ongoing barriers to screening, receiving positive results and follow-up care. Sub-themes for patient participation in research included participation in research versus participation in a screening program, objectives and community definitions of success for CCN and areas of future research in women's health.

**Table 1:** Themes and sub-themes used in the development of the focus groups script and semi-structured survey

Women's Health	CervixCheck North	Patient participation in research
What is women's health?	Ongoing barriers to screening	What is a successful intervention?
Experience of cervical cancer screening	Acceptability of project & test	Additional objectives for CervixCheck North
	Stigma surrounding STI screening	Attitudes towards research
	Partner influence on screening	Future women's health research
	Cultural safety of screening project	
	Receiving positive results	
	Follow-up care	

In accordance with Indigenous and patient oriented methodologies which both prioritize patient voice, the focus group script questions were designed to be open-ended and general, incorporating iterative feedback from participants, in order to allow meeting participants to have control over the flow of the conversation, and over which topics were discussed in greater detail during the focus group meetings. This was to ensure that the project’s results reflected the opinions and concerns of community members, unmarred by a restrictive interview guide.

Community health representatives (CHR), community nurses, Health Directors and MOAs assisted with recruiting women to this project. Based on their recommendations, women who had participated in the CCN project, and women who had previously demonstrated an interest in research or women’s health issues were identified and personally invited to the meetings. Participants were also recruited via posters, social media advertisements and word of mouth; also, some participants enrolled because of an existing relationship that I had formed with them at community engagement visits, by sharing coffee and stories. This method of recruitment parallels Indigenous methodologies best, because it demonstrates the power of relationships in building trust between researchers and community members (35). The meetings were facilitated by me, and when possible, and Elder or knowledge holder from the community was present to help to maintain cultural safety, and to provide support to participants in the event that emotional or traumatic topics were brought up during the meetings. During the talking circles, an introductory lecture introducing HPV, cervical cancer, Pap screening, HPV screening and the CCN project was delivered. Following the lecture, participants were encouraged to ask

questions regarding the lecture material. This step ensured that group members had a clear familiarity with any background information that forms the foundation for the focus group conversation topics, before being asked to comment on it. After, focus groups began, where participants were guided to comment on their perspectives on women's health, cervical cancer, cervical cancer screening, follow-up care and the CCN screening program. Meetings occurred during the lunch hour, and meetings were audio recorded. Women were offered the opportunity to have a one on one interview if they felt uncomfortable with the focus group environment.

Immediately after the focus group, the participants were asked to complete an anonymous survey regarding their experiences with, and impressions of the screening program. It consisted of 11 "yes or no" and three 5-point Likert rating scale questions, as well as a final section for additional comments. The survey was deliberately delivered after the meeting, in order to ensure the participant's answers during the focus group interviews remained unmarred by the vocabulary used in the survey. To maintain equity, in cases of limited literacy, the questions for the survey were delivered orally. In order to foster rationality within the project, participants were encouraged to discuss the questions with other focus group members; however, were also allowed to remain anonymous while answering potentially sensitive questions. After the survey was submitted, participants were compensated for their time and contribution with a \$75 grocery gift card. Following each community visit, field notes describing overall feel of the focus group, as well as my personal observations, were recorded. Initial data was collected in Takla, Yekooche and Stellat'en, in August of 2019, where two individual interviews and three group meetings were conducted.

The focus group recordings were transcribed verbatim manually, and transcripts were reviewed via comparison to audio recordings for accuracy. Data analysis occurred as immediately after each community visit as possible, where Dr. Mitchell-Foster and I concurrently analyzed the transcript data using Nvivo12 software. Main recurrent themes were selected and developed using coding thematic analysis described by Braun and Clarke (57). Initially, a bottom up analysis was used, where data was categorized into low inference codes (58). Low inference codes were subsequently categorized into groups of high inference codes. Then, a top down analysis was employed to develop themes based on the theoretical framework of this project. Themes were reviewed to ensure that all codes within a theme shared similar patterns, and that all of the themes were consistent with the data set in its entirety (57). After analysis of the data collected in the first round of data collection, the focus group script and survey were modified based on the initial themes chosen, in order to ensure that the script

facilitated the most generative discussion possible, to foster the collection of strong supporting data in the second round of data collection. The second round of data collection occurred in October 2019 at the Southside health and wellness centre, and followed identical methods to the first round. Data collection concluded once a community in each geographical region that the project is engaged with had participated, and when theme saturation occurred.

The survey results were analyzed using descriptive statistics. The qualitative data was combined results of the thematic analysis of the focus groups meetings and field notes, to provide a complete picture of study results. The proportion of codes belonging to each theme was calculated, in order to understand how much each theme was reflected in the data and to inform the importance of each theme. A network analysis was also conducted on themes and subthemes in order to describe the interconnectedness of the results (Appendix D) (59, 60). This was used to inform which themes hold the most influence over women's overall cervical cancer screening experience, based on the number of other factors the theme is related to. By enumerating every possible connection between themes, the subjectivity regarding the emphasis on certain themes over others caused by the researcher's personal lens can be minimized, and themes with the greatest impact on other themes emerge as those best targeted by programmatic recommendations and policy changes. A thematic network depicting all of the themes and subthemes from thematic analysis was made, and connections were drawn manually between themes that were related through processes, values, emotions, concepts and systems. For example, a sub-theme regarding the fear of STIs and cervical cancer being rooted in the potential impacts to fertility is related to a subtheme regarding concern over youth's sexual behaviours through a cultural belief of the sacredness of children. In this case, a connection would be made between these themes. Connections between themes at the same category were drawn in brown, and connections between themes of different categories were drawn in blue. All connections were given an equal weighting, and the number of connections between themes was tallied.

Following the completion of data analysis, a community visit was organized where the results were brought back to the community of Stelat'en in December of 2019, and to Takla and Yekooche in February of 2020. These communities were selected as representative of more remote communities and less remote communities who were engaged in this CCN sub-project. Women who had previously participated in the focus group sessions, and other women with an interest in the results were invited to coffee and cookies at their local community health center. Informal, individual discussions were conducted with women where the survey and thematic analysis results were presented; in an iterative process, the participants were asked to review the

results for accuracy, and rank the themes in order of which they found most interesting or valuable. The themes highlighted by community members are those that are going to be discussed at greater lengths in this thesis. This was to ensure that the main themes derived from the focus groups, and results of the survey reflected the correct sentiments and experiences of their community with respect to the community’s research objectives and potential adaptations to the screening initiative, and so that community-selected themes were the primary focus of analysis. The analysis of results was modified based on the feedback received by participants.

### 4.3 Results

In total, 30 women participated in a focus group or individual interview and completed the survey, and one woman sent in her handwritten responses to the focus group questions and completed the survey.

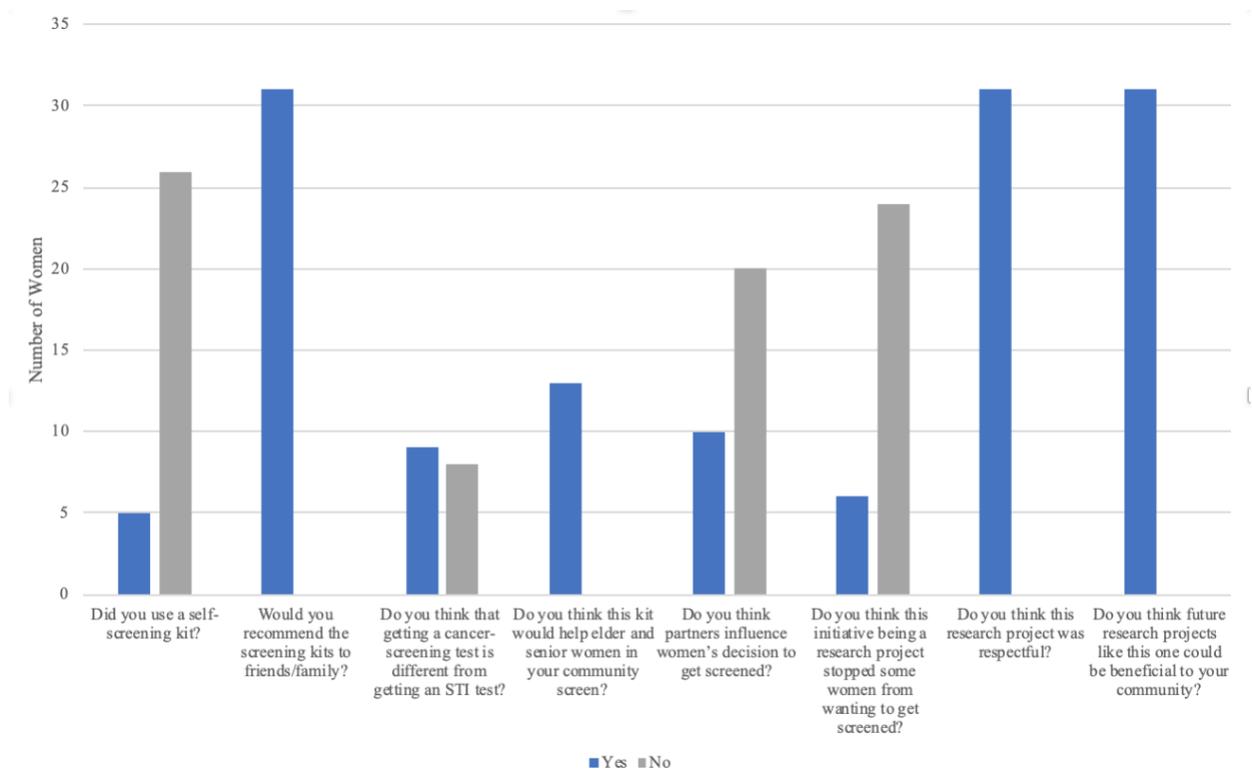
**Table 2:** Survey raw data

	Yes	No	Maybe	N/A	Total	
<b>Did you use a self-screening kit?</b>	5	26	0	0	31	
<b>Would you recommend the screening kits to friends/family?</b>	31	0	0	0	31	
<b>Do you think that getting a cancer-screening test is different from getting an STI test?</b>	9	8	0	0	17	
<b>Do you think this kit would help elder and senior women in your community screen?</b>	13	0	1	0	14	
<b>Do you think partners influence women’s decision to get screened?</b>	10	20	0	1	31	
<b>Do you think this initiative being a research project stopped some women from wanting to get screened?</b>	6	24	0	1	31	
<b>Do you think this research project was respectful</b>	31	0	0	0	31	
<b>Do you think future research projects like this one could be beneficial to your community</b>	31	0	0	0	31	
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Total</b>
<b>How culturally safe do you think the program was?</b>	0	0	3	10	18	31

\*Question, “Do you think that getting a cancer-screening test is different from getting an STI test?” was changed to question, “Do you think partners influence women’s decision to get screened?” after initial data collection was completed.

Of the 31 survey respondents, 5 women had participated in the self-screening intervention (Table 2). All of the participants responded that they would recommend the screening kit to friends and family, that the research project was conducted respectfully, and that they believed future research projects like this one could benefit their communities (Figure 4). However, six participants answered that the fact that this initiative was a research project may have been a barrier to some women eligible women participating.

**Figure 4:** Distribution of results of “yes or no” style questions completed by 31 survey participants

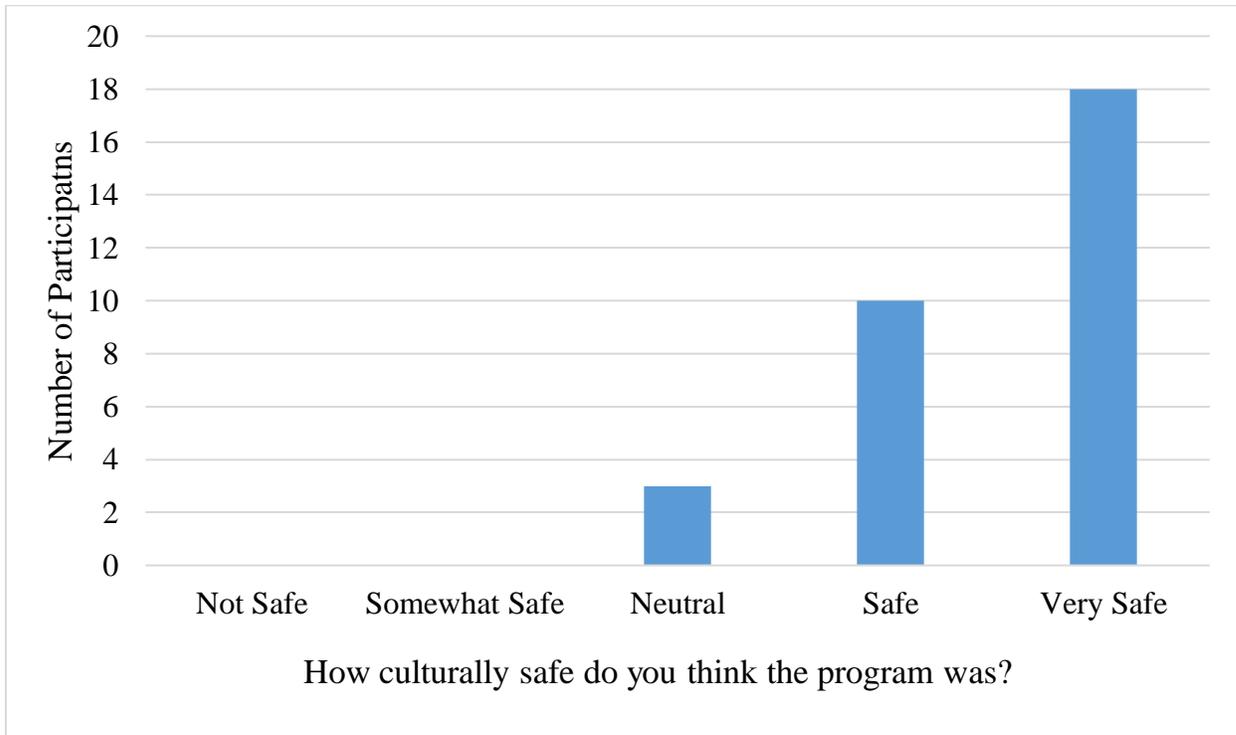


\*Question, “Do you think that getting a cancer-screening test is different from getting an STI test?” was changed to question, “Do you think partners influence women’s decision to get screened?” after initial data collection was completed.

The cultural safety rating of the project ranged from neutral to very safe, with the majority of participants answering that they believed the project was very safe (Figure 5). The majority of respondents indicated that they believed the project to be beneficial to elder/older women in their communities. With respect to intimate partners impacting screening, 66% of women believed that partners can influence women’s decision to get screened. Furthermore, 53% of women believed that getting a cancer screening test is somehow different than getting testing

for an STI. Of the women who had completed a self-collection kit, three received some form of follow-up care, and no women who were recommended for follow-up care denied this care (Table 3). All of them answered that the kit was either comfortable or very comfortable, and they were all either confident or very confident that they used the kit correctly.

**Figure 5:** Distribution of responses for 31 respondents to the question, "How culturally safe do you think the program was?"



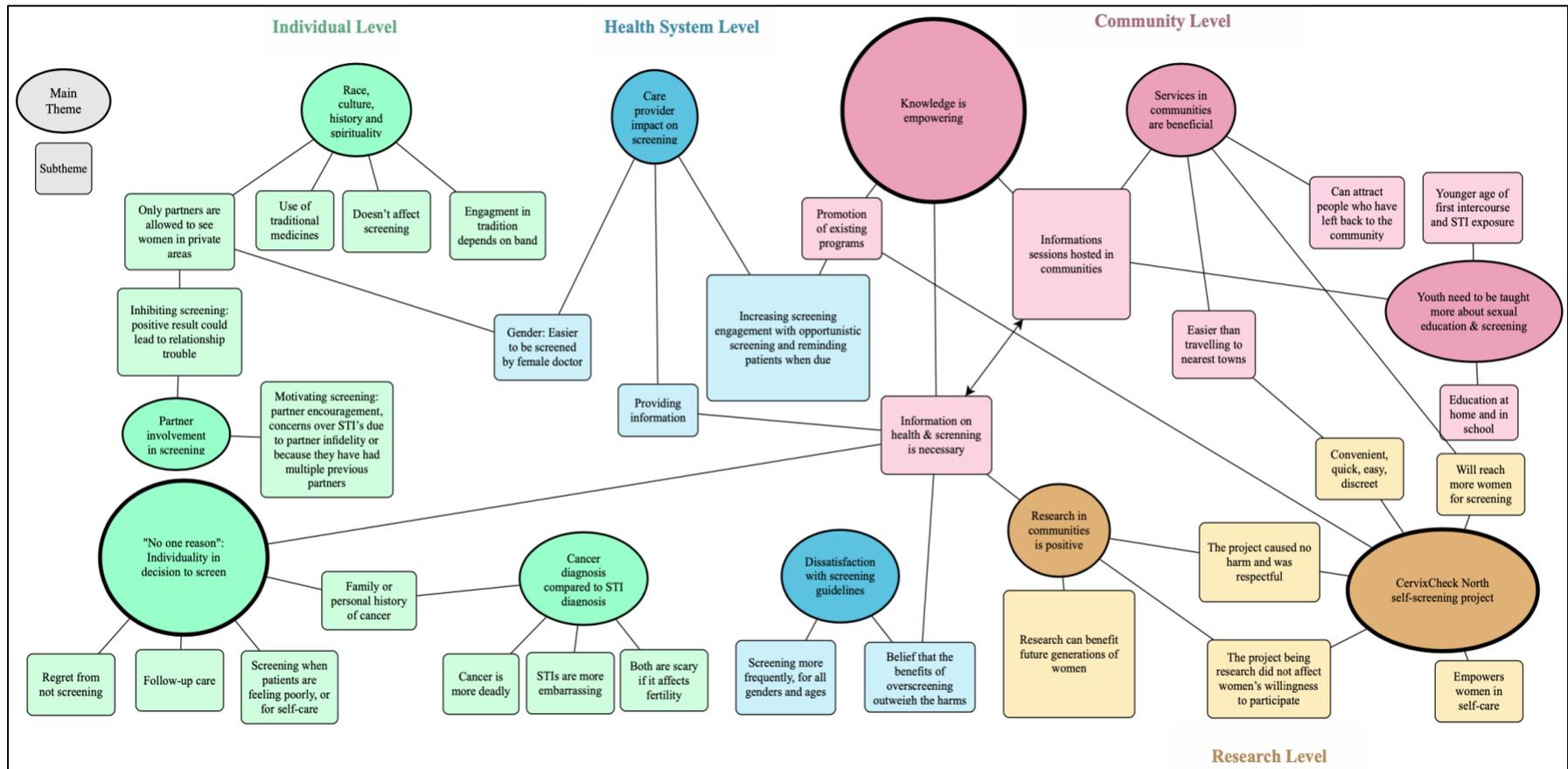
**Table 3:** Survey answers from women who reportedly participated in the CervixCheck North HPV self-screening initiative

	Yes	No	Total			
<b>Would you choose the screening kit again for screening?</b>	5	0	5			
<b>Did you receive any follow up care? (Pap test, colposcopy)</b>	2	3	5			
<b>Did you decline follow up care?</b>	0	5	5			
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Total</b>
<b>How comfortable was the sampling device to use?</b>	0	0	0	1	4	5
<b>How confident are you that you used the kit correctly?</b>	0	0	0	2	3	5

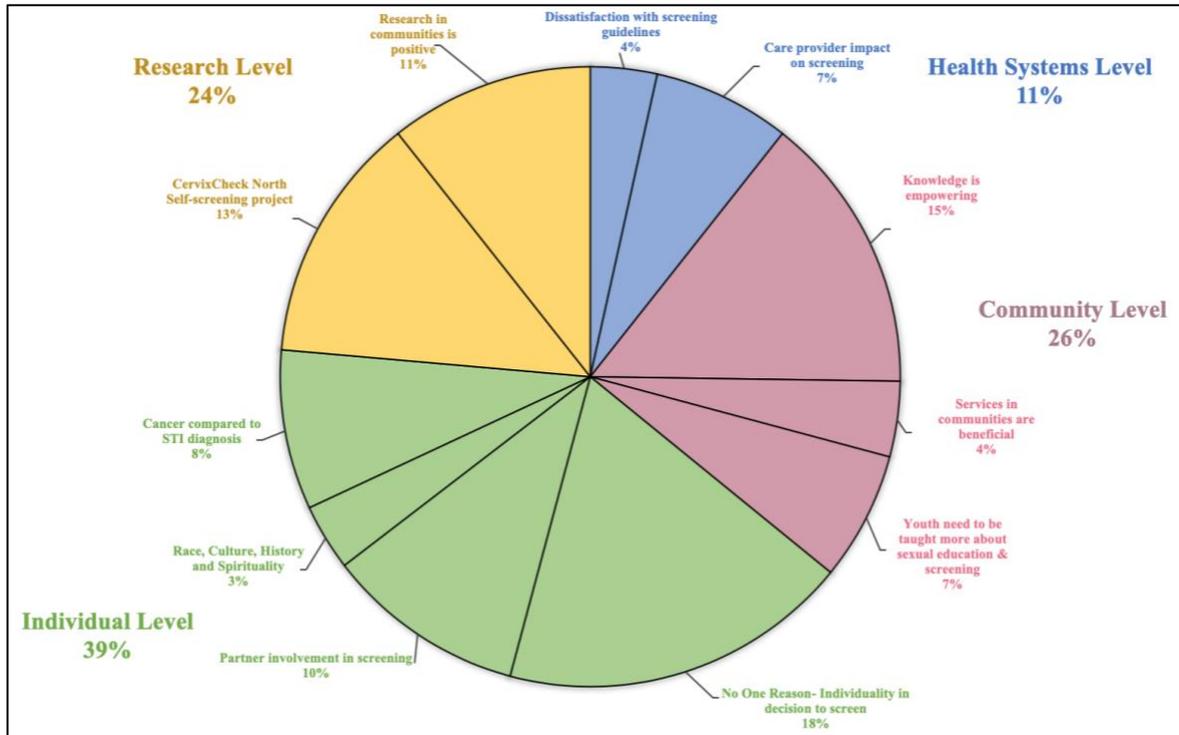
Following thematic analysis, eleven themes were selected by myself, Dr. Mitchell-Foster, and by community members as being prominent within the transcript data (Figure 6). The themes are divided into four categories of impacts to screening; those at the individual, community, health systems and research levels. Themes at the individual level refer to personal impacts to screening that exist for women; these include the “No one reason” attitude many participants described with respect to the individualistic nature of women’s decisions on whether to attend regular screening, the difference in attitudes and perceptions between cancer and STIs, intimate partner influence on screening, and the role of race, culture, history and spirituality in screening. Community level themes encompass impacts to screening that are controlled by the community and/or affect the community. These include the expression of the need for more information regarding health and screening for all community members, with a specific emphasis concerning youth in the community, and finally, the idea that more services being offered in the community would be beneficial. Health systems level themes refer to considerations that should be made by care providers and policymakers regarding screening; these are the notion that care providers have a critical hand in engaging women in cervical cancer screening, and that there is a deep dissatisfaction with the current provincial cervical cancer screening recommendations. Finally, the research level themes included any themes related to research in general, or more specifically, the CCN project; it was concluded that the self-screening project is a beneficial and relevant intervention, and that bringing research into the community in other forms will benefit current and future generations of women and other community members.

The majority of codes were allocated to the individual level category, followed by the community level category (Figure 7). Together, these categories made up 65% of the coded transcript data. Within the individual level themes, the most prominent theme within the data was the “No One Reason” attitude towards screening decisions at 18%, followed by partner involvement at 8%. At the community level, the majority of the codes surrounded the value that knowledge is empowering, at 15% coverage. The codes at the research level consisted of 24% of the coded data, with data surrounding CCN encompassing 13 % of the coded data and data surrounding research being a positive influence on communities taking up 11% of the data. Finally, health systems level codes encompassed 11% of the coded data.

**Figure 6:** Map of prominent themes selected from transcript data following thematic analysis of two individual interviews and five group interviews.



**Figure 7:** Pie chart of proportions of coded transcript data categorized into each theme, and category of theme



#### 4.3.1 Individual Level

Four themes regarding individual impacts to screening were selected based on the transcript data. The first surrounded the idea of autonomy, and that women’s individual life circumstance affects their decision on whether or not to access regular cervical screening. Participants expressed that with respect to screening and follow-up, there are a huge variety of reasons why women choose to screen, and on the other hand, choose not to screen. One group member stated, “I think its each individual, they have back history, and like any other women if they want testing for something that we do that testing, not putting anything else into that”. For example, it was expressed that if participants had had previous sexual trauma, or if they had had a negative experience with screening in the past, they may choose to forego screening rather than endure the further trauma that a Pap test may cause. With respect to the decision to not be screened, two participants commented, “Could be something from the past like what happened to them when you were younger and they just still feel uncomfortable with people going down there”, and “maybe fear of the first screening, was painful for them, they might not want to go and do it again”. Notwithstanding, the predominant attitude towards screening across the groups

was accepting that it is a regular part of life, with most agreeing that, “it's [screening] just something you have to do nowadays”.

People also commented on how for those with family or personal histories of cancer, getting screened regularly becomes priority. For example, one participant said, “My auntie had cancer, she got her breasts removed. and, my sister she's one year younger than me, we keep having these cysts, and they say it goes away on its own. So that's recently I keep getting screened”. In addition to having this extra motivation to be screened, it was brought up how it is better to know whether they have cancer than not, because knowing can be empowering, and not knowing can harbor regret in the future if they are ever diagnosed with a later stage cancer. A group member telling the story of a family member who did not screen for cervical cancer said, “I have a sister-in-law that was actually diagnosed with it [cervical cancer] and she's had to go in and do the biopsy and she's kicking herself for not having her regular Pap tests on a yearly basis”. Alternatively, many individuals expressed that they would rather know their HPV status, no matter what the consequences. These comments included, “I like to know what's going on with my body, so personally, like for myself, I have to know” and “The way I look at things, people should just know. If it's there it's there”. The sentiment expressed here that knowledge is empowering is echoed at the community and research levels, and will be expanded upon in those sections.

Another reoccurring theme that affects screening on an individual level is the impact that intimate partners have on the screening experience. Group members comment that the level of impact their partner has varies from motivating screening, to inhibiting screening, for a variety of reasons. One participant described how her partner has an active involvement in decision she makes regarding her health,

“I know it's none of his business I tell him, ‘I know it's none of your business but I'm gonna get this thing done. [HPV screening]’ he goes, ‘What is it?’, ‘It's for me and you’, I tell him... I tell him everything before I do anything, any testing”.

However, this opinion was not echoed in all groups. Frequently, participants commented how they did not ask their partners before seeking out screening, rather, told them after doing the test. In response to the above comment, another participant said, “Me I'm the other way around. I do it [screening] before I tell him. I just like, go do it then come back and say, ‘Oh yeah I got this done’”. It was also noted by a participant that this difference in approach to communication between partners could be a generational effect, stating,

“My husband is, he's involved if I want him to, whether he wants to be or not, he will do it very begrudgingly. But my son, with him and his girlfriend, fiancé, totally different person. He is totally different. He is like when something happens ... he is right there a part of it and knows everything that she is going through to do it”.

Whether the partner was actively involved in the decision to screen or passively informed about the screening after the fact, no participants mentioned the possibility of a partner denying the women the right to screen.

However, concerns of partner infidelity or having multiple previous partners was brought up as a reason to access screening. A group member stated that, “If you've had maybe numerous partners, if you find out your partner...was not behaving himself or herself then you want to go in for an STD [test]”. However, another group member commented on how receiving a positive STI test result after being in a committed relationship for many years could cause personal trauma and stress on the relationship. They state,

“To me being married for quite a few years, that [receiving a positive result] would be very very impactful on me because it wouldn't be me fooling around so it's obviously somebody else's doing wrong. So yeah it would be horrible. To me it would be almost worse than can-, well no it wouldn't be worse than cancer, but it would be horrible. Really horrible”.

Partner involvement in screening is also present within the third main theme affecting screening on an individual level, the impact of culture, race, history and spirituality on screening.

Many focus group participants called attention to the fact that in some families' cultures, only a woman's husband is allowed to see her genital area. A group participant told the story of her grandmother, who died from cervical cancer because of this cultural value,

“One of the things that I've noticed, a lot of our elderly that have passed on, is that they had cervical cancer and even though they're passed their stage of menstruating they won't say anything because only the male is to see the wife down there. So, they won't go in for that Pap and stuff, and that's just their beliefs from long ago right. I know my grandmother died from cervical cancer and she could have been living today but she chose not to do those tests. Because its forbidden, you know. Especially in I think First Nations women, in our elderly women”.

Another cultural consideration brought up during focus groups was the fact that culture, race, history and spirituality do not generally affect cervical screening, and that adherence to tradition varies from band to band. One participant stated,

“Each nation is different too, because one of the nations in Burns Lake, they're very heavy in their traditions and how they teach their young the rights of passage and all that. And I don't know, growing up on the North side and South side that wasn't really instilled in us”.

Although some commented that they did not participate in ceremony or use traditional remedies, others found it to be central to their health care. For example, some participants who were engaged in cultural practices told stories of how family members whose cancer could not be cured using Western medicine had looked to traditional medicines and ceremonies for relief. They state that, “we just use our own medicine cause she make our own and we drink that and we help other people too. We save one lady from Fraser Lake. She's got cancer and she lose all her hair and we help her with the soapberries. That's all I know. Don't need pills”.

Regardless of whether bands were actively engaging in traditional cultural remedies and ceremony, participants made it clear that they did not wish to be treated differently because they were First Nations women; two participants voiced this when they said, “I think there's too much talk on how much Natives have things more than anybody else, I don't believe that” and, “I don't know of any cultural influence”.

The final individual level theme encompasses the attitudes of community members towards both cancer and STIs. Participants described how an STI diagnosis would be more embarrassing than a cancer diagnosis. One group member said, “STD test, I've never had to do that thank goodness but it's kinda embarrassing right?”. In contrast, at no point in the focus groups did a participant describe a cancer diagnosis as being embarrassing or shameful. Instead, a group member said this about cancer, “The word cancer comes with a stigma, like, there's an impact behind it. A very strong impact. Anybody hears that word, and, deer in the headlight. Like you just kinda freeze”. This quote demonstrates a fear and sense of foreboding associated with cancer, that does not accompany an STI diagnosis. Although STIs were generally positioned as less severe than cancer by focus group members, this paradigm was shifted when discussing the impacts on fertility an STI or cancer diagnosis may have. Broadly, participants believed that any diagnosis that could impact fertility would be devastating. For example, someone said that an STI diagnosis could be scary because, “you don't know how you'll be affected, like if your fertility stuff will be jeopardized”. In parallel, the way cancer could affect fertility was also commented on, “I think it would be probably scary like because if it has something to do with cancer, you know, because if it could impact being able to have a child”.

Again, in this quote the root of the fear associated with the cancer diagnosis exists at the possible impacts the disease would have on fertility.

#### 4.3.2 Community Level

At the community level, predominant themes centered around access to information and services in the community. Participants reported that having more services accessible from within the community has been beneficial to the community. Since lack of transportation and funding for transportation came up as a barrier to accessing follow-up care following a positive HPV result, having follow-up services in community could help to circumvent the complexities associated with having to travel for health care. For example, when discussing follow-up care, a participant said, “it'd be good if they come up here and did it up here”, instead of having to travel up to three hours away on precarious logging roads in order to access Pap screening or colposcopy. A group member voiced the fact that offering more services in the community may have the potential to attract community members back to the community who had left due to a lack of available services. She told a story of a conversation with her daughter who had moved away from the community, where her daughter said that she didn't know services like HPV self-screening were being offered in her small hometown. Her mother said, “‘Everything is coming up this way.’ I tell her. Try to get her to come home too eh. That's what she needs”. Furthermore, group members voiced that many people living in the community rarely left their houses, and often suffered from depression due to a lack of activities. They said, “I know some of them that just stay inside and they get really stressed out”, and “A lot of people don't really leave their houses”.

A specific service in the community that group members emphasized was a need for information sessions offering education surrounding health, cervical cancer and screening. A participant described the importance of such sessions as,

“Education is a big one. Get the information out there, the knowledge for people that the information that the stuff is there. Making it available, readily available. Easy access for people. The easier it is the more they're gonna use it”.

Moreover, group members voiced the benefits of having regular visits by members of the CCN research team for information and promotion of programs in the community. They said, “Well even just you being here right now right, you're promoting tests by being here, you're promoting the importance it, of the testing and everything”. Specifically, group members wanted information sessions to not only be geared towards women, but to have information for men,

youth and elders regarding “female problems”. With respect to men’s education, participants said, “Get them all educated about it [HPV]”, “I think maybe if they have some kind of knowledge and know that, ways to help protect women, I think it would be good”, and “they should be educated on any kind of STDs that are going around so they can protect themselves as well”. For elderly women, participants commented on how a better understanding of the screening process could potentially save lives, as mentioned in the previous section.

The third major theme at the community level was a need for youth to be taught more about sexual education and screening. Participants were concerned over the impression that youth in the communities were engaging in sexual activity at a younger age, and therefore becoming susceptible to STI’s at a younger age. One participant commented, “They do things [sexual activities] earlier than what we did... is true, because the teens are catching stuff that people usually get in maybe their 40s”. Due to this concern over earlier exposure, group members believed that parents and schools should be emphasizing sexual health education, and that having teen information sessions would be beneficial in preventing cervical cancer, and eventually, reducing the incidence rate of the disease in their communities. A mother who was a member of one of the focus groups told a story of how she brought her daughter with her when she got a Pap test, in order to teach her what she will have to do to take care of herself when she got older. She said, “Every time I had my Pap test done, I used to let them [her daughters] come in and watch them do it. When Dr. sent, next time they came in. I said go and tell them that this is what they're gonna go through when they get older”. Other participants echoed this belief, and commented that screening may be increased if youth are taught about screening as early as possible. For example, a group member said, “Before they can have the Pap test, of the age, information should be right out there, and let that information get to them”.

#### 4.3.3 Health Systems Level

On a health systems level, two themes arose as affecting the screening experience for women. First, there was a dissatisfaction with the current cervical cancer screening guidelines, with participants expressing concerns that screening should begin earlier, and occur more frequently for women. With respect to the three-year recommended time interval between tests, a group member said, “That's a long time, and just like Pap they've upped it and same with breast it used to be one year and now it's two. It's like why do they do? I mean they're trying to save money or what? Do you know what I mean?”. The belief that screening had been set to every three years due to a desire to cut costs to the health care system was prevalent throughout

numerous groups. Furthermore, women were perplexed as to why HPV screening guidelines recommended starting screening at age 30, 5 years later than current Pap recommendations suggest. They commented, “I wonder why they picked the age. Do you know what I mean? Like you'd think once you can have a Pap, that's when this thing should start”. Although the focus group members had an understanding of why the minimum age for screening was set higher than they would have expected, many participants believed that, notwithstanding the fact that younger women would be able to clear the transient HPV infections, and regardless of the emotional trauma it would cause a young women to know her HPV status, it would be beneficial for them to know if they were positive, as to not spread the virus around further. This participant express concerns that without knowing that they have HPV, they might unknowingly spread the virus, “You were saying that the teens fight this off. I mean they're gonna have that in their body regardless, and if they don't know this, they're gonna be doing around and sharing the wealth, so to speak you know what I'm saying?”. Additionally, since for many women, screening is part of their self-care routine that leads to an empowered feeling of being cancer-free, having limits placed on how often they can screen is seen as an infringement on their bodily autonomy. Women also made comments regarding the burden of HPV management being placed solely on women, when the virus can be transmitted by both men and women. A group member suggested with respect to HPV screening, “I think it [HPV screening] should be directed towards both genders if this HPV can be spread by male and female”, and similarly, another participant said, “It shouldn't be just targeted towards women, it should be targeted towards both genders”.

The other main theme at the health systems level is the influence that care providers have on the screening experience. Women commented on how doctors, nurses and clinic staff had a great impact on whether they were screened for cervical cancer. Many participants described how they never remembered themselves that they were due for screening, but it was their care provider who reminded them, and therefore, they were screened regularly. For example, one member said, “They just tell me I'm due and I do it [screening]”. Additionally, group members told stories of how their care providers used opportunistic screening to catch them for screening when they had visited the clinic for reasons unrelated to their reproductive health. A woman told this story of their experience at their local health centre, “I came here to get stitches out of my hand and...they came, and I had to have a Pap test! I just came to get stitches out, so I blame it on them”! Moreover, groups discussed how care providers can increase screening engagement by promoting interventions such as the CCN project. An MOA working in one of the communities said this in a group, “the nurses and CHR and I have been telling people if we

know that they're due for Paps or stuff like that that they can come in and this [self-screening] is an option”.

Another care provider related subtheme that was prominent in the focus group was the impact that having a female care provider had on women’s willingness to access screening. Groups discussed how having only male doctors visiting the communities may be a barrier to women accessing regular Pap screening, because they aren’t comfortable with a man performing a pelvic exam. This sentiment is summarized by these quotes, “some women are uncomfortable with a man, checking out their business”, “...but I'm glad more female doctors are coming in now, because before, it was the male”.

Group members also commented on how they relied on their care providers to provide them with information about health, screening, and diagnoses. A participant describes how her commitment to screening regularly came from an interaction early on with a care provider in this quote,

“Seeing the nurses in Takla back...15 years ago, she kinda embedded it in my head that it’s important to get screened...So, to me I think it’s important and she kind of, the way she explained it to me, it’s kinda important to get it done...Dr. Berg, I had him for 24 years he was my family doctor. He always, always, every appointment, ‘make sure you, you know, update your, do all your testing to make sure you, you know, take care of yourself’ so to me that just became an important factor to get screened so I guess the doctors and nurses were the ones that [influenced me]”.

This story demonstrates how effective a trusting relationship with a health professional can set the stage at an early age for women to be dedicated to screening regularly. In fact, in one focus group, many of the participants described how a large portion of their health education was delivered to them at school, from a community nurse. They said, “we used to have visits from the public health nurses when I went to school at Grassy Plains, they'd come and that's when we'd hear the talk you know”. These visits by community nurses proved to be the source of the majority of this community’s sexual health education.

#### 4.3.4 Research Level

Two prominent themes were selected at the research level that impact screening in the communities. The first is how the CCN project has affected the community and the screening experience for women. Group participants commented on how the self-screening kits themselves made screening convenient, quick, easy and discreet, and how they believed that the intervention

would be able to reach more women for screening than regular Pap screening alone. For example, a woman said, “I think just the convenience of having to live way out here and make an appointment in town and try and get to town”. As a result of the kits being available in the community, it is saving them time and the resources needed to go into town by screening in the community. Another woman commented, “What I like about the kit is it's simple, it'll be quick, and it'll be private probably”. When comparing the kits to the speculums that nurses use for Pap tests, one participant said,

“I like that it's not steel and scary looking like the other ones that the nurses use! And it's more convenient, or I don't know, smaller than the ones they use... as soon as you showed me the kit, I wanted to use it! Because for me it's less scary than the other tools that they use in the doctor's office.”

Overall, the kits were very well received, and were regarded by the groups as a better option for screening than a physician conducted Pap test.

Furthermore, the intervention was described as being able to empower women in their self-care, and create inroads to other health care interventions. A former health care worker who was a participant in a group said,

“You know, I think if people, if we could get people to be involved with issues like this and taking responsibilities for going and getting this kind of a test done, it would probably transfer over into other areas of health too you know. Sorta like, if you can do this, there's a lot of things that aren't as hard as that! You know, and so I think it would just be a really good thing”.

The second research level theme that was selected from the transcript data surrounds a shift in perception regarding research in communities, from something to be avoided to something that can bring about positive change in the community. Although historically research was not well received in many First Nations communities, participants in these focus groups did not believe that the CCN intervention being a research project was a deterrent from women engaging with self-screening. One member said, “I don't think it affects [participation] just because it's research. I mean...I think that it would be successful, then it'll be all over the place. Not only in here, in Takla here, everybody that has access to it. It would be amazing”. Here, we can see that the research aspect of the intervention was well received by this participant, but also that they felt that having the project introduced more universally would be an ideal as a future goal. In fact, the sole concern regarding the research project came from concern that the service in the community would not continue to be offered once the project is completed. A participant

commented on how they didn't want their community to be involved in a project that ends up being cancelled in this quote, "maybe you go through all of that and your research stuff gets shut down and they went through all that stuff for nothing. Maybe that would be a thought". Another subtheme related to the positive reception of research exists surrounding how research can benefit health in the present and in the future. A group member summarized that sentiment as follows, "I don't mind participating in anything that will benefit our health. If it helps, especially research. It'll help our future generations". Participants were asked to give examples of health-related topics and issues that they were passionate about, and that they believed research might be able to help with in their community might be able to benefit from research relating to this issue. Examples brought up included birth control, the pancreas, blood clots, menopause, pregnancy, nutrition, pregnancy and nutrition, illegal and prescription drugs, impacts of stress, breast cancer and mammogram screening, mental health and counselling.

#### 4.3.5 Network Analysis

Analysis of the connections between themes and subthemes was conducted in order to gain a better understanding of the relationships and reciprocity between themes (59, 60). A total of 105 connections were made between themes and subthemes. The majority of connections existed at the individual level with 35 connections, however most of these connections were intracategorical. The community level demonstrated 34 connections, and at this level, intercategory connections made up 67.6% of the connections, with connections branching into all three other categories of themes. The community and individual levels were linked through 10 connections, the community and research levels were linked through seven connections, and the community and health systems levels were linked through six connections. Within the individual level, areas of convergence of connections were around "Family or personal history of cancer", and "No one reason: Individuality in decision to screen". At the community level, items with more than five connections were, "Knowledge is empowering", "Information on health and screening is necessary", "Youth need to be taught more about sexual education and screening", and "Information sessions hosted in communities". At the health systems level, the main area of connection surrounded the sub-theme, "Increasing screening engagement with opportunistic screening and reminding patients", and at the research level most connections were to, "Research in communities is positive".

**Table 4:** Network analysis results displaying number of connections between themes within the same category (intracategorical) or between categories (intercategorical) through processes, values, emotions, concepts and systems

	<b>Individual Level</b>	<b>Community Level</b>	<b>Health System Level</b>	<b>Research Level</b>
<b>Individual level</b>	20	10	3	2
<b>Community level</b>	10	11	6	7
<b>Health system level</b>	3	6	6	0
<b>Research level</b>	2	7	0	12
<b>Total connections</b>	35	34	15	21
<b>Total Intercategory</b>	15	23	9	9
<b>Proportion of connections that are Intercategory (Total Intercategory/Total Connections)</b>	0.428571	0.676471	0.6	0.428571

## **Chapter 5: Empowering Women, Decolonizing Research and Improving Self-Screening through Patient Oriented Research**

### **5.1 Limitations**

This project was limited by factors that impacted the voices that were heard during the project. The study included the voices of 31 women, from six communities in NBC, however, this small sample size may limit the results' generalizability to other Northern First Nations or rural BC communities, especially those outside of the jurisdiction of CSFS. Although the sample size remained small, an effort was made to conduct a focus group in a community representative of the unique circumstances of that area. For example, Stelat'en and Nadleh are approximately 25 kilometers apart, and are similarly resourced, therefore, a focus group was only conducted in Stelat'en. Another notable shortcoming to this research project lies in the recruitment strategy used by the project. As with any patient-oriented research project, the question arises surrounding what kind of person chooses to engage with research; in the case of this project, who are the Indigenous women who frequent the health centers who would be willing to dedicate two hours of their time talking to a non-Indigenous woman about cervical cancer. A postcolonial understanding of this scenario informs that women who feel safe sharing their ideas with me are likely farther along in the healing journey from colonialism than someone who would avoid a visiting non-Indigenous researcher. For this reason, the voices of community members who may have a unique perspective on the CCN project may be lacking in this project. Furthermore, all of the community meetings where the data for this project was collected were held over the lunch hour. Therefore, the results of this study may be biased to not include women who are working, have children, or have no way of reaching the health center in the afternoon. These voices may have added a richness to the data that was collected, as these women would occupy a unique social position, as understood through an intersectional lens. Future research should consider using a patient partner from the local community, who would due to their trusting relationships within the community, community members would feel more comfortable sharing their stories and experiences with.

Although this project was focused on Indigenous women's experiences with the CCN project, recruitment was not limited to women who self-identify as Indigenous. Data regarding whether women self-identified as Indigenous or not was not collected. Therefore, at the Southside health and wellness centre which services both Indigenous and non-Indigenous communities, many participants were non-Indigenous. Although these women likely had similar lived experiences living in a remote community, they lacked the social experience that

Indigenous women have with respect to interacting with a Western health care system. Additionally, the presence of non-Indigenous women at the group may have prevented some women from feeling comfortable interjecting in the conversation and discussing cultural beliefs or traditions that could impact screening. During the group, efforts were made to ensure each participant had an equal opportunity to speak, however, it should be noted that the women who appeared to be non-Indigenous answered all the questions during the group and participated actively, but some Indigenous women listened attentively but remained silent throughout this group. As such, results regarding cultural sensitivity and experiences of Indigenous women may have been skewed by the focus group that occurred at the Southside clinic.

A final potential source of bias occurred because only five participants in this study had actually self-reportedly engaged in HPV self-screening. Therefore, there was a lack of voices of those who had firsthand lived experiences with self-screening. However, the feedback that was received from both women who has self-screened and had not self-screened was overwhelmingly positive, indicating that women's lived experiences with self-screening are similar to women's perceptions on self-screening. Therefore, although including more voices of women who have self-screened may have added more supportive data, it likely did not skew the results of this study.

The themes that are most likely to be affected by the biases listed above are those that revolve around the individual decision to screen, and specific critiques to CCN. For example, participants described how they did not believe partners would prevent anyone from screening, however, women with controlling partners may have been less likely to have attended the focus groups. This has implications for screening, as controlling partners could potentially prohibiting women from screening. With respect to the lack of involvement of race, culture, history and spirituality on screening, there is also a possibility that due to the fact that I am a non-Indigenous researcher, participants did not feel comfortable sharing cultural information that may impact screening. It is possible that the voices of some community members who had differing opinions and lived experiences from those described above were missed. These biases were considered throughout the analysis of this project.

The theoretical framework selected for this project was effective in situating women's experiences with cervical screening within the study population's unique sociocultural experiences of health due to both gender and colonialism. However, this framework was unable to capture the nuanced reasons under screened women are choosing whether or not to engage in screening. Future research projects should consider implementing a framework that includes a

health belief model, theory of reasoned behaviour and sense of community theory (61-63). These theories would help to ascertain the nuanced decision-making process women undertake when considering weighing personal safety, accessibility, and the health benefits associated with deciding whether or not to screen for cervical cancer. This framework would also be able to explore better the impacts that community and family members have on empowering others to engage in screening.

## 5.2 Discussion

The rate of cervical cancer among BC First Nations women is unacceptably higher than the rate among non-First Nations women (15). The CCN pilot project is seeking to bridge the cancer divide, by providing self-collected HPV screening to women, to allow them ownership over their bodies while screening, and empower them in their self-care. In order for such a project to be successfully introduced into communities province-wide, patient voice must be meaningfully incorporated into the health intervention (51). Findings from his project illustrate how HPV self-screening projects can be rolled out such that they provide the most thorough, long-lasting benefits to First Nations communities, and suggest how health policy adjustments can function to foster self-determination and reconciliation.

The themes selected from the transcript data point to impacts to women's cervical screening experience functioning at four levels. These levels, individual, community, health systems and research, mimic the social determinants of Indigenous health levels. Individual level impacts are akin to the proximal determinants of health in that they are unique depending on the patient's individual circumstances. Impacts at the community, health systems and research levels are parallel to the intermediate determinants of health. Although no themes exist explicitly at the distal level, all of the themes at the proximal and intermediate levels are impacted by colonialism and the historical, political, social and economic contexts that the women who participated in this project experience.

Network analysis revealed that although themes and subthemes were selected as discrete areas of prominence within the transcript data, the themes and subthemes are highly interconnected. This means that women's screening experiences are multi-layered and complex, with forces at each level impacting their realities. The theory of intersectionality describes the complexity and interconnectedness of women's social experiences based on their social positions; therefore, it is logical that women's cervical screening experiences demonstrate similar patterns of intricacy (2). The majority of connections between categories led to community level

impacts, meaning that recommendations focusing on community level programs, projects, and policies will carry the greatest impact across all other levels. An area of convergence centered around the theme that “knowledge is empowering”. For this reason, particular attention will be paid to the use of health education as a source of empowerment for communities.

### 5.2.1 Program Recommendations

As self-collected HPV screening interventions become available throughout the country as options for rural First Nations women to screen for cervical cancer, evidence points to a need to take a patient-centered approach. When taking a “No one reason” approach to understanding why women choose to engage or not to engage with screening, an intersectional lens can be beneficial (2). It offers an understanding that all factors in a woman’s life will work concurrently to affect her ability to engage with screening. This means that interventions should not only focus on one particular barrier to screening, but rather, give women a variety options to screen, that they can select based on their level of comfort with physicians, their geography, their personal history and their time availability. For example, offering a community-based HPV self-screening program with a health centre-based recruitment strategy, as is used in CCN, would effectively reach women who are comfortable in their local health centre, or those who have a good relationship with the community nurse; however, the lack of alternative enrollment strategies for women would miss women who do not have time to come into the health centre, and who may not feel comfortable interacting with the local care provider (26). For this reason, women should be offered as many options for engaging in screening as possible, in order to maximize their chances of participating. Self-collected projects offering a variety of recruitment strategies have been shown to have the highest uptake rate (28). Therefore, giving women options on where, when, and how they screen, is another way that programs can empower women in their self-care.

Although intersectionality is critical when developing relationships with patients as it provides an understanding of their social position, individuality must be considered before assumptions based on gender, class, ability, etc (2). During community meetings, women described the lack of an impact that culture, race, history and spirituality has on screening. Even if targeted screening programs are intended to diminish barriers, this theme serves as evidence that putting too much of an emphasis on race can be alienating to patients and disrupt the trust between care provider and patient. Indigenous women have a clear frustration with the damaging stereotypes associated with Indigenous people, and Indigenous women in particular, with respect

to having an increased susceptibility to diseases than non-Indigenous people. In turn, having screening interventions geared specifically towards Indigenous people rather than to under screened populations as a whole may come across as offensive and culturally insensitive. Research utilizing a strengths-based approach have tended to be more successful in Indigenous communities, and are understood to be more culturally sensitive than deficit-based approaches (45). Given that CCN was advertised as an option for First Nations women, perhaps this targeted approach was viewed as culturally insensitive, and therefore, participants did not rate CCN's cultural safety as being "Very Safe" (Figure 5). Although it is true that there are higher rates of cervical cancer among First Nations women, a strength-based perspective highlights that a central cause for the higher rates of cervical cancer is a health systems failure to provide culturally safe care, not any inherent difference due to race (15). Thus, targeted interventions such as CCN should avoid singling out Indigenous women because of their race, and instead, highlight the project as a way to improve gaps in care. They must describe the project as a way to make the health care system's approach to cervical screening work better for women than it has in the past.

An example of how the health care system historically did not function adequately for First Nations women due to culturally specific reasons lies in the experiences of cervical screening for older Indigenous women. Anecdotal evidence from this research, as well as research on perceptions of screening among Cree women, shows that this demographic of women has tended to avoid screening due to the belief that only their husband should see them in their "private areas" (64). Thus, accessing a pelvic exam, especially one conducted by a male care provider, is an impossibility. This highlights the importance of having screening interventions informed by cultural contexts, and targeted at Indigenous women in their fifties and sixties, because, for First Nations women in communities with similar histories to those in the Northern Interior of BC, they may not feel comfortable screening. Furthermore, it demonstrates a need for information on screening options that includes self-collected interventions such as CCN to be targeted towards older Indigenous women, because due to this value, they will require accommodative screening.

Although data from the focus groups demonstrates that First Nations culture, tradition, and beliefs and histories of colonialism do not play a part in women's decision to screen, it should be noted that Indigenous worldview may act in a subconscious way to influence screening. Since individuality was isolated as the central factor that influences screening, culture, tradition, and beliefs are incorporated into people's worldview depending on their lived

experiences, then women use their worldview to inform their decisions regarding screening. Worldview is inextricably connected to personal history, beliefs and culture (3). Therefore, women's screening experiences may be informed by aspects of tradition and culture through worldview, without being explicitly associated to culture. This concept may be reflected in the survey data, where not all respondents ranked the CCN project as being very culturally safe, however feedback from the focus groups indicated that the project had no shortcomings related to cultural safety (Figure 5). This discrepancy could be evidence of the fact that Indigenous worldview impacts screening, however, it is simply and engrained part of women's thinking rather than an explicit recognition that culture, tradition and beliefs impact screening.

An example of the potential impact of worldview influencing the data is that, in some First Nations bands, there is a belief that if a disease is acknowledged, it is put into the universe; therefore, it may come back to you. For example, if someone were to say the words 'cervical cancer', they now have a higher likelihood of having cervical cancer at some point in their lives, or if someone were to access cervical screening, they could be bringing the disease upon themselves. Although this belief was not voiced in any focus groups, it was brought up by Dr. Holyk and Marion Erickson as a worldview that may have caused women to avoid discussing traditional beliefs surrounding cancer, or cancer itself, and may prevent women from engaging in screening. This belief, accompanied by the knowledge that many Indigenous communities have opted for a shift towards a holistic model of health that emphasizes a balance between the health of the mind, the body and the spirit, with a focus of preventative medicine, provides guidance for designing a program based on prevention. Preventative medicine is central to many Indigenous band's worldviews, as demonstrated by the fact that Indigenous populations in Canada have high vaccine uptake rates (65). Consequently, self-screening programs should be emphasizing the preventative nature of screening, using similar language to those used in vaccination programs to increase engagement, and cultural sensitivity. Rather than using the threat of cervical cancer as a motivator for screening, which many repel many community members from participating, using rhetoric surrounding the preventability of HPV may prove to be beneficial. This strength-based approach will emphasize holistic health, and the autonomy of Indigenous women over their bodies.

The delivery of HPV and cervical cancer health education to rural Indigenous communities can also be informed by the deep fear of cancer that was evident through this project, and the respect for preventative medicine prevalent in Indigenous cultures. Education campaigns that are teaching women about HPV and cervical cancer must articulate clearly that

cervical cancer is caused is HPV, and that HPV is nearly ubiquitous (6, 66). Additional areas that should be highlighted are the fact that, in most cases, HPV is cleared by the immune system within two years of the infection, that it takes 10-20 years to develop into cervical cancer, and has highly effective treatment options for dysplasia available. By highlighting the nearly ubiquitous nature of HPV, and the fact that dysplasia that is caught early can easily be treated, the mystery, fear and stigma surrounding the virus can be reduced. Furthermore, women will understand that they have many years and ample opportunities to catch HPV or precancers before they turn into a “scary, mysterious cancer”. This can also function to mitigate the confusion that many women, not only from this study population, but patients broadly, share regarding the causes of various cancers, or confusion regarding the difference between ovarian cysts, cervical dysplasia and cervical cancer (67). Placing the emphasis on HPV being very common among all populations, and having highly effective treatment options allows a shift in perception to occur. Evidence from this project demonstrates that currently, in CCN communities, STIs are slightly stigmatized as being embarrassing, but are not a forbidden discussion topic. This is in contrast to some other ethnicities, including Ugandan and Southeast Asian, where STIs are highly stigmatized. For Southeast Asian populations, emphasizing the HPV virus as the cause of cancer could be detrimental to participation in screening programs (68, 69). However, in First Nations populations, because of the belief that knowledge can be empowering, and that preventative medicine is important, further sexual health education could normalize STI screening as preventative medicine (70). Also, cervical cancer would no longer be perceived as “mysterious and unpreventable”, but a disease that can easily be avoided with early detection and treatment against HPV. With this extra knowledge, women can be empowered to engage in HPV screening as a means of preventing cervical cancer before it has a chance to become a threat to their health. In fact, an HPV self-collected project in Northern Ontario First Nations communities supplemented the program with HPV and cervical cancer education, and found it beneficial in engaging women and their communities more thoroughly in the project (71). As a result, strategic HPV education, as described above, has the potential to increase uptake of HPV screening in First Nations communities.

The impact of partners on screening must also be considered at the programmatic level. Although in the focus groups there was no mention of partners directly forbidding women from engaging in screening, there was concern over the impact that a positive STI diagnosis may have on a relationship. While a cancer diagnosis certainly deeply impacts a family, an STI diagnosis could bring about questions of infidelity for either partner, that can rupture trust and lead to

relationship tension (70). This has implications for screening, because Pap screening is typically regarded as a cancer test, and a positive Pap test is perceived as a potential cancer. However, an HPV test is testing for an STI, and an STI diagnosis has associated stigmas (66). The implication of a positive STI test can be that a member of the partnership was not faithful, and thus, acquired an STI. As women find out that HPV is a sexually transmitted infection, they may be less willing to participate in HPV self-screening based on concerns over their relationship's stability, and therefore would prefer to opt for the Pap test (72). This may be why a large number of participants indicated on the survey that they believed partners impact women's decisions to screen (Table 2). This finding is not unique to First Nations women, but a common concern among many BC women (72). As a result, it is important because should there be a provincial switch to HPV screening as the form of primary screening for cervical cancer, then there could be women who regularly participated in Pap screening who choose not to engage in HPV screening for this reason (70). This harkens back to how HPV can be strategically described to women, and their partners, as nearly ubiquitous, but with the potential to cause cancer, in order to give them a clear understanding of the link between cervical cancer and HPV, but also not scare them away from engaging in screening.

An increase in strategic HPV education would also have impacts at the community level. The evidence from this project, and previous qualitative studies of attitudes towards HPV screening, demonstrates a community desire for education surrounding cervical cancer, HPV and screening that is inclusive of all members of the community, not directed solely at women who are of screening age (70). Consequently, communal sessions should be held, where women can attend with their partners, children, parents and friends to learn about sexual health (73). These sessions would facilitate a more holistic approach to health education, where issues such as cervical cancer screening are not siloed as an individual health issue, but interconnected with conversations surrounding smoking commercial tobacco, HPV, mental health, and other related topics. For partners, this will offer them the opportunity to gain an understanding of what women must go through to protect their sexual health. As a result, they may be more willing to support their partners by reminding them when they are due for screening and encouraging them to attend screening and follow-up. This finding appears in cultures outside of Indigenous communities, as studies in Kenya have also found that men tended to have a low level of knowledge regarding HPV and cervical cancer, but were eager to support their partners in undergoing screening (74). Although not all partnerships hold space for the sharing of sexual health information, co-learning in a community environment has the potential to strengthen

relationships and build empathy and understanding (71). Furthermore, a community learning environment is concurrent with a holistic Indigenous worldview and offers a safe space where the trust that is developed during health education sessions may also serve to open the door for communities to talk about historical traumas that remain taboo and clouded in shame for many residents (20). By creating a place for discussion, and sharing of experiences, overall community mental health can be improved, and critical steps towards healing from colonization can take place.

The emphasis on sexual health education for youth demonstrates a growing concern among women in the community regarding youth's sexual behaviours. Due to the perception that youth are engaging in intercourse younger, there is a fear they may contract an STI such as HPV at a young age, which could eventually lead to devastating consequences such as cervical cancer. This fear for the future generation could also be rooted in the fact that due to the high rates of cervical cancer among First Nations women, people in the community have had to see women that were highly respected in the family and community at the hands of cervical cancer (15). For some participants in the focus groups, at an early age, they were exposed to quality health education delivered by a trusted professional, and consequently, they developed healthy relationships to screening. This makes it clear why women are demanding that youth in their communities receive the same quality of health education, in order to foster an understanding of the importance of preventative care including screening. As a result, there should be opportunities to educate youth starting before they begin engaging in sexual activity regarding the importance of preventative sexual health care. By emphasizing educating youth before the minimum age for screening, there is an emphasis on preventative medicine, self-care and better health for future generations.

This concern for youth and future generations of community members also manifested itself in the group participants voicing their dissatisfaction with the current screening guidelines, which suggest screening women age 25-65, every 3 years. The evidence points to a disconnect in communication between researchers, practitioners and patients with respect to explaining the benefits of screening in context with the limitations to the screening technology (72). Participants demonstrated a clear appreciation for the capability of screening to catch precancers, and desired for those benefits to be available for men, younger women, and at a higher frequency. This finding has been echoed in the literature, with women in BC, of a variety of ethnicities expressing dissatisfaction with screening guidelines, and feeling more comfortable being screened younger and more frequently (72). Although males carry HPV and can be screened

using HPV testing, most men are not being screened in BC because screening is futile without effective treatment options against HPV (75). Across focus groups, there was a desire for men to share the burden of preventing the spread of HPV and in turn, cervical cancer. The frustration participants described, although it was directed at the screening guidelines, is likely actually a dissatisfaction with the technology that currently exists for screening and treatment of HPV infection. For example, screening women more often than every 3 years or using the technology on younger women can cause very real harms (76). The consequences of over screening and screening too young outweigh the benefits. Due to the limits of the screening technology, over screening poses multiple dangers, including the emotional trauma from a false positive result, and complications in pregnancy from the treatment of a false positive result, including preterm delivery and low birth weight (76). Further, since screening is essentially suggesting that a healthy person undergo a medical procedure that has the potential to cause them harm, guidelines must be rigorous and responsible in only including people who might actually benefit from being potentially being placed in harm's way. Therefore, in essence, when screening women under 25, the harms outweigh the benefits and the screening tool simply does not work (77). While the benefits of screening have been successfully communicated to patients, as evidenced by high uptake rates and positive feedback from community members, the limits to the screening technology have not been adequately described (30). This demonstrates a need for practitioners to openly describe both the strengths and weaknesses associated with screening options, in order for women to feel as though they have control over decisions made regarding their health. If an Indigenous woman who is under 25 comes to a clinic wanting to be screened, and is turned away without an explanation, it can be seen as an imposition of a Western construct, the screening guideline, on her. This would be a limitation of her bodily autonomy, and thus, an act of colonial violence. However, if this same patient is offered an explanation of the risks associated with her undergoing screening, she is able to understand the reasons behind imposing that guideline, and seek out other measures of prevention, like vaccination. Thus, she can be refused the screening and still be empowered in her self-care. More comprehensive education regarding screening guidelines that offers both the strengths and weaknesses of the current technology provides the opportunity to engage more women in screening, give them autonomy over whether they decide to engage in screening or not, and allow them to engage in self-care as they wish (78).

Although education holds profound impacts on women's relationship to screening, findings from this research project shows that their care providers also profoundly affect screening. Participants commented on how their care provider's ability to keep track of their

screening history and remind them of when they're due for screening, as well as their provider's gender impacts whether they are able to access screening or not. Since many women voiced that they do not keep track on their own when they are due for screening, it falls on the health centre staff to reliably track patient's screening records, and remind them when they are due for screening. Opportunistic screening in smaller communities was evidenced to be a useful strategy in recruiting women for screening (28). However, although this approach can be effective in reaching women who come into the health clinic for reasons other than screening, it still fails to miss women who do not regularly visit the clinic. Additional efforts need to be made to reach women who do not feel comfortable at the clinic, and those who cannot confidently engage with the health care system; these women must also be monitored to ensure that they attend follow-up, as screening women without supporting them through treatment is unethical. As a result, it is critical for local health centres to accurately keep track of screening records. Up-to date records will allow patient's screening and treatment history to be tracked, and can facilitate keeping women up to date on screening regardless of location, and whether they move communities. However, health centers should also be aware of the potential for loss of patient autonomy as a consequence of the use of electronic medical record systems where patient data can be accessed by any care provider across the province. Women from a small community may experience embarrassment should a health centre worker who they know in a social capacity reads the personal information held within a medical record (19, 79). It also points to the need of a vigilant reminder system for care providers, that can assist them in keeping their patients up to date on screening. In some smaller communities in Northern BC, medical records are kept in paper form can be easily misplaced, electronic records become inaccessible during frequent power failures, and community members move fluidly between communities without notifying the clinics. Consequently, for women who rely solely on their care providers to remind when they are due for screening, it becomes easy for them to fall through the cracks and unintentionally become under screened. With this understanding, rigor is an imperative in ensuring that records are kept up to date and timely reminders are sent out for screening.

With respect to the CCN project, research partners from CSFS identified that, as opposed to an online, mail-to all, or door to door strategy, a community centre-based recruitment strategy as their ideal recruitment method. However, feedback from the community members in this project illustrates that women actually believe offering a variety of recruitment strategies, in order to fit the unique needs of all under screened women, would be the best recruitment strategy. Programs should be asking key stakeholders regarding their preferences for recruitment,

but additionally, should take an intersectional approach and consult the patients that the programs are being designed for, in order to ascertain which strategies they believe would work best for their own unique lives.

Additionally, with respect to recruitment, the fact that the majority occurs on an opportunistic basis, exposes a potential shortcoming in the recruitment strategy employed by the project. Since most women rely on their care providers to remind them to screen, and care providers are limiting the scope of the CCN project to those who frequent the clinic, it can be assumed that the majority of women who are coming into the clinic regularly are those that are regularly reminded to screen. As a result, they are likely not under screened. Additionally, although community health centers are set up to be safe, communal spaces, there may still be community members who do not feel comfortable going to the health centre. This is because the centre is an institution for Western medicine, and historical traumas in the Indian Hospital system makes visiting the clinic too traumatic for some women. The women who are suffering from the intergenerational effects of colonialism are more likely to face poor health outcomes, as described in the social determinants of Indigenous health model, including higher rates of HPV (20). Limiting recruitment to the self-screening project to opportunistic screening from the health clinic could be missing women who need the service the most. One of the benefits of using a self-collected HPV test is that it can be offered in many settings with numerous strategies (28). For this reason, in this setting, a house to house recruitment strategy, where women have the option to self-collect at home or at the clinic will likely reach more under screened women, and specifically target the women who are most vulnerable.

Although all care providers impact screening, physicians play an important role in educating on, encouraging and conducting screening. In the communities serviced by CSFS, and many similar communities in the North, there is rarely, if ever, a doctor who works full time at the health centre. Instead, a doctor will travel from a larger city at regular intervals to see patients, or attend appointments via tele-health. However, there is a limited number of physicians who will take the time to travel long distances, down potentially dangerous, ill-serviced roads to provide care to such communities. As a result, some clinics are only serviced by male physicians. Since women expressed that the gender of care providers impacts whether or not they would access screening, communities that are serviced solely by male physicians would likely have a lower rate of participation in screening programs. This finding is echoed in Anishinaabek and Cree communities, where women described being uncomfortable with a male care provider administering a Pap test (30, 64). Thus, gender needs to be considered as a factor affecting

participation rates in screening programs, and should be strategically employed to increase participation.

Evidence from the focus groups brought to light some of the barriers women may face when engaging in screening programs, however it also illustrated how targeted projects such as CCN can positively impact communities. From the survey results and focus groups, it is known that the self-screening project was well received, and universally liked by both participants and non-participants. Participants comments regarding the ease of the self-screening kits point to the positive ripples having an intervention such as CCN can have in communities. Offering a service like self-screening to under screened women is an opportunity for the health care system to re-engage with a person who may have been alienated from care by a bad experience in their past or their family's past. The self-screening project can offer a gentle re-introduction the health system for women who are at the margins of Western medical care. Community members showed a deep faith that projects such as CCN had the potential to provide accessible cervical cancer screening to rural First Nations women who unable to engage in the provincial Pap screening program. For this reason, self-collected screening projects should be expanded to service more Northern and rural regions in BC.

Although communities were happy with how the CCN project was being run, their main concern was the possibility that the project would end, and the self-collection service would no longer be offered. This points to the importance of having long-term accountability to the communities that are involved in research projects (49). An Indigenous methodology demands that all research projects done with Indigenous people have long term benefits to the people involved, and hold reciprocal benefits for both researchers and communities (45). Communities engaged in CCN are trusting researchers to fulfil their promise of reciprocity in the project. This means that in order to be respectful, the self-collection service must continue to be offered in the community, even when the research project has met its objectives. This can be difficult, due to the fact that research funding can be unpredictable and may not be renewed by the funding agency. For this reason, partnerships with organizations like CSFS are critical, in order for projects to be handed over to communities should the funding expire, so that the service can continue being offered to community members. The fact that this concern was brought up could also be indicative that although the relationship to research is beginning to shift towards being more positive, the trust is still being built, and people are still wary of the possibility of the promises being made by researchers being broken. Nevertheless, a shift in perception regarding

research can occur when projects such as CCN follow an Indigenous methodology and prioritize reconciliation.

During the development of the CCN project, CSFS nursing staff were consulted regarding recruitment and branding strategies. At their recommendation, graphics depicting female reproductive systems, and the word 'cervix' was removed from all of the project materials. This is due to concerns regarding potential histories of sexual trauma for women, and the possibility that having such graphics on advertisements would deter women from attending project events out of concern that they would be gossiped about in the community. However, evidence from participants in this research project indicates that women are wanting more information on health, and that they believe putting information out for all of the community can help people gather in relationality and heal as a community. Women have said that they do not want to be sheltered from the truth of their health. Information and transparency regarding women's health, for all community members, will allow communities to move forward from traumatic histories, into a place of openness and healing (71). Giving women a platform to talk about their sexual health with confidence that they are in a safe place is, in and of itself, a radical recommendation. Moving away from a shame-based approach to health information, towards a strength-based model, that prioritizes openness and transparency, would provide longstanding impacts on individual and community physical and mental health.

Evidence from this research demonstrates that future research projects should be done in partnership with First Nations communities, and can cause positive impacts for the communities. If an Indigenous methodology is followed, communities are more open to research partnerships. While grassroots projects often require crowdfunding or donations in order to be implemented, research projects have the advantage of having access to funding from government organizations. As a result, partnerships with research communities at universities has the potential to bring funding into communities that would have been inaccessible without the involvement of research. Increasing the presence of service-based research projects in First Nations communities would provide numerous positive impacts to the community as argued in an above paragraph; including improving mental health, strengthening the community and attracting community members back to their home community. Furthermore, if a patient oriented research approach is employed, community members would become fully immersed in the research projects, be paid by the project and given recognition on publications (53). This approach would allow community members to build careers as researchers, communities to gain

ownership over research they are involved with, and institutions to become more flexible as they decolonize.

Future self-collected HPV screening interventions should consider incorporating community-based patient partners into the programs to improve recruitment, meet the holistic health needs of the communities and actively promote self-determination. For communities such as those involved in CCN, a useful strategy would be to hire a trusted community member onto the research team, who would improve communities' engagement with the project. Studies have shown that community health fair and door-to-door recruitment strategies are best for reaching women for screening (28, 30, 71). However, CCN relies largely on community nurses to recruit women to the study; unfortunately, many nurses are already overwhelmed with work, and simply do not have the time to dedicate hours to towards using alternative recruitment strategies to reach women who are reluctant to engage in screening, or offer enough information for women to feel empowered to make decisions regarding their sexual health. Thus, having a care provider directly responsible for recruiting women to the project and managing follow-up appointments for women who test positive for HPV will increase the number of women screened and follow-up attendance. Evidence from other studies shows that hiring community health workers can increase positive health outcomes in communities (26, 80). Projects like CCN should hire a community member who has trusting ties in the community to spend a few hours each week working on recruitment and education in order to take advantage of their connection within the community. The bonds of trust that this community partner has would be instrumental in reengaging women with screening (81). This community partner could also be enlisted to give information sessions to the community regarding HPV and cervical cancer. For example, perhaps information regarding the parameters of cervical cancer screening guidelines would be better understood and received when coming from a trusted member of community, rather than a doctor or researcher who is an outsider to the community. Furthermore, this partner could offer information sessions and community discussions on other health-related topics, in order to give the community the empowerment that accompanies a thorough health education (71). Finally, this would be an important step towards fostering self-determination in communities. Instead of research project coordinators managing the project from outside the community, a community member in charge of the project from within their community would allow them ownership over how the project can best be delivered to their community. Research should be done by and with Indigenous people, instead of on or for Indigenous people, and having a community champion for the projects would be a valuable step towards reconciliation.

Evidence from this research project demonstrates the power of patient oriented research, in combination with Indigenous methodologies, to reconcile the historically colonial relationship between Indigenous people and Western academia. Marcia Anderson writes that,

“Research will be transformative at the structural level to benefit Indigenous Peoples only if it is explicitly antiracist and anticolonial. A reconciliation-based research paradigm will require non-Indigenous researchers to move beyond beneficent notions of allyship to become active disrupters of the systems of whiteness and racism that continue to harm Indigenous Peoples today. This includes moving beyond mentorship to giving up places of power and privilege to Indigenous researchers, in academic or community settings, as a fundamental step to the realization of the right of Indigenous self-determination” (82).

CCN took deliberate steps to conduct a culturally safe, interventional project. It was informed by both Indigenous worldview, and Indigenous methodologies. The partnership with CSFS ensured the project took the ethically required steps to be delivered in a culturally safe manner to the First Nations communities. Extensive community engagement prior to the project ensured that a trusting relationship was developed between researchers and community members, and community member voice informed the project. Evidence from this research project shows that CCN was perceived to be respectful, beneficial and safe by First Nations women. Further, it demonstrates a shift in the perception of research, from being exploitative and colonial, to being beneficial and offering hope for the future. This review project sought to further pursue reconciliation by enlisting a patient partner to join the research team, co-develop the focus group script and survey, and review the project results for accuracy. Their expertise was paramount to the success of the project, and as such was recognized, and will continue to be recognized as an equal member of the research team. In order to disrupt colonial systems within academia, researchers who are working with Indigenous people must heed Anderson’s advice; they must move beyond allyship, and privilege Indigenous voice at the forefront of Indigenous health research. The use of an Indigenous patient partnership provides the perfect methodology to combine with Indigenous methodologies in order to increase equity within health and academia, build capacity in Indigenous patients and communities, and combine worldviews towards a shared understanding. Future Indigenous health research should employ patient oriented research in order to endeavour towards self-determination and reconciliation.

### 5.2.3 Policy Recommendations

According to the 2019/20 - 2021/22 BC Ministry of Health Service plan, provincial goals include increasing funding for medical travel, improving rural health services, creating well-paying jobs in BC, and emphasizing preventative health care through health education, screening and vaccination (83, 84). Evidence from this project can inform changes to government mandates that will likely improve health for rural Indigenous women more directly than current policy would dictate. Currently, community members from CSFS member nations have to travel up to 600km to Prince George, or travel by aircraft to Vancouver, in order to access specialist care. Some communities have access to a medical transport vehicle that makes trips from community, to Prince George, twice weekly to bring patients to their appointments, but community members who do not have access to this service must find their own transport, either by driving themselves down poorly maintained roads or by relying on rides from friends, family or neighbours. With respect to medical travel, part of the health minister of BC Adrian Dix's plan to improve rural health services is to allocate more funding towards medical travel. However, for First Nation communities in the Northern interior, thousands of dollars are already being spent on medical travel. In fact, in 2019, CSFS spent \$817,778 on medical travel for member nations (85). Although it is true that many health services cannot be performed in smaller communities, patients are travelling to larger city centres for procedures that could easily be conducted in community health centres. For example, many women have had to travel to receive Pap tests, even though the local clinics are fully equipped for the screening test to occur on-site. As demonstrated by this research projects, community members do not want to travel for their health care. Having services in the community will allow spending costs on medical travel to be cut, and allows patients to interact with the health care system while surrounded by their communities as support systems. This could be accomplished by directing travel funding from patients travelling to cities for care, to offering nurses, nurse practitioners, physicians and specialists cultural competency training, and funding their travel to more remote areas to deliver care. Research has shown that increasing health services in community will improve patient experience, provided that care providers are aware of the barriers to care associated with the colonial history of the health care system and intergenerational trauma, and equally, that the decentralization of care does not compromise the quality of care being delivered to communities (19). Therefore, by allowing patients to access health services within their communities, relationality between community members, and trust between the community and the health system has the potential to improve.

Another strategy to develop trust between First Nations communities and the health care system, improve rural health services access, and actively fulfill the national responsibility for reconciliation is for the province to commit to training Indigenous care providers to work in their communities. According to the 2018/19 BC Service Plan Report, 200 nurse practitioner jobs and 200 general practitioner jobs were created in the province in 2018 (86). There is evidence that the University of British Columbia is taking important step towards training more Indigenous physicians, with over 90 Indigenous medical students completing their program since 2004 (87). Although the ministry has promised to create well-paying jobs in the country, and also, facilitate an active role for Indigenous people in the collective well-being, it is unclear how many of these practicing physicians are working in their home communities, and how the government is facilitating the creation of related jobs in the health sector for Indigenous people. A more meaningful way to impact rural health, and enable Indigenous people to play an active role in their health would be to prioritize the training of Indigenous doctors to work in Indigenous communities, monitor where graduates are choosing to practice, and support graduates who would prefer to deliver services in their home community. The impact of having Indigenous physicians bringing an Indigenous lens to healthcare across all sectors is profound, however, at a community level, the delivery of care by individual who share similar worldviews and lived experiences with community members would mark an unprecedented leap forward in terms of cultural safety of care, and fostering self-determination for Indigenous communities.

A focus on preventative medicine through health education, screening and vaccination was also recommended in the 2019/20 – 2020/21 Service Plan, with a deliberate emphasis placed on working with Indigenous groups to inform holistic health. Based on evidence from this research project, First Nations women in Northern interior rural communities are not satisfied with the amount of health education being offered in their communities. Women are seeking more comprehensive health education, in order to be able to make informed decisions regarding their health, feel knowledgeable and supported after receiving diagnoses, and be empowered in their health. For this reason, there must be a policy recommendation for offering community-based health education to remote communities, with an emphasis on youth education. In parallel to the benefits that comprehensive health education would have at the programmatic level, health education campaigns have the potential to strengthen community bonds, normalize preventative health for youth, and empower communities in their health (71). More resources need to be allocated at a provincial level to offering culturally sensitive health education to rural Indigenous

communities, in order for the province to meaningfully deliver on its promise for reconciliation, preventative medicine, and holistic health.

Although health education was presented as a goal for the ministry of health, it is clear from this research that women in rural First Nation communities in the Northern Interior do not feel as though there is adequate health education for them, and the youth in their communities. For this reason, information sessions in the community regarding multiple diverse health topics must become a priority. By prioritizing the delivery of health information, the province can demonstrate its respect for Indigenous worldviews that emphasize preventative medicine, and achieve its goals of improving rural health services, and improving provincial mental health services. Community health engagement sessions offer the opportunity for community members to come together in relationality, and gain knowledge that can inspire self-care. From the data, we know that there is a desire from the communities to have more information regarding various areas of health, and that feeling knowledgeable about a health subject is empowering and can make receiving diagnoses or making decisions regarding health easier. Furthermore, a determinants of health framework informs that a greater sense of community facilitates better overall health in the community. Therefore, having health information sessions regarding topics that communities have asked to know more about can, not only empower community members, but also offer benefits that will improve overall holistic community health. For example, a focus group participant raised a concern that some community members rarely leave their house, and thus suffer from poor mental health. Perhaps having more activities in the community such as health engagement sessions would bring together friends and family, and motivate people to leave their homes. This social interaction with the community could, over time, improve mental health. Another example of an additional benefit to having a service in community such as regular health information sessions is the potential for health delivery organization such as CSFS to hire and train community members to deliver health seminars for their community, thus creating jobs in the province where Indigenous people are actively involved in their health. If health information is delivered by a trusted and knowledgeable community member, it is more likely to be taken in fully by the community (80). Also, with this model, a person from community is able to receive compensation in the form of pay and tangible skills for a service that will be directly positively impacting their community.

Finally, since such a strong emphasis is placed on prevention of disease in an Indigenous worldview, a possible limit to women's empowerment in self-care surrounds the limits placed on access to free HPV vaccination. Currently in BC, the HPV vaccine is publicly funded for boys

and girls born in 2006 or later, provided they start their course before their 19<sup>th</sup> birthdays. The vaccine is also free for HIV positive individuals ages 9-26, males who have sex with males or may be questioning their sexuality, transgender people, and street-involved males (13). Males 9-18 who are in the care of the Ministry of Children and Family Development, and youth in custody also receive the vaccine for free. However, the vaccine is recommended but not covered for all women age 9-45. Since Indigenous women have higher rates of cervical cancer than non-Indigenous women, the provincial government has promised to make preventative health measures that function for Indigenous people, and communities are seeking ways to empower members in their self-care, a meaningful step forward would be to increase the availability of free HPV vaccines for Indigenous women (15). Although there is evidence that the HPV vaccine is less effective in older adults because they have likely already been exposed to HPV, and generally older adults have less new sexual partners who could potentially cause the infection, this intervention would still have positive effects for some exposed and unexposed individuals in the community. Cost/benefit analysis should be conducted on whether or not offering Indigenous women under the age of 27 access to publicly funded HPV vaccines will significantly reduce rates of cervical cancer among BC First Nations women. Aside from the benefits associated with preventing cervical cancer, evidence shows that women are empowered by being able to learn about vaccines and through vaccines as a form of self-care (88). For example, since over screening for HPV is impossible because it is associated with risks, if women are distressed by being unable to screen for HPV, they may be reassured and empowered by the fact that they can receive a vaccine that could prevent any further infections from HPV, with relatively few harms. Since vaccination uptake in Indigenous communities is generally high, this change would likely be well received (65). Most importantly, it would be an example of the government taking deliberate action to deliver on health care promises to Indigenous communities that foster healing and self-determination, and privilege Indigenous women's voice over Western constructs such as cost-benefits analysis and cost to the system effectiveness.

Canadian and BC health policy is working towards meaningfully adhering to the health policy recommendations outlined in the Truth and Reconciliation Commission's Calls to Action (89). This should entail facilitating Indigenous people to become care providers working in larger city centers or in their home communities, the incorporation of Indigenous medicine and worldview into health care and the inclusion of Indigenous voice in policy making decisions. However, there continues to be a lack of action being taken at the policy level to provide Indigenous communities and people with the health care and services that should be inherent.

Communities are asking for health services and professionals that can provide culturally safe services, and they are willing and able to work with Western institutions to create a shared vision of health for the future. Paying lip service to reconciliation is not sufficient to repair the relationship with Indigenous people. Policymakers must take steps to modify a system that is deeply engrained in Western ideologies, in order for it serve Indigenous people effectively.

Western ways of knowing tend towards binary thinking; for example, gender is either male or female, a vaccine is either harmful or beneficial, a person is either Indigenous or non-Indigenous (47). This binary thinking is the foundation upon which oppression within the healthcare system is built, because when there are only two options, one must come out on top. In the past, Western colonial structures have prevailed, and denied Indigenous people access to both Western and traditional medicines. This research project has demonstrated the power of harmony between worldviews. Its incorporation of patient oriented and Indigenous methodologies allowed for Western institutions with non-Indigenous researchers to work with First Nations communities and patients to achieve equity within the health care system. The careful balance that has proven to be so powerful in attaining reconciliation is achieved through meaningful, trusting relationships and mutual understanding. A continued effort on the part of the health system to incorporate Indigenous voices, alternative understandings of health and worldviews can serve as a new foundation for the realization of the promise of reconciliation.

### 5.3 Conclusion

Through a lens of the social determinants of Indigenous health for compassion, intersectional theory for empathy, postcolonial theory for context, and Indigenous feminism for the pursuit of a better future, this project was able to make recommendations based on community voice for ways to elevate HPV self-screening interventions in First Nations communities to have a greater impact on future generations. Although the self-collected cervical screening pilot project has been able to offer accessible screening to First Nations women in Northern BC, evidence from this project point to areas of the project that could be improved. These include a greater emphasis on cultural safety, more information of screening and holistic health for all community members, and a more strategic recruitment of participants. A patient oriented research approach offers the ideal means of improving the project in order for it to reach more women, use research as a tool for reconciliation. The evidence gathered throughout this project points to a collection of modifications to the implementation of HPV self-screening interventions in First Nations communities that can help the projects reach more under screened

women and provide longer-term benefits to the communities, while emphasizing reconciliation and self-determination. For CCN to be a successful intervention in Indigenous communities, it must follow an Indigenous methodology. As such, the incorporation of Indigenous voices throughout the research journey becomes a critical point, to ensure that the project maintains respect, responsibility, reciprocity and relevancy, while fostering relationships between researchers and community members, between science and tradition and between past, present and future. To continue the important work of incorporating patient voice into women's health, and Indigenous health interventions, future research should include increasing number of communities consulted regarding HPV screening and vaccination programs, using a POR approach. This project should increase the scope of responsibilities of patient partners to include conducting focus group meetings, and data analysis. As such, research seeking to develop a comprehensive framework for POR with Indigenous people and communities must be created. This project should be in direct, equitable partnership with Indigenous people from diverse backgrounds. Such a POR framework would function to further the creation health equality, representation within the health care system, and function to fully allow for research's capacity for reconciliation. In order for federal and provincial governments to made good on their promises to Indigenous people, they must do more than offer to hear Indigenous perspectives when making policy and budgeting decisions. They must do the difficult work of dismantling the Western ideologies that have been so deeply engrained into life in Canada, and take action by increasing the employment of Indigenous health care workers, funding traditional preventative medicine, and incorporating Indigenous worldview into health care. A shared vision of health, pulling from the strengths of both a Western and Indigenous worldview is how health care delivery can move forward towards offering the best possible care for all Canadians.

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## Appendices

### A: Summary of studies surrounding HPV testing and HPV self-screening

Study	Question	Methods	Population	Main Findings
Maar M, Wakewich P, Wood B, Severini A, Little J, Burchell A, et al. 2016 (24)	What is the cervical cancer screening experience for Northern Ontario First Nations women?	Qualitative: Interviews and focus groups	Care providers to First Nations women in Northern Ontario	<p>Community level barriers: lack of qualified care providers, lack of training in cultural and linguistic customs, lack of transportation to nearby medical clinics, a lack of health education in schools and clinics teaching women about cervical cancer and HPV, and a lack of recall systems to remind women to participate in screening. Personal barriers: inability to take time off of work, inability find reliable childcare for the often-daylong trips to health centers to get screened.</p> <p>Barriers due to colonialism: intergenerational effects from the history of residential schools and Indian Hospitals, increased rates of sexual abuse in First Nations communities, shame surrounding women's bodies, mistrust in healthcare providers, fear of leaving the community to receive screening.</p>
Wakewich P, Wood B, Davey C, Laframboise A, Zehbe I, Grp A. 2016 (21)	What is the cervical cancer screening experience for Northern Ontario First Nations women?	Qualitative: Interviews and focus groups	First Nations women in Northern Ontario	<p>Colonialism is the root cause of negative body perception and negative experiences with government health services.</p> <p>The power of relationality between mothers and daughters, patients and health care providers and culture and education</p> <p>Hopefulness if the ability of self-collected HPV screening to increase women's autonomy over the screening experience, and empower women in their self-care.</p>
Mustafa R, Santesso N, Khatib R, Mustafa A, Wiercioch W, Kehar R, et al. 2016 (12)	Compare test accuracy of the HPV test (physician collected) and cytology (cervical smear)	Systematic review and meta-analysis	32 studies with at least 100 nonpregnant women	<p>HPV testing: sensitivity = 94% [95% CI: 89-97], specificity= 90% [95% CI: 86-93]</p> <p>Pap testing: sensitivity = 70% [95% CI: 57-80], specificity = 95% [95% CI: 92-97].</p>

Ogilvie G, van Niekerk D, Kraijden M, Smith L, Cook D, Gondara L, et al. 2018 (25)	Is HPV testing as effective as Pap testing for primary screening for cervical cancer?	Randomized controlled trial Experimental group: HPV testing, Control gorup: Pap testing	19009 women with no history of HPV, cervical cancer or CIN in the last 5 years	HPV testing identified significantly more CIN3+, and CIN2+ than the Pap test at baseline. At 48 months, there were significantly higher rates of CIN2+ and CIN3+ detected in the control group than in the intervention group, indicating that more cases of CIN were caught at an earlier stage using HPV testing.
Polman N, Ebisch R, Heideman D, Melchers W, Bekkers R, Molijn A, et al. 2018 (27)	Non-inferiority test of self-collected HPV testing samples versus physician collected samples	Randomized controlled trial Experimental group: self-collection, Control gorup: Physician collection	187473 under and regularly screened women to the study	Self-sampling: sensitivity = 92.9% [95% CI: 87.3-98.4], specificity = 93.9% [95% CI: 93.4-94.5] Physician-sampling: sensitivity = 96.4% [95% CI: 92.9-99.9], specificity = 96.4% [95% CI: 93.6-94.8] Relative accuracy: sensitivity = 0.96 [95% CI: 0.90-1.03]. , specificity 1.00 [95% CI: 0.99-1.01]
Arbyn M, Smith S, Temin S, Sultana F, Castle P. 2018 (28)	Non-inferiority test of self-collected HPV testing samples versus physician collected samples	Meta-analysis	56 accuracy trials with a minimum of 400 participants	Relative sensitivity for CIN2+ = 0.99 [95% CI: 0.97-1.02], for CIN3+ = 0.99 [95% CI: 0.96-1.02] Average specificity of detection of CIN2+ and CIN3+ = 0.98 [95% CI: 0.97-0.99]
Nelson E, Maynard B, Loux T, Fatla J, Gordon R, Arnold L, et al. 2017 (26)	What is the acceptability of HPV self-screening?	Systematic review and meta-analysis	37 studies including 18516 regularly & under-screened participants	Acceptability = 97% [95% CI: 95% - 98%] Preferred self-collection = 87% [95% CI: 73% - 95%] Likes: ease of use, less embarrassment, and increased privacy and comfort Dislikes: uncertain about sampling correctly, pain or discomfort with collection, anxiety, and discomfort with touching themselves
Zehbe I, Moeller H, Severini A, Weaver B, Escott N, Bell C, et al. 2011 (22)	What is the acceptability of HPV self-screening in a Northern Ontario First Nations community?	HPV self-collected screening pilot study	49 First Nations women aged 25-59 who had participated in cervical screening before	Ease of use = 77% Little to no discomfort = 85.1% Would participate in self-sampling again as their preferred method of screening = 87.2%

<p>Zehbe I, Jackson R, Wood B, Weaver B, Escott N, Severini A, et al. 2016 (31)</p>	<p>Does HPV self-collected screening increase engagement in cervical screening among First Nations women?</p>	<p>Randomized controlled trial Experimental group: First offered HPV self-screening Control group: First offered Pap testing</p>	<p>834 eligible First Nations women from 5 Northern Ontario communities</p>	<p>Women were 5.7% [CI: -11.6 to 34.0, p=0.628] more likely to participate in screening when initially offered self-collected HPV testing, than when initially offered Pap testing. In communities where CBRAs were lay health workers, there was a higher level of participation</p>
<p>Zehbe L, Wakewich P, King A, Morrissette K, Tuck C. 2017 (30)</p>	<p>What are Northern Ontario First Nations women's experiences with Pap and HPV self-screening?</p>	<p>Qualitative: 10 interviews and 10 focus groups</p>	<p>15 First Nations and non-First Nations care providers. Community members from each participating community</p>	<p>Cervical screening practices: no regular screening, follow-up, transportation, lack of provider flexibility, and privacy concerns Physical comfort level: pain with Pap testing, less pain with self-sampling Psychological comfort level: male care providers, age factors, self-sampling more comfortable Convenience of self-sampling: increased privacy, no appointment needed Education: women being blamed for STIs, stereotypes, need to explain self-sampling</p>
<p>Arbyn M, Smith S, Temin S, Sultana F, Castle P. 2018 (28)</p>	<p>Does HPV self-sampling increase participation in cervical cancer screening among under-screened women?</p>	<p>Meta-analysis of controlled trials: Experimental group: Self-collected HPV screening Control group: pap testing</p>	<p>25 participation trials including under and never screened women</p>	<p>Mail-to-all participation: HPV collection kit = 19.2% [95% CI: 15.7-23.0], Pap invitation = 11.5% [95% CI: 8.3-15.1], relative participation rate = 1.87 Door-to-door participation: relative participation rate = 1.99 Opt-in participation: HPV collection kit = 7.8% [95% CI: 5.2-10.9], Pap invitation = 13.4% [95% CI: 10.2-16.9]. Community campaign participation: HPV collection kit = 94.2% [95% CI: 83.0-99.9], Pap invitation = 53.3% [95% CI: 10.5-93.2], relative participation = 2.58</p>
<p>Racey C, Withrow D, Gesink D. 2013 (18)</p>	<p>Does mailing HPV kits increase participation in cervical screening compared to mailed Pap invitation letters?</p>	<p>Systematic review and meta-analysis</p>	<p>10 studies that from developed countries targeting under or never screened women</p>	<p>Screening increased by 200% when patients were offered the self-collected HPV test than when they were sent the Pap reminder letter. HPV kits were highly acceptable HPV kits delivered high quality specimens</p>

<p>Racey C, Gesink D, Burchell A, Trivers S, Wong T, Rebbapragada A. 2016 (34)</p>	<p>Does offering HPV self-collection to under-screened rural women increase screening uptake when compared to a Pap invitation letter or opportunistic screening?</p>	<p>Randomized controlled trial: Experimental groups: HPV self-screening, Pap invitation letter Control group: Opportunistic screening</p>	<p>818 under or never screened rural women</p>	<p>Women who were offered the self-collected HPV test were three times more likely to undergo screening than women who received no intervention. Mean acceptability score = 92.6% Participants who would use self-collection again in the future = 90%</p>
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## B: Focus Group Script

1. Introductions: names, nation, clan, something recently that you have done for selfcare.
2. What in the past has motivated you to get screened for cervical cancer?
3. How do Carrier beliefs (culture, history, spirituality) impact screening?
4. How does being an Indigenous women impact going to the doctor for women's health screening?
5. When you were young, how did you first learn about cervical cancer screening?
6. How do you think this project could impact elder or senior women in your community?
7. What do you think a young woman's first screening experience is like?
8. What do you think it is like for women to find out they have HPV?
9. If a woman found out they have HPV, what do you think influences their decision to get follow-up care or refuse follow-up care?
10. Are there any barriers in your community to women accessing follow-up care? If there are what could we do to overcome them?
11. What do you like or dislike about the screening kits?
12. Do you think of going to get a test to check for a sexually transmitted infection like HPV different than going to get a test to check for cancer?
13. Should men be involved in women's health screening? How should they be involved?
14. What do you think about involving men in discussions like this?
15. If our ultimate goal is to have a "successful" project, in your community, to you, what does success for this project look like?
16. Were there any unintended harms to the project?
17. How can we reach more women in your community?
18. How do you think we can make this project better?

19. This screening program was created to help women get screened more easily, but there is also has a research component to it. Its goal is also to answer questions like how many women have cervical cancer in northern BC, how many extra women are getting screened using the kits, and how do we successfully provide this service to small communities in northern BC.
20. Do you think that the fact that this program was a research program affected women's willingness to participate? Why or why not?
21. When you think of research, how is this project different from what comes to mind?
22. How do you think people from your community could be involved in future research projects?
23. While we're visitors in your community, we want to make sure that questions that are important to you are being addressed. So, what other women's health, other general health topics are of interest to you, or what services would you want to see available in your community?

### C: Semi-Structured Survey

1. Did you use a self-screening kit?      Yes                      No - *Skip to question 7*

2. How comfortable was the sampling device to use?

1	2	3	4	5
Not Comfortable	Somewhat Comfortable	Neutral	Comfortable	Very Comfortable

3. How confident are you that you used the kit correctly?

1	2	3	4	5
Not Confident	Somewhat Confident	Neutral	Confident	Very Confident

4. Would you choose the screening kit again for screening?                      Yes      No

5. Did you receive any follow up care? (Pap test, colposcopy)                      Yes      No

6. Did you decline follow up care?                                                              Yes      No

(Optional) If yes... would you share why you declined follow up?

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7. Would you recommend the screening kits to friends/family?                      Yes      No

8. How culturally safe do you think the program was?

1	2	3	4	5
Not Safe	Somewhat Safe	Neutral	Safe	Very Safe

9. Do you think this kit would help elder and senior women in your community screen?

Yes      No

10. Do you think that getting a cancer-screening test is different from getting an STI test?  
Yes No

11. Do you think partners influence women's decision to get screened? Yes No

12. Do you think this initiative being a research project stopped some women from wanting to get screened? Yes No

13. Do you think this research project was respectful? Yes No

14. Do you think future research projects like this one could be beneficial to your community? Yes No

15. Do you have any additional concerns/ suggestions/ comments?

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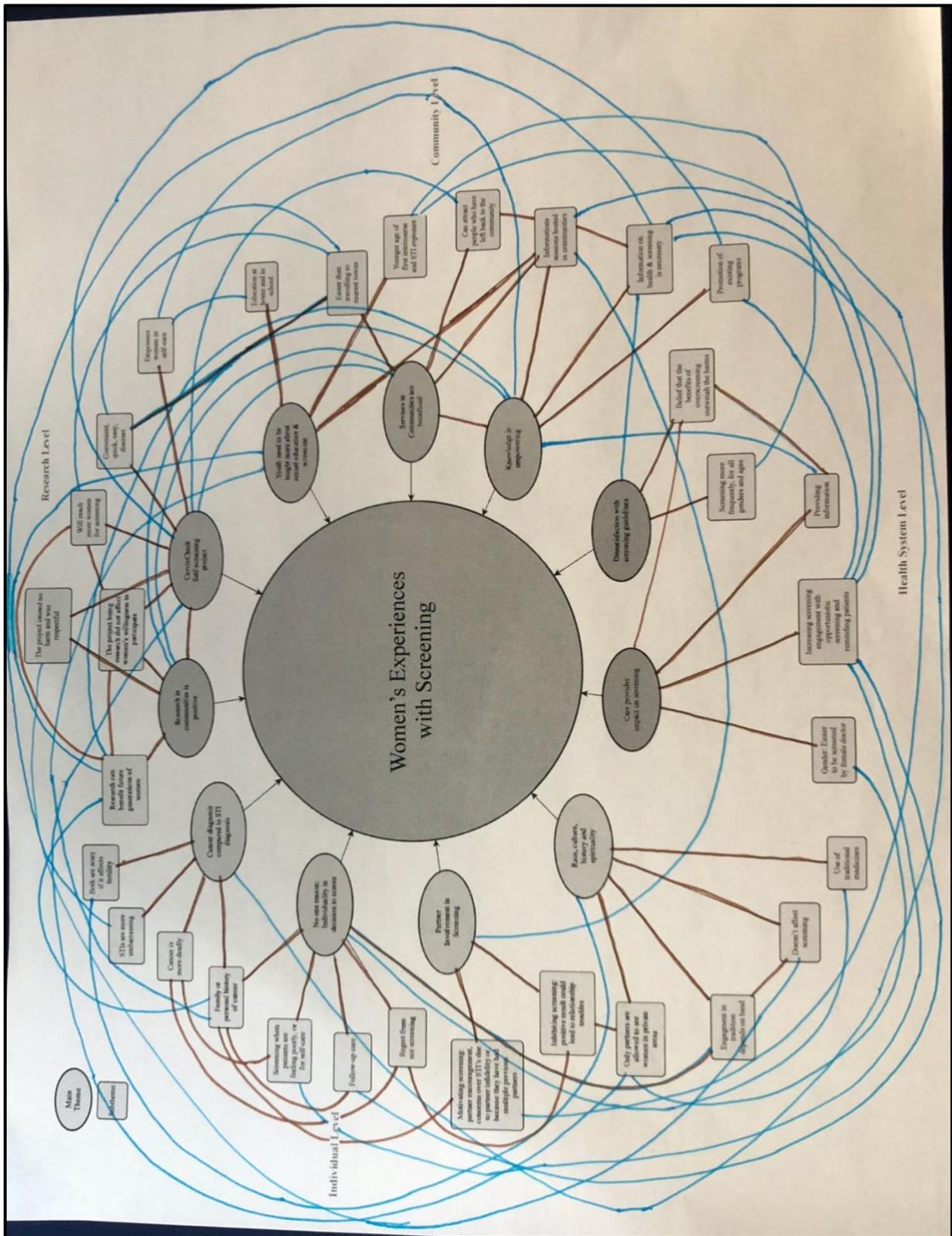
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# D: Network Analysis Thematic Sociogram of Connections Between Themes and Sub-themes\*



\*Intracategorical connections are in brown and Intercategorical connections are in blue