

CERVICAL SCREENING AMONG  
SOUTHERN ALBERTA FIRST NATIONS WOMEN LIVING OFF-RESERVE

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A Thesis  
Submitted to the School of Graduate Studies  
of the University of Lethbridge  
in Partial Fulfilment of the  
Requirements for the Degree  
MASTER OF SCIENCE (HEALTH SCIENCES)

School of Health Sciences  
University of Lethbridge  
LETHBRIDGE, ALBERTA, CANADA

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## Abstract

### Cervical Screening among Southern Alberta First Nations Women Living Off-Reserve

First Nations women face nearly three times the risk of cervical cancer and mortality rates of up to six times higher than their non-Aboriginal counterparts. While cervical cancer is almost completely preventable, Southern Alberta First Nations women seldom access cervical screening services. The purpose of this qualitative focused ethnography was to gain an understanding of the cervical screening needs of un- and under-served First Nations women living off-reserve. Thirteen purposefully selected First Nations women participated in three focus groups utilizing semi-structured interviews.

Personal self-worth and cervical screening awareness and relevance are essential to the pursuit of cervical screening. Barriers and incentives for screening and opportunities for acceptability and sustainability are explored. A holistic approach, intersectoral collaboration and cultural safety are described by focus group participants as foundational for optimal service delivery.

### *Acknowledgements*

I would like to express my thanks to the people who shared and supported me in my “journey of discovery”. I would like to extend my thanks to the women who generously shared their stories, laughter, and cultural wisdom. With their encouragement, I have gained a greater awareness of the challenges they face and an appreciation for their strength, spirit and determination as they forge new paths for themselves and their community.

To my thesis supervisor, Dr. Ruth Grant-Kalischuk, I would like to express my gratitude for sharing this journey – for your vision, leadership, and encouragement. To my thesis committee, I extend my thanks – to Dr. Jo-Anne Fiske, for her passion, dedication to the empowerment of First Nations women and “big-picture” perspective and to Dr. Brad Hagen for his perceptiveness, patience, practicality and focus.

I am grateful for the friendship and support of my co workers: Marg Brewin, for her authenticity and genuine caring for the lives she touches, Terri-Lynn Fox, Roxie Vaile and Ryan Heavy Head who freely shared their wisdom, insight, and aspirations for the First Nations community; Reta Berte for her patience as I juggled work and school commitments, and Marcie Burka-Charles and Andy Stonehouse for their insightful comments as I prepared this manuscript. I would also like to thank Deb Tajiri and Beth Flitton for their assistance with data transcription and formatting and Kyle Richtsfeld for assistance with electronic concept mapping.

To my children, Janine, Ryan and Julie: you are my inspiration, and in many ways, the reason for my journey. I hope that I have encouraged you to pursue your

dreams, to persist (even when the way is not always easy or clear) and to embrace diversity and challenge with an open heart and mind.

To Doug, thank you for your strength, courage and support. The journey has not always been easy, yet you have never wavered in your encouragement. Thank you for freedom to immerse myself in this learning opportunity.

Thanks are extended to Alberta Cancer Board, who, in collaboration with the Chinook Health (CH) Family Health Program, provided funding to support this project. Additional scholarship funding was provided by the CH Bigelow Fowler Educational Fund, Foothills Hospital School of Nursing, Government of Alberta (Advanced Education) and University of Lethbridge.

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## Chapter 1

### Cervical Screening and Southern Alberta First Nations Women Living Off-Reserve

#### *Introduction*

Canadian First Nations women have faced up to six times the risk of developing and dying from cervical cancer in comparison to women in the general population (Clarke, Joseph, Deschamps, Band & Atleo, 1998). Despite being “potentially one of the most preventable cancers” (Fitch, Greenberg, Cava, Spaner & Taylor, 1998, p. 441), First Nations women living off reserve have seldom participated in Pap testing programs (Clarke et al., 1998). As we strive to improve the health of the Chinook Health<sup>1</sup> (CH) population, low screening rates in this underserved ethnic group have presented a puzzling dilemma. Why are First Nations women not taking advantage of this relatively simple, potentially life-saving procedure?

#### *Significance*

Cervical cancer is considered a significant health issue for Canadian women (Steven, Fitch, Dhaliwal, Kirk-Gardner, Sevean, Janieson, et al., 2004). In spite of strong evidence supporting cervical screening as a tool to prevent cancer, less than 40% of eligible CH women received a Pap test in 2004-05. Similarly, this trend is reflected by CH Cervical Screening Program attendance where fewer than five First Nations women received Pap testing in the last six months of 2003-04 (Chinook Health Cytology Laboratory, 2004).

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<sup>1</sup> The name of Chinook Health Region was changed to Chinook Health in spring 2006. For the purposes of consistency the region will be referred to throughout this document as Chinook Health. Reference citations produced previous to this date will retain the Chinook Health Region terminology.

Despite facing an inordinate burden of cancer incidence and mortality, Canadian First Nations women have been among the least likely to access preventive services. Aboriginal women, older women, recent immigrants, and women living in poverty have been among those least likely to receive Pap testing. The harsh reality has been that “the benefits of cervical screening come to those who are actually screened” (Fitch et al., 1998, p. 441).

To date, discussion about First Nations issues has focused “almost exclusively on First Nations communities in rural areas. This oversight...ignores the realities of Southern Alberta’s urban First Nations communities” (Hanselmann, 2001, p.1) where, in 2001, “72.1% of Aboriginal women lived in non-reserve communities” (Statistics Canada, 2006, p. 182). The urban Aboriginal population has continued to grow (Demsey, 1997; Fox, 2004; Romanow, 2002; Statistics Canada, 2006).

As regional medical clinics have restricted caseloads to existing patients, disparity in access is potentially magnified; this has been of particular concern for First Nations women relocating to Lethbridge from regional reserves. Often these women have “slip[ped] through the cracks,” their health care needs unaddressed. Alarming low First Nations Pap testing rates reported by regional laboratories have testified to these unaddressed needs. Lab-reported cervical screening rates and regional clinic utilization rates for women of First Nations ethnicity have stood in stark contrast to self-reported screening rates.<sup>2</sup> The need for further exploration has been clearly warranted. Who is better able to discuss these discrepancies, identify challenges, and offer solutions than the women themselves?

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<sup>2</sup> High self-reported screening rates for women on reserves (53.4%, n=120/227) are inconsistent with anecdotal reports of cervical screening utilization (Chinook Health Region Population Health, 2002). Social desirability and historical recall biases may have affected responses.

### ***Background***

In February 2000, the Alberta Cervical Cancer Screening Program provided seed funding to Chinook Health to promote cervical screening of unserved and underserved Alberta women. Among those targeted for enhanced cervical screening recruitment and education were First Nations women residing on the Piikani Reserve in Brocket and the Blood Reserve in Standoff (Barsky, 2002). Recruitment and education were either offered to naturally occurring groups or on an “as requested” basis. All eligible women (aged 18- 69 years) attending educational sessions were encouraged to visit their family physician, gynaecologist or the CH Cervical Health Program for Pap testing.

In Alberta, cervical screen testing can be performed by physicians, nurse practitioners or extended nurse practitioners. In contrast to other health regions, all cervical screen tests are processed by the central CH laboratory. This is an advantage in that centralized specimen and data collection have allowed for regional cervical screening monitoring and standardization of certain processes. For example, results and recommended date of next Pap testing (based on current clinical practice guidelines, Appendix A) are forwarded to the woman’s family physician. The woman who has had Pap testing also receives an annual reminder. If abnormal cells are detected, letters are sent to the woman and her family physician indicating the need for further diagnostic testing. If the recommended testing is not carried out within the specified time period, an additional reminder is sent (T. Trotter, CH Laboratory, personal communication, October 14, 2005). To date, the program has achieved a nearly 100% success rate in reaching women with abnormal Pap smears, allowing the opportunity for timely, informed decision-making (Barsky, 2002). While this regional recall system has been highly

successful in prompting return visits, it has failed to address awareness of the importance of cervical screening among those who have never received Pap testing.

In an attempt to reach all unserved and underserved women regarding the importance of regular Pap testing, the Alberta Cervical Cancer Screening Program is planning to send letters of invitation to all Alberta women aged 18 to 69 years. Yet this approach is flawed in several ways. First, the mobility of First Nations has posed unique challenges for reaching this population by mail (Statistics Canada, 2006). Secondly, mail out information, in isolation, has been found ineffective in motivating behaviour change among certain high-risk groups (Chen, Sallis & Castro as cited in Oelke, 2002).

Health regions are also challenged by the lack of ability to profile underserved, high-risk populations. Ethnicity is not a routinely collected data element in regional databases. Recently ethical approval to capture this information through a provincially standardized survey has been extended to Alberta Cancer Board-sponsored programs. While this data collection will enhance the understanding of screening behaviours of women attending these programs, the ability to generalize findings to the general population (e.g., women who are screened at physician clinics or who are not screened) has remained limited.

In 2004, the Alberta Cervical Cancer Screening Program awarded the Chinook Health funds to hire a First Nations lay community worker to provide individual and group cervical screening counselling. While lay community workers<sup>3</sup> have demonstrated improvements in preventive and primary health care delivery, research specific to their effectiveness in promoting cervical screening, while promising, is limited (Christopher,

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<sup>3</sup> The term lay community worker has been used synonymously with lay health advisors, Messengers for Health, and community health worker.



2004; Dang, Doan, Kguyen, Lai, Wong, Mock, McPhee, Nguyen et al., 2004; Lewin, Dick, Pond, Zwarenstein, Aja, van Wyk, et al., 2005; Oelke, 2002; Schwann, 2002).

Will provincial and regional strategies make a difference to health-seeking behaviours of high risk under-served First Nations women? Do First Nations cultures influence, and indeed determine, the quest for personal and community health? To better understand First Nations people and their culture and to provide culturally suitable health care services, a basic knowledge about the First Nations people of southern Alberta is fundamental (Clarke et al., 1998; Fitch et al., 1998, Smylie, 2000).

### ***First Nations People in the Chinook Health Region***

According to the 2001 Canadian Census, approximately 7% of Chinook Health's regional population have claimed some Aboriginal ancestry, nearly double provincial and national rates (3.8% and 3.3% respectively) (Cardinal, Schopflocher, Svenson, Morrison & Laing, 2004). Over 11,000 Aboriginal people currently reside in the region (approximately 7.3% of the total population). In December 2004, Indian and Northern Affairs reported the following statistics for Registered First Nations people (see Table 1).

Table 1

Registered First Nations: On- and Off-Reserve Residence as of Dec. 2004		
<b>Gender and Residence</b>	<b>Blood</b>	<b>Piikani</b>
Males on own Reserve	3,697	1,131
Females on own Reserve	3,662	1,152
Males on other Reserve	42	12
Females on other Reserve	36	18
Males off Reserve	975	491
Females off Reserve	1,264	570
Males/Females on own Crown land	<5	0

Total Registered Population	9,679	3,374
Indian and Northern Affairs Canada (2005)		

In comparison to their non-Aboriginal counterparts, Aboriginal populations are “clearly younger with relatively few Elders” (Cardinal et al., 2004, p. 9). Approximately 45% of the regional Status Indian population is under the age of 20 years (Cardinal et al. 2004; Statistics Canada, 2001a, 2006) (see Appendixes B & C).

According to Canada’s 1982 Consitution Act, the Canadian Aboriginal population is made up of of three broad groups: North American Indians, Métis and Inuit (Benoit, Carroll, & Chaudhry, 2003; Smylie, 2000; Statistics Canada, 2006). While many terms have been used to describe the Indigenous peoples of North America (e.g., Aboriginal, First Nations, Native, and Indian (K. Anderson, 2000)), the term “First Nations” has been used throughout this document, in recognition that this often-preferred terminology recognizes these individuals as descendants of Canada’s first inhabitants (Dempsey, 1997; Smylie, 2000).<sup>4</sup> In some places I have used the term “Aboriginal” to indicate that I am talking in a more global sense about the First Nations peoples. Yet Smylie, a Saskatchewan Métis physician, has acknowledged that Aboriginals most often “refer to themselves by their specific tribal affiliation” (Smylie, 2000, p.2). In the CH region, Blackfoot is the most common tribal affiliation encountered. The term “Blackfoot” actually embraces three tribes: <sup>5</sup> the Sik-si-kah or Blackfoot tribes of Southern Alberta and Northern Montana, Kai’nah or Many Chiefs (now known as the

<sup>4</sup> The term “First Nations” is considered by some to be politicaly charged. Heavy Head (2006) prefers the term, “Nisitapiaakiiksi” or “real people women” when referring to the Aboriginal women of Southern Alberta (R. Heavy Head, personal communication, May 19, 2006).

<sup>5</sup> “Sik-si-kah or Blackfoot, so named because of an incident whereby their moccasins became black from the soot of prairie fires; Kai’nah or Many Chiefs, now Bloods, the latter from a Cree term Mik-kwee-ye-ne-wuk or Blood people, apparently from their use of red ochre; and Api-ku-ni or Scabby Robes (shortened to Peigan [and later changed to Piikani]), so-named for a time when their hides were not properly tanned by the women” (Johnson and den Otter, p. 23).

Bloods) and Api-ku-ni (known as the Peigan or, more recently, Piikani) (Galt Museum, 2006; Johnson & den Otter, 1985). “European fur traders along the North Saskatchewan and Missouri rivers first came into contact with the Blackfoot and hence, this tribal name came to be applied to the entire nation” (Johnson and den Otter, 1985, p. 23).

Collectively, they call themselves Sow-ki-tapi or Prairie people.

The Bloods, Blackfoot and Piikani of Southern Alberta have shared a common language, Blackfoot, a branch of the Algonkian language family common to Southern Prairie and Eastern Canadian tribes (Dempsey, 1997; Johnson and den Otter, 1985; Smylie, 2000). While the Blackfoot tribes have had many common cultural characteristics, each has had its own distinct history and culture. Even within tribes, cultures and histories have not been homogeneous (Indian and Northern Affairs Canada, 2004).

Of the forty-four First Nations located in Alberta, only the Blood and Piikani reserves lie within CH boundaries (see Figures 1 & 2). After signing Treaty 7 in 1877 the Blood and Piikani lands were reduced to tracts of lands known as reserves. The Blood reserve is “Canada’s largest Native reserve” (Webber, 2006, p. x). As the white man encroached onto traditional native lands, exterminating the buffalo (a major source of food and economic livelihood for the Alberta First Nations tribes), these Treaties secured land for the colonized peoples in exchange for limited services and the right to dwell on federally owned Crown land known as reserves.

Official registry into the federal Indian Register gave the Indian Status rights and benefits unavailable to non-Status Indians, including health care coverage under the Medicine Chest clause (Isaac, as cited in Smylie, 2000). Uninsured health benefits

received today (including pharmaceutical medication, supplies and health care services) are the modern day medicine chest the federal government is obliged to provide under still-existing treaty agreements (J. Fiske, personal communication, September, 2004; Smylie, 2000).

***Historical influences.***

In spite of Treaty agreements, colonization has taken a dramatic toll on the health and well-being of the First Nations population in the ensuing years. Children were taken away to residential schools, cultural influences were suppressed, foreign religious practices imposed, and families and communities disrupted. Physical, emotional and sexual violence escalated. Disease and malnutrition, introduced by the influx of colonists, caused a steady decline in this population (K. Anderson, 2000; Crowshoe & Manneschmidt, 2002; Dempsey, 1997; Mihesuah, 2003; Smylie, 2000). First Nations women living off reserve continue to be challenged by “pervasive poverty, persistent racism, and a legacy of colonialism...caught in a cycle that has been perpetuated across generations” (Romanow, 2002, p. 218). In many ways, women living off-reserve have faced challenges not unlike those of their ancestors. Shifting cultural expectations and “tangled” traditional and western ideologies and lifestyles have often presented as illness (Fox, 2004; Mussell, 2005).

***Health of the First Nations people.***

The poor health of First Nations people has stood in stark contrast to the health of non-First Nations Canadians (Cardinal et al., 2004; Dion Stout, 2005; First Nations & Inuit Health Board, 2003; LeTendre, 2002). First Nations communities are plagued by shortened life spans, high rates of suicide, injury, alcoholism, diabetes, mental health

illnesses, respiratory disease, teen births, and infant mortality (Cardinal et al., 2004; LeTendre, 2002). Growing levels of inactivity, community violence and problem gambling are reaching critical levels (Dion Stout, 2005; Kinnon, 2002; Smylie, 2001). Emerging First Nations health issues have included new cancers (attributed to smoking and second-hand smoke exposure) and high levels of sexually transmitted disease.

Recent statistics have reflected the disproportionate burden of ill health experienced by Aboriginal women (Cardinal et al. 2004; Hanselmann, 2001; Romanow, 2002; Statistics Canada, 2006). For example, while potential years of life lost have been twice as high for First Nations men in comparison to non-First Nations men, these figures have escalated to three times as high for First Nations women in comparison to their non-First Nations counterparts. Furthermore, Canadian First Nations women have been at greater risk than men for diabetes. Cervical cancer rates of Saskatchewan First Nations women have been six times that of non-First Nations women, while in Manitoba, mammography screening has been half as likely to have been accessed (Wilson, 2005; Prairie Women's Health Centre of Excellence, 2001; National Coordinating Group on Health Care Reform and Women, 2003). The urgent need to address these health disparities within a culturally sensitive context has been clearly evident (Cardinal et al., 2004; Chinook Health Region [CHR] Population Health, 2003; CHR Population Health, 2005b, 2005c; Kinnon, 2002; Romanow, 2002).

The poor health status experienced by First Nations people has mirrored the dismal socioeconomic trends faced by this ethnic group. For example, Aboriginal Canadians have been twice as likely as non-Aboriginal Canadians to be in lone parent families. They have been over-represented in the criminal justice system, both as victims

and as offenders, and have been more likely to experience domestic violence (Hanselmann, 2001; Statistics Canada, 2006). First Nations people have been more likely to have lower levels of education, higher unemployment rates, and lower income levels (CHR Population Health, 2003; First Nations Centre, 2004; Health Canada F.N.I.H.B., 2003; Statistics Canada, 2006). Unemployment, underemployment, and poverty plague the CH First Nations population; 36% have reported being unemployed (CHR Population Health, 2003). “In concert with the lower employment seen in the First Nations, average income is also below that of the Canadian population as a whole – at any age or education level”(Hull, as cited in Health Canada F.N.I.H.B., 2003, p.64).

Underemployment and low wages may have been a contributing factor to the startling 41% of employed regional food bank users. It is speculated that these people represent the “working poor” - living marginally above the poverty line. Somewhat incongruously, 34.3% of regional Aboriginal survey respondents reported that they moved off reserve to find a job. Nearly half reported that lack of on-reserve opportunities was a key factor in their decision not to return to the reserve (CHR Population Health, 2003). As such, it is not surprising that First Nations people have been more likely to experience homelessness and have greater housing needs (Hanselmann, 2001). Even basic means of communication have often been unavailable. Telephones, and increasingly computers with Internet service, are considered essential tools for education and full participation in the modern economy. This gap, referred to as the digital divide, may have important implications for the economic and social well-being of First Nations people (Assembly of First Nations, 2004; First Nations Centre National Aboriginal Health Organization, 2004).

In the face of these multifaceted and inter-related challenges, a beginning awareness and desire to address First Nations health is emerging. First Nations culture, independently, and in combination with the other health determinants, is exerting a profound and indispensable health influence that cannot be ignored when planning health care services for this population. The inter-relationship between First Nations philosophies and the determinants of health has been depicted in the Calgary Health Region Aboriginal Health Program Conceptual Framework (see Figure 3). This framework has recognized that health challenges faced by First Nations individuals and communities are often fundamentally linked to larger social issues, demanding a collaborative, intersectoral approach to improving health and health-related issues (Applied Research & Analysis Directorate, 2004; Browne, Fiske, & Thomas, 2000; Goodstadt, 2005; Public Health Agency of Canada, 2003; Raphael, 2005). A collaborative approach to health and healthcare acknowledges that First Nation perspectives of health are harmonious with Western philosophies of population health,<sup>6</sup> health promotion,<sup>7</sup> health protection<sup>8</sup> and disease prevention<sup>9</sup> (Calgary Health Region, 2005). Dion Stout, an Alberta Cree author, (2005) has emphasized that “while healing and wellness programs have their place in the short term, it is economic and social reforms that will bring lasting change” (p. 19). By working together towards this common vision, First

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<sup>6</sup> Population health views health from the context of the population as a whole, rather than focusing on the people at risk for a certain disease. A population health approach addresses the entire range of factors that determine health and by so doing affects the health of the entire population..Population health promotion combines diverse, but complementary approaches and aims, particularly those aimed at effective and concrete public participation (Thurston & O’Conner, 2005; Public Health Agency of Canada, 2005).

<sup>7</sup> Health promotion is the process of enabling people to increase control over, and to improve their health (Nutbeam, 1998).

<sup>8</sup> Health protection is the process of providing protection against infectious diseases and other dangers to health, including chemical hazards, poisons and radiation (Health Protection Agency, n.d.).

<sup>9</sup> Disease prevention covers measures not only to prevent the occurrence of disease, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established (Nutbeam, 1998).

Nations and non-First Nations communities will be empowered to address the full spectrum of health determinants in an efficient and effective way (Calgary Health Region, 2005). Browne et al. (2000) have stressed that in order to empower First Nations communities, research must “move beyond simply exploring and documenting phenomena of concern to women” to one that is “critical, action-oriented, and contribute[s] to the development of strategies for addressing women’s oppression” (p. 27). Laverack and Wallerstein (2001) have contended that the role of the health promoter is to “enable individuals and groups to gain or seize power through their own power-from-within” (p. 183). This will require an approach of facilitating, enabling, coaching and guiding. The need for collaborative and culturally sensitive approaches to improve the health of First Nations people is becoming apparent. An obvious place to begin is by examining culture as an important factor that influences or determines the health status of First Nations people. The next section examines the relationship between First Nations culture and health. Common First Nations cultural traits and the role of women in transmitting cultural knowledge, beliefs and values are explored.

### ***First Nations Culture. A Determinant of Health***

It is widely accepted that culture is one of a myriad of inter-related, multi-dimensional factors that influence individual and community health (Browne et al., 2000; CHR Population Health, (n.d)a; Dion Stout, 2005; Public Health Agency of Canada, 2003; Raphael, 2005; Romanow, 2002; Thurston & O’Conner, 2005). Culture is one of eleven inter-related health influences or determinants that has been formally recognized by Chinook Health as foundational to achieving health and well-being. In addition to culture, the determinants include income and social status, social support networks,



education, employment and working conditions, physical environments, biology and genetic endowments, personal health practices and coping skills, healthy child development, gender, and health care services (CHR, n.d.a; Zollner & Lessof, 1998). While in general agreement with a determinants of health approach, the National Aboriginal Health Organization (2001) has criticized the health determinants for not including factors integral to First Nations' worldviews (e.g., holism and balance, the reciprocal interconnectedness of individual, family and community, and physical elements of wind, water and fire) (National Aboriginal Health Organization, 2001). Others have insisted that a First Nations health determinants approach demands a past, as well as a present and future perspective, recognizing the significant impact of government institutions, residential schools, prejudice, education, the church and the media on health and wellbeing of the First Nations people (K. Anderson, 2000; Dion Stout, 2005; Dion Stout & Kipling, 1998).

Yet the important role of culture as a determining factor of health and wellbeing often goes unrecognized. Within the current health system, Aboriginal "ways of knowing" are forced to assume "second class" positions (LeTendre, 2002; National Aboriginal Health Organization, 2001) in light of "western society's demand for the scientific basis of medical care and the systematic recording of knowledge" (LeTendre, 2002, p. 84). Western biomedical philosophies have often conflicted with traditional Aboriginal philosophies of health (LeTendre, 2002; Svenson & Lafontaine, 1998). Wilson, a Manitoba Cree, (2004) has stressed "the importance of moving beyond the scientific approach to health and healing, to integrate holistic understanding of and approaches to health (including traditional healing practices) into health care practices

and policies” (p. 28). Obviously, the role of culture in relation to health cannot be ignored.

Culture, the fluid and responsive system of meanings that a group of people share, includes language, thoughts, communications, actions, lifestyle, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups (Fox, 2004; Geertz, 1973; Massachusetts League of Community Health Centers, 2005; Thornhill, 2005). Kagawa-Singer and Chung (1999) have described culture as a “ tool which defines reality for its members” (p.178). Within this perception of reality, the individual’s purpose in life emerges through a process of socialization in which he or she learns the appropriate beliefs, values, and behaviours shared by society (Huff & Kline, 1999; Kagawa-Singer & Chung, 1999). Cultural beliefs and values have provided a sense of identity while at the same time prescribing behavioural rules that support an individual’s sense of self-worth and maintaining group function and welfare (Huff & Kline, 1999; Kagawa-Singer & Kassim-Lakha, 2003; Thornhill, 2005).

Culture and ethnicity are closely related and tend to overlap in the way they are used. While culture is concerned with symbolic generalities and universals about social and family groups, ethnicity is concerned with one’s sense of identification and belonging to a specific reference group within a given society (e.g., common racial, national, tribal, religious, linguistic, and cultural origin or background) (Merriam-Webster, 2006). Ethnicity often shapes culture, influencing the ways in which we think, relate, feel and behave within and outside of our reference group. Ethnicity defines patterns of behaviour, providing a sense of belonging and continuity with his or her ethnic group over time (Slonin, 1991, as cited in Huff & Kline, 1999). The distinction

between ethnicity and culture is aptly described by McKay, a contemporary Manitoba Cree. He explains, “My heritage is Indian. But it is not my culture” (Krotz, 1980, p. 94). McKay described how he never saw an Indian costume; beads and feathers and buckskins, nor a traditional Indian dance until after he moved to Winnipeg, when he was almost fifty years old. Krotz (1980) stated that the urban Indian is identified not by reserve affiliation, treaty status or socio-economic position. “He or she is identified by ethnicity and heritage and by the fact of having made a conscious choice to maintain and reinforce their ethnicity and [cultural] heritage even (or especially) while living in the city” (p. 156).

What is First Nations cultural heritage? Traits commonly associated with traditional First Nations cultural heritage are language, family and community, spirituality, and oral traditions.

Language and literacy are essential to understand the inner and outer worlds of First Nations people; they are necessary to make meaning of family stories as well as other stories than enrich identity, knowledge and ability to transmit culture (Mussell, 2005). While the number of Southern Alberta First Nations women whose knowledge of the language of origin is dwindling, communication difficulties continue to be faced by many of the elderly First Nations people in encounters with the health care system (Hungry Wolf, 1996). Frank Daniels, an Alberta First Nations elder (2002) spoke of this dilemma: “Most of the time we think Aboriginal but we have to speak English. We have to interpret what we’re going to say in our communication. One thing that we have to work on is to understand one another” (as cited in Cardinal et al., 2004). Daniels pointed out the difficulty in translating between First Nations and Anglo-American oral and

written languages. In Blackfoot, words and phrases have often been fraught with multiple meanings; ultimately the richness of the language of origin may be impossible to capture (Bastien, 2005; Cardinal et al., 2004, Fox, 2004). Bastien (2005), a Piikani/Blackfoot author and researcher further explained, “Our worlds are holistic and so are our words.”

Interdependence was a key aspect of First Nations culture (Cheah & Nelson, 2005). The care and nurture of Blackfoot family members has traditionally been the responsibility of a large extended network of grandparents, aunts, uncles, and cousins (Wolfleg, 2005). To First Nations families,

Aboriginal children are precious... because they represent the future. They are not considered possessions of the biological parents; rather, they are understood to be gifts on loan from the Creator. Because of this, everyone in the community has a connection to the children, and everyone has an obligation to work for their well-being. (K. Anderson, 2000, p. 159)

The family was the principal means of social, economic and political negotiations; family leaders exercised economic rights to territory and resources and were represented in councils charged with collective decision-making.

For Blackfoot people, decision making was intimately connected with spirituality (T. Fox, personal communication, November, 2004; R. Heavy Head, personal communication, May 19, 2006; Hungry Wolf, 1996; R. Vaile, personal communication, November, 2004). K. Anderson (2000) stated, “Even now, many Native peoples do not divorce spirituality from politics, business, education, health or social organization” (p. 71). Creation stories have reflected the spiritual power of First Nations women, who, by virtue of their role as creators of life, played an intermediary role between the spirit world and earth (K. Anderson, 2000; R. Heavy Head, personal communication, May 19, 2006). Women played a central role in Blackfoot ceremonies

(e.g., the Okan Sun Dance). They were often keepers of sacred bundles, bearers of culture, for example, Thunder Pipe ceremonies and members of influential Blackfoot societies (Crowshoe & Mannes Schmidt, 2002). Communication with the Creator and the spirit world have commonly taken place through dreams, visions, prayers, the traditional smudge or burning of sweetgrass, and chants. These foundations of Blackfoot culture have been transmitted from generation to generation through stories and oral traditions.

First Nations traditions, cultural nuances and wisdom, and healing philosophies have been passed from generation to generation through word of mouth by community and spiritual elders or through ceremonies (Fox, 2004; Hungry Wolf, 1996; Mussell, 2005). With the aging and passing of First Nations elders, many have feared that the ability to transmit this vital cultural information to the younger generations is in jeopardy (Fox, 2004; Hungry Wolf, 1996). Rapid socio-economic and cultural change have demanded that we examine not only traditional First Nations' worldviews, but look more closely at the evolution of First Nations cultures.

Throughout history, First Nations women have played a central role in the intergenerational transmission of cultural knowledge, beliefs, and values. As knowledge keepers, community guardians and educators of young children, women have been held in high esteem by the traditional First Nations' community (Kenny, Faries, Fiske, & Voyageur, 2004). Within contemporary society, First Nations women have continued to play a pivotal role in shaping cultural beliefs and values, influencing individual and community perceptions of health and well-being and shaping political, health and social environments. Today, "there is spectrum of multiheritage women, in between 'traditional' and 'progressive,' who possess a multitude of [values, personalities, and]

opinions on what it means to be a Native female” (Mihusuah, 2001, p. 1249). First Nations women of today have been essentially free to choose from all the available possibilities within their dynamic cultural framework. Each may have differed significantly in her worldview of what constitutes health and disease, from cause and prevention to treatment and cure (Huff & Kline, 1999).

First Nations women have faced dramatic cultural contrasts on moving from reserves to urban centres. Hostility toward First Nations people whether labelled as racism or ethnocentrism has become a major social issue (Balls Organista, Chun & Marin, 2000; Jayaraman, 2000). Examples are readily found in local newspapers (Chief-Calf, 2005; Nordquist, 2005; Phillips, 2005) with headlines loudly proclaiming: “Racism a Reality,” “Letter on Racism Difficult to Believe,” and “Making Progress on Racism but still far to go.” Discrimination within their “new” community and rejection by their on-reserve peers have been commonly experienced by First Nations women living off-reserve. Caught between traditional roots and white society, they have been marginalized and at risk for sociocultural stress because they have not been not fully accepted in either culture (Mihesuah, 2003; Williams & Ellison, 1996).

Yet change and resilience are not new to First Nations women (Dion Stout, n.d.). Ecological change, ever-changing insights, and the creation of temporary harmonies interdependent with the forces of change are encompassed within traditional First Nations’ worldview (K. Anderson, 2000; K. Anderson & Lawrence, 2003); Kenny et al., 2004). Research on First Nations cultural adaptation has required reciprocal, respectful, genuine and practical dialogue with First Nations women (K. Anderson, 2000; Dion Stout, n.d.; Mihesuah, 2003). As more and more First Nations women have encountered

health services in non-traditional health and social settings, the need to examine the effects of cultural transition has become urgent.

### ***Culture and the Healthcare Setting***

The importance of clarifying cultural beliefs and values within healthcare settings has been highlighted by Huff and Kline (1999):

There are many different ways of perceiving, understanding, and approaching health and disease processes across cultural and ethnic groups with which health practitioners need to become better acquainted. Cultural differences can and do present major barriers to effective health care intervention. This is especially true when health practitioners overlook, misinterpret, stereotype, or otherwise mishandle their encounters with those who might be viewed as different from them in their assessment, intervention, and evaluation planning processes. (p. 6)

Blackhall (1999) has stated that “Without understanding the fundamental nature of culture and the integrity of differing belief systems, the risk of conflict and its negative impact on health outcomes is inevitable” (as cited in Kagawa-Singer & Kassim-Lakha, 2003). Brislin and Yoshida (1994) have noted that health care professionals often lack knowledge about health beliefs and practices of culturally diverse groups. Problems in intercultural communication have led to “significant challenges in the provision of health care services to multicultural populations” (as cited in Huff & Kline, 1999).

Research has shown that risk behaviours, health practices, psychological coping skills and clinical treatment philosophies vary between cultures (Kagawa-Singer & Kassim-Kalha, 2003; Balls Organista & Marin, 2000). In order to come to mutually agreeable health outcomes and strategies, patient/family wishes and biomedical feasibility must be objectively considered. Williams (1996) has pointed out that health care interventions involving personal change have been effective only when clients have been encouraged to become responsible in culturally relevant ways (§ 6).

Health care organizations and individuals are encouraged to be culturally sensitive, culturally competent, and culturally safe. Cultural sensitivity is the awareness of the diversity in values, beliefs and lifestyles that exist among population groups in society. A culturally sensitive approach

values First Nations tradition and culture, recognizes the importance of ritual and ceremony, values the wisdom and role of elders, emphasizes connectedness, works to restore balance, supports nurturing and mutually-respectful relationship, honors the central place of women, accepts the client as a whole person, [and] assumes equality between service provider and service user. (Kinnon, 2002, p. 33)

A culturally sensitive approach necessitates culturally competent staff working in partnership with First Nations people to plan and design programs, make decisions, evaluate successes, identify opportunities for improvement, and design and utilize culturally relevant research. Cultural competence reflects the ability to apply the knowledge about cultural differences to the delivery of healthcare. Jackson , Camacho, Freund, Bigby, Walcott-McQuigg, Hughes et al. (2001) have suggested that a presupposition of cultural competency is that no one and no system is culture free. A culturally competent health provider is aware of the general medical culture, the patient's culture, and the personal culture that he or she brings to the table (Jackson et al., 2001). The skilled provider defines inherent cultural strengths, evaluates health behaviours and illness within the context of culture and cultural adaptation and negotiates among potential differences to reach mutually desired goals for care, as differences in health behaviours and management of illness are often culturally determined (Kagawa-Singer & Kassim-Lakha, 2003).

Cultural safety practices “recognize, respect and acknowledge the rights of others” and enable people from minority groups to access and utilize health care service



“in ways that do not diminish, demean, or disempower them”(Cooney as cited in Browne et al., 2000). Minority groups need to be safe within the health care environment and supported in accessing health care services that “will decrease risk factors, and enhance health” (J. Anderson et al., 2005, ¶1). “Ultimately, cultural safety is concerned with [reflective practice], changing attitudes and ... gaining an awareness of the political and historical forces shaping the dynamics of health care interactions with Aboriginal people” (Browne et al., 2000, p.9).

***Engaging and empowering First Nations women.***

Many First Nations women have found themselves marginalized and without decision-making power in today’s health system (Browne et al., 2000). Historical impacts of colonization and patriarchal thought have continued to linger and reverberate across multiple generations, resulting in blame, fear of intimate relationships, distrust, caustic shame, isolation, powerlessness, expectations of failure, and lack of ability to cooperate and collaborate. Powerful traditional roles held by Southern Alberta First Nations women have been disrupted by the introduction of Christian and patriarchal ideologies (K. Anderson, 2000). For many women, balanced gender roles are still not evident in contemporary society (Mihesuah, 2003). Others have faced disempowerment associated with power inequities and discrimination within off-reserve institutions and communities .

Many authors have suggested that empowerment of First Nations people is key to improving the health of the First Nations community (Dion Stout, Kipling, & Stout, 2001; Smylie, 2000; Browne et al., 2000). Empowerment is the “means by which people experience more control over decisions that influence their health and lives” (Laverack &

Labonte, 2000, p. 256). Empowerment entails building individual and community control, resources and capacities toward economic, social and political change in response to community-identified needs (Laverack & Labonte, 2000).

The 2002 Romanow Report heralded the national move towards increased governmental transfer of power to First Nations people on reserve. Yet Wilson, a Cree Opaskwayak researcher (2004), has advised that First Nations people need to be supported throughout this process:

Health care practitioners, providers, and policy makers, as well as federal and provincial governments need to assist Aboriginal communities in the development of infrastructure, development and human resources needed to create and control health care services that are rooted in the cultural practices and values of the Aboriginal people they are serving. (p. 23)

Community empowerment within a culturally safe environment holds promise as an important catalyst for change. While a community empowerment approach seems promising, Laverack and Labonte (2000) have pointed out that lack of clarity about the community empowerment process often results in insufficient means to make this concept operational within a conventional program context. Furthermore, long term vision, commitment, and investment in community empowerment are limited by short term funding and support, and complicated by fragmented provincial and national funding (Kinnon, 2002). Dion Stout et al. (2001) have suggested that community empowerment, ownership and involvement in achieving health of Alberta First Nations will be achieved through building upon identified strengths of men, women, children, and elders. Wilson (2005) has suggested that women's traditional role as decision-maker and nurturer of children places them in a unique role to impact change. By returning "honor and respect to women for the roles they perform in their families and communities" and

in turn, “reclaim[ing] and acknowledge[ing] the importance of women” everyone in the First Nations community will be empowered (p. 22).

### ***Culture and Research***

For the health researcher working with First Nations people, all phases and decisions of the research process are influenced by culture. Identifying personal perspective, values and assumptions is critical – particularly in ethnographic studies, where the researcher becomes an “instrument” of the research. In her lecture, Ogilvie (2004) has suggested that the researcher “needs to be cognizant of culture, history, power relations in addition to the research design and approach”. Furthermore, the researcher and health care professional need to be aware of individual and collective cultural adaptation as an important variable in health research and care.

CH professionals are highly likely to encounter First Nations people in their day to day practice. Despite the trend toward urbanization, the fundamental influence of culture and status rules have continued to impact the health of First Nations people. To be most effective, health promotion and health care must be holistic, culturally competent and grounded within each individual’s cultural worldview and values. This study provides the opportunity to explore the changing culture of regional First Nations women living off reserve as it affects their health practices and behaviours from their personal perspectives – through their eyes.

### ***Purpose***

The purpose of this research study was to gain an understanding of the cervical screening needs of First Nations women living off-reserve in the CH region and to involve them in identifying solutions to barriers they face. Objectives of this research

study were to explore strategies that will encourage First Nations women to access cervical screening services and to determine perceptions about appropriate and acceptable services (including service location, service provider and interaction).

### ***Assumptions and Guiding Questions***

This research study was based on the following assumptions:

1. First Nations women living off reserve possess valuable insight into the needs of their community (emic approach). Consequently, they are the most appropriate people to involve in strategic planning of a Cervical Screening Clinic that will meet the needs of this under-served population.
2. The focus group context provides an opportunity for a rich exchange of ideas and information in a culturally familiar setting (e.g., talking circle).
3. A simultaneous bottom-up and top-town approach will promote shared meaning and insight (Laverack & Labonte, 2000).
4. The CH Cervical Screening Program can achieve better outcomes for these women (e.g., increased access to culturally sensitive services) by examining current structures and processes within the context of First Nations' cultural worldviews.
5. Focus groups provide an efficient means of data collection in light of time and resource constraints.
6. Cross-cultural exchange of information will mutually benefit both researchers and participants and may provide collegial groundwork for future collaborative endeavours.

### ***Research Question***

The primary research question that guided this qualitative study was: What needs, barriers and solutions are important to take into consideration in relation to cervical screening of First Nations women living off reserve in the Chinook Health region?

### ***Summary***

Findings from this study will enhance our understanding of the cultural values and insights of First Nations women living off-reserve in relation to their utilization of CH cervical screening services. Oelke (2002), in a comprehensive review of the literature, stressed the importance of “knowing the target population and tailoring interventions to meet the needs and barriers that exist for them” (p. 28). By actively including First Nations women in service planning and decision-making, CH programs will be better equipped to meet the needs of this underserved population.

Locally, provincially and nationally, we are at a critical juncture in First Nations health, with the opportunity to empower, nurture, and work towards health for all. This must be done in a culturally sensitive and safe way by working in partnership with First Nations people. A participatory, qualitative study was an ideal way to assess the needs of regional First Nations women living off reserve and involve them in the planning of strategies that would better meet their needs.

This thesis is presented in five chapters, followed by a reference section and Appendixes. In chapter 1, cervical cancer is presented as a significant issue for First Nations women residing in the Chinook Health region. The context for cervical screening among regional First Nations women is presented. The critical influence of First Nations

cultures and cultural worldviews is explored in relation to health and wellbeing. Chapter 2 provides an overview of empirical evidence related to First Nations cervical screening in Alberta. Chapter 3 explores the philosophical, theoretical and personal perspectives of the researcher and describes the methodological, analytical and ethical underpinnings of this study. Chapter 4 outlines the study results and discusses the findings in relation to current literature. Finally, in chapter 5, an overview and summary of the study methodology and key findings are presented. Personal and team learning are discussed and recommendations for education, practice, policy, and research are presented.

The future is not someplace we are going to, but one we are creating. The paths are not to be found, but made; and the activity of making them changes both the maker and the destination.

John Schaar. (nd). John Schaar.

## Chapter 2

### A Review of the Literature: Cervical Screening and Alberta First Nations Women

The literature review is essential to “recognize a previously reported concept or pattern, refer to established explanations and theories, and recognize any variations between what was previously discovered and what you are now seeing” (Morse & Richards, 2002, p. 169). The review of the literature for this study was both deductive (beginning with general principles and prior knowledge) and inductive (prompted by the discovery of concepts through the course of the study). The search was completed using the EBSCO collection of health-related research databases (including MEDLINE, Biomedical Reference Collection, Nursing & Allied Health Collection, and Psychology and Behavioural Sciences Collection). This review was supplemented by grey literature,<sup>10</sup> sentinel articles referenced in reviewed documents, and discussions with Blackfoot leaders and scholars. A final comprehensive, focused review of current literature was completed at the end of the study.<sup>11</sup> This allowed for detailed examination of the focus group findings in relation to current knowledge.

Published literature specific to Alberta First Nations women and cervical screening was scarce. “Virtually every research document devoted to analyzing and profiling the urban Aboriginal population begins by noting the lack of reliable statistical information” (Kastes, as cited in Hanselmann, 2001). Lack of historical data has traditionally limited the ability to observe trends over time; hence, the diverse needs of

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<sup>10</sup> Grey literature for this review was retrieved from sources such as the Canadian Women’s Centers of Excellence, Health Canada Status of Women, First Nations website.

<sup>11</sup> Search terms included First Nations, Aboriginal, Indian and cervical screening. Articles were limited to those reflecting Canadian First Nations and Washington, USA Indian practices with publication later than 2000. The literature review was restricted to the Great Plains Indians of Southern Alberta and the northern American states bordering Canada (Hardy, 1975).



First Nations people have often gone unrecognized. In addition, confidentiality restrictions related to ethnicity and data ownership have complicated the ability to collect and use information, and may have accounted for the dearth of published, culturally specific, evidence-based best practice literature (Kinnon, 2002).

Furthermore, the current literature review highlighted the fact that published material in relation to First Nations culture and health written from a First Nations women's perspective was not readily available in Medical and Psychological databases, but rather, was obscured within the grey literature or found in the literature of other disciplines (e.g., sociology, anthropology). Even more difficult to unearth was research conducted by First Nations women; frequently distinctions between emic and etic authorship were not readily apparent.<sup>12</sup> This was important, in that historical accounts of Alberta Indian Tribes have been criticized for often presenting "half truth" portrayals of First Nations people (Wolfleg, 2005). Instead of accurate portrayals of First Nations culture from an *insider* viewpoint, "there is a large body of literature written by professionals for professionals, primarily to suggest how to identify and treat this population of women" (Field, B. as cited in Rutman, Callahan, Lundquist, Jackson, & Field, 2000). As First Nations women have worked independently and collaboratively to reflect cultural realities in published literature, this has slowly begun to change (K. Anderson, 2000). This chapter provides a summary of current empirical evidence regarding First Nations women and cervical screening from the viewpoint of First Nations authors.

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<sup>12</sup> Author surnames are no longer embedded in traditional nonclamenture, leaving the scholar to search out and authenticate biographies.

***Cervical Cancer: Prevalence and Mortality***

Canadian First Nations women have experienced higher incidence of cervical cancer and mortality than their non-First Nations counterparts (Clarke et al., 1998; Steven, Fitch, Dhaliwal, Kirk-Gardner, Sevean, Janieson et al., 2004; Young & Choi, 1985; Young, Kliewer, Blanchard & Mayer, 2000). Current published information regarding cervical cancer incidence and mortality for First Nations was scarce; Morgan and Laing (1981) reported cervical cancer in situ as the most “frequent neoplasm” for Registered Alberta Indian women (1974 – 1987), constituting “almost 30% of female cases” (p. 33). They went on to state that this pattern was “markedly different” for registered (First Nations) females than for the general population. Young & Frank (1983) speculated that higher rates of cervical cancer found among Alberta Indians (in comparison to First Nations women in other provinces) might have been associated with the “stronger urban influence” and “history of more intensive acculturation” (p. 519). A recent Canadian study reported age-standardized invasive cervical cancer incidence rates 3.6 times higher for women residing on Manitoba Indian reserves (1984 – 1997) in comparison to rates for non-Aboriginal Manitoba women (Young et al., 2000).

Cervical cancer has been considered a “modern” cancer in Aboriginal/Native American women, the result of rapid social and lifestyles changes (Hildes & Schaefer, as cited in Young et al., 2000). Early age of marriage or first intercourse, high frequency of intercourse, multiple sexual partners, uncircumcised sexual partners, vaginal deliveries, cigarette smoking, low socioeconomic status, urban lifestyle, and Human Papilloma Virus have been identified as risk factors associated with increased incidence of cervical cancer (Strickland, Chrisman, Yallup, Powell & Squeoch, 1996; Steven et al., 2004; Fitch

et al., 1998; Young & Frank, 1983; Young et al., 2000). Higher education or income level were associated with increased likelihood of receiving a Pap test. Gupta, Roos, Walld, Traverse & Dahl (2003) suggested that more highly-educated women may have possessed the attitude, knowledge and resources to “avoid emerging risks and to take advantage of new protective factors” (p. 2086). Yet, in 2002, 8.1% of urban and 10.9% of rural regional First Nations men and women<sup>13</sup> had a junior high education (CHR Population Health, 2003). The 2002 Chinook Health Regional Aboriginal Health Project Needs Assessment also highlighted the growth of First Nations families living below the national poverty line. At higher risk for cervical cancer incidence and mortality, yet with lower education and income levels, the First Nations population is further compromised.

For First Nations women, the loss of women to cervical cancer was especially poignant. “Cervical cancer robs a people of its childbearing women, its mothers, its elders... its hope for survival and the passing on of the culture” (Wisdom of the Elders, as cited in Strickland et al., 1996). Canadian First Nations women also have faced a higher risk for cervical cancer-related death; mortality rates of up to six times higher were reported for First Nations women in comparison to non-First Nations women in British Columbia (BC) (Band et al. 1992 as cited in Hislop, Clarke, Deschamps, Joseph, Band, Smith et al., 1996; Clarke et al., 1998).

Yet cervical cancer is “potentially one of the most preventable cancers” (Fitch et al., 1998, p. 441).<sup>14</sup> “Up to 90% of invasive cervical cancers [can] be prevented [through] regular Pap tests” (Public Health Agency of Canada, 2005a, ¶ 4). While vaccines may

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<sup>13</sup> A convenience sample of 396 male and female First Nations residing in the Chinook Health region.

<sup>14</sup> Initial studies examining cervical screening as a prevention method were conducted in Canada by Clarke & Anderson, 1979. Their case-control study demonstrated a threefold protective effect for the women who had received a Pap smear in the previous 5 years (Fitch et al., 1998).

soon play an important role in primary cancer prevention, currently-available vaccines have offered incomplete protection against all strains of HPV precursor to cervical cancer. Results of long-term efficacy trials were not available at the time of this review. Until comprehensive multivalent vaccines become widely available at a price that women can afford, cervical screening will continue to be conducted as an effective method of reducing cervical cancer incidence and mortality (Dobson, 2006; Foerster & Murtagh, 2005).

Despite the recognized value of cervical screening, Canadian First Nations women have continued to be inadequately screened (Fitch et al., 1998; Hislop et al., 1996; Medd, Wotton & McDonald, as cited in Young & Choi, 1985; Steven et al., 2004). In a study of 4,400 BC Status Indian women (13-59 years), Band et al. (1992) found that 52% had received a Pap test within the past 3 years in comparison to 85% for the general BC population. Similarly, Hislop et al. (1996) reported screening rates of 62% for Vancouver BC First Nations women (18-69 years) in comparison to 84% for the general BC population. Hislop et al. found no significant difference in screening rates for First Nations women residing on-reserve in comparison to their off-reserve counterparts (62%, 62% respectively). In a descriptive multicultural exploratory study including 30 Ojibwa and Oji-Cree women (age 40+ years) from northwestern Ontario, Steven et al. (2004) reported a 33% refusal rate for internal examination (cervical screening) as compared to 0% to 8% for other ethnocultural groups.

Cervical screening programs have been reported to decrease invasive squamous cervical carcinoma incidence and mortality by 75-80% (Anderson, Boyles & Benedet, as cited in Deschamps, Band, Hislop, Clarke, Smith, Ng et al., 1992; Cramer, Petterson,

Bjorkhom & Karnstrom, as cited in Fitch et al., 1998). Yet Fitch et al. (1998) pointed out that screening programs tend to target women of normal risk rather than women of low income, immigrants, and Native women. For First Nations women, the pursuit of health-related activities and services and the likelihood of engaging in cervical screening behaviours were closely linked to personal philosophies of health and wellbeing, and steeped in tradition and culture (Bottorff, Balneaves, Sent, Grewal & Browne, 2001). Steven et al. (2004) stated that First Nations' worldviews of health and wellness, illness, and death are significant factors to be considered when planning strategies that target these cultural groups.

### ***Health and Wellness Philosophies within a Southern Alberta First Nations Context***

Interestingly, the words “health” and “wellness” have no direct translation into the Blackfoot language (Blackfoot elders, as cited by T. Fox, personal communication, May 14, 2006). Instead, Prairie First Nations peoples have viewed health and wellbeing as a gift from the Creator (Letendre, 2002). Health has been viewed as an intricate interrelationship between personal dimensions of health existing in balance, harmony and interdependence with human and natural environments. Similarly, personal health and wellness have been envisioned as an interconnected balance between mind, body, spirit, and emotions (Cardinal et al., 2004; Castellano, 2002; 1996; Clarke et al., 1998; Fox, 2004; Hislop et al., 1996; Huff & Kline, 1999; Saskatoon Aboriginal Women's Health Research Committee, 2004; Strickland et al., 1996; Wilson, 2004) (see Figure 4, Medicine Wheel). This concept of balance has often been represented in the literature by a “Medicine Wheel” (CHR Population Health, 2005a; Calgary Health Region Aboriginal Health Program, 2005). Distinctive to Prairie First Nations peoples, the circular Medicine

Wheel symbol has conveyed the interdependence of people, families, communities and nations with the natural and spiritual order of the universe.

First Nations' perspectives and expectations of health and wellbeing have often been determined by "distinct paradigms or ways of thinking that stand outside of Western thinking" (Dion Stout, n.d.; Saskatoon Aboriginal Women's Health Research Committee, 2004, p. 11). Western medicine has focused on illness, "us[ing] an analytical approach" (LeTendre, 2002, p. 82), and "[offering] a diagnostic and prescriptive method to treat disease" (Saskatoon Aboriginal Women's Health Research Committee, 2004, p. 1). One Treaty 7 Tribal Council leader recently explained to an Alberta provincial advisory group, "The [white man's] system looks at health from a sickness perspective whereas our people look at it from how well you are" (Head, as cited in Cardinal et al., 2004).

Western medicine and traditional medicine also have differed in terms of structure and guiding principles. In contrast to the formal, impersonal service delivery system of Western health care services, traditional First Nations services have traditionally been provided in an informal environment. Healing rituals have often been held out of doors to "connect with the spirits of nature that are felt to be responsible for any powers of healing that the medicine men may have" (Morse et al., as cited in LeTendre, 2002). In contrast to Western medicine, where the patient's history and physical signs and symptoms have been used by the physician to diagnose a problem, traditional medicine has encouraged the patient to identify the problem and need for treatment (Morse et al., as cited in LeTendre, 2002). In Western medicine, interaction with the physician has often been limited. Tasks, such as taking blood pressure and administration of medications or treatment have often been delegated to other healthcare providers. The individual has

often been viewed as divided into body parts, for example, cervix and breast with diagnosis and treatment falling under the purview of many different specialists (Heavy Head, 2005; LeTendre, 2002). In contrast, the traditional healer “[has worked] in close contact with the patient throughout the course of treatment” (Morse et al., as cited in LeTendre, 2002, p. 83). Multiple, holistic strategies have been directed toward mental, physical, spiritual, and emotional elements of a person (LeTendre, 2002).

Power differentials have existed between the two paradigms. In Western medicine, the physician has been placed in a position of authority and power in relation to the patient, in contrast to the partnership approach that has existed in traditional healing treatments and ceremonies. While the doctor or healer has been viewed in both Western and traditional medicine as having healing powers, in traditional medicine “the credit is given to the Creator and the spirit that is called on for healing” (Morse, as cited in LeTendre, 2002).

It is critical to recognize that regular preventive screening is not a familiar concept to Blackfoot people. In contrast, this community accepts that forewarnings of bad things about to happen have been received through dreams<sup>15</sup> (R. Heavy Head, personal communication, May 19, 2006). Unhealthy forces and oppressive effects have been challenged through songs, dreams, prayers, dances, and prophecies (Dion Stout, n.d.; Heavy Head, personal communication, May 19, 2006). In traditional and contemporary Blackfoot culture, ceremonial rituals and sacred bundles have provided an opportunity to connect with the spiritual world and renew health and wellbeing as well as ensure “the survival and health and wellbeing of the community bands, extended

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<sup>15</sup> Dreams of fire or flood often warn of imminent danger (R. Heavy Head, personal communication, May 19, 2006).

families, and individuals” (Crowshoe & Manneschmidt, 2002, p. 19). Crowshoe & Manneschmidt reported (p. 19) that each bundle contains cultural materials that are specific to its function and role. “Animals and natural phenomena (like thunder) have physical representations that are part of the bundle. The abstract elements of the bundles are the songs and prayers that are essential to all ceremonial procedures.” The authors point out that “Sun Dance bundles, Thunder Medicine Pipe bundles, Beaver bundles, various society bundles, and smaller personal bundles” are recognized in Peigan/Blackfoot cultures (p. 19). Bundles are cared for by a man and woman (bundle keepers) who have received “transfer rites” and are knowledgeable in the ceremonial procedures associated with that particular bundle (Crowshoe & Manneschmidt, 2000; R. Heavy Head, personal communication, May 19, 2006).

For the Bloods, the Naotoas bundle (a ‘woman’s bundle’ central to the Sun Dance ceremony) and societal bundles (e.g., Horn and Buffalo Women society bundles or ‘Motokiks’) have continued to play an important role in healing ceremonies, where the emphasis has been on “preventive and general health concerns” (Crowshoe & Manneschmidt, 2002, p. 21; R. Heavy Head, personal communication, May 19, 2006; 2005). The Sun Dance (or Okan), a significant annual Blackfoot ceremony, has served the central function of “re-balancing all misgivings between humans, Creation and the Creator and ...re-establish[ing] harmony beyond earthly considerations” (Crowshoe & Manneschmidt, 2002, p. 21). Harmony with nature and the cosmos have been reflected in the balance between personal and community health. During the ceremony a Blackfoot woman traditionally receives a sacred bundle representing the Sun’s gift to the wife of Morning Star, his son. The power bestowed by the Sun dance bundle and the



sacrifice of the Holy woman “[restores] balance when there [has been] health [problems], when there [has been] a conflict between people themselves or people and the environment, and when there [has been] a lack of buffalo”(Crowshoe & Manneschmidt, 2002, p. 21). While women did not traditionally participate in the Sun Dance or in sweats, this practice has changed in recent years, congruent with the shifting roles that women have taken on (Diane Eaglespeaker, as cited in J. Anderson, 2003).

For the Piikani, the Beaver Bundle has played an important role in health and healing. The contents and opening of the Beaver Bundle (also known as Tobacco Bundles, Water Pipe bundles, or Water Bundles) have strongly emphasized the bundle’s power in “restoring health to the sick or dying.” In the Northern Blackfoot version of the origin of the Beaver Bundle,

a wife goes to a lake and comes back with instructions on how her husband will obtain the Beaver bundle. The Sun and Moon come down to lead the ceremony, and all water creatures are present. The Sun gives the songs to the man, and after four nights of singing, the Beaver bundle is given to the man with instructions to open it in the spring and perform the tobacco planting ceremony. (Crowshoe & Manneschmidt, 2002, p. 22; R. Heavy Head, personal communication, May 19, 2006).

Today, many Blackfoot people continue to go “in the first days of spring and just before winter, to [re-enact the exchange of the bundle] to dance as those animal spirits, restore harmonious social relations, resolve sickness, and escape danger” (Heavy Head, 2005. p. 108).

Society bundles and personal bundles have also played a significant role in health and healing (R. Heavy Head, personal communication, May 19 2006). Society bundles have been unique to highly-structured Blackfoot (primarily Blood) societies. Materials and songs that directed the creation of the bundle were often revealed to a society

member through visions or dreams. In present-day Horn and Buffalo (Motokiks) societies, women have continued to have a strong role and have continued to use these bundles in their ceremonies (Crowshoe & Mannes Schmidt, 2002). Personal bundles, “regarded as sacred and therefore powerful,” have often served as protection from sickness or death. “Smaller objects have often included necklaces, wristlets or buffalo stones, ... specially shaped rocks in animal or human form” (Crowshoe & Mannes Schmidt, 2002, p. 25).

Inherent to the nature of Aboriginal spirituality, these religious practices have also formed the “basis of illness treatments that are specific to traditional medicine” (LeTendre, 2002, p. 81). Sickness and the treatment of illness are the topics of the next section.

### *Perceptions of Sickness, Healing and Death*

Prairie First Nations<sup>16</sup> people have viewed sickness as an “imbalance” between physical, mental, emotional, and spiritual states; sickness has encompassed not only physical imbalances but imbalances such as “getting into trouble” (R. Heavy Head, personal communication, May 19, 2006) or “a loss of one’s sense of self and identity” (Strickland et al., 1996; Wilson, 2004). J. Anderson et al. (2005) have postulated that:

[i]n order to have good health and a good life as Aboriginal people, we have to become secure again with our Aboriginal cultures and selves. If we are alienated from who we are and where we have come from, we experience an intellectual, emotional and spiritual rupture that can make us sick. (p. 5)

In other instances, local First Nations people have viewed sickness as originating from within the community, prompting the individual to seek advice and healing from

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<sup>16</sup> Included are Blood, Piikani, Siksika, Stoney (Bears paw, Chiniki, Wesley), and Tsuu T’ina Nations.

outside of their “home” community (e.g. through nearby Siksika Nation healers) (Heavy Head, personal communication, May 19, 2006).

Perceptions and treatment of sickness and healing have differed between men and women. Knowledge about men’s illnesses and cures has been more explicit, Heavy Head, explained. “If a man believes that he is being pursued by sickness he will initiate a ‘sweat’ where he will take on the ‘good qualities’ of the other persons invited to the sweat (similitude).” In contrast, the unique and direct relationship that Blackfoot women have had with the spirit world has made it unnecessary for them to seek out cures. In contrast to their male counterparts, their bodies have been regularly purified through monthly menstrual (moon) cycles (R. Heavy Head, personal communication, May 19, 2006).

An Alberta Cree author, Dion Stout (n.d.) has described healing for both men and women as “[employing] the power of the Great Spirit and the power of ... ‘medicine’, [to evoke] the wisdom and the strength of living and spirit creatures who have found ways to overcome adversity” (p. 7-8). “Power and medicine do not reside in, nor do they belong to an individual” (Crowshoe & Manneschmidt, 2002, p. 1). Medical practices and healing rituals that bring an individual back to a state of health and wellbeing have continued to be carried out in the community by accepted, culturally trained native healers (CHR Population Health, 2002; Crowshow & Manneschmidt, 2002; Fox, 2004; Heavy Head, 2005; Hungry Wolf, 1996; Huff & Kline, 1999; LeTendre, 2002). Common activities have included prayer, chanting, dancing and drumming rituals, use of paints, purification ceremonies, diagnostic disharmony smudges, physical manipulations and/or prescription of adjunctive botanical medicines or “Asokinakiks.”

Spiritual connections attained through these activities have enabled women to “refocus, gather confidence, anchor themselves and recollect their identities” (Wilson, 2004, p. 18).

Knowledge related to sexual and reproductive health, childbirth, and family planning has traditionally been possessed by older women of the tribe (Hungry Wolf, 1996). An array of herbal teas and over a hundred natural plants were used to influence menstruation and fertility. “Much of the knowledge of traditional healing practice and rituals has gone underground or died out as a result of fear of repression from the church and fear of exploitation” (Anderson & Lawrence, 2003, p. 180). Repercussions of colonialism and historical cultural influences have continued to play an important role in women’s decision-making in relation to sexual health and wellbeing, and, more specifically, to Pap testing.

Other cultural nuances have provided additional insight into Pap testing behaviour from a First Nations’ worldview. Often health providers have promoted preventive care (and cervical screening) as a way of preventing death. Heavy Head, a local Blackfoot anthropologist, explained that the Blackfeet believe that death is “not something to be feared or controlled”; alternately, death is viewed as a natural part of the life cycle (R. Heavey Head, personal communication, May 19, 2006; Strickland et al.1996). Thus the threat of death “cannot be used to motivate First Nations people toward preventive services” (Strickland et al.1996, p. 146). Furthermore, thinking about death is often perceived as “inviting death to come to you” (R. Heavy Head, personal communication, May 19, 2006).

The importance of keeping all body parts intact (e.g., nails and hair) has been a strongly-held Blackfoot belief which has direct relevance to the cervical screening

procedure, where “taking a few cells” may have jeopardized culturally-based principles (R. Heavy Head, personal communication, May 19, 2006; Strickland et al.1996).

Furthermore, anything that has been taken from the body (e.g., cancerous or non-cancerous cells obtained for testing) must be returned back to the earth (R. Heavy Head, personal communication, May 19, 2006). This offering symbolizes the symbiotic and reflexive relationship between the individual and his or her earthly and spiritual environment integral to Blackfoot culture.

Yet diverse cultural and tribal beliefs, values and customs have been embraced by First Nations people and communities. Mihesuah, a Choctaw scholar (2001), stated, “[There] isn’t a single [authoritative voice] among Native women.... Rather, there is a spectrum of multiheritage women, in between ‘traditional’ and ‘progressive’ who possess a multitude of opinions on what it means to be a Native female” (p. 1249). This diversity has been further compounded by rapidly changing demographic and political environments that must be taken into account when planning services for this heterogeneous population. By examining factors that influence First Nations women to participate in cervical screening, the capacity to work together toward meaningful and practical solutions is fostered.

### ***Cervical Screening: Barriers***

Over the past decade, in an attempt to attract women who have never been screened or those who are screened irregularly, many researchers have explored barriers to Pap testing faced by Canadian First Nations women (Bottorff et al., 2001; Browne et al., 2000; Clarke et al.,1998; Deschamps et al., 1992; Fitch et al., 1998; Hislop et al., 1996; Saskatoon Aboriginal Women's Health Research Committee, 2004; Steven et al.,

2004; Strickland et al., 1996; Young et al., 2000). While some barriers have been specific to the health care system and the Pap testing procedure, others have arisen from intergenerational effects of historical events and injustices or have been rooted in broad socio-economic determinants.

### ***Health System Barriers to Cervical Screening***

In one Saskatchewan study, First Nations women pointed out that service agencies lacked a coordinated approach, sometimes working “against each other” (Saskatoon Aboriginal Women's Health Research Committee, 2004, p. 17). Bottorff et al. (2001) found that rather than provide holistic women’s care, services at a British Columbia clinic were “limited to cervical and breast screening, in part, to gain support and patient referral from community physicians” (p. 31). While politically astute, this approach has been inconsistent with fundamental cultural philosophies which have promoted a comprehensive and holistic understanding of the woman as a person and member of the family and community (Bottorff et al., 2001; Clarke et al., 1998; Fitch et al., 1998; Steven et al., 2004). In several studies, First Nations women expressed concerns regarding access to Pap testing services (e.g., location and hours of operation), and confidentiality (Fitch et al., 1998; Saskatoon Aboriginal Women's Health Research Committee, 2004; Strickland et al., 1996). First Nations women in one Northern British Columbia community reported feeling marginalized from mainstream health care services (Browne, Fiske & Thomas, 2000). Feelings of marginalization reported by Browne et al. may have been due, in part, to the gaps in health care services provided to Aboriginal people identified by the Royal Commission on Aboriginal Peoples in 1996:

First, urban Aboriginal people do not receive the same level of services and benefits that First Nations people living on-reserve obtain from the federal government.... Second, urban Aboriginal people often have difficulty gaining access to provincial programs available to other residents.... Third, ... [First Nations] would like access to culturally appropriate programs that would meet their needs more effectively. (p. 538)

### ***Cultural Barriers to Cervical Screening***

In addition to health system barriers, First Nations women often faced overwhelming cultural barriers to cervical screening including lack of respect and insensitivity to cultural beliefs and traditions within the current health care system (Browne et al., 2000; Clarke et al., 1998; Wilson, 2004; Young et al., 2000). Health care settings have often been identified as being devoid of cultural influence, lack “warmth” or are situated in unsafe neighbourhoods (Clarke et al., 1998). Health care employees may be prejudiced toward people of First Nations ethnicity; opportunities for meaningful, well-paid employment may be limited (Balls Organista, Chun & Martin, 2000, Browne et al. 2000, Dion Stout, n.d.; Jayarman, 2000, Smylie, 2001). In one British Columbia study, First Nations women new to the city often did not know where to go for Pap testing or did not know which doctors were receptive to First Nations clients (Clarke et al., 1998). Many First Nations women avoided seeking encounters with health care providers beyond essential (acute) care due to marginalization and insensitive, sometimes discriminatory, attitudes (Browne et al., 2000; Bottorff et al., 2001; Clarke et al., 1998).

Outside of the acute care setting, busy physician practices have often bustled with frenetic activity, long waits and short appointment times. Limited time has been allotted for establishing relationships with patients (Fitch et al., 1998; Bottorff et al., 2001). This has sharply contrasted the slower-paced, informal, story-telling approach familiar and comfortable to First Nations people. Trust-building and continuity have

been further challenged by the tendency for urban First Nations people to be transient with infrequent health care contacts and high rates of physician turnover (Bottorff et al., 2001; Clarke et al., 1998; Hanselmann, 2001).

### ***Knowledge Barriers to Cervical Screening***

Several studies revealed a general lack of information about cervical screening among First Nations women (Fitch et al., 1998; Young et al., 2000). Silenced by embarrassment or shyness, and reluctant to ask questions of health care professionals, many women turned to family or friends for information (Deschamps et al., 1992; Fitch et al., 1998). Responses by health care professionals to their questions were often mired in complex medical terminology or lost through information “overload.” Family and friends may have lacked accurate information. As a result, misconceptions have thrived. For example, people often associated Pap screening with sexually transmitted diseases, believed Pap testing to be a prerequisite to obtaining birth control, or thought that testing was necessary only for young people (Deschamps et al., 1992; Fitch et al., 1998; Strickland et al., 1996). Lost on many people were the basic tenets of Pap screening – the purpose of the test, how often it should have been done, where testing was available, and what test results meant (Deschamps et al., 1992; Fitch et al., 1998; Hislop et al., 1996; Saskatoon Aboriginal Women's Health Research Committee, 2004; Steven et al., 2004).

Yet knowledge, in isolation, has been shown to be an insufficient incentive to promote Pap testing. Hislop et al. (1996) reported that many Canadian First Nations women lacked the motivation or desire to have Pap testing done. Many procrastinated, not realizing their increased risk for cervical cancer or the benefit of Pap testing (Centers for Disease Control and Prevention, 1998; Fitch et al., 1998). For many Aboriginals,



screening may have been viewed as merely “looking for trouble,” or “[inviting] the cancer spirit to enter one’s body” (Burhansstipanov, 2000, p. 31), or simply too time-consuming (Fitch et al., 1998). In a qualitative study with Ontario First Nations women, Fitch et al. (1998) found that most older First Nations women attributed their lack of screening to their physician not “recommending it” (p. 442). For others, the procedure itself was a significant barrier.

### ***Procedural Barriers to Cervical Screening***

As well as being physically uncomfortable and conversationally awkward, many First Nations women described the Pap testing experience as “psychologically” stressful - an invasion of personal privacy (Browne et al., 2000; Clarke et al., 1998; Deschamps et al., 1992; Fitch et al., 1998; Hislop et al., 1996; Steven et al., 2004). In a comparative study of several ethno-cultural groups in northwestern Ontario, Steven et al. (2004) reported that the Ojibwa and Oji-Cree “women were much more likely [than Finnish, Italian, and Ukrainian women] to mention feelings of having their privacy violated and of being shy about having a physician examine them” (p. 309). Women felt embarrassed, powerless, vulnerable, and occasionally angry. Pap takers may have been insensitive to the discomfort of the procedure (J. Kinch, personal communication, October 19, 2006). Many women expressed fear that sexual history or abuse might be exposed (Fitch et al., 1998). Others were afraid of being diagnosed with cancer or a sexually transmitted disease (Clarke et al., 1998; Hislop et al., 1996; Strickland et al., 1996).

Many women expressed discomfort at having male Pap takers (Clarke et al., 1998; Fitch et al., 1998; Hislop et al., 1996; Strickland et al., 1996). For some, recollections of past dealings with white society (e.g., residential schools, or social

service interventions including child apprehension) have resulted in low self-esteem, lack of self-confidence and generalized mistrust of the health care system<sup>17</sup> (Bottorff et al., 2001). Yet other women faced even more basic challenges impacting their use of cervical screening services.

### ***Socio-economic Barriers to Cervical Screening***

Many First Nations women lived in poverty and isolation where “meeting basic needs for an adequate income, food, housing, and child support often [took] priority over preventive health care, such as Pap testing” (Bottorff et al., 2001, p. 39). Browne et al. (2000) found that First Nations women in Northern British Columbia felt that personal circumstances (in particular socio-economic circumstances) were often disregarded. Paradoxically, Burhansstipanov et al. (2000) reported no increase in screening participation when poverty-related barriers (e.g. childcare, transportation, and cost) were addressed. This poses a dilemma. How can we better meet the needs of these women? Gupta et al. (2003) stated:

Differences in knowledge and resources have their largest effects when the health care system is passive; ... (when individuals are charged with sole responsibility for accessing preventive care). In contrast, active system-preventive care programs in which society assumes part of the burden of activity for prevention and early detection – hold the potential to increase population coverage rates and minimize socioeconomic disparities. Unlike passive screening, an active program includes recruitment, recall and follow-up, quality assurance and quality control, and evaluation of program performance and outcomes. (p. 2086)

An active approach requires examining factors that have been shown to positively influence health behaviours of First Nations women.

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<sup>17</sup> In a 2001 British Columbia cervical screening study, one key informant commented: [Some First Nations women are] very, very fearful and they are really scared of being traced. And going into a Pap test clinic you have to give a lot of information and there are women who would stay away from a setting such as that simply because they don't want to be found (Bottorff et al., 2001, p. 39).

*Strategies to Address Barriers*

Within the context of qualitative or mixed-method evidence, First Nations women have offered reflections on factors that positively influence Pap testing within their communities. Canadian First Nations women commented on the need for clearly presented information about Pap testing, including the purpose and how the testing is done. While most women recommended a “culturally sensitive” approach, mixed opinions were expressed as to who should provide this information (Strickland et al., 1996). The women stressed that information must be targeted to a potentially diverse audience. While educating the younger women in their community was seen as important, little mention was made of the relevance or importance of Pap testing for older women (Young et al., 2000).

First Nations women recommended that Pap testing visits be paced to allow sufficient time for clear explanations and questions to be posed. For women with limited English fluency, the women suggested that allotted time must allow for translation. In published literature there was limited acknowledgement of the divergent (and often culturally influenced) communication styles that could have potentially impacted visit timing (e.g., storytelling).

Effective communication, enhanced by positive, long-term relationships between the women and cervical screening personnel, was seen as paramount. Women commented on the importance of holistic, personalized care, and active listening within a context of respect, trust, and caring (Bottorff et al., 2001; Browne et al., 2000; Clarke et al., 1998; Fitch et al., 1998; Hislop et al., 1996). Many women commented on the importance of choice regarding who would perform the Pap testing (e.g., female gender,

ethnicity or membership in their community) and availability of a support person (Clarke et al., 1998). Others stressed the importance of active participation in health care and policy decisions (Browne et al., 2000).

Canadian First Nations women valued cervical screening program support for connecting them with the mainstream health care system (e.g., through community health providers), initiating discussions related to women's health and/or cervical cancer, and interpreting and responding to abnormal test results (Clarke et al., 1998; Saskatoon Aboriginal Women's Health Research Committee, 2004). First Nations respondents suggested that Elders, healers, and Medicine women and men work in conjunction with mainstream medical healthcare (Saskatoon Aboriginal Women's Health Research Committee, 2004). For most women, a strong sense of cultural identity, involvement of Elders and heads of households, strengthening mother-daughter relationships and practicing the First Nations way of life were seen as integral to promoting First Nations health (Browne et al., 2000; Clarke et al., 1998; Hislop et al., 1996; Strickland et al. 1996). Yet few of these anecdotal health promotion strategies have been tested through well-designed quantitative research studies.

It is clear that "cultural beliefs, attitudes and practices are important considerations when addressing barriers to effective First Nations breast and cervical screening" (Steven et al. 2004, p. 305). Health promotion strategies evidenced to be effective in reaching underserved populations have included the involvement of community members in delivering interventions and building capacity (Hancock et al. as cited in Oelke, 2002; Ramirez et al., as cited in Oelke, 2002), providing culturally sensitive videos (Yancey, Tanjasiri, Klein & Tunder as cited in Oelke, 2002; Yancey and

Walden, as cited in Oelke, 2002) and using TV celebrity ads and physician letters of invitation (Byles, Sanson-Fischer, Redman, Dickinson, and Halpin, as cited in Oelke, 2002).

Limited, yet mounting evidence has been found for utilizing lay community workers (Dignan et al., as cited in Oelke, 2002; Messer, Steckler, Dignan, as cited in Oelke, 2002; Lewin et al. 2005; Christopher, 2005; Fiske, personal communication, September 14, 2005), offering Pap testing to inpatients or to all women undergoing diagnostic pelvic exams in emergency room settings (Engelstad et al., as cited in Oelke, 2002), and conducting Native talking circles (Hodge, Fredericks, Rodriguez, as cited in Oelke, 2002).

The effectiveness of multiple strategies (including education, on-site screening, follow-up, community speakers, letters of invitation, home visits, phone-call reminders, and female Pap-takers) showed promise in some research (Holschneider et al., as cited in Oelke, 2002; White, Fishman, Guthrie & Fagan, as cited in Oelke, 2002; Calam, Norgrove, Brown & Wilson, as cited in Oelke 2002; Project WWSCH Well Women's Evaluation Report, as cited in Oelke, 2002), yet appeared to be ineffective in others (Bottorff et al. 2001; Dignan, Michielutte, Wells & Bahnson, as cited in Oelke, 2002; Michielutte et al., as cited in Oelke, 2002). The extent to which individual activities and strategies documented in the literature actually contributed to increased screening rates for First Nations women has often been unclear. Ongoing evaluation research is critical to ensuring the best use of limited health care resources.

### *Summary*

While factors instrumental in influencing cervical screening have been explored with First Nations women residing in other Canadian provinces and with international Aboriginal populations, information representing the unique needs of First Nations women in Southern Alberta has been limited. Diversity among tribes may have limited the generalization of previous studies to regional First Nations women. Few studies have explored the changing needs, attitudes, and health promotion challenges faced by First Nations women as they move from reserve to non-reserve settings. These gaps have been addressed within the current study.

Chapter 3 outlines the ethnographic, participatory approach used to frame this qualitative study and explore cervical screening from the diverse perspectives held by First Nations women. This approach required bracketing (or setting aside what was already known personally and from the literature about the phenomenon of interest) in order to allow concepts to emerge from the data (Morse & Richards, 2002). It also has exemplified the respectful approach that has served as a catalyst for meaningful change.

Culture is not simply a cognitive map that people acquire, in whole or in part, more or less accurately, and then learn to read. People are not just map-readers; they are map makers. People are cast out into imperfectly charted, continually shifting seas of everyday life. Mapping them out is a constant process resulting not in an individual cognitive map, but in a whole chart case of rough, improvised, continually revised sketch maps. Culture does not provide a cognitive map, but rather a set of principles for map making and navigation. Different cultures are like different schools of navigation designed to cope with different terrains and seas.

Frank, C.O. (1977). Plying frames can be dangerous: Some reflections on the methodology in cognitive anthropology.

The vital and difficult truth is that everything is related in one way or another to everything else. It's what makes the practice so challenging. It's also what gives it such great promise.

A.G. Johnson. (1997). The forest and the trees: Sociology as life, practice & promise.

## Chapter 3

### Research Design and Methodology

Little published information about cervical screening for Alberta First Nations women exists. Even more elusive is information about preventive health practices of Alberta First Nations women living off reserve. Hampered by a lack of consistent, provincial, race-specific information regarding health seeking behaviours (e.g., Pap testing), we know anecdotally that First Nations women seldom access regional cervical screening services. Regional clinic attendance by this ethnic group is inconsistent with the ethnic makeup of the region; 7.3% of regional population is registered First Nations living on reserves, yet few First Nations attend the regional cervical screening clinic or have Pap tests processed by the regional laboratory.

Several Canadian studies have explored incentives and barriers to cervical screening as perceived by First Nations women (Botorff et al., 2001; Browne et al., 2000; Clarke et al., 1998; Fitch et al., 1998; Hislop et al. 1996; Saskatoon Aboriginal Women's Health Research Committee, 2004; Steven et al., 2004; Wilson, 2004; Young et al., 2000). Yet it is important to acknowledge the diversity of First Nations cultures and beliefs; we cannot assume that the existing literature reflects the unique perceptions of First Nations women living off-reserve in the Chinook Health region in southern Alberta (Clarke et al., 1998). We also cannot assume that the needs of First Nations women living on-reserve mirror those of women transitioning to or living off-reserve. The need for information that reflects the perception of Southern Alberta First Nations that "goes beyond the numbers" is readily apparent (Mayan, 2001, p. 6).



This chapter focuses on the research design and implementation. I examine underlying theoretical and personal perspectives and assumptions, and explore the research strategies guiding the research method and design (Creswell, 2003; Cushing, as cited in Kalischuk, 1999). Secondly, theoretical sampling and sample selection (along with consent and ethical considerations) are addressed. Finally, I discuss the collection, management and analysis of the data with a focus on establishing scientific rigor.

### ***Philosophical and Theoretical Perspectives and Assumptions***

The researcher always approaches a study with a particular philosophy or set beliefs, which, according to a naturalistic perspective, are both “inevitable and desirable” (Polit, Beck & Hungler, 2001, p. 13). Philosophical stance is generally concerned with the search for meaning. It embraces theoretical knowledge, informs the theoretical perspective and determines the “what” and “how” of scientific enquiry (Creswell, 2003; Gortner, as cited in Kalischuk, 1999).

Polit et al. (2001) describe four concepts underlying theoretical stance: 1. *ontology* (What is the nature of reality?), 2. *epistemology* (How is the inquiry related to those being researched?), 3. *axiology* (What is the role of values in the inquiry?) and 4. *methodology* (How is the knowledge obtained?). Kalischuk (1999) states, “The way in which knowledge is gained is directly related to the paradigm perspective adopted by the researcher and the corresponding ontological and epistemological claims” (p. 36). In this chapter, I present the philosophical and theoretical stances that underlie this research study in relation to these core concepts (ontology, epistemology, axiology and methodology) and explore my personal situatedness and values in relation to this inquiry.

## ***Ontology***

Ontology addresses the *nature of reality* for the researcher (Creswell, 1998; Polit, Beck & Hungler, 2002). Creswell states that “multiple realities exist...including the realities of the researcher, those of individuals being investigated, and those of the reader or audience interpreting the study” (p. 76). He goes on to state, “[t]he qualitative researcher needs to report on these realities.” Accordingly, I will describe aspects of my personal reality pertinent to this research study.

### ***Personal philosophical stance.***

While many philosophies informed this research (e.g. postpositivism, postmodernism, poststructuralism, constructivism and critical theory), my research views, and those of the research participants, primarily reflect a constructivist paradigm. In other words, I believe that “facts and principles are inextricably embedded within a particular historical and cultural setting” (Tinkle & Beaton, as cited in Kalischuk, 1999). I ascribe to the philosophy that multiple forms of truth are valid and that the ethnographer can make efforts to “establish identification between the observer and the observed” (Denzin & Lincoln, p. 328). Fundamental to my approach is the view that “reality” is a social construct developed through co-created, shared meaning (Denizen & Lincoln, 2000; Sandelowski, 2000; Morgan & Stewart, 2002). I believe that reality can be understood only through the perspective of the persons involved, that realities vary from “group to group” and “place to place,” and that they can be “constructed and re-constructed by individuals during the course of their lifetime” (Kalischuk, 1999, p. 37; Rubin & Rubin, 1995, p. 35). For example, I believe that the worldviews of First Nations women are recreated as they relocate from reserves to urban settings, and that their realities are

influenced by their situatedness in “life’s journey” (Strickland, Squeoch, & Chrisman, 1999). While my views are consistent with those of the critical theorists (I believe that First Nations women’s perspectives are influenced by “social, political, cultural, economic, ethnic, and gender values”), (Guba & Lincoln, in Denzin & Lincoln, 2005, p.193), the perception that values are “crystallized over time” differs from my own view that values are continually constructed and co-constructed. (Guba & Lincoln, in Denzin & Lincoln, 2005, p.193)

***Theoretical framework.***

Prior to and throughout the course of my research, I continued to search the literature for existing comprehensive theoretical frameworks. While a specific theoretical framework did not frame the study design, my preliminary review of the literature provided the underpinnings for theoretical sampling, promoted congruency between the “methodological claims and research method and questions asked,” and presented a contextual awareness of existing knowledge that would allow for the comparison of emerging concepts to existing theory (Morse, personal communication, August 6, 2004; Siegel, as cited in Kalischuk, 1999). To allow concepts to emerge from the data required this previous knowledge to be placed aside, or “bracketed” to allow for encounters to be “fresh...and describe[d] precisely as it is perceived”(Giorgi, as cited in Morse & Richards, 2002).

Foundational to the theoretical frameworks that underlie this study, I believe that culture interconnects with a wide range of social factors to influence and determine the health status of the First Nations people. Within the population health literature, these influences are known as the “determinants of health.” In addition to culture, the

determinants include income and social status, social support networks, education, employment and working conditions, physical environments, biology and genetic endowments, personal health practices and coping skills, healthy child development, and health services (Applied Research & Analysis Directorate, 2004; Barnett, White, & Horne, 2002; Cardinal et al., 2004; CHR Population Health, 2005b; Deiter & Otway, 2001; Health Canada First Nations & Inuit Health Branch, 2003; Gillies, 1998; Meadows, Thurston & Berenson, 2001; National Aboriginal Health Organization, 2001; National Coordinating Group on Health Care Reform and Women, 2003; Public Health Agency of Canada, 2003; Raphael, 2005; Romanow, 2002; Thurston & O'Conner, 2005; Wilson, 2004). While the purpose of this study is not to explore each of these determinants, this philosophical framework highlights the fact that health challenges faced by First Nations women are often fundamentally linked to larger social issues, demanding a collaborative, intersectoral approach to improving health and health-related issues.

***Theoretical stance.***

Three theoretical frameworks that reflect my theoretical stance include:

1. the *Health Promotion Model* (Pender, Murdaugh, & Parsons, 2002) ,
2. the *Model for Understanding Native Cultural Group Identity and Behaviour Patterns* (National Native Association of Treatment Directors, 1989, as cited in NECHI, 2005), and
3. the *Healing Journey Model* (Connors, 2000, as cited in NECHI, 2005) (see Figures 5-7).

Each of these theoretical frameworks is summarized below:

1. The *Health Promotion Model* (Pender et al., 2002).

Pender (2005) describes the health promotion model as a “new direction in health care...in which health promotion and disease prevention are the “primary focus” in health care... with care in illness becoming a priority (only after health promotion and disease prevention strategies) fail to prevent problems” (Pender, 2005a, ¶8). Pender’s theoretical model examines the interaction between individual characteristics and experiences, and behaviour-specific cognitions and affect. These precursors ultimately determine behavioural outcomes.

The model is based on the following theoretical propositions:

1. Prior behaviour and inherited and acquired characteristics influence beliefs, affect, and enactment of health-promoting behaviour.
2. Persons commit to engaging in behaviours from which they anticipate deriving personally valued benefits.
3. Perceived barriers can constrain commitment to action, a mediator of behaviour as well as actual behaviour.
4. Perceived competence or self-efficacy to execute a given behaviour increases the likelihood of commitment to action and actual performance of the behaviour.
5. Greater perceived self-efficacy results in fewer perceived barriers to specific health behaviour.
6. Positive affect toward a behaviour results in greater perceived self-efficacy, which can in turn, result in increased positive affect.
7. When positive emotions or affect are associated with behaviour, the probability of commitment and action is increased.
8. Persons are more likely to commit to and engage in health-promoting behaviours when significant others model the behaviour, expect the behaviour to occur, and provide assistance and support to enable the behaviour.
9. Families, peers, and health care providers are important sources of interpersonal influence that can increase or decrease commitment to and engagement in health promoting behaviour.
10. Situational influences in the external environment can increase or decrease commitment to or participation in health-promoting behaviour.
11. The greater the commitment to a specific plan of action, the more likely health promoting behaviours will be maintained over time.

12. Commitment to a plan of action is less likely to result in the desired behaviour when competing demands over which persons have little control require immediate attention.
13. Commitment to a plan of action is less likely to result in the desired behaviour when other actions are more attractive and thus preferred over the target behaviour.
14. Persons can modify cognitions, affect, and the interpersonal and physician environment to create incentives for health actions (Pender, Murdaugh, & Parsons, as cited by Pender, 2005c, p. 1-2).

Frequently cited in nursing research, Pender's theoretical framework highlights the importance of gaining an insiders view and involving the community in health promotion endeavours (Polit et al., 2001).

While this model acknowledges culture as an influence on health behaviour, cultural worldview and history (concepts integral to my theoretical stance) are not explicitly recognized. This perspective is foundational to the two models shared by a Wolfleg, a First Nations elder at a Southern Alberta cultural awareness conference. Consistent with a constructivist paradigm, these models highlight the changing face of reality experienced by First Nations people (NECHI Training, Research & Health Promotions Institute, 2005).

2. *The Model for Understanding Native Cultural Group Identity and Behaviour Patterns* (National Native Association of Treatment Directors, as cited in NECHI Training, Research & Health Promotions Institute, 2005).

This theoretical model explores First Nations worldview as a continuum of perspectives from "new traditionalists... embracing traditional cultural values" to "assimilated Indians... Indians that don't want to be Indian" (National Native Association of Treatment Directors, as cited in NECHI Training, Research & Health Promotions Institute, 2005; B. Wolfleg, personal communication, Sept. 21, 2005).

According to Wolfleg (2005), central on this continuum (and most desirable) is the “International Human being” who is healthy, values his/her own culture without putting down other cultures, and appreciates the gifts of both First Nations and non-First Nations worlds. Wolfleg commented that consistent with an International worldview, he “has his feet in two canoes,” living on a Southern Alberta First Nations reserve and working off-reserve as a mediator for the justice department. While NECHI endorses this model for the promotion of cultural awareness, Wolfleg acknowledges that this model is not universally accepted by all First Nations. This lack of acceptance may be related to the heterogeneity between individuals (versus group identity and behaviour) or to a lack of awareness or acknowledgement of the philosophical differences that exist among and between First Nations individuals.

3. *The Healing Journey Model* (Connors, as cited by the NECHI Training, Research & Health Promotions Institute, 2005)

The healing journey model represents the journey of healing faced by First Nations people in relation to historical events and cross-cultural contact. It portrays the cross-generational impact of exposure to the dominant culture and goes on to present reclaiming of traditional culture, redeveloping healthy relationships and lifestyles, and building on the “best of the past” as part of the healing process (Connors, as cited in NECHI Training, Research & Health Promotions Institute, 2005). Building upon the theoretical underpinnings of this study, I would play a significant role in identifying, interpreting and analyzing the culture under study as an instrument of research.

### *Epistemology*

Epistemological assumptions examine the relationship between the inquiry and the researcher. My role as a participant and investigator provided me with the ability to explore culture (including values, and the affective and subjective nature of the data) and gave me the opportunity to reflexively and collectively (in partnership with the research team and participants) contribute to the First Nations community.

Mihesuah, a Choctaw American Indian author (2001), cautions that writing and research about Aboriginal women by non-Aboriginals must necessarily promote appreciation for women's heterogeneity and sensitivity in relation to "researching, interpreting, and formulating ideas about 'others'" (p. 1247). The critical emic (or insider) perspective of reality provided by the First Nations participants and research team members, together with the etic (outsider) perspective of the researcher and research assistant, provided the opportunity for examining personal perceptions and fostered shared interpretation and understanding. "Both (insider and outside) views are important ...and necessary if the ethnographer is to understand and accurately describe situations and behaviours...and develop conceptual or theoretical interpretations" (Boyle, 2001, p. 166). Over the course of the research study, the exposure of the research team members to First Nations cultural worldviews increased, "minimizing the distance" (Guba & Lincoln, as cited in Creswell, 1998) between those being researched and the non-First Nations team members. First Nations team members also examined their cultural worldview in light of alternate First Nations worldviews. This, in turn, fostered trust between the research team and participants, promoted shared meaning and catalyzed a practical, participatory approach (Denzin & Lincoln, 2005).



### ***Axiology***

Axiological assumptions examine the role of values in an inquiry (Creswell, 1998; Polit et al., 2001). Consequently, the researcher is obliged to acknowledge how his or her values might shape the enquiry (Creswell, 1998; Lincoln & Guba, 1985, as cited in Kalischuk, 1999; Patton, as cited in Mayan, 2001).

Any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity. There are no objective observations, only observations socially situated in the worlds of the observer and the observed. (Denzin & Lincoln, 2000, p. 5)

Despite the best of intentions to accurately represent participant stories, the researcher becomes implicated in the interpretation of meaning, particularly where the topic of discussion is personal and value-laden (Kalischuk, 1999). In response, I will discuss my personal situatedness as a researcher.

### ***Personal situatedness.***

I am a white, middle-class woman and mother of three grown children. Over the past thirty years, I have combined the traditional female role of homemaker with that of nurse within the hospital, community and home care settings, business entrepreneur and nurse educator. I currently work as health care analyst for the Chinook Health Family Health Program. Similar to many of the First Nations women interviewed, I have lived, for a time, as a single mother and provider for three young children with limited personal income.

My interest in First Nations cultures was piqued at an early age, when my parents revealed that early in their marriage they had contemplated adopting a young First Nations youth. My mother, in particular, always spoke with empathy regarding the

plight of First Nations families in the Northern Saskatchewan town where she resided. I grew up drawing pictures of Aboriginal children and have always had a thirst to learn more about First Nations cultures and “ways of knowing”. In a place of honour in my home I have pictures of four young Aboriginal children. Yet, in reality, I knew little about this cultural group. I struggled with the dichotomy of seeing unkempt or inebriated Aboriginals wandering the streets juxtaposed with my innate perception of a misunderstood, genuine and gentle ethnic group. I wanted to learn more.

The opportunity to study about First Nations people came when I was asked to initiate a program evaluation study involving unserved and underserved women at the CH Breast/Cervical Clinic. My key assumption prior to this study was that First Nations women living off reserve could provide valuable insight into the needs of the on-reserve and off-reserve First Nations community. I believed that, given the opportunity, the women might share their personal perceptions of health values, beliefs, and practices. I believed that many First Nations beliefs are derived from their culture and that these beliefs vary between and within cultures. I was aware of the powerful influence of social and political environments on health and healthcare and recognized that cultural stereotyping occurs within the health care system and broader community. I believed that “through the use of focused questions, the facilitator can help people recall relevant information” (Lederman, as cited in McDaniel & Bach, 1996). Ultimately, I believed that culture-specific and universal care practices could be identified and used as a basis for nursing care practices.

***First Nations values and the research process.***

The research process was also guided by First Nations values and beliefs formalized through principles commonly embraced by Aboriginal researchers (Saskatoon Aboriginal Health Research Committee, 2004) including:

1. The communality of knowledge and reciprocity. This principle reminds us that as researchers, we are the interpreters, - not the originators or owners – of knowledge. It states that research findings must be relevant, useful, and accessible to the communities that are involved in our research.
2. The acknowledgement of spiritual connections. This principle reminds us that we should make every attempt to respect and adhere to personal, local and community protocols throughout the research process.
3. Relation accountability. This principle reminds us that, as researchers, we are accountable for the process and outcome of our project.
4. Holism. This principle reminds us that the concept of holism should be incorporated throughout the research process, from design to final report. (S. Wilson, as cited in A. Wilson, 2004)

***Methodology***

Methodology of a study refers to how the knowledge is obtained, the “conceptualization of the research process” (Creswell, 1998, p. 76). A qualitative focused ethnography methodology was the primary method selected to present the lived experiences and meanings the First Nations women give to them. (Benoit et al., 2003; Olsen, 2005). These methods and their inter-relationship are described below.

***Focused ethnography.***

Ethnography is a powerful means by which to achieve “extremely rich and comprehensive data about people, places, symbols, rituals and patterns within a specified time and place. [The researcher is provided with the opportunity] to enter the world of the informants to obtain their recurrent and familiar world view meaning, attitudes and lifeways” (Leininger, 1985, p. 35). More than the study of people within a cultural group,

“the essential core of ethnography is the concern with the meanings of actions and events to the people [we] are trying to understand” (Spradley, as cited in Streubert & Carpetner, 1995).

Ethnography can “take different forms, depending upon the type of research question, the research scope and the researcher perspective” (Morse & Richards, 2002, p.53). In traditional ethnography, emic data (e.g., perceptions, knowledge and language) is rigorously and systematically studied and classified in order to grasp the persons’ inside view about a specific phenomenon. Ethnography reflects a comprehensive, full-scale study of general and particular features of a designated culture, including language, kinship, social structure, worldview, values and environmental factors. The culture is unfamiliar to the researcher and may focus on a single setting. Generally the study takes place over a considerable period of time (e.g., greater than a year) (Morse & Richards, 2002), with “results often reported in book form” (Leininger, 1985, p. 38).

In contrast, focused ethnography is narrower and more specific in focus. “Instead of applying ethnographic methods to the study of an entire culture, the ethnographic, holistic approach is used to describe a social unit or isolatable human group” (Werner and Schoepfle, in Boyle, 1994, p. 172). In focused ethnography, the “topic is specific and may be identified before the researcher commences the study” (Morse & Field, 2002, p. 53). The target population is often a small sub-group of a specific social group with a smaller number of informants involved. In comparison to a full-scale ethnography, the observation period is shorter and the contextual description less comprehensive. The researcher gives attention to the general lifeways of the people living in their specific environment (Higgins & Demerth, 1999; Wright, 2002;

Leininger, 1985; Streubert & Carpenter, 1995). Focused ethnographies “help us to understand the cultural rules, norms, and values and how they are related to health and illness behaviour. They often are used to generate descriptive theories about phenomena of interest” (Boyle, 2001, p. 172).

Focused ethnography is well suited to the goals of health care studies where the richness of entering and studying the real world of people is desired, yet the time for long-term field studies is not available (Boyle, 2001; Leinger, 1985). Accordingly, a focused ethnography approach was deemed the most pragmatic approach to address cervical screening practices of First Nations women living off reserve.

Cervical screening utilization patterns of off-reserve CH First Nations women can only be understood within the context of First Nation’s meaning and purpose. The focused ethnography would “provide the understanding of the (observed) behaviours, including ‘why’ and ‘under what circumstances’ Pap testing services are or are not being accessed” (Boyle, 2001, p. 162). Perhaps the most valued aspect of the focused ethnography approach lies in the “pragmatic outcomes for both theory and practice” (Boyle, 2001, p. 169).

### ***Data collection and procedures.***

The focus group technique is “well-suited” to gather information for ethnographic studies (Carey & Smith, 1994; Gray-Vickery, as cited in Morse & Richards, 2002; Hollander, 2004; McDaniel & Bach, 1996; Morse & Richards, 2002).<sup>18</sup> The format of the focus group resembles traditional First Nations “healing circles” and allows the opportunity to nurture traditional story-telling. In addition, the focus group process

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<sup>18</sup> Hollander (2004) describes the focus group as a research “site” – a place to observe the processes of social interaction, rather than a research tool or strategy (p. 630).

reflects the Aboriginal research principles of the communality of knowledge (in that focus group researchers interpret knowledge that is presented to them by or originates with the group participants) and relational accountability (in that the researchers are not directly in control of the contributions participant make, but instead, must be accountable for creating and preserving a space in which participants can share knowledge. (Wilson & Sarson, as cited in Wilson, 2004)

Strengths of the focus group as a data collection strategy include: convenience (Morgan, 1998), reduced participant pressure (or experimenter demand) (McDaniel & Bach, 1996), and enhanced access to data (Carey & Smith, 1994; Morgan, 1998; Webb & Kevern, 2001; McDaniel & Bach, 1996). Because the format of a focus group is a social setting, conversations may mirror those that participants might have in their daily lives, enhancing candour and spontaneity (Carey & Smith, 1994; Kitzinger, 1994) stimulating memory, and providing a sense of community (Hollander, 2004). At the same time, group pressure may actually discourage participants from providing inaccurate or misleading information (McDaniel & Bach, 1996; Morgan, as cited in Hollander, 2004). Depending on their composition, groups can facilitate the discussion of otherwise “taboo” or sensitive topics (Affonso, as cited in Goss, 1998; Hollander, 2004; Webb & Kevern, 2001). Others caution that personal disclosure may be inhibited, particularly if the participants’ perception of safety, comfort or presentation of self is threatened (Welling, Brandigan & Mitchell, as cited in Hollander, 2004; Mansell et al., 2004).

In preparation for the focus group, I voiced my fears that the women would feel constrained and reluctant to speak up about this potentially sensitive topic within a group setting. My First Nations co-worker, amused and aware of the congenial and social nature of the invited focus group participants, assured me that it was more likely that I would

face the problem of having to find ways to have the women stop talking! (T. Fox, personal communication, September, 2004)

Attitudes, decision-making, participant roles and organization are inherently unobservable (Morgan, 1998; Hollander, 2004); other behaviours (e.g., the Pap testing procedure) are too private to offer opportunities for meaningful observation (Morgan, 1998). Within the focus group format, researchers are provided with an opportunity to directly observe similarities and differences in opinions and experiences, non-verbal responses and group interaction. Researchers may also stimulate exploration and clarification of individual assumptions and points of view and facilitate collaborative construction of meaning or performance (Morgan, 1998; Polit & Hungler, 1995; Stewart & Shamdawani, as cited in Esser-Stuart & Lyons, 2002).

Focus groups have been criticized for providing an “unnatural social setting” (Morgan, 1998) or for influences that may be exerted by the group or group moderator, including pressures to conform, “group think”, social desirability, censoring, and data polarization (Carey & Smith, 1994; Hollander, 2004; McDaniel & Bach, 1996; Morgan, 1998). The ability to obtain in-depth data or data over time may be limited; small sample sizes may limit the generalizations that can be made to larger groups (McDaniel & Bach, 1996). Ultimately, it may be impossible to determine the validity of self-reported data (Morgan, 1998). Despite recognized limitations of this method, I anticipated that the focus groups approach would be logistically and culturally appropriate with the potential to provide a rich, rapid source of naturalistic data for program design, implementation and evaluation (Hollander, 2004; McDaniel & Bach, 1996; Morgan, 1998; Morse & Richards, 2002).

***Participant selection: Sampling strategy.***

The goal of qualitative sampling is to seek and describe (Goss, 1998). While my initial intent was to examine cervical screening among “Aboriginal women” in Southern Alberta, I soon realized that I needed to narrow my focus to “First Nations” women. A purposefully selected sample of approximately twelve First Nations women aged 18-69 years residing off-reserve in Chinook Health was targeted to attend two semi-structured interviews in a focus group format. Included were Treaty Status and Non-status Indians. Excluded were Inuit, Métis and women who had a Pap test within the last year.

The CH Aboriginal lay community worker and Community Health Representative (local First Nations women) recruited eligible women to participate. Their involvement in the recruitment process enabled them to “exercise some control over the research and acknowledged the importance of their knowledge of the community, community members, and local and community protocols” (Wilson, 2004, p.7). Key informants were selected based on their representativeness of the community of interest by virtue of their roles, status, age, gender, tribe of origin, and their “knowledge and experience with the domain or phenomena under study” (Leininger, 1985, p. 47). Purposive sample heterogeneity also promised to “encourage richer discourse as participants attempt to explain themselves to other group members” (Hollander, 2004, p. 612). It was recognized that careful identification of respondents who might potentially reveal substantive data was key to cultural discovery and exploration. “Word of mouth”



invitations were supplemented by written invitations to participate (see Appendixes E1 and E2).<sup>19</sup>

Establishing heterogeneity was challenging. The recruiters were limited by the availability of women willing to participate. Additionally, both First Nations recruiters had previously established relationships within the Blood tribe (providing them with “insider” privilege); relationships with the women of Piikani heritage were more difficult to establish. As well, contact with Piikani First Nations women was discouraged by regional planners, as a concurrent CH-Piikani initiative (the Chronic Disease Prevention and Management Initiative at Pincher Creek) would have resulted in a duplication of demands on this small population. To increase focus group participation, theoretical snowball sampling was used (Morse & Richards, 2002; Polit & Hungler, 1995).

To improve the representation of the perspectives of younger First Nations women and to enhance data saturation, a third focus group was planned. This focus group discussion would also serve to “round out” and verify emerging theoretical conceptualizations (Creswell, 2003, p. 209). As additional information provided by the new informants yielded little effect on the pattern within the data, the data were determined to be “saturated”, and the sample size considered satisfactory.

### *Questions.*

The goal of this ethnographic interview was to obtain rich emic descriptions directed toward the focused area of interest. Examination of the literature, consultation with experts, and selected research methodology provided insight into the “formulation of questions and probes that will enhance current levels of knowledge” (Goss, 1998, p.31).

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<sup>19</sup> All written materials used for this research study were at a Grade 6 to 8 reading level (Flesch-Kincaid scoring, Microsoft Office Suite, Windows XP Professional).

Focus group questions served as an outline, promoting discussion of points “key” to the research objective.

In this study, flexible, open-ended questions were designed to stimulate and facilitate group discussion (Leininger, 1985). Ordered from general to specific, neutral to sensitive, nonthreatening to threatening, initial questions asked about broad concepts of health and wellbeing, funnelling down to the more sensitive topic of Pap testing directed toward Blood and Piikani worldviews of health promotion and prevention (specifically, cervical screening) (see Appendix F1). The importance of story-telling was recognized by asking participants to relay positive and negative health care experiences (Browne et al., 2000; Strickland et al., 1999). Additionally, it was anticipated that stories would allow the individual to decide “if the story applies personally and if personal change [e.g., cervical screening] is needed” (Strickland et al., 1999, p. 193). This was a secondary, yet core goal of the focus groups. This culturally appropriate decision-making approach has been aptly described by a respected Yakima elder: “I tell a story, and if it applies and you are ready to hear the message, you will be able to take it with you and make it your own. I cannot know or be able to tell you what you need to do; only you know that” (Strickland et al., 1999, p. 194).

An interview guide (which included “probes” to increase response specificity) was reviewed by the First Nations research team members prior to the focus groups (McDaniel & Bach, 1996) (see Appendix F2). As well, a participant-completed demographic survey (completed at the end of the focus groups sessions) provided an overview of the focus group participant characteristics and inter-relationships, and allowed for a more comprehensive analysis (see Appendix G).

Morgan (1998) stressed the importance of pilot-testing in instances involving discussion of a potentially controversial topic. In October, 2004, a small group of First Nations participants and cervical screening program stakeholders gathered prior to conducting the first focus group. The agenda included roles and responsibilities of team members, anticipated questions, and ethical responses to the potential disclosure of sensitive or traumatic information during the focus groups. In addition, the demographic survey was piloted with the stakeholders. Consequently, the stakeholder team discussed the need for a regional counselling and support resource list (available for distribution as-required), Breast/Cervical Program brochures and business cards, and culturally-appropriate educational materials.

Scheduled focus groups also provided an optimal opportunity to address participant questions, provide factual information about cervical screening and ensure immediacy of follow-up. The focus group members also promised to familiarize participants with the clinic location and provide the opportunity to build trust across and between ethnic groups. To minimize the introduction of bias, the formal educational component of the focus groups was scheduled to occur at the end of the sessions.

A plan for a First Nations-guided cultural-awareness education session for the Women's Health Program staff was initiated by the pilot group. In addition, the pilot of the demographic survey resulted in the request by First Nations participants that all personal identifiers be removed from the demographic profile. They also requested that the category "unemployed and looking for work" be added, and the occupation, "homemaker" be placed first on the list of employment options. While these changes limited the ability of the researcher to link any demographic information with the

qualitative component of the study, compliance with their requests signalled sensitivity and respect for their wishes, and reinforced the importance of their input into service planning for the women of their community.<sup>20</sup>

***Data collected through other sources.***

Congruent with my methodological approach, study data included observations of participant behaviours, interaction, and response to the focus group discussion, technical and non-technical information sources (such as census data, maps, and newspaper articles), discussions with First Nations co-workers, colleagues and identified “experts” as well as my intuitive grasp of these data sources (e.g., debriefing notes, diary). The intent of this multimethod data collection was to contribute to understanding of the phenomenon under study (Denzin & Lincoln, 2005; Kalischuk, 1999).

***Setting.***

Few opportunities existed for off-reserve First Nations women residing in Chinook Health to meet collectively (R. Oka-Fox & R. Vaile, personal communication, October, 2004). Bringing the women to the Breast/Cervical Health Program would familiarize them with the cervical program setting. I speculated that this, in turn, would enhance their willingness to return for their Pap testing visit and provide a positive experience that would be shared with other First Nations women in the community. Participant needs (e.g., in relation to weather, transportation, room size, and a non-threatening, comfortable environment) directed the selection of time and place of interviews. In addition, the focus group team projected an inclusive, non-judgmental

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<sup>20</sup> Permission was later granted to utilize identifiers to analyze concepts in relation to participant age. Identifiers are not included in the display of demographic data.

attitude to foster freedom of expression, confidentiality, and emotional safety. Sessions lasted approximately one to two hours. Transportation was provided on an as-needed basis. Translation capabilities were also available, as one member of the research team was fluent in Blackfoot.

A small conference room in a Chinook Health facility was selected for the first two focus group sessions. The room was long and narrow, framed by full length windows. It was conducive to small group interactions, free of interruption and well ventilated (Goss, 1998). The focus of the room was a circular table decorated with colourful table runners. This circular seating arrangement provided a “powerful symbol of unity and the unique equal value of each individual in the circle” (Strickland, 1999, p. 193). Each place was set with a leaf motif coffee mug that would later be given to the women as a token of appreciation for their contribution to the research. Place cards were available for the participants to record their name. On a nearby table, peppermint tea (made from peppermint leaves provided by a First Nations elder) and refreshments were available. On a side table an educational display focusing on Aboriginals and cervical screening was displayed. On another table, Breast and Cervical health pamphlets, a brochure outlining regional resources (see Figure 8) and contact cards for the Lay Health Worker and Breast/Cervical Screening Program were exhibited.

In contrast, a third focus group was held in the evening at the Opokaa’Sin Early Intervention Society at the request of the young First Nations participants. This child-friendly community child care centre radiated warmth, with First Nations motifs and children’s drawings decorating the walls. The room featured three computers and child play equipment neatly stored in the large play area at the back of the room. While this

environment stood in sharp contrast to the more “sterile” hospital setting, seating arrangements and presenter materials were arranged in a manner similar to previous focus groups.

Focus group agendas included a welcome and introduction, completion of the consent form, explanation of focus group ground rules, exploration of focus group questions, completion of the demographic questionnaire and selection of pseudonyms for purposes of any publications. At the end of the focus groups, education on Pap testing was provided using an educational video targeted to Aboriginal women, “The Pap test. A positive step for Aboriginal women’s health” (Genereux & Johnson, n.d.). The women were provided with an opportunity to ask questions, and to book an appointment for a Pap smear appointment at the regional Breast/Cervical Program or with their family physician.

***Research team, roles and responsibilities.***

The research team included two CH First Nations staff (the Cervical Health lay community worker and Population Health Aboriginal community health representative), the Coordinator of the CH Regional Cervical Program (Health Promotion Specialist), and me (the Family Health Program health care analyst and University of Lethbridge Masters student). My role was that of primary investigator and focus group moderator. While the researcher often takes the role of observer in order to fully attend to the focus group, I chose to assume the moderator role for the learning opportunity it provided. My responsibility was to guide the interview, promote discussion of pre-selected questions, and encourage all individuals to participate. The focus groups were co-facilitated by the

other research team members.<sup>21</sup> In addition to recruiting participants, and providing transportation to and from the groups to participants who required it, the First Nations members acted in an advisory role and provided insight into First Nations worldview and the interpretation of results. The Cervical Health Program Coordinator responded to participant questions about cervical cancer or screening that arose during the sessions. She also led the educational session that followed and participated in debriefing sessions. Each of the co-facilitators observed and recorded the group interaction (see Appendix H) and operated the tape recorders. Non-First Nations team members limited their involvement in the focus group discussion to ensure that the participants' points of view were reflected and to minimize the introduction of bias. The facilitators remained alert for participant cues, respectfully encouraging the participants to share their thoughts and often diverse opinions, clarifying participants' responses and verifying researcher interpretations during the course of the discussion (Morgan, 1998; Hollander, 2004). Sessions lasted approximately two hours; for the most part this timeframe allowed for the research goals to be reached, but left little time for the formal educational component and summary of the focus group discussion. This has been mentioned in the literature as a common pitfall for inexperienced qualitative researchers. On several occasions timelines were further compromised by the late arrival of participants. Fortunately, much of the education had occurred informally and spontaneously, interspersed throughout the focus group discussion.

### ***Changes to the proposal.***

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<sup>21</sup> The First Nations research team members did not participate in the third focus group.

Changes to the original proposal were made in relation to the sampling method, and the sequencing of data collection. As previously mentioned, additional sampling methods (e.g., snowball sampling, discriminant [theoretical] sampling) were required to enhance data saturation. Changes to the sequencing of questions were required for several reasons. First, the late arrival of focus group participants required researcher flexibility. Second, to our surprise, many participants were anxious for the opportunity to discuss sexuality and women's health issues with their peers, broaching the topic early in the discussion. Others had come with their own agendas. In these instances, researcher flexibility allowed scheduled questions to fit fluidly into the discussion at hand. Thus, the needs of both the researcher and the researched were met. In addition to the planned questions, the third focus group included probes to clarify information gleaned at the first two focus groups, for example, the prevalence of sexual abuse, the role of spirituality, and the speculation of contrasting needs of younger versus older First Nations women hinted at in earlier sessions. The refinement of questions over time is addressed by Carey and Smith (1994), who state:

Often it is useful for the guideline questions to be refined with increased understanding of the topic as the study progresses. Although analysis across sessions will be somewhat limited by the lack of total comparability of data, the refined questions should provide more useful data. (as cited in Webb & Kevern, 2001)

***Data management.***

For the purposes of the focus group, two tape recorders were available to record the conversation completely and accurately (Streubert & Carpenter, 1995). Focus group questions were outlined on a nearby flip chart; written questions were interspersed with visual depictions, for example a stick drawing of a woman was used to stimulate and



record discussion of topics that the women would like to discuss with their physician at a visit. The flip chart also served as a “back-up”, which, together with research-assistant notes provided an alternative means of recording the discussion should the participants express discomfort with, or refuse to have the conversation audiotaped. The second tape recorder also provided a backup when, in the third focus group, one tape recorder malfunctioned. Supplementary notes were recorded by research team members who documented “what was seen and heard without interpretation” (Streubert & Carpenter, 1995, p. 103).

Following each focus group session, the investigators debriefed in a quiet place, making notes about what occurred, checking the audiotapes, summarizing the focus group discussion, and comparing impressions about the discussion (Kruger, 1998; McDaniel & Bach, 1996). Debriefing provided the opportunity to explore cultural nuances, triangulate emic and etic perspectives, and, in the case of discrepancies, recheck the audio tapes (Kruger, 1997; C. Caulfield, personal communication, August 3, 2004). Field notes were compiled following each debriefing session. These objective, descriptive accounts of the focus group interactions were conducted to “capture the lived experience of the participants and to describe the community in which they are a part” (Morse & Field, 1995, p. 112). Discussions included the impact of the researchers on the setting and reflections, feelings, ideas, moments of confusion, hunches and interpretations about what was observed. My fieldnotes provided the opportunity to clarify thoughts, make sense of the data, and plan the next step of the observation process (Mayan, 2001). These discussions proved to be invaluable as the First Nations research assistants provided socio-political background information, elaborated on focus group discussion and

provided assistance in clarifying cultural meanings in relation to the discussion as required (e.g., one First Nations research team member discussed traditional First Nations' spirituality and the role of Napii, the "trickster"). The debriefing sessions and the recording of field notes occurred soon after the focus groups to reduce historical bias and to provide context (e.g., tone, pace, inflection, nonverbal communication) and subsequent meaning (satire, humour, emotion, intensity) to transcript data (Carey & Smith, 1994; Kreuger, 1998; Goss, 1998). This information was key in the next phase of the research project, the management and analysis of the data. At the request of the participants, notices regarding participation in the cervical screening focus group were sent to their family physician (see Appendix I).

Kruger (1998) suggests that the investigator who conducts the group interview is the most appropriate person to conduct the analysis of data due to his/her complete knowledge of what actually took place in the focus group. As well, the analysis by a single person promotes "consistency across the data collection, transcription, and [the] data analysis process" (Mansell et al., 2004, p.86). He continued, this is "key, due to the complex nature of the data collected."

### ***Data analysis.***

Descriptive analysis of participant demographic questionnaires was completed using the Statistical Package for Social Sciences (SPSS v.14). The raw data included no personal identifiers – each survey was randomly assigned a number for analytical purposes. Results were transferred to an Excel table; any data that might allow for individual identification was excluded or grouped to a higher category (e.g., the response

of occupation, lay community worker, was changed to health care professional to prevent identification of the only person working in this capacity).

The analysis of the qualitative focus group data required a different, and for me, a less familiar approach. Webb and Kevern (2001) stress the importance of compatibility between analysis and selected methodology, in this instance, focused ethnography. They also point out that information regarding the analysis of focus groups data varies. Most authors describe identifying recurrent themes, patterns or units of meaning within a cultural or social context, followed by further reduction of the themes (or concepts) into larger categories or domains, and definition of semantic relationship within and among concepts and/or domains (Leininger, 1985; Streubert & Carpenter, 1995). Carey and Smith (1994) describe processes varying from the “less intense” (coding and categorizing)<sup>22</sup> to the more intense (grounded theory) (p.126). Quantification of qualitative data by counting frequencies of words, phrases or themes is inappropriate unless the question is asked of each participant (Carey & Smith, 1994; Webb & Kevern, 2001).

The collection and analysis of the qualitative data were concurrent and iterative; data collection was followed by analysis, which in turn gave direction for new data collection (Giacomini, 2001; Streubert & Carpenter, 1995 ). Data were “constantly compared” back and forth between data collection and analysis, within and among groups to determine commonalities and variations and refine theoretically relevant categories (Goss, 1998; Polit & Hungler, 1995; Webb & Kevern, 2001). This systematic process was essential to attaining trustworthiness; data were checked, focus maintained, the fit of

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<sup>22</sup> Sometimes this process is referred to as content analysis (Miles & Huberman, Higginbottom, and Robinson as cited in McDaniel & Bach, 1996).

the data and the conceptual work of analysis and interpretation monitored and confirmed. There was a constant interplay between what was known and what knowledge was still required. Throughout the analysis process, similarities and differences were examined, often using both quantitative and qualitative analysis of data. Convergent ideas (e.g., consistency with existing literature) pointed to confirmability; while unusual responses were recorded for divergent analysis.

Consistent with the recommendations of Burard (1991) and McDaniel and Bach (1996), the following steps were used to analyze the interview data. The entire interview was transcribed verbatim, including incomplete sentences, phrases, unfinished thoughts. Debriefing notes and observations, journal entries, and demographic data supplemented transcription materials. Transcripts were compared to the tapes and notes for accuracy (e.g., identification of participants, attribution of statements) and sections relevant to the research question(s) identified.

Prior to analysis, I read the verbatim transcripts several times to “immerse” myself in the data and “become more fully aware of the ‘life world’ of the respondent[s]” before coding the textual data (Burard, 1991, p. 462). Notations regarding non-verbal communication were added into the transcripts. Each focus group transcript was independently reviewed and organized into categories, to identify themes, patterns, and similar words and context, initially using colored highlighters, then later (as the data became increasingly dense) transferred into QRS Nudist Qualitative Software. Words, context, internal consistency, and the specificity of responses were examined during the course of finding the “big ideas” (Kreuger, 1988; McDaniel & Bach, 1996). In contrast to the line by line coding suggested by Strauss & Corbin (1990) and Charmaz (as cited in

Denzin & Lincoln , 2005), “meaning units”<sup>23</sup> were used to represent the First Nations women’s voices, perceptions, and stories (Glaser, 1978, as cited in Kalischuk, 1999). Wherever possible, phrases used by the participants were used to describe the thematic concepts. Categories were grouped together and collapsed into broader categories; repetitions were eliminated. My thinking processes in relation to coding decisions and observations were captured using “memoing”, and documented in Microsoft Excel. Later the memoing function of the QRS software was used to record decisions regarding the collapsing of categories (Field & Morse as cited in Burard, 1991; Kalischuk, 1999). Quotations that reflected the voice of the women and provided examples of the coding categories were highlighted. Each step of the analysis process was retained as evidence of a decision trail, an integral part of auditability, confirmability, and credibility.

The First Nations research team members who participated in the interviews provided feedback on the selection of themes. Independent coding and comparison of themes of the first focus group were conducted by both a First Nations and a non-First Nations research team member. While the transcripts that I coded were categorized in greater detail, there were no discrepancies between reviewers in the broad themes identified. This was likely related to the discussion that occurred in the debriefing sessions.

The process of categorizing was consistently repeated for each focus group. The constant comparative method (Glaser & Strauss, 1967) was used to compare thematic findings between focus groups and from the focus group transcriptions to central themes. The concurrent analysis process also prompted new observations and additional questions to explore emerging concepts, to validate relationships and assigned categories, and to

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<sup>23</sup> Words, phrases or paragraphs representing meaningful ideas

clarify cultural roles and relationships (Streubert & Carpenter, 1995), for example, emerging concepts prompted me to conduct a third focus group.

The transfer of data from a manual to computer-based coding system required that the data be recoded. This transfer prompted a review of selected categories and a further data reduction, resulting in a process similar to that suggested by Morgan (1998):

[The researcher should] repeat the process with clean copies of the transcripts. This allows the investigator to pick up the “big ideas” that may be difficult to select when actively involved in the analysis. This process of data reduction provides content analysis and an ethnographic summary. (McDaniel & Bach, 1996, p. 58)

The examination of verbal and nonverbal communication, and observations of behaviour were also integral to the analysis process (McDaniel & Bach, 1996). Hollander (2004) suggested that the focus of attention in a focus group “should be on understanding and analyzing the multiple, complex interactional forces that lead participants to share some truths, withhold others, and manufacture new versions of reality in a given context” (p. 632).

The social contexts of focus groups – that is, the relationships among the participants and between the participants and the facilitator, as well as the larger social structures within which the discussion takes place – affect the data that are generated in ways that have not yet been widely acknowledged by focus group researchers. (p. 604)

As suggested by Hollander (2004) the data were examined in terms of the common characteristics that brought the participants together, influenced group conversation and dynamics (e.g., long-term implications for the participant, risk of breach of confidentiality on the part of the participants and team members [associational context], and the relative positions of the participants in local or societal status hierarchies [e.g., gender, race, age, sexual identity, status identity or social class]).

Expectational theory postulates that the higher the status, the more likely the participant is to talk and to assume a group leadership role. The congruency of the conversation with cultural norms or the discussion at hand (e.g., the acceptability of speaking about the topic in a public context, the appropriateness of the tone of the conversation, or the acceptability to express emotion) were examined (conversational context), as was the degree of prior acquaintance among the participants (relational context). Observation of these characteristics within and between groups were recorded in an Excel spreadsheet.

Hollander (2004) also suggested that it is important to consider what is not said [non-disclosure]. Silences may reflect personal experiences not or incompletely shared. Efforts to minimize nondisclosure were addressed through clear instructions given to each group and probes to encourage the sharing of each participant's opinion. Iteration between data collection, analysis and theory development continued until further observations yielded minimal or no new information (informational redundancy) and the addition of new information did not further challenge or elaborate the framework (theoretical saturation).

Core concepts emerged through a constant comparison between and among codes and between and among focus groups. For example, themes frequently recurred between questions and were repeated by subsequent focus groups. Wherever possible, the terminology used by the participants was used to categorize themes. This was accomplished using the "NVivo" coding function of the N6 software. Throughout the process of concept development, similar elements were refined or combined with other elements or collapsed into broader categories (Burard, 1991). By subcategorizing and

synthesizing themes,<sup>24</sup> making connections between major concepts<sup>25</sup> and examining the relationship between themes, a conceptual map was developed using Inspiration software, a software program that created graphic organizers to visually represent concepts and relationships. The conceptual map was then organized into the three main focus areas of the key research question of interest: needs, barriers and solutions.

Multiple data sources provided for a “full rich description and increased the validity of the collected data” (Wright, 2002, p. 211). Throughout the research process, I maintained a separate diary of personal insights, observations, activities and social artifacts. Spradley (1979) suggested that this documentation can contribute to the data richness of the cultural scene.

Consistent with an ethnographic methodology, I was alert to pertinent political, economic and social<sup>26</sup> influences in recognition of their potential influence on the research and to provide cues for data analysis (Leininger, 1985). During the timeframe of the study, the Piikani Nation was facing financial difficulties with attendant political unrest; a vote to determine a new Chief on the Blood Reserve was underway. Politically and financially the First Nations people and general public were demanding increased accountability and transparency. Simultaneously, increased ownership and joint responsibility for “financing, organizing, and delivering health care services” were being promoted by the Canadian government (Romanow, 2002, p. 224). CH ties with regional First Nations were being strengthened through co-sponsoring diabetes centres on reserves, sponsoring cultural camps and hiring First Nations staff (e.g., Population Health community health representatives, Breast/Cervical Health Program lay health worker).

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<sup>24</sup> Selective coding

<sup>25</sup> Axial coding

<sup>26</sup> Political, kinship, social, economic, religious and cultural values, beliefs and practices



*Establishing Scientific Rigor*

While some authors have argued that the terms “validity” and “reliability” are situated within a positivist paradigm and that rigor in qualitative research should be defined in terms of trustworthiness or truth value, credibility, applicability, transferability, consistency and dependability (Leininger, 1994; Lincoln & Guba, 1985; Morse & Richards, 2002), others maintain that “determining reliability and validity remains the qualitative researcher’s goal” (Morse & Richards, 2002, p. 168). Regardless of the approach selected, “rigour is integral to both qualitative and quantitative inquiry” (Mayan, 2001, p.25). While I recognized the efforts to establish a “common language” that can be shared between qualitative and quantitative researchers, I felt that a firm grounding in the original concepts of qualitative research was foundational, thus, I defined the scientific rigor of this study in terms of the “truthfulness” of the results and through the study design and execution.

The ethnographer's work must meet rigorous criteria of ‘trustworthiness’ or credibility (Lincoln & Guba, 1985; Giacomini, 2001). Ultimately, the researcher hopes to accurately know and reconstruct the world of the research informant. Empirically based insights “emerge from systematic observations and competent interpretation” (Giacomini, 2001, p. 4) to reflect the social reality of the participants and provide meaning or relevance to clinicians. Internal validity is established through complete confidence that the conclusions come from the data. External validity refers to the “fit” – “the degree to which the audience or reader of the report is able to transfer the research findings to context outside the study situation to other settings” (Mayan, 2001, p. 26) - a direct function of the similarity of “fit” between contexts. Thick, rich , clear and detailed

description allows the reader to determine the transferability of the findings across settings.

Accordingly, I use the criteria of data “trustworthiness” to describe the processes I used to establish rigor in this study. The criteria and process used to establish the criteria within the study are described in Table 2 below.

Table 2

<i>Establishing Rigor</i>	
<b>Criterion</b>	<b>Process used to establish the criterion</b>
Credibility	<ul style="list-style-type: none"> <li>• Using a systematic process throughout the planning, data collection and analysis process and ensuring methodological coherence (Mayan, 2001).</li> <li>• Including investigators of similar ethnicity on the research team.</li> <li>• Selecting participants who best represented or had knowledge of the research topic.</li> <li>• Building trust and rapport with key informants through prolonged engagement (Kalischuk, 1999; Lincoln &amp; Guba, 1985).</li> <li>• Dynamically formulating and reframing<sup>27</sup> questions (Krefting, as cited in Kalischuk, 1999).</li> <li>• Concurrently collecting and analyzing the data (Mayan, 2001).</li> <li>• Inviting focus group participants to provide feedback to the project report, noticing their ability to recognize their own</li> </ul>

<sup>27</sup> Repeating or expanding

Criterion	Process used to establish the criterion
	<p>comments based on their reading of the data [member checking] (Lincoln &amp; Guba, 1985).</p> <ul style="list-style-type: none"> <li>Actively seeking out negative cases to ensure that the emerging theory represents the reflections of all it intends to represent (Kalischuk, 1999).</li> </ul>
Transferability	<ul style="list-style-type: none"> <li>Providing thick, rich, clear and detailed description (Mayan 2001).</li> <li>Using theoretical (or discriminant) sampling methods to promote data comprehensiveness and data saturation (Kalischuk, 1999; Leininger, 1994; Lincoln &amp; Guba, 1985; Mayan 2001).</li> <li>Establishing the presence of recurrent patterning, identifiable patterns of sequences of behaviours or actions (Leininger, 1994).</li> </ul>
Dependability	<ul style="list-style-type: none"> <li>Providing an audit trail,<sup>28</sup> including decisions, choices and insights (e.g., Thesis proposal, raw data (focus group transcripts and debriefing notes), research team observations, my reflexive journal, portfolio of news articles and government briefs, documentation of the ethical review process, my analysis and synthesis) (Kalischuk, 1999; Mayan 2001).</li> <li>Clarifying data interpretation and coding with research co-investigators (e.g., through debriefing and comparing data</li> </ul>

<sup>28</sup> “a recording of activities over time which can be followed by another individual... [the objective] of which is to, as clearly as possible, illustrate the evidence and thought processes which led to the summaries” (Streubert, 1995, as cited in Kalischuk, 1999).

Criterion	Process used to establish the criterion
	coding with that of an independent peer).
Confirmability	<ul style="list-style-type: none"><li>• Paraphrasing participant responses (Kalischuk, 1999; Leininger, 1994).</li><li>• Involving select participants in identifying and naming key concepts (Kalischuk, 1999).</li><li>• Presenting evolving theory to participants (Kalischuk, 1999; Leininger, 1994).</li><li>• Triangulating findings within and across groups, investigators, and data collection methods (e.g., reflexive journal, interviews, participant observations, and non-technical data sources). Etic views were studied in relation to emic perspectives (Krefting, as cited in Kalischuk, 1999; Leininger, 1994; Lincoln &amp; Guba, 1985).</li><li>• Providing an audit trail of the decision-making process used during theory development (Kalischuk, 1999; Leininger, 1994).</li></ul>

Rather than work deductively from a theoretical framework, the data were examined inductively, with decisions made strategically rather than using instructions in a rote fashion, often in consultation with my thesis supervisor and advisory committee (Mayan, 2001).

### *Ethical Considerations*

Ethnography is usually considered low risk ethically, as it does not involve physically intrusive procedures or mind or body treatments. Informed consent and the protection of privacy, anonymity, and confidentiality were maintained during the period of data collection and analysis. Other ethical considerations included the “potential use of findings and power relationships among various levels of the study population, objectivity versus subjectivity with regard to selection, recording and reporting of phenomenon and intervention activities of the subculture” (Streuber & Carpenter, 1995, p. 110).

Underpinning the study design were the Tri-council “Ethical Guidelines for Research Involving Humans” published by the Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada (2003). These guidelines provide specific recommendations that foster inclusiveness and respect in relation to naturalistic observation, personal interviews, and research involving Aboriginal peoples. They recognize that “Aboriginal peoples have a unique interest in ensuring accurate and informed research concerning the heritage, customs and community” (Section 6.2).

The ethical review process was complex, complicated by feedback and suggestions provided by four independent reviewers: the Alberta Cervical Cancer Board, Community Research Ethics Board of Alberta (CREBA), the Chinook Health Research Committee, and my thesis advisory committee. Each change to the proposal or consent required that I notify the previous review group – often resulting in further changes and

sometimes conflicting advice. Finally, the proposal was deemed ethically sound, compliant with Tri-council guidelines, and met the needs of all parties involved.

Ethical approval was received from the Community Research Ethics Board of Alberta (CREBA), CH Research and Ethics Committee and the University of Lethbridge Human Subject Research Committee. As a component of a regional evaluative study, project approval was also received from the Alberta Cancer Board. Critical ethical components that will be discussed in greater detail include informed consent, protection of privacy, confidentiality and anonymity.

### ***Informed Consent***

Upon invitation to participate in the focus groups, the lay community worker explained the purpose of the study to potential participants. For the most part, this information was shared orally, although written descriptions were available to supplement the oral information (see Appendix E2). I reviewed the consent with the participants at the start of the focus group sessions to ensure that they were aware of the general nature and goals of the study, and that the consent information was understood (see Appendix J). Support was available for several individuals who had low literacy skills or a limited comprehension of written English. Visual aids (e.g., posters, models, medical equipment) were available to clarify medical terminology within the consent form (e.g., cervix, pap smear). Participants were informed that their participation was voluntary; they had the right to withdraw at any time without consequences.

Risks and benefits of the study were explained. No adverse affects were anticipated. Nevertheless, it was possible that an individual participating in the proposed pilot project might express some discomfort in discussing or disclosing information about

the sometimes-embarrassing experiences related to having a Pap smear. A support and counselling resource list was readily available in the event that professional help was needed (see Figure 8). As practicing registered nurses, two members of the research team had the skills and knowledge to assess if further referral or follow-up were required. Potential benefits of the focus group included an increased awareness of risk factors, and early identification, intervention, and treatment of cervical cancer. Additional benefits could also include the identification of cultural-specific barriers to cervical cancer screening, increased staff cultural sensitivity and the identification of opportunities for improvement.

Consents were obtained from all participants. While the consent included approval for guardianship/non-English speaking clients, this aspect of the form was not required by women attending the groups. Research study participants were provided with a copy of the consent form, which included contact numbers should further questions or concerns arise. The director of the Women's Health program was the contact for questions related to the Pap testing procedure or the CH Women's Health Program, while the University of Lethbridge Research Services was the contact identified for general questions or concerns regarding the research study.

### ***Protection of Privacy and Anonymity***

Respect for participants' privacy was promoted through verbal and written information included in consent agreements. Prior to commencing the focus group, and before signing the consent forms, I stressed the importance of keeping any information shared within the focus group setting confidential. A commitment to maintain the confidentiality of other group members was reinforced in the consent form.

Confidentiality agreements were signed by all CH employees and were reinforced in lay community worker orientation sessions.

***Confidentiality of the Subculture during the Period of Data Collection***

Participant anonymity in computer programs, databases, recorded audio tapes and transcripts was honoured; in written reports, participants were identified by pseudonyms unless requested otherwise. All information on CH computers was secured by an employee-specific password with access limited by password to the data entry clerk and the health care analyst. The analysis dataset included no identifiers; linkage between it and other CH databases was not possible. All transcript responses were confidential and released only to the researchers conducting the focus groups. Identifiers will be replaced with pseudonyms should the transcripts be requested by the Thesis Advisory Committee.

Aggregate information was used for reporting interview and survey data. Specific quotations, referenced by pseudonyms, were used to exemplify concepts within the data. Quotations were limited to those that did not allow for personal identification. When writing the results of the focus groups, the data was presented in a cumulative format so it was not possible for an individual to be identified. Raw data, transcripts, journal records, and consent forms were kept in a locked filing cabinet with access restricted to the Health Care Analyst and designated data entry clerk. Access to raw data on computer files was password protected. Data will be kept for eight years as per CH document retention policy and will be shredded at the end of the retention timeframe. Focus group tapes were destroyed once they were transcribed and reviewed.



Before the completion of the final report or relevant publications, the interview participants were provided the opportunity to react and respond to the research findings as per the Tri-Council Guidelines and to ensure the “trustworthiness” of the data (Section 6). No requests for exclusion of data from the findings were received.

### ***Unforeseen Problems and Highlights***

Throughout the course of the study, several unforeseen problems were encountered. Following the second focus group, the First Nations lay community worker, a key member of the research team, terminated her position with the Chinook Health region. This meant that some of the initial groundwork in establishing relationships needed to be revisited and re-established.

New insights and awareness, and a growing relationship of trust were fostered among the research team participants. During the course of the study, it was discovered that appointments for cervical screening were refused unless the woman could provide an Alberta Health number. As a result of this finding, Breast/Cervical Screening Clinic staff re-examined this practice. Currently application forms for health care insurance coverage are available to distribute to women attending the clinic who lack insurance coverage.

The focus groups also provided an opportunity to enhance cross-cultural awareness and foster collaborative strategic program planning. The women’s comments, insights, and suggestions are discussed in chapter 4.

At the most elemental state, focus groups tell us how people communicate with others within the context of a particular social group. At best, they provide a window of opportunity to enhance and advance our insight and knowledge, the ultimate goal of research.

C. Jensen-Ross, 2004

## Chapter 4

### Results and Discussion

The purpose of this descriptive focused ethnography was to gain an understanding of the cervical screening needs of First Nations women living off-reserve in the Chinook Health region and to involve them in identifying solutions to barriers they face. This chapter begins with an overview of participant demographics and key observations. Focus group responses are presented using an interpretive (or illustrative) style (Krueger, 1998; Wolcott, 2001), “a summary description with illustrative quotes, followed by an interpretation” (Kruger, 1998, p. 111). This style of analysis provided the opportunity to reflect, compare and contrast participant responses to current literature. Themes that emerged within and between interview questions, and within and between focus groups are explored in relation to the key question of interest. While presented as distinct concepts, themes are often intimately inter-related.

Throughout this chapter, focus group responses are reflected through the voices of the women to retain the original intent of their meaning (Lincoln & Guba, 1985). While some participants were able to advocate clearly for their personal and community needs, others were less articulate, often speaking in broken phrases or incomplete sentences. In these instances descriptive summaries are presented. When prompted, even the most reticent participants shared stories about their health care experiences. While few stories were specific to cervical screening (due to lack of exposure to this experience) the stories they shared provide “real life examples” and rich, dense descriptions that embodied core First Nations philosophies and values. Pseudonyms have been used to protect participant

anonymity. This chapter begins with a description of the women who participated in this study.

### *Focus Group Demographics*

Thirteen women, ranging in age from twenty-six to seventy-four years (mean forty-five years) participated in three focus groups held between November 2004 and June 2005. While the majority of the women were from the Blood Tribe (n=7), participants included women of Cree, Piikani, or a blend of Blood and Piikani heritage. Nearly half were married or lived common-law (n=6), the remainder were single or widowed. While most had attended college or university (53.8%, n=7); three had a Grade 9 or lower education. Over one-third of the participants had attended residential school (38.5%, n=5). All but one participant had Treaty Status and, with the exception of one participant, resided off-reserve. All respondents knew at least one other focus group participant as a friend (n=9), acquaintance (n=6), co-worker (n=5), or relative (n=3) (see Table 3).

Table 3

*Focus Group Participant Demographics*

Respondent #	Age	Marital Status	Education	Residential School	Occupation	Ethnicity	Treaty Status	Income
101	52	Single	College or university	Yes	Health Care Professional	Cree	Yes	Employment Insurance
102	61	Widowed	Gr 1-6	Yes	Homemaker	Other	Yes	Guaranteed Income Supplement
103	43	Married/ Common Law	College or university	Yes	Health Care Professional	Blood	Yes	Employment Income
104	63	Married/ Common Law	Gr 10-12	Yes	Homemaker	Blood	Yes	Guaranteed Income Supplement
105	74	Widowed	Gr 7-9	Yes	Homemaker	Blood	Yes	Pension
106	36	Married/ Common Law	Gr 7-9	No	Homemaker	Blood/ Piikani	Yes	Other
107	43	Single	Gr 10-12	No	Other	Cree	No	Other
109	26	Married/ Common Law	College or university	No	Student	Blood	Yes	Other
110	48	Married/ Common Law	College or university	No	Other	Blood	Yes	Employment Income
111	33	Single	College or university	No	Other	Blood	Yes	Employment Income
112	35	Married/ Common Law	College or university	No	Other	Blood	Yes	Employment Income
113	37	Single	College or university	No	Health Care Professional	Piikani	Yes	Employment Income

While two participants fell outside study eligibility guidelines, their responses have been included in recognition of their “insider” knowledge of urban First Nations women’s worldviews. One participant, selected for her traditional wisdom, was over 69 years old. Her comments added richness, depth of understanding, fluidity and a historical perspective to the focus group discussion. Another participant was a mother who lived in “both worlds”. While she resided on-reserve, she spent the majority of her time off-reserve, working or attending her children’s off-reserve activities. Her comments provided valuable cross-cultural insight. The CH lay community worker and Population Health community health representative were both First Nations women living off-reserve. Their intimate cultural knowledge prompted their inclusion as focus group respondents as well as research team members. Excluded are the comments of two

women who arrived too late to participate in the third focus group discussions; each received cervical screening education. It is interesting to note that several participants invited to the first focus group did not attend due to the unexpected announcement that hunting season had opened.

***Focus Group Characteristics: Non-verbal Communication and Participant***

***Interaction***

In focus groups, non-verbal communication and participant interaction are often as important as the conversation that takes place (Hollander, 2004). While several participants were passionate and forthright, others were quiet and reserved, reluctant to speak. By encouraging each person to participate in the focus group discussion, we recognized the value of each participant and promoted a rich dialogue representative of the group heterogeneity. The focus group format offered the opportunity for greater depth of discussion and reflection than might have been obtained through a different research approach; individual comments often prompted reaction and further comment from the other women. For example, one health professional spoke of using the Medicine Wheel framework to discuss health with a group of First Nations. This, in turn, prompted lively discussion of varying perceptions of the Medicine Wheel.

Throughout the focus groups, a casual, informal atmosphere was fostered. Initially, this happened quite by accident. Just prior to the first focus group session, a cup of coffee spilled over all of the carefully prepared focus group documents. This small, yet significant, occurrence had the women scurrying to clean up and immediately broke the ice as everyone united in this simple activity. For some participants discussion in a group setting may have been intimidating. For example, one participant, on the ride home,

shared with the lay community worker that she was "just now thinking of all these things to share with the group"; she expressed that she had kind of a "mental block" and "difficulty sharing" within a group setting.

Body language is an important facet of focus group communication. In several instances the participants' body language did not match their non-verbal communication. For example, one participant commented that she was "holding back" in the focus group (Mary), yet her body language and demeanour (direct eye contact, forward-shifting posture when speaking, alert) gave the impression that "she [knew] what she need[ed] - very grounded" (Kate). In contrast, one participant, who eventually shared a long-kept secret, was initially quiet and withdrawn, with her head bowed. This behaviour prompted the research team to provide support, safety, and opportunity to voice her concerns. Personally revealing information was met, in one instance, by a respectful silence pregnant with unshared thoughts. In another instance, non-verbal nods seemed to affirm similar experiences or perceptions. For example, Rox, a First Nations participant, observed: "When xxx talked about her situation – [the women] all kind of snickered 'cause... that has happened before, not that same thing, but something similar."

### *Sense of Community*

A sense of community was evident among the off-reserve focus group participants. Despite differing tribal origins (e.g., Blood, Piikani, Cree), participants commented that they did not restrict their contacts to people of their own tribal background. Many women also maintained close connections with Canadian and American colleagues. "When there's a Pow Wow [in nearby Montana], we'll go" (Rox).

Sometimes the participants considered their move off-reserve to be temporary, for example, to attend high school or to pursue post-secondary education. Discussions often drifted to the need of friends and family on-reserve. Rox explained, “[First Nations women living off-reserve are] still concerned about the people on the reserve.... [On and off-reserve boundaries] matter *more to the politicians*, and not to the Blood Tribe members.”

Blurred “on” and “off” reserve boundaries noted by the women in this study are common among First Nations tribes, perhaps a remnant of cross-border territories occupied by early North and South Blackfoot tribes. Among contemporary First Nations people, mobility is commonplace. “A significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth” (Hanselmann, 2001, p. 3). Among urban First Nations women, mobility within and among cities is common (CHR, 2005a; Hanselmann, 2001; Hull, 2003; Statistics Canada, 2006). Despite this transience, close relationships and ties among family and friends continue to exist.

The sense of community embraced by the First Nations participants is well-documented in the literature. Community ties are “strong[ly] rooted in their families, embracing friends, neighbours, peers, colleagues, and people with shared experiences and interests and extending to their individual First Nations groups” (Wilson, 2005, p. 6). While distinctions between on- and off-reserve residence remain relatively unexplored in the health literature, it would seem that a sense of community extends between women and families regardless of on- or off-reserve residence.



### ***Cultural Diversity***

Despite close-knit community relationships, cultural diversity was also apparent - diversity between individuals, ethnic family groups, tribes, between on- and off-reserve residents, and between cultures and philosophies. Mary, realizing that her perceptions were different than another participant half-jokingly commented, "We're just Bloods." Other women spoke of cultural differences they experienced in moving from the reserve. Cody emphasized, "There is a *big* difference between urban Natives and the Natives that live on the reserve." While she did not articulate the difference, other participants were quick to point out the differing philosophies between the younger and older generations. Anne described sharply contrasting philosophies she encountered when she moved from the reserve to attend a local community college.

Off Reserve, it's strict.... They have rules, they are set. But once you go to the Reserve school it's kind of like, well I can get around this easily.... Teacher(s) [don't] want to be strict because they want to be liked.... So students kind of walk all over their teachers.... There's some that get out of high school and can barely write or read.... They don't want to get after that kid, or else ... he'll go home and tell his parents and his parents will get after his 'gram' or something like that.... It all comes back to being accepted ... you know. That's how I see it. (Anne)

Vastly different worldviews are encountered by these young women in many facets of their lives. Health and healthcare are no exception. Health promotion education (often provided in school settings on- and off-reserve) requires an awareness of culturally diverse approaches to learning.

Distinct differences between younger and older First Nations women were noted and later confirmed by focus group participants. Participants over the age of fifty-five years more frequently required transportation and language translation assistance. They were also less vocal. Their philosophies were more commonly influenced by traditional

First Nations cultures (e.g., respect for tribal elders, spirituality as an integral component of health) and historical events (e.g., residential schools). In contrast, younger participants often arrived independently (e.g., by taxi, bus, or car), sometimes in spite of injuries that impacted their mobility (e.g., crutches, walking cast). Younger participants' philosophies, while influenced by historical events, often reflected a blend of old and new cultural values (e.g., blended traditional and Western approaches to health and healing). Intergenerational differences were highlighted by one participant, who, commenting on her mother's non-assertive response to an awkward situation, stated, "For me, I would have never done that.... There is such a big difference between us" (Rox).

Diversity noted by First Nations women may be due, in part, to rural and urban cultural orientations or socioeconomic factors. Gupta et al. (2003) note a discrepancy in the effectiveness of interventions targeted toward rural Manitoba women in comparison to their urban counterparts. Mobile screening clinics, found to be effective in "lowering the transportation and distance barriers faced by rural residents of all economic levels," are not as effective for the urban poor, where "time spent seeking health care, high residential mobility, lack of continuity of care, and cultural and knowledge barriers" are to be significant issues (p. 2090). In contrast, Clarke et al. (1998) report that British Columbia First Nations women's recommendations for improving cervical screening (e.g., knowledge, environment, and health care providers) are "almost identical" among *off-reserve* and *on-reserve* [italics added] participants" (p. 37).

### ***Cultural Identity: Culture in Transition***

It soon became apparent that First Nations cultures were in transition. Mary, an elder living off-reserve, expressed her feelings of displacement, softly sharing, "I'm lost

from my Native heritage." Traditional values are being challenged. For example, one young participant commented that her teenage daughter attends off-reserve physician clinics out of frustration at the priority given to the elders when waiting for health visits at the on-reserve clinic. Another young mother expressed frustration at entrenched traditional worldviews.

What are we living in? Are we living in reality or in a dream world? You know, we got to really tackle these issues and yeah that's how some people grew up, but we are forever changing these days. You know. Last year's computer is no longer.... You have to get one every year. So people are just thinking, change, change, change and we are not even catching up to meet these changes.... We create these advances, so you know we got to be able to say, 'Hey wait a minute. You know what's really happening in the real world. Not in the dream world.' (Terri-Lynn)

One mother of school-aged children reflected on the loss of traditions transmitted from older to younger generations. She spoke of her children's reaction to visiting her parents on reserve.

You know the feasts that go on and everything ... it's all traditional food, traditional [tribal] food, you know. For me to go home (basically my children are raised here) ... they're asking me everything that's on the table, you know.... They're kind of afraid that they might get "beaver beans" or something! Going home was traditional, sure. (Dee)

The diverse perspectives held by First Nations youth in comparison to the older "contemporary" generation is recognized by several First Nations authors (Fox, 2004, Strickland et al., 1996). Strickland et al. (1996) explore the continuum of perceptions held by Yakima women as they move along the "journey of womanhood" (p. 141). In contrast, Wolf Leg (2005) describes First Nations behaviours and perceptions as ranging from "new traditionalists" (going back to the land and traditions) to "assimilated Indians" (those who have adopted new norms and cultural identities) (National Native Association

of Treatment Directors, 1989 as cited in NECHI, 2005). Consistent with cultural theory, these comments reflect the ambivalent, fluid, multilayered character of culture.

Sometimes this blend of cultures necessitated a flexible approach to the focus groups. For example, while participants with pre-arranged transportation arrived early, many participants arrived late. Several women who arrived early commented on having to adjust their traditional approach to meet the needs of their non-First Nations hosts. Yet waiting for late focus group members did not seem to be an inconvenience for them. Staggered arrival times resulted in time spent “visiting” and provided an opportunity for informal conversation. At the same time late arrivals challenged the ability to attain responses to pre-determined focus group questions, limited the amount of time available for the planned cervical screening education sessions and demanded increased researcher flexibility. First Nations “intuitive, personal and flexible concept of time” stands in sharp contrast to the emphasis on time and timeliness typical of non-First Nations society (Brant, 1990, p. 536; Schilling and Brannon as cited in Huff & Kline, 1999). This accepted First Nations approach has implications that must be taken into consideration when planning culturally sensitive health encounters.

Throughout each session, the women joked and cajoled with each other. Their sense of humour was infectious. Many were acquainted through intimate or distant relationships. “We’re all related somehow,” one participant laughingly observed. Contrary to our expectations, most of the women were eager to discuss Pap testing and the factors that influenced them to have Pap testing done. This, after all, was the reason that they had come, to share their wisdom and insight.

### ***Focus Group Responses***

The women shared their perceptions about the cervical screening needs of First Nations women in their community and the barriers they faced, and offered suggestions as to how the CH Cervical Screening Program might best meet identified needs. These topics frame the the results and discussion of focus group responses that follow.

After initial introduction by the moderator, focus group participants were asked to introduce themselves in any way that they were comfortable. Shannon, a young First Nations woman, puzzled, responded, “You mean, the meaning of my name?” The influence of culture was immediately apparent. In turn, each woman shared her reasons for attending the focus group. Most hoped to increase their knowledge about Pap testing. Others sought the opportunity to share their cultural insights and advocate for accessible, responsive Pap testing services for the women of their community.

### ***Cervical Screening: A Health Priority?***

While the women were eager to contribute to the health and wellbeing of their community, in general, cervical screening was not perceived as a priority health issue. In contrast, focus group participants outlined the struggle faced by First Nations women in meeting basic necessities. They pointed out that many women and families live in poverty and isolation, some without access to telephones or transportation. Friends and family living on reserve were often lacking access to even the most basic necessities including clean drinking water. Lack of education was cited as a major health challenge. Lack of education, they explained, limited the ability of First Nations women to provide a better life for themselves and their families. Compounding this problem, older First Nations women, fluent in Blackfoot, often struggled with language barriers.

Early exposure of youth to sex and teen pregnancy were also identified as major health issues faced by the First Nations community. It was not unusual for women in their mid-thirties to be raising a second family, the children of their children. Still others expressed concern about rising rates of chronic conditions (such as diabetes, arthritis, and deafness) or of children, grandchildren, or siblings affected by fetal alcohol syndrome, mental illness or suicide. Cervical cancer was not mentioned as a primary health concern. The majority of concerns expressed by the women lie within factors foundational to, and which ultimately determine, the health and wellbeing of the First Nations people. Many of the concerns identified by the women were beyond their control. Gillies (1998) advises that partnerships

across sectors, across professional and lay boundaries and between public, private and non-government agencies...[are essential to] tackl[e] the broader determinants of health and well-being in a sustainable manner, as well as in promoting individual and health-related behaviour change. (p. 99)

Perhaps the most critical partnership in addressing cervical screening behaviours is with the un- and underserved First Nations women in the Chinook Health community. It is essential that cervical screening services are examined in light of their perceived needs, barriers and solutions. I begin by examining perceived cervical screening needs.

### ***Cervical Screening: Perceived Needs***

#### ***Information.***

Susan advised, "If you were to open up a [cervical screening] clinic [for First Nations women] ... the word is to get it out, just information, information, information." Focus group participants acknowledged that women on- and off-reserve lack knowledge about cervical cancer and cervical screening. Most were unaware of who should be tested

and how often, what the testing was for, where testing was available, how the procedure was done and why testing was relevant for First Nations women. The women stressed that First Nations women must be aware that cancer, detected at an early stage, is treatable. They also highlighted the importance of distinguishing between testing for cancer versus testing for sexually transmitted diseases.

Misconceptions and misinformation in relation to Pap tests thrive. Cervical screening, often associated with sexuality and sexually transmitted disease, is shrouded in secrecy. Cervical cancer risk factors remain unaddressed, even within the context of traditional mother-daughter or grandparent-grandchild discussions.

I think a lot of it has to do with like our grandparents and that they don't talk about sex, like they don't talk about (anything) sexual .... Like it's almost like it's a dirty thing.... That's how I see it. Like ... your mom ... won't just come out and talk to you about it until ... it's too late. And so that's what I think they really need to get through, like ... it's OK to talk about it. (Rox)

***Responsive services and service delivery.***

The women envisioned an ideal cervical screening clinic as being available, accessible, and client centered. For First Nations women, client centered services offered choice, confidentiality, cultural safety, and collaboration.

Participants emphasized that services must be accessible on- and off-reserve. Rox commented, "These people are concerned about their sisters, their daughters, their aunts, you know, they're not concerned so much about themselves.... They want *all* their people to receive [accessible Pap testing services]." Several women suggested that transportation and day care services be available as needed "because a lot of people ... don't have anyone to watch [their children], or [they] don't have a ride over there" (Cody). She explained,

A lot of people aren't mobile, like with vehicles, to come into town. So like, they go to the doctors ... [on the reserve], so like there's walking distance.... If there were something like that ... [on the reserve], I think a lot of people would go there.

The women also suggested that enhanced hours of operation (e.g., increased days of the week, evenings, walk-in service) would promote access.

If you were considering [offering Pap testing services] in town, then you would probably have it after hours. Like in the city ... a lot of the people are in school, and that's the same for any groups, they're in school, they're working, [or] they have to catch the bus (Julie).

In some instances, previously established relationships with a personal physician meant that Pap Screening Clinic services were not required. Some participants expressed concern that attending a Cervical Screening Clinic would be viewed unfavourably by their personal physicians. One participant told of a friend who was chastised by her rural physician after being seen in emergency and hospitalized in an urban center. In contrast, Dianne was encouraged by her rural physician to attend a screening clinic, but no contact information (e.g., phone number or pamphlet) was provided.

Offering choices whenever possible was viewed positively by the women. For example, many women wanted the choice in who would do the Pap test. Most participants assumed that Pap testing would be done by a physician. While most of the women expressed the desire for the Pap test to be done by a female, several participants indicated that the gender of the person doing the testing would not affect their decision to have a Pap test done. Dianne pointed out that regardless of who did the testing, invasion of privacy was a significant issue. "Well I have a lady doctor ... and she's delivered two of my babies, but I still feel uncomfortable going there." The women wanted the option of having a support person available during the Pap test. For some, having a support



person available during the procedure helped to allay fears or language barriers. For others, privacy during the procedure was paramount. When asked if Pap taker qualifications (e.g., doctor, nurse practitioner) would make a difference in having a Pap test, Julie responded, “I don’t think so, as long as they knew what they were doing, and they talked [the women] through it.” While many participants felt that First Nations staff at Pap testing clinics would encourage First Nations women to attend, Anne disagreed, “I would go to a white doctor rather than to a native doctor. I don’t know why.... A lot of it has to do with confidentiality.”

Confidentiality was a major concern expressed by many of the participants, Due, in part, to the close-knit nature of the First Nations community, several women expressed fear that going to a cervical health screening clinic would rouse suspicion of AIDs or other sexually transmitted diseases. Susan emphasized, “Even if you got [Pap testing clinic staff] to sign a confidential[ity] waiver, I think the fear would still be there.... I think [First Nations women] would want to [know] how that would be handled.”

Congruent with the concept of cultural safety, the women wanted access to “health care service in ways that do not diminish, demean, or disempower them”(J. Anderson et al., 2005, ¶1). The women expressed the need for respect for their unique cultural heritages, experiences, and worldviews. Many recounted experiences of unfriendly waiting rooms and judgemental attitudes encountered at local health clinics and businesses. Dianne reflected:

I think that community has to ... not just label or judge.... Like for example, if a child does not come to school maybe the last week of the month, there is a reason. It’s not because they are playing hooky, it’s not because the parents are out [on] a big drunk you know. It’s not because the children have taken off. There is a reason and a lot of that reason is because these parents are on fixed incomes.

Many participants hoped, ultimately, to positively influence the attitudes of hospital and community health care providers toward First Nations women.

Nearly all of the women agreed that a personal, respectful approach is essential for client-centered service. Rox commented, “I think that the personal touch ... how you just approach people in general, that’s really going to make the difference.”

Several new mothers recounted positive health care experiences; Cody recalled the attentive care she received when she and her newborn infant needed to be re-hospitalized. Susan commented on the personal attention she received at home following the discharge of her premature infant. Another young woman spoke of participating as an active and respected member of the paediatric health care team during the hospitalization of a young relative who had been in a “bad” car accident.

I got to stay with her in the hospital for the two weeks that she was there and they treated me with [respect].... They [had] a portable phone that people could call. I stayed there for two weeks ... they gave me all the information so I was able to pass that information.... They even brought a mat, but I slept with her in her bed. (Julie)

Common to the positive experiences they shared were active listening, caring, friendliness, respect, and responsiveness to voiced concerns.

Other focus group participants recounted less positive experiences, citing a lack of courtesy, respect, and acceptance. Most often, misunderstandings stemmed from a lack of cultural awareness.

My Dad went in to the hospital. They called our family 'cause they thought he was going to be passing on that evening.... We have a big family, and he had friends...we were all there.... They were getting annoyed with us being there [not recognizing that] that's how Natives are with each other. They all like to be with each other, and support each other.... It felt really like we were invading their space.... We didn't feel comfortable being there, but we wanted to be there.... Because they [wouldn't] allow us to be there all the time, we were phoning to get information, and they're rude to us, you know, like, 'We can't release any information, and we're not a telephone directory service, so, can you quit phoning.' (Cody)

Marie, a First Nations elder, reluctantly shared a humiliating experience that, to her, exemplified a lack of communication, personal attention and respect.

I went to [one of the Lethbridge medical clinics] and the nurse told me to take all my clothes off, didn't give me a gown! And I was standing there in the nude, um, and I must have stood there for an hour. I didn't know what to do!

In the traditional native spirit, most focus group participants seemed most comfortable when asked to share their stories (Barnett et al., 2002; Deiter & Otway, 2001; Fox, 2004; Kirkham, 2002; Labonte & Feather, 1996; Napoli, 2002; Saskatoon Aboriginal Women's Research Committee, 2005; Dion Stout, 1999; Dion Stout, Kipling & Stout, 2001). The stories shared by the women often provided insight into complex situations and promoted a shared understanding of the "peculiarities and meaning of First Nations experiences" (Labonte & Feather, 1996, p. 5).

Shared understanding and partnership between physician and patient were not always evident. Many times explanations were unclear. The need for simple, non-medical, easily understood language and pictorial representations was reinforced as participants struggled to understand terms such as "ethnicity" and "cervical vault" ("You know – your *Hoo-Hoo*," one participant explained to another). Several women commented that they had difficulty in interpreting medication labels or instructions provided by their local physicians. Marie revealed, "Myself, I had very little education,

and I have a hard time understanding things sometimes.” One focus group participant stressed the need for clear, simple language to be used in letters requesting that the women return for a follow-up cervical screening visit.

Rox outlined the respectful approach of her local physician:

It’s really good because [my doctor will] even do a drawing.... [For example, when discussing contraceptives, my doctor explained] ‘The blood vessel is like this, so if you had a clot ... it makes a thickening in the blood vessel.’ She really explains it to you so that you don’t walk out of there still wondering, you know.

Several women suggested that a slower pace of interaction and adequate time be allotted for physician office or screening clinic visits.

Most of [the older First Nations people accessing services off reserve] have Blackfoot as their first language.... Things are really slowed down because words in English are converted to Blackfoot and they have to convert it back to English so that the rest of us can understand it.... It’s really a slow pace you know.... When you have to go to the doctor’s office and ... you’ve got 15 minutes and you’re here for one item, and by the time you get it processed ... your 15 minutes is up.... [Feeling rushed and misunderstood] probably happens with the other immigrants in the community [as well as] our Aboriginal people, that’s a big concern. (Rox)

Cody commented,

[My doctor] schedule[s] me so, like, I [won’t] be rushed.... So usually ... [when I make an appointment he’ll] slot me for this much time.... This way he’ll be able to spend time with me ... [to address] all the things I need to know.

Several participants emphasized that cervical screening services needed to be responsive to First Nations women’s needs. Marie, a Blood elder, commented that the focus group provided a valuable opportunity to identify concerns and generate solutions: "I wish the reserve would start doing that... they should be...trying to form a group like this." Active participation in decision-making regarding their health and the health of their community was viewed as essential. Diane reflected on the need for women to recognize cervical screening as an important step toward personal health. “I’m saying

that if it's for your own health, it's for your own good, you will stop and say, 'Hey, I really need to do that. I really need to go'." (Dianne)

The cervical screening visit was viewed as an opportunity to discuss "just anything" (Julie) with their physician, including current health status, test results, and ways to improve their health, including lifestyle changes and general health concerns. Many of the women indicated that the cervical screening visit should provide the opportunity to address woman-specific health issues such as birth control, menopause, pregnancy, sexuality, sexual health, and concerns related to their children and families. Their comments reflected the need for cervical screening services to be provided in the context of holistic, women- and family-centered care. Collaboration across and between organizations, for example, social services and the health care system, was seen as essential.

One participant shared her admiration of the collaborative, seamless approach experienced by her grandmother, a First Nations medicine woman, in the final stages of her cervical cancer-related death.

The community was very small, so the doctor was almost like a part of the family.... He thinks of my grandma like his grandma. When he looks after her, it's like looking after his own family ... so the care was very, very good.... He made sure that when they sent her out [of the hospital] everything was explained to her and [he] gave her a call at home. (Dee)

A collaborative, seamless approach across and between Chinook Health and community programs was demonstrated when one focus group participant shared that she had been sexually abused. Disclosure of this closely guarded secret prompted a follow-up home visit, as the woman had no access to a telephone and limited access to transportation. Support was provided during a subsequent Pap testing procedure. With

her permission, referrals to a professional counsellor, sexual health services and her family physician were initiated.

Overall, service and service delivery needs expressed by these Southern Alberta First Nations women are similar to those found in the literature; they reflect the importance of collaborative seamless service (Arquette, Cole, Cook, LaFrance, Peter, Ransom et al., 2002; Cavanaugh & Cheney, 2002; Deeks, 2004; Rosentretter, 2005; Wilson, 2004) and respectful, personalized care within a context of active listening and care (Bottorff et al., 2001; Browne et al., 2000, Clarke et al., 1998; Dion Stout, 2005; Fitch et al., 1998, Hislop et al., 1996; Hume, 2006; LeTendre, 2002; Kinnon, 2002; Napoli, 2002; Romanow, 2002; Saskatoon Aboriginal Women's Health Research Committee, 2004; Svenson & LaFontaine, 1998; Wilson, 2005).

Yet this study also differs from previously-conducted research. Allen et al. (2003) reports a tendency for individuals from minority groups to seek out providers from the same racial or ethnic group or providers who are fluent in their language. This did not seem to be important for many focus group participants. Their increased comfort with non-First Nations physicians may be related to changing cultural values or to the perception of increased anonymity when dealing with non-First Nations health care providers. In some instances the participants were unaware that a choice of providers is an available option. Yet choice is a central health promotion philosophy and an integral component of traditional First Nations' approaches (Hislop et al., 1996).

Confidentiality of information, seldom mentioned in previous Canadian studies of cervical screening, was identified as a significant need by the focus group participants. These findings are similar to those of Strickland et al., (1996) who report that Indian

women seeking Pap testing at an American family planning clinic face a similar dilemma: “Everyone in the community knows” (p. 145). Close-knit communities may inadvertently jeopardize privacy and consequently limit participation in Pap screening.

***Cervical Screening: Perceived Barriers***

The women identified barriers to cervical screening participation. The most common barriers cited were historical and social influences, physical and psychological factors and readiness for change.

***Historical and social influences.***

Many First Nations women have continued to struggle with the historical impacts of residential school. Many attributed their passive approach to personal well-being to condescending atmospheres and attitudes that pervaded the school setting. Some were left with little sense of self-worth or self-esteem. Yet the impact of residential schools was not limited to the older participants. Younger participants often had parents or relatives who had attended local residential schools. Lack of parenting skills, high risk behaviours, and sexual abuse were cited as evidence of long-term, cross-generational impacts of colonization. Many attributed their general mistrust of non-First Nations health care professionals to lingering effects of cultural repression and loss of cultural identity. Often chasms between First Nations and non-First Nations ethnic groups continue to be perpetuated in contemporary society.

Perhaps the greatest concern expressed was being First Nations in a non-First Nations society. Anne commented on the isolation she felt upon moving to town to go to school “with discrimination and stuff like that. You come from the Reserve or say just going ... from [the reserve to town] you feel like you are discriminated against.” The

implications of discrimination on the pursuit of health and wellbeing among First Nations people cannot be underestimated.

We've been treated so badly from every group out there that why are we going to value ourselves? Why, you tell me why, because no one else has. So now why all of a sudden am I going to value myself? ... That's something that's going to take time. (Terri-Lynn)

Stigmatization was not limited to the non-First Nations community. Anne commented, "[Discrimination] starts with your own people ... that's where it comes from." She continued,

[When I moved from the reserve] I just start feeling discriminated against [by my own reserve community]. Like well, I'm better than her. I know I'm better than her; like that.... A lot of it has to do ... definitely with how you value yourself. There is just nobody out there that is telling you, that's telling everybody, 'Oh, well you are special.'

Another reflected on the animosity she experienced on moving from the reserve from members of her home reserve. Despite being in a crisis situation, she found herself no longer eligible for financial resources available to on-reserve families. It is not surprising that a sometimes imperceptible, yet deep-seated anger smouldered within several off-reserve First Nations women encountered by the writer.

For one elder participant, attention to personal health and wellbeing required re-examining long-held beliefs.

I think my problem is (maybe there's some survivors of residential school ... they have the same problem) ... like I wasn't taken to the doctor.... When I was a teenager I broke my ankle, I wasn't allowed to go to the doctor, so I think in the back of my brain, if I'm sick, I'm scared to go to the doctor, or it doesn't matter. (Mary)

Consistent with the findings of K. Anderson, (2000, 2005), the women reaffirmed that personal value and self-worth were central to the decision to participate in self-care behaviours. A sage research team member reflected:



What I am hearing you say is ... if we want people to have a Pap test because we want to give them better care, the first message is that they are valuable in the world, in the universe and that every single person is that. Right? ... Somewhere we have to plant the seed about the worth of every individual in the universe. And that's everybody's job. (Kate, Co-facilitator)

***Physical and psychological factors.***

Many participants perceived the Pap test as physically uncomfortable or psychologically intrusive or invasive. Some expressed discomfort with the procedure being done by a male Pap taker. Shannon commented, "A lot of women don't like to have 'em because a male doctor does them. So I get 'em done, but not very often because my doctor's a male." Physical and psychological barriers obviously play a part in compliance with national and provincial Pap testing guidelines.

Fear was a commonly identified barrier to Pap testing. Sylvia confessed,

I'm scared of ... scared to get that test.... Last year that they had this program.... I made an appointment, and then I backed off because I was scared. I thought ... 'I'll have to go through with it, [I'll] tell [my granddaughter] to come with me', and she said sure.... So we made an appointment and when it got closer I got scared and I told her, 'I'm sick -I can't go'.... ( group laughter).... And she tell me, well grandma, I'll wait for you, I'll go.... And I end up didn't go. Since I heard about [cervical screening through this focus group], I want to go; I'm not going to back off.

One young woman, haunted by the trauma of childhood abuse, was extremely uncomfortable and fearful when faced with the prospect of having Pap testing done. Shannon explained, "I just don't like the doctor touching me.... I don't like anybody touching me.... I can't *stand* [italics added] anybody touching me. I think that's my fear; even [with] my daughter.... 'Don't touch me'."

Another participant was afraid that the results of Pap testing might reveal unwelcome news. "We're afraid to go see the doctor. He might tell you [that] you have a disease you know.... That's what we're afraid of" (Mary). One elderly participant

observed that many First Nations women avoid Pap testing due to modesty or feelings of vulnerability experienced during the physical examination.

Indian women are very modest, you know. They have a hard time going to the doctor and having this done.... A lot of us have a lot of children, we should be used to it, you know. I have eight kids and, but still, you know, um, we're always reluctant about going .... We really do know the importance of it, you know.... It's just that [speaking to the other focus group members], you guys are too modest. (Marie)

Mary, a residential school student, concurred:

[This] is how we were brought up. We're supposed to be ashamed of our body, that's really been stressed to us often.... That's the part we can't seem to get out of.... That's why we're shy ... trying to cover our body all of the time, you know.

***Readiness for change.***

It became apparent that awareness of the importance of the Pap test in preventing cervical cancer did not guarantee screening follow-up. Several respondents acknowledged that they were aware of, yet did not follow through with, annual Pap testing. Psychological preparation was essential for personal health screening pursuit and follow-through. Often this preparation involved overcoming fear of the procedure, the unknown and in exposing personal vulnerabilities. For some, the support and encouragement of their peers strengthened their resolve to take care of their health needs.

Barriers to cervical screening mirror those of other Canadian First Nations women (Browne et al., 2000; Clarke et al., 1998; Deschamps et al., 1992, Fitch et al., 1998; Hislop et al., 1996, Steven et al., 2004). Yet few First Nations studies of cervical screening address the gap between intention to screen and health screening follow-through. This is an important consideration when attempting to influence the adoption of a new behaviour. Readiness to screen may have been an important factor in the study of

Northwest Ontario Oji-Cree and Ojibwa women conducted by Steven et al. (2004). In this study nearly one-third of the native women had “refused at some time to have an internal examination” (p. 309).

Rather than viewing participation in cervical screening as the “movement from a less desired to a more desired behaviour,” a “readiness to change” approach encourages “alterations in participants’ attitudes toward change ...increased intentions to change, and contemplation of “topics ... overlooked in the past” (Buckley et al., 2003, p. 386).

Several authors have explored readiness for change as a predictable continuum with strategies targeted toward each stage of readiness (Buckley, Goering, Parikh, Butterill & Foo, 2003; Prochaska, DiClemente, & Norcross, J et al., 1992).

Behaviour modelling by elders or individuals who have achieved success and peer influence have also been suggested as a motivator for change (Elias et al., 2000; Fox, 2004). First Nations advocates can be catalysts for responsive change by addressing identified barriers and promoting culturally appropriate, culturally safe, and effective services for the women in their community (Christopher, 2004; Rand, 2005). Advocates can also play a key role in providing support to First Nations women who are “reluctant to use the existing health care services due to unfamiliarity with the services that are available or because they are uncomfortable accessing the system” (Assembly of First Nations, 2004, ¶6).

Concerns for cultural safety (Browne et al., 2000) were implicitly expressed by the women. While the term “cultural safety” was not used by the participants, their expressed needs for respect, acceptance, and recognition of historical impacts and unique cultural worldviews are encompassed under this terminology. In contrast to previous

literature, physical safety concerns were not raised by the women in this study. At present, regional Pap testing services are located at an urban hospital setting. As strategic plans to enhance service availability and access are considered, cultural and physical safety must be taken into account.

Solutions based on identified needs and addressing identified barriers are a critical first step in moving toward comprehensive and responsive services for Southern Alberta First Nations women. Solutions suggested by the focus group participants are presented in the following section.

### ***Cervical Screening: Proposed Solutions***

The women suggested that the place to begin to promote Pap testing was through a “grass roots” approach. Several women suggested that the best way to reach off-reserve First Nations women was to start by reaching on-reserve women. Dianne emphasized, “It has to start at the grassroots people and then it will ripple out there.”

#### ***A grass roots approach.***

Participants encouraged the cervical screening program to collaborate with the Blood Health Centre where a female First Nations physician currently practices. Anne commented:

We are just now at a stage where we are ...developing our Health Centre on the [Blood] reserve. [Previously] they had to take us off the reserve to get checked for cancer. So now that it's on the reserve [new opportunities are opening up.] ... They don't have a place where you can go for your mammogram and all that.

Monthly Women's Health Days, attended by a non-First Nations female physician are currently available at the Kainai Wellness Centre on the Piikani reserve (Yellow Horn-Melton, personal communication, May 2, 2006).

Opportunities to link with existing mobile health clinics were explored by focus group respondents. One participant suggested working with the “Screen for Limb, I-Sight, Cardiovascular and Kidney” (SLICK) screening program. This mobile clinic travels to “all Alberta First Nations communities ... [screening] for metabolic, kidney and cardiovascular complications of diabetes .... [They also offer] early identification and lifestyle counselling” (FNIHB, n.d., p. 26). Another suggestion, collaborating with the mobile Alberta Cancer Board Screening Mammography team to provide concurrent breast and cervical screening on reserves, was viewed positively by participants. Focus group participants also suggested that doing Pap testing in conjunction with other health care services (e.g., physical examination following the birth of baby) would increase cervical screening rates.

Building upon established resources promotes entrance into the community, enhances community capacity and ensures that health promotion efforts targeting First Nations women are sustainable over time (Allen et al., 2003; Cavanaugh & Cheney, 2002; Gillies, 1998; Labonte & Laverack, 2001; Strickland et al., 1996; Swerissen & Crisp, 2004). Linking with existing resources is also consistent with the women’s expressed preference for holistic, women-centered services. Yet entrance into the community is just a beginning. One First Nations health care professional described the commitment required to establish a successful and sustainable First Nations initiative.

When we first started [promoting immunization among CH First Nations the health unit]... had records, stacks of them with our entire Aboriginal people.... They had a stamp that has no show, no show, no show, no show, cancel, cancel. And you know. It was embarrassing. It was really sad for our people, but you know and it took a few years to get people to feel like they can go into the Health Unit and get their kids immunized and they’ll be OK there. That the staff won’t you know, look disgusted at them or you know, whatever. And it took years. So, I think we have to be in that position to do the long hauls. (Rox)

Labonte and Laverack (2001) suggest that program sustainability can be enhanced through building upon the capacity of communities to “define, assess, analyse and act on health ... concerns of importance to their members” (as cited in Gibbon, Labone & Laverack, 2002). Investment in community and commitment to their young are well-known hallmarks of First Nations societies.

***Reaching First Nations women, children and youth.***

Dianne expressed the complexity of reaching the First Nations community.

How do we get that awareness [of cervical screening] out in[to] the community? How do we shape? Because it's very important! And yet I realize it's such a sensitive issue. It's very sensitive, but again we have to look at it in a healthy aspect of things. It's what need[s] [to be] done.... It's our health.

One participant offered, “We would do a presentation. And if you have booklets, um, or even a brochure or even, they'll contact you. Because that's the place to start if you want to get your message across” (Dianne). During the timeframe of this study one-on-one counselling, transportation, health promotion teaching and support to the urban First Nations community were provided by an Alberta Cancer Board sponsored CH lay community worker. May emphatically suggested, “Have more funding and more people available like [the lay community worker].” Others suggested designating someone to come to the reserves to promote cervical screening awareness. This person could offer presentations to inter-agency groups, organize on-reserve presentations in collaboration with the sexual health program, and provide cervical screening presentations to groups of women on and off-reserve with concurrent Pap testing available. Annual telephone reminders (rather than letters of invitation) were suggested as a way to encourage regular Pap testing.

They forget, ‘Oh! It’s been a year; I’ve got to make an appointment.’ If there is any way that the staff could have that come up and they can give them a call and say ‘you haven’t been here for a year’ – reminders. (Rox)

Focus group participants stressed the need to reach First Nations children and youth. Several young mothers pointed out that sexually explicit material on television and the Internet puts young people at risk for “normalization” of early sexual encounters. They suggested that cervical screening education should include information about cervical screening risk factors, sexuality, and sexually transmitted diseases.

One college student suggested that education about cervical cancer prevention should begin as early as elementary school, before children are sexually active. Another participant wondered if First Nations youth might perceive the topic of cervical cancer as irrelevant. In response, other participants suggested that education targeting young people should be integrated with fun events, such as camp presentations featuring fashion shows, healthy sexuality, and Pap testing.

Urban First Nations youth are exposed to technologies unheard of by previous generations. Risky and sexually irresponsible behaviours permeate and are often glamorized through this “new” media (Fox, 2004, Young et al., 2000). Yet technological advances are a reality for contemporary First Nations youth. For example, one young First Nations focus group participant was the creator and moderator of an on-line web dating service. Yet focus group members did not recognize this form of communication media as a way to educate the (mostly younger) electronic-savvy generation (Steven et al., 2004). Yet the women recognized the need to move from a world of silence to one of open sharing of sensitive information.

One young woman shared how she was beginning to break the circle of silence with her young family.

For my generation, my Grandmother would never talk to me about this. She would never talk about this because it's such a – an 'off' topic. You're not supposed to talk about this stuff and my mom she never talked to us about this stuff because of what she learned. So I'm the next generation. And now I'm just starting to talk to my 10- year old about sex. You will not hear that from my Mom because it's just, just so against what she believes in (Cody).

The majority of women agreed that the best way to promote cervical screening among the First Nations community was by word of mouth from mother to daughter, grandmothers to granddaughters, and between family members and friends.

It goes back ... to the grassroots of the people. It has to come from your parents. It has to come from somebody that's older. My mom was the one that said, 'OK, when you get to a certain age you have to go get this done' and she took me for my first Pap.... Because if she didn't then I wouldn't have known that I had to go.... And then she told me like what goes on, you know like that, cause if I didn't know I probably would have been terrified because of the fact because I thought well it's not OK just to talk about it. Like ... sex and stuff like that. (Anne)

Community elders and women heads of households have continued to be influential in traditional and contemporary Blackfoot societies. One Blackfoot participant suggested nurturing a mentoring relationship between the local First Nations youth and elders, and encouraging a return to traditional approaches and ancestral ways of knowing as a means of promoting self-care. She suggested that a spiritual ceremony similar to that practiced by Dakota Indian [and Blackfoot] women (Hungry Wolf, 1996) might provide a unique opportunity to to honour the passage from youth to adulthood and introduce healthy approaches to sexuality.



The mothers and the daughters ... do this ceremonial thing ... when the daughter is becoming a woman.... They will care for her (in a tent or tepee) for about a week (like when she was just like a little girl or their little baby). She'll dress her and then she'll teach [her] about them becoming a woman and then they finally have like this big ceremony at the end where they dress them all in...their native...regalia...a ribbon dress or something like that. And then they take them out and ... say her daughter now is a woman.... It makes them feel special. (Terri-Lynn)

This ceremonial approach embodies a traditional First Nations approach to self-care behaviour, one that is motivated by “health” rather than “illness.”

While ceremonies celebrating passage into womanhood were suggested as a way to pass important, yet potentially sensitive health information, from one generation to the next, the women in this, and previous studies (Hislop et al., 1996), pointed out that Pap testing is often considered a subject not ‘brought out in the open, not talked about’ with family members and friends. Use of lay community workers, comfortable with their own sexuality and familiar with health promotion principles, may be able to bridge this gap (Christopher, 2004; Love & Gardner, 1992; National Health Education Training Centers, 2004; National Training Center for the Prevention and Early Detection of Cancer, 1998; RAND, 2005).

### ***Building bridges.***

Promoting cervical screening among on- and off-reserve women demands that we begin to build bridges with the First Nations community. Essential are an environment of cultural competence and trust and a holistic approach to service delivery. Ultimately services must enrich and enable the women we hope to reach.

Dianne stressed the importance of cultural sensitivity in addressing the First Nations women's needs.

It's just being conscious of the sensitivity around it and in time you will find women will be talking. If you are conscious about sensitivity you are going to get people that will work with you. But if you are not, you are going to get negative feedback and people are going to maybe reject [it].

The critical role that culture and cultural worldview play in the health and wellbeing of First Nations people is well-recognized (CHR Population Health, 2003.; Fox, 2004; Huff & Kline, 1999; Mussell, 2005; Public Health Agency of Canada, 2003; Raphael, 2005; Romanow, 2002; Dion Stout, 2005; Dion Stout & Kipling, 1998; Thurston & O'Conner, 2005). Essential for the provision of culturally sensitive services is "an awareness of the diversity in values, beliefs, and lifestyles that exist among population groups within a society" (Jackson et al., 2001, p 554).

A culturally competent staff is essential to promoting cervical screening among women of diverse ethnic backgrounds. A culturally competent staff is able to apply knowledge about cultural differences in the workplace and "advocate for and tailor services to the special needs of women .... [They] possess the deep understanding that each woman is unique, based on her life experience, culture, spirit, mind, and body" (Allen, Maxwell & Harpole., 2003, p. 197). Jackson et al., 2001 suggest that, in addition to culturally competent and sensitive staff,

institution[s] must have minority women in key leadership and policymaking positions, ... strategies to solicit input from the communities being served, and mechanisms to incorporate the communities' recommendations into the day-to-day operations of the institution. (p. 556)

Building trusting relationships, linking with others, promoting active community participation, assessing problems and "asking why" are key to building the capacity to respond to voiced concerns, sustain change efforts, and enhance the ability to identify and address health, economic and social issues (Labonte & Laverack, 2001; Romanow,

2002). Cultural competence means embracing cultural diversity while recognizing universal truths (NECHI, 2005; Wolfleg, 2005).

Diverse approaches to health and healing exist. Traditional practices embraced by many participants were not universally supported. Cody commented, “[Spirituality is] based not so much [on one’s ethnic] background ... [but on] how much your family is involved in it.” For others, religious influences of residential schools are intermingled with traditional spirituality. Sylvia, a former residential school student, has continued to embrace her Catholic faith. In contrast, one young woman commented, “Our family has always been involved with the Native way of life ... smudging and praying, attending ceremonies, attending sweats, just being with family, extended family. It’s just a natural way of life – the way we were brought up” (Julie).

In contrast to traditional cultural spirituality highlighted in the literature, a blending of spiritual approaches was practiced by focus group participants. This finding is consistent with Fox (2005), a Blackfoot researcher, who states: “Slowly sacred ... indigenous (ways) ... are disappearing from the daily lives ... of many Aboriginal peoples” (p. 25). Yellow Horn-Melton points out that “modern” Southern Alberta First Nations women embrace a blend of cultures and philosophies in their pursuit of health and wellbeing (personal communication, May 2, 2006). The breadth of beliefs shared by focus group participants may signal the need to address cervical screening using a broad range of approaches. Yet one focus group participant pointed out the universality that transcends cultures. “I think we're all the same as any culture, we’re always searching, you know”(Rox). Kate reflected, “It’s not all about being Aboriginal. It’s not. It’s about us being women.”

***The need for a holistic approach to cervical screening.***

The need to approach cervical screening from a holistic perspective was stressed. For focus group participants, a holistic approach meant achieving a balance between physical, mental, emotional and spiritual health within the context of family and community (rather than a focus on the cervix). The Medicine Wheel has often been depicted as a “concept central to the cultures of many Native Nations people” (Weaver, 2002, p. 6) and suggested as a culturally appropriate framework for discussions of health and wellbeing (Deiter & Ottway, 2001; Saskatoon Aboriginal Women’s Health Research Committee, 2004; Weaver, 2002). Its use is common in Canadian healthcare settings, prisons and detoxification centers (Fiske, personal communication, May 2006).

While most focus group participants acknowledged the importance of a “balanced” lifestyle, the graphic depiction of the Medicine Wheel was not recognized by many Blackfoot participants. One Blackfoot health professional spoke of using the Medicine Wheel framework with minimal success. In response, an older participant challenged this approach.

There’s such a thing as Medicine Wheel in the Blackfoot? The Medicine Wheel is used when interpret[ing] the tepee rings.... I’m sure there are four sides, and those are the sides when the enemy is coming. Like in the olden days.... They go out this way, North side, West, whatever. That’s why those lines are there. (Mary)

Another First Nations health care professional explained, “It’s kind of like ... an American Indian kind of philosophy” (Rox). She went on to describe:

It's a new concept.... We've implemented it in ... some of our [Chinook Health] programs ... to help us in keeping balance.... It's a tool that makes us kind of think we can't put too much into ... [one area and ignore the rest. For example] exercise junkies get this really fit body, but mentally they may not be that balanced, because they're so focused on this physical activity that they don't think about their family life, their social life, their mental health, you know...those kind of things. So ... we try to use it as a tool to try to get people to look at maintaining a balanced life.(Rox)

Blackfoot literature and historians substantiate that the Medicine Wheel conceptual framework, originally developed by the Crees, is not consistently embraced by all Prairie tribes (Dion Stout, n.d.; Fox, 2004; Heavy Head, personal communication, May 2006; Weaver, 2002). Heavy Head, a local Blackfoot anthropologist, points out that the Medicine Wheel fails to recognize the symbiotic relationship between Blackfoot men and women (symbolic of the cosmic relationship between the sun [fire] and moon [water]), a concept central to Blackfoot mythology (personal communication, May 19, 2006). While recognizing differing tribal interpretations, Dion-Sout, an Alberta Cree, postulates,

[Overall, the medicine wheel provides a] useful illustration of the Aboriginal approach to health. In short, by calling upon individuals to be personally committed to inward and outward balance, not only does such an approach prioritize wellness over illness but it also serves to highlight the manner in which the mind, the body and the spirit are all connected to the state of one's health. (Dion-Stout, n.d., p. 7-8)

It becomes apparent that when used with a First Nations population, awareness and a shared understanding of the philosophical underpinnings of the Medicine Wheel are essential for cultural relevance and personal empowerment.

McCubbin & Cohen (2002) describe empowerment as increasing personal, interpersonal, or political power so that individuals, families, and communities can take action to improve their situation. Focus group participants were encouraged and

empowered to advocate for personal and community needs. One woman was encouraged to share her fears of the procedure with her doctor. Another was encouraged to contact the taxi company whose driver neglected to give her the correct amount of change.

Dianne, a mother of school-aged children shared her sense of empowerment as she advocated for her people as a member of an off-reserve planning team:

I was determined to work with the [planning team] .... [My children and other First Nations children] were running into problems.... Somebody has to advocate.... [As a result of First Nations involvement in strategic planning, there is now] more understanding about ... our cultural ways.... We're starting to see some of the inroads.... [In the end, the team members] said, "If we are going to do this, we better walk our talk." (Dianne)

She also described the courage her involvement required:

You don't know how humiliated I was... because I was the only woman...and there were all men that were educated. Like there were some of them [who had] doctor [degrees]... . There were times when I didn't even want to go to the meetings I just felt so humiliated. I was even scared to open my mouth.

Terri-Lynn countered,

However, you were the doctors of your culture.... Education [is] not just in a classroom, but our whole life experience. You can't forget that.... When we talk about educating people, well, we could have someone with a PhD but just has no people skills at all, so are they really educated?... We have Elders that are educated 'to the T' in the culture and we won't say that they are not educated; you know, they are. They are teachers, teachers of the culture.

One of the most positive aspects of the focus group was voiced by the CH First Nations representative, who, on returning from driving the women home from the focus groups, commented, "[The focus group participants] did feel important, you know, and ... that really makes a difference" (Rox).

Empowerment is key to facilitating and enhancing people's capacity to change for the better and to have a sense of control over their own lives (Gutierrez, as cited in McCubbin & Cohen, 2002; McCubbin et al., 2003). By involving people in planning,

providing choices and working toward making their visions a reality, First Nations women are empowered to contribute to improving the health of their on- and off-reserve communities (Allen et al., 2003; Arquette et al., 2002; Assembly of First Nations, 2004; Bastien, 2004; Barnett et al., 2002; Clarke et al., 1998; Cardinal et al., 2004; Currie & Wiesenberg, 2003; Dickson & Green, 2001; Dion Stout, 1999; Laverack & Labonte, 2000; Napoli, 2002; Saskatchewan Aboriginal Women's Health, 2004; Smylie, 2001; Steven et al., 2004; Strickland, 1996; Thurston & O'Conner, 2005; Wilson, 2005; 2004).

The empowerment fostered by the focus groups extended beyond the participants to the research team, as evident in the following statement:

Most significant [is that] we're committed to sharing this information with the rest of the Chinook Health region – so that the awareness level goes up.... [Others simply] talk about it .... [We] want it to go to the front line staff .... That's the key thing. (Kate)

### ***Promoting Cervical Screening: Promoting Health***

Promoting cervical screening is an important step toward promoting the health of the First Nations community. Elias et al. (2000), in a study of health-promoting behaviours among Manitoba First Nations, reports that positive health behaviours tend to cluster within individuals. In other words, an individual who adopts one healthy behaviour is more likely to adopt other positive behaviour changes.

While focus group participants described the ways that they take care of their physical health - through healthy eating, adhering to special diets and participating in regular exercise, little mention was made of secondary prevention activities (e.g., cervical screening) as a way to maintain personal health and wellbeing. Only one participant commented that she scheduled annual mammograms "...because, well, I'm getting up there in my age" (Dianne). In describing her approach to health, another young

participant stated, “I don’t smoke, I don’t do drugs, I don’t have alcohol in my life.... Those are big factors that probably keep me healthy” (Susan). Yet this participant did not identify smoking as a risk factor for cervical cancer. In contrast, several participants were observed smoking prior to the focus groups. “Tobacco has really been apart of our culture,” one First Nations research team member explained.

Several participants reported that they kept healthy by visiting their doctor regularly. One young participant commented, “I really go to the doctor a lot ... [I] make sure I work with the doctor [on maintaining my health]” (Cody). Physicians are commonly perceived by society at large as source of health. There may be a perception that necessary screening will be automatically performed at the doctor’s visit. For many regional physician clinics, this is not a current standard of practice (CHR Cytology Lab, 2004). It is essential that physicians promote cervical screening as an integral health promotion strategy.

To date, effectiveness literature has focused on modification of individual behaviours in relation to health promotion and disease prevention. While this approach has been found to be most effective with the approximately one in four individuals who are “better off, better motivated, and better educated”(Gilles, 1998, p. 98), the needs of First Nations women often go unaddressed. New population-based approaches to First Nations health are required, directed toward meeting the needs of this underserved and often unserved population. The women have provided their suggestions for enhancing services for the women in their community. It is time to listen.



### *Summary*

The literature reflects the critical need to share cultural perspectives, establish trusting relationships, raise awareness of “sometimes uncomfortable issues” and address barriers experienced by women in the community” (Barnett et al., 2002, p. 41). The focus groups offered by the Cervical Screening Program have provided an opportunity for the women to identify and explore options for culturally relevant cervical screening services.

In the final chapter of this thesis, I will summarize the steps I have taken along this journey of discovery. First, I will review the questions that originally stimulated this investigation. I will review the methodology, analysis process and the key findings of the study. I will summarize the findings in relation to current literature and the theories that provided the underpinnings of this study. I will highlight findings unique to this field of inquiry, explore opportunities for further research and examine the concepts of reflexivity and reciprocity in relation to this research study. In closing, I will provide recommendations for education, practice and policy based on study findings.

Today the only constant is change. Change is a material and lasting difference. Indigenous communities face the same dilemmas of constant change that people face everywhere.

M. Dion Stout. (1999). Keynote Presentation.<sup>29</sup>

Those who expect moments of change to be comfortable and free of conflict have not learned their history.

Scott. J. W. (n.d.).

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Note. From Keynote Presentation, by M Dion-Sout (1999, August 25). Retrieved Feb. 7, 2006, from [http://www.pdfforum.org/dion%20Dion Stout.html](http://www.pdfforum.org/dion%20Dion%20Stout.html) Copyright (n.d.) by M. Dion Stout. Reprinted with permission.

## Chapter 5

### Overview and Conclusions

#### *Introduction*

The purpose of this focused ethnography was to gain an understanding of the cervical screening needs of First Nations women living off-reserve in this Southern Alberta Chinook Health region and to involve them in identifying solutions to barriers they face. Canadian First Nations women face increased rates of cervical cancer and mortality up to six times higher than the general population. The costs of failing to address this preventable cancer are great: the loss of women, mothers and elders, and the lost transmission of culture and cultural values (Band, Gallagher, Threlfall, Hislop, Deschamps & Smith, 1992; Clarke et al., 1998; Steven et al., 2004; Strickland, 1996; Young & Choi, 1985, Young et al., 2000). Yet the reality is stark, cervical cancer is almost totally preventable through a relatively simple procedure, the Pap test. However, First Nations women seldom utilize available Pap testing services. Chinook Health is faced with the task of determining how best to promote Pap testing with this high risk population to prevent further loss of life. First Nations women living off-reserve are in an ideal position to provide valuable insight into the design of preventive interventions and services to meet the needs of women in their community.

This focused ethnography has provided an opportunity to examine current Pap testing services from an urban First Nations' perspective and to investigate what does and does not work for the purpose of informing our understanding of culturally competent care (Bottoroff et al., 2001). This study is unique in that it provides one of the first glimpses of cervical screening and utilization of cervical screening services from the

perspective of Southern Alberta First Nations women living off-reserve. It is also significant in that it lays the groundwork for culturally sensitive, collaborative program planning and research, foundations essential for eliminating the significant health care service disparities faced by the First Nations population.

### ***Study Methodology***

Thirteen purposefully-selected First Nations women 18-69 years, living off-reserve, participated in three focus groups held between November 2004 and June 2005. Conducted in collaboration with First Nations CH staff and the health promotion specialist from the CH Breast/Cervical screening program, these focus groups provided a rich insight into incentives and barriers to cervical screening faced by off-reserve First Nations women. Respected First Nations community leaders engaged in interactive dialogue, sought clarification, supported, yet challenged each other's ideas and collectively shared their insights as to how to effectively reach on- and off-reserve First Nations women. This heterogeneous group also shared their rich accounts and stories about their health care experiences and their pursuit of health and wellbeing.

### ***Results***

In general, cervical screening was not a high priority among focus group participants. For many, the pursuit of health-promoting behaviours (e.g., Pap testing) was overshadowed by the lack of basic necessities such as safety, clean water, transportation and adequate income. Many of the challenges faced by the urban First Nations' community fell within the multiple, inter-related factors that "determine health." Artificial on- and off-reserve boundaries were challenged by the participants as they moved freely between these two settings. They stressed the importance of reaching *all*

First Nations women regarding cervical screening. First Nations women lacked basic knowledge about cervical cancer and Pap testing. Focus group participants suggested that few women in their community knew how and why cervical screening was important for First Nations women. For some the topic of cervical screening was shrouded in secrecy or fear. Many misconceptions about cervical screening still thrive. The women expressed the need for cervical screening to be provided in the context of balanced, culturally sensitive, holistic, family and community-centered care. They highlighted the importance of being able to openly discuss women's health and sexuality in a safe environment. Respect, choice, flexibility, and for some, a more relaxed approach were desired. This research project affirmed the important links between health and wellness, and cultural identity and self-worth. Healing of historical wounds and reclamation of personal identities and self-worth were deemed prerequisite to the pursuit of self-care.

Concepts that emerged from the data are compatible with and build upon existing nursing, psychosocial and population health theory. In this chapter, I compare study results to existing literature, practice and theory by examining consistencies, differences and unique findings. I reflect on my personal and team growth, and provide recommendations for education, practice and policy. In conclusion, I examine opportunities for further research.

### ***Comparing Results to Existing Literature, Practice and Theory***

Many of the findings of this qualitative research study echo existing published findings regarding cervical screening and Canadian First Nations women. This study supports the intimate relationship between culture, cultural worldview and the health of First Nations communities. First Nations cultural diversity is highlighted – in

philosophies of health and wellbeing, in preferences related to health services and service delivery and in the traditional practices embraced. Similar to other Canadian studies, this research points out the need to disseminate basic, relevant knowledge about cervical cancer and Pap testing to First Nations women. Furthermore, it highlights the need to reach a diverse audience. Consistent with existing literature, the women have expressed the need for responsive, client-centered services that provide the opportunity to openly address sensitive women's health issues in an environment that fosters choice, confidentiality and cultural safety. The significance of being truly "listened" to and treated with respect, highlighted by the participants, has been frequently recognized in the literature (Allen et al., 2003; Andrews, 1998; Assembly of First Nations, 2004; Barnett et al., 2002; Cardinal et al., 2004; Cole, 2002; Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000; Kenny et al., 2004; Mihsuah, 2001; Saskatoon Aboriginal Women's Health Research Committee, 2004; Smylie, 2000, 2001; Wilson, 2005). It reiterates that the ability to meet basic human needs (Canadian Public Health Association, 2002; CHR, n.d., CHR Population Health, 2005b; Canadian Public Health Association, 2002; Calgary Health Region, 2005; Raphael, 2005) and a strong sense of personal self-worth are prerequisite to addressing health promotion and self-care (K. Anderson, 2000).

Commonly cited concerns about the Pap testing procedure for example, fear and perceived procedural and psychological discomfort need to be recognized and addressed and prompt close attention to new methods of prevention and detection of cervical cancer. Finally, the importance of meaningful input and active involvement in strategic planning, leadership and research, commonly mentioned in the literature (Browne et al.,

2000; Oelke, 2002; Wilson, 2004) have been emphasized by the First Nations participants.

To date, few health research and policy writers have distinguished between on-reserve and off-reserve First Nations needs (Dion Stout, 1998). Furthermore, First Nations people are often subsumed within the broader category of “Aboriginals” (CHR 2002, 2003). Infrequently discussed in previous studies, this study highlights the heterogeneity of First Nations cultures and cultural worldviews. Cultural diversity and evolving First Nations cultures demand that health care professionals understand First Nations cultures through a lens of “displacement, transplantation, disruption, positionality, and difference” (Denizin & Lincoln, 2005, p. 326). In the past, mainstream policy makers and academic researchers have shown very little interest in issues and challenges facing Canadian Aboriginal women (Dion Stout, 1998, p. 20). While this situation has “improved somewhat...large gaps in the literature continue to exist” (Dion Stout, 1998, p. 20).

Infrequently recognized in published Canadian medical, nursing and psychological literature, yet reflected in the stories shared by these Southern Alberta First Nations women is the significant cross-generational influence that historical events and inequities continue to have upon health and health-seeking behaviours (Mussel, 2004). Similar to the Saskatoon Aboriginal Women’s Health Research Committee (2004), the women in this study have experienced fragmentation across programs, disciplines and sectors. They have emphasized the need to move beyond current approaches focusing on health disparities, illness and negative outcomes to an approach that builds on strengths, resiliencies, capacity building and advocacy (Abonyi, 2006; E. Johnson, 2006; Smylie,

2006; Weaver, 2002). This study suggests the need to examine the gap between intention to screen and participation in Pap screening in relation to readiness for change rather than compliance.

Several findings documented in the literature are not reflected in focus group discussions. While cultural safety concerns were voiced, the off-reserve Chinook Health First Nations women did not identify physical safety concerns in relation to cervical screening (Clarke et al., 1998). Cultural and physical safety are important factors to consider as the Chinook Health region plans for satellite “outreach clinics.” Gaps between provincial and federal funding and policies for First Nations people and programs, commonly identified in the literature, were not discussed by focus group participants. While several of the First Nations participants were acutely aware of local tribal election issues and financial struggles faced by the reserves, their knowledge of broader funding and policy issues may have been limited or not perceived as being within the scope of focus group questions asked.

Several new findings are highlighted. This study is one of the first to examine the cervical screening needs of First Nations women in Southern Alberta. It emphasizes that on- and off-reserve residence and population mobility are important considerations when planning services for Southern Alberta First Nations women. The need to begin with grassroots people on the reserves when addressing the cervical screening needs of off-reserve First Nations women is new. Many opportunities to build upon established resources have been shared. By building upon these foundations, acceptability, sustainability and capacity-building among First Nations women and communities will be promoted.



This study presents practical solutions to the barriers faced by Southern Alberta First Nations women. Culturally relevant, acceptable, “made in Alberta” suggestions from First Nations women intimately aware of the needs of their community are provided. This project demonstrates that First Nations women are prepared and committed to participate in this endeavour.

Within this qualitative study, several contradictions and potential opportunities are apparent. While the sharing of sensitive information by word of mouth and from mother to daughter was suggested as the optimal way to reach First Nations women, this seems to be contradicted by the “culture of silence” and misinformation mentioned as concerns by focus group participants. Additionally, the close-knit nature of First Nations communities may paradoxically be a barrier to confidentiality.

While the literature has addressed information sharing from elders to youth, and from First Nations to non-First Nations people, little recognition is made of the two-way learning within and between tribes, on- and off-reserve and between cultures. Many opportunities for multi-directional, cross-cultural sharing and education and negotiated philosophies of health exist.

While regions continue to work towards improving the health of First Nations people, many contradictions continue to exist within the practice area. For example, stories, rich sources of information and an integral part of First Nations culture, are often negated in the current system by demands for efficiency and immediacy and are further discouraged by dismissive attitudes exhibited by healthcare personnel. Few health practitioners recognize that the Medicine Wheel framework is not acknowledged by many First Nations, including those living in Southern Alberta. This is important

considering the widespread use of this framework in multiple settings (e.g., drug treatment and prison environments). While there is verbal acknowledgement of the need to listen to and enhance the empowerment of First Nations women, few opportunities exist for meaningful involvement, leadership or well-paying positions for CH First Nations individuals. Short-term funding initiatives (such as this project) lack a recognition and acknowledgement of the value of, and necessity for, sustained, long-range, community and population health approaches.

There exists a need to acknowledge the diverse cultural perceptions intimately associated with First Nations health and health practices. Foundational to self-care behaviours is the need to address the determinants of health. The limited ability of individuals to affect improvements in the determinants of health must be recognized. Strategies must acknowledge the need for a collaborative, multidisciplinary, cross-sectoral, population-based approach.

This study builds upon the theoretical frameworks that provided the underpinnings of this study. Consistent with Pender et al.'s health promotion model (2002), off-reserve First Nations women's abilities to initiate and adopt new behaviours is mediated by numerous factors, including individual characteristics, knowledge, attitudes, competing demands and preferences, and situational and interpersonal influences. Expanding upon Pender et al.'s theory and consistent with the theoretical models proposed by the National Native Association of Treatment Directors (NECHI, 2005) and Connors (as cited in NECHI, 2005), this study suggests that acknowledgement of diverse cultural worldviews and healing of historical and social wounds are critical to self-esteem, self-worth and ultimately self-care. Furthermore, a culturally competent staff

and a culturally safe, collaborative approach were viewed as instrumental in promoting positive behavioural change. Pender et al.'s model does not mention knowledge as a prerequisite for action, nor is the incremental decision-making process (the "readiness to change") that precedes commitment to change recognized. In contrast to Pender et al.'s model, First Nations worldviews demand that individual health be considered within the context of family and community health. The women viewed early intervention (e.g. education of children and youth) as a critical aspect of reducing the risk for cervical cancer and providing holistic service.

### ***Personal and Team Growth***

This study has stimulated a rich, diverse, multidisciplinary and cross-cultural exchange of ideas and opinions and nurtured personal and team growth. In the next section, I reflect on my personal learning and the learning of others on the research team. I explore my hidden assumptions and unexpected learning and, in closing, present recommendations for policy, practice and research.

### ***Reflexivity***

It is appropriate that my journey of reflection is a circular one. In reflecting upon the things I have learned and the distance I have travelled, I must go back to my personal diaries and assumptions made at the start of this journey. Less than two years ago, I had little knowledge about First Nations people and First Nations culture, even though I have resided in a community in which nearly 7% of the regional population is of First Nations ethnicity (CHR Population Health, 2003). I had no knowledge of residential schools, even though the last federally funded residential school closed less than twenty years ago (Indian Residential Schools Resolution Canada, 2006).

My participation in this study demanded that I question and explore my role as a “tool of the research,” my relationship with others, how I perceive social and organizational realities and my way being in the world. It has given me the opportunity to learn more about focus groups and participate in new and challenging roles. My perception of the focus group as an efficient means of data collection has been challenged. The collection and analysis of qualitative focus group data was arduous and time-consuming. Yet, in retrospect, it has provided a depth of information impossible to attain through empirically-based studies. This focused ethnography has given me a greater awareness of issues, of different perspectives, of responsibilities and ethical action and of “how we might transform academic, organizational, and social practice” (Cunliffe & Junn, 2002, p. 4). It has forced me to “ ‘complexify’ my thinking by exposing contradictions, doubts, dilemmas, and possibilities” (Cunliffe & Junn, 2002, p. 5). I have been prompted to examine, clarify and reshape my personal philosophies of health and have come to appreciate the need for a holistic perspective that incorporates epidemiological study, health promotion and prevention, risk reduction and culturally-mediated service delivery. This philosophy is similarly reflected in the “population health” framework embraced by Health Canada and the Canadian Public Health Association (Zollner & Lessof, 1998; McCubbin, 2001). While my knowledge of First Nations health is immature (*okaki*), this study has played an important first step in my personal quest for an integrated, mature First Nations understanding of health and wellbeing (*mokakssin*) (R. Heavy Head, personal communication, May 19, 2006).

### ***Team Growth and Capacity Building***

Several comments made by the research team reflect that they, too, have grown. Terri-Lynn commented, “In my own research, I know what is expected of me and solely me and when you’re part of a team, it’s different... You have different responsibilities. That’s new to me.” The project has demanded flexibility and spontaneity. The research team had to have confidence and trust in each other. Kate reflected, “When we’re talking about trust – we learned it too. It wasn’t just the ladies that learned it. We kind of [learned it] with each other.” The participatory group process requires a new way of working, shifting from the researcher as “expert” to one of “work[ing] together to develop a greater collective capacity to change the circumstances of their own lives [through]...*collective capacity building* [italics added]” (Kemmis & McTaggart, 2005, p. 598).

### ***Hidden Assumptions and Perceptions***

Unexpectedly, the focus groups unearthed hidden assumptions and perceptions. The first insight I had was when one young woman walked into the focus group. She didn’t look “First Nations” so I asked her if she had been invited. It was revealing to me that I had already labeled this person and assumed that all First Nations women would *look* First Nations. “[Yet] she is more traditional than [the other group participants],” one of the First Nations co-facilitators pointed out.

In another instance, I found myself feeling unsettled when the nurse in the “culturally appropriate” video, “the Pap test” (Genereux, n.d.) was a First Nations woman and the learner a young white woman. In sharing this reaction with a Blackfoot woman who had not participated in the focus groups, she recounted a similar experience. When

buying shoes she was surprised to find that the First Nations woman who served her was not a salesperson, but rather the proprietor of the shoe store. During the course of this study, I attended an on-reserve funeral; I was surprised at how unfamiliar it felt to be one of the few non-First Nations persons in a First Nations community setting. I also encountered mixed feelings: elation when I discovered a children's book celebrating First Nations heritage and identity, yet discomfort when I experienced First Nations presenters proclaiming, "We will gain power once again." I could very much identify as Kate, the health promotion specialist joked with the First Nations community health worker, "Sorry, but I was on a learning curve.... I'm a white man!" For me these experiences suggest that this new collaborative learning is incremental, multi-directional and will require a delicate balance of giving, receiving, and sharing across and between cultures.

### ***Unexpected Learning***

While not totally unexpected, the focus groups reinforced the fact that on- and off-reserve women are often isolated with limited access to Chinook Health resources due to lack of transportation and/or telephones. The willingness of focus group participants to share intimate details of their lives, in particular sexual health issues, was surprising, yet provided an opportunity for frank and open discussion about often-hidden experiences and concerns. Many First Nations research participants, on reviewing the results of this study, requested that their actual names (rather than pseudonyms) be used. In addition to confirming the accurate reflections of their perceptions, this also provides an indication of the pride they feel in being a part of the research process and being able to contribute positively to improving the health of their community.

### *Dialectic Learning*

Dialectic learning moves beyond personal reflexivity to a “shared meaning” that results from the rich, diverse exchange of ideas and opinions. As this diverse group explored barriers and worked together to find solutions to identified concerns, dialectic learning was stimulated. This study, therefore, has served not only as a qualitative inquiry, but has provided a platform to bring together First Nations women, community members, academics, researchers and practitioners from divergent disciplines and sub-disciplines. Consistent with dialectic learning, this project has resulted in self and group learning, construction and reconstruction of meanings, examination of the relationships between culture and health, and incremental, yet significant change. As projected, the focus group context has provided an opportunity for active input, a rich exchange of ideas, and a collegial groundwork for pragmatic, collaborative ventures. Central to this project has been a “faith in the power of dialogue” and the belief that “dialogue, fellowship, and solidarity are essential to human liberation and transformation” (Friere, as cited in Kamberelis & Dimitriadis, 2005). The focus groups served as a catalyst for most of the participants to subsequently book and receive Pap testing.

In addition to answering our questions, the research process has resulted in many more questions left to be explored. This iterative process is reflected in Denzin & Lincoln (2000):

Current cultural critique mixes disciplinary genres, - those that emphasize experience, subjectivity, reflexivity, and dialogical understanding - that order of signs and practices, relations and distinctions, images and epistemologies – drawn from a historically situated cultural field – that come to be taken-for-granted as the natural shape of the world and everything that inhabits it – can reveal or uncover internal contradictions as arbitrary and negotiable – it is ‘never total or complete; it is always porous.’ (p. 330)

***Implications for Policy, Health Practice, and Research***

Reducing the gap between “what we know” (the research) and “what we do” (policy decision) is key to providing evidence-based cervical screening services (Findlay, 2004). Many opportunities to promote service utilization and enhance the cervical screening experience for First Nations women have emerged from this study. Discussions and suggestions are pragmatic and relevant, “grounded in ...personal experiences and life challenges” (Dion Stout et al., as cited in Benoit et al., 2003). Study findings should be taken into consideration when designing a cervical screening clinic for First Nations women living off-reserve in the Chinook Health region. Recommendations for cervical screening that have emerged from this study will be presented in terms of professional practice (issues related to education and program planning), and operational policies (issues related to system functions).

***Professional Practice Implications***

***Cervical screening education.***

Southern Alberta First Nations women living on- and off-reserve need basic information about cervical cancer - who, what, when, where, why & how often cervical screening should be done. The women need to know why Pap testing is of particular relevance to women in their community. They need to be aware that cervical cancer, if detected early, is treatable. The use of simple non-complex terminology is essential; diagrams and literature in traditional Blackfoot language are of particular importance when discussing intimate and personal subjects such as identity, sexual, and cervical health. Similarly, Pap testing results and written requests for follow-up should be simple, clear and in a language understood by the recipient. For older First Nations participants,



transmission of information may be best accomplished orally with the assistance of a translator fluent in Blackfoot. The close-knit nature of kinship relationships and on- and off-reserve mobility demand consistency of information between health care providers and sites.

For women of all ages, education and regular screening activities must be encouraged within the context of diverse cultural and spiritual beliefs. A variety of educational approaches is required to meet the needs of the heterogeneous First Nations population. Off-reserve focus group participants have found the “talking circle” approach a valuable way to share and learn. One elder residing off- reserve has suggested that similarly formatted educational sessions be conducted on-reserve. For some, a one-on-one approach was preferred. Rather than focus on illness prevention, First Nations cervical screening education should be approached within the context of holistic care and health promotion. Cultural teachings and stories (a central part of traditional and contemporary Aboriginal culture) are powerful places from which to guide and teach health and wellness practices.

Cultural sensitivity and safety should be compulsory components of staff education. Prerequisite to culturally competent care is a basic understanding of First Nations people, their culture and history, and the unique economic and socio-cultural challenges they face. Confidentiality, a major concern for focus group participants, should be stressed at the outset of educational sessions and at each cervical screening visit. Lay community workers should be recognized as important links between First Nations and the Chinook Health region. Ideally, these workers should be role models, well-respected community members or elders. Resources and training need to be

provided to the lay community workers to promote holistic, consistent, evidence-based health information.

Healthy sexuality and self-care behaviours need to be introduced early to First Nations children and youth. Educational activities also provide a unique opportunity to promote positive self-identity and self-worth, integral in the pursuit of personal health and wellbeing.

New and innovative ways of reaching the mostly younger, technologically savvy population (e.g. interactive computer and MP3 software) and blended traditional and contemporary approaches (e.g., traditional ceremonies celebrating the passage into womanhood) might be explored and integrated into current marketing and educational strategies.

***Cervical screening service delivery.***

Cervical screening programs for First Nations women should clearly outline a culturally sensitive service delivery model that is harmonious with CH's mission and goals. To be accepted by First Nations women, cervical screening services need to be provided within a family- and community-centered context that promotes a shared holistic understanding of identity and well-being (Wilson, 2005). Cultural tolerance, acceptance, and respect should be evident throughout the health care encounter.

Sufficient time for the traditional story-telling approach familiar and preferred by many First Nations women should be allotted when booking appointments. Open discussion of women's health issues should be encouraged. Choices, including multiple points of access, service provider ethnicity, gender and qualifications, and support person or translator assistance should be offered wherever possible. Chinook Health cervical

screening service options (including availability of female pap-takers) and contact numbers should be disseminated to regional physician clinics and throughout the community.

First Nations women have recommended that cervical screening services be available on-reserve in conjunction with already established services. Collaborative opportunities and solutions hold promise for maximizing resource use, reducing costs and promoting acceptability. Identified barriers to screening provide a regionally specific, pragmatic starting point for CH Breast/Cervical Program quality improvement activities.

Measures of program success should build upon individual and community strengths and recognize and acknowledge readiness to change. Cervical screening rates, in isolation, should not be the sole measure of program success. Consistent with a community development approach, process measures, that is, the progression from one stage of readiness to another or the development of trusting relationships, should be integrated into measures of program success, with resources and support allocated in response to identified needs and successes.

### ***Policy Implications***

Chinook Health should actively support the prevention and early detection of cervical cancer among on- and off-reserve First Nations women. Culturally sensitive approaches to education and program design are essential for project sustainability and adoption of new behaviours and attitudes. It is essential to move from a negative First Nations focus to one of self-value, resilience, capacity and capacity building. As population demographics shift and the multicultural makeup of the region expands, the role of a “cultural advocate” may go far in reaching out to the First Nations community,

reducing health disparities and encouraging the CH mission, the “best of health for everyone.” Cross-cultural understanding is fundamental to reducing the marginalization that continues to be experienced within and between cultural groups.

This research study highlights the importance of moving toward a culturally safe approach, one that “recognizes, respects and acknowledges the right of others” (Conney, as cited in Browne et al, 2000). At an organizational level, structural communication must be “radically altered to allow for transfers of power to First Nations governments” (Browne et al., 2000, p. 9). The opportunity for meaningful input into decision-making, program planning, research, and policy development should be extended to the First Nations community. Decision-making on regional issues that will impact the First Nations community should include both on- and off-reserve communities. At the same time, requests for First Nations participation in Chinook Health projects should be orchestrated to minimize the demands faced by First Nations. It has been said, “Aboriginal people...are the most studied – but least understood – group in Canadian society” (Hanselmann, 2001, p. 3).

The focus groups have provided the impetus for the First Nations women to play pivotal leadership and advocacy roles in promoting personal and community health, modelling positive behaviours, and working collaboratively to reduce barriers faced by women in their communities. Ongoing opportunities for women to work together, actively support and celebrate each other’s success and identities should be encouraged (Wilson, 2004). Regional guidelines and policies should provide guidance when dealing with issues identified by study participants (e.g., Pap testing frequency, Pap taker

qualifications, cultural competency and ethical guidelines for dealing with sensitive issues such as sexual abuse).

Broader social policies are required to address the health and well-being of the First Nations people. These include maintaining and increasing funding for Aboriginal women to achieve higher education, better paying employment, adequate housing and affordable day care and family support services and support of Aboriginal languages in an effort to preserve unique cultural knowledge (Deiter & Otway, as cited in Wilson, 2004). Organizations and service providers (e.g., gynecologists, family practitioners, nurses, social workers, community cultural advocate groups and academic organizations) should be encouraged to collaborate and cooperate in the delivery of programs. Partnerships that cross jurisdictional boundaries should be fostered.

### ***Suggestions for Further Research***

Many opportunities for further research exist. The effectiveness and cost-effectiveness of cervical screening interventions are relatively unexplored, as is research regarding the effectiveness of varying types of media and marketing approaches in encouraging health-seeking activities (e.g., art, posters, pamphlets, visual or written resources, books, electronic media). Optimal teaching and service delivery approaches for First Nations women require further investigation. Ongoing assessment of the changing needs of First Nations women and the success in meeting identified needs is essential.

The introduction of the lay community worker to provide education to un- and underserved First Nations women stimulates new questions and research opportunities. How effective are off-reserve First Nations women in providing education for their on-

reserve peers? How can cross-cultural reciprocal learning and leadership be enhanced? Other questions are stimulated. How can the gap between knowledge and action (in relation to cervical screening) be addressed? Does a “readiness for change” approach narrow this gap? Do interventions targeting racism and poverty enhance self-esteem and self-worth, and in turn, enhance self-care behaviours?

To date, most qualitative and quantitative research investigating cervical screening among First Nations women is descriptive, examining cultural issues and perceived incentives and barriers for screening. A transition from descriptive to higher levels of evidence is urgently needed (Young & Frank, 1983). Published information regarding Canadian First Nations women and cervical screening is scarce. Literature examining the health and healthcare needs of this vulnerable population must move from its “grey literature” relegation to one of acknowledgement within recognized academic resources. Promotion and publication of health literature written by Alberta First Nations women should be encouraged.

Specifically, the next research that needs to be conducted includes: a) well-designed studies examining the effectiveness of suggested interventions (e.g., the use of the lay community worker) in relation to cervical screening behaviours of First Nations women and b) further development of non-intrusive methods of primary and secondary prevention of cervical cancer (e.g., longitudinal effectiveness research in relation to multivalent Human Papilloma Virus (HPV) vaccines, and the use of carrageenan to intercept HPV-cellular linkages (Buck et al., 2006).

### *Reciprocity*

Many gains have been made in association with this project. First steps toward holistic and comprehensive women's health services are underway. CH breast and cervical screening programs now operate under a women's health umbrella. Jointly sponsored women's health education, recruitment and marketing provide evidence of cross-program collaboration. CH Women's Health (previously Breast/Cervical) Program staff and community stakeholders are committed and passionate in their quest to provide culturally appropriate, culturally safe and culturally competent care.

Bridges between on- and off-reserve Blood tribe members and the Breast/Cervical screening programs have been re-energized and trusting relationships built throughout the course of this study continue to be nurtured. Urban Aboriginal groups have provided funding for two First Nations lay community workers, one targeting on-reserve and the other targeting off-reserve women. They continue to support the growth of collaborative projects. Space within the Blood reserve clinic has recently been allocated to the CH lay community worker. CH lay community workers have been instrumental in reintroducing traditional Blackfoot ceremonies celebrating the passage of youth to womanhood. These ceremonies provide the opportunity to reach young First Nations women, introduce healthy approaches to sexuality and reinforce pride in cultural traditions and identity (LeTendre, 2002; Weaver, 2002). The project has stimulated communication with American Indian research colleagues who have shared their experience and expertise in establishing successful on- and off-reserve lay community worker initiatives.

First Nations colleagues have been empowered through respectful, supportive and collaborative relationships. Their roles as educators, mentors, leaders and researchers have

been recognized (e.g., the First Nations lay community worker initially involved with this project now teaches at a local community college).

The extended timeframe spent establishing a trusting and respectful relationship with the First Nations CH staff and lay community worker has been pivotal to gaining access to the First Nations community and was precursor to meaningful participation in this project. Critical “insider” views provided by the First Nations lay community worker and the community health representative were invaluable to understanding First Nations cultural worldviews. Their emic perspective also has prompted us to be aware of key political and interpersonal relationships. Trusting relationships have provided the groundwork to link with and build upon already established resources (e.g., First Nations conferences held annually at the University of Lethbridge, church groups, and summer family camps) and enhance project sustainability. There has been widespread dissemination of project findings by focus group participants, CH health professionals and lay community workers. Most importantly, First Nations participants have expressed pride in being able to positively impact the health of their community.

### ***Limitations***

This research study faces limitations common to focus groups, for example, this qualitative study does not propose to make generalizations about the entire population from this non-random sample of respondents (Benoit et al., 2003; Creswell, 1998; Denzin & Lincoln, 2005; McDaniel & Bach, 1996). Group participants may have had limited knowledge about cervical screening; their perceptions may not have been representative of all viewpoints of the off-reserve First Nations community. Piikani women were not well-represented in the selected sample at the request of the regional health authority. A



concurrent CH Primary Care Project in Pincher Creek focusing on this First Nations community threatened to tax the limited resources of this small population. There are some areas where additional information and research would have further validated findings (e.g., more indepth discussion of healthy lifestyles and behaviours) (Mishler, as cited in Leininger, 1985; Morgan, 1998).

While the opportunity to become totally immersed for an extended period of time in First Nations culture was limited and may have resulted in less intense contextual description than a full ethnographic study, this focused ethnography has given attention to the general lifeways of the off-reserve First Nations in relation to the CH cervical screening program (Higgins & Demerth, 1999; Wright, 2002; Leininger, 1985; Streubert & Carpenter, 1995).

### ***Ending the Research Relationship***

My enthusiasm for the project has continued well beyond the focus groups as I observe and follow the endeavours stimulated by this research project. As a researcher, I am caught in the dilemma of wanting to participate, but realize that I have to “let go” and allow the program to continue to build these bridges. I am encouraged by the words of Wilson (Cree Opaskwayak, 2004) who stated, “as communities assume more control and ownership of their own cultures, both communities and women become stronger and healthier” (p. 21).

### ***Summary***

Alberta First Nations women face a significantly higher risk of cervical cancer than their non-First Nations counterparts. The ability to meet basic human needs and a strong sense of self-identity and self-worth and are prerequisite to addressing health

promotion and self-care. This study re-emphasizes the need to address the multiple factors, or determinants of health, through a collaborative, multisectoral approach. Recognizing and addressing perceived barriers are essential to accessible and acceptable cervical screening services for urban First Nations women.

Achieving health for First Nations women and increasing access to culturally suitable and appropriate health care services requires a pro-active, bi-cultural approach to individual, family, and community health. Success will only be achieved through genuine partnerships based on open dialogue, transparency and cooperation. As regions begin to partner with First Nations communities to meet the provincial goal of “health for all,” it is critical that research, evidence-based practice, and policy support this vision. “Getting knowledge is only halfway there. The final challenge is to use it, to close the gap between what we know and what we do, so our health care is based on research evidence about what works best” (AHFMR, as cited in Findlay, 2004). First Nations people are poised to actively participate in this adventure. The time is ripe:

The Aboriginal community has long known the power of dreams... this dream will transform the lives of aboriginal people in our community in a way we can't imagine. (Mayor Bob Tarleck, as cited in Shurtz, 2005)

## Glossary

**Aboriginal.** Within the 1982 Canadian, Constitution Act, three groups of Aboriginal people are described: a) Inuit people (Aboriginal people of Arctic Canada), b) Métis, and c) Status and non-status Indians.

**Associational context.** “The common characteristic that brings the participants together” (Hollander, 2004, p. 615).

**Band.** A body of Indians (a) for whose use and benefit in common, lands, the legal title to which is vested in Her Majesty, have been set apart before, on or after September 4, 1951; (b) for whose use and benefit in common, money are held by Her Majesty; or (c) declared by the Governor in Council to be a band for the purposes of the Indian Act, 2000 (Fox, 2005, p. 14).

**Cervical.** Relating to the neck, or to the neck of any organ or structure. Cervical lymph nodes are located in the neck. Cervical cancer refers to cancer of the uterine cervix, which is the lower, narrow end (the “neck”) of the uterus (National Cancer Institute).  
[http://www.cancer.gov/search/ViewClinicalTrials.aspx?cdrid=441189&version=patient&protocolsearchid=1756104#AlternateTitle\\_CDR0000441189](http://www.cancer.gov/search/ViewClinicalTrials.aspx?cdrid=441189&version=patient&protocolsearchid=1756104#AlternateTitle_CDR0000441189) (Alberta Cancer Board,  
<http://www.cancerboard.ab.ca/accsp/glossary.html#c>)

**Cervical Screening.** See Pap test

**Circle.** The basic symbol of life and meaning for Aboriginal people (Dickson & Green, 2001).

**Confirmability.** (auditability). An audit trail of the researcher’s decisions can be followed by an independent investigator, who would reach similar conclusions about the data (Lincoln & Guba, 1985; Polit & Hungler, 1995). Confirmability requires: documentation of the decisions made regarding sample selection, a record of analytic decisions, a report of the data sources included in the analysis, and evidence of congruency between actual data and the conclusions drawn (Polit & Hungler, 1995).

**Confirmability.** the repeated direct participatory and documented evidence observed or obtained from primary informant sources (Leininger, 1994, p. 105).

**Conformity.** Participants may withhold things that they might say in private (Morgan, 1998, p.15) in accordance with some prevailing standard or custom (Merriam-Webster online dictionary, retrieved May 7, 2006, from <http://www.m-w.com/dictionary/conforming>).

**Constructivist.** A constructivist paradigm assumes that what is perceived as real is socially determined based on co-creation of shared meaning (Guba & Lincoln, as cited in Denzin & Lincoln, 2000).

**Context.** What was taking place at the time, voice inflections, the animation with which the words or phrases were used, and whether the words were spoken as statements or questions (McDaniel & Bach, 1996).

**Conversational context.** Within the context of the conversation at hand (Hollander, 2004, p. 619).

**Credibility.** Truth, value or believability of the findings that have been established by the research (Leininger, 1985, p.105). Credibility refers to the “truth,” value, or “believability” of the findings that have been established by the researcher through prolonged observations, engagements, or participation with informants or the situation in which cumulative knowing is the “believable” or live-through experiences of those studied. Credibility refers to the truth as known, experiences or deeply felt by the people being studies (emic or local) and interpreted from the findings with co-participant evidence as the “real world” or the truth in reality. Etic (or outsider’s views) are studied in relation to emic perspectives (Leininger, 1994, p. 105).

**Critical social theory.** A critical social theory is concerned in particular with issues of power and justice and the way that the economy; matters of race, class, and gender; ideologies; discourses; education; religion and other social institutions; and cultural dynamics interact to construct a social system (Kincheloe & McLaren, p. 306).

**Culture.** “A system of shared beliefs and values that gives a ‘worldview’. Culture is learned, changes, and is transmitted from one group to another. It is embedded within one’ person – it is implicit and beyond awareness” (J. Morse, personal communication, August 5, 2004). Culture includes language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups (Massachusetts League of Community Health Centers, 2005, Fox (Blood/Blackfoot), 2004, Geertz, 1973).

**Culture.** “Is learned, shared and transmitted from one generation to the next, and it can be seen in a group’s values, norms, practices, systems of meaning, ways of life, and other social regularities. Factors such as familial roles, communication patterns, beliefs relating to personal control, individualism, collectivism, and spirituality and other individual, behavioural and social characteristics are not inherently ‘cultural’: but may help define culture for a given group if they have special meaning, value, identity, or symbolism to the group’s members. In such a group, these and other factors may be directly or indirectly associated with health-related behaviours and /or with acceptance and adoption of health promotion programs and messages” (Kreuter et al., 2002. p. 133).

**Cultural competence.** Reflects the ability to apply the knowledge about cultural differences to the delivery of healthcare.

**Cultural safety.** Practices that enable people from minority groups to access and utilize health care service in ways that do not diminish, demean, or disempower them, but instead, enable them to access and utilize health care services in ways that will decrease risk factors, and enhance health (J. Anderson et al., 2005, ¶1). “Ultimately, cultural safety is concerned

with changing attitudes and with gaining an awareness of the political and historical forces shaping the dynamics of health care interactions with Aboriginal people” (Browne et al., 2000, p.9).

**Cultural sensitivity.** The awareness of the diversity in values, beliefs, and lifestyles that exist among population groups in society.

**Deductive reasoning.** The deriving of a conclusion by reasoning; specifically: inference in which the conclusion about particulars follows necessarily from general or universal premises: a summary reached by logical deduction (Merriam-Webster online dictionary, retrieved December 2, 2005, from <http://63.240.197.92/cgi-bin/mwdictaj>).

**Dependability.** Allows a second researcher to follow logically the processes and procedures that the first researcher used in a study. Dependability reflects “data stability over time and across various conditions” (Polit & Hungler, 1995, p. 363).

**Diary.** The researcher often keeps a separate diary of personal insights as well as observations of individuals, activities and artifacts that are part of the social situation, not merely focusing on interactions for the report. This documentation can contribute to the data richness of the cultural scene (Spradley, 1979).

**Elder.** An older person who is knowledgeable about the culture, history and traditions of his or her tribe. Within the Aboriginal community, an elder is seen as possessing life experience and tends to be held in high regard (Fox (Blood/Blackfoot), 1995, p. 72).

**Empowerment.** Refers to the means by which people experience more control over decisions that influence their health and lives (Laverack & Labonte, 2000).

**Emic perspective.** The “insider's” or “native's” interpretation of or “reasons” for his or her customs/beliefs. Personal view from the group itself (Retrieved December 2, 2005, from <http://www2.eou.edu/~kdahl/emicdef.html>).

**Etic perspective.** The external researcher's interpretation of the same customs/beliefs (Retrieved December 2, 2005, from <http://www2.eou.edu/~kdahl/emicdef.html>).

**Ethnography.** “Ethnography focuses on the culture of a group of people” (Polit et al, 2001, p. 213). Inherently a mixed method, ethnography is usually comprised of interviews, observations and other sources of information (e.g. psychometric tools, quantitative surveys) (J. Morse, personal communication, August 5, 2004).

**Feminism.** Sometimes viewed as a subset of critical theory, feminism focuses on “woman” as subject and gender as an analytical tool in the acquisition and critique of knowledge.

**Field notes.** Are objective, descriptive accounts of what is happening in the research setting. The researcher's goal is to capture the lived experience of the participants and to describe the community in which they are a part (Morse & Field, 1995, p. 112). Fieldnotes should describe the impact of the researcher on the setting and reflections, feelings, ideas, moments of confusion, hunches and interpretations about what is observed. The researcher's fieldnotes provide the opportunity to clarify thoughts, make sense of the data, and plan the next step of the observation process (Mayan, 2001).

**First Nations.** Often preferred by Aboriginal people, this recent terminology replaces the familiar term "Indian". It recognizes First Nations people as descendants of the first inhabitants of Canada (Royal Commission on Aboriginal Peoples, 1996).

**Grounded theory.** An approach to collecting and analyzing data with the aim of developing theories and theoretical propositions grounded in real-world observations (Polit & Hungler, 1995, p. 643).

**Healing circle.** "A cleansing and healing practice combining various traditional and contemporary rituals; a circle format, the burning of sweet grass; prayers; talking in turn, sharing personal joys or pains, using a blessed stone to designate the speaker; silent listening and compassion from the others; and group support and confidentiality" (Dickson & Green, 2002, p. 475).

**Health promotion.** Is the process of enabling people to increase control over the determinants of health and thereby improve their health. Health promotion represents a comprehensive social and political process. It not only embraces actions directed at strengthening the skills and capabilities of individuals but also action directed towards changing social, environmental, and economic conditions so as to alleviate their impact on public and individual health (Nutbeam, 1998).

**Human papillomavirus (HPV).** HPV is the common name for a group of related viruses, some of which occur on the cervix and are risk factors for cervical cancer. (Alberta Cancer Board website, Glossary <http://www.cancerboard.ab.ca/accsp/glossary.html>)

**Immunization.** Stimulating the immune system to destroy infectious micro organisms such as bacteria or viruses.

**Indian.** A person who is registered as an Indian or is entitled to be registered as an Indian under the Indian Act.

**Inductive reasoning.** The inference of a generalized summary from particular instances. Merriam-Webster online dictionary, retrieved Dec 2, 2005, from <http://63.240.197.92/cgi-bin/mwdictaj>).

**Lateral violence.** Refers to such things as competitiveness, gossip, or family feuds that may develop within communities, separating and isolating community members. Lateral violence is associated with multi-generational trauma or the repercussions suffered by professional care givers (J. Fiske, personal communication, April 14, 2006).

**Pap smear/Pap test.** A test in which cells are removed from the cervix and examined under a microscope. Devised by Dr. George Papanicolaou, the Pap smear is an effective way to detect abnormal cells or cancer. (Alberta Cancer Board, <http://www.cancerboard.ab.ca/accsp/glossary.html>)

**Phenomonology.** An approach to human inquiry that emphasizes the complexity of human experience and the need to study that experience holistically as it is actually lived (Polit & Hungler, 1995, p. 643).

**Polarization.** Participants express more extreme views in a group than in private (Morgan, 1998, p.15).

**Postmodernists.** Accept multiple beliefs and multiple ways of understanding and experiences that privilege no single authority, method or paradigm (Denzin & Lincoln, 2005, p. 961).

**Postpositivism.** Espouses the belief that ‘real’ reality is imperfectly and probabilistically apprehensible (Denzin & Lincoln, 2003, p. 195).

**Poststructuralism.** Links language, subjectivity, social organization, and power. The centerpiece is language. Language does not ‘reflect’ social reality but rather produces meaning and creates social reality (Denzin & Lincoln, 2003, p. 961).

**Prevention.** Covers measures not only to prevent the occurrence of disease/disorder/problem, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established.

**Primary Prevention.** Reduction of elimination of a disease/disorder/problem by measures intended to prevent or avoid onset of the disease/disorder/problem BehaveNet-Capsule <http://www.behavenet.com/capsules/index.htm>

**Relational Context.** The degree of prior acquaintance among the participants. (e.g. the level of intimacy already established among the participants) (Hollander, 2004, p. 620).

**Reliability.** The consistency with which an instrument or method will provide the same or equivalent results when administered to another sample (McDaniel & Bach, 1996, p.54). Reliability is evidenced by the ability of an investigator to follow the decision trail or audit trail of the original investigator is used to establish reliability in qualitative research. Careful review of the description of the procedure used to select subjects, the methods of observing and recording, and the process of data analysis. This enables other researchers to follow the decision trail and replicate the process – thus

establishing the scientific rigor of the qualitative research (McDaniel & Bach, 1996). Data analysis by more than one researcher may be used to enhance reliability (McDaniel & Bach, 1996; Higginbottom, as cited in Webb & Kevern, 2001).

**Reserve.** A tract of land that has been set apart for the use and benefit of a band. The legal title of this land is vested to her Majesty, Queen of England (Indian Act, 2000).

**Saturation.** The “sense of closure that the researcher experiences when data collection ceases to yield any new information” (Polit & Hungler, 1995, p.531). Saturation is the “full ‘taking in of occurrences’ or full immersion into phenomena in order to know it as fully, comprehensively, and thoroughly as possible” (Leininger, 1994, p. 106).

**Scientific rigor.** The accuracy or precision of the study) is established through the measurement of reliability and validity (McDaniel & Bach, 1996, p.54).

**Secondary prevention.** Reduction or elimination of a disease/disorder/problem by interventions for asymptomatic and at risk individuals identified prior to development of clinical manifestations of disease/disorder/problem. Secondary prevention aims to stop or slow an existing disease/disorder/problem by early detection and appropriate treatment. Problem. BehaveNet-Capsule <http://www.behavenet.com/capsules/index.htm>

**Strategies.** Refer to intervention approaches aimed at achieving overall program goals. Education programs and structural, system, and policy change are examples of intervention strategies (Steuart, as cited in Strickland, 1999).

**Status.** “The government classifies First Nations people according to whether or not they are registered under the federal Indian Act. ‘Status Indians’ are registered under the Act and numbered 610,874 in 1996. First Nations people who are not registered under the Act are referred to as ‘non-status Indians’” (Smylie, 2000, p. 2).

**Transferability.** The ability of findings from one study to be applicable to another similar context, group, or setting (Leininger, 1994, p.55).

**Targeting.** 1. The use of a single intervention approach for a defined population subgroup that takes into account characteristics shared by the subgroup’s members: 2. The process of identifying a population subgroup for whom an intervention or program is to be developed (Krueter, 2002, p.1360).

**Tertiary Prevention.** Reduction or elimination of a disease/disorder/problem by interventions (commonly referred to as treatment) for symptomatic individuals identified after development of clinical manifestations of disease/disorder/problem. (BehaveNet-Capsule <http://www.behavenet.com/capsules/index.htm>)

**Vaccine therapy.** A type of treatment that uses a substance or group of substances to stimulate the immune system to destroy a tumor or infectious microorganisms such as bacteria or viruses.



**Validity.** “The certainty that an instrument or method does measure what it claims to measure” (McDaniel & Bach, 1996, p.54). Validity is enhanced by providing detailed, rich descriptions of the data from which the conclusions are drawn.

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## Figures

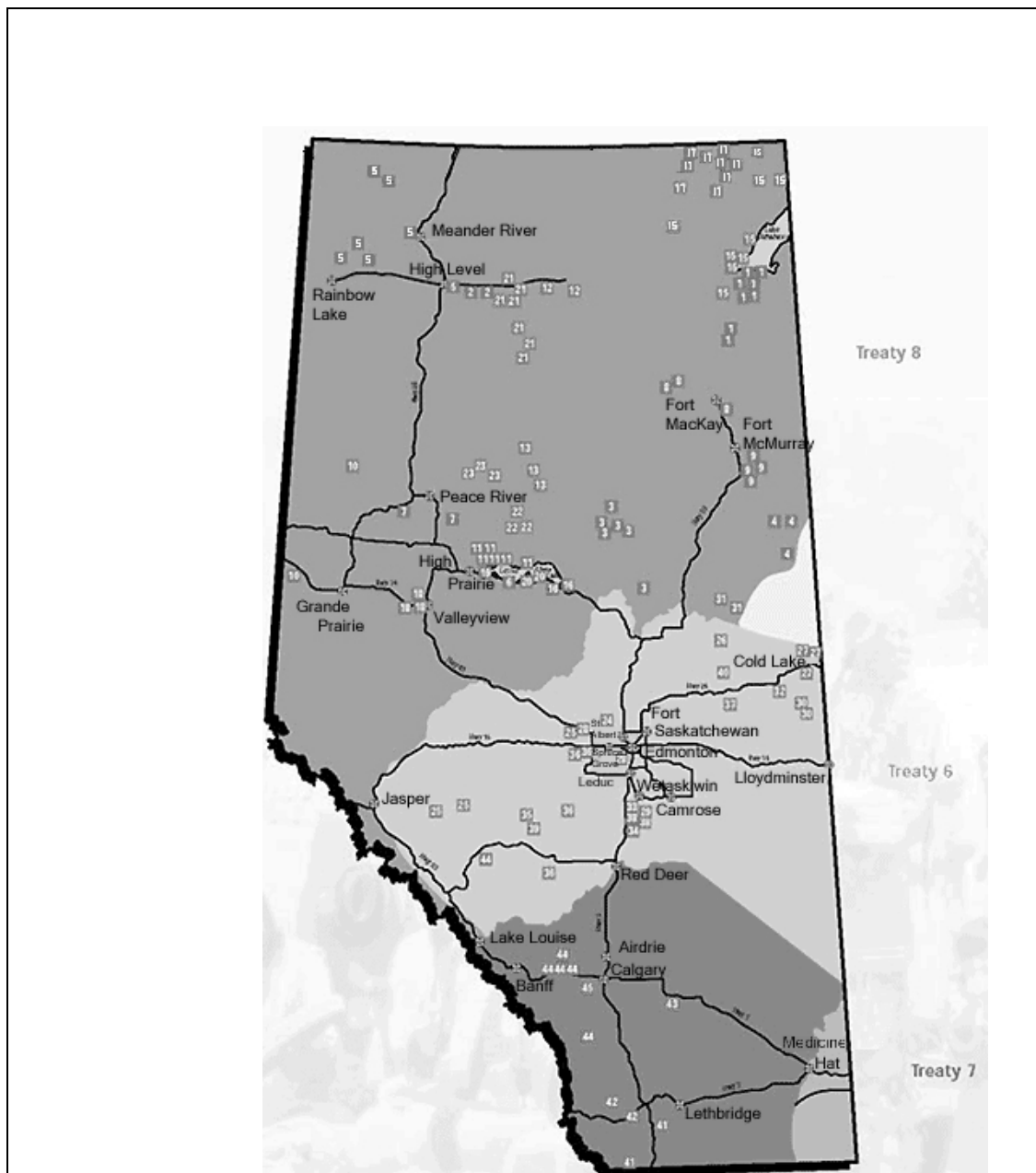


Figure 1. Alberta treaty areas.

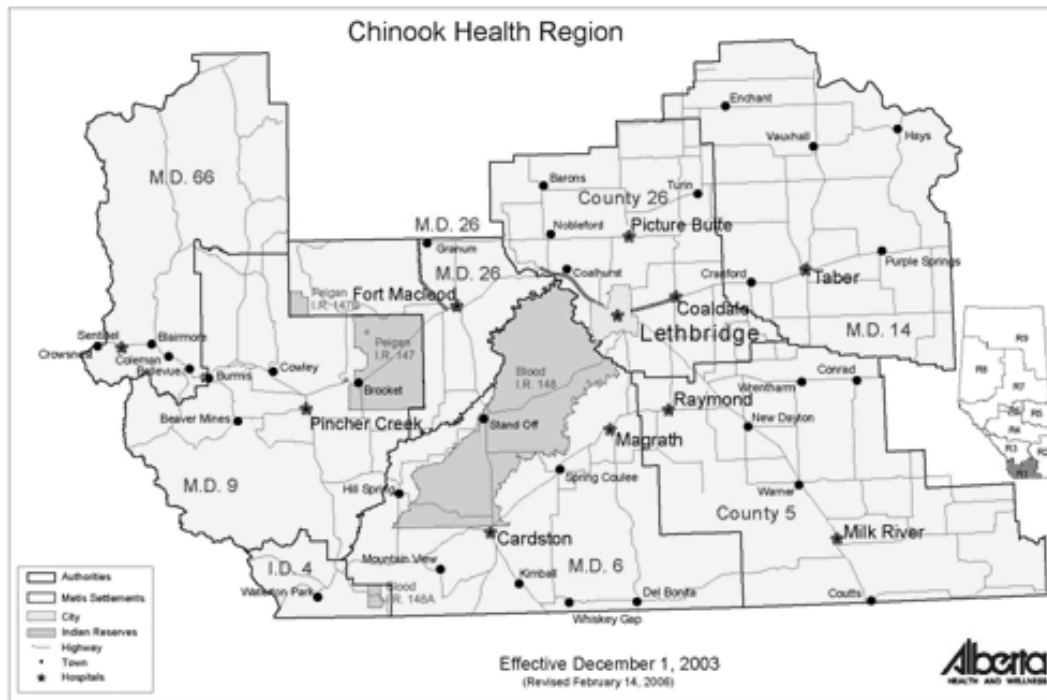


Figure 2. First Nations reserves located in Chinook Health.



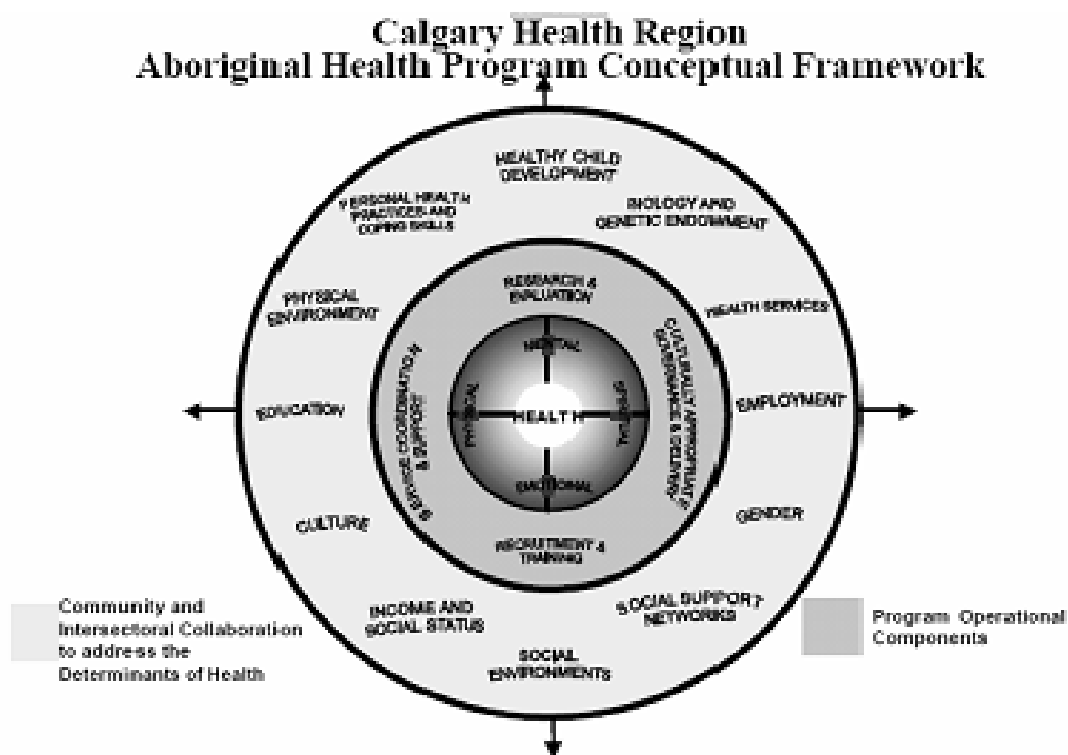


Figure 3. Calgary Health Region Aboriginal conceptual framework.

Linking the Circle of Life Medicine Wheel with a Population Determinant  
of Health Framework

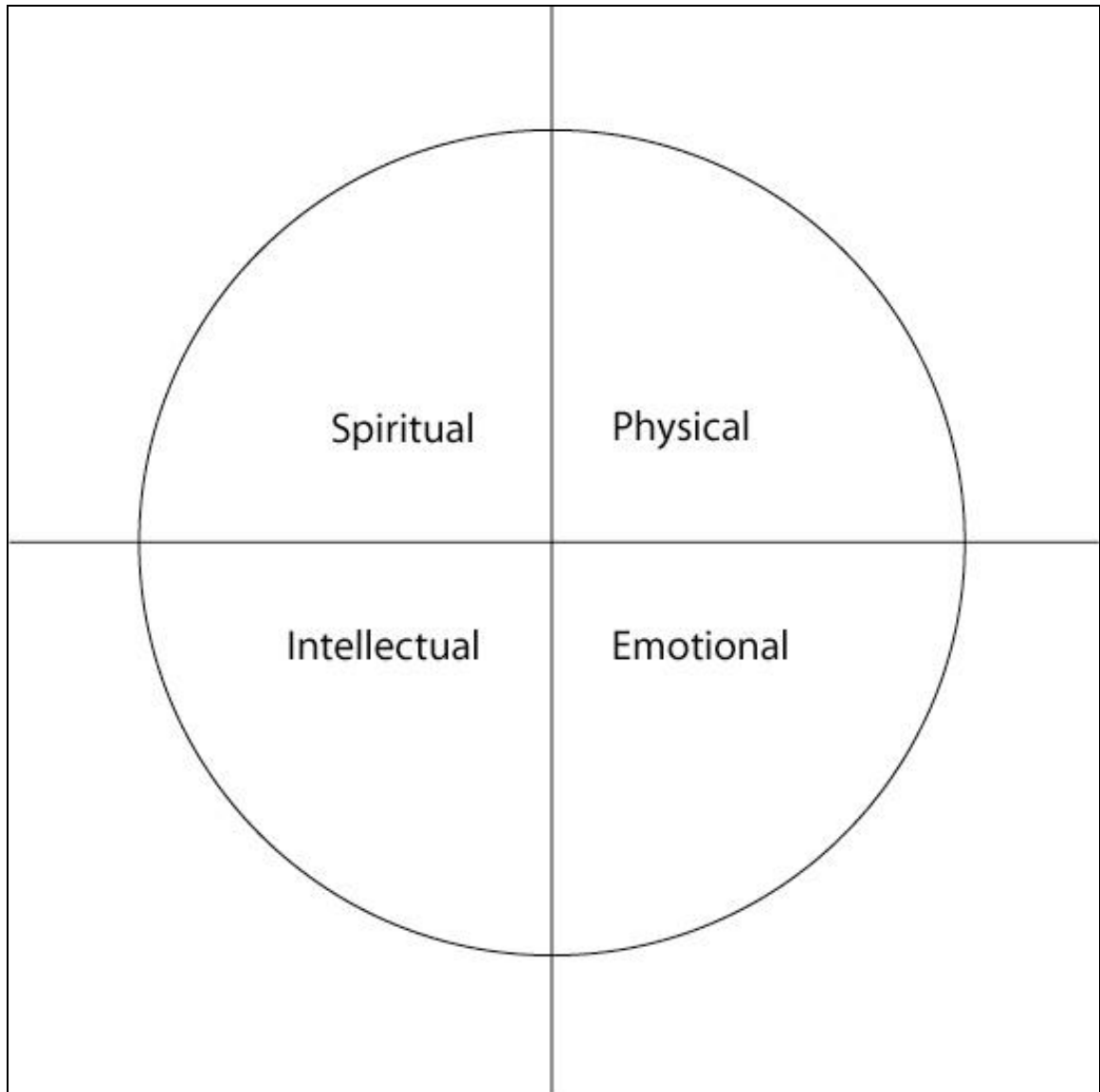


Figure 4. The Medicine Wheel.

All that is necessary for life can be explained by the sacred circle. A person should strive to maintain optimal wellness in their emotional, physical, mental [intellectual], and spiritual being. When this is not achieved we become more susceptible to illness and disease. (CHR Aboriginal Health, n.d.)

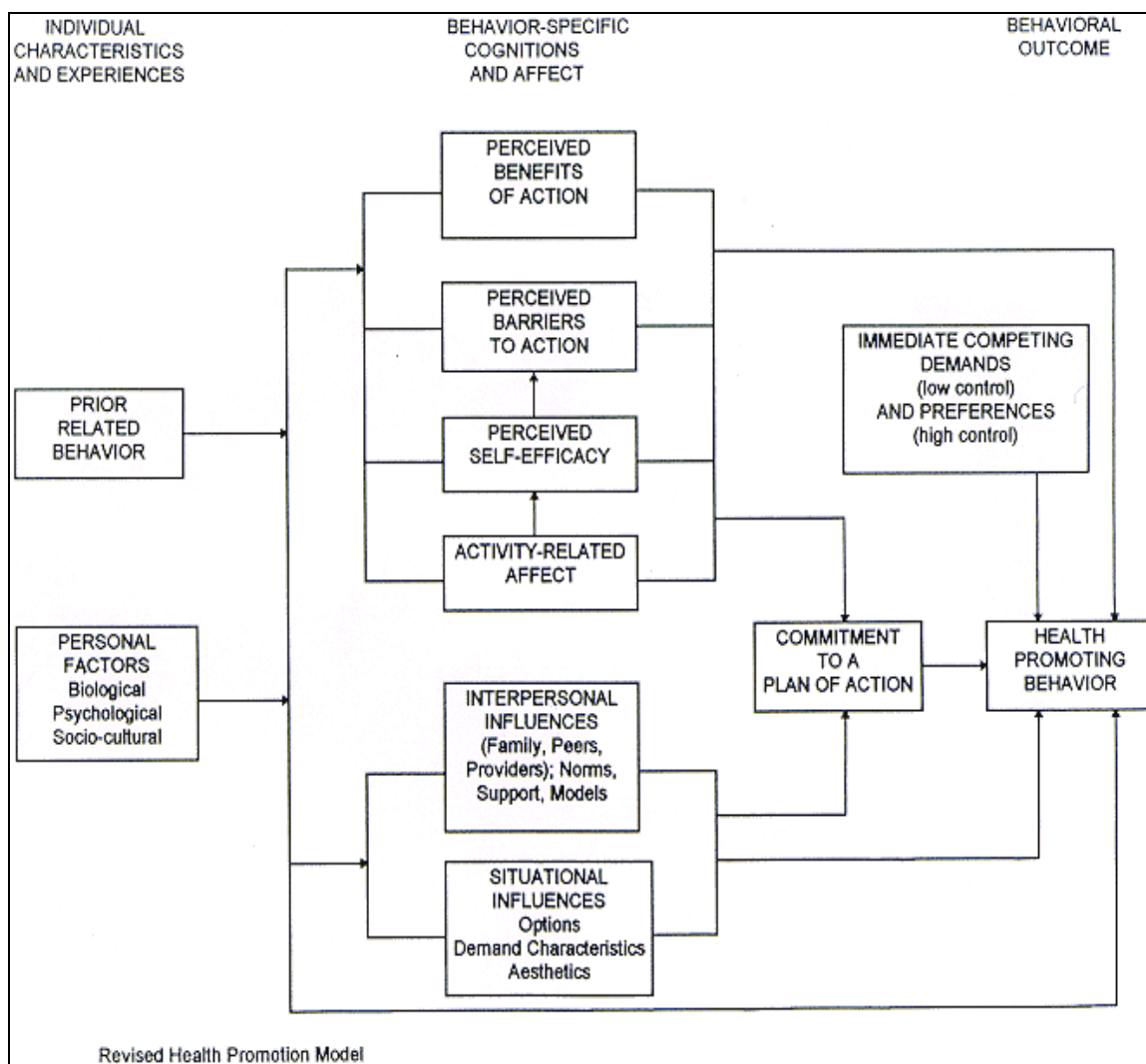


Figure 5. Health promotion model (Pender et al., 2005).

A model for understanding native cultural group identity and behavior patterns				
New traditionalists	Lost identities	International human beings	The traditionalists	Assimilated indians
<ul style="list-style-type: none"> <li>• “born again” Indians</li> <li>• strident-moving in a direction</li> <li>• racist</li> <li>• articulate</li> <li>• younger generation</li> <li>• re-programmed</li> <li>• group-oriented</li> <li>• often not raised within a strong sense of culture; usually indoctrinated as young impressionable adults searching for identity</li> <li>• open display (braid, ribbon shirt, etc.)</li> <li>• “going back to lane and traditions”</li> <li>• mixture of belief systems from all sources</li> <li>• often unwilling to learn knowledge that goes behind belief system (i.e. “elder” title, “medicined person”)</li> <li>• may not necessarily set a good example</li> <li>• imposes values and beliefs on others.</li> </ul>	<ul style="list-style-type: none"> <li>• powerless due to transitional stress</li> <li>• in limbo</li> <li>• unprepared</li> <li>• ambivalent</li> <li>• mixture of beliefs</li> <li>• vacillating between extremes</li> <li>• cultural/social breakdown</li> <li>• identity confusion</li> <li>• “acting out”</li> <li>• grief</li> <li>• dependency</li> <li>• “deprived syndrome”</li> <li>• epitomize social problems (alcoholism, drug addiction, etc.)</li> <li>• low economic level</li> <li>• poorly educated</li> </ul>	<ul style="list-style-type: none"> <li>• appreciates gifts of both worlds</li> <li>• healthy spirit</li> <li>• adaptability</li> <li>• comfortable in both worlds</li> <li>• accommodating</li> <li>• anti-racist</li> <li>• socially conscious</li> <li>• few in number</li> <li>• healthy spirit</li> <li>• has vision for the future</li> <li>• is a mover and a shaker</li> <li>• appreciates both languages</li> <li>• in tune with the environment</li> <li>• has courage of heart</li> <li>• values own culture without putting down other cultures</li> </ul>	<ul style="list-style-type: none"> <li>• strong cultural beliefs are foundation</li> <li>• strong emotional peer support</li> <li>• history is dear</li> <li>• practice and beliefs are rooted</li> <li>• in tune with environment</li> <li>• cooperative society</li> <li>• ecology oriented</li> <li>• raised within the culture</li> <li>• cultural knowledge of all areas</li> <li>• strong spiritual base</li> <li>• responsible for passing on knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• adoption of new norms</li> <li>• possesses technical skills</li> <li>• has paid own social or cultural costs</li> <li>• changed behavior</li> <li>• “me” identity</li> <li>• materialism</li> <li>• unable to be a role model for traditionalists</li> <li>• accepts hierarchical power</li> <li>• competitive</li> <li>• does not value native beliefs</li> </ul>

Figure 6. The model for understanding Native cultural group identity and behaviour patterns (National Native Association of Treatment Directors, 1989, as cited in NECHI, 2005).

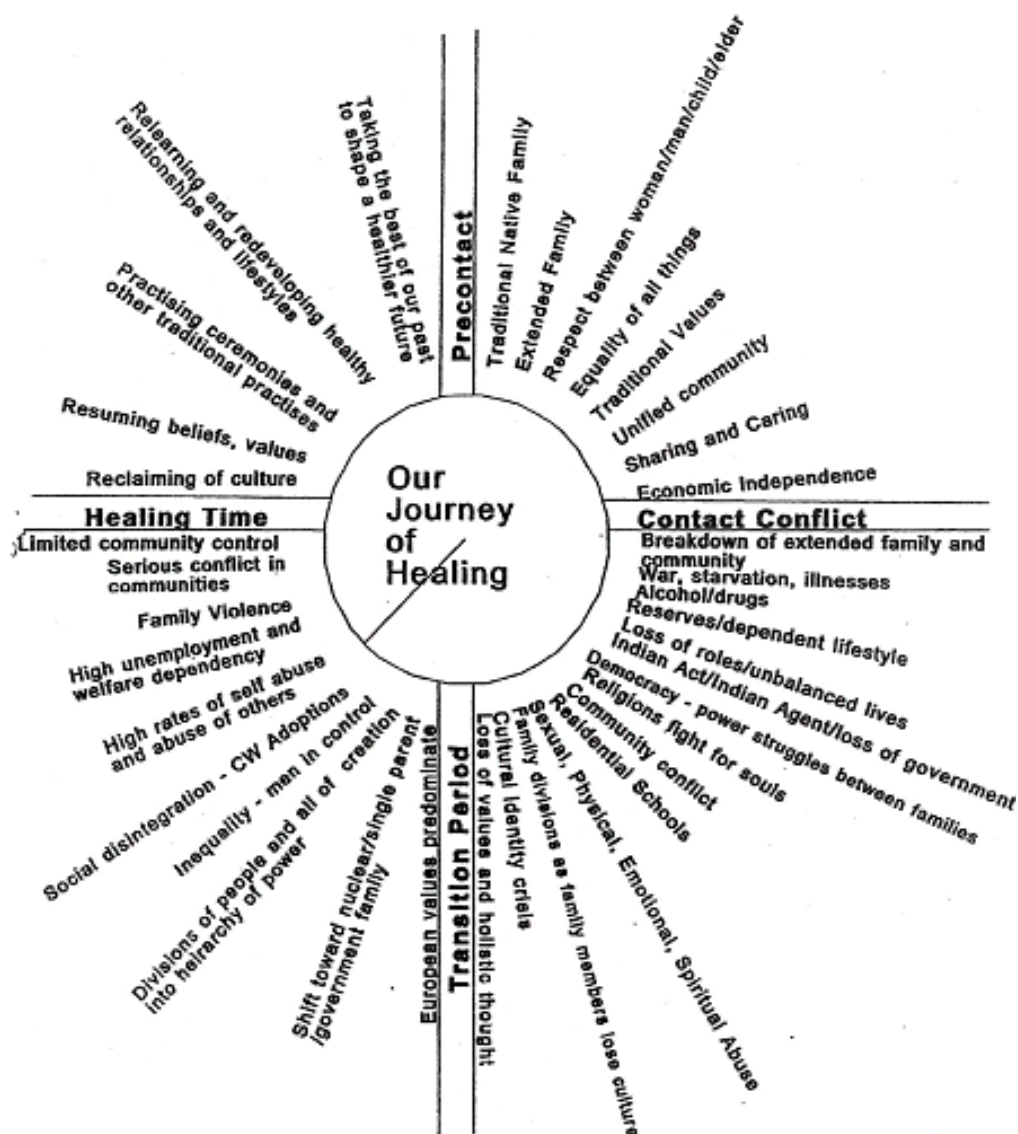


Figure 7. The healing journey model (Connors, as cited in NECHI, 2005)

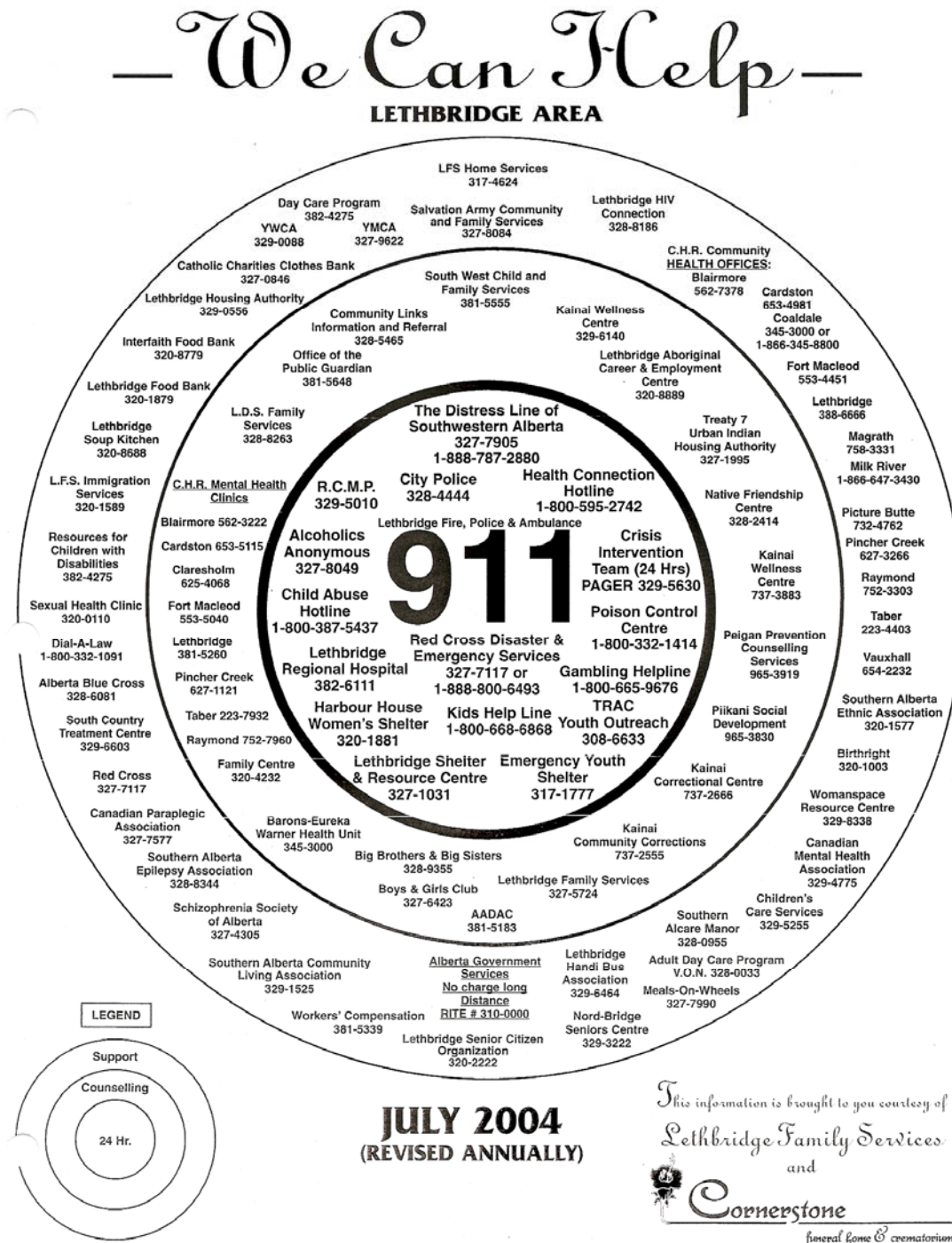



Figure 8. We Can Help resources guide (Lethbridge Family Services and Cornerstone, 2004).

## Appendixes

## APPENDIX A

Guideline for Screening for Cervical Cancer: Revised (AMA, 2005).<sup>30</sup>

<div> <b>GUIDELINE FOR SCREENING FOR CERVICAL CANCER: REVISED</b>  <div> <b>ALBERTA CERVICAL CANCER SCREENING PROGRAM</b> 2005 Update </div> </div> <div> Toward Optimized Practice Administered by the Alberta Medical Association </div>	
<p><i>This guideline is a revised version of the guideline developed in February 2000, by the Cervical Cancer Screening Working Group.</i></p> <p><i>This guideline currently recommends that routine screening be performed annually for eligible women 18-69. Many expert groups recommend less frequent screening, especially if an organized screening program is in place. With the implementation of the Alberta Cervical Screening Program, which is being phased in across Alberta between 2003 and 2006, the recommendation for routine screening in Alberta will be reviewed.</i></p> <p><b>ISSUE</b></p> <p>Failure to be screened or being underscreened is a significant risk factor for developing cervical cancer.</p> <p><b>GUIDELINE GOALS</b></p> <ul style="list-style-type: none"> <li>♦ To assist health care providers and women in the implementation of cervical screening to ultimately decrease morbidity and mortality from cervical cancer.</li> <li>♦ To list uniform and consistent recommendations for cervical cancer screening, for cervical cancer screening tools, and the management of test results.</li> </ul> <p><b>SUMMARY RECOMMENDATIONS</b></p> <p>Although most invasive cervical cancers are squamous cell carcinomas that arise from premalignant lesions (squamous intra-epithelial lesion, SIL) and evolve slowly over many years, occasionally the cancer appears to have progressed more rapidly. The goal of cervical cancer screening is to detect the disease in its premalignant phase when it is completely curable.</p> <p><b>Recruitment</b></p> <ul style="list-style-type: none"> <li>♦ Episodic contacts should be used to develop a good physician/patient relationship and promote the value of routine screening.</li> <li>♦ Mechanisms to recruit eligible women will be developed as a component of the ACCSP.</li> </ul> <p><small>The above recommendations are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. They should be used as an adjunct to sound clinical decision making.</small></p>	<p><b>Eligibility (see Algorithm Chart)</b></p> <ul style="list-style-type: none"> <li>♦ All women aged 18 and over who have had sexual intercourse should be actively encouraged to participate in cervical cancer screening unless they are: <ul style="list-style-type: none"> <li>• Women who have had a total hysterectomy for <b>BENIGN DISEASE</b> if there is: <ul style="list-style-type: none"> <li>- adequate pathological documentation that the cervix has been completely removed <u>and</u></li> <li>- no history of cervical malignancy or premalignancy.</li> </ul> </li> <li>• Women older than 69 with a cervix and who have had at least two satisfactory and negative smears (taken at least 3 months apart) in the past 3 years, provided there is no history of cervical malignancy or premalignancy.</li> </ul> </li> </ul> <div> <p><b>PRACTICE POINT</b></p> <p>Regardless of the Pap smear findings, a visibly abnormal cervix should be investigated by colposcopy and abnormal bleeding should be investigated by appropriate referral.</p> </div> <p><b>Frequency of Screening</b></p> <p>a) <u>Routine Screening</u></p> <div> <p><b>PRACTICE POINT</b></p> <p>Eligible women aged 18 to 69 should have annual Pap smears.</p> </div> <ul style="list-style-type: none"> <li>♦ There is no evidence to support the benefit of routine Pap screening in eligible women who are under the age of 18.</li> <li>♦ Women older than 69 and who have never been screened: <ul style="list-style-type: none"> <li>• Should have two consecutive Pap smears six months or more apart. <ul style="list-style-type: none"> <li>- if results are negative and satisfactory, screening may be discontinued.</li> </ul> </li> </ul> </li> </ul>

Note. from Guideline for Screening for Cervical Cancer: Revised [Electronic version], by the Alberta Medical Association Cervical Cancer Screening Working Group, 2005. Edmonton, Alberta, Canada: Author. Retrieved November 11, 2006, from the Alberta Doctors, Toward Optimized Practice Web site: <http://www.albertadoctors.org> Copyright 2005 by the Alberta Medical Association. Reprinted with permission.



## b) Increased Surveillance

Some women, because of increased risk or current or past cervical disease, require more vigilant surveillance. These include:

- ♦ Women who have had a recent abnormal Pap smear result.
- ♦ Women with treated cervical malignancy or premalignancy.
- ♦ Women at increased risk because of immunosuppression.

## Optimal Specimen Collection (see Appendix)

- ♦ A dual collection technique (spatula and brush) should be used to sample the transformation zone.
- ♦ Mid-cycle is the optimal time in menstruating women.
- ♦ Smears should not be repeated within a 3 month period.

## Follow-up and Management of Abnormal Pap Smears

Follow-up and management of the abnormal Pap smear should be based on clinical signs, symptoms, prior history, and the Pap smear report (See Table 1).

### PRACTICE POINT

Colposcopy is not a screening tool and is not appropriate for use in asymptomatic women with negative cervical cytology

## ADVICE TO PATIENTS

The Alberta Clinical Practice Guidelines Program supports the right of the patient to make informed decisions about her health care options. Patient decisions will vary as a result of individual fear of cancer and the individual interpretation of the evidence relative to health benefits. It is important for women to be aware of the consequences of their decisions to be screened or not screened. The ACCSP has developed patient information pamphlets to assist women in decisions related to cervical cancer screening. These pamphlets have been endorsed by the CPG program and replace the previous CPG patient brochure.

## BACKGROUND

### Introduction

Cancer of the cervix is the 11th most frequently diagnosed cancer amongst Canadian women. In 2002, it was estimated that 1,400 Canadian women would develop cervical cancer and 410 would die from it. There has been an overall reduction in age-standardized mortality rates from invasive cervical cancer from 7.4 per 100,000 women in 1969 to 2.2 per 100,000 women in 1996 and a reduction in incidence rates from 21.6 per 100,000 in 1969 to 9.3 per 100,000 women in 1999. This decline is mostly attributable to screening.

The delivery of cervical cancer screening may be opportunistic or organized. Opportunistic screening depends entirely on the individual woman's and/or her physician's initiative and does not achieve optimal screening coverage of the eligible population. An organized screening program allows a standardized approach to screening, follow-up, and treatment and requires a registration database of eligible women.

The database of an organized screening program will enhance recruitment by identifying those women who have never been screened and facilitate the recall of women overdue for routine screening and those who have not had appropriate follow-up of an abnormal smear. Currently, the practice in Alberta is opportunistic screening, however a population-based, organized screening program is being developed and will be implemented in Alberta over the next several years.

The Alberta Cancer Board registers 120 to 150 newly diagnosed cases of invasive cervical cancer annually and there are 30 to 50 deaths from this disease each year. In a study of the screening histories of Alberta women with invasive cervical cancer, 85% had stage 1B tumors or higher and the most significant risk factor for cancer development was infrequent or no participation in Pap smear screening.

### Natural History

Approximately 70% of cervical malignancies are squamous cell carcinomas and the remainder are mainly adenocarcinomas. Both types of carcinoma arise from premalignant lesions. Human Papillomavirus (HPV) has long been suspected and evidence to date indicates that it is a causative agent of both squamous and glandular premalignancy and malignancy. Transit times between low grade squamous intraepithelial lesion and invasive squamous cell carcinoma average 20 years, although the range may be quite variable.<sup>14</sup>

Occasionally the disease appears to have progressed more rapidly. This may be due to a more aggressive cancer or to specimen collection, preparation and/or interpretation issues. Premalignant squamous lesions are classified as either low grade squamous intraepithelial lesion (LSIL) or high grade SIL (HSIL). The majority of LSIL appears to clear spontaneously and infrequently progresses to invasive carcinoma. In contrast, approximately 13% of untreated HSIL will progress over time to invasive carcinoma<sup>4</sup>. Therefore, by detecting SIL, treatment can be implemented and invasive carcinoma obviated.

### Risk Factors

The association between HPV and cervical squamous premalignancy and malignancy is virtually beyond question. The number of sexual partners, age at first sexual intercourse, age at first pregnancy, race and socioeconomic status are surrogate markers for infection with HPV<sup>5</sup>.

In an immunocompetent host, HPV infection alone does not appear to be sufficient to induce the step from SIL to invasive carcinoma and other co-factors/exposures may be necessary.<sup>6</sup>

The only other independent factor that is currently accepted to be an important contributor to risk is cigarette smoking. There is increasing evidence that long term oral contraceptive use may also be a risk factor.<sup>7</sup>

### Frequency and Eligibility for Screening

The optimal age at which to initiate and discontinue screening and the optimal screening frequency is controversial.<sup>8-10</sup> The Programmatic Guidelines for Screening for Cancer of the Cervix in Canada<sup>8</sup>, a consensus document endorsed by major Canadian medical associations, recommend that all women aged 18 and over be screened, initially with two smears one year apart. If these smears are satisfactory then rescreening every three years is advised until the age of 69. The recommendation for a three-yearly interval is predicated on the presence of a system for recall and quality assurance within an organized screening program. Currently some provinces/territories recommend biennial screening, while others recommend annual screening.

The Alberta Cervical Cancer Screening Program (ACCSP) was established in 2000, but has not been fully implemented throughout Alberta. Although annual

screening is currently recommended, this interval is under review and will likely change within the next few years when the ACCSP has been implemented province-wide.

**Screening in pregnancy:** The first prenatal visit and the '6 week postpartum' check-up are often used by physicians as opportunities to perform cervical screening. However, this may result in overscreening. In addition, cervical changes associated with pregnancy and delivery may make Pap smears more difficult to interpret. Before performing Pap smears routinely at these visits, the physician should consider if a woman has had a recent pre-pregnant Pap smear and whether she has been a regular screener, as well as the likelihood that she will return for screening at an appropriate time.

### Screening in women who have had hysterectomies:

Since the yield of Pap smear screening is low in women who have had hysterectomies<sup>10</sup>, routine screening is not recommended. A woman who has had a hysterectomy for benign disease with complete removal of the cervix and who has no history of biopsy-confirmed cervical premalignancy or malignancy, does not need to be screened. If the cervix remains, or the woman has had biopsy-confirmed cervical premalignancy or cervical cancer, continued screening is recommended. Women who have hysterectomies for endometrial carcinoma should not be screened if their cervix was completely removed.

### OPTIMAL SPECIMEN COLLECTION

Most cervical squamous premalignancy and malignancy develop in the transformation zone and extend to the ectocervix. The purpose of specimen collection is to obtain a specimen of cells from both areas. The transformation zone is an area of cells characterized by columnar cells proximally, squamous metaplastic cells centrally, and mature squamous cells distally. This zone is located 8 to 13mm proximal to the ectocervix, but may extend as far as 20 to 30 mm into the cervical canal. The area of transformation is higher within the cervix in older women and those who are pregnant.

The ideal sample has both ectocervical and transformation zone cells in adequate numbers to detect abnormalities. Factors resulting in variability in this ideal sample are the sample taker's skill, individual variations in the transformation zone, and hormonal influences.

The technique with the least variability between sample takers and the highest consistency in providing an adequate sample involves the use of both a cervical spatula and an endocervical brush. This technique improves the adequate smear rate to 94-98%<sup>11</sup>. Use of the double collection technique also corrects for individual hormonal variability in the transformation zone.

In general, during the reproductive years, the mid-cycle is the best time for taking a smear. This produces the most easily interpreted specimen and avoids the menstrual and premenstrual leucocytic component in the mucous. Excess mucous on the cervix may be removed with a cotton swab prior to sampling if this is a problem.

#### PRACTICE POINT

Smears should not be repeated within 3 months. This time is required for the surface layer of epithelial cells to regenerate and be available for sampling.

The use of the endocervical brush in pregnant women was contraindicated in the past because of the increased incidence of bleeding and concern regarding the possibility of spontaneous abortion. A literature review<sup>12</sup> indicates that this concern is unfounded and endocervical sampling with the brush is an option.

Collection of smears in women without a cervix, but with a previous history of SIL requires scraping of the vaginal vault. The apex of the vault should be swiped with the blunt end of a spatula.

#### PRACTICE POINT

In some instances, a smear may not provide representative material and additional investigations for diagnosis are more appropriate.

This is true in circumstances where the physician observes an obvious lesion of the cervix and is suspicious of cancer. They include lesions that are:

- i) elevated;
- ii) keratotic;
- iii) ulcerated or covered with bloody necrotic exudate.

## LIMITATIONS

### False Negative Results

A false negative result occurs when the Pap smear fails to detect an abnormality that is present on the cervix. False negatives occur because either the abnormal cells are not present on the smears due to limitations of cervical sampling and smear preparation or because abnormal cells in the smears were not identified by the laboratory. Cervical cancer screening is not completely sensitive; the Pap test has a false negative rate that varies widely (13-70%) in published studies and may be higher for a single patient visit.<sup>13,14</sup> Repeat screening at regular intervals is necessary to provide adequate lifetime protection from cervical cancer.

### NOTES ON REPORTING TERMINOLOGY: THE BETHESDA SYSTEM

The Bethesda System (TBS) for reporting Pap smears is the recommended standard for use in Canada and by the Alberta Cervical Cancer Screening Program. The Bethesda 2001 Workshop reviewed issues regarding terminology and reporting of cervical cytology and made changes to the system.<sup>15</sup>

The report includes a statement of adequacy and the diagnosis. There are two categories of specimen adequacy. "Satisfactory For Evaluation" and "Unsatisfactory For Evaluation." The "Unsatisfactory For Evaluation" category indicates the smear was rejected/not processed or that the specimen was processed and examined but was unsatisfactory for evaluation of epithelial abnormality. The reasons the smear was considered "Unsatisfactory For Evaluation" will be given in the report (e.g. too few cells were collected or the cells on the smear were spread too thickly).

#### PRACTICE POINT

Unsatisfactory smears are mostly due to cervical sampling and specimen collection issues.

The diagnostic categories are "Negative for Intraepithelial Lesion or Malignancy", "Epithelial Cell Abnormality" and "Other". Smears interpreted as "Negative for Intraepithelial Lesion or Malignancy" indicates that the smear was satisfactory and that the woman should continue with routine screening, or that the smear was satisfactory with qualifiers and that it should be repeated in 12 months. The latter is the

category formerly called "Satisfactory but limited for evaluation". The type of qualifier will be given in the report. Smears interpreted as "**Epithelial Cell Abnormality**" include both those that represent cervical carcinoma and those that have changes considered to indicate increased risk of cervical carcinoma.

Changes indicative of increased risk for cervical carcinoma are reported as "**Atypical Squamous Cells of Undetermined Significance (ASC-US)**", "**Low Grade Squamous Intraepithelial Lesion (LSIL)**", "**Atypical Squamous Cells – cannot exclude HSIL (ASC-H)**", "**High Grade Squamous Intraepithelial Lesion (HSIL)**", "**Atypical Glandular Cells**" and "**Adenocarcinoma in Situ**."

## MANAGEMENT OF WOMEN BASED ON PAP SMEAR RESULTS

Table 1 on the following page provides guidelines on the management of women based on Pap smear results. The management of abnormal Pap smears in pregnant women is the same as for non-pregnant women with the following exception: if a woman has an ASC-US or LSIL result in a Pap smear taken at the first prenatal visit and has not had any other recent abnormal Pap smear, the usual recommendation would be to repeat the Pap smear in 6 months. However, rather than doing this repeat Pap smear in the third trimester, it is recommended to wait until at least 6 weeks postpartum.

Endometrial cells after age 40 may be associated with benign endometrium, hormonal alterations and less commonly endometrial or uterine abnormalities. The management recommendation is: clinical correlation is recommended and endometrial biopsy and/or endocervical curettage may be appropriate.

Women who are estrogen depleted may have atrophic cells on the Pap smear. These may falsely mimic intraepithelial abnormalities and may be reported as ASC-US. In this circumstance, repeating the Pap smear after a course of intravaginal estrogen is recommended (see Appendix for recommended protocol). If the repeat Pap smear is normal (NIL), the woman can return to routine screening.

Women with atypical glandular cells on the Pap smear should be referred for colposcopy; repeat cytology is not sufficient.

Women who have undergone colposcopic assessment and treatment and have been discharged from colposcopy should be managed according to the

guidelines in Table 1, and should not be referred back to colposcopy after a single ASC-US or LSIL result.

## Colposcopy

Colposcopy is a technology that has been used for several decades to identify sub-clinical abnormalities of the uterine cervix. The cervix is magnified through a binocular scope with a high intensity light. This allows for the identification of abnormalities based upon epithelial density (white epithelium) and vascular patterns (punctuation, etc.). Using these parameters, an area of abnormality can be identified in order to direct a tissue biopsy by one of several available methods (punch biopsy, loop electrosurgical excision, etc.).

## HPV Testing

The prevalence of cervical HPV DNA in women with **NORMAL** Pap smears and no history of premalignancy is approximately 10% whereas the rate amongst those with a history of cervical premalignancy is approximately 30%. The HPV can be detected by a number of methods. The most sensitive are those that detect viral deoxyribonucleic acid (DNA). There are more than 85 types of the virus and approximately 30 are associated with cervical carcinoma. Viral DNA detection rates correlate directly with the grade of cervical premalignancy and upwards of 99% of cervical carcinomas are HPV DNA positive.<sup>16</sup>

Amongst those with a smear result of ASC-US, HPV testing is sensitive in detecting HSIL.<sup>17</sup> Future use of routine HPV testing in this group will be decided by the Alberta Cervical Cancer Screening Program following appropriate consultation. Routine HPV testing is currently not available in Alberta.

## Future Directions

At this time, a population-based, organized screening program is being developed in Alberta. The ACCSP will implement an information system that will invite women who haven't been screened, recall women when their next screening is due and ensure that women with abnormal screening results are being followed up. The ACCSP will also develop strategies and resources to increase recruitment of unscreened women and implement quality improvement initiatives at all stages of the screening process. When all the components of an organized screening program are in place, the recommended routine screening interval will be reviewed, and may be extended. However, until that time, the recommended routine screening interval is annual.

**Table 1** (See text for additional information)  
**Guidelines for the Management of Women Based on Pap Smear Results**

Result	Recommended Management
Unsatisfactory	Repeat smear in 3 months.
Negative for Intraepithelial Lesion or Malignancy (NILM) • Women >40	a) Satisfactory smear - routine screening b) Satisfactory with qualifiers - repeat smear in 12 months. • Endometrial biopsy and/or endocervical curettage for confirmation
ASC-US (Atypical Squamous Cells of Undetermined Significance)	If specific pathogen identified, treat if clinically appropriate. • Repeat smears every 6 months for 2 years (4 smears); if any of these smears is ASC-US or worse, refer for colposcopy. If smears in follow-up period are all NILM, return to routine screening. • If smear is atrophic, repeat smear 1 week after completion of a course of intravaginal estrogen therapy. The Pap smear should <u>not</u> be repeated before 3 months. • If smear was at first prenatal visit and there are no other recent abnormal Pap smears, recommend waiting for repeat smear until at least 6 weeks post partum.
LSIL (Low Grade Squamous Intraepithelial Lesion)	• Repeat smears every 6 months for 2 years (4 smears); if any of these smears is ASC-US or worse, refer for colposcopy. If smears in follow-up period are all NILM, return to routine annual screening. -- • If smear was at first prenatal visit and there are no other recent abnormal Pap smears, recommend waiting for repeat smear until at least 6 weeks post partum.
ASC-H (Atypical Squamous Cells-cannot exclude HSIL)	Refer for colposcopy.
HSIL (High Grade Squamous Intraepithelial Lesion)	Refer for colposcopy.
Atypical Glandular Cells Adenocarcinoma in Situ (AIS)	Refer for colposcopy and endocervical curettage. Endometrial biopsy may be appropriate. Repeat PAP smears are insufficient
Squamous Cell Carcinoma Adenocarcinoma Other Malignant Types	Refer to specialist care.

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## Toward Optimized Practice (TOP) Program

Arising out of the 2003 Master Agreement, TOP succeeds the former Alberta Clinical Practice Guidelines program, and maintains and distributes Alberta CPGs. TOP is a health quality improvement initiative that fits within the broader health system focus on quality and complements other strategies such as Primary Care Initiative and the Physician Office System Program.

The TOP program supports physician practices, and the teams they work with, by fostering the use of evidence-based best practices and quality initiatives in medical care in Alberta. The program offers a variety of tools and out-reach services to help physicians and their colleagues meet the challenge of keeping practices current in an environment of continually emerging evidence.

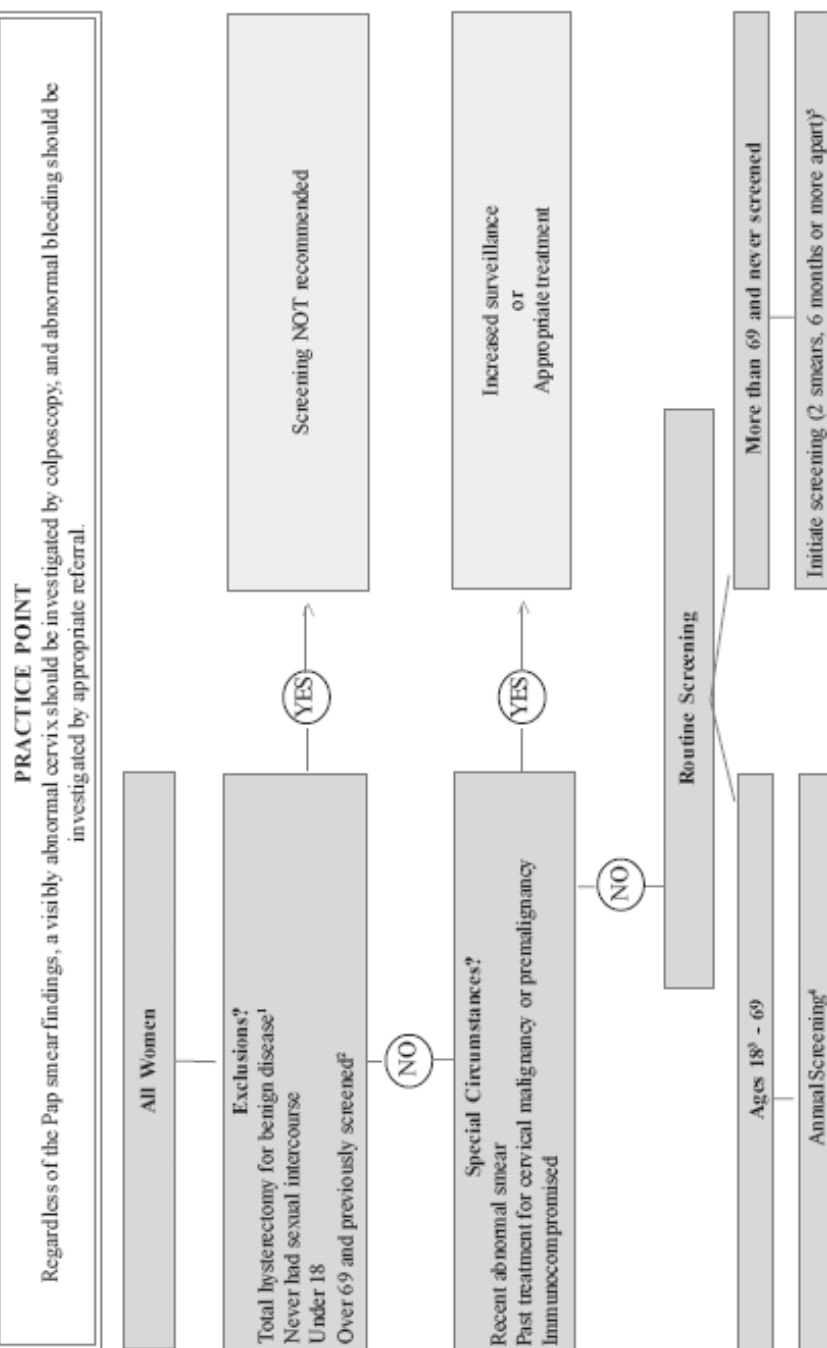
## TO PROVIDE FEEDBACK

The Working Group encourages your feedback. If you need further information or if you have difficulty applying this guideline, please contact:

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*Cervical Cancer, February 2000  
Revised January 2003  
Revised January 2005  
Publication Mail Agreement #1630008*

## ALGORITHM: CERVICAL CANCER SCREENING

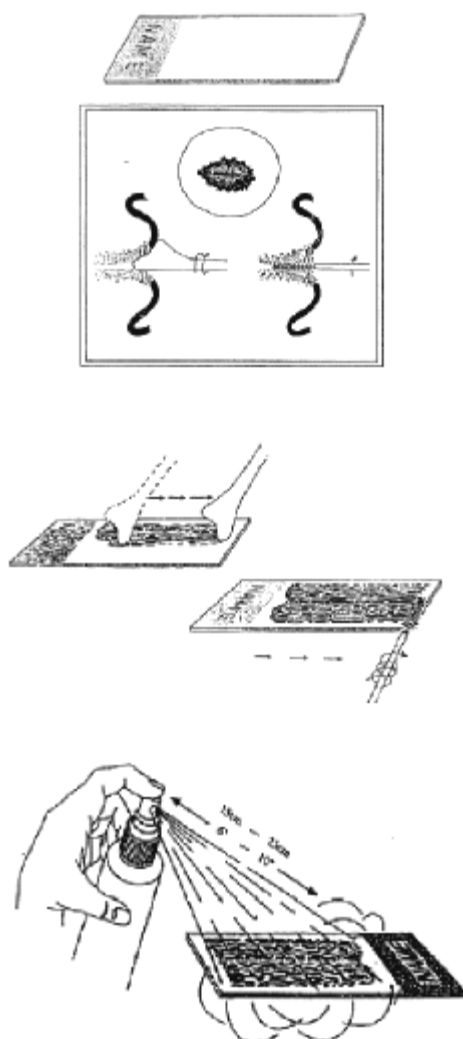


## Notes:

1. If there is adequate evidence that the cervix has been completely removed and there is no history of cervical pre-malignancy or malignancy.
2. Screening may be discontinued in women over 69, provided there have been at least two satisfactory and negative Pap smears, taken at least 3 months apart, in the past three years and there is no history of cervical malignancy or premalignancy.
3. The Alberta Cervical Cancer Screening Program does not recommend routine screening in women <18 or >69. Screening in these age groups may be needed in some individual cases.
4. At present the Alberta Cervical Cancer Screening Program recommends annual screening. When the Program is fully implemented, recommended frequencies will be reviewed.
5. If these smears are NIL and satisfactory, no further screening is necessary.

## Appendix for Pap Smear Preparation

*This appendix is adapted from the Ontario Cervical Screening Reference Card. It compliments the CPG: Screening for Cervical Cancer prepared by the Alberta Clinical Practice Guidelines Program.*



### COMPLETE REQUISITION FORM

- Ensure consistency of labelling
- Ensure relevant history is complete

### LABEL SLIDE WITH FULL NAME

- With PENCIL, on frosted side of slide

### VISUALIZE CERVIX

- lubricate speculum with warm water
  - use lubricant gel sparingly
- Assess position of transformation zone.  
Ensure zone will be sampled with appropriate device.

### OBTAIN BOTH SAMPLES

To obtain a proper Pap smear, use a spatula and an endocervical sampling device (e.g., brush) and then apply both specimens on a single slide

- (1) SPATULA
- rotate once through 360°
  - keep spatula well applied
  - end in the horizontal position. Retain the sample on the upper side of the spatula during transfer
- (2) BRUSH
- or other endocervical sampling device
  - insert gently
  - TURN THROUGH 90° ONLY.

**NOTE:** Over inserting the brush increases trauma without improving the quality of the sample. Insert no further than the bristles.

### APPLY SAMPLE

Use ONE slide. Apply each sample on one half of slide, in immediate sequence, as shown - keep separate

- (1) SPATULA
- spread in a single uniform motion
- (2) BRUSH
- sample will dry quickly
  - roll on in one motion

**THIS SEQUENCE SHOULD BE PRACTICED TO AVOID DELAY. APPLY BOTH SAMPLES SIMULTANEOUSLY.**

### FIX SAMPLE

- immediately
- allow sample to dry before closing mailer



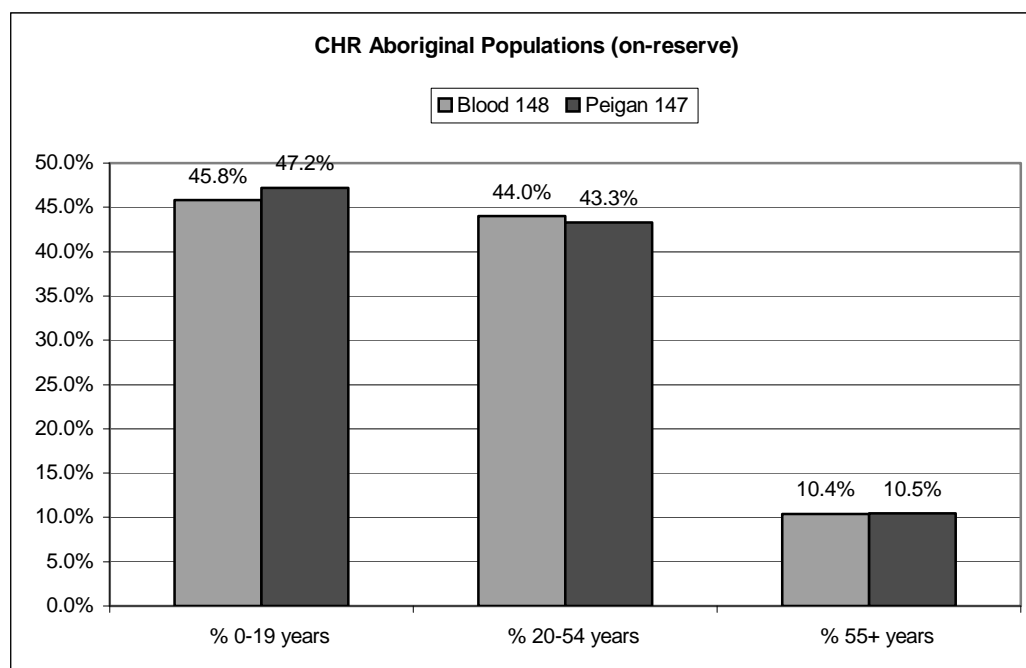
## APPENDIX B

## CH Aboriginal On-reserve Profile: Blood &amp; Piikani (Peigan)

<b>Chinook Health Region Aboriginal Population (on-reserve)</b>			
	<b>Blood 148</b>	<b>Peigan 147</b>	<b>Alberta</b>
<b>Population in 2000</b>	3,852	1,537	2,974,800
<b>Population in 1996</b>	4,326	1,662	2,696,800
<b>% Change</b>	<b>11.0%</b>	<b>7.5%</b>	<b>-10.3%</b>
<b>Total Population &gt;=15 years</b>	2,490	975	102,525
<b>Age Characteristics</b>			
Total - All persons	3,795	1,525	156,220
% 0-19 years	45.8%	47.2%	44.3%
% 20-54 years	44.0%	43.3%	47.8%
% 55+ years	10.4%	10.5%	7.4%
<b>Legal Marital Status</b>			
Single %	61.2%	68.2%	55.4%
Married %	28.1%	22.6%	29.5%
Separated/Divorced %	5.8%	4.1%	4.8%
Widowed %	4.8%	5.6%	7.0%
% in a common law relationship	25.1%	26.2%	9.1%
Proportion 0-19 to 65 years	10.9	11.1	13.5

\* Treaty Indian or Registered Indian as defined by the Indian Act of Canada

Source: 2001 Aboriginal Peoples Survey Community Profiles



## APPENDIX C

### CH Aboriginal Community Profiles

<b>Chinook Health Region Aboriginal Population (on-reserve)</b>		
	<b>Blood 148</b>	<b>Peigan 147</b>
<b>Total Aboriginal Population*</b>	3,800	1,530
> 15 years	2,490	980
% of Population >15 years	66%	64%
North American Indian	2470	970
Metis	NA	NA
Inuit	NA	NA
% of adults who did not finish high school	45.5%	45.9%
% students at residential or industrial school	39.0%	32.0%
% of adults with family members who attended residential or industrial school	100.0%	100.0%
% who speak their primary Aboriginal language very or relatively well	74.0%	63.0%
% with access to primary Aboriginal Language: Health Services	86.0%	48.0%
% who hunted for food	NA	90.0%
% who fished for food	45.0%	46.0%
Unemployment rate	31.2%	36.6%
<b>General Health</b>		
% of adults who say their health is		
Very good or excellent	40.0%	44.0%
Good	52.0%	44.0%
Fair or poor	9.0%	12.0%
<b>% who saw or talked on telephone about physical, emotional or mental health in past 12 months</b>		
Family doctor or GP	75.0%	59.0%
Traditional Healer	20.0%	19.0%
Nurse	20.0%	30.0%
Dentist or orthodontist	31.0%	36.0%
Other health professional	43.0%	56.0%
<b>Long term health conditions</b>		
% of adults with one or more long-term health conditions	24.5%	6.1%
% with diabetes	NA	11.2%
% with respiratory problems (asthma, chronic bronchitis, emphysema)	5.6%	6.1%
% with high blood pressure, heart problems or effects of stroke	6.9%	11.2%
% with communicable disease (Hepatitis, TB or HIV/AIDS)	NA	NA
% who used a computer in the past 12 mos.	38.0%	43.0%
% who used the Internet in the past 12 months	28.0%	35.0%
% who have always lived in same city, town, or community	91.0%	80.0%
% who did not move in th past 5 years	NA	41.0%
% in homes without a telephone	29.0%	14.0%
% saying water available to home is not safe to drink	14.0%	NA

\* Treaty Indian or Registered Indian as defined by the Indian Act of Canada

Source: 2001 Aboriginal Peoples Survey Community Profiles

APPENDIX D

Comparing Cultural Values (Huff & Kline, 1999, p. 89)

<b>Other Ethno-Cultural Groups</b>	<b>Anglo-American</b>
Harmony with nature	Mastery over nature
Fate	Personal control over the environment
Being	Doing/activity
Hierarchy/rank/status	Human equality
Group welfare	Individualism/privacy
Elders	Youth
Birthright inheritance	Self-help
Cooperation	Competition
Past or present orientation	Future orientation
Formality	Informality
Indirectness/ritual/ “face”	Directness/openness/honesty
Idealism	Practicality/efficiency
Spiritualism/detachment	Materialism

APPENDIX E1

Letter of Invitation



Health Program Pilot Project 2004/05

Chinook Health Region Cervical Health program

FOCUS GROUP PARTICIPANT INFORMATION SHEET <sup>31</sup>

- The purpose of this research study is to obtain your ideas on how we can improve services for women in the Chinook Health Region. At the same time, we would also like to tell you about the Pap test. This test can detect unhealthy changes in the cells of the womb that may be an early sign of cancer. Pap tests can help prevent problems before they happen.
- The Alberta Cancer Board has provided funding for the last three years to teach women about cervical health. This year, we want to encourage women from your community to take part.
- The Chinook Health Region (CHR) together with the University of Lethbridge is conducting this study. Information you provide will be used for my Thesis under the supervision of Dr. Ruth Grant-Kalischuk, Associate Professor, University of Lethbridge. If you are between the ages of 18 and 69 years, and a CHR resident living off reserve, we invite you to take part in a group session (talking circle) with other women from your area.
- Sessions will be about one and a half hours in length. In the first half of the sessions, we will discuss what health means to you and how the CHR might best meet the needs of women in your community. In the last half of the session, we will discuss the Pap test, and the importance of regular screening.
- You may choose not to take part in this study and can stop at any time without affecting the service you receive. You may choose not to answer questions. You do not have to give a reason and it will not affect your care. Your responses will be confidential. Only the focus group leaders will be able to identify information specific to you. Your comments will be taped to ensure that the information we collect is accurate. The tapes will be destroyed after copying them to written records for easier analysis by the

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<sup>31</sup> 11/7/2004 Flesch Kincaid Grade level 9.2 (Grade 7.5 with organizational identifiers removed)

researchers. We will not use your real name on any records or notes. All information will be kept in a locked place and destroyed at the end of the study.

- At the end of the session, we will ask you how we could let other women in your area know about Pap testing. You will be offered the chance to book a Pap test with your doctor or through the screening clinic. Your test results will be shared with the Clinic physician and Cervical Health Program staff and you will be contacted if there are any concerns.
- After the study, the final report will be shared with the Chinook Health Region women's Health Program and the Alberta Cervical Cancer Screening Program. If you would like a copy, we can send one to you. If so, please place your address at the bottom of this form.
- The Human Subject Research Committee at the University of Lethbridge, the Research and Ethics committee of the Chinook Health Region and the community Research and Ethics Board of Alberta have approved this research project. If you have questions specific to the Pap test or CHR Women's Health Program, please call the CHR Director of Women's Health at (403)388-6281. For questions that are more general, please contact the University of Lethbridge Research Services (403)329-2747.
- We would like to thank you for taking part in this focus group. If anything is unclear to you, please let the group leaders know and they will explain further.

APPENDIX E2

Notice: Community Groups/Agencies Targeting Aboriginal Women



Client Notice

WE NEED YOUR HELP

Within the coming months, the Chinook Health Region Cervical Team will be doing a study focusing on preventive health practices, (specifically in relation to cervical health and screening). For the past three years, the Alberta Cancer Board has provided funding to teach women from many different communities about cervical health and to encourage them to have an annual Pap test. This year, we want to encourage women from your community to participate.

We will meet with small groups of women age 18-69 years who are Chinook Health Region residents living off reserve to discuss their perception of health care and service delivery needs. The study will provide service providers and policy makers with information about how to plan an effective program that will meet the needs of the community and to identify any gaps that need to be addressed. Suggestions to enhance cervical screening will be explored.

We are inviting you to take part in a 1-1/2 hour Cervical Screening Educational session and focus group (talking circle) here at \_\_\_\_\_ with about seven other women. We will be asking you for information about how you maintain your health, health concerns facing women in your community, factors affecting your decision to have/not have a Pap test, and where you receive your information about Cervical Screening. We will ask you for your advice in planning a Cervical Screening Clinic that would meet the needs of Aboriginal women. Your answers to these questions will be kept confidential and your name will never be recorded with your answers. The advice we get from these sessions will provide us with information that will improve the services for Aboriginal women in your community. We are offering a small gift to those women who participate in this project.

If you are interested, please contact Christine Jensen-Ross at 388-6173 or Marg Brewin at 388-6111, or you can contact \_\_\_\_\_ for more information.

We look forward to meeting you and working together to improve Chinook Health Region services.

APPENDIX F1  
Focus Group Questions

Interview topic	Question (Qualitative Methodology)	Purpose
1. Introduction	Please tell us your first name, a bit about the members of your household	
2. Personal Health and Wellbeing	What are some of the ways that you maintain your personal health and wellbeing?	To determine perceptions of health, attitudes and behaviours toward maintaining health.
3. Identified Needs	What are some of the main health concerns affecting Aboriginal women living off reserve today?	To determine factors that influence Aboriginal women living off-reserve to have cervical screening done
	What would you like to be able to discuss with your health care provider at a screening visit?	To explore their perception of important topics they would like to be able to discuss with their health care provider.
	Can you tell us about a particularly good experience you or your family had with health care?  Can you tell us about a particularly negative experience you or your family had with health care?	To explore factors that positively or negatively affect access to health care services?
3. Visioning: Optimal Service	If you were designing a Pap Screening Centre for Aboriginal women, what would the Centre look like?	To encourage participants to share their point of view about what optimal Pap Screening Services for Aboriginal Women would look like.

## APPENDIX F2

### Moderator Guide

#### **Pap Cancer Testing: A Focus on Aboriginal Women**

#### **Focus Group Moderators Guide<sup>32</sup>**

##### *Schedule*

Group #	Participants	Location	Date/Time
1.	101-106	4K145 Lethbridge Auxiliary Bldg.	Nov 17/04 10:00 – 12:00
2.	107-110	4K145 Lethbridge Auxiliary Bldg.	January 18/05 10:00 – 12:00
3	111-113	Opokaa'Sin	June /05 19:00 – 21:00

##### *Purpose*

This research will aid in determining Southern Alberta Aboriginal women's perceptions of optimal Pap testing services in light of their unique needs and Alberta Cancer Board guidelines,

Specifically, the research is set out to:

- Identify the needs of Aboriginal women in relation to their health and well-being and more specifically, getting a Pap test
- Explore strategies that would encourage Aboriginal women to access Pap testing services
- Determine perceptions of appropriate and acceptable service provider, location
- Facilitate women in accessing Pap test services (e.g. through their regular physician or the Cervical Screening Clinic, Lethbridge Regional Hospital)
- Assist in identifying other Aboriginal women or groups who would be receptive to learning more about the benefits of regular Pap testing.
- Provide women with information about Pap testing and reinforce the importance of regular Pap tests

For a summary of focus group interview questions, please see Appendix A.

PROP: TAPE RECORDERS (2), FRESH BATTERIES, EXTENSION CORD, PEN TO LABEL TAPES, TAPE LABELS, PLACECARDS, PENS FOR PARTICIPANTS.

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<sup>32</sup> Adapted from Environics, 2003



## **Introduction – 10 minutes**

Hello. Welcome. My name is Christine Jensen-Ross. I'll be one of the discussion leaders for today's group together with my co-workers, Marg Brewin and Terri-Lynn Fox. We will be here for approximately 1-1/2 hours. In the first half hour you will have opportunity to discuss your questions about Pap testing and what it means to you. In the last hour I would like to explore your opinions and thoughts about the health and well-being of Aboriginal women living in the Chinook Health Region.

The Lethbridge Cervical Screening Clinic came into being in 2003. Our goal is to promote early detection and treatment of cancer for women residing in the community. The reason you have been chose for this session might be obvious, you are all Chinook Health Region residents, Aboriginal women living off-reserve, and of course, women. We are speaking to many Aboriginal women in our region about Pap testing and hope to get a clearer understanding of your point of view and that of other Aboriginal women in the community. The feedback received today will help us to improve services for you, your friends, and your community.

## ***Review of Standard Focus Group Information***

About me: I'm a Health Care Analyst working with the Chinook Health Region Family Health Program. My background is in nursing. I am not employed by the Provincial government or by Indian and Northern Affairs. I do not work for a drug company, a private business and I am not selling any healthcare products. I am here today to gather your opinions and to answer your questions about cervical cancer and the Pap Test. This information will be used to improve services provided to Chinook Health Region residents. Please **feel free to express your opinions** about what we discuss – good or bad – because that's the reason why we have come here today.

Before I go any further, I would like to tell you about today's session. Has anyone been to a focus group (Talking Circle) before? The room we are in today is set up to record our discussion. You'll note that I have a tape recorder here and my co-worker, Marg Brewin is here to observe and take notes. All this is so we can listen closely to what you have to say, keep all your comments straight, and so that I don't have to take a lot of notes myself over the course of the discussion. Each of you will be invited to sign a consent form. Participation in this study is completely voluntary. **(REVIEW CONSENT AND HAVE PARTICIPANTS SIGN)**

I'd like to set out a few guidelines to make this as easy as possible:

- Talk one at a time, in a voice as loud as mine
- Sometimes it is easy to **let other people speak more**, or even sometimes to think that your opinions aren't important or interesting or that other people know a lot more about what we are discussing.. That's not why we asked you here – we asked you here to hear from each of you – your thoughts and feelings. We want to **hear all sides of each question**. I'd like to thank you in advance to being willing to speak up and take part. At the same time, I don't expect that each and every

person will have something to say on each and every question – although I do hope to **hear from each one of you** over the course of our discussion.

- If you naturally tend to be someone who has lots to say, please be aware of this and be sure to give the **quieter people** a chance to speak, and if you're more on the quiet side, I'm going to ask you to make that extra effort to speak up when you have something to say or add to the discussion.
- I'll be the discussion leader, but you don't need to address all your comments to me. Just jump in and respond to someone else's comments whenever you like to.
- BUT there is a rule that just **one person talks at a time** – Please don't have side conversations with your neighbors, or I won't be able to hear what everyone is saying.
- So just to sum up, we're here to gather all the opinions we can. There are no right or wrong answers. Don't let the group sway you – and if you change your mind on something, that's fine too.
- Just a couple of practical items; there's no smoking in this room. Please turn off your cell phones. There are washrooms "down the hall" and if you need to leave the room, just go right ahead. Also, help yourself to coffee and treats before we get started.

#### PROP: COFFEE, JUICE AND TREATS

##### *1. Respondent Introduction – (10 minutes)*

To begin, I'd like to go around the table and get each of you to tell me:

- A bit about yourself. Please tell us your first name, and what you hope to gain from today's session

##### *2. Personal Health Practices and wellbeing (10 minutes)*

Objective:

1. To determine perceptions of health, attitudes and behaviours toward maintaining health.
2. To determine factors that influence Aboriginal women living off reserve to have Pap testing done.

**Question: What are some of the ways you maintain personal good health?**

#### PROBES

- a) What does health mean to you? (spiritual, mental, physical, and social)
- b) Does the Medicine Wheel influence your definition of health?
- c) Do you have regular physical checkups? Why or why not?
- d) Have you had a Pap test in the past 3 years? In the past 2 years? In the past year?

#### SHOW OF HANDS

- e) What are some of the reasons you have not had testing done?

Possible responses:

- I'm not at risk
- Unavailable facilities or medical personnel

- Not reminded that testing was due
- Not experiencing any symptoms
- Family barriers
- Embarrassing or uncomfortable
- No one I know gets tested

- f) Has anyone influenced your decision to have a Pap test?
- Your family?
  - Others people in your community?
  - Lay community worker?

**3. Educational Session (30 minutes)**

Objective: To respond to identified educational needs as per #4

PROP: CULTURALLY APPROPRIATE EDUCATIONAL VIDEO, OVERHEADS

**4. Visioning: Identified Needs and Optimal Services (50 minutes)**

Objective:

1. To encourage participants to share their point of view about what optimal Pap testing Services for Aboriginal Women would look like.
2. To explore their perception of important topics they would like to be able to discuss with the health practitioner
3. To incorporate oral tradition and storytelling as a means of expressing perceived needs

**Question: If you were designing a Pap testing Clinic for Aboriginal women, what would the Clinic look like?**

PROBES:

- a) Where would it be located?
- b) Who should be able to attend the clinic?
- c) Who would staff the clinic?
- d) Who would provide the Pap screen tests?
- e) What qualities would you look for in staff?
- f) Is staff gender important?
- g) When (hours of day, days of week) would the centre be open?
- h) Are there any important aspects to be taken into consideration?
  - Transportation
  - Child care
- i) Where do you currently go to be tested? What facilities or resources are available to you in your community?

**Question: Using this drawing, what would you like to be able to discuss with your health care provider at a testing visit?**

PROP: STICK WOMAN DRAWING, FELT PEN, FLIP CHART

PROBES

a) Have sexual health or gynecological concerns been mentioned? If not, explore why...

**Question: Can you tell me about a particularly good experience you or your family had with health care?**

**Question: Can you tell me about a particularly negative experience you or your family had with health care?**

**Question: Have you or anyone you know of been diagnosed with cervical cancer? What was their experience like?**

**Question: What are some of the main health concerns affecting Aboriginal women living off reserve today?**

PROBES:

- Are there different issues that would need to be addressed, depending upon the age of the woman?

#### **5. Demographics and Pseudonym Selection**

Objective:

- To encourage women to complete a demographics questionnaire and select a pseudonym for use in any reports or publications

PROPS: DEMOGRAPHICS SHEET, ATTENDANCE SHEET WITH SELECTED PSEUDONYM

#### **6. Pap test Appointment Booking**

Objective:

- To encourage women to book an appointment for Pap testing, either with the regular physician or through the Lethbridge Cervical Screening Clinic,
- To arrange transportation, child care as required,
- To provide women who will return to their regular physician for Pap testing with specially marked lab requisitions indicating their participation in the research study

**Question: Would you like to book an appointment for a Pap test?**

[Note: Travel and babysitting *may* be available on an *as-needed* basis.]

PROMPTS:

**Own physician-** distribute lab requisition for woman to take to her physician visit.

PROP: LABELED LAB REQUISITION

**No physician or request to visit clinic** – Book appointment

PROP: APPOINTMENT BOOK

**Question: Do you know of other women or groups who would like to learn more about Pap screens/Pap tests?**

PROP: LAY HEALTH WORKER BOOKING SHEET

**7. *Wrap-up***

Objective:

- To summarize the talking circle discussion (Refer Back to Flipchart Notes made in discussion)
- To re-emphasize the importance of early detection
- To share with the women when the report will be completed, provide them with an opportunity to review the findings prior to sharing the report with others
- To obtain group demographics
- To encourage the participants to identify other women or groups in the community who might be receptive to educational sessions.

Thank you. Are there some things anyone would like to add before we finish?

Thanks to you all again very much. We've really gained a lot from all of your comments – I thank you for the opportunity to discuss this sensitive topic so openly and appreciate your coming and sharing your views.

If you have any outstanding questions about today's session or would like to speak further with the Health Promotion Specialist at the Pap Cancer Clinic please contact Marg Brewin at 388- 1340 or Christine Jensen-Ross at 388-6173.

PROP: BUSINESS CARDS, PAP TESTING PAMPHLETS

APPENDIX G

Cervical Screening Participant Demographic Questionnaire

Date of Interview: _____	
Number of individuals currently living at home _____	
Age: _____ years	
Please tick (✓) the most appropriate response:	
Marital status:	<input type="checkbox"/> Married/Common-law <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Other
Highest level of education completed:	<input type="checkbox"/> Did not attend school <input type="checkbox"/> Grade 1-6 <input type="checkbox"/> Grade 7-9 <input type="checkbox"/> Grade 10-12 <input type="checkbox"/> College or university <input type="checkbox"/> Other, please explain _____
Did you attend a residential school?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Occupation	<input type="checkbox"/> Homemaker <input type="checkbox"/> Student <input type="checkbox"/> Health care professional <input type="checkbox"/> Other, please explain _____
Do you have any health concerns?	<input type="checkbox"/> Yes, Please explain _____ <input type="checkbox"/> No
Ethnicity	<input type="checkbox"/> Blood <input type="checkbox"/> Piikani <input type="checkbox"/> Cree <input type="checkbox"/> Other, specify _____
Do you have Treaty Status?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Residence	<input type="checkbox"/> On Reserve <input type="checkbox"/> Off Reserve <input type="checkbox"/> Other, specify _____
Do you know anyone in this group?	<input type="checkbox"/> Yes <input type="checkbox"/> No If yes, how do you know them? Please tick (✓) ALL that apply: <input type="checkbox"/> Relative <input type="checkbox"/> Friend <input type="checkbox"/> Co-worker <input type="checkbox"/> Acquaintance <input type="checkbox"/> Other
What is your main source of income?	<input type="checkbox"/> AISH <input type="checkbox"/> Pension <input type="checkbox"/> Employment Insurance <input type="checkbox"/> Workers' Compensation <input type="checkbox"/> Guaranteed Income Supplement <input type="checkbox"/> Employment Income <input type="checkbox"/> Other, please explain _____
Thank you for your responses.	

APPENDIX H  
Focus Group Observation Sheet

Author	Suggestions for Observation of Group Interaction
Twinn as cited in Webb, 2001	<ul style="list-style-type: none"> <li>• One member dominance, effects of “significant group members”</li> <li>• Alternative opinions</li> <li>• Effect of the number of group members</li> <li>• Status and relationships of participants, relationship to group leader</li> </ul>
Robinson, as cited in Webb, 2001	<ul style="list-style-type: none"> <li>• Specific comments, jokes, anecdotes, questions</li> <li>• Censorship</li> <li>• Changes of mind</li> <li>• Deferring to the opinion of others</li> </ul>
Reed and Payton, as cited in Webb, 2001	<ul style="list-style-type: none"> <li>• Sequences of discussion – e.g. as an example of how consensus evolved over the course of the discussion</li> <li>• dominance</li> </ul>
Idvall and Rooke, as cited in Webb 2001	<ul style="list-style-type: none"> <li>• Interaction quotations</li> </ul>
Stevens, as cited in Webb, 2001	<ul style="list-style-type: none"> <li>• How closely did the group adhere to the issues presented for discussion?</li> <li>• Why, how and when were related issues brought up?</li> <li>• What statements seemed to evoke conflict?</li> <li>• What were the contradictions in the discussion?</li> <li>• What common experiences were expressed?</li> <li>• Were there alliances formed among group members/</li> <li>• Was a particular member of viewpoint silences?</li> <li>• Was a particular view dominant?</li> <li>• How did the group resolve disagreements?</li> <li>• What topics produced consensus?</li> <li>• Whose interests were being represented in the group?</li> <li>• How were emotions handled?</li> </ul>
Mansell (2004)	<ul style="list-style-type: none"> <li>• Were participants: <ul style="list-style-type: none"> <li>○ Defending their positions</li> <li>○ Supporting the positions of another</li> <li>○ Clarifying a point made earlier</li> <li>○ Making a new proposition</li> <li>○ Changed mind within discussion</li> <li>○ What was the emphasis or intensity of statements made</li> </ul> </li> </ul>
Hollander (2004)	<ul style="list-style-type: none"> <li>• Who has status or power in the situation</li> <li>• Who speaks first?</li> <li>• What kinds of thoughts, feelings or experiences might be expected in the context</li> <li>• What kinds might not be expected?</li> <li>• Are expectations the same for all participants?</li> <li>• What are the consequences (immediate and long-term) for the individual participants of disclosing sensitive information?</li> <li>• What are the potential rewards for conformity or nondisclosure?</li> <li>• Perceived presence of others not physically present at the discussion but whose imagined presence affects the participant</li> </ul>
The researcher’s goal is to “obtain the world view, attitudes, meanings and experiences of the people so that truths and realities can be known” (Leininger, 1985, p. 46). Comparative emic and etic differences are sought.	

APPENDIX I

Physician Cervical Screening Notice



Breast/Cervical Health Program  
4<sup>th</sup> Floor Auxiliary Bldg  
Lethbridge Regional Hospital  
March 23/05

Dear Dr. \_\_\_\_\_

In 2004-05 the Chinook Health Region Cervical Team has been doing a study focusing on preventive health practices, (specifically in relation to cervical health and screening). For the past three years, the Alberta Cancer Board has provided funding to teach women from many different communities about cervical health and to encourage them to have an annual Pap test. This year, we met with small groups of women age 18-69 years who were Chinook Health Region residents living off reserve to discuss their perception of health care and service delivery needs. The advice we get from these sessions will help make our program better and improve services provided to Aboriginal women in your community.

Your patient, \_\_\_\_\_ recently attended a Cervical Screening Education and Focus Group.

If you would like more information about the Chinook Health Region Breast/Cervical Health Program please contact Marg Brewin or Linda Lacny at 388-6324. For more information about the focus group results, contact Christine Jensen-Ross at 388-6173.



## APPENDIX J

### Consent Form

Study # \_\_\_\_\_

Cervical Health Program Pilot Project 2004 /2005 - Chinook Health Region

#### CERVICAL HEALTH PROGRAM CONSENT FORM

The purpose of this project is to let you know about Pap testing and the need for regular checkups. The Pap test looks at the cells of the neck of your womb. It can sometimes show changes in these cells that are not healthy. Cells that are not healthy can sometimes lead to cancer. Pap tests can help prevent problems before they happen.

You are invited to learn more about Pap tests and to share your ideas for improving service to aboriginal women. You may be seen on a one-to-one basis or in a group with other women from your area. Sessions are one and a half hour long. At the end of the session, you will be asked how we could let other women in your area know about Pap testing. You will be offered the chance to book a Pap test with your doctor or through the screening clinic. Rides to and from the clinic may be available.

You may choose not to answer questions. You do not have to give a reason and it will not affect your care.

Your comments will be written down or recorded and shared in a final report. Your real name will not be used in the report or on any forms or notes. All information will be kept in a locked place.

Women between the ages of 18 to 69 years of age who have not had a Pap test in the past year are welcome to come to the program.

Health Program Pilot Project 2004 /2005 - Chinook Health Region

CERVICAL HEALTH PROGRAM CONSENT FORM

Study #\_\_\_\_\_

Please circle your response:

Do you agree to participate in a learning session?	Yes	No
Do you agree to participate in a discussion group (group sessions only?)	Yes	No
Do you understand that you have been asked to be in a research study?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had a chance to ask questions and discuss this study?	Yes	No
Do you want us to inform your family doctor that you are participating in this study?	Yes	No
If so, please provide your doctor's name: _____		
Do you agree to release the results of your Pap test to the Cervical Health Program?	Yes	No
Do you agree to allow your comments to be recorded on audiotape? Your name will not be associated with the audiotapes and all identifiers will be removed.	Yes	No

This study was explained to me by : \_\_\_\_\_

***A COPY OF THIS CONSENT IS TO BE GIVEN THE RESEARCH PARTICIPANT***

I agree to take part in this study. I can withdraw my name at any time without affecting the service I receive. I understand that I may stop at any time by calling LeeAnn DeCecco, Chinook Health Region at 403-388-6003.

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
My Phone Number:

\_\_\_\_\_  
My Date of Birth  
(dd/mm/yy):

\_\_\_\_\_  
My Personal Health Care Number:

\_\_\_\_\_  
For use in obtaining consent of a non-English speaking client:

\_\_\_\_\_  
Signature of client:

\_\_\_\_\_  
Date (dd/mm/yy):

\_\_\_\_\_  
Time:

\_\_\_\_\_  
Signature of Interpreter:

\_\_\_\_\_  
Date (dd/mm/yy):

\_\_\_\_\_  
Time:

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee \_\_\_\_\_ Date \_\_\_\_\_

**If you have questions specific to the Pap test or CHR Women's Health Program, please call the CHR Director of Women's Health at (403)388-6281. For questions that are more general, please contact the University of Lethbridge Research Services (403)329-2724.**

Thank you for your input!



Reta Berte, Senior Program Director, Family Health Program

Linda Lacny, Women's Health Program

Christine Jensen-Ross, Health Care Analyst, Family Health Program



Dr. Ruth Grant-Kalischuk, Department of Health Sciences

Dr. Brad Hagan, Department of Health Sciences

Dr. Jo-Anne Fiske, Women's Health Studies

***A COPY OF THIS CONSENT IS TO BE GIVEN THE RESEARCH PARTICIPANT***