Indigenous Peoples' Health Research Centre

Miyo-Māhcihowin
A report on Indigenous Health in Saskatchewan:

Report of the
Indigenous Peoples' Health Research Centre

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Foreword

The Indigenous Peoples' Health Research Centre, a joint initiative of the University of Saskatchewan, the University of Regina and the First Nations University of Canada, is pleased to share its report, *Miyo Māhcihowin: A report on Indigenous Health in Saskatchewan.* The report overviews key issues in Indigenous health and points to directions for the Indigenous health research agenda in the province. The report emerges out of a desire to strengthen our community mandate as the IPHRC works toward developing the Indigenous health research agenda for the province. It is a follow-up to the Saskatchewan Health Research Foundation Provincial Research Strategy Report, 2004, which focused on Saskatchewan Health and health research issues for the province as a whole. The focus of this report is on Indigenous health generally, and Indigenous health research, specifically.

The IPHRC is jointly funded by the Canadian Institutes of Health Research through the Institute of Aboriginal Peoples' Health, and the Saskatchewan Health Research Foundation. We wish to express our appreciation for the financial support of these agencies.

Dr. Eber Hampton
Principal Investigator and Acting Director
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Acknowledgements

This report is based upon a series of consultations with Indigenous people in the province of Saskatchewan and highlights the words and experiences of people engaged in the work of Indigenous health including community and band health directors, managers, workers, and other health staff, Indigenous academics, and Indigenous key "advisors" in various positions within the Saskatchewan health network. The views contained herein are representations of those consultations and although every effort has been made to represent the words of the community people as accurately as possible, any errors or omissions are ours.

We would like to express our appreciation to the participants in this consultation who took time from their overloaded schedules to meet with us.

A special thanks to Tania Lafontaine, Dr. Caroline Tait, and Sherri Pooyak who carefully and thoroughly edited and provided feedback on this report.

Kinanâskomitinawâw
Megwetch
Masi Cho

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i. List of Tables and Charts

[1] See Reading & Elias (1999). Chapter 2, First Nations and Inuit Regional Health Survey

ii. **Clarification of Terms**

In this report, we use the term “Indigenous to refer to the first peoples of Canada which includes Indigenous peoples as defined in the Canadian constitution – that is to say, Indian, Inuit, and Métis people. However, for greater clarity, where we refer specifically to Métis people, the term “Métis” is used.

1.0 Executive Summary

Indigenous health in Saskatchewan is in a critical state that requires immediate and focused attention. The statistics from several reports including the Canadian Community Health Survey (2000/01), the 2001 Census Aboriginal Population, the First Nations Regional Longitudinal Health Survey (2002/3), the Statistical Profile on the Health of First Nations in Canada (2003), and the Saskatchewan Health Research Strategy (2004), reflect poor conditions of Indigenous health and wellness in Canada and Saskatchewan. This report validates the findings of those studies and, it is hoped, will serve to bring those issues to the forefront of the local health agenda.

Indigenous community members, health workers, academics, and researchers are at the frontlines of health in communities and are, therefore, the experts of current conditions. In general, there is an urgent request to move from rhetoric to action; to find ways to address the issues and implement strategies that have positive, tangible benefits and outcomes for communities. The communities in Saskatchewan, as well as other research and institutional experts who were surveyed are very clear about what is needed in health and health research. Indigenous health research institutes, mainstream health research institutes, the academy, and most importantly, the funders, need to listen and be willing to shift policies and programs to better reflect the needs and wishes of Indigenous peoples.

The recommendations arising from the consultation fall under several categories. These include, in order of significance,

- Indigenous Health Research Capacity building;
- Improving access to and quality of healthcare;
- Enhancing resources in the mental and social health areas;
- Monitoring the development and dissemination of traditional knowledge to ensure protection and adherence to OCAP[2] principles;
- Ensuring funding sustainability and revising Indigenous health research funding strategies and priorities;
- Increasing Indigenous-specific epidemiological studies to deal with increasing incidence of chronic disease;
- Enhancing research in areas related to increasing economic development and it's relationship to health;
- Evolving strategies for health research communication to ensure the streamlining of research efforts and to disseminate research "best practices" theory and processes.

[2] Ownership, Control, Access, and Possession. For more information, see Gideon, V. (2002). Understanding OCAP and its ties to privacy. Summer 2002, NAHO Network News Hhttp://16016.vws.magma.ca/english/pdf/summer2002.pdfH or Schnarch, B. (2004). Ownership, Control, Access, and Possession (OCAP) or self-determination applied to research. Journal of Aboriginal Health Vol. 1(1). Available at Hhttp://www.research.utoronto.ca/ethics/pdf/human/nonspecific/OCAP%20principles.pdfH

The recommendations made from the collected data show a vast array of health and health research concerns. Participants were eager to share their experiences and opinions; there was optimism that their input would have an impact on policy and service delivery in the province. Regional differences become clear throughout the consultation and the differences can be observed in the data tables (1-3). In the northern regions of the province, which is sparsely populated geographically, there is logically an emphasis on health services access and delivery. Chronic disease and social/other[3] issues figured prominently. In the central region, issues falling within the category of Indigenous Healing, including mental health and addictions, were prominent, followed closely by social/other issues. In the south, social/other issues dominated followed by Indigenous Healing and Chronic Disease.

Collectively, we are at a point where policy and program decisions could have a significant impact on the health of future generations in the province. The Indigenous population in Saskatchewan is increasing rapidly. Combined with expanding economic development and an increase in Indigenous political voice and influence, a growing population could bode well for reshaping health and health research policy and program development in the near future if partnership approaches based upon respect and reciprocity are applied, or we could see an increase in the health status quo. The principles of OCAP, which articulate an ethical research framework, need to be applied to the arena of health policy development and program delivery. Specifically, governments and funding agencies must engage in an ethical relationship with its Indigenous constituents and heed the expertise of those who live at the front lines of Indigenous health practices. Indigenous people are not satisfied with the status quo of health and are not satisfied with health outcomes that reflect systemic problems in policy, funding, and program design and delivery. This document contains recommendations that can serve as starting points for dialogue. Any of the participants in this strategy would be willing to engage in such dialogues and they eagerly await collective action to redress issues that impact negatively upon the state of Indigenous health in this province.

[3] Social/other issues consist primarily of teen pregnancy, infectious diseases/STDs, poverty, and unemployment.

2.0 Introduction

Indigenous health in Saskatchewan and in Canada as a whole, is in critical condition and requires immediate attention. The statistics from several recent studies including the Canadian Community Health Survey (2000/01), the 2001 Census Aboriginal Population profile, the First Nations Regional Longitudinal Health Survey, (2002/3), and the Saskatchewan Health Research Strategy (2004), reflect dismal conditions for Indigenous people's health and wellness in Canada and Saskatchewan. Social, economic, political, and cultural changes have had significant impacts on health and well-being. The Indigenous population represents the fastest growing segment of the population and experiences a disproportionate burden of illness. Given the poor state of health, the growing population is identified as a crucial determinant for a concerted effort to develop a health research strategy to address health issues. The growing population may be a key factor in the success of the Indigenous population in addressing health disparities. The report of the Saskatchewan Health Research Foundation in 2004 – Saskatchewan Health Research Strategy - identified this province as "uniquely placed to do something about the issue, and that a strong and productive Indigenous sector is critical to Saskatchewan's accomplishments in future". The Indigenous Peoples' Health Research Centre recognizes that the supportive health research environment, coupled with a growing awareness and capacity in the Indigenous population to address health issues, will contribute significantly to collaborative Indigenous health research endeavors in the near future. IPHRC is a joint initiative of the University of Regina, University of Saskatchewan, and the First Nations University of Canada, funded by the Canadian Institutes of Health Research (CIHR) through the Institute of Aboriginal Peoples Health (IAPH) and the Saskatchewan Health Research Foundation (SHRF). IPHRC is engaged in establishing a research environment to increase Indigenous health research capacity and in facilitating the development of Indigenous health research in Saskatchewan to support continued success in the areas of Indigenous health and health research. We recognize that despite the plethora of health issues, the Indigenous population is increasing and making strides on many fronts including education and health research.

Saskatchewan is a large province covering diverse geographical terrain that has many implications in terms of population and settlement, access to services and service delivery, and types of economic activities, to name a few. For these reasons, there are different health 'issues' depending upon the locale that is under examination. For example, access to services means one thing to those who live in the central area of the province and have ready access to an urban centre with health facilities. It means something different to individuals who live in fly-in communities north of LaRonge (a 'northern' city that is geographical central in the province). Each author was responsible for facilitating community based Indigenous health research in one specific area and focused on the communities in their geographical region. Accordingly, the health issues in general, are strikingly similar; however, we see a few distinctions that may be attributable to geographical locale. These issues reflect a different priority depending upon their north, central, or southern location in the province. The authors restricted their respective commentaries to their region of focus, which serves to highlight the issues.

This report records and summarizes a collection of information from key advisors and Indigenous community members, all of whom work in the area of health or are involved in Indigenous health and Indigenous health research in some capacity.

We anticipate that this dialogue from the heart of Saskatchewan's Indigenous communities will help shape the health research agenda in the province and guide researchers in our province towards an approach to research that is founded upon the expressed needs and desires of the communities. The normalization of chronic disease with Indigenous communities is a testament to the critical need for a proactive, practical, and relevant health research agenda. Indigenous people in Saskatchewan are not happy with the existing healthcare system, or the current state of health. There is a desire to be proactive, and many see research as a means to move ahead with a community-based agenda.

> *We're tired of… getting stuffed full of antibiotics. We want to move on and take personal responsibility for our health and wellness.*

The format of this report includes an overview of the consultation methodology; an articulation of health issues in the three geographical areas of the province – north, central, and south regions – a summary discussion, and a set of recommendations.

At the outset, we wish to be clear that there are limitations to the representativeness of this report. The Dene population in the north is less represented in the findings than the large central and southern Cree population. Similarly, the smaller Saulteaux and Dakota populations are also less represented. However, for the purpose of the report, we have not differentiated between the First Nation populations and we include a recommendation that a more detailed nation specific comparative study may be a valuable exercise in the future, especially for interested nations. Further, due to the limited Métis representation in this report, the recommendations also include the need for a Métis specific consultation because we recognize that the Métis experience is socially, economically and politically distinct from First Nations in the province. We were able to consult with a good number of Métis representatives in the north and Table 2 is included to illustrate where health and health research issues diverge between First Nation and Métis populations. Overall, the authors attempted to be as inclusive as possible; however, due to political change within the Métis nation at the time of the consultation, our overall Métis representation, especially in the central and southern regions, are limited and hence, the transferability of this report to the Métis population is limited.

An additional limitation of the consultation includes the population of participants consulted. Community members and participants identified issues primarily related to living in a rural area and not an urban one, where the issues affecting community members may be different.

3.0 Methodology

The process of the Indigenous health research consultation began in the Fall of 2003 after internal discussions about seeking Indigenous community direction and mandate for the work of the newly formed Indigenous Peoples' Health Research Centre – the Saskatchewan Aboriginal Capacity and Developmental Research Environment (ACADRE) Centre. The IPHRC committed funds to pursue a province wide consultation and the three Community Research Facilitators

employed by the IPHRC were given the task of interviewing key advisors working in the area of Indigenous health and Indigenous health research.

3.1 Ethics

Discussions about an ethics approval process for the consultation process were held in order to ensure that the proposed consultation considered any necessary ethics approval requirements. It was anticipated that ethics would not be required since the project was modeled upon the Saskatchewan Provincial Health Strategy initiated by the Saskatchewan Health Research Foundation. For certainty, the lead Community Research Facilitator contacted the University of Saskatchewan Ethic Office to make ethics-specific inquiries. It was determined that as a process designed to enhance organizational and program quality, in effect quality assurance, the province-wide consultation process was not research and, therefore, there was no requirement for an ethics application or approval certificate.

At the time of the initial consultations, the principals of OCAP (Ownership, Control, Access and Possession) were relatively new. In our work in Aboriginal health research, the IPHRC has been challenged on many levels and had many opportunities to discover how to incorporate and honour the principles of OCAP into the work of aboriginal health research. With respect to the application of OCAP to this consultation, we have been diligent in sharing the creation, outcomes, and ownership of this report with the aboriginal population of Saskatchewan. We were clear with the participants that we would do everything in our power to ensure that the final report would accurately represent their concerns and their recommendations. We encouraged participants to view their participation as speaking directly to policy makers and funding bodies. The report was vetted through the participants and some chose to make edit and other recommendations for the report. Lastly, this final report will be returned to all participants as well as all aboriginal communities in Saskatchewan for their use and benefit. We believe that the intention of the consultation – to inform IPHRC mandate and ascertain the state of aboriginal health and health research in Saskatchewan – has been met.

3.2 Scope

The consultation process that underpins this report was designed to reach a wide group of people in the Indigenous health field. In particular, we hoped to speak with First Nation and Métis community Health Directors and Health Coordinators, Tribal Council Health Directors, Health Department staff members in the communities, representatives of the Métis Nation of Saskatchewan, and members of key health organizations and institutions (such as the Northern Intertribal Health Authority, the Regional Health Authorities, and the First Nations University of Canada). The goal of the consultation process was to be as inclusive as possible, while respecting the busy schedules of potential participants, the full schedules of the IPHRC Community Research Facilitators, and recognizing that research issues might not be a priority interest for some communities.

Individual key advisors were invited by phone and letter to participate in face-to-face interviews. Bands and Tribal Councils were invited to participate in focus groups. Potential participants were sent an information brief [Appendix I] about the process and consultations

were booked. The interviews and focus groups took approximately a year and half to complete and were completed between the Autumn of 2003 and Winter of 2005.

Two types of consultation sessions were held:

1. Community respondent and focus group sessions – with members of health department staff and/or health related organizations in individual First Nations and Métis communities.
2. Key advisor interviews – with individuals from relevant education and health organizations that cover multiple communities, urban and rural, in the region.

In the vast Northern Region, 20 consultation sessions (individual and group) were held and included approximately 115 participants. In the central region, 13 consultation sessions (8 individual and 5 groups) were held which included a total of 82 individuals. In the southern region, 13 consultations (4 individual and 9 groups) were held that included a total of 57 individuals. Across the province, we consulted with 254 Aboriginal health respondents.

The community research facilitators recorded responses or the focus group participants were given the questions to discuss and the responses of the group were recorded using a flip chart. The draft final report was sent back to participants (or a contact person for the group sessions) to check for accuracy and for the records of the participants.

The following questions formed the basis for the consultation sessions, although these questions did not preclude additional probing questions for clarification:

1. In your opinion, what are the top five health issues facing Indigenous communities in Saskatchewan?
2. Do you know of any research projects either already completed or currently underway or in the planning stages that look to address these issues?
3. What is your assessment of the current state of capacity in terms of health research in Indigenous communities?
4. What do you perceive as the current weaknesses, and strengths in Indigenous health research?
5. What do you believe must occur in order to build capacity in community based Indigenous health research?
6. What are your thoughts about traditional health systems and protocols in research projects? What are some of the issues surrounding this?
7. Do you have any other comments about Indigenous health issues, or health research issues in Saskatchewan?

The questions for the key advisors who worked for organizations or institutions that cover multiple communities were phrased slightly different in order to have a broad perspective, but covered essentially the same points. For example, the first question was generally worded “What do you perceive as the top health issues among the Indigenous population in Saskatchewan?”

The recorded responses and findings from group processes were then compiled and synthesized according to the questions. Responses to question one form the bulk of the information received and the responses have been analyzed according to the four theme areas of the IPHRC that include:

1. Chronic Disease, Nutrition, and Lifestyle
2. Indigenous Healing: Including addictions, mental health, and the judicial system
3. Health delivery and control; including ethics, community development, and governance
4. Prevention and environmental health.

Charts based upon a ranking of the responses into ordinal data allow for a visual representation of the relative importance of the theme areas as well as comparison between the regions in the province (see Charts 1, 2 and 3 following).

The responses to the remaining questions are summarized in order within each region. The synthesis of information is compiled in the discussion of the findings, and the collective recommendations arising from the consultation project are outlined in the final section of the report.

4.0 Consultations

Since the responses to the first question, "what are the top health issues in your community/communities?" generally took the form of a list of issues, responses have been compiled into ordinal pie charts to provide a visual representation of the issues according to the four theme areas of the IPHRC. It should be noted that in order to compile the responses in this way, some subjective decisions had to be made in terms of the ordinal rankings of the responses. The facilitators agreed upon the following ranking strategy and then coded and ranked their respective regional data.

Ranking Key
4 = Serious concern: requires immediate attention/frequent mention and concurrence
3 = Significant concern: increasing incidence/mentioned regularly in consultations
2 = General concern: important issue/mentioned several times in multiple consultations
1 = Mild concern: mentioned more than once and agreed upon by other participants

In terms of sampling, the sample population was not randomly selected. A snowball sample was used and key health advisors along with all tribal councils, band councils, and Métis organizations were faxed information on the strategy, followed by a phone call to confirm participation. Therefore, the following results should not be considered statistically representative. In general, less importance should be placed on the numbers as compared to the patterns and trends they reveal. However, given the number of highly knowledgeable people surveyed, those patterns and trends are likely a good reflection of what is happening across the

province. The subsequent survey questions are presented in the order outlined in the community-briefing letter [Appendix III]. The results were synthesized by the Community Facilitator from each region following the interview and focus group sessions.

We begin with the findings of the Northern region, followed by the Central region and then the South of the province.

NORTHERN REGION

4.1 Findings of the Consultation Session – Northern Region

The following results are presented according to the format of the questions.

4.1.1 What are the top health issues in your community/region?

The responses to this first question are compiled in Tables 1 and 2, and Chart 1 below. Table 1 is a list of all the issues that were brought out during the consultation sessions, and sorted in the order of issues mentioned most frequently, to those mentioned less frequently. This Table shows fairly clearly that the top three issues are: addictions/substance abuse, social determinants of health, and diabetes. When the data is separated into First Nations and Métis responses (Table 2) a couple of interesting patterns emerge. Addictions and substance abuse were the most commonly identified issues for both Métis and First Nations communities, followed closely by social determinants of health and diabetes. However, Métis responses indicated inadequate facilities, services and benefits as the second most commonly identified health issue. This pattern reflects the fact that Métis peoples do not have access to the same funding structures and sources as status First Nations, even though they experience many of the same health challenges. Some other interesting patterns: Métis respondents cited infectious diseases and difficulty in accessing services just as often as they cited diabetes as an important health issue; and injuries, accidents and violence were a significant health issue for First Nations respondents.

Table 1: Top Health Issues in Northern Communities

Addictions/substance abuse	4	Cancer	2
Social determinants of health (especially education, poverty, legacies of colonization	4	Cardiovascular disease	2
		Lack of physical activity	2
Diabetes	4	Need for more youth services and programs	2
Prevention: Injuries, accidents, violence (including suicide)	3	Need to strengthen cultural identity	2
		Transportation issues in health services	2
Prenatal and perinatal health/ parenting skills/ teen pregnancies	3	Dental health (children)	1
		Depression	1
Inadequate facilities/ services/ benefits	3	Elder abuse/loss of Elders	1
Inadequate services - mental health and addictions	3	Inadequate services - general	1
		Low immunization rates	1
Infectious diseases (Hepatitis B and C, HIV/AIDS, STDs, Tuberculosis)	3	Need for better planning and promotion	1
		Need for holistic healing	1
Mental Health (general)	3	Other specific health concerns	1
Obesity/ poor nutrition	3	(boils, thyroid)	
Housing conditions - mould/pests	3	Schizophrenia	1
FAS/FASD	3	Systemic issues in health services	1
Problems in accessing services (general)	3	delivery (government)	
Respiratory illness/lung disease	3	Indigenous men's health	1
Water quality and food safety	3	Chronic diseases (general)	1

Housing conditions - overcrowding/shortage	2	Environmental contaminants	1
Lifestyle (general)	2	Language barriers in accessing services	1
Youth issues	2	Métis Health	1
Arthritis (especially rheumatoid)	2	Need for better child and family services	1
Attracting and retaining health care professionals	2	Need for culturally appropriate health Models	1

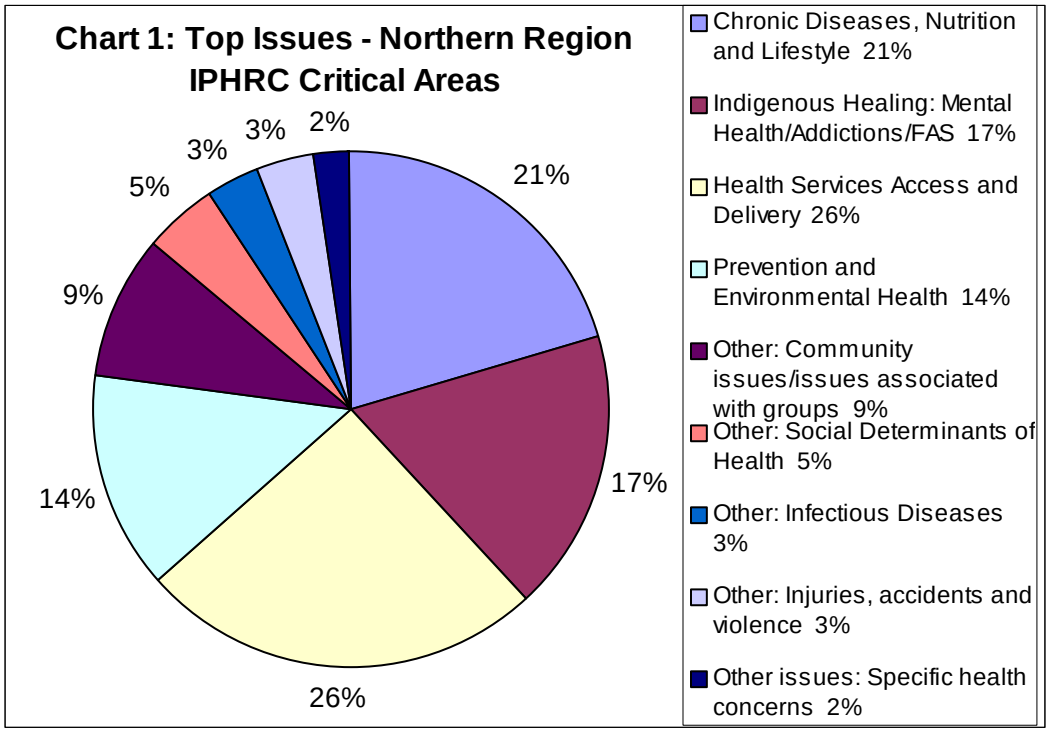


Table 2: Top Health Issues by First Nations and Métis Response – Northern Region							
Issues – Specific Category	Total	First Nations	Métis				
Addictions/substance abuse	4	4	4	Attracting and retaining health care professionals	2		2
Social determinants of health (especially education, poverty, legacies of colonization)	4	4	4	Cancer	2	1	2
				Cardiovascular disease	2	2	1
				Lack of physical activity	2	2	
				Need for more youth services and programs	2	2	1
Diabetes	4	4	3				
Prevention: Injuries, accidents and violence (including suicide)	3	3	1	Need to strengthen cultural identity	2	2	
				Transportation issues in health services	2	2	1
Prenatal and perinatal health / parenting skills / teen pregnancies	3	3	2	Dental health (children)	1	2	
				Depression	1	1	1
Inadequate facilities / services / benefits	3	2	4	Elder abuse / loss of Elders	1	2	
				Inadequate services – general	1	1	1
Inadequate services – mental health and addictions	3	3	2	Low immunization rates	1	2	
				Need for better planning and promotion	1	2	
Infectious diseases (Hepatitis B and C, HIV/AIDS/STDs, TB)	3	2	3	Need for holistic healing	1	1	1
				Other specific health concerns (boils, thyroid)	1	2	
Mental health (general)	3	3	1				
Obesity / poor nutrition	3	3	1	Schizophrenia	1	2	
Housing conditions – mould / pests	3	3		Systemic issues in health services delivery (government)	1	1	1
FAS / FASD	3	3	1				
Problems in accessing services (general)	3	1	3	Indigenous men's health	1		
				Chronic diseases (general)	1	1	
Respiratory illness / lung disease	3	3	1	Environmental contaminants	1	1	
Water quality and food safety	3	3		Language barriers in accessing services	1	1	
Housing conditions – overcrowding / shortage	2	2	1	Métis health - general	1		1
				Need for better child and family services	1	1	
Lifestyle (general)	2	2	2				
Youth issues	2	2	2	Need for culturally appropriate health models	1	1	
Arthritis (especially rheumatoid	2	2					

Chronic Diseases, Nutrition and Lifestyle

In the area of chronic diseases, nutrition and lifestyle, diabetes was the most commonly identified health issue. Overall, it ranked as the third most commonly mentioned health issue when First Nations and Métis responses are considered together. Many people observed that the prevalence of diabetes is tied to larger issues of lifestyle, physical activity and nutrition. Some people noted that diabetes tends to be more acute than in the past, and that it is being found increasingly in younger people. That being said, a number of people also indicated that there is already a fair amount of education and prevention work being done around diabetes,[4] and that perhaps some of the other issues which have not received as much attention should have more resources devoted to it. On a positive note, one community indicated that in recent years the number of cases of diabetes had stabilized, and that some improvements were being seen in this area.

As noted above, issues such as nutrition, obesity, physical activity and lifestyle were mentioned fairly often in association with diabetes. At least two participants noted that in the North, the issue of poor nutrition was connected in part to the high cost of food. Similarly, some northern communities noted that they had very few facilities and resources for physical activity programs. On the positive side, a couple of First Nations communities noted that traditional foods were still fairly available and widely used by community members, contributing to better health and nutrition.

In terms of other chronic diseases, heart disease, cancer and arthritis (rheumatoid arthritis in particular) were the most commonly mentioned. One individual noted that rates of cancer had really increased in the last 5-10 years. One participant noted that chronic disease was probably the area that has received the most attention in terms of research.

Indigenous Healing: Mental Health and Addictions

The most significant health issues for many Métis and First Nations communities were in relation to mental health and addictions. Addictions and substance abuse were the most commonly cited health issue for both First Nations and Métis communities in Northern Saskatchewan. Many respondents noted that mental health and substance abuse operate as a cycle that is very difficult to break. One respondent noted that this issue would soon overtake diabetes as the most important health issue in the community. Another respondent observed that mental health had been identified as a key issue for northern First Nations communities 12 years ago, and that it still remains the key issue for many communities. A number of respondents observed that substance related addictions were shifting from primarily alcohol related to primarily drug related, and that the kinds of drugs were shifting to substances such as cocaine, solvents and crystal methamphetamine. Of course, drug and alcohol abuse is connected to other issues such as family and street violence and can have intergenerational impacts in terms of FAS/FASD, and mental health implications. A number of respondents also noted that mental health and addictions issues were related to the larger social determinants of health – particularly

[4] Notably, the Northern Diabetes Prevention Coalition has been very effective in terms of health promotion around diabetes in the North.

poverty, lack of education and employment opportunities. These underlying issues are often complex, systemic, and difficult to address through research and/or programming.

A number of respondents pointed to models of Indigenous healing and community development as potentially positive approaches to dealing with addictions and mental health issues in particular. For example, it was suggested that research around traditional knowledge, and bringing out the importance of language, cultural identity, history and kinship could go some way towards addressing these issues. A strong cultural identity, support of friends and family, education, and holistic approaches to healing were all cited as potential ways to positively impact the social determinants of health, particularly in regards to mental health issues.

Health Services Access and Delivery

Both First Nations and Métis communities identified health services delivery and access as important health issues; however, the relative importance of these issues appears to be greater among Métis respondents, where inadequate benefits, funding, and access to services were among the top three most commonly mentioned health issues. Both Métis and First Nations respondents suggested that additional services and programs were needed for the youth population in particular, and in relation to addictions treatment programs and counseling. In addition, northern communities faced challenges in terms of inadequate or difficult access to services. It was noted that people in remote and northern communities did not have the same services as those in urban areas. Travel to larger centers for health care (for example, dialysis) was also problematic, for Elders in particular. It was not so much the availability of transportation that was the issue; more so, it was the associated costs that would allow Elders to travel in a stress-free way (for example, being able to bring family members for support, allowing more time for rest, or the ability to travel at a slower pace after treatments). Some specific health care delivery issues mentioned by respondents included low immunization rates in some communities, and the need for better overall planning and health promotion.

One issue mentioned by respondents in the North was around the difficulty in developing and implementing programs and obtaining high-quality infrastructure in communities with small and remote populations. In particular, facilities for respite care for Elders and the disabled, facilities for youth programs, and facilities for mental health and substance abuse counseling were lacking. Those facilities that are in place are generally stretched to maximum capacity and are not able to meet the health needs of the community. Lack of services and resources for mental health issues was noted for both Métis and First Nations communities. Severe cases are generally referred to larger centers such as Prince Albert or North Battleford, and when specialists are brought in, they generally do not have enough time to spend with individual patients.

An associated issue in northern communities is the difficulty in attracting and retaining health care professionals. One suggestion in response to this issue was to work on promoting math and science in primary and secondary school programs, in order to encourage more Indigenous children to pursue careers in the health sciences. This might be one way to meet the need for health care professionals in the future, particularly in northern communities where the population is growing.

Prevention and Environmental Health

The most commonly identified environmental health concerns were in relation to water quality (particularly for First Nations communities) and housing issues (overcrowding, mould, and associated respiratory illnesses). The housing issues were found in both First Nations and Métis communities. It was observed that overcrowding could also lead to stress and family violence, as well as increased transmission of infectious diseases. In the area of prevention, injuries, accidents, violence (in particular, increasing street and gang violence associated with drug use) and suicide were cited as important health issues, particularly among First Nations respondents.

This category has a slightly smaller proportion of responses; however, that could be due partially to the fact that it encompasses less of a range of issues compared to some of the other categories.

Other Concerns

In addition to the issues that clearly fall into one of the four critical areas of health identified by IPHRC, respondents noted a number of other issues. The most commonly identified "other" issues included:

- Prenatal, perinatal, and children's health (including dental health)
- Parenting skills
- Social determinants of health (poverty, lack of education and employment opportunities, and the legacies of colonialism – i.e. residential schools, racism, government control of services, etc).
- Infectious diseases (including STDs, Hepatitis B and C, HIV/AIDS, Tuberculosis)

In addition, issues unique to particular communities, such as high incidences of thyroid problems, boils and methicillin-resistant staphylococcus aureus (MSRA)[5] were mentioned in individual cases.

4.1.2 Do you know of any research projects either already completed or currently underway or in the planning stages that look to address these issues?

For the most part, research projects that were specifically mentioned were those that had been finished very recently, or were currently underway. The main projects that people mentioned were in the following categories:

- Projects coordinated by Health Authority:
  - FAS/FAE pilot project in four communities to train and introduce "FAS advocates" to work with mothers at risk.

[5] MSRA is a specific strain of staphylococcus aureus that is resistant to all penicillins, commonly known as a "superbug".

    - Multi-year study on MSRA funded through the Canadian Institutes for Health Research
    - Training in mapping community needs
- Projects coordinated by the Tribal Councils or FSIN:
    - Environmental scan of housing conditions and health status
    - Cardiovascular health risk assessment project coordinated through a tribal council
    - Survey of mould in houses on reserves
- Projects carried out at the community level:
    - Needs assessments around various issues such as medical transportation, community development, daycare, dental health needs
    - Health transfer evaluations
    - Research on cultural heritage and genealogy
    - Aboriginal Healing Foundation projects
- Projects funded through IPHRC on:
    - Healthy diets and obesity
    - Integrated Mental Health Service Delivery
    - Métis youth addictions
    - Integration of Indigenous knowledge and perspectives in the health sciences curriculum in southern Saskatchewan
- Other projects:
    - Research on attitudes towards HIV/AIDS in four northern communities
    - Northern Diabetes Prevention Coalition
    - Community Vitality Monitoring Partnership

In addition, a northern Population Health Unit and Northern Medical Services personnel have been involved in numerous other health research projects.

The above list shows quite a broad awareness of research activities currently underway in the North. Some projects (for example, the project on HIV/AIDS behaviours and the project on FAS advocates) were mentioned on several occasions. Of course, as one person astutely observed, "there has always been research going on, but now we hear about it more because there is more of a focus on consultation."

In addition to these specific research projects, a number of respondents noted that there is on-going needs assessment in the communities coordinated by the health departments for program planning and evaluation purposes (particularly around health services transfer). These research activities are carried out primarily for internal planning purposes, or to meet reporting requirements. A number of individuals noted that it would be good to do something more focused with all the information that is collected on a regular basis, rather than just filing the information away once it has been reported. A number of people suggested that although a lot of research has been done, the results have not been applied because the information is not returned to the community in a usable format. A couple of respondents felt that they had been "researched to death" and that people were generally tired of research. One First Nations Elder suggested very strongly that the priority should be placed on action rather than research - to stop *talking* and start *doing*.

4.1.3 Do you have people in your community who can do research on those issues?

Responses to this question generally fell into three categories:

1) A number of respondents felt that there would be some interest in and potential for having health department staff members work on research projects. This response was often qualified by saying that some training might need to be provided, and that the amount of time staff would have to devote to research activities would be somewhat limited.

2) Roughly an equal number of respondents suggested that if training were provided, and there were resources available for salaries, there would likely be people in the communities (other than those already working for the health department or at the local clinic) who would be interested in working on research projects. This would serve the dual purpose of involving community members in research, and providing employment opportunities in communities with high unemployment rates. It was noted that the HIV/AIDS project had hired local people to work on the project, and had incorporated training for those people into the research. This was viewed as a positive approach that contributed to building capacity at the community level. Many Health Directors and Health Coordinators indicated that their staff members were already overburdened and would not likely have the time to devote to research activities.

3) A small number of respondents stated that there was currently not much capacity for involvement in health research at the community level, either because of lack of time, lack of individuals with the appropriate skills, or guarded attitudes towards research.

In general, the prevalent attitude was that there would be some interest, particularly if training was provided, and that this would increase the community's sense of ownership of research projects. Many people suggested that Elders should be involved in research projects, and a number of people also noted that they would like to see the youth get involved as well. The capacity for health department staff to be involved in research varied from community to community.

4.1.4 How would you like to see your community getting involved in its own health research?

The suggestions in this area focused on community control of and participation in the research process. One community proposed a vision of a Research Centre, located at the community Health Clinic, complete with a research library collection. Another suggestion in a Métis community was to coordinate research through the local Friendship Centre or the Village Administration, drawing on strong leadership qualities in the community. Another respondent suggested that there should be greater communication and cooperation *between* Indigenous communities. This could be realized, for example, in terms of joint research projects and applications.

Emphasis was placed on having community involvement in all phases of the research project which would make the project more responsive to community needs, ensure that

communities received project results in a usable format, and to increase the sense of community ownership over research. One respondent suggested that this could be an empowering process, if a community would take responsibility for a health issue and then get involved in the solution. The importance of the *community* identifying and initiating research projects (rather than the academic) was noted by a number of respondents. It was noted that in the past, research had often been pushed on Indigenous communities, for which very few benefits had been received. It was also noted that some research tools, such as surveys, put people off participating, especially where the community had not initiated the project. In addition, many people felt that information from previous research studies had not been returned to the communities. They wondered what had happened to all the information that had been collected, and what it was being used for. There was a very strong sentiment expressed that when information originates in the community, the community should retain control and ownership over that information. A number of venues were suggested for sharing the results of research projects, for example schools, health centers, clinics, and hospitals.

Not only is community control and involvement important in an ethical sense, but one person observed that when research results were written up entirely by outsiders, there was a concern that the information would not be correct from a community perspective. Particularly where language is a factor, there is great potential for miscommunication and misunderstanding between researchers and community members. Where community members are part of the research team, this will hopefully be less of a danger. It was suggested that it would be important for academic partners in research to spend time in the community in order to get to know the local context, and to make connections with local people.

Some interest was expressed in receiving training in research methods so that staff members could better participate in projects. As noted in Section 4.3 above, some people felt that a positive approach to community involvement in research would be to hire and train people from the local community to work on projects, particularly where health department staff and health care professionals are already overworked in their job duties. One respondent suggested that the best people to work on research projects were those people that had some personal experience with the issue being studied – particularly in areas such as addictions. According to this respondent, “we need people to tell their own stories – people learn best from those who have first hand experience, especially when you are trying to get information across to children and youth.”

As a positive approach to researching health issues, it was suggested that emphasis could be placed on researching what had worked well in other communities; for example, looking for positive models of best practice, rather than always focusing on the negative side of things. It was also suggested that it was important to recognize and build on the strengths that already exist in communities; such as, recognizing and building on the fact that many health department staff engage in various types of research as part of their regular job duties (see Section 4.2 above). Along similar lines, it was suggested that traditional approaches to research be recognized and valued for example in the past community members had to learn about and understand weather patterns and other aspects of the natural environment in order to survive and thrive. These “traditional research skills” might be incorporated into contemporary research projects. A number of people suggested that communities could be more actively and meaningfully involved

in research projects if they had a better understanding of the research process in general. Awareness of these issues has been growing in recent years as communities have become more involved in the research process. Still, however, the profile of research – both its strengths and limitations – needs to be raised with key groups and individuals, such as the Regional Health Authorities and local health centers.

In addition, a number of people emphasized that a good starting place would be to review work that had already been done in the community (i.e., reports by consultants, community needs assessments, etc) and to use this information as a foundation for future work. Another suggestion was to concentrate on smaller-scale projects with a strong local focus, rather than trying to cover too much ground in a single study.

One respondent noted that it was important to look at the long-term picture, to see where the community research project might go after the development stage. It was suggested that more than just "seed money" was required, as often in the past projects had started up, but had been discontinued through lack of funding and resources. The value of external supports for funding and expertise was recognized by a number of people, with the qualification that the community should retain control of the project. It was noted that a major challenge in terms of community control of research is the fact that funding for research is typically controlled by the academic institutions and outside agencies. With these outside institutions setting the parameters for research, for example, by defining priority areas for funding and by restricting who can hold research funds, it makes it difficult for communities to define and control their research agenda.

> *The power is in controlling the funds and resources, and that is still in the hands of the bureaucracy… There needs to be more equity in the research process, with power on both sides.*

It was observed that there are many new researchers and research organizations in the area of Indigenous health research in Saskatchewan, perhaps due to the increase in availability for funds in this topical area. Funding institutions are increasingly looking to support research that addresses Indigenous health needs; they want to see real community involvement in order to fund projects. This may be an opportunity for communities (to have their interests and needs addressed through research) but may also be a burden as communities receive increasing numbers of requests to support various research projects. The challenge for communities, and the obligation for researchers, is to ensure that community support and involvement is genuine, rather than token. One respondent suggested:

> *Time and energy needs to be focused on tying research to community needs and supporting communities in their current initiatives – it is important not to spread the resources too thin and/or divert resources away from community priorities and initiatives.*

In particular, it was suggested that roles and responsibilities be negotiated up front, and that there be a strong emphasis on communication throughout the project.

A strength of the research environment in northern Saskatchewan is that the research community is relatively small, which allows for easier communication and collaboration. Similarly, northern communities tend to be open to partnerships and collaborative relationships. There are already a number of mechanisms for bringing together researchers, communities, and health professionals in northern Saskatchewan, notably the Northern Health Strategy Working Group and the Polypartite Research and Development Working Group coordinated by Northern Medical Services. These working groups offer good points of contact for researchers and demonstrate the commitment of northern communities to cooperation and collaboration.

It was also suggested that emphasis should be placed on the practical application of research results; for example, in terms of program planning, as evidence to support future funding applications, and as a basis for curriculum development in the education system. If these practical outcomes are emphasized, communities may take a greater interest in being involved in research. It was noted that a major strength in terms of Indigenous health research is the growing number of Indigenous students who are completing their post-secondary education. Some of these students may return to their communities as health professionals with the capacity to be involved in future research projects. It was recognized that programs such as the Indigenous Peoples' Health Research Centre help to build this capacity by supporting Indigenous students and encouraging the incorporation of training activities into research projects.

4.1.5 How do traditional ways of dealing with health fit with health research?

The purpose in including this question in the consultation sessions was to gauge the level of interest and/or concern in addressing traditional health knowledge in research projects. Traditional medicines and approaches to healing are obviously of great importance to many Indigenous people and communities; the question is whether it is appropriate or acceptable for academic researchers to access and/or document this knowledge.

The most common response to this question was that the interest in looking at traditional health and the protocols for doing so, would vary from community to community and would have to be addressed on a case-by-case basis. As one respondent stated:

> *Some communities will want to incorporate traditional medicine in their health care, others will not. It is important to respect the wishes of individual communities – it is like the Aboriginal version of academic freedom… It is fine to ask about traditional knowledge and health, but if communities or individuals do not want to speak about it, you must respect their wishes. Individuals will use their judgment as to whether it is appropriate to share certain information – if it is not appropriate [because the knowledge is sacred or private] then people won't talk about it. There will be different levels of comfort about this.*

A related issue is the fact that there may be tensions and disagreement *within* a community around the use of traditional healing and medicines, and that researchers would have to tread very carefully in order not to make those tensions worse. Part of this internal tension may stem from the particular history of colonization and missionary work in different

communities. It was noted that within any given community, there may be members with strong Christian religious beliefs, members with strong traditional beliefs, members that combine the two systems, and some members who do not want any kind of religious belief to be part of health services delivery.

Almost universally, it was stated that community Elders would have to be involved in any project that touched on traditional knowledge and healing, and that the Elders would be the ultimate authority in determining whether and how such a research project might take place. It was suggested by a number of respondents that it would be possible to address traditional health and healing in research projects, but only if the research was approached very carefully and thoughtfully. For example, it would be important to set out expectations and guidelines for the project from the outset; in particular, around the issue of publication - what can and cannot be published at the end of the project. Another suggestion was to follow traditional protocols in the research process; for example, by holding ceremonies and feasts at the beginning and end of the project to share information.

Another common response to this question was that there would be interest in researching and documenting traditional health knowledge, but that there were serious concerns about the potential for exploitation of that knowledge, especially in terms of to traditional medicines. It was suggested that, even more so than in other areas, any project touching on traditional knowledge and healing should be initiated by the community, and not by academic researchers.

> *There is a dilemma around whether to share that information – on the one hand, if the information is not shared, it might be lost; on the other hand, you do not want to share the information with the wrong people.*

In some cases, it may not be appropriate to write down certain kinds of knowledge, for example, spiritual knowledge and prayers, recipes for specific medicines, and there was also concern that standard academic approaches to research may not be able to accurately capture traditional healing knowledge.

Many people expressed the belief that traditional knowledge held by Elders is an important source of information, and that they would like to see that knowledge being accessed and used by community members. A number of people observed that in the past people lived healthier life styles, and knew how to live “in a good way.” It was suggested that there may be less sensitivity in documenting traditional lifestyles, attitudes, and philosophies for healing and good health, compared the documentation of specific medicines, which, in some cases remains quite private and the purview of individuals and families to use and pass along. In some cases, however, communities were interested in researching and documenting specific medicines in order to ensure that those medicines continue to be used and available to community members. There was some concern that aspects of this knowledge are being, or have been lost, through disuse even though it was not that long ago that Indigenous communities relied primarily on their own medicines and healing knowledge. For those communities wanting to document traditional medicines, it was noted that it would be important to identify those Elders in the community that are respected authorities. Even for those communities wanting to research and document

medicinal knowledge, there was still some uncertainty around the role that outside funding agencies and researchers could play.

It was suggested by a number of people that the role of Elders in health and healing should be supported and strengthened.

> *As a First Nations person with responsibility for managing health services, I find it problematic that what we are implementing is only the health care system that has been passed on to us through the colonial structure… More and more, people are wanting to return to traditional health models and medicines – especially when mainstream medicine fails them.*

It was suggested that some work needs to be done around how to integrate this traditional knowledge with the mainstream system. This is one avenue through which research might be helpful in a relatively non-intrusive way – by documenting and sharing information on models already in place in various Indigenous communities around the world that integrate traditional and mainstream medicine, to look for models of success on which to build. It was suggested that cultural erosion is at the root of many of the social issues in Indigenous communities, such as addictions, mental health issues, and violence and that strengthening cultural traditions and knowledge may be part of the healing process itself.

Métis respondents suggested that there may be interest in looking at traditional healing practices, and that this was a potential area for research, although some people may be hesitant to discuss it due to past stigmas on traditional practices. It was noted that Métis communities often have a strong Roman Catholic affiliation; however, traditionally there were some Indian (or Indigenous) medicines that were known and used, particularly those derived from the Cree side of Métis ancestry. In the old days, people needed to know how to survive on the land, and so would be taught about the herbal medicines. It was noted by a number of respondents that traditional healing was closely connected to language (Michif, Cree or Dene). A number of health services programs currently bring in Elders and/or incorporate traditional ceremonies in their programs.

4.1.6 Do you have any other comments about Indigenous health issues, or health research issues in your community?

Participants in the consultation session used this opportunity to comment on a wide range of health issues, and health research issues. A sample of these comments is summarized below under topical headings.

Coordination of Health Services

A number of respondents identified the coordination of health services in different jurisdictions as being a problematic issue. In particular, it seems as though issues often arise where there is a First Nations reserve adjacent to a municipal community. A number of respondents felt that the arrangements needed to be clarified for accessing these services, both for when Band Members utilize off-reserve services, and for when municipal residents access

services on-reserve. These arrangements include both financial clarification, and also just a better understanding of the different programs that are offered in the different settings. One respondent from a Métis community suggested that everyone would benefit from a system that was better coordinated (to avoid duplication of services), more flexible, and more responsive to local and regional needs. Along similar lines, one respondent noted that programs and services are often developed at the Tribal Council level, and may not be suitable to the individual needs of specific communities, thus suggesting more of a focus on locally developed and appropriate services.

Lack of Facilities

Another issue identified by northern communities that relates to high incidences of diabetes and cardiovascular disease is the lack of facilities for physical and therapeutic exercise in many communities. One community envisioned building an indoor pool that could be used for recreation and for physical therapy, but was discouraged by lack of funding and resources available for such an initiative. One community described a locally developed walking program that rewarded participants with coupons for buying healthy food at the local grocery store. Although this program was quite popular, it was discontinued due to lack of funding.

Cultural Connections to Health

A number of respondents tied the high rates of illness to loss of cultural knowledge, (including kinship knowledge, traditional healing knowledge, and language) and the legacy of residential schools. It was suggested by a number of respondents that the intergenerational impacts of residential schools would need to be addressed in order for healing to begin – particularly in relation to issues like substance abuse, family violence, and mental health.

Health Promotion Issues

Many respondents spoke of the importance of community education on health issues to aid in disease prevention and health promotion. There was a desire to identify the best way to get the information across to community members, and to find ways to encourage greater community participation in the programs and services that are currently offered. It was noted that, in particular, young people, men, and Elders were sometimes difficult to reach with health promotion messages.

Other Issues around Research

Around health research issues, respondents offered a number of comments, observations and suggestions. People generally agreed that it would be important for Indigenous communities to define priorities and research questions. In some cases, it was felt that the health problems were well known; it was suggested that in those areas, research could be helpful in providing the evidence to support funding applications for program development and delivery. In other cases, it was felt that enough research had probably been done in other locations, and what was needed was translation of that information to the local community context. Even research done in international contexts – particularly research with Indigenous peoples in other countries – might have some value to Indigenous communities in Saskatchewan if that information was translated

into a usable format. Ultimately, respondents wanted to see research that resulted in practical outcomes and tools for the participant communities, with strong follow-up on communicating research results. There was also very strong support for the notion of community ownership of information, and of solutions to health concerns being developed from *within* the community. There was a great deal of support for building training activities into research projects in order to increase capacity for research at the community level and ensure community involvement and benefit. Some Métis respondents observed that, in general, there had not been as many opportunities for Métis communities to access funding for research, and that this imbalance should be addressed. There was openness to working in partnership with academic researchers, with the understanding that the flow of knowledge would be two ways. As one respondent noted:

> *Up until now, it has always been the Indigenous people who have had to learn and adapt to the Western system – now it is time for the Western people to learn about Indigenous ways, and learn how to fit in that system.*

Positive Developments in Community Health

A number of respondents took this opportunity to highlight positive developments in their communities that have contributed to better health outcomes and quality of life. For example, one First Nations respondent noted that a number of new houses had recently been built, making some progress towards lessening the housing shortage in their community. In addition, that community had increased services through the development of the Health Centre, the establishment of a Healing Lodge, and plans to develop a Youth Centre. They also valued their beautiful natural setting, with easy access to lakes, forests, and walking trails. A number of communities highlighted the important and positive role that Elders play in community health and wellness. One First Nations community has established a formal Elders' Council, with one Elder attached to each program area as a respondent. Other positive developments in northern communities include the new hospital in La Loche, the planned construction of the new hospital in Ile-a-la Crosse, increased communication and inter-sectoral cooperation, and the willingness of communities to work together.

CENTRAL REGION

4.2 Findings of the Central Region

Most of the information in the Central consultations is a synthesis of the words of the participants in an effort to stay true to their articulations.

4.2.1 In your experience, what are the top five health issues facing Indigenous communities in Saskatchewan?

In summary, the top health issues in the central region include diabetes, obesity, addictions, mental health and distress issues, lateral violence and abuse, and an exponential increase in rates of cancer and mortality rates due to violent death, suicide, and accidental death. In addition, environmental health is an emerging concern.

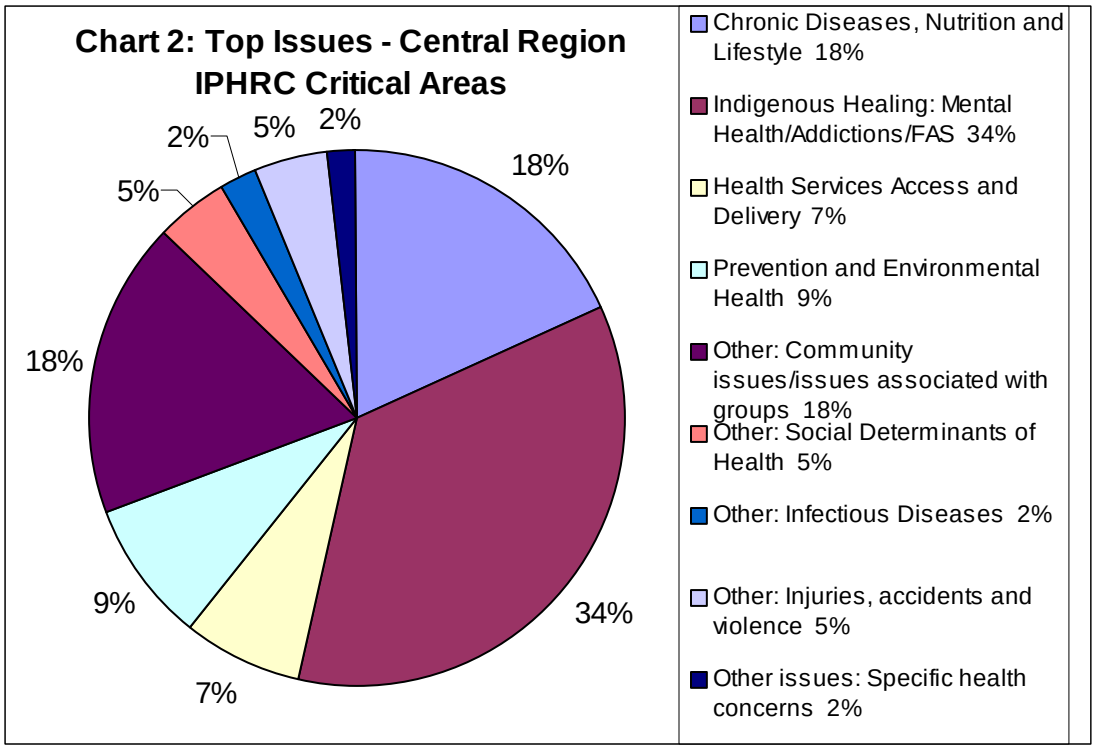
Chronic Diseases, Nutrition and Lifestyle:

"Diabetes is the big one."

Without question, diabetes is the number one concern among the participants in the central region consultation process among both First Nations and Métis, regardless of urban or rural context, although there is recognition that communities closer to large urban centres are suffering more diabetes diagnoses. Participants articulated familiarity with the various manifestations of diabetes and its corollary impacts, and generally, community understanding of diabetes is high although understanding of prevention and remediation are low. Of great concern is the fact that not only is diabetes diagnosis increasing exponentially, diagnosis is occurring at younger ages. Indeed, diabetes is becoming normalized in many communities. Although communities recognize the relationship to obesity and articulated the multiple complications from diabetes including, amputations, heart disease and stroke, high blood pressure, kidney problems, and dialysis, there is not enough being done to address or alleviate the epidemic. It was observed that diabetes is creating more interaction with the health care system which, in turn, highlights related issues such as access to and quality of health service delivery.

Participants recognize that there are significant problems in terms of diabetes information and knowledge translation which impacts negatively upon treatment compliance, especially where language might present a barrier. The increase in diabetes has also given rise to the need for services pertaining to dealing with the emotional consequences of diagnosis.

Table 3: Top Health Issues in Central Communities			
Diabetes & related illnesses	4	Poverty	3
Cardiovascular disease	4	Increasing youth issues	3
Cancer	4	Unhealthy community environments	3
Obesity	4	Cultural change - lack of physical, social,	3
Lack of access to services	4	economic activities	
Lack of culturally relevant services	4	High blood pressure	3
Depression, suicide, low self-esteem	4	Stroke	3
Alcohol	4	Easy access to poor quality food	2
Prescription drug abuse	4	Poor access to good quality food	2
Cocaine & crystal methamphetamine	4	Culture change impact on diet	2
FAS/FAE	4	High carbohydrate/low protein	2
Lateral violence	4	Drug-induced schizophrenia	2
Youth issues - gangs/criminal justice/	4	Lack of knowledge of traditional services	2
Drop out/mental health		Culture of trauma	2
Housing and related impacts	4	Youth and child sexual abuse	2
Black mould	4	Culture of silence around abuse	2
Gossip and lateral violence	3	Youth addictions increasing – injection	2
Kidney disease/dialysis	3	Lack of accessible services	2
Lack of social activities/exercise	3	Medical transportation funding restrictions	2
Serious mental health issues	3	Overcrowding	2
Self medication	3	Lack of privacy and confidentiality	2
Marijuana	3	Unhealthy interpersonal relationships	2
Solvent and gas sniffing	3	STDs	2
Gambling	3	Thyroid disease	2
Smoking	3	Postpartum depression	2
Addiction consequences - STDs, pregnancy,	3	Lack of Indigenous mental health workers	2
violence, theft		Holistic treatment centre needed	1
Loss of traditional services	3	Elders underutilized	1
Spiritual abuse/confusion about teachings	3	Time delays in access	1
Normalized abuse and violence	3	Immunization rates	1
Elder, child, spousal abuse and neglect	3	Infrastructure and capacity building	1
Normalized intergenerational issues	3	Garbage dumps and sewage	1
Lack of quality/respectful care	3	Sanitation	1
Water quality	3	Stray dogs	1
Apathy	3	Allergens	1
Lack of community support	3	Dependency on band staff for programming	1
Divisiveness and power struggles	3	Internet relationship impacts	1
Parenting skills	3	Hepatitis A, B, C	1
Teen pregnancy	3	HIV/AIDS	1
High unemployment	3	Dental	1



Diabetes intervention and treatment are urgently needed. There is some confusion between adhering to contemporary treatments and utilizing traditional forms of treatment. The lack of compliance can result in more sickness, which then leads to complications as listed above. Again, these issues are exacerbated by lack of access to services.

In terms of chronic disease such as cardiovascular disease, it was questioned why Aboriginal people are not represented in heart programs. Key advisors working in the area recognize that there is problem in this regard considering the statistics on cardiovascular issues that include high blood pressure, heart problems, and stroke. Indeed, the Heart and Stroke Foundation recently contacted the IPHRC because of their desire to increase their service involvement with the Indigenous population.

Cancer is a significant concern that was voiced repeatedly in the course of the consultations with particular concern directed at the increasing incidence of all types of cancer, especially breast cancer in women with diagnosis occurring at younger ages. Leukemia and prostate cancer were also being noted as on the rise.

Participants suspect that diet and exercise are the primary causes of ill health. Health program and delivery problems exacerbate the issues. At the community level, poor quality of care and poor access to care are the norms, and communities see the consequences of these in community health including individual physical and mental wellbeing, and community wellness.

Diet is a significant determinant of health and, in Aboriginal communities diet has been unrecognizably altered as the result of colonization and cultural disruption. Formerly independent and vibrant communities are now dependent upon grocery store chains and small

grocers who freight food into smaller communities at a high cost. The high poverty rate on reserves often precludes access to vehicles, which assists in accessing cheaper food prices in urban centres.

Economic and geographical issues are intricately related to the physical health of Indigenous people in Saskatchewan. Limited budgets reduce access to choice of food/quality/price resulting in diets that are high in carbohydrates (cheaper) and lower in protein (expensive). Fresh fruit and vegetables are expensive to freight – in the north (some Central bands are north of Prince Albert) a green pepper can cost seven dollars ($7.00). The main consequences of diet shifts are diabetes and obesity, which go hand-in-hand. Children, raised on diets high in carbohydrates are becoming obese in epidemic proportions at young ages. The Elders recognize that disease is related to the food we eat; a traditional diet was based on wild game. They recall that in the very recent past, no one died of cancer and diabetes.

The participants noted the irony that the health care profession still insists that the Canada food guide is an appropriate guide for Indigenous people.

> *"In the north - when nurses say you have to have four vegetables a day it's not feasible. A green pepper can cost 7 dollars and was not a part of traditional diets".*

Given the inordinate costs and "easy access to poor quality food" (fast food), some participants argued that the food guide is not relevant for Indigenous people and may be to blame for ill physical health among the Indigenous population. One tribal council has been working on an Indigenous food guide. Unlike the Northern region, Central participants did not report widespread hunting or use of traditional foods as a mitigating factor to diet and quality of food problems.

Indigenous Healing: Mental Health and Addictions

Respondents were also clear about the relationship between physical and mental health and those linkages were reiterated many times throughout the survey. As one respondent noted:

> *"The top illnesses – diabetes, obesity, cancer, breast cancer…those illnesses derive from environmental, political, and social issues. The primary issue is creating a healthy environment for people and promoting health environments holistically – spirit, mind, body, heart."*

Mental health is a growing concern in the central region of the province and is a multifaceted issue that covers the increasing concerns of drug-induced mental illness to suicide and depression, especially among youth. Participants indicated that many people are not receiving the treatment that they need as existing mental health services are culturally irrelevant and people are not being diagnosed in a timely manner and waiting lists are too long. There is a stigma associated with mental health issues which creates barriers to treatment and services. The limited funding for community health programs means that the resources are not available for mental health workers to go to communities and provide services. Further, community workers are being burdened by increasingly complicated mental health issues that they may not be trained

to deal with. There is a need to break down the barriers because young people, especially, are vulnerable to mental health problems such as depression and suicidal ideation. Often individuals within communities "self-medicate" with alcohol or drugs as a way of coping with difficulties. There is a significant need for capacity building in the area of mental health services and in the training of Indigenous mental health workers.

Abuse issues are also of great concern to central region communities. These concerns include domestic violence as well as Elder and child abuse and neglect. Elder health issues are a growing concern. There is a lack of services and supports, as well as nursing home beds. Elders also need information on consumer fraud. Elder support systems are an area of need and the need will increase as the population increases and ages.

Abuse issues seem to often correlate with mental health, poverty, and other socioeconomic determinants of health. In Indigenous communities, intergenerational issues are taking a toll and manifesting in multiple forms of abuse and lateral violence. Domestic violence is a huge problem and one that is exacerbated by the lack of services and access to services. Leadership plays a role here as well. Chiefs or Councillors have tremendous power to facilitate or hinder community interventions or programming to deal with the issues. There is a problem of abuse becoming normalized in many communities.

Similarly, addictions are an every increasing problem among central communities. The top addiction concerns include alcohol, smoking, gambling, and increased prescription drug abuse. Many of the concerns centered around the fact that youth and children are becoming involved in addictive behaviours at younger ages. Of concern is the appearance of crystal methamphetamine and injection drug use. These bring additional concerns of infectious disease.

Addictions such as alcohol, smoking, and gambling are normalized through intergenerational behaviour in some communities. As a result, the consequences of FAS and FAE are having an impact on communities, services, and programs. Communities recognize that alcohol related issues contribute to cirrhosis, stroke, and heart disease, and other chronic illnesses. Among youth, some of the consequences being observed include sexually transmitted diseases, increasing pregnancy rates at younger ages (with risks of FAS/FAE), violence, vandalism, theft, and child neglect.

Youth, in particular are vulnerable to addictions as the result of poor socio-economic conditions and social/cultural conditions in communities. The lack of economic, social, and culture activities has led to what participants are describing as simple boredom among youth, the consequences of which are disastrous and include higher pregnancy rates, as young as 14; high drop out rates, lack of supervision, destructive behaviour, gang behaviours, and hyperactivity. Some communities are seeing an increase in drug induced mental health problems among youth, including drug-induced schizophrenia. Unfortunately, programming for youth is reported as inconsistent and there is a distinct lack of treatment programs and centres. All available resources are being used, which then puts the healthy young people at risk of being overlooked in programming and services.

Health Services Access and Delivery

Access to healthcare is one of the most critical problems in Indigenous health. Repeatedly, community participants raised concern about the lack of accessible services which is exacerbated by geographical restrictions for communities, and especially remote communities. Across the board, access to quality care in a timely and respectful manner was asserted as very problematic. Respondents reported being treated with disrespect, contempt, and rudeness by medical personnel. Many reported being patronized by their physicians and nurses, as well as clinic staff. Poor quality service delivery increases resistance to regular care and leads to non-compliance in terms of physician visits. Minor problems then become chronic. The Elderly do not want to attend at their doctor's offices.

In terms of health service programs and delivery, the political leadership needs to support the issues or communities tend to lose programs. Decisions about what is needed must be based on community needs. Communities face some jurisdictional challenges in terms of dealing with provincial/federal responsibility for Indigenous health.

Prevention and Environmental Health

Housing is a significant concern to many of the central communities and the number one problem is black mold. Communities report substandard housing and building practices that have resulted in high incidences of black mold in communities which is related to multiple health problems including respiratory ailments, allergies, headaches, and fatigue, among others. Overcrowding contributes to the problem as the lack of available housing in communities is significant, which results in issues of lack of privacy, problems with sanitation in houses, and limited water (as well as water quality).

In some communities, additional environmental concerns include old garbage dumps and sewage. There is worry about the impact of these on the local water supply and water quality. Stray dogs are a problem and concern in some communities as well.

Métis Health

The main issues among the Métis communities as described by the key advisors include diabetes and its corollary impacts including heart disease, kidney disease, and strokes. Diet and lifestyle were second, and other health concerns include drugs and drug abuse, and cancer. Additionally, there is some concern about the health of Métis women as respondents noted increases in chronic disease rates in Métis communities.

Other Concerns

Other health issues that were mentioned among central participants include a concern about immunizations. It was not clear if the concern was about too many immunizations or a lack of immunizations getting to communities. Thyroid incidence is very high in Saskatchewan and appears to be increasing in the Indigenous community, especially among women. Elder issues

are also a growing concern. Many Elders are not well and most nursing homes have long waiting lists. Some communities report Elders being dropped off at the band office because families have exhausted their resources to care for sick Elders. It is also difficult to find respite care for the Elderly. Lastly, dental problems were noted and the lack of access to services was recognized as a contributor to the problem.

4.2.2 Do you know of any research projects either already completed or currently underway or in the planning stages that look to address these issues?

The majority of the respondents were aware of one or two existing research projects. These included:

- FASD research partnership between Community University Institute for Social Research and a northern Tribal Council
- The Prairie Women's Health Centre of Research Excellence has been working on a project pertaining to an Indigenous women's health centre.
- The University of Saskatchewan has been working with community groups on Diabetes and Obesity. An example is the Pathways in Motion project.
- The Dream multi-year project on diabetes out of a central tribal council that has national and international investigators involved.
- The Regional Health survey out of FSIN.
- Study of Homelessness in Saskatoon.
- Aboriginal Women's Cervical Cancer Screening (urban).
- Health Quality Council – aboriginal access to health.
- Community based Mental health needs assessment at a central tribal council.
- Community based Diabetes Screening project at a central tribal council.
- Community based Family Violence Survey.
- Community based Daycare needs assessment.
- Aboriginal PhD students engaged in research in Saskatchewan – diverse areas of Aboriginal health.

Do you have people in your community who can do research on those issues?

Most respondents in the central region indicated an awareness of increasing numbers of Indigenous people who are becoming knowledgeable about conducting health research, especially in urban centres. The rural communities have fewer skilled researchers and there seems to be a trend for health centre staff, nurses in particular, becoming involved in community based research. There is a sense that skills are slowly transferring to communities that have research project involvement especially as more projects include capacity building elements and there are increasing numbers of trained community surveyors and interviewers. FSIN has conducted 1 day training on how to handle sensitive information. Unfortunately, skilled researchers are overworked.

4.2.3 What is your assessment of the current state of capacity in terms of health research in Indigenous communities?

> *It's an area that really needs and requires a lot of support…[set up the terms so that the community needs are front and centre and that the research belongs to the community…at the end of the day, it must be in favour, under control and ownership of the communities. [If] you could demonstrate how research has benefited other communities, they would see you as an ally and not a stranger.*

The perspective of health research capacity in the communities is that there is a general lack at this time, although some positive inroads are being made. Some participants who are less involved in health research perceived a significant lack of people doing ethical research as well as a lack of mentoring. The FSIN has some trained researchers although there appears to be limited capacity, even in educational institutions, of formally trained, community-based researchers. With the development of community based research guidelines, more community members are getting experience in different aspects of existing projects. However, finding people at the community level to engage in capacity building through participating on projects is difficult.

In the urban centres, in Indigenous institutions and health agencies, there is a perception of tremendous potential in the area of Indigenous health research. Capacity is limited but growing at a rapid rate. There has been an exponential increase over the last few years due to health transfer and self-governance in the area of health. Predominantly Indigenous boards, bands and tribal councils are responsible for services and want to gather data to be accountable for delivery of service and to strengthen the case for increased funding. People are realizing how important the information is as well as how it is gathered and reported. Research is one part of developing progress and services instead of research being "on" the people, it has evolved to research "with, for, and by" the people, with pertinent goals/ends attached to it. Participants see research as a means by which they can demonstrate successes rather than getting mired in negativity.

4.2.4. What do you perceive as the current weaknesses, and strengths in Indigenous health research?

> *The weaknesses are not having skills or knowledge, or relevant knowledge. Especially a lack of researchers; the ones we do have are stretched.*

The primary weakness in Indigenous health research is a lack of capacity in terms of researchers and research knowledge. Researchers who are working are in demand and stretched to their limits. Systemic racism is a barrier on certain levels and can be attributed to the fact that systems have been deficient for far too long. Non-Indigenous people would not have tolerated the situation Indigenous people tolerate in terms of health and well-being. Slow economic development is a hindrance and although capacity is increasing, it is inadequate at every level. More qualified people are needed.

The strengths in Indigenous health research rest in the continued attachment to the land and the culture. There is a high level of interest in post-secondary education, higher levels of post-secondary retention, and better quality jobs available. There is recognition of the need and importance of Indigenous ownership of solutions and processes. Many respondents reported an awareness and understanding of the principles of OCAP. Existing barriers are being reduced through cooperation which allows the alignment of services despite divisive research categories regarding ownership. Respondents urged institutions and organizations to build capacity; participants working in those institutions should direct their efforts towards research development and capacity building despite the multiple demands on Indigenous academics. That way more funds will get to the Indigenous researchers and communities.

4.2.5 What are your thoughts about traditional health systems and protocols in research projects? What are some of the issues surrounding this?

Be most careful about how you're going to deal with it. The teachings were very clear. Some things you just don't share or talk about or write about.

In traditional health systems there should be traditional Elders involved full-time in all health – you don't just grab any Elder; you make sure the Elders is able to do it.

There are many issues at play in discussions about traditional knowledge – health systems and protocols – and research. Some respondents were unwilling to discuss the issues and the consultation on the topic was halted. Other respondents were willing to state that for those who are engaging in this type of research, protocols are a key element. Without proper understanding and application of protocol, the research is problematic and is resisted by communities because of the risk of knowledge being taken advantage of or co-opted. For example, patents on traditional medicines would fall in this category. There was concern about "divide and conquer" tactics being used by researchers who, if they receive a negative response from some individuals or communities, will just go ahead and approach another individual or community who will say yes to the research.

Communities who perceive themselves to have maintained fairly strong traditional roots and knowledge are concerned about the sharing of knowledge with western researchers because of exploitation as well as spiritual rules that define what can and cannot be shared. Indeed, one community refused to go further with the discussion other than to say these things cannot be talked about in any forum other than the spiritual teaching forum.

Communities who are willing to explore the realms of traditional knowledge and protocols were unanimous in articulating that protocols do exist for learning and researching in Indigenous communities. These protocols must be followed and included in research processes. The principles of OCAP are recognized and supported by most communities who see the principles as a means of protecting communities from harmful research. With respect to traditional knowledge, respondents were very clear that people must be very careful and respectful about how they approach traditional knowledge because protocols vary in each community and they must be respected. The community dictates as to what protocols are to be

followed. Research is based upon relationships and researchers must make the commitment to make those relationships effective. This includes approaching the right people in the community such as the Chief and Council and Elders who know the issues. Ascertaining the protocol for each community will also take time. In the cities, a standard protocol may not work because of the different nations represented, but there will be people who can provide the guidance on those aspects of the research project.

The different approaches to research, western and Indigenous, are playing out in Saskatchewan at all levels of health research. Research requires commitment and decision-making. Access to healers is only part of traditional health systems. The use of traditional knowledge is problematic in some regards and contradicts western approaches. For example, traditionally pregnancy was considered a sacred state and the traditional knowledge around it does not fit well with western medical knowledge on the same issue.

> *Need to keep eyes, ears, hearts, and spirits open to the intangibles of methodology including intuition and feelings. Those are vital tools when you're working with Indigenous knowledge systems. Those tools will only work if you're well grounded. Otherwise they will not be effective. Researchers in Indian country need to be comfortable in their relationship with themselves. Comfort and acceptance they get with being grounded – leads to openness to other ways of knowing.*

Some respondents noted that traditional knowledge itself has been affected by colonization. Elders have been heard to speak against traditional knowledge and medicine because of the teachings they have received from the churches. Those types of dialogues cause tremendous confusion amongst communities.

> *One of the things I'm noticing is that there's a very mixed view on collecting Indigenous knowledge or oral tradition. I notice that it varies from province to province and community to community. Some are very rigid and say no, we're not going to share this with anybody; this is ours.*

There are multiple issues that are of concern to communities that need to be brought into the discussion arena. People are concerned about confusion around Elders and Elders' teachings. The diversity of nations and teachings is lending confusion in the sense that many communities will bring Elders in from other areas and their teachings are different from local customs. Although traditional knowledge is re-emerging, the diversity of teachings is sometimes contradictory and can cause confusion. Communities recognize the role of the church and the influence of institutional religion on perspectives towards traditional knowledge. Some Elders who have been raised in a western church have very negative perspectives of traditional knowledge and communities report teachings that traditional knowledge is devil worship.

In the contemporary context of "reclaiming traditions", these contradictory messages are confusing for youth, particularly when they are being told that Elders in general have traditional knowledge and should be respected. Often people do not discern between Elders who merely have senior years and Elders in the 'traditional' sense of the word - Elders who have the training and knowledge in a certain area and who have the responsibility to impart this knowledge to

others. Without the training and background in the traditions, the people report that there are individuals who take on the "Elder" title and engage in power and control strategies, and other abusive behaviours with vulnerable individuals, groups, and organizations. Communities are interested in the dissemination of knowledge including questions such as "what are the steps to becoming an Elder?" This would alleviate the problem of individuals taking on the Elders/Healers role in order to take advantage of the title, Elder, for power.

4.2.6 What do you believe must occur in order to build capacity in community based Indigenous health research?

In terms of capacity building, there was some recognition that the Indigenous Peoples' Health Research Centre (IPHRC) is a key institution in furthering the health research agenda. It is ideal to have an Indigenous health directed research institute with an Indigenous board of directors, dedicated to capacity building. It is an indication of strength in Indigenous research generally. This addresses the need to expand beyond health care and services. The systems need to work together to have the accountability – work the interface between government institutions – to respond to the needs of the people and the community.

Building capacity in communities is viewed as a way of allowing skills and knowledge to stay within the communities. In order to do so, trust building activities would need to take place with communities. Participants view capacity building activities as bi-directional in that university researchers need to learn about communities and about how to conduct research in an informed and ethical way. Community research training will be valuable but the training requires follow up. There have been lots of different types of training, however, these skills have not been utilized.

Training needs to include the big picture; research design, proposals, implementation, evaluation, and research follow-up. People are not knowledgeable or comfortable with the processes of reporting. Most importantly, communities need information about research and how it can benefit communities and how they can become involved and use research as a tool. Lastly, Indigenous leadership is needed to support research initiatives and find effective means for transferring research information and knowledge to the community level.

Ethics

> *Who owns the research? If anyone's doing research on aboriginal people, the aboriginal people should be the ones owning the research and the researchers need to be asking permission to use the research...because researchers have taken information and we haven't owned the information.*

There were numerous comments about the ethics of research with central communities. There is still a general mistrust of researchers. Questions around ownership, control, access, and possession (OCAP) of research arose with regularity and participants were adamant that Indigenous people must own research and that research paradigms must shift. Those working in institutions are aware of conflicting value systems pertaining to research and at the same time there is urgency in terms of finding ways of bringing traditions and traditional knowledge into the contemporary context. Many see research as a tool that needs to be reshaped in order to be

applicable to Indigenous communities and to be effective for researchers who want to conduct research with Indigenous people.

There were multiple recommendations for enhancing the ethics of research as well as capacity building for health research in Indigenous communities. Most communities echoed a desire for training as indicated. Specifically, proposal writing, data analysis, and project development were cited as training subjects of interest. There is a need for people who can conduct all elements of research in communities. In those few communities where the expertise exists, those individuals are overworked. Communities are generally very receptive to the notion that research can be beneficial, and most alluded to the importance of relationship building as a way of establishing trust. Communities are particularly open to research that incorporates Indigenous protocols and culturally relevant practices. These would serve to alleviate some cultural barriers such as language and knowledge translation problems. In particular, protocols such as Chief and Council inclusion into research inquiries and consent for research activities were considered very important.

4.2.7 Do you have any other comments about Indigenous health issues, or health research issues in Saskatchewan?

The participants had multiple suggestions for addressing health issues in the communities. They were keen on the notion of research having practical applications in terms of concrete health outcomes. Needs assessments for various issues were proposed including a survey of family violence issues. For example, statistics were suggested as a way to measure what programs are working or not. Additionally, education for service providers is needed, as well as general education on health issues at the community level. Community members need to understand the specifics of urgent issues including diabetes and cardiovascular disease. Specific ways of applying community education training and workshops were suggested and many ideas about curriculum were put forth including risk information, prevention knowledge, training follow-up, cooking, nutrition, and childcare.

In terms of general health, there is a need for facilities such as drug and alcohol treatment centres and support systems for family violence problems. A community health centre with integrative services was suggested as it would give the community members a sense of belonging which was identified by respondents as lacking in many communities. This sense of belonging is believed to be vital to health and well-being of the individual and the community as a whole.

Health Governance

Health governance and access to healthcare emerged as topics of concern and are elaborated on here. Several issues among the Métis population were also highlighted. There were also several successes in health that were shared.

Governance and administration in Indigenous health and health research are in a capacity building stage and there is a need for bidirectionality; that is, a two way flow of information and knowledge. This is necessary for level of skills and knowledge in administration and health delivery, but also for governance over health service delivery systems and input through

representation at Regional Health boards. There are federal issues around transfer that need attention, for example, adequate funding around services that have been transferred which points to increasing need in the area of infrastructure.

Community Issues

> *We have a culture of poverty and we probably have a culture of trauma…. Decisions need to be made based on what communit[ies] need.*

Community issues are emerging as a critical socio-economic indicator of health in terms of barriers to wellness and manifested intergenerational issues. The cultural disruption of the last century has left many communities in a state of turmoil and anomie. Many communities report a general sense of apathy and lack of community involvement and support for program and activities aimed at community development. As a result, there is difficulty in disseminating information and hence, there is a lack of knowledge about health issues. Efforts at awareness building would be helpful.

Problematic interpersonal and intracommunity communication and relationships are viewed as one of the serious consequences of the residential school system and other disruptions to traditional kinship relations. Respectful behaviour is waning and issues of confidentiality and anonymity suffer, and are exacerbated by dysfunctional habituated community communication styles including gossip and lateral violence. Issues such as STDs risk becoming centred around shame and stigma, hence people will not seek the care that they need. The imposition of foreign systems of health has led to dependence and many people in communities are now dependent upon band staff to run programs.

Interpersonal relationships are very problematic in many communities and there is a growing lack of respect between the generations. Traditional forms of relating including visiting have gone by the wayside. Many communities are factionalized because of the relationships between economics and politics at the local level. Resulting power struggles can be divisive and destructive. The problems, as reported by participants, are normalized.

Communities are seeing significant changes to the social fabric of Indigenous life as western ways of living influence younger generations. For example, attitudes towards sexuality and reproductive health have shifted dramatically.

Recommendations for addressing the plethora of issues include acquiring resources to address issues of community communications and drawing upon traditional healing and helping knowledge. The communities need people trained in these areas, and attention on community development, community workshops and community education to develop best practices is necessary. Researchers need to be out in the communities to get at the issues.

Métis Health

Métis communities report most of the same health issues as the First Nation participants but the primary difference that exists is that although Métis respondents indicate that the skills and the capacity for researching exist in the Métis communities, the funds and resources are lacking. They perceive First Nations as receiving the bulk of resources for health research, programming, and delivery. Métis participants indicate that the lack of core funding and resources is the most severe restriction in terms of addressing the health issues within the Métis communities. Given adequate resources, there would be a focus on education for knowledge transfer as well as strategies to enhance awareness of specific health issues in the Métis population.

Successes

Success is taking place in small steps across the province. For example, many communities are beginning community development activities and discovering their own capacities and abilities. Economic development is growing rapidly and impacting upon community well-being. One tribal council is experimenting with community gardens and other ways of addressing the diabetes epidemic. They are working on a culturally appropriate food guide given that Canada's food guide is not serving the interests of the Indigenous population. Collective kitchens are being run in many communities and serving the important role of addressing communication and relationship building issues. Participants reported that they are witnessing a greater number of people, many in leadership roles, taking responsibility for their own health and well-being. These people are in an important role modelling capacity. There is also an increase in the number of people getting involved in health issues and a sense that mainstream institutions are willing to listen and be open to learning. Partnerships with university research institutes are providing the means of addressing some key health related problems. Two examples given included a partnership with the Community University Institute for Social Research as well as another with the Prairie Women's Health Centre of Excellence.

IPHRC

Participants were supportive of the activities of the IPHRC and pointed out that the institution is a good example of the positive progress of addressing health concerns. They see that the IPHRC can play a pivotal role in asserting the Indigenous health agenda and will be on the frontline of encouraging universities to be more cooperative in approaches to research. They see that the IPHRC is instrumental in helping to change the conventional culture of Indigenous health research and that it has an important role as an extension of self-governance. There is a desire for transparency and accountability in the operation of the centre because these principles are aligned with a philosophy of balance and harmony. Participants asserted that it is up to the IPHRC to work towards changing rhetoric into positive health outcomes.

SOUTHERN REGION

4.3 Findings of the Consultation Sessions – South

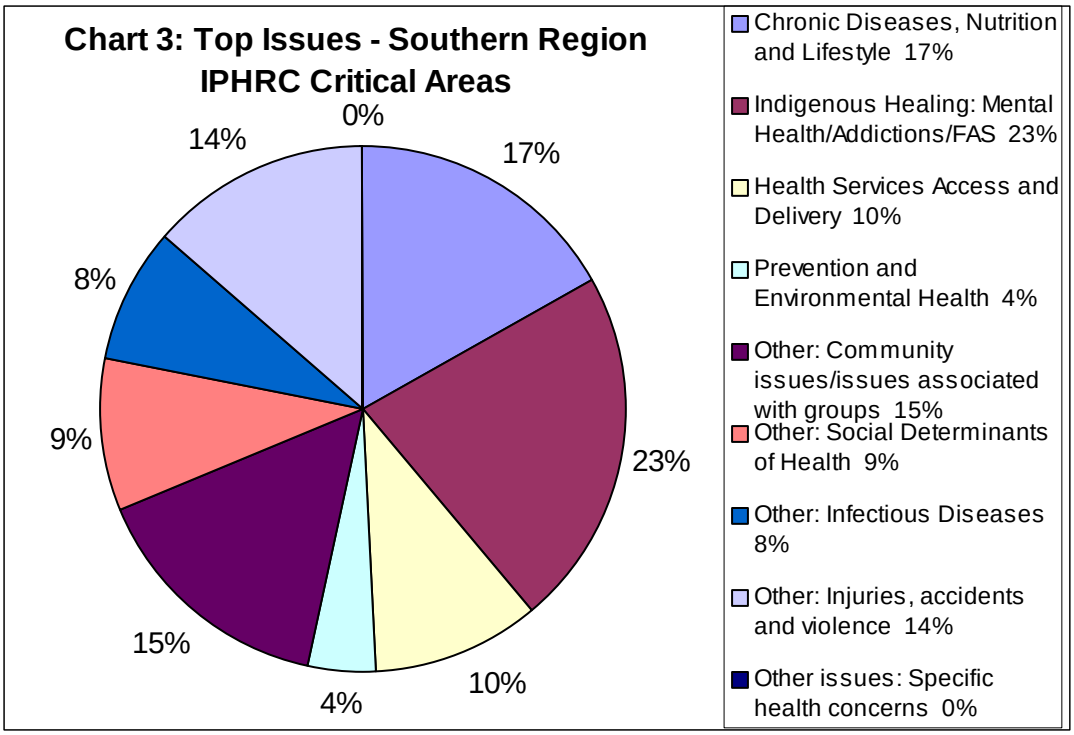
4.3.1. What are the top health issues in your community?

Southern communities in Saskatchewan indicated that the most significant health issues in their communities were diabetes, alcohol and drug abuse, teen pregnancy and prescription drug abuse.

This question was typically answered with a list of specific health issues in each community and a small amount of commentary. The following table represents the issues identified by respondents in the southern region, weighted by their significance or prevalence in the community.

Table 4: Top Health Issues in Southern Communities

Diabetes	4	Heart disease	2
Alcohol/drug abuse	4	Lack of healthy communication	2
Teen pregnancy	4	Arthritis	1
Prescription Drug Abuse	4	Poor lifestyle choices	1
Cancer	4	Solvent abuse	1
Parenting skills	4	Self-esteem issues	1
Suicide	4	Holistic treatment centre needed	1
Addictions	4	Feasts and ceremony for Elders	1
Communicable disease, STDs	4	Medical transportation funding	1
Poverty	3	Funding for workshops/education	1
Unemployment	3	Need program expansion	1
Domestic violence/abuse	3	Immunization rates	1
HIV/AIDS	3	Public safety (need justice coordinator)	1
Teaching cultures, traditions, languages	3	Asthma	1
Lack of youth facilities/services	3	Water quality	1
Attracting/Retaining health professionals	3	Allergens	1
Hepatitis A, B, C	3	Elder bullying/abuse	1
Learning respect	3	Sexual health	1
Poor turnout for events/activities	3	Gang activity	1
Traffic control & speeding	3	Youth legal issues	1
High Blood Pressure	2	Social assistance issues	1
Inactivity	2	Indifference toward abuse	1
Lack of social activities	2	Stroke	1
Obesity	2	Need more volunteers	1
FAS/E	2	Public transportation	1
Better service planning	2	Smoking	1
Maintenance of public areas	2	Mental health diseases/disorders	1
Employment for people returning from treatment	2	Injuries (intentional and unintentional)	1
Understanding abuse cycles	2	Safety at work	1



Chronic Diseases, Nutrition and Lifestyle

Diabetes was by far the most commonly discussed specific health issue and was mentioned in almost every interview or focus group. Specifically, issues of prevention, dealing with diabetes related complications, and maintenance were important to community members. However, it was also widely recognized that there were a number of initiatives such as the Aboriginal Diabetes Initiative in place and that other health issues are equally pressing and need further research and programming.

Another significant chronic condition in the communities was cancer. Several respondents expressed concern at the rate of increase of cancer in the communities, which in their view is significant. These rates, as perceived by community members have drastically increased over the past ten years, making it one of the top ten critical issues in southern Saskatchewan.

Indigenous Healing: Mental Health/Addictions/Fetal Alcohol Syndrome

Alcohol and drug abuse, including prescription drug abuse was highly visible (representing three of the top eight) among the top overall issues listed by respondents. Substance abuse has been rampant in some Indigenous communities for many years according to several respondents, and concern was expressed about the young age at which individuals begin abusing drugs and alcohol. Several respondents felt that if the issue of drug/alcohol abuse and addictions could be tackled, it would positively affect many other health and social issues. The lack of youth treatment facilities was mentioned as an important factor in this area.

Health Services Access and Delivery

Lack of access to health services was considered an issue in several areas. Not surprisingly, this was especially true in communities more distant from urban centres. Very specific issues such as funding for medical transportation and service planning were raised as concerns, but the most significant challenge in health services was attracting and retaining health professionals in the community. The health staff in most communities was highly praised; however there simply are not enough to meet all needs.

Prevention and Environmental Health

Maintenance of public areas and public safety (judiciary) were generally the largest prevention and environmental concerns in the southern communities. While these are prevention issues, particular environmental issues were also addressed, such as air and water quality, and allergens. However, issues in this area were of lower priority in southern Saskatchewan communities.

Other Issues

There were many responses that fell outside the themes identified by IPHRC and must be given equal attention. Although there was overlap in some areas, issues were grouped into four categories according to the context of the discussions of each issue:

Family issues: Teen pregnancy and parenting skills were classified separately since they are both in the top six health issues, indicating considerable concern. There were a number of suggestions in the community discussions regarding how to deal with these issues in a positive way, most significantly, bringing the young parents together with grandparents and elders for guidance. These will be important issues for future research in southern Indigenous communities.

Infectious Disease: Communicable disease/STD's, HIV/AIDS and Hepatitis A, B, and C were all central concerns in southern Saskatchewan with significant discussion again focused on the sexuality of young people. Several communities mentioned that they had already conducted or desired to conduct, information sessions on Hepatitis and HIV/AIDS specifically to inform people of the dangers and risks of these diseases as they become more prevalent.

Injuries, accidents, violence: Suicide was a significant problem that affected many communities. Although it is a serious issue, very little seems to be known in the communities about how best to address the issue, possibly due to reluctance to discuss the problem. However, several community health professionals are committed to finding ways to prevent suicide and provide emotional support.

Domestic abuse was also a concern in southern communities and discussions included the lack of understanding and indifference as barriers to dealing with the problem.

Social issues: Poverty and unemployment were the top social issues listed by respondents. These were often linked to specific health issues, such as drug and alcohol abuse,

low self-esteem and mental distress that together created a cycle of despair that is very difficult to break.

4.3.2. Is there any research being done on those or other issues in your community?

Approximately one-third of respondents stated that there were no research initiatives on-going at the present time, with the most common reason being that the community health staff were overworked. This lack of human resources was a common thread throughout the consultations whether community-level research was being conducted or not. A certain degree of frustration was present in some communities as evidenced by responses such as, “no probably not, they probably don’t have the money or don’t have the resources”.

It was clearly stated in many communities that “information is given through workshops, but no research is taking place”. A significant number of respondents indicated that an important aspect of community health information sharing/research is workshop reporting and community level workshops. Many communities’ health staff have the opportunity to attend workshops in any number of health areas. Most indicated that an important outcome of these opportunities is the dissemination of information to the community so that the community benefits as well.

A number of respondents referred to “information gathering” activities, often done at the band level to determine services and activities the community would like to see offered. They also believed that there was the potential for research in follow up to these activities, if the resources could be put into place. In addition, statistics are occasionally collected on health issues being monitored by community health staff.

Another important means of information sharing is the conducting of community and school level workshops whenever possible. Health staff, in partnership with outside community health professionals, provide workshops in order to promote health education and promotion throughout the community, especially with young people. For example, information sessions and workshops on diabetes care and maintenance (i.e. – diabetic foot care) were conducted in several communities as well as sessions on issues such as HIV/AIDS with young people in the schools.

Several respondents were aware of research initiatives currently taking place on community issues and stated that people were trying but more needed to be done. The desire to conduct research and its perceived value to the communities was clear in these discussions.

> *I think that Aboriginal communities want to participate in and know that it will be useful to them but they simply do not have the capacity. I am working on a research project that is trying to build this capacity and ensuring that the community guides the research and creates strong partnerships, in the truest sense.*

4.3.3. Do you have people in your community who can do the research on those health issues?

Slightly more than half of respondents indicated that there are community members that they believe are very capable of doing research including health teams, health professionals (i.e.

Community Health Representatives, Community Health Nurses, etc.), educated home care staff, and others. The majority of those who responded positively to this question were certain that the community could definitely contribute to the research process given the opportunity. Among those less sure of community capacity, there was a marked interest in the need for more research and researchers.

In approximately one quarter of the responses, there was discussion of research training and guidance. It was generally felt in these instances that training and guidance would be a great help in ensuring that the community would be able to drive the research. Several respondents referred to IPHRC's Partnership/Network Development grants as an example of the benefits of research training and guidance.

Again, the scarcity of human resources was a common point of discussion in both response categories. However, the possibility of hiring students was considered to be a means of alleviating some of this difficulty in several discussions. It was felt that students could assist with surveys and questionnaires "not just to help the staff but to also provide an opportunity for students to learn".

It was also felt that current information on health status and issues was lacking and when available was incomplete, leading to the perceived need for community research initiatives to be a priority.

Despite the many positive responses to this question, there were also a number that felt it was just not possible in the current environment for community-led research. Most of these were due to acute overwork in community health. Very few felt that their community and community members were incapable of participating in research initiatives.

Overall, southern communities believe that they have the capability/capacity to participate in research projects in a number of roles, with the major challenge being a serious lack of resources, particularly human resources.

4.3.4. How would you like to see your community getting involved in your own health research?

There were a wide variety of excellent suggestions and ideas in response to this question. One of the most significant trends in response to this question was emphasis on mobilizing the community. The issue of community members not being involved in current initiatives such as workshops and information sessions was a problem in a large number of communities throughout the southern region. Finding more ways of getting people involved (i.e. some kind of incentive program) in order to have greater dissemination of health and health research information was an important point in many sessions.

Recommendations such as community questionnaires which examined how members would like to see issues approached, or promoting community forums/meetings were identified as ways of garnering community support. This was recognized as a key step in successful

community based research. According to one participant, “A local hands on approach is essential”.

Acting on community feedback was also identified as a means of embarking on research that is relevant to community members. By utilizing data already being collected through community surveys and other means, research questions could be formed giving local leaders a way to address community health concerns.

A number of respondents also stressed the importance of youth leadership in health and health research with additional guidance from Elders and seniors. Involvement of the young and old was a strong undercurrent in the discussion on how the community viewed potential research participation:

> *There needs to be a concrete community plan that incorporates all viewpoints and perspectives of community members to bring real change.*

It was made very clear by all respondents (with the exception of one community that felt community involvement was just not currently feasible) that total community involvement is essential to the success of all community research endeavours. In fact, it was recognized that each community is unique and they should be the ones to advise what issues are important and “what works best for them in terms of research and programs”.

In some cases, establishing partnerships with universities, faculty members and students was seen as important to community research success. In this case, reciprocal learning through community/university teamwork would be advantageous. Additionally, assistance with dissemination was also mentioned as an important part of this teamwork.

Another noteworthy point of view with respect to research funding was identified by one key respondent:

> “I think that funding agencies need to be more flexible in terms of “deliverables”. The strength of IPHRC is that it allows that process of relationship building to occur and this is fundamental. If that process does not occur in a good way, then the research is going to be meaningless… I believe that relationship building is the key to capacity building”.

Finally, one statement that truly captured the essence of community sentiment in research participation was simply, “Start small but think big”.

4.3.5. How do traditional ways of dealing with health fit with health research?

Responses to this question were extremely varied. In some cases, respondents chose not to discuss this topic.

> *This is not talked about much because it is personal. For example, a cancer patient being treated by a healer's medicine is between the healer and the individual. We try to keep it separate out of respect*.

A small number of other respondents stated that it was too difficult to answer since the two are so different, like having to choose between herbal and prescription remedies. Another respondent stated, "I'm not sure they do or can, not many people have respect for our traditional ways anymore". Another community also felt the loss of traditional ways and noted that working with traditional healers was increasingly rare.

However, a majority felt that traditional ways are key to positive health outcomes for many different reasons. The most significant of these was the provision of balance. This concept of balance was integral to health in many southern Indigenous communities. "We come from a cultural background that paid attention to balance within life… [in] all aspects".

In addition to the broader concept of balance, there were a number of mental health issues that were addressed through traditional ways. These included the development of identity (in youth as well as adulthood) and addressing self-esteem issues. "Many traditional teachings deal with illness prevention, emotional balance, spiritual wellness, [and] self-discipline". One community Health Director provided an excellent example of a traditional view of mental health:

> *Elders consider those with livelier spirits to be gifted; the western way is to consider them ADHD children and medicate them. This effectively destroys their spirit, so where does that leave that child?*

There was significant mention of grandparents and Elders throughout these discussions as the source for these teachings and respondents stressed the importance of passing the teachings down to the youth in the communities. It was widely acknowledged that the grandparents and Elders could teach values, respect, and balance in order to improve health outcomes.

> *Going back to the old ways of parenting like our grandparents taught: to have respect for everyone and everything. We must start with the kids, teaching them the values of the old ones*.

The importance of traditional understanding and education was not limited to the community. Respondents discussed the importance of researchers and medical professionals gaining an understanding of these ways as well.

> *The problem isn't with 'fitting'. Scientists work by classifying things but the traditional ways are not all the same and so they can't be 'classified'. This concept has been confusing to researchers in the community.*

Having more open-minded mainstream professionals and the acceptance of "other" ways were important to many community members. "More coordination is needed between traditional and contemporary ways. It doesn't necessarily have to be one or the other".

4.3.6 Is there anything else you want to say about health issues in your community or health research in your community?

Several additional specific issues were brought up in these discussions that reinforce the importance of the concerns described in Question 1. For example, several discussions touched more on suicide, particularly youth suicide and the need for awareness and prevention. Other areas for prevention activities were the bullying/abuse of elders, epidemic drug abuse, and teen pregnancy. Regularly scheduled workshops and community meetings were listed as ways to raise awareness of these issues.

Another significant point of discussion was funding. Many respondents discussed the lack or inadequacy of funding for programs and education in the community along with a lack of understanding on the part of funding agencies as to the level and commitment needed on their part to properly fund local programs:

> *One of the weaknesses is that it still takes a long time to build trust and relationships. Often, funding agencies do not recognize this, yet it is absolutely fundamental if the research is to be meaningful and successful in the long term*.

Closely related to the issue of inadequate funds was the mention of several specific shortcomings of service delivery. Some of these concerns included: paying twice as much for ambulance services on reserve as compared to off reserve, prescription drugs "falling off" the Non-Insured Health Benefits Drug Benefit List, and capacity and retention of human resources, to name a few.

Lack of consultation directly with communities by government agencies and health professionals was mentioned in approximately one third of the consultations, and appreciation was expressed for our consultation process to determine important health issues and potential future directions in community health research.

Holistic health and traditional ways of dealing with health were discussed as important to positive health outcomes in the future. The value of balance - emotional, physical, spiritual and mental health was stressed and incorporating all aspects of the Medicine Wheel was seen as essential to good health.

Commonly, health programs demonstrate the ability, capacity, and desire to improve health outcomes, despite a lack of both human and financial resources. Many cited the Brighter Futures program as an example of a program instrumental to the improvement of community health. A number of other initiatives undertaken at the community level to promote health and wellness were also discussed as improving community health. The health staff in southern

Saskatchewan communities was seen to be doing an exceptional job with the limited resources available to them.

5.0 Discussion of Results

5.1 Limitations of the Consultations

There are several limitations associated with this consultation strategy that should be acknowledged. First, although we did our best to speak to as many people as possible, we did have time and financial constraints on the process and at a certain point had to stop the consultation sessions despite wanting to survey all health personnel in the province. Second, by default, the people that we spoke with were generally those that were either supportive of or at least open to the idea of research. Clearly, those individuals and communities that had no interest in research, or who may have had bad experiences with research in the past, did not choose to participate. Therefore, there are likely additional concerns with research that may not be adequately reflected here and the reporting of research issues may be skewed. Third, the coverage of Métis-specific issues is not as comprehensive as the First Nations data. Although an information session was held with elected representatives of the Métis Nation of Saskatchewan (MNS) at a central meeting in Saskatoon, and interviews were held with several key advisors and health personnel in the north, this process occurred at a time when the MNS was holding its general elections, and this transition period made it difficult to contact appropriate representatives. Nevertheless, a key respondent session was held with the director of the Métis Women's representative. In the northern region, sessions were held with Métis Board Members of one of the Regional Health Authorities, and with the Métis Addictions Council of Saskatchewan in Prince Albert. The information provided was sufficient to provide us with a nascent picture of Métis health and health research issues (see Table 2).

Lastly, although we strove to ensure widespread advising from all the Aboriginal groups in the province, the report does not proportionally represent the Cree, Dene, Saulteaux, Dakota/Lakota/Nakota, and Métis people in respect to population ratios. It does, however, include respondents from all of these nations.

5.2 Saskatchewan Indigenous Health and Health Research Issues

This consultation process provided an excellent starting point for addressing the health research needs of Saskatchewan's Indigenous population. Consultation participants were very clear in outlining their health issues and needs, their thoughts and ideas about research, and what needs to be done for successful, meaningful research to take place in Indigenous communities. The following discussion highlights key similarities across the province, representing areas important to Indigenous communities in Saskatchewan. Recommendations for future research directions are included.

Specific Areas for Research:

There are more similarities than differences in health issues between the regions of the province. At a glance, we can see that in the north, logically, the category of highest concern pertained to Health Services Access and Delivery (see Appendix II, Figure 1). In the central region of the province, the category of highest concern is Indigenous Healing, which includes

Mental Health, Addictions, and FAS. In the south, the data indicates that social issues are predominant, followed closely by issues within the category of Indigenous healing. There were several specific health issues emphasized in all three regions. Diabetes remains the most important concern across the province with all three regions reporting this in the top three health issues they face. Links to nutrition and lifestyle in association with diabetes were identified by most communities, and many communities reported work being done on this issue through both research and program/service delivery, and expressed a need for other areas to be addressed as well.

Cancer was identified as a central health concern and for communities is one of the top health issues province-wide. Of specific concern is the rapid increase in rates of cancer. Participants observed that until fairly recently, cancer had been a health problem of lesser importance, affecting few of their community members. Links were again made to lifestyle and cultural changes in these discussions. Burgeoning statistics for chronic illness and disease such as cancer in the Indigenous population lend urgency to the need for improved service delivery and access to services, especially for the northern population. Access strategies must be developed and streamlined so that Indigenous people do not suffer disproportionately as the result of isolated geography. Further to this, attention to the quality of service provision and delivery is important because currently many Indigenous people are experiencing poor quality services due to racism and discrimination. A significant consequence of this fact is poor compliance with medical visits and most likely, treatment regimes.

There is a general sense of urgency and concern that unless efforts are mobilized in this area, cancer and diabetes have the potential to take on epidemic proportions in Indigenous communities. However, participants are cynical of government interventions that are imposed upon communities rather than allowing communities to participate in their own program development and then supporting those programs through funding.

An additional area that needs considerable research and program development is that of addictions and substance abuse. Again, this was identified as a top priority in virtually every participating community. Addictions and substance abuse have plagued Indigenous communities for many years with little significant progress made at a population level of successfully preventing and treating these problems.

Communities also indicated a shift in substance abuse, primarily from alcohol abuse to drug abuse (including prescription drugs). Drugs such as cocaine and “crystal meth” are also becoming an increasing problem and indicate an escalation of substance abuse. Many also expressed concern at the amount of drug-induced mental illnesses affecting their communities because of more toxic drugs entering communities. The connection between drug abuse and youth distress is well recognized but communities are at a loss as to how to address the issues involved. Again, government devised and funded programs provide some short-term relief but do not get to the crux of the issues.

Culturally relevant treatment is recognized by the Indigenous community as key to healing, especially in relation to mental distress and addictions. Holistic and traditional healing were mentioned throughout the consultation and in all regions. These services could be provided

through the community health centres with the appropriate resources in place. Communities are well aware that culturally relevant approaches are more effective but need increased resources to engage in community mobilization and development that is necessary to implement effective strategies.

In addition, communities indicate that there is a pressing need for family and youth services, programs, and facilities. Youth issues such as addictions, substance abuse, and legal concerns, as well as family services and parenting skills are identified as significant concerns. Communicable diseases, specifically HIV/AIDS, STDs and Hepatitis B/C are mentioned in all regions of the province and in many cases are closely linked to discussions on youth sexuality, emphasizing the need for family and youth services. Participants clearly expressed the need to address social determinants of health, particularly poverty and unemployment. These issues were openly related to many of the other problems listed particularly addictions, mental illness and distress including depression and suicide.

Health research capacity is lacking in Indigenous communities and there is a great need for development in this area. Many participants indicated that the health staff in their communities are capable of participating in meaningful health research, however, they are greatly overworked and those with research experience are overloaded. Research training and guidance are suggested as a means of ensuring true "community-driven" research. Hiring and training local people in research development are clearly articulated goals for community health research. Communities are committed to the principles of OCAP and recognize that community control and participation in research is necessary. Community based research training and education is needed that will allow for the creation of expertise in all elements of research from proposal writing to implementation. The communities are committed to the notion that practical outcomes of research are needed so that communities can experience concrete health changes and outcomes.

Community "buy-in" is important. This takes place through Chief and Council. Appropriate adherence to protocols in research inquiries and consent are important. Traditional rules and protocols can vary, but must be followed. Consultation is essential. Elder involvement and youth involvement are necessary. The communities see research as a way of bringing traditional knowledge into a contemporary context. In knowledge acquisition activities Elders have to be involved and treated as authorities on the research process; which is about integrating traditional knowledge with mainstream knowledge systems. Research must focus on the coordination between the two because strengthening and reclaiming traditional knowledge may be part of healing. Although it was recognized that some Indigenous peoples have embraced the Western medical approach to health, many of our participants articulated a desire for reclaiming traditional knowledge in the health and healing process. This however did not mean they saw the two systems as mutually exclusive, with one replacing the other, but rather that they would like to have the opportunity to draw upon the benefits and supports of both medical systems.

It is apparent from the respondents, especially in the north and central regions, that the Métis urgently need health funding and resources. As an institution dedicated to meeting the needs of all Indigenous people, the IPHRC is an important sources of support and resources to the Métis populations.

6.0 Conclusion

According to Ermine, Sinclair, & Jeffery (2004), although "research has brought many benefits to human society, it has also been a negative experience for many of the world's Indigenous Peoples" (p.45). Based upon the findings of our consultation with Saskatchewan Indigenous communities and stakeholders, we venture to say that the health research enterprise, with very few exceptions, has been an unsuccessful enterprise for Aboriginal communities and has mostly served to alienate them from the research process. The basic requirements for a health research agenda that focuses on Indigenous peoples in Saskatchewan must include research that has practical benefits and is culturally relevant. Research that will be valuable to Indigenous peoples can only be understood within the parameters of benefiting Indigenous communities and the protection of cultural and intellectual property from needless exploitation. The methodology for this report considered the principles of OCAP – Ownership, Control, Access, and Possession – and the ownership of this information rests with the communities and the participants.

The participants of this consultation, which included Indigenous Elders, community health workers, Indigenous health researchers and academics, and community members, confirmed the links between health issues such as mental and physical health, food consumption and physical well-being, economics and health, and lifestyle and youth issues. Their compiled responses validate the connection made between the contemporary consequences of colonialism as manifested through cultural disruption, and the general poor health of Indigenous people in Canada. As asserted by Reading and Elias in their introduction to Chapter 2 of the First Nations and Inuit Regional Health Survey (1997) titled, "An examination of residential schools and Elder health", "the reader is particularly encouraged to consider health survey indicators in a holistic context of past residential school experiences as a significant cohort-specific determinant of health (p.30). To residential schools, we would add the subsequent experiences of the child welfare era that has seen thousands of children removed from their families and placed into foster, institutional, and adoptive homes most specifically between the 1960s and the early 1980s, but even into present day where Indigenous children continue to be overrepresented in the child welfare system. Further, the harmful social dynamic of racism, oppression, marginalization, and social exclusion must be considered as well.

The health priorities in the Indigenous communities include an array of issues from physical health and chronic disease issues to mental and psychological epidemics of demoralization, low self-esteem, and addiction. Historical trauma and colonization account for a wide range of factors in terms of physical illnesses. These historical realities are included in the list of social determinants of health because emotional and mental wellbeing as indicators and determinants of physical health are becoming firmly established. Reading and Elias recognized the "Multiple causative factors in the etiology of ill health" and argue that "failure to acknowledge the potential impacts of the past events and current social, political, economic and cultural circumstances in the complex etiology of poor health will likely lead to an incomplete understanding of the root causes of ill health (31). This echoes Duran and Duran (1995) who, commenting on psychological theory in relation to Indigenous people stated, "Without a proper understanding of history, those who practice in the disciplines of applied social sciences operate in a vacuum, thereby merely perpetuation…ongoing neocolonialism" (Part I). We can infer that the same lack of understanding might also lead to incomplete or irrelevant solutions to health

problems. This consultation provides a window into the complex relationships between physical and mental wellbeing and chronic disease through the words of the participants who recognize and articulate those interrelationships.

The increasing incidence of disease was repeatedly connected to the types of foods consumed. Participants understand that cultural transition from wild game and "country food" based diets to pre-packaged high carbohydrate diets is having disastrous impacts upon the health of Indigenous communities in Saskatchewan. They also voice anxiety that solutions to the problems of poverty and food choice seem to be unattainable. For example, in remote communities, people do not experience a sense of control or empowerment in the types of foods delivered to them. Similarly, mental and psychological well-being is strongly impacted by colonization and is a key determinant of physical health in Indigenous communities. These determinants help to clarify the root source of dis-ease in Indigenous communities. The fact that cancer and diabetes were very rare just a few decades ago, and are now two leading causes of illness and death in Indigenous communities, is cause for great concern, however, communities are not surprised by the burgeoning statistics. There is a high level of understanding in terms of the intricate relationships between the various determinants of health and the poor health status of Indigenous populations. Indigenous communities recognize sources of ill health, have specific concerns with the medical system, are interested in working towards practical solutions, and articulate the potential obstacles to achieving these solutions.

Reading and Elias reporting for The First Nations and Inuit Regional Health Survey (1999), developed a theoretical framework for determinants of health that are more socio-economically and politically relevant to Indigenous people in Canada. The diagram below (Figure 19, Reading and Elias, 1999) indicates the factors that the authors conclude have contemporary significance with respect to health outcomes. The boxes that are shaded in grey indicate those factors that are "theoretically impacted by Residential school". This diagram, from page 50 of Chapter 2 of the First Nations and Inuit Regional Health Survey, provides

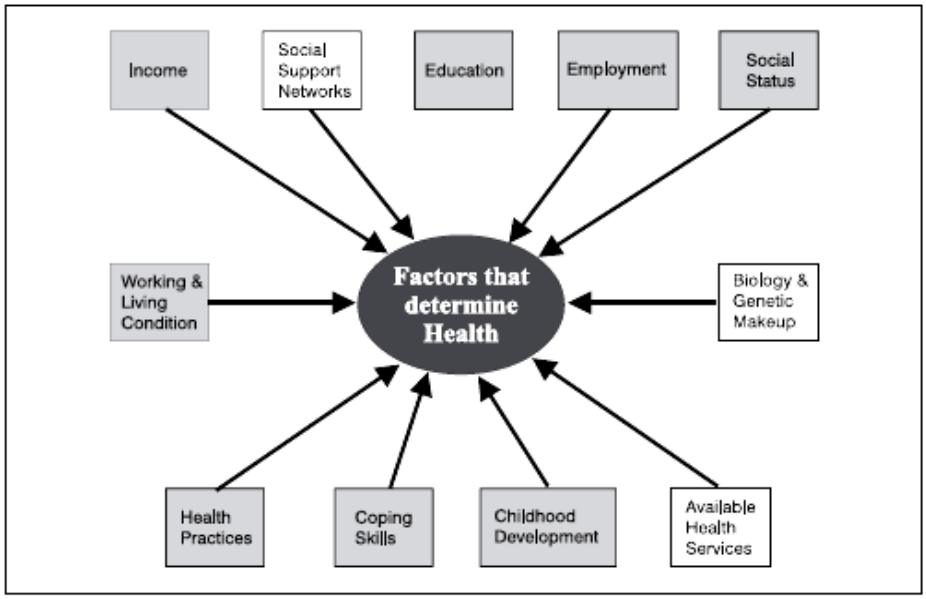


Figure 19 ;
Determinants of Health - Shaded Factors Theoretically Impacted by Residential School

a visual representation of some of the determinants of health in Indigenous communities as well as how far reaching the impacts of residential schools are on contemporary Indigenous health and well-being.

The findings of this consultation clearly indicate that social support networks within Indigenous communities, which may fall under social contexts and include individual, family, and community relationships, have been significantly impacted by colonization. Although we can specify how damage to the traditional communitarian ethic has impacted upon health, we can infer from the sadness expressed over the loss of community activities, that there are negative outcomes. Similarly, available health services, whether the reference is to quantity or quality of service, is certainly marked by institutionalized racism and discrimination. These are now inherent aspects of life for aboriginal people in Saskatchewan and factors that arise time and again in surveying the experiences of Aboriginal peoples in this province. Hence, the single factor in the theoretical model which might remain outside the purview of colonialism, at this time, is "biology and genetic makeup" although some participants alluded to intergenerational memories and trauma being retained in body cells, and some Elders share knowledge pertaining to intergenerational transmission of trauma.

What participants understand at this time is that there is a widespread "normalizing" of ill health among Indigenous people that demands immediate attention and action. Although the will to address the issues exists, the capacity is lacking both in Indigenous communities in terms of moving forward with the health and health research agendas, and in the non-Indigenous communities in terms of understanding the unique context of Indigenous ill health and responding effectively to community assertions and community knowledge. Research capacities need to be enhanced within Indigenous communities to locate research dollars, to initiate and conduct research, and to implement the findings of research. Bridges of understanding need to be constructed with mainstream researchers, agencies, and institutions in order to ensure that efforts coming from the mainstream milieu are conducive to the principles of OCAP and serve the interests of improved health in Indigenous communities. In order to support increased capacity in health research, resources need to devolve to the communities from bodies such as the three national research funding agencies[6]. There is little point to increasing research capacity if communities cannot access research funding. Therefore, upstream funding processes must be re-evaluated and restructured so that communities can access research funding and conduct community relevant research.

[6] The three national funding agencies include: The Canadian Institutes of Health Research (CIHR), the Social Sciences and Humanities Research Council of Canada (SSHRC), and the Natural Sciences and Engineering Research Council of Canada (NSERC).

7.0 Recommendations

We begin our recommendations with a reiteration of two principle recommendations from IPHRC's (2004) recent report, *The Ethics of Research with Indigenous Peoples* to serve as the foundation for health research in Saskatchewan. Respondents in the consultation process continuously alluded to these principles:

Indigenous Peoples' Jurisdiction

The jurisdiction of Indigenous peoples to their culture, heritage, knowledge, and political and intellectual domains must be explicitly recognized. Indigenous communities' rights to cultural and intellectual property must be respected and considered in the formulation of the rules of ethical research conduct. It is Indigenous peoples' right and duty to develop their own cultures and knowledge systems. Appropriate mechanisms need to be established by any granting agencies in concert with Indigenous authorities for the approval and review of research proposals in involving Indigenous peoples. It would then be the responsibility of institutions and governments to adapt to this principle of jurisdiction in any research involving Indigenous peoples.

Ownership, Control, Access, and Possession (OCAP)

To protect their heritage, Indigenous peoples must also exercise control over all research conducted within their territories, or which uses their peoples as subjects of study. This includes the ownership, control, access, and possession of all data and information obtained from research involving Indigenous peoples, usually formalized through research agreements negotiated and formalized with authorities of Indigenous jurisdictions before research begins. Researchers and scholarly institutions should return all elements of Indigenous peoples' heritage to the traditional owners upon demand, or obtain formal agreements with the traditional owners for the shared custody, use and interpretation of their heritage. Additionally, researchers must not publish information obtained from Indigenous peoples or the results of research conducted on flora, fauna, microbes or materials discovered through the assistance of Indigenous peoples, without identifying the traditional owners and obtaining their consent to publication. Granting agencies must stipulate this in policy and as conditions of any funding for researchers and institutions contemplating doing research involving Indigenous peoples.

Recommendation 1: Capacity building in Indigenous Health Research

- Resources must be directed towards enhancing health and health research knowledge transfer to Indigenous communities in order to develop the capacity for community initiated and directed health research. Specifically, training and workshops that will enhance knowledge of research and research processes in Indigenous communities are needed. Resources directed to community-based research curriculum development to take place in collaboration and conjunction with Indigenous communities and resources for a province-wide training strategy must be secured. Communities want to engage in their own health research but are limited in the availability of human, financial and expertise

resources. Develop community-based research curricula for research training and education workshops.

- Continue to raise the profile of research in Indigenous communities and organizations and amongst potential Indigenous undergraduate, graduate, and post-doctoral students and build upon the capacity building success of the ACADRE program through sustainable long-term funding and through partnerships and collaborations.
- Indigenous and non-Indigenous educational institutions must direct resources to building health research capacity in curriculum and training;
- Identify and provide resources to support health information dissemination – including community level workshops, training initiatives and the strengthening of community derived "best practices".
- Place priority on supporting those research projects that have clearly been initiated by Indigenous communities, and refrain from "recruiting" Indigenous communities to participate in projects that have been designed primarily by academics and for academic purposes only (i.e. scientific publications and teaching).
- Continue to support community ownership of research data and results through the principles of OCAP.
- Support training initiatives for community members in the area of research and ensure that these activities are built into funded projects/funding opportunities.

Recommendation 2: Access to health care

- Improvements in provincial health care services for Indigenous populations are needed. These include the availability of services as well as the quality of services delivered. Systemic and institutional racism and discrimination on the part of health care providers must be dealt with swiftly and thoroughly. Discrimination that allows for longer waiting times or second-rate services for Indigenous peoples is unacceptable. Conflicts in policies between First Nations and Inuit Health Branch and health agencies that result in poor health outcomes must be redressed.
- Support research that looks at positive models of intervention or strength based approaches emphasizing individual and collective resilience, rather than focusing on illness and disease alone.

Recommendation 3: Mental and Social health/distress research

- Extra resources are needed in the area of mental health/distress and addictions in response to the high priority placed upon this topic by many communities. Culturally and sociologically relevant strategies must be researched and developed.
- Develop an alcohol and drug abuse (especially Crystal Methamphetamine) strategies as these issues represent a significant challenge in Indigenous communities (and it is widely felt that this will contribute to the overall healing process).
- Attention must be given to youth health issues.

Recommendation 4: Traditional knowledge

- Research touching on traditional knowledge, including plant and medicinal methods and healing should only be supported where the project has been clearly initiated by the community, and special protocols should be developed in consultation with communities for assessing these projects, touching on the principles of ethics and OCAP.

- Any research touching on traditional knowledge and healing should clearly demonstrate Elder guidance and participation, and appropriate consultation processes.
- Recognize the unique nature of each community and work with those who identify traditional healing as an important aspect of community health – work toward improving the coordination between traditional and western medicines.
- Significant resources should be provided in developing traditional healing and community development initiatives.
- The principles of OCAP must be adhered to stringently which means that funding agencies must accommodate lengthier and more detailed ethics processes between institutions and communities.

Recommendation 5: Funding considerations

- Explore ways of supporting research projects beyond the developmental phase; explore Community-based funding grants.
- Explore options for locating research funds in the communities, rather than in the academic institutions.
- Educate funding bodies and health practitioners on the ethics and protocols of research with Indigenous communities.
- Ensure that funding resources meet the research "capacity building agenda" of governments. Such funding must be accessible to communities.

Recommendation 6: Epidemiological Studies

- There is a need for epidemiological studies given high incidence and increasing prevalence of chronic disease. These studies must support immediate and tangible health strategies for Indigenous communities and must be directed at the health priorities of communities. Funding agencies such as the Social Sciences and Humanities Research Council of Canada (SSHRC), Natural Sciences and Engineering Research Council of Canada (NSERC), and Canadian Institutes of Health Research (CIHR) need to prioritize health research that proposes the amelioration and mitigation of poor health conditions in Indigenous communities above other research.

Recommendation 7: Economic development and health research

- Indigenous communities that are engaged in economic development activities (urban reserves, casinos, construction, and promotion of entrepreneurship) should take the opportunity to engage in health research projects that will serve their community's long-term health interests. Examples might include community inventories of health conditions, issues, assets, and changes over time; to monitor the impact of economic development on community health over time.

Recommendation 8: Enhance Indigenous Health Research Communications

- Ensure increased and on-going communication and consultation with Indigenous communities with respect to the exploration of health issues and health research initiatives.
- Look at ways of supporting communities in using "research data" that is already collected through on-going program planning, evaluation, and needs assessment activities.

- Create venues for sharing information and research results within and between Indigenous communities.
- Continue to develop the IPHRC website to include an information clearing house on Indigenous Health Research beyond IPHRC generated projects and reports.

Recommendation 9: Métis Specific Consultations

- Métis peoples have unique health interests and needs and these should be addressed through additional consultations specifically with the Métis community of Saskatchewan. These consultations should further explore and clarify these needs in order to set future directions for Métis health research and capacity building.

Recommendation 10: Knowledge Transfer and Education

- Many of the participants indicated a lack of knowledge and education in the area of jurisdiction regarding access to health care, specifically accessing and providing services. For example, Métis respondents identified "inadequate benefits, funding, and access to services" as being top health services priorities.
- Providing accessible information and education around jurisdiction regarding the "provincial/federal responsibility for Indigenous health" to community members is a priority. For example the information should include exactly whose responsibility it is and what their role is in regards to providing health care services to its members. Once the information is collected it can be distributed to community members for their benefit.

Recommendation 11: Prevention and Environmental Health

All three regions in this consultation process identified a preponderance of environmental health concerns, in particular, water quality in First Nation communities. A second concern is housing. The issue of overcrowding due to lack of available funding for housing was identified. Mould was a significant concern mentioned in relation to environmental health.

- It is recommended that further research be done in regard to the quality of water on Saskatchewan First Nations.
- Further research should be conducted on the issue of inadequate and/or substandard housing. Specific attention should be paid to the number of residents per household and the overall health effects of living in close quarters.
- Research on housing conditions should examine housing structures themselves, with particular attention paid to mould and the health implications mould has on residents.
- Data that is collected regarding environmental health concerns need to be forwarded to provincial and federal delegates outlining the seriousness of these issues.

Recommendations for IPHRC:

- Maintain flexibility in the priority areas in order to provide scope for individual communities to identify their priorities for research.
- Enhance knowledge transfer in health research processes, focusing on community-based training and on workshops on health research topics prioritized by communities.
- Evolve the Community Research Facilitator position from one that links community projects to Academics, to including research workshop/training role in order to facilitate Indigenous health research knowledge transfer.

- Enhance uptake of traditionally based research knowledge and methods, including ethics, to university academics through institutional and departmental workshops and develop bi-directional educational approaches to working with institutional research bodies.
- The focus of this study was specific to the issues surrounding rural communities. Future studies should include Indigenous health issues affecting those living in urban areas as well. Youth involvement and exploitation in the sex trade is an example of an urban issue that might not have come forth in this consultation since it focused on rural and remote community issues.

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Appendices

I Provincial Strategy Brief
II Provincial Strategy Comparison Data
III Participant List

Appendix I

COMMUNITY CONSULTATIONS ON INDIGENOUS HEALTH RESEARCH ISSUES

What we are doing:
The Indigenous Peoples' Health Research Centre (IPHRC) is in the process of asking Métis and First Nation communities, groups, institutions, and key advisors about priorities, issues, and concerns in the area of health in order to develop an Indigenous Health Research Strategy. The goal of the consultation process is to find out from the Indigenous health sector what the health research issues, questions and priorities are, how these questions can be addressed, and the best methods for addressing them.

Why we are doing it:
The IPHRC is committed to Indigenous control and ownership of research at the community level and this commitment will guide the consultation process at all times. By consulting with the Indigenous health sector, we plan to:

- Learn about Indigenous health research issues in Saskatchewan
- Parallel and complement the current provincial consultation process being conducted by the Saskatchewan Health Research Foundation (with our process focusing on Indigenous health)
- Make sure that IPHRC has the right priorities, from a community perspective and from the perspective of experts in the area of health
- Return this information to the communities

Key advisors are offered the option on an in-person or telephone interview or a written email response. The following questions are posed:

8. In your opinion, what are the top five health issues facing Indigenous communities in Saskatchewan?
9. Do you know of any research projects either already completed or currently underway or in the planning stages that look to address these issues?
10. What is your assessment of the current state of capacity in terms of health research in Indigenous communities?
11. What do you perceive as the current weaknesses, and strengths in Indigenous health research?
12. What do you believe must occur in order to build capacity in community based Indigenous health research?
13. What are your thoughts about traditional health systems and protocols in research projects? What are some of the issues surrounding this?
14. Do you have any other comments about Indigenous health issues, or health research issues in Saskatchewan?

Appendix II

Regional data comparison

Figure 1: Weighted responses by theme

Responses by Theme Categories	Weighted Responses		
	North	Central	South
Chronic Diseases, Nutrition & Lifestyle	18	36	20
Indigenous Healing: Mental Health, Addictions, FAS	15	68	26
Health Services Access and Delivery	22	14	12
Prevention and Environmental Health	12	17	5
Other: Community issues/issues associated with groups	8	35	18
Other: Social determinants of health	4	9	11
Other: Infectious diseases	3	4	10
Other: Injuries, accidents, violence	3	9	16
Other issues: Specific health concerns	2	3	0

Figure 2: Weighted percentages by theme

Responses by Theme Categories	Weighted Responses – Percentages		
	North	Central	South
Chronic Diseases, Nutrition & Lifestyle	21%	18%	17%
Indigenous Healing: Mental Health, Addictions, FAS	17%	34%	23%
Health Services Access and Delivery	26%	7%	10%
Prevention and Environmental Health	14%	9%	4%
Other: Community issues/issues associated with groups	9%	18%	15%
Other: Social determinants of health	5%	5%	9%
Other: Infectious diseases	3%	2%	8%
Other: Injuries, accidents, violence	3%	5%	15%
Other issues: Specific health concerns	2%	2%	0%

Figure 3: Category responses by Region (similar issues highlighted in yellow)

North	Central	South
Chronic Diseases, Nutrition and Lifestyle		
Diabetes	Diabetes & related illnesses	Diabetes
	Kidney disease/dialysis	
Cardiovascular disease	Cardiovascular disease	Heart disease
	Stroke	Stroke
Cancer	Cancer	Cancer
Obesity/poor nutrition	Obesity	Obesity

	Easy access to poor quality food	
	Poor access to good quality food	
	Culture change impact on diet	
	High carb/low protein	
Lack of physical activity	Lack of social activities/exercise	Inactivity
	High blood pressure	High blood pressure
Arthritis (especially rheumatoid)		Arthritis
Lifestyle (general)		Poor lifestyle choices
		Sexual health
Chronic diseases (general)		
Indigenous Healing: Mental Health/Addictions/FAS		
Addictions/substance abuse	Alcohol abuse	Alcohol/drug abuse
	Prescription drug abuse	Prescription drug abuse
	Solvent and gas sniffing	Solvent abuse
	Smoking	Smoking
	Marijuana	Addictions
	Cocaine and crystal methamphetamine	
	Gambling	
	Self medication	
	Youth addictions increasing – injection	
	Addiction consequences – STDs/pregnancy/violence/theft	
FAS/FASD	FAS/FAE	FAS/FAE
Mental health (general)	Serious mental health issues	Mental health diseases/disorders
Depression	Depression, suicide, low self-esteem	Self-esteem issues
Need to strengthen cultural identity	Loss of traditional services	Need for teaching culture, traditions, languages
	Lack of knowledge of traditional services	
	Spiritual abuse/confusion about teachings	Need for learning respect
	Elders underutilized	
Need for holistic healing	Holistic treatment centre needed	Holistic treatment centre needed
Schizophrenia	Drug induced schizophrenia	
	Youth issues – gangs/ criminal justice/drop out/mental health	
	Normalized intergenerational issues	
	Culture of trauma	
	Postpartum depression	
	Lack of indigenous mental health workers	
Health Services Access and Delivery		
Inadequate facilities/services/ benefits	Lack of quality/respectful care	Need program expansion
Inadequate services – mental health/addictions		

Inadequate services (general)		
Need for better planning and promotion		Better services planning needed
	Infrastructure and capacity building	Funding needed for workshops/ education
Need for more youth services and programs		Lack of youth facilities/services
Need for better child and family services		
Systemic issues in health services delivery (government)		
Problems in accessing services	Lack of accessible services	
	Time delays in access	
Attracting and retaining health care professionals		Attracting/retaining health professionals
Need for culturally appropriate health models	Lack of culturally relevant services	
Low immunization rates	Immunization rates	Immunization rates
Transportation issues in health services	Medical transportation funding restrictions	Medical transportation issues
Language barriers in accessing services		
Prevention and Environmental Health		
Water quality and food safety	Water quality	Water quality
Housing conditions – overcrowding/shortage	Overcrowding	
	Housing and related impacts	
Housing conditions – mould/pests	Black mould	
Respiratory illness/lung disease		Asthma
	Allergens	Allergens
	Garbage dumps and sewage	Maintenance of public areas
	Sanitation	
Environmental contaminants		
	Stray dogs	
Other: Community issues/issues associated with groups		
Prenatal and perinatal health/ parenting skills/teen pregnancies	Teen pregnancy	Teen pregnancy
	Parenting skills	Parenting skills
Elder abuse/loss of Elders	Elder, child, spousal abuse and neglect	Elder bullying/abuse
		Feasts and ceremonies needed for Elders
Youth issues	Youth and child sexual abuse	Youth legal issues
	Increasing youth issues	
	Gossip and lateral violence	
	Apathy	
	Lack of community support	Poor turnout for events/activities
		Lack of volunteers
	Unhealthy interpersonal relationships	Lack of healthy communication

	Unhealthy community environments	
	Internet relationship impacts	
Indigenous men's health		
Métis health		
	Cultural/social changes	
	Divisiveness and power struggles	
	Lack of privacy and confidentiality	
	Dependency on band staff for programming	
		Lack of public transportation
Other: Social Determinants of Health		
Social determinants of health (especially education, poverty, legacies of colonization)	Poverty	Poverty
	High unemployment	Unemployment
		Lack of employment for people returning from treatment
	Cultural change – lack of physical, social, economic activities	Lack of social activities
		Social assistance issues
Other: Infectious Diseases		
Infectious diseases (Hepatitis B and C, HIV/AIDS, STDs, TB)	Hepatitis A, B, C	Hepatitis A/B/C
	HIV/AIDS	HIV/AIDS
	STDs	Communicable diseases/STDs
Other: Injuries, accidents, violence		
Injuries, accidents and violence (including suicide)		Suicide
	Normalized abuse and violence	Domestic violence/abuse
	Culture of silence around abuse	Indifference toward abuse
		Lack of understanding of abuse cycles
	Lateral violence	
		Injuries (intentional and unintentional)
		Traffic control and speeding
		Public safety
		Safety at work
Other issues: Specific health concerns		
Other specific health concerns (boils, thyroid)	Thyroid disease	
Dental health (children)	Dental health	

Appendix III

Participant List[7]

Bands:
Thunderchild First Nation
Onion Lake First Nation
Cowessess First Nation

Tribal Councils:
Yorkton Tribal Council
Touchwood Agency Tribal Council
File Hills Qu'Appelle Tribal Council
Battleford Tribal Council
Agency Chiefs Tribal Council
Prince Albert Grand Council
Meadow Lake Tribal Council

Institutions & Agencies:
First Nations University of Canada
Saskatchewan Indian Institute of Technology
Northern Medical Services
Federation of Saskatchewan Indian Nations
Saskatoon Health Region
Métis Nation of Saskatchewan
Beaver River Community Future
La Loche Hospital
Saskatchewan Labour
National Aboriginal Health Organization

[7] Individuals not identified to maintain confidentiality