



DIGNITAS

**DIGNITAS INTERNATIONAL
FEASIBILITY STUDY REPORT**

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***Improving Access to Quality and Culturally Safe Health Care
for Aboriginal Communities in Canada***

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EXECUTIVE SUMMARY

During the fall of 2013, Dignitas International commissioned a feasibility study to explore the collaboration potential between medical non-governmental organizations (NGOs) and Aboriginal health stakeholders to improve Aboriginal communities' access to quality and appropriate health care.

This involved engaging in a dialogue with a variety of stakeholders including Aboriginal health authorities and health centers, First Nations Provincial and Territorial Organizations (PTOs), First Nations community stakeholders, federal and provincial government representatives, and academic institutions. Through a series of interviews with key informants and an online survey distributed to various stakeholders, the consultative element of the feasibility study gathered stakeholder perspectives related to health priorities, challenges, opportunities, and potential partnership models for NGOs, with a particular focus on infectious and chronic diseases and conditions, services and programs in remote and rural Aboriginal communities.

Respondents identified the following as the most pressing chronic diseases in Aboriginal communities:

- Diabetes and related complications;
- Addictions;
- Mental health;
- Cancer; and
- Heart disease.

Often patients present with multiple and complex chronic health issues, which may for some, be exacerbated by mental health issues. Respondents identified infectious diseases, such as sexually transmitted infections, HIV/AIDS, TB, hepatitis and seasonal influenza, as priority health concerns as well.

Service gaps and issues identified by interview respondents included:

- Chronic health staff turnover and lack of access to continuing education for community based health workers;
- Fragmentation of programs and services;
- A lack of coordination of care and poorly managed transitions between care settings;
- High rates of complex chronic health issues and severe lack of access to needed services; and
- The lack of integration between traditional Aboriginal approaches to or understanding of health and wellness and mainstream modalities.

Strengths included the movement within communities toward cultural revitalization as well as strong health management, leadership and governance structures. The consultation highlighted the emergence of multi-stakeholder projects aimed at strengthening coordination and collaborative approaches to various health issues as well as a number of recent successful partnerships involving NGOs and other partners. In fact, there was a strong sentiment of

readiness and interest to partner with NGOs.

Respondents suggested that in any future partnerships, NGOs can look to a rich repository of success stories from which to learn. In addition, collaborating with key partners and leveraging existing infrastructure would also be necessary criteria for successful collaboration.

Respondents were very forthright about necessary partnership principles. In particular, they spoke to the need to embrace community development and social accountability approaches and ensure that communities lead in identifying their needs and priorities. Partners should also demonstrate a respectful awareness of Indigenous social determinants of health, and historical, cultural and community dynamics. Being respectful of culture and community autonomy implies also acknowledging and affirming community knowledge. An ability to facilitate respectful dialogue, build trusting relationships and ensure transparency in all processes and activities also are important criteria for collaboration. Most importantly, partners should be cognizant of the need to support advocacy around health needs, inequities and the inclusion of these perspectives in policy and priority setting at various levels of government.

Respondents pointed to a number of frameworks, approaches and principles that they felt could be helpful and should be explored in any future partnership projects. These included:

- Expanded chronic disease model;
- OCAP in research and evaluation;
- Social accountability;
- Cultural safety; and
- Community development.

Some specific roles that respondents identified as potential opportunities for NGOs included:

- Support and facilitate the implementation of new initiatives and approaches, especially at the early stages by mobilizing communities and providing or sharing specific expertise drawn from their experiences with other projects and in other jurisdictions;
- Support the development of inter-professional roles and teams;
- Facilitate continuing health and medical education, especially training for Community Health Workers and knowledge exchange and transfer;
- Advocate for the health interests and priorities of communities and partners especially around cross-jurisdictional barriers;
- Support the development of local health services and evaluation processes and data; and
- Support community health system development through task shifting and training.

In particular, respondents felt that NGOs “may be well positioned to build capacity by enhancing existing health systems and services and/or supporting the design, implementation and evaluation of community-based health programs.” NGOs like Dignitas International could be instrumental as a facilitator to convene the multiplicity of stakeholders (both Aboriginal and non-Aboriginal) involved at all levels of Aboriginal health service delivery and “establish a collaborative platform for dialogue and knowledge exchange.”

This feasibility study showed there is a definitive role for NGOs to collaborate with First Nations communities to improve access to health care and many First Nations stakeholders are interested in exploring a partnership.

1 INTRODUCTION

1.1 BACKGROUND AND RATIONALE FOR THE FEASIBILITY STUDY

Dignitas International (DI) is a medical organization that works in partnership with patients, health workers, researchers, and policymakers to tackle health care barriers in resource-limited settings. In Canada, a number of challenges including geographic isolation, low resources (human and financial), high medical staff turnover rates, and the lack of culturally safe care, continue to impede remote and rural Canadian Aboriginal populations from accessing quality health care. As a non-governmental organization (NGO) committed to health equity, DI's interest in Aboriginal health stems from a desire to understand how innovative and culturally relevant approaches in public health can be applied to address health disparities experienced by Aboriginal communities. To this end, DI commissioned a feasibility study to explore the collaboration potential between medical NGOs and Aboriginal health stakeholders to improve Aboriginal communities' access to quality and appropriate health care.

As part of the feasibility study, DI engaged in a dialogue with a variety of stakeholders including Aboriginal health authorities and health centers, First Nations Provincial and Territorial Organizations (PTOs), First Nations community stakeholders, federal and provincial government representatives, and academic institutions. Through a series of interviews with key informants and an online survey distributed to various stakeholders, the consultative element of the feasibility study gathered stakeholder perspectives related to health priorities, challenges, opportunities, and potential partnership models for NGOs, with a particular focus on infectious and chronic diseases and conditions, services and programs in remote and rural Aboriginal communities.

1.2 AIM OF THE FEASIBILITY STUDY

The aim of this study was to explore the potential role of medical NGOs in improving the access of Aboriginal communities to quality and appropriate primary healthcare in Canada. Specifically, there was an interest in identifying potential niche opportunities for medical NGOs, working within a public health approach and with an interest in the screening and management of chronic health conditions and infectious diseases to improve the accessibility, quality and appropriateness of healthcare for Aboriginal communities.

1.3 ABORIGINAL HEALTH ISSUES IN CANADA

Aboriginal people experience significant health-related challenges including high rates of chronic and infectious diseases and reduced life expectancy. For example amongst First Nations and Inuit populations:

- Heart disease is 1.5 times higher;
- Type 2 diabetes is 3 to 5 times higher among First Nations people and rates are increasing among the Inuit; and
- Tuberculosis infection rates are 8 to 10 times higher.
- Fifteen percent of new HIV and AIDS infections occur in Aboriginal people.¹

The impact of governmental policies including the legacy of colonization and residential schools and the resulting historical trauma which has led to poor overall health and mental health in Aboriginal communities, is well documented.^{2,3,4,5,6,7} The current state of Aboriginal health can only be understood within the context of the multi-generational impact of social, political, economic and cultural marginalization and assimilation policies and processes, losses of land and traditional lifestyles.^{8,9,10} The negative consequence of these processes still impact on the health and wellbeing of Aboriginal individuals, families and communities today.

1.4 COMPLEX JURISDICTIONS FOR ABORIGINAL HEALTH SERVICES

As part of its fiduciary responsibility¹¹, the federal government has responsibility for some health service provision to First Nations and Inuit people¹², however all Aboriginal people also qualify for insured health services and other health programs delivered by provincial agencies. The jurisdictional responsibility for provision of Aboriginal health services is therefore complex and varies by regions. For example, in Ontario it is dependent on many factors including:

¹ Health Canada Website. First Nations and Inuit Health. Accessible at <http://www.hc-sc.gc.ca/fniah-spnia/diseases-maladies/index-eng.php>

² Bombay, A., Matheson, K., & Anisman, H. (2009). Intergenerational Trauma: Convergence of Multiple Processes among First Nations peoples in Canada. *Journal of Aboriginal Health*, November, 6–47.

³ Brave Heart M. (1998) The Return to the sacred path: Healing the historical trauma and historical unresolved grief response among the Lakota through a psychoeducational group intervention. *Smith College Studies in Social Work*. 1998; 68:287–305.

⁴ Brave Heart M, DeBruyn L. (1998) The American Indian holocaust: Healing historical unresolved grief. *American Indian Alaska Native Mental Health Research*. 1998; 8:60–82.

⁵ Walls, M. L., & Whitbeck, L. B. (2012). The Intergenerational Effects of Relocation Policies on Indigenous Families. *Journal of family issues*, 33(9), 1272–1293. doi:10.1177/0192513X12447178

⁶ Waldram JB, Herring DA, Young TK: Aboriginal health in Canada: Historical, cultural and epidemiological perspectives. 2nd edition. Toronto: University of Toronto Press.

⁷ Whitbeck L, Hoyt D, Simons R, Conger R, Elder G, Lorenz F, Huck S. Intergenerational continuity of depressed affect and parental rejection. *Journal of Personality and Social Psychology*. 1992; 63:1036–1045.

⁸ National Collaborating Centre for Aboriginal Health. (2013) *An Overview of Aboriginal Health in Canada*. Prince George, BC.

⁹ Reading, J., & Halseth, R. (2013). *Pathways to Improving Well-Being for Indigenous Peoples: How Living Conditions Decide Health*. Prince George, BC National Collaborating Centre for Aboriginal Health.

¹⁰ Whitbeck L, Walls M, Johnson K, Morrisseau A, McDougall C. The prevalence and correlates of perceived historical losses among North American Indigenous adolescents. *American Indian/Alaska Native Mental Health Research Journal*. 2009; 16:16–41.

¹¹ The Crown's Fiduciary Relationship with Aboriginal Peoples, Library of Parliament, found at:

<http://www.parl.gc.ca/Content/LOP/researchpublications/prb0009-e.pdf>

¹² First Nations and Inuit Health Branch as described on Health Canada's website <http://www.hc-sc.gc.ca/fniah-spnia/index-eng.php>

- Aboriginal status of the population (i.e. First Nations, Inuit, Métis);¹³
- Place of residence (e.g.: located on or off reserve);
- Size of the community;
- Organization of federal and provincial services (e.g.: transfer agreements with the federal government¹⁴ or access to provincial Aboriginal health access centre services); and
- Geographic location (e.g.: Local Health Integration Networks (LHIN), northern, southern, rural and/or isolated).

Aboriginal communities are therefore challenged to integrate multiple levels of services accessible to community members such as:

- Primary care and health promotion services funded by Health Canada under the First Nations and Inuit Health Branch (FNIHB) and other services provided on reserves;
- Primary care and health promotion services funded by the Ontario Ministry of Health and Long-term Care (MOHLTC) under Aboriginal Health Access Centres;
- Services provided by primary health care teams and physicians insured under OHIP and/or funded by the MOHLTC;
- Regional health and mental health service networks provided by Local Health Integration Networks and Public Health Programs;
- Children and youth mental health services funded under the Ontario Ministry of Child and Youth Services (MCYS);
- Services provided by First Nation and regional health transfer authorities;
- and many others.

An ongoing focus on service integration and facilitation of access to care is critical in order to develop an increasingly seamless service delivery for Aboriginal people and to ameliorate gaps in health care and health status.

¹³ Aboriginal people is a term which refers to First Nations, (Status and non-status Indians) Inuit and Métis people within Canada.

¹⁴ “The 1988 Indian Health Transfer Policy provided a framework for increasing control of health services by First Nations people. It set forth a developmental approach to transfer centred on the concept of self-determination in health.” Through this process, communities who opt to participate in health transfer, are able to take control of health program responsibilities at a pace in line with their community context and health management capabilities. Within the existing funding base of federal health programs for First Nation and Inuit peoples, First Nation and Inuit communities assume responsibility for providing certain mandatory programs such as communicable disease control, environmental and occupational health and safety programs, and treatment services.” Quoted from *Ten years of health transfer First Nations and Inuit control*. Accessible at http://www.hc-sc.gc.ca/fniah-spnia/pubs/finance/_agree-accord/10_years_ans_trans/index-eng.php

2 METHODOLOGICAL APPROACH TO THE FEASIBILITY STUDY

2.1 PURPOSE AND RESEARCH QUESTION OF THE STUDY

The purpose of this study was to explore the feasibility of the role that medical NGOs could play in improving health care in Aboriginal communities in Canada. The research question that guided the study was:

“What is the role of medical NGOs in improving the access of Aboriginal communities to quality and appropriate health care in Canada?”

To answer this question, DI identified the following action areas for this feasibility study:

1. To conduct a review of community health priorities, current service gaps, strengths and opportunities in relation to existing service provision and initiatives by government (including federal, provincial and Aboriginal health authorities), and non-governmental and community actors within First Nations communities. This included a review of documents and literature as well as direct engagement with key stakeholders from First Nations communities, government, and research and medical institutions. As part of the dialogue, ideas were generated around potential niches for medical NGOs in developing and/or contributing to health initiatives and partnerships to advance Aboriginal health.
2. To analyze the findings for shared principles for partnership, engagement and intervention. During the analysis, culturally based principles and values for NGO-First Nation collaboration emerged. These principles and values were then cross referenced with existing models for engagement and intervention in health care that represented a promising fit. The analysis situates promising applicable models in the context of existing political, strategic and regulatory realities. Opportunities for collaboration and leveraging existing initiatives and best practices are also discussed and presented in this report.
3. The need to commit to the principles of participation and meaning collaboration were stressed by participants as key elements of successful partnership between NGOs and Aboriginal communities. All participants and key Dignitas staff members were invited to provide feedback on the draft report with the options of choosing editorial feedback on the draft in writing or during a webinar or in person presentation. The report was the updated accordingly.
4. The final step in the feasibility study was the development of recommendations for next steps specifically tailored for DI in expanding its work into Aboriginal health, in relation to the models of engagement and intervention options identified. The recommendations are presented in a separate document.

The methodology of the feasibility study consisted of a literature review, an electronic survey and telephone interviews with identified key informants.

2.2 LITERATURE REVIEW

A systematic and analytical literature review was undertaken, in order to (1) gain an overview of the major trends in HIV/AIDS, tuberculosis (TB), primary care, and rural health initiatives in remote Aboriginal communities across Canada (and beyond); and (2) identify the various actors involved in developing and implementing Aboriginal health initiatives within these fields and the nature of their engagement.

An online search of electronic scholarly databases and publications of both Aboriginal and non-Aboriginal governmental and non-governmental agencies was undertaken. Full peer-reviewed academic articles were accessed through the University of Toronto library website. A Google search was also carried out to identify relevant grey literature. The literature review is reported in a separate document, however a brief overview is provided below.¹⁵

A total of 128 resources referring to Tuberculosis/Lung Health (TB), HIV/AIDS and other relevant healthcare interventions (primary care, rural health, technology-based) in remote Canadian, Australian, American or New Zealander Aboriginal populations were identified. The initial search criteria uniquely focused on identifying TB and HIV/AIDS interventions, but were later expanded to capture the broader landscape of Aboriginal healthcare initiatives. Exclusion criteria included articles unrelated to Aboriginal populations and TB, HIV/AIDS, primary care or rural and remote health.

Of the total 128 resources identified, 66 resources were located that addressed potential relevant health priorities (HIV/AIDS, TB/lung health, primary care and rural and remote health) and specified health service delivery and interventions. Forty one (41) resources were extracted for inductive analysis based on their classification into one of four categories:

- training healthcare professionals,
- community healthcare workers,
- community health initiatives, or
- health systems and services.

Within each of these categories, interventions were analyzed according to their approach type, implementing actor(s), context, target group(s), scale, evaluation type, and impact. The results were summarized under seven key areas described in Aboriginal Health Interventions: Approaches: 1) task shifting; 2) eHealth; 3) training; 4) tools; 5) information, education and communication; 6) quality improvement; 7) capacity building.

¹⁵ 2013 Stefanie Freel, 2013. Aboriginal Health Feasibility Study. Literature Review Report. On file at Dignitas International.

2.3 STAKEHOLDERS GROUPS ENGAGED IN THE DIALOGUE

An important consideration in the design of the study was the commitment to learn directly from First Nations community stakeholders, health care providers, educators and policy makers. The following stakeholder groups were identified for participation in the consultation process:

1. Aboriginal health authorities and First Nations and Aboriginal health centers;
2. Key informants from First Nations communities;
3. Aboriginal Provincial and Territorial Organizations (PTOs);
4. Primary healthcare professionals (physicians and nurses);
5. Medical researchers and/or academics focusing on rural and northern health;
6. NGOs with successful relationships with First Nations; and
7. Government representatives (including federal and provincial).

Stakeholders were invited to contribute to the feasibility study through key informant interviews and an electronic survey.

Although the majority of the stakeholders identified were based in Ontario, the consultations also included the perspectives and experiences of others who work with Aboriginal communities outside of Ontario.

Key informants and survey respondents were identified through outreach to individuals and organizations known or referred to DI and the consultants, and additional stakeholders were identified through the literature review. Accordingly, consultations should not be perceived as comprehensive or systematic, but rather, as a dialogue to capture a variety of different perspectives. From the perspective of qualitative, interview based research, the study was rigorous and the major themes reached saturation.¹⁶

2.4 KEY STAKEHOLDER INTERVIEW

Key stakeholders interview and electronic survey questions were developed based on the literature review. The interview questions were also informed by the expertise of the consultancy team and refined by the DI staff. Introductory communication documents delineating the nature and rationale for the feasibility study undertaken by DI were sent out by the DI team to selected key informants, inviting them to participate in the interview. Sixteen (16) interviews were conducted (14 by phone and 2 in person) and ranged from 30 to 60 minutes during the months of September and October 2013.

The interviews were analyzed thematically.

¹⁶ Qualitative researchers collect interview data until a point of data saturation is reached. Data saturation occurs when researchers are no longer hearing participants raise new topics during interviews. (Although each of these topics or themes may have regional variations.)

2.5 KEY STAKEHOLDER ELECTRONIC SURVEY

Key informants were requested to send an online survey to additional staff members in their organizations. Additional survey requests were sent to other key informants by DI staff. Survey responses were collected through a web link and analyzed. During the months of September and October 2013, twelve (12) surveys were fully completed and a further thirteen (13) were partially completed, of which 3 were excluded. The survey included ample opportunity for free text responses, which were also thematically analyzed.

2.6 SCOPE OF THE STUDY

Aboriginal people and communities in Canada are very diverse in terms of culture, geography, living conditions and their ability to access health services. There are important differences in the structure and types of health services in Canadian provinces and territories, resulting in varied health care needs and gaps in First Nations people living on and off reserve, Métis and Inuit people. **To reflect all of these perspectives would require a comprehensive national study, which was outside of the scope of the current feasibility study. Instead, the study focused more narrowly on specific prioritized health issues and communities.** First Nations communities in Northern, rural and remote areas face some of the most challenging barriers to health equity and are also subject to the effects of complex and unique cross-jurisdictional barriers stemming from a combination of federal and provincial responsibilities for health on reserve. **This study was therefore focused on the needs of First Nations people living on reserve and particularly in rural and remote areas in Ontario. However, in also seeking contributions from stakeholders residing outside the province, and reviewing interventions from (across) Canada, Australia, New Zealand and the United States, DI hopes that the discussion of findings will have value to other communities.**

Aboriginal people often have concepts of health, mental health and wellness that differ from those held by primary care and mental health providers in mainstream health services. It is therefore critically important to develop strategies to invite extensive and meaningful input from all Aboriginal stakeholders in any project. In this project, First Nations and service provider stakeholders who are knowledgeable about First Nations health and health services in Northern Ontario were the focus for engagement. Some stakeholders had experience with First Nations and/or Aboriginal issues on a national level and in other regions of Canada. In those cases an effort was made to understand how their feedback was applicable in the Ontario context. In addition, these contributions potentially extend the relevance of study findings to communities outside of the province, particularly in relation to good practice in partnership approaches, frameworks and values. While the study was focused on the feasibility of the development of partnerships between health care NGOs with First Nations communities, many of the findings spoke to general principles that apply to NGOs working with Aboriginal people and can therefore inform this type of engagement and partnership development more generally.

2.7 LIMITATIONS

There are several limitations related to this feasibility study:

1. The study focused on chronic illness and infectious diseases, which are areas of specific interest to DI. Some stakeholders expressed health priorities more broadly including wholistic¹⁷ health, mental health and addictions and social determinants of health.
2. Although respondents were drawn from a wide diversity of communities and the health sector, which vary by geographic location, health service landscape, environmental, political, social, historical and cultural factors, it is not possible to broadly generalize about the health priorities of Aboriginal people and communities. Each Aboriginal community is unique and additional efforts are required to understand the unique perspective of each community with which DI and other NGOs may be engaged in the future.
3. Key informant interviews provided rich data on the diversity of community issues as well as common issues. However, they should only be interpreted as a snapshot of perspectives that may be helpful in providing high-level insight into health care related challenges and opportunities, not as an authoritative overview of conditions, priorities or best practices in Aboriginal communities.

¹⁷ A variant spelling of holistic: often used by Aboriginal people to underscore the importance of addressing the whole body or person. Please refer to Annex 1: Glossary of Terms.

3 FINDINGS

In this report we first provide a short summary of the literature review; the full review is described in a separate document.¹⁸ The remainder of this section provides a thematic analysis of participants' responses provided during the interviews and in the electronic survey under the topic headings that were specifically explored with participants:

- Priority Health Issues;
- Priority Gaps and Issues in the Health System;
- First Nations Community Health Strengths;
- Successes in Partnership Approaches; and
- Community and NGO Readiness to Engage in Partnerships.

3.1 HIGHLIGHTS OF THE LITERATURE REVIEW

The majority of documented interventions in Aboriginal populations address primary care issues within the context of community health and health systems and services, by enhancing community awareness and evaluating access to healthcare services. In relation to HIV/AIDS, a number of initiatives focus on disease prevention, cultural training (for healthcare professionals) and building research capacity. Aboriginal health organizations (non-governmental organizations) have also produced a broad range of HIV/AIDS tools designed to guide healthcare workers in developing, implementing and/or integrating various prevention programs in Aboriginal communities. Interventions aimed at enhancing access to tuberculosis treatment and care, remain largely unaddressed.

Recently, the federal government has demonstrated interest in standardizing professional training and practices for Community Health Representatives (CHRs) and other Community Health Workers (CHWs) through its participation in workshops, releasing guidelines for training and certification funding, and by setting the stage for policy development. Some of the literature emphasizes the lack of standardization in CHRs and other CHWs professional functions and highlights the pivotal role held by these individuals in Aboriginal health systems. Though promising, these initiatives and programs have not yet been formally implemented on a large scale. Overall, relatively few studies address the human resource gap characteristic of remote Aboriginal communities. Likewise, relatively few resources exist to train Aboriginal healthcare professionals or build CHR and CHW capacity through continuing education and/or mentorship programs.

Of the identified Aboriginal health interventions, an overwhelming number operate outside the formal health system. This is due to the fact that many initiatives are driven by the academic community and/or Aboriginal health organizations and have not been scaled-up, mandated or

¹⁸ 2013 Stefanie Freel, 2013. Aboriginal Health Feasibility Study. Literature Review Report. On file at Dignitas International.

formally supported by either Aboriginal or non-Aboriginal health authorities. While the majority of Aboriginal health projects focus on establishing prevention and/or education initiatives, government funding largely supports interventions in Aboriginal health systems and services. Federal government units such as the Public Health Agency of Canada and Health Canada as well as the Health Council of Canada¹⁹ mainly provide high-level analyses of the Aboriginal health status across the country in the form of environmental scans or compendiums of best practices. In recent years however, a number of interesting partnerships have emerged between federal/provincial governments, Aboriginal governance authorities, and the academic community and/or Aboriginal health organizations. eHealth appears as a predominant theme in multi-stakeholder partnerships, with initiatives focusing on building health workers' cultural competency using eHealth strategies, enhancing the use of Information and Communication Technologies (ICTs) in Aboriginal health research and service provision, and supporting innovative interventions such as a mobile diabetes clinic in remote Aboriginal communities. It should also be noted that governmental agencies generally tend to play a more secondary role in relation to piloting new approaches to Aboriginal healthcare by providing funding and/or policy direction to Aboriginal health organizations, governance units (tribal councils and health authorities) and/or non-Aboriginal academic institutions.

The academic community mainly develops interventions focused on community health and CHWs through collaborative partnerships with local communities and/or Aboriginal governance leaders. The majority of these projects focus on establishing prevention programs or developing high school curricula designed to enhance awareness of HIV/AIDS and primary care issues. Aboriginal health organizations also tend to operate within the HIV/AIDS and primary care fields, through a focus on training healthcare professionals, enhancing CHW capacity and improving access to culturally sensitive health services. When compared to initiatives addressing primary care and HIV/AIDS issues, documented accounts of governmental interventions in the field of TB are scarcer. As such, there is an ongoing absence of practical interventions designed to improve the prevention, treatment and care of TB in remote Aboriginal communities. In terms of the service continuum, particular gaps exist in the areas of treatment, care and collaborative care, and aftercare.

Findings suggest that across all health priorities – HIV/AIDS, TB, primary care, and rural health – a potential entry point could involve developing innovative interventions designed to overcome the challenges specific to remote Aboriginal communities, through multi-stakeholder partnerships. Other opportunities include establishing initiatives aimed at providing ongoing education and training to healthcare professionals and community workers, exploring the application of ICTs across a range of program areas, evaluating new approaches and innovative programs, and enhancing the cultural appropriateness of Aboriginal health systems and services.

¹⁹ The Health Council of Canada is an independent, non-profit organization which receives funding from Health Canada (<http://www.healthcouncilcanada.ca/content.php?mnu=5>).

3.2 PRIORITY HEALTH ISSUES

For the purpose of this study, health concerns were studied from the perspective of health priority issues for chronic and infectious diseases. However participants did not necessarily make these distinctions in disease categories and saw health and wellness more holistically. Many diseases have acute and chronic sides to them, and these need to be managed together.

3.2.1 Chronic Illnesses

Interview respondents identified the following as the most pressing chronic diseases in First Nations communities:

- Diabetes;
- Cancer;
- Mental health and addictions (alcohol and prescription medications); and
- Heart disease.

Other health priorities included obesity, arthritis, hypertension and dementia. Often patients present with multiple and complex chronic health issues, which may for some, be exacerbated by mental health issues.

The health priorities offered by participants are congruent with the current literature on First Nations health issues in Ontario as well as in Canada at large.

The top health issues in First Nations are closely interrelated for many reasons. Diabetes, heart disease, obesity, mental health and addictions are all strongly influenced by disadvantages in social determinants of health (SDOH) that many First Nations communities experience disproportionately in Northern Ontario and elsewhere. For example disadvantages in SDOH include income, child and maternal health, education, health systems, coping skills and personal health practices, health literacy, social networks and access to health services.

While regional data for Northern Ontario Aboriginal communities is difficult to obtain, the Trillium Foundation analyzed data collected in 2006 and reported the following statistics for Education, Employment and Income for Aboriginal people in major regions of North Eastern Ontario:

“While younger generations are becoming better educated, a large proportion of First Nations people, and in particular people living on-reserve, have no certificate, degree or diploma.

In 2006, the unemployment rate for First Nations people was double that of the [general] population. Aboriginal people in [the same region] are more likely to have part-time or seasonal work than full-time employment.

There is a significant income gap Aboriginal people in [this region] —\$10,000 lower than the average for the general population in [the region].

A high proportion of Aboriginal people in [the region] live below the low-income cut-off.

Especially disadvantaged are the youngest children—38.7% of Aboriginal children under 6 live below the low-income cut-off.”²⁰

Chronic health and mental health issues are not only strongly influenced by the traditional SDOHs, but also the historic legacy of colonialism. The multi-generational impact of historical trauma on Aboriginal people’s health and mental health is well documented. Aboriginal health, mental health and addictions must be understood within the context of the multi-generational impact of social and cultural marginalization and assimilation policies such as the residential school system, because the consequence of these negative processes still impact on Aboriginal families, children and youth today. This multigenerational connection between colonial forces and health, mental health and addictions is supported by a substantial body of literature.²¹

Services to treat mental health and addictions are particularly fragmented and often nonexistent in northern communities. Despite relatively high rates of mental health problems, there is no national Aboriginal mental health strategy in Canada. The few fragmented national services in the area of addictions treatment and mental health promotion are mainly geared towards First Nations people living on reserve. Provincially and federally funded Aboriginal services are currently insufficient to meet the demand for all levels of services including prevention, treatment and rehabilitation.

In addition, provincially funded mainstream services typically lack the capacity for service provision that is culturally safe and meets the complex needs that are often observed.²² Treatment for mental health and addictions is further complicated by social determinants that further exacerbate mental health and addictions and may include:²³ (1) Exposure to racism and marginalization of Aboriginal culture; (2) Extreme poverty and lone parent family structures; (3) Increased exposure to family violence; (4) Aboriginal youth in Canada have among the highest rates of suicide in the world; (5) Although there is still a paucity of good epidemiological data, research does show that Aboriginal youth experience higher rates of mental health disorders, complex and concurrent disorders; (6) Poor access to culturally safe mental health and addictions services; and fragmentation of services due to lack of integration of provincial and federal funding structures.^{24,25}

Given these realities, it is not surprising that complex or dual disorders are found at higher frequencies in First Nations communities. Patients often present with chronic health issues that

²⁰ The Ontario Trillium Foundation: Aboriginal Communities in Profile: Algoma, Cochrane, Manitoulin, Sudbury. The Ontario Trillium Foundation; no date. Accessible at http://otf.ca/en/knowledgeSharingCentre/ab_acms.asp

²¹ Brave Heart MY, De Bruyn LM: The American Indian Holocaust: Healing historical unresolved grief. *Am Indian Alsk Native Ment Health Res* 1998, 8 (2):56-78. Kirmayer LJ, Brass GM, Holton T, Paul K, Simpson C, Tait C: Suicide Among Aboriginal People in Canada. *Aboriginal Healing Foundation*; 2007:1-189. *Healing Traditions: The Mental Health of Aboriginal Peoples in Canada*. Edited by L. J. Kirmayer, G. G. Valaskakis, 2009. Vancouver, UBC Press. Dion Stout M, Kipling G: *Aboriginal People, Resilience and the Residential School Legacy*. Ottawa Aboriginal Healing Foundation; 2003.

²² Maar, M. and M. Shawande. Traditional Anishinabe Healing in a Clinical Setting: The Development of an Aboriginal Interdisciplinary Approach to Community-based Aboriginal Mental Health Care. *Journal of Aboriginal Health*. 2010. Maar, M. , B. Erskine, L. McGregor, M. Sutherland, D. Graham, T. Larose, Marjory Shawande, and T. Gordon. Innovations on a shoestring: A Study of a Collaborative Community-based Aboriginal Mental Health Service Model in Rural Canada. *International. 2009. Journal of Mental Health Systems* 3:27.

²³ Health Canada. *The Human Face of Mental Health and Mental Illness in Canada*. 2006:164-176.

²⁴ First Nations Regional Longitudinal Health Survey (RHS) 2002/03 accessible at [<http://www.rhs-ers.ca/english/pdf/rhs2002-03reports/rhs2002-03-technicalreport-afn.pdf>].

²⁵ The Ontario Trillium Foundation: Aboriginal Communities in Profile: Algoma, Cochrane, Manitoulin, Sudbury. The Ontario Trillium Foundation; no date.

involve health and mental health issues. These patients require careful case management to ensure the illnesses are managed effectively. However specialized services and the capacity for case management are lacking in many communities.

Most importantly, chronic illnesses require long-term, ongoing management and care, and have a large impact on the health system. Many communities are unable to respond to the needs of their patients and patients often do not receive adequate care or services in line with Canadian guidelines for chronic disease management. Chronic diseases therefore progress rapidly for many patients and additional co-morbidities can develop.

3.2.2 Infectious Diseases

Infectious diseases identified as priority health concerns most frequently include:

- TB;
- Sexually transmitted infections;
- HIV/AIDS;
- Hepatitis; and
- Seasonal influenza.

Childhood dental caries (another infectious disease) was described in the more rural and remote areas as a key issue, with a disproportionate number of anesthesia-assisted dental surgeries possibly reflecting less emphasis on early education and prevention. Infectious disease is a serious issue in many communities, however the high rates of chronic illnesses and complexity of chronic disease management tends to overshadow infectious disease in discussions about community health. The type of infectious disease of concern in communities varied more than the fairly consistent identification of chronic diseases. Variations in infectious disease, and the existence of pockets of infectious diseases in different Aboriginal populations, are consistent with the literature on infectious diseases in Aboriginal communities.

3.3 PRIORITY GAPS AND ISSUES IN THE HEALTH SYSTEM

Respondents described the following themes as key system impediments and service gaps as priority areas for intervention:

3.3.1 Lack of Access to Continuing Education for Community Based Staff

3.3.2 Fragmentation of Programs and Services

3.3.3 Lack of Coordination of Referrals and Discharge Transfers

3.3.4 Complex Chronic Health Issues Coupled with Lack of Access to Specialized Services

3.3.5 Lack of Integration of Clinical and Traditional Aboriginal Approaches to Health and Wellness

3.3.1 Lack of Access to Continuing Education for Community Based Staff

High turnover and difficulties in recruitment and retention of health human resources are major issues in rural and remote Aboriginal communities. This is exacerbated by the lack of access to ongoing education and training for health staff working in these settings. Participants noted the following:

“Community based health workers are dependent on the training that might have come along [locally] within their program area. Many community based workers [in our area] are not formally trained and don’t have academic credentials such as diplomas or degrees. There is a limited amount of training for community based workers and there is the issue of travel time and time away from family and financial resources to access it.”

Interview respondent

“There is a lack of training opportunities and there are no funds for training or funds for travel to training. Regional training opportunities are needed yet with high turnover it is hard to establish or build capacity within communities.” *Interview respondent*

In order for the service landscape to improve significantly, a broader set of capacities is needed within communities, as noted by one interview respondent:

“Education is needed to help people better plan at a community level. To take a step back and use a system level lens to identifying needs and to use tools to map out the services that are needed. Training, education, support, consultation is needed at the community level to enable them to do this.” *Interview respondent*

Other training and education needs were described, for example prevention and promotion activities are generally designed to affect change in awareness levels, but few address changing attitudes, behaviors or health policies. A greater focus on training to create sustainable change is needed to prevent chronic health issues downstream.

Client centered care focuses on the experience of the client from his/her perspective, minimizing vulnerability, and maximizing control and respect. Empowering the client improves client satisfaction and outcomes.²⁶ One participant shared the following example:

“Current chronic illness management creates dependency; a new approach is self-care management to help determine where clients want to go with their health and to engage them as partners in their care. This approach minimizes the prescriptive, medical model approach so that instead of giving people instructions, which at times leads to non-compliance, support is given to people and they are engaged in determining where they want to go with their health. Providers can use motivational interviewing to help clients or patients identify their care needs and goals. For example a client goal may be "being able to walk around the block" or "having energy to play with my grandchildren" as opposed to "lower my blood pressure". The patient is encouraged to work with the

²⁶ Registered Nurses Association of Canada guidelines and definition found at: <http://rnao.ca/bpg/guidelines/client-centred-care>

provider to help achieve the goal.” *Interview respondent*

Many health care workers would require **training in patient/client centered care** and strategies to support clients in managing more of their own care. Training such as motivational interviewing and other self-efficacy techniques would be helpful.

Health services management and quality improvement were also identified as training needs, specifically health planning, governance, inter-professional collaboration, conflict resolution, communication skills, and establishing working relationships with mainstream health systems (working styles between First Nations and non-Aboriginal organizations can be quite different and cultural barriers often exist). First Nations health managers need the confidence and skills to build these relationships and maintain them over the long-term.

“Knowledge of good management is an issue and there is a lack of training for managers.” *Interview respondent*

3.3.2 Fragmentation of Programs and Services

A lack of service integration across programs and providers both internally (among health and social service programs on reserve) and externally (between on and off reserve programs) were noted. In particular, respondents spoke of health prevention and promotion programs diffusing efforts across a wide spectrum of activities, which have been developed in response to varying program mandates and priorities:

“The problem is, they seem to be all working in silos in their promotion and prevention activities. There is a need to coordinate and integrate the [health] messages and strategies in order to maximize outcomes.” *Interview respondent*

In some regions there are numerous agencies, organizations and departments involved in health service delivery with little coordination.

“There are multiple providers with all kinds of jurisdictional issues [in our region] for example, the Northeast Local Health Integrated Network, Weeneebayko Area Health Authority, Porcupine Public Health Unit, Federal departments, Public Health Agency of Canada, Health Canada, Aboriginal Affairs and Northern Development Canada, municipalities, and the First Nations communities themselves.” *Interview respondent*

The development of a coordinated approach amongst these diverse programs and jurisdictions would require time and requires specific focus, skills and patience.

“The key is that there is no single program, organization or Aboriginal Health Access Centre that can [deliver services] across the whole continuum of care. We need good partnerships with everyone, schools, hospitals. These are relationships which take time to develop. Often we are all busy doing the same thing, leading to the same results – rather than how to explore working better with hospital boards or schools, for example. We need to develop these relationships and not give up after having gone to just one meeting where we meet with disagreement. We disengage and then we become the

barrier by getting our back up for no reason. We forget the community members that could have benefited from better collaboration and services.” *Interview respondent*

A particular area of need therefore is **collaborative team approaches** as noted by one interview respondent.

“There are many good care providers such as nurses, many good paraprofessionals, [who] need to be more supported to further their skills, especially CHRs, who know the community, need to be mentored to work as an interdisciplinary team.”
Interview respondent

Overall, a lack of quality, access and continuity of care were identified as contributing to prominent gaps in chronic illness services.

3.3.3 Lack of Coordination of Referrals and Discharge Transfers

The provincial health care system is frequently perceived as operating with little knowledge of and collaboration with the on reserve federal health services. In addition, increasingly early discharges from institutional and hospital care to community services are having an impact on First Nations as supportive services are frequently lacking.

“[It is] systemic, there is no case management, no interdisciplinary care, no patient or client centered care [...] In NWT as some [residential school] survivors were sharing their story, one was about a man who had been discharged from Edmonton Hospital and told he could go home [providers meant to a local boarding home]. So he went back to his home community to the elders and bachelors housing and he had had a colostomy. He was in the community for two weeks before the nurse knew he was home. He almost died.” *Interview respondent*

Support for the development of protocols for sustainable discharge planning and referral systems with primary care providers, hospitals off reserve and community-based programs, is urgently needed in many regions. The development of protocols to share patient health information and standardized assessment tools between on and off reserve care providers would be one step towards facilitating shared care planning. For example, a home care assessment tool used by community-based workers could be linked to an electronic medical record (EMR) administrated by a primary care system. This would help to identify needs and develop an appropriate care plan.

In communities with both community-based (band) staff as well as FNIHB managed nursing stations, there is often a lack of integrated planning and service delivery between the community workers, such as Home and Community Care nurses and Community Health Representatives, and nursing station staff. In some instances, it is so severe that no pathways have been developed to share health records or to collectively plan for community health:

“The Homecare program is “band run [i.e. community based]” and...[staff are] not able to link with staff in Nursing Stations effectively. Homecare staff are all separately reporting

to the Health Director, as do the Nursing staff, but with separate charting system. There is no integration.” *Interview respondent*

Respondents described additional “silos” between on and off reserve health care teams:

“A clear gap is in the area of prevention and management, especially lack of integration of services at all levels; regional, provincial and federal. Different prevention programs are all addressing the same issues; a more collaborative approach would likely give a better result than the one-off events. Being more strategic would be better but often there are small silos.” *Interview respondent*

“Chronic disease management has acute care gaps, aligning care planning, discharge planning from hospital as well as management gaps, in terms of community workers as well as primary care gaps.” *Interview respondent*

In the area of public health, there is no coordinated continuum or framework to align services across the various jurisdictions that are implicated.

“Governance issues are a problem in the region as we have the Public Health Unit, Health Canada, and the federal programs all implicated in public health. When they do legal orders in public health, there is no enforcement as they get caught up in provincial and federal jurisdiction issues. The community does not get services. Everyone seems reluctant to enforce anything. [Their attitude is] “*we don’t want to touch it, we have no authority, not our jurisdiction*”... There are multiple providers of public health and health services such as the hospital, the municipality, Health Canada. All have different mandates. There is no alignment and consequently there are massive gaps in services, even around ages which are eligible for services.” *Interview respondent*

These findings were consistent throughout interviews and surveys, which indicated that poor healthcare provider communication and cooperation with Aboriginal communities, as well as the lack of integrated services, was an issue related to this service gap.

It is important to note that a certain level, coordination difficulties are found even in urban health systems where patients are also at risk of sub-optimal coordination between primary care, tertiary care and rehabilitative services providers. Compared to these quality of care issues experienced in urban populations, the lack of integration experienced in First Nations is however much exacerbated by additional health system and health policy factors. The lack of integration of federal and provincial health services results in much more severe health services gaps.

3.3.4 Complex Chronic Health Issues Coupled with Lack of Access to Specialized Services

A content analysis of the top three health care service gaps for chronic illness findings indicated that cultural sensitivity, low availability of healthcare and services and human resources were significant barriers to chronic illness service. Interview respondents consistently described diabetes and resultant complications, cardiovascular disease as well as mental health issues, as some of the more pervasive health issues in the communities. More importantly, they noted

that patients are often presenting with a complex matrix of issues which are all inter-related and often need specialized services, such as dialysis, cancer treatment and other services which are not available within remote or geographically isolated communities. As noted by one interview respondent:

“People have to move [to a city] to access dialysis as they are only supported for three months for travel [from their community] even though this is a lifetime issue to manage. Then they have to find their own accommodation, and it is very difficult for many to move off reserve.” *Interview respondent*

Participants stressed that communities require broader, comprehensive and more wholistic responses to manage chronic health issues in terms of the health services and resources needed.

“Education on chronic illness management and development of a community strategy, self care and pain management is needed; it is hard for people to get out of the community to access training, need more community based presentations, and online training, need the tools to prepare community education materials, others could help to develop these for First Nations.” *Interview respondent*

According to some interview respondents, current chronic illness management approaches often reinforce dependency. New approaches are desired that enhance self-care management and engage clients as partners in their care. Such an approach requires both a shift in thinking as well as training and support for community health workers, collaborative care planning and cultural safety training for off reserve providers.

Access to specialized services via telehealth is another area that requires the development of capacity and health services networks. While First Nations often have access to telehealth technology, access to specialists to provide services via telehealth are often missing. Identification and engagement of specialists who are committed to culturally safe care in First Nations is urgently needed.

3.3.5 Lack of Integration of Clinical and Traditional Aboriginal Approaches to Health & Wellness

As noted earlier, many of the health issues and presenting concerns within communities are nested in a complex matrix of inter-related issues such as historical trauma and the social determinants of health. Accordingly, community based responses must be devised to address this complex set of issues. Additionally, “silo” approaches should be recognized as being at odds with a wholistic Aboriginal understanding of health. Often Aboriginal patients are presenting with a range of health issues, which are inter-related and cannot be discretely isolated or addressed by a single program or service. One interview respondent advised:

“Pilot projects should explore how to improve the system to address chronic illnesses – all of them – it can’t be an approach isolated to just one. It should be wholistic as the risk factors and processes for intervention, prevention and management are similar.”

Interview respondent

Many respondents suggest that traditional health or medicine (TH/M) could play a role in understanding and improving community health issues by placing health problems within a culturally relevant framework inclusive of wholistic Aboriginal approaches to health.

External partner's roles in supporting traditional approaches to health and wellness must be carefully negotiated and defined within each community. Aboriginal communities and people within Aboriginal communities vary in their interest in offering traditional Aboriginal health services within the clinical setting.

It is important also to acknowledge that external partner's support for a traditional wholistic understanding of health may be more important than the actual provision of access to traditional medicine in the clinical setting.

3.4 FIRST NATIONS COMMUNITY HEALTH STRENGTHS

Despite many gaps, participants also noted important strengths within First Nations that could support community health. These are important to consider in partnership development between First Nations and NGOs as well as in the design of interventions. A analysis of participants' responses are provided under two thematic headings:

3.4.1 Community and cultural revitalizations

3.4.2 Strengths in Leadership and Governance

3.4.1 Community and Cultural Revitalizations

A number of communities have sought to integrate community and cultural strengths in their health promotion and prevention activities, mental wellness approaches and other health services. Respondents suggested many Aboriginal community strengths can help to address healthcare service gaps. For example, tight knit families and social networks represent important strengths in social capital and lead to strong community commitment to improving community health and services. Cultural strengths, including traditional knowledge, wholistic approaches to health and strong ties to the land, should also be leveraged. Respondents felt that community health outcomes could be improved by integrating TH/M and Western medical practices.

“We really would like to do more strategic alignment between traditional healing and the medical model. For example, our Traditional Healing program has been in operation for 5 years. In the beginning we had 600 client contacts for year one - now we see over 6000 contacts per year. There is a huge interest in traditional approaches to health and healing which includes the spectrum of prevention right through to aftercare and end-of-life. *Survey respondent*”

An important distinction however, is that there is a strong emphasis on having the traditional cultural approaches “interweave” with western approaches, rather than run in parallel. As noted by one interview respondent:

“We don’t want the systems to run parallel but rather have them interweave and support one another.” *Interview respondent*

Respondents generally felt that community health outcomes could be improved by integrating TH/M and Western medical practices. Further, while communities have begun embracing the development and integration of traditional cultural approaches, these efforts have been largely undertaken within the context of existing resources and with little formal support. As noted by one interview respondent:

“[in our area] there is no formal process to integrate traditional approaches into western approaches; it is up to each community to do this within the resources they have, it is all piece meal as there is no real push to integrate through a partnership or strategy.”

Nonetheless, ensuring culturally appropriate services and care are available within communities represents an important emerging avenue to explore. The processes involved in integrating western and traditional approaches for mental health services delivery in Ontario First Nations communities is described in several articles.²⁷ “This initiative provides a good example of best practices aimed at strengthening Aboriginal health systems, building health worker capacity and enhancing access to care, which resulted in positive outcomes for both patients and providers.”²⁸

Documented promising approaches and fundamental key steps are identified as follows:

- Development of traditional healing protocols;
- Inter-professional education for healthcare providers and community members;
- Emphasis on facilitating client access to traditional health services;²⁹ and
- Collaborative inter-professional models of care involving traditional and clinical providers.³⁰

Another interesting program, described in the literature is entitled the Traditional Healing, Medicines, Foods, and Services (THMFS) initiative at the Sioux Lookout Health Centre (SLMHC). The project “was developed through consultations with community members, 50 Elders, and First Nations chiefs, political and spiritual leaders.”³¹ Through its focus on the physical, emotional, mental and spiritual aspects of health, the THMFS program represents a wholistic approach to care and includes Aboriginal language interpreters available 24 hours a

²⁷ 2010. Maar, M.A., Shawande, M. Traditional Anishinabe Healing in a Clinical Setting: The Development of an Aboriginal Interdisciplinary Approach to Community-based Aboriginal Mental Health Care. *Journal of Aboriginal Health*. Accessible at http://www.naho.ca/jah/english/jah06_01/v6_l1_Traditional_Anishinabe_Healing.pdf

²⁸ Maar, M.A., Shawande, M. (2010). *Ibid*.

²⁹ Maar, M.A., Shawande, M. (2010). *Ibid*.

³⁰ 2009 Maar, M., B. Erskine, L. McGregor, M. Sutherland, D. Graham, T. Larose, Marjory Shawande, and T. Gordon. Innovations on a shoestring: A Study of a Collaborative Community-based Aboriginal Mental Health Service Model in Rural Canada. *International Journal of Mental Health Systems* 3:27. Available from: www.ijmhs.com .

³¹ Walker, R. Cromarthy, H., Linkewich, B., Semple, D., St. Pierre-Hansen, N., Kelly, L. (2010).

day, access to traditional foods, patient escorts, and access to traditional healers and medicines.³² As an integrative program, THMFS permeates a number of health services offered at SLMHC and provides patients and healthcare providers with an alternative to conventional clinical practices.

These two examples depict ways in which community health programs and services can incorporate traditional approaches and cultural strengths to improve the quality and appropriateness of health services. These examples also show that high levels of support and advocacy are needed including training of both traditional and clinical providers in order to provide quality care as an inter-professional team.

3.4.2 Strengths in Leadership and Governance

Interview respondents shared their view that while there may be turnover in health administration, management and leadership in some communities, there are also many communities with longstanding, experienced and insightful leadership, and this is a critical success factor for effective health delivery in these communities.

“[health management experience] varies by each community – some have health directors who have many years of experience and have built capacity within their health services while others struggle with turnover in key positions.” *Interview respondent*

“Leadership in communities can be a strength. It is the key to having good community services and programs which would support good health outcomes. It makes a difference. Consistent good leadership is a strength.” *Interview respondent*

Moreover, First Nations leaders can provide important guidance, advocacy and advice in support of health planning and strategies.

“The Chiefs in our area participate on the Chiefs Committee on Health which was established to help move forward and implement the Anishnaabe Health Plan. We support and provide secretariat services to get their input as they guide our work in the Anishnaabe Health Plan.” *Interview respondent*

As noted by respondents, it is critically important to recognize and leverage the political will to improve community health and established Aboriginal governance structures that facilitate community engagement. In fact, particular attention to communications and decision-making protocols amongst Aboriginal and Band health authorities, as well as Chief and Band Councils and Tribal Councils, and the role of such Aboriginal governance entities in community health activities and partnership development with NGOs, is strongly advised. Accordingly, it is very important for NGO partners to learn about First Nations governance bodies and protocols for engagement in order to build viable collaborations.

³² Walker, R. Cromarthy, H., Linkewich, B., Semple, D., St. Pierre-Hansen, N., Kelly, L. (2010).

3.5 RECENT SUCCESSES IN PARTNERSHIP DEVELOPMENT

Participants reported many examples of successful programs that were developed in partnership with various organizations.

3.5.1 Examples of Successful NGO/First Nations Partnerships

A number of First Nations community/ NGO partnership projects were described in the interviews including:

- St. Elizabeth Healthcare collaborated on the development of ICT platforms to provide online training for community health workers and has completed numerous other projects centred around a community development approach;
- Quality improvement initiative of health services linked to an accreditation process;
- Development of a public health framework through collaborative partnership planning;
- Heart and Stroke Foundation partnership project focused on improving hypertension management in First Nations on Manitoulin Island;
- Northeast Aboriginal FASD Education Partnership Project (NEAP) collaboration agreement involving Health Sciences North, Noojmowin Teg Health Centre, Union of Ontario Indians, Shkagamik Kwe Health Centre and the North Shore Tribal Council. Services include an FASD diagnostic clinic, an accredited FASD certificate program designed for community health workers and a program coordinator.
- An initiative to improve cancer screening rates in Aboriginal under/never screened populations in Northeastern Ontario; and
- Ultimate Frisbee - Smoking prevention and tobacco education for youth in M'Chigeeng First Nation.

Other pilot projects and emerging innovative examples were also identified in our literature review. Of the 41 articles selected for review, some twenty examples of projects are described.

Respondents to the electronic survey also described interesting initiatives including:

Yellowknife Health Care Centre's "comprehensive healthcare program for diabetes care, which incorporates dietary, physical exercise and medical components. The program is provided at the **primary health level** and is **multi-disciplinary** in nature. It positions both medical specialist and local and Aboriginal healthcare providers at its centre in hopes of improving the quality and cultural relevance of care for remote communities."

A similar **wholistic initiative**, conjointly implemented by Saint Elizabeth and the Grand Council Treaty 3, integrates concepts of food sovereignty and nutrition in the prevention of chronic diseases.

Saint Elizabeth has also implemented a **patient wait time guarantee framework** for the prevention, treatment and care of diabetic foot ulcers in partnership with the Assembly of

Manitoba Chiefs. This initiative was developed in response to the disproportionate level of amputations amongst First Nations people living with diabetes in Manitoba.”³³

According to the findings from the electronic survey, these and other examples of existing small-scale community health initiatives revealed the success of comprehensive healthcare programs conducted at the primary healthcare level and implemented by multi-disciplinary health teams. Wholistic initiatives created and carried out in partnership with Aboriginal communities and/or Band Council members, designed to address specific community needs and empower local decision-making, also provide useful models.

Other projects, including those which focused hypertension, diabetes, HIV/AIDS, sexual health, safe houses for youth and women, and emergency wilderness medicine, were also shared by the electronic survey respondents.

Another example described by an interview respondent involves a creative approach to addressing human resource recruitment challenges in remote, northern regions.

“Our Aging at Home (AAH) Program granted us the opportunity to develop a more flexible HR model to work with. In the beginning, we had difficulty recruiting a Facilitator to oversee the program at the community-level. In order to address this issue, we broke down some of our project work into smaller pieces so that we can hire consultants to work with us as we continued to look for a full-time person. Consultants worked with us on the design of an exercise video for seniors within our region as well as the creation of educational resource materials. While we worked with the consultants on the tools we were able to hire someone full-time. This individual was then able to hit the ground running because a lot of resources were in place. We were fortunate the NELHIN was willing to work with us in order to address our recruitment challenges.” *Interview respondent*

One example of an approach to overcoming jurisdictional impediments in planning and delivering health services is the Trilateral First Nations Senior Officials Committee:

“The Trilateral First Nations Senior Officials Committee is one group that tries to interact and coordinate to fill gaps. I believe there is some movement towards addressing jurisdictional barriers, realigning resources and better coordination to address gaps. There is also some movement by the province to try to involve First Nations, for example in the area of health promotion. The process is slow however, as with all political processes, but they want to work with First Nations as full partners regardless of the perception that this is a federal responsibility. A lot of services are accessed outside the community, which is a big issue for Northern and isolated communities. Additionally, there are a lot of people who are living off reserve.” *Interview respondent*

³³ Dignitas International, Aboriginal Health Feasibility Study, Electronic Survey Report prepared by Stefanie Freil, on file at Dignitas International

3.5.2 Successful First Nations Lead Initiatives

Exercising leadership and formulating effective governance to guide health services and program development represents another example of a particular strength in First Nations.

Sioux Lookout's Anishnaabe Health Plan, and the process which was undertaken to develop it, is an example of cohesive long-term health planning that can lead to improved outcomes in the First Nations being serviced.

“When we worked on the Anishnaabe Health Plan – supported a partnership we could foster with communities – we established some working relationships with health directors of First Nations, Tribal Council health directors, medical community, different partners – having them involved in the planning, giving them an opportunity to participate in the planning, give feedback and ideas.” *Interview Respondent*

This is a critical success factor for effective project development. The importance of local ownership of projects was a recurrent theme in the electronic survey findings.

In fact, as described in these findings, community involvement and ownership of health initiatives was highlighted as one of the most crucial elements to a successful partnership project in Aboriginal communities.

3.6 COMMUNITY AND NGO READINESS TO ENGAGE IN PARTNERSHIPS

Interview respondents were quite receptive and optimistic in expressing the view that there would be interest either from their own organizations, or from communities themselves and other health service entities in these communities, to partner on potential projects with NGOs. In addition, there were several organizations who are at the early stages of embarking on the development of more formal research agendas.

“Yes there is interest, there is mandate from the Grand Chief to do outreach to NGOs.”
Interview respondent

“There is interest at all levels; at tribal council levels and community and at our PTO.”
Interview respondent

“There is a chiefs' resolution to develop a research institute. We are beginning to explore if there is anyone who wants to do this partnership.” *Interview respondent*

“Just now establishing a research unit with [the Health Centre] where we are co-funding a physician and a unit that would pursue partnerships with other organizations and establish relationships with partners like Dignitas.” *Interview respondent*

NGO readiness on the other hand requires training and ongoing education of NGO staff on Aboriginal health issues, culture and partnership development. DI's feasibility study is an important step towards achieving NGO readiness at DI and other NGOs.

4 FIRST NATIONS SUPPORTED APPROACHES AND VALUES RELATED TO NGO COLLABORATION

Participants stressed that approaches to First Nations-NGO collaboration will require culturally safe approaches and build on values that are acceptable in First Nations. In this section we describe promising approaches and core values that emerged from interviews and survey responses as part of the thematic analysis.

4.1 PROMISING APPROACHES

Promising approaches included the discussion of practical strategies to further leverage the benefits of NGO activities.

4.1.1 Build on Existing Networks and Systems

Any new endeavor will “need partnerships to move forward” and should work with and leverage existing organizational capacity or infrastructure. Potential partners such as First Nations health authorities, provincial/territorial organizations (PTOs) (eg.: Nishnawbe Aski Nation, Union of Ontario Indians), the Northern Ontario School of Medicine (NOSM), and other local agencies such as Aboriginal Health Access Centres and First Nations Health Centres can support credibility and build upon relationships which are already established. Reaching out to engage partners is an important element within a well-conceived community development approach.

“So many health problems boil down to the need for good community development. We cannot move any of these issues along until we have good community development and reach out to good partners.” *Interview respondent*

As one respondent succinctly stated:

“In our area it is best to go with the Health Authority when health is involved - we have a program and services mandate vs. a political mandate. In addition, there is an infrastructure to support community engagement – for example, our board is made up of representatives from each of our communities that we serve and these individuals are appointed by their Chiefs and Council. They in turn deliver the key messages back to their leadership.” *Interview respondent*

4.1.2 Learn from Local Success Stories

Other organizations, such as NOSM, have developed formal long-standing partnerships with First Nations in Northern Ontario. NGOs could learn how these relationships have been maintained and how these existing partnerships could be leveraged or expanded to include NGO mandates, as it is important that projects that are built upon existing capacities, resources,

infrastructure, processes and mechanisms. In particular, projects that make the most sense are about “helping communities to look at what they have and look at how this can be utilized in the best possible way, help to strategize to work with the assets.” *Interview respondent*

Other projects have also been successful by focusing on the development of strong partnerships and closer integration and collaboration. An interview respondent shared the following example:

“The Aboriginal Health Access Centres (AHACs) are excellent examples of partnerships, for example, [the Tribal Council] works with discharge planning with hospitals, in partnership with Community Care Access Centre. AHACs realize they are not an island, they are not everything to their patients [and] they bring other organizations into integration of the services.” *Interview respondent*

Other examples of success have already been described in the *Findings* section of this report (3.4 1. Recent successes in partnership development) that also apply to this section.

Another example of a partnership approach to program development described in the literature review involves the National Indian and Inuit Health Representatives Organization (NIICHO). They have proposed “a model designed to overcome both the fragmented characteristic of Aboriginal healthcare and the duplication of labour amongst Aboriginal health and wellness workers – resulting from the existing overlap in professional functions.”³⁴ The model proposes a core competency training, which would cover a number of areas - including public health care, community relations, cultural competence, disease prevention and health promotion, emergency care and ethics - with subsequent options for treatment specialization. The framework was developed through an innovative collaboration process involving 30 multi-disciplinary stakeholder organizations including Aboriginal non-governmental organizations, federal public health agency representatives, national and local policy leaders, and Aboriginal governance representatives.”³⁵ It represents a promising system and capacity building endeavor to built upon extensive collaboration and work with stakeholders and grassroots community organizations.

4.2 PROMISING CORE VALUES

Various **values and philosophical approaches** emerged during the engagement process that participants identified as values that should provide a basis for successful partnerships. They are described below.

³⁴ Hammond, M. & Collins, R. (2007).

³⁵ Hammond, M. & Collins, R. (2007).

4.2.1 Commitment to Support Community Leadership in Identification of Their Needs

Although a number of key health concerns were expressed as potential priorities such as diabetes, mental health and cancer screening and prevention, interview respondents were quick to note that in any potential project the community partner should always take the lead in identifying the needs.

“[NGOs] need to engage [each of] the communities themselves to determine what these priorities are. Even though we can probably guess them as workers or providers, BUT in the true spirit of a collaborative approach, it is important that they determine and have a final say in what their priorities are.” *Interview respondent*

True participatory approaches mean respectful engagement that allows the community to lead and set the priorities and pace in the project’s development.

“Good collaboration needs to involve First Nations right from the start, involving the leadership, community health representatives, elders, a strategic group, need representation from the people they are working with....” *Interview respondent*

4.2.2 Demonstrate Respect for Culture and Community Autonomy

When asked about how meaningful collaboration should be undertaken, participants in the interviews noted that:

[the NGO partner] “would need to learn about the culture, traditional beliefs, history and wellbeing in the community.”

Moreover, while there are certainly indications that projects in partnership with an NGO would be of interest, there is also a strong sentiment concerning ownership and control of both the project and any outcomes to rest with the community.

“I think, it would be about listening and finding out what the NGO is able to offer and what control the community can keep; control of information will need to be safeguarded in a positive way.” *Interview respondent*

4.2.3 Build On and Support Community Knowledge

A rich repository of knowledge and potential solutions exist within communities. This community knowledge is not necessarily based on Western epistemologies or acquired in traditional school or academic settings. Instead it is based on Indigenous epistemologies such as people’s lived experience, Indigenous Knowledge and oral traditions. Projects should seek to uncover, respect and build upon this knowledge base in a culturally appropriate manner. As an example, one interview respondent described their experience in seeking community knowledge into a project as follows:

“In this project we held three community gatherings including one with their traditional healer advisory group. When we asked each community to describe what was the most significant change from their work, each community had a different story and were respected for that. Community development means recognizing and respecting where each community is at.” *Interview respondent*

“The Wait Times report is another example, where we talked with 8 pilot communities. They all shared that this was the first time anyone had asked them for their ideas and their solutions. The report itself contains a model that made sense based on community recommendations.” *Interview respondent*

4.2.4 Establishing Trust and Track Record

Some of the most critical issues in working with First Nations communities are building trust, developing relationships and establishing a track record of working with communities, according to interview respondents. As expressed by one respondent, it is important to:

“Make sure that you ‘Walk the talk’; do what you say you are going to do and honor commitments.” *Respondent*

It is equally important to “start small” with well defined activities that are set up for success. In particular:

“It is generally better to be focused when carrying out these initiatives [focused on a specific disease/health priority].... choosing 2-3 things [to respond to] and to do them well.” *Interview respondent*

In line with the community development approach as expressed earlier, projects should “start in the communities and work up from the ground” in order to grow trust and a track record.

4.2.5 Transparency

Another important principle to observe is to ensure that any actions or activities are undertaken in a respectful and transparent fashion and have observed appropriate communications protocols with community leadership, health authorities and political bodies. An interview respondent suggested the following approach:

“Be respectful, don’t make it a surprise when you contact communities; come in through the front door, not the back door; Make sure you have introduced yourself to [...] the PTO.” *Interview respondent*

This view was echoed by other respondents. Another suggested that “transparency of activities and mandate” is an important criteria for a successful partnership.

4.2.6 Advocacy

Numerous interview respondents described the level of inequities in services and the gap between accessible services versus the critical needs expressed by the community. The general consensus was that the First Nations health system was never designed for, and has never been able to keep pace with, the complex and critical needs of the communities it purports to serve. The various critical levels of government have not collaborated to systematically address First Nations health. It would be important for any NGO partner to be mindful of this inertia that First Nations have experienced in their dealings with provincial ministries and federal departments. An NGO would ideally serve as an advocate in whatever capacity it can.

“Advocacy is needed – First Nations feel they are on their own – and no one realizes or recognizes their issues. NGOs may be helpful in this regard.” *Interview respondent*

“An NGO can help with political lobbying to advocate for services, help to get the attention of the government.” *Interview respondent*

This notion was identified as important by many respondents:

“The most important elements in a successful partnership between Aboriginal communities and an NGO were community involvement in and ownership of health initiatives and program/research goals, good communication and an ability to facilitate dialogue between concerned stakeholders, respectful collaboration and the formation of strong partnerships, relationship and trust building, respect for Aboriginal culture and an ability to listen, and a will to empower local communities and/or advocate on their behalf.” *Interview respondent*

5 PROMISING FRAMEWORKS AND MODELS

Based on our review of the literature, key informant interviews and electronic surveys, several frameworks and models were identified as representing promising approaches to health care improvements through partnerships between First Nations and NGOs. It is always important that these models are adapted to the specific First Nations needs and values. They are described in this section along with further examples from interviews and surveys in support of the model and approach.

5.1 EXPANDED CHRONIC DISEASE MODEL

Increasing incidence of chronic diseases, such as diabetes, was identified as a key health concern amongst all respondents. Often patients who are presenting with a chronic illness may also be affected inter-related co-morbidities, which are mired in a complex set of factors and social determinants of health that cannot be discretely isolated and addressed.

Compartmentalized or “silo” approaches are viewed as being at odds with a wholistic understanding of health. As noted by interview respondents:

“Social determinants and lack of access to care, affordable housing, lower access to education, food security, high unemployment rates, ties into all the other issues, and high rates of disabilities related to other chronic issues...” *Interview respondent*

“Pilot projects should explore how to improve the system to address chronic illnesses – all of them – It can’t be an approach isolated to just one. It should be wholistic as the risk factors and processes for intervention, prevention and management are similar.”
Interview respondent

The Chronic Care Model (CCM)³⁶ is a framework to align health services to more effectively care for individuals with chronic disease. Through multi-pronged approaches, CCM assists practitioners to improve clinical and functional outcomes for patients through both proactive practice teams and more informed, active patients. However, this model emphasizes clinical aspects of care and therefore lacks engagement of First Nations community health care system and workers.

The Expanded Chronic Care Model takes the CCM’s clinical approach a step further through the inclusion of health systems interactions and relationships amongst multiple actors including community members, other healthcare professionals, organizations, partners and community groups.³⁷ It combines population health promotion with the social determinants of health and community participation to improve chronic illness care. For example, interdisciplinary teams may identify and work with community supports and strengths to deal with a client’s health

³⁶ Wagner E., H., C. Davis, J. Schaefer, M. Von Korff, and B. Austin, 1999. “A survey of Leading Chronic Disease Management Programs: Are they consistent with literature?” *Managed Care Quarterly*, 7(3): 56-66.

³⁷ Barr VJ, Robinson S, Marin-Link B, Underhill L, Dotts A, Ravensdale D, Salivaras S. The Expanded Chronic Care Model: an integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hosp Q*. 2003;7(1):73-82.

concern by addressing root causes and barriers to positive health improvements. Using knowledge of these barriers, the team can support the community in addressing the issues such as food security, social isolation or transportation. By working from both prevention and treatment ends, this integrated interdisciplinary chronic care model perhaps provides the best of both worlds to combat the increasing burden of chronic disease.

This is congruent with Aboriginal concepts of health. Aboriginal people embrace the concept of wholistic health that views health as including not only physical wellbeing, but mental, emotional and spiritual wellbeing. Moreover, individual health is nested in the context of the collective wellbeing of the community or nation. Poor health, on the other hand, has to be understood in the context of a full range of social determinants of health such as socioeconomic circumstances, poverty, and poor housing as well as those determinants related to the colonial history including community violence and multi-generational effects.

“High rates of heart disease and high blood pressure with people affected by stroke, younger people having stroke... obesity is a huge contributing factor. People can’t afford good nutrition especially in remote communities, more difficult in isolated communities and reliant on food flown in.” *Interview respondent*

“TB is still a concern due to factors such as housing, older [people] more compromised as they may also have diabetes. [There is a] reactivation of TB due to poverty, overcrowding, poor water, poor nutrition - all contribute.” *Interview respondent*

“Social determinants and lack of access to care, affordable housing, lower access to education, food security, high unemployment rates, ties into all the other issues, and high rates of disabilities related to other chronic issues....” *Interview respondent*

Respondents highlighted that for infectious diseases, the social determinants of health such as lack of safe drinking water, education and high poverty rates, and the low availability of health information, are clearly significant health issues. Similarly, this also applies to chronic illness in which disadvantages in the social determinants of health (e.g. housing, income, education, social isolation) and cultural barriers to care represent particularly significant hurdles to accessing health services for chronic illness. The importance of addressing the social determinants of health, and integrating cultural safety into prospective community health interventions, was stressed throughout the feasibility research.

5.2 OCAP IN RESEARCH AND EVALUATION

The word ‘research’ has been associated with negative feelings and suspicion among Aboriginal people, who generally feel over-studied, measured, classified, and counted by externally-based researchers.³⁸ Research has also produced data that describe a magnitude of health disparities

³⁸ Smylie J, Kaplan-Myrth N, Tait C, Martin CM, Chartrand L, Hogg W, Tugwell P, Valaskakis G, Macaulay AC. 2004. Health sciences research and aboriginal communities: Pathway or pitfall? *J Obstet Gynaecol Can* 2004 Mar 26: 211-6.
Castellano MB. 2004. Ethics of aboriginal research. *J Aborig Health* 1:98-114.

and social problems that affect Aboriginal communities. However, workable solutions are rarely addressed. Furthermore, there are abundant examples of poorly designed, non-collaborative health research conducted in Aboriginal communities. The shortcomings of past research have led to extreme research fatigue in many Aboriginal communities, which often viewed government and academic research as an extension of mainstream colonialism and a contributor to ill health in their communities.

This history of research must inform the development of data collection and evaluation of health interventions. To ensure a positive research relationship with Aboriginal communities involved in intervention projects a Participatory Action Research (PAR) approach, based on respectful and meaningful collaboration, is required.

Interview respondents were asked if their community or organization would support the study, evaluation and documentation of promising health initiatives if a partnership project were to be undertaken in their community or organization. OCAP principles were identified as important for NGOs to understand and observe by many participants. As noted by one key informant:

“Any project would definitely need some First Nations ownership and control over these studies. It is in the approach and true partnership!” *Interview respondent*

Principles of ownership, control, access and possession of research and data (OCAP) set out how First Nations people wish to take responsibility for research and data collection processes in their communities as well as their desire to decide how their information is used. The right of First Nations communities to own, control, access and possess information about their peoples is intimately linked with principles of self-determination. The principles as described by the First Nations Information Governance Centre are stated as follows:³⁹

“Ownership: Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Control: The principle of control affirms that First Nations, their communities and representative bodies are within their rights in seeking to have control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information etc.

Access: First Nations must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal

Ten Fingers K. 2005. Rejecting, revitalizing, and reclaiming. First Nations work to set the directions of research and policy development. *CJPH* 96:S60-S63.

Prior D. 2007. Decolonising research: a shift toward reconciliation. *Nursing Inquiry* 14:162-168.

Bailey J, Veitch C, Crossland L, Preston R. 2006. Developing research capacity building for Aboriginal and Torres Strait Islander Health Workers in health service settings. *Rural Remote Health* 6:556 (online).

³⁹ As stated by the First Nations Information Governance Centre; found at: <http://rhs-ers.ca/node/2>

protocols.

Possession: While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete. It refers to the physical control of data. Possession is a mechanism by which ownership can be asserted and protected.”

As such, details of the methodology and in particular data collection, storage and access should be negotiated through a process of collaboration. NGOs should work with a community-based Project Steering Committee on all aspects of research design, methodology, research instruments and analysis of findings. The Project’s Steering Committee can also provide ongoing direction and guidance for projects with NGOs.

Participants shared the view that partnership projects with NGOs would be supported if OCAP principles were observed.

“There is a lot of mistrust still from the past; there have been many studies etc. and no good outcome, so they wonder: what is the value? Any project would definitely need some FN ownership and control over these studies. It is in the approach and true partnership!” *Interview respondent*

“Yes I think so, it would be about listening and finding out what the NGO is able to offer and what control the community can keep. The control of information will need to be safeguarded in a positive way.” *Interview respondent*

“[research is supported] as long as it respects OCAP and communities interests.”
Interview respondent

The specific application of OCAP may vary and should be discussed and put in writing prior to research and evaluation on any NGO-partnered programs. Some regions such as Manitoulin support community-based First Nations research ethics committees with existing processes, which are valuable resources for NGOs to learn about First Nations perspectives on research.⁴⁰

⁴¹

The literature review identified that the Canadian Aboriginal AIDS Network (CAAN) incorporates capacity building in its research initiatives by involving Aboriginal communities, Aboriginal persons living with HIV/AIDS (APHAs), and representatives of regional Aboriginal AIDS Service Organizations (AASOs).⁴²

⁴⁰ Guidelines for Ethical Aboriginal Research (GEAR), accessible at <http://www.noojmowin-teg.ca/SitePages/MARRC.aspx>

⁴¹ 2007 Maar, M., M. Sutherland and L. McGregor. A Regional Model for Ethical Engagement: The First Nations Research Ethics Committee on Manitoulin Island. In *Aboriginal Policy Research. Moving Forward, Making a Difference. Volume IV*. Edited by J. P. White, S. Wingert, D. Beavon and P. Maxim. Thompson Education Publishing: Toronto.

⁴² Masching, R., Archibald, L. & Jackson, R. (2006). Capacity Building as a Component of Aboriginal Community-based HIV/AIDS Research. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 2, 5-17.

5.3 SOCIAL ACCOUNTABILITY

In 1995, the World Health Organization (WHO) reported on the increasing societal demand for accountability in the health sector to demonstrate that investments lead to improved health care and health status in society⁴³. In medical education, social accountability was described as based in collaboration across multiple sectors and with the community stakeholders they serve.

The WHO defined social accountability specifically for medical schools as follows: “The obligation of medical schools to direct education, research and service activities towards addressing the priority health concerns of the community, region or nation that they are mandated to serve. The priority health concerns are to be identified jointly by governments, health care organizations, health professionals and the public.”

Further, the WHO described that education which exposes students to the needs of underserved, low income populations and ethnic minorities will increase students’ sensitivity to these groups and their needs, and will, through various pathways, eventually lead to improvements in health equity.

The global consensus statement for social accountability in medical schools was developed in 2012 using a Delphi process involving 130 people and individuals. It identifies key challenges for medical education as:

- improving quality;
- equity;
- relevance and effectiveness in health care delivery;
- reducing the mismatch with societal priorities;
- redefining roles of health professionals;
- and providing evidence of the impact on people’s health status.⁴⁴

Health Canada adapted the WHO definition of social accountability and affirmed the notion of medical schools’ responsibility to learn about, serve and advocate for the needs of the community.⁴⁵

Based on the findings in this research, the concept of social accountability is an excellent framework to guide activities undertaken by NGOs in partnership with First Nations to improve health. It is a concept that has been successfully utilized by NOSM as the foundation for its partnership development with First Nations and Métis communities.

⁴³ 1995. Boelen C, Heck JE. Defining and measuring the social accountability of medical schools. Geneva: World Health Organization; 1995. Available at: http://whqlibdoc.who.int/hq/1995/WHO_HRH_95.7.pdf

⁴⁴ 2010. Global Consensus for Social Accountability of Medical Schools <http://healthsocialaccountability.sites.olt.ubc.ca/files/2011/06/11-06-07-GCSA-English-pdf-style.pdf>

⁴⁵ Health Canada. Social Accountability. A Vision for Canadian Medical Schools. Health Canada. 2001. Available at: http://www.afmc.ca/pdf/pdf_sa_vision_canadian_medical_schools_en.pdf.

5.4 CULTURAL SAFETY

Health inequities are a reflection of inequalities in the social determinants of health and exacerbated by limited access to culturally safe care. The importance of the role of culture in facilitating or impeding access to health care for Aboriginal people has been increasingly recognized.⁴⁶ In 1994, the province of Ontario developed an Aboriginal Health Policy in consultation with Aboriginal people, emphasizing the need to involve Aboriginal people in health care planning and to acknowledge and design health care that includes Aboriginal concepts of health. In Ontario, this has been an important step towards the recognition of the importance of cultural competence and cultural safety in health care.

The concept of **cultural safety** originates with the Indigenous people of New Zealand and has gained increasing recognition in health care with Indigenous people internationally. It has recently been used as the basis for a report by the Health Council of Canada.⁴⁷ Cultural safety is based on an understanding of the power differentials that may exist between providers and clients in health service delivery. It focuses on the skills, knowledge, and attitudes of practitioners including self-reflection and the role of the patient in defining safe health services. Perhaps the most important aspect of cultural safety is that it is based on the perspective of the client patient or community. Cultural safety and cultural competency are increasingly recognized as important aspects of improving health services for Aboriginal people. Research on how to teach these concepts effectively to health care providers is still developing, however cultural safety must be an integral part of any health intervention in First Nations.

Cultural safety was a concept that was raised by participants who often identified the lack of cultural safety as a particular health service gap in chronic illness. Cultural barriers to care represented particularly significant hurdles to accessing health services for chronic illness. In relation to infectious diseases service impediments, gaps in cultural sensitivity included low cultural safety, local ownership, and community involvement in care as well as few available integrated health services (traditional practices and Western medicine).

Other respondents saw lack of cultural safety in (1) poor local ownership of health services, (2) insufficient communication between healthcare providers and patients on healthcare access as well as (3) attempts to apply a 'one size fits all' model to health systems design and services across highly culturally diverse Aboriginal communities.

Cultural safety is a concept that should not only be applied in the development of projects by NGOs, but a project could also focus on increasing cultural safety in the health system.

⁴⁶ James Waldram, D. Ann Herring, T. Kue Young. 2006. *Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives*. U of T press. Health Council of Canada. 2012. *Empathy, dignity, and respect: Creating cultural safety for Aboriginal people in urban health care*. Accessible at http://www.healthcouncilcanada.ca/rpt_det.php?id=437

⁴⁷ 2012. Health Council of Canada. *Empathy, dignity, and respect: Creating cultural safety for Aboriginal people in urban health care*. Accessible at http://www.healthcouncilcanada.ca/rpt_det.php?id=437.

5.5 COMMUNITY DEVELOPMENT

Collaborative projects with First Nations communities have a better chance for success if they are predicated on strong community development. This means that projects should be community lead, designed and paced, and result in clear benefits and outcomes for the communities involved. Reciprocity is an important First Nations value and should be observed. While an external partner can bring valuable expertise, experience and insights from other jurisdictions, community partners must be equally acknowledged for their strengths, knowledge and capacities and should be encouraged to lead with support from the partner.

“Health services that work best are the ones that are designed with the community for within the community context.” *Interview respondent*

First and foremost, projects should respect principles and values of community development in which communities themselves are empowered to build on their own strengths to identify priorities and devise solutions. In the words of respondents, community development can be facilitated and supported but not driven by NGOs.

“When we talk about community development we believe it means caring enough to create the safe spaces for communities to talk, share, develop their own solutions and do their own work.” *Interview respondent*

Community development can be defined as a process of community action in which the people:

- *organize themselves for planning and action;*
- *make clear their common needs and problems;*
- *make group plans to meet their needs and solve their problems;*
- *carry out these plans depending most upon local community resources (their own community resources); and*
- *use other resources from outside their own community only when needed.*

The underlying belief in community development is that the people themselves can improve their community by:

- *getting together and talking together about what they can do about the problem(s) in their community;*
- *making use of the things people in the community can do; and*
- *finding what experience and skills can be developed as people work together.*⁴⁸

Moreover, respondents express the view that the approach must be sustainable over the long term by supporting communities in building their own capacity and skills.

“Communities would want an NGO to work *with* them not *for* them. The work must be sustainable. NGOs can have a role in coaching, mentoring and working alongside

⁴⁸ Krawl, Marcia (1994). Understanding the role of healing in Aboriginal Communities. Ottawa: Ministry of the Solicitor General of Canada.

communities to transfer expertise.” *Interview respondent*

NGOs can also share specific expertise drawn from their experiences with community development on other national or international projects and jurisdictions.

“They can bring expertise and they may know of things that have worked to improve the health of other indigenous populations in other parts of the world.” *Interview respondent*

“NGOs can help to build capacity within communities, supporting champions and leaders to move community health forwards. Using their experience from work in other parts of the world could be helpful.” *Interview respondent*

Additionally, some respondents expressed their view that an NGO can have a role in supporting and mobilizing communities at the earliest stages:

“NGOs have community mobilization experience which is very needed. NGOs can help to build capacity within communities, supporting champions and leaders to move community health forwards.” *Interview respondent*

“We can learn from *US collaborative learning groups*⁴⁹ that engage communities and specific health experts. The communities identified the issues and the experts mentored them in areas identified by the communities with good results; FNIHB is exploring this model to support communities to change their systems that includes coaching and mentoring, a guide will not do it. Need to learn how to support communities best.” *Interview respondent*

However caution must be exercised, when outside expertise or specialist services are provided to ensure that:

“Specialists should support locals, not the other way around.” *Interview respondent*

Interventions must be truly community based meaning that they are developed and implemented from within the community with the involvement of community resources. The community decides where to begin, when it is ready to begin, what the best response for the community is, whereas external partners support the processes.

In fact, projects should “provide mechanisms for [external partners] to be consultants and supporters including via telehealth backup.” (*Interview respondent*) And further, projects should ensure that there are “incentives and rewards for specialists to provide a support role” (*Interview respondent*) as opposed to simply providing the service and not engaging, supporting or transferring knowledge to community based health staff.

⁴⁹ Indian Health Services in the United States is using collaborative learning groups in their Improving Patient Care efforts which are aimed at improving the quality of, and access to, care through the development of a system of care called the “Indian health medical home.” The Improving Patient Care (IPC) process creates a learning community through face-to-face meetings of the improvement teams, regular web-based teleconferences, and ongoing listserv dialogue for sharing questions, ideas, experience, and information (http://www.ihs.gov/ipc/index.cfm?module=dsp_ipc_models_collab).

Most notably, some community respondents who were interviewed expressed the view that NGOs can bring a vital, impartial perspective to bear where other entities may be hindered by jurisdictions, mandates and other factors.

“Communities see you as a trusted partner and know that you are impartial. Because NGOs are non gov’t [sic], non political – there is greater leverage to work toward common goals and to put differences aside. People have come to the table who would never have come otherwise.” *Respondent*

5.6 KNOWLEDGE TRANSLATION AND EXCHANGE

Train-the-trainer approaches, with an emphasis on sustainable shifting of tasks, is another model that may fit well with First Nations partnerships in health.

"Other interesting initiatives cited include a train-the-trainer approach for core public health interventions and strategies (e.g. alcohol counseling, smoking cessation training and mental health screening), community based control of sexual health programs grounded in the Alaskan Nuka model” *Respondent*

The Nuka model is an Indigenous model created by Alaskan Native people that provides integrated primary health care.

“It offers medical, behavioural, dental and traditional services and involves the community, the Indian Health Service, Medicare, Medicaid and other stakeholders in developing strategies tailored to individual healthcare needs. The Nuka model includes outcome and process measures and has resulted in a 50% decrease in urgent care and emergency department use due to same-day access to care, a childhood immunization of 93% and an overall customer and staff satisfaction beyond 90%. The model is transferable, having been applied in Oregon, British Columbia, Saskatchewan, and Alberta.⁵⁰

In one example of the application of the Nuka model, local staff are trained to work at the top of their license in small teams and all but the most critical tasks are delegated to non-health care providers. For example, the role of the registered nurses (RNs) may be shifted to chronic disease management. Many of the RNs day-to-day clerical tasks were delegated to advanced administrative staff or case management support (CMS) staff. Day to day clinical tasks were delegated to certified medical assistants or CMAs.⁵¹

Systems impediments however can threaten sustainability when outside support teams leave the community and the health system is not capable of sustaining community programs. Long-

⁵⁰ Health Council of Canada (2013).

⁵¹ Blash, L., Dower, C., Chapman, S., Southcentral Foundation – Nuka Model of Care Provides Career Growth for Frontline Staff, Centre for Health Professions at UCSF, January 2012

term monitoring and support may be required.

6 OPPORTUNITIES FOR NGOS

Interview respondents shared a number of suggested strategic roles that NGOs could potentially play in partnership with communities and community health service organizations. Community autonomy is however always important and the identified themes can best serve as a springboard to determine individual community support and engagement on each topic.

6.1 SUPPORTING THE DEVELOPMENT OF INTERPROFESSIONAL ROLES AND TEAMS

One area that bears exploration is the development of inter-professional teams and delineation of roles and mechanisms to support this. As noted earlier, often programs have evolved which are disease- and topic-specific due to the nature of funding streams with specific mandates and priorities. Community health workers are accordingly often cast into roles that are very discrete in response to the program constraints. This is at odds with the wholistic view of health in Aboriginal communities.

Furthermore, in some communities, where nursing stations employ federally funded nurses, there are limited opportunities to collaboratively plan with community health nurses who are funded by the band administration. In addition, there has been a slow erosion of the central coordination functions of the community health workers such as community health representatives (CHRs) and community health nurses (CHNs) and less capacity to undertake collaborative team planning amongst their peers and other workers at the community level and with external providers.

“[CHRs] used to be renowned for their care and their support for community members from “cradle to grave”. They knew all the families and history of community. There has been a huge loss of that role as silo funded health delivery services came into place like Canada Prenatal Nutrition Program, Aboriginal Diabetes Initiative and a host of others. Communities lost the central role of CHR which was a huge public health role at one time.” *Interview respondent*

This sentiment is echoed in the following statement in which an interview respondent describes the need to further empower CHRs.

“There are many good care providers such as nurses, many good paraprofessionals, need to be more supported to further their skills, especially CHRs, who know the community, need to be mentored to work as an interdisciplinary team - in particular how can para-professionals and professionals work together? Need opportunities to mentor and engage para-professionals and professionals.” *Interview respondent*

As noted by one interview respondent:

“Helping with education to build interdisciplinary teams with professionals and paraprofessionals can have a great impact on the community and on the workers, building confidence in the worker that is often lacking.” *Interview respondent*

In particular, there is interest and receptivity to projects which are “supporting CHRs to strengthen their role.”

To enable this, there is strong interest in activities that can foster knowledge exchange, networking and sharing of best practices.

“We need better coordination of services for example between Home and Community Care nurses and Aboriginal Diabetes Initiative workers. I am not sure how much support is there in terms of opportunities or forum to exchange of best practices and to learn from one another. Many community health workers seem to be left working on their own. Better communication is needed.” *Interview respondent*

6.2 CONTINUING HEALTH/MEDICAL EDUCATION

As described in the literature review, few resources exist to train Aboriginal healthcare professionals or build capacity through continuing education and/or mentorship programs.

As noted in the previous section, there is strong interest in building capacity via knowledge exchange and transfer, training and professional development for community health workers. However, training needs to be adapted and customized to the needs of the particular community partner.

“NGOs have resources to deliver training and any partnership could help build capacity in communities. Our region is huge and there is wide variation across the region from community to community. It would be important to recognize that no one cookie cutter model will work. Any program of training and its delivery model would have to be adjusted to communities.” *Interview respondent*

Moreover, training or knowledge exchange opportunities need to be offered in a sustainable fashion with the long term aim of equipping communities to design, develop and deliver their own training.

“There may be a role in getting a Community of Practice (COP) established and handing it over quickly to the community, especially since DI has experience and knowledge with the knowledge translation (KT) platform.” *Interview respondent*

There seems to also be interest in moving towards different approaches to delivering care such as client or patient centered care as noted earlier. However, it must be enabled and supported with appropriate training.

“Another area that would be of interest is in moving care to a more client centered approach. Supporting clients so that they know how to manage more of their own care. This means that health care workers need training in understanding patient/client centered care and in moving them towards that perhaps with motivational interviewing techniques etc.” *Interview respondent*

“Need better coordination of services. How much support is there in terms of exchange of best practices etc., for community health workers to learn; many are working on their own.” *Interview respondent*

Quality improvement in health services is another area that is needed in communities. An example of a model that seems to be very effective would be the US Indian Health Services’ “Improving Patient Care” model, which is a quality improvement initiative.⁵² Their Collaborative Care Model approach provides an opportunity for communities to identify an issue they wish to work on and links them with expertise in educational institutions, health service organizations and other providers to discuss, troubleshoot, problem solve and trial interesting approaches. It is a mentoring and coaching approach that builds confidence and competencies within the community and one that Health Canada is exploring in its work in First Nations. Support in terms of training, professional development, mentoring and coaching would be critical to embracing such new service models.

6.3 ADVOCACY IN CROSS JURISDICTIONAL BARRIERS

As noted previously, jurisdictional issues are huge impediments to seamless health service delivery within First Nations settings. Federal departments, provincial departments and regional planning bodies, like the LHINs, have varying roles, mandates, program and priorities within health services delivery in communities and it is often unclear as to who should be providing or paying for the health services. The issue is best summed up by the following interview respondent quote:

“Jurisdictional issues are also creating gaps, and are making it difficult to fill gaps as there are differing federal, provincial and First Nation policies and approaches. There is progress however as federal departments work with Regional Health Authorities and with others. Additionally, provincially funded Aboriginal Health Access Centres provide primary care services on reserve which is a huge gap for many communities.”
Interview respondent

These jurisdictional issues have their roots in the “medicine chest” clause contained in the historical numbered treaties.⁵³ For this reason, First Nations maintain that there is a clear federal obligation to provide health services. However, as insured services are the responsibility of the provinces for all residents, it leaves much room for jurisdictional debates and barriers over responsibility for First Nations health services on reserve. This issue is described further in the following interview respondent quotes:

“Communities see the Federal government as mandated to provide health services but they have been negligent. [There is a] concern if they take resources off other groups – they feel they have let the federal government off the hook.”

⁵² Indian Health Service, Improving Patient Care website. Accessible at <http://www.ihs.gov/ipc/>.

⁵³ Barkwell, Peter Alan. "The Medicine Chest Clause in Treaty no. 6." *Canadian Native Law Reporter*, no. 3 (1981): 1-23.

“Health Canada is not attending to their responsibility, so NGOs can help First Nations to catch up to the rest of Canada. Monies have flowed to the province, but it stops at the boundary of the First Nations communities... [in any] Relationship with First Nations, NGOs can help with political lobbying to advocate for services, help to get the attention of the government... Communities are behind for decades for example, building health centres in some areas, again lobbying is needed.” *Interview respondent*

As noted earlier, interview respondents feel that advocacy is an area in which NGOs can play a role in supporting the removal of cross jurisdictional barriers and improvements in a continuum of care.

6.4 SUPPORTING THE DEVELOPMENT OF LOCAL HEALTH SERVICES AND EVALUATION DATA

Another potential contribution that NGOs could make is in the area of building capacity for better planning using data, evaluation and research more effectively, as noted by interview respondents.

“Where do we start? Look at quality control for patients, data for helping assess needs for the aging populations; getting screening rates up will increase cancer treatment rates and support is required for that.” *Interview respondent*

“[what is] Also missing - we have no way of knowing or collecting data – no capacity to collect, analyze or use data – no system to help move health planning. We would love a tool – physicians are using EMR but they are the only ones using or accessing this. Limited access by other health providers – [data would] give feedback, help prioritize health activities.” *Interview respondent*

“Capacity building and training is a huge need in the communities and certainly developing tools like data collection, or even say, for bringing best practices in our communities around screening, teaching, etc.” *Interview respondent*

“What’s missing however is data that helps in quality decision making. There is no capacity or infrastructure to prove what is needed. We can only get funded for various things. But it might not be the right thing.” *Interview respondent*

“Education is also needed to maximize the use of technology, such as electronic Community Based Reporting Templates (CBRT) for example, where people are motivated to use them but are not doing data collection consistently or systematically.” *Interview respondent*

“Knowing what you are dealing with is very important. Health directors need good data to plan for services for their citizens and they need to know immunization status of their population, particularly during outbreaks.” *Interview respondent*

However, beyond simply training, there is strong recognition that the issues surrounding data collection, analysis and reporting are tied up with community concerns, especially OCAP

principles. The following quote alludes to the issue.

“There are many issues related to data collection, capacity as well as jurisdictional.”
Interview respondent

“There are gaps around linkages with the provincial system for public health, the collection of data, surveillance and monitoring etc. There is a slow uptake with Panorama (system for data collection for immunizations and infectious disease surveillance). Privacy issues are taking a long time to work through and this also applies to chronic illness. There is a need for a better relationship with provincial systems and infectious disease management. These are difficult although people are working on working them out. It is also very tedious and complex at the community level to gather information about immunization status of their citizens as the information may be spread across many health care providers and health centres. Pandemic planning in relation to H1N1 and SARs has been an impetus to resolve some of these issues.”
Interview respondent

6.5 IMPROVING HEALTH SYSTEMS THROUGH TRAINING AND TASK SHIFTING

Within the context of health systems and services, several participants acknowledged the importance and relevance of task shifting in overcoming barriers associated with insufficient health human resources in remote Aboriginal communities. “Task shifting is the name given to a process of delegation whereby tasks are moved, where appropriate, to less specialized health workers.”⁵⁴

“Look at drawing in paraprofessionals into the care and health team; some communities need more help with this and some have more severe silos. FNIHB nurses can be very territorial in communities with FNIHB nursing staff. How can we bring the group together for the benefit of the people? All are there for the same reason but are not always working together, this would be a great thing to work on.” *Respondent*

One participant explained that successful task shifting “comes down to training, trust and confidence. However, there is a range of competencies and comfort levels amongst CHRs in First Nations.” It is therefore important to understand that some communities will be more or less receptive and ready to consider task shifting. Figuring out how to tackle that will require regional implementation research to determine the fit in each community. Task shifting will also require strong inter-professional commitment that can be developed through inter-professional planning. Collaborative planning involving inter-disciplinary teams will also enhance comfort levels between future team members. The use of care maps and practice plans were identified as important facilitators for task shifting involving physicians, CHNS and CHRs.

⁵⁴ World Health Organization, First Global Conference on Task Shifting, January 2008.

The literature review also included evidence of the effectiveness of evidence-based task shifting (from physician to nurse) in a study focusing an on-reserve First Nation community in northern Saskatchewan. The study assessed the effect of a nurse-directed hypertension treatment on changes in patient systolic blood pressure (after 12 months), diastolic blood pressure (over time) and alterations in urine albumin. The home care nurse followed a predetermined treatment algorithm of pharmacologic antihypertensive therapy while primary care physicians made treatment decisions in the control group. Though both groups experienced a decrease in systolic blood pressure, changes in the local health system were shown to have long-term effects on improving blood pressure.⁵⁵

The C-CHANGE (Canadian Cardiovascular Harmonization of National Guidelines Endeavour) Initiative seeks to harmonize clinical practice recommendations for cardiovascular disease (CVD) prevention and treatment.⁵⁶ The focus is to include cardiac and stroke rehabilitation, diabetes, dyslipidemia, hypertension, obesity, physical activity, and smoking cessation recommendations in target screening and management strategies for CVD and CVD risk factors in family and primary care practice (these chronic illnesses were identified as high priorities in First Nations in this feasibility study). Accredited train the trainer sessions are currently offered and adapting this type of guidelines-based training to the First Nations health care environment (involving primary care and paraprofessionals) could serve the health priorities as well as training priorities identified in this study.⁵⁷

⁵⁵Tobe, S. W., Plypchuk, G., Wentworth, J., Kiss, A., Szalai, J. P., Hartman, S., Ironstand, L., & Hoppe, J. (2006). Effect of nurse-directed hypertension treatment among First Nations people with existing hypertension and diabetes mellitus: the Diabetes Risk Evaluation and Microalbuminuria (DREAM 3) randomized controlled trial. *CMAJ*, 174(9), 1-6.

⁵⁶ C-Change website accessible at <http://c-changeprogram.ca/>

⁵⁷ C-CHANGE Initiative

7 CONCLUSION

This feasibility study showed there is a definitive role for NGOs to collaborate with First Nations communities to improve access to health care and many First Nations stakeholders are interested in exploring a partnership.

There are significant health concerns in First Nations which are exacerbated by gaps in the health system, lack of access to culturally safe care, cross jurisdictional barriers, fragmentation of services, and lack of integration of services between on and off reserve.

Many opportunities exist for collaboration between NGOs and First Nations, however it is of utmost importance to observe cultural protocols and to respect core values as outlined in this report, if projects are to be successful.

Existing models of intervention and care are helpful to inform interventions, however they must be adapted to fit within the local culture of First Nations.

Above all, it is important to respect the local right for self-determination and autonomy of each Aboriginal community.

ANNEX 1: GLOSSARY OF TERMS

Aboriginal: The term “Aboriginal” is defined in the Canadian Constitution Act and includes all people of Indigenous descent: First Nations (legal term is Status Indian), Inuit, and Métis.

AHAC: Aboriginal Health Access Centre, a provincially funded health centre built on the community health centre model. There are 12 in Ontario.

CHR: Community health representatives, a community health worker funded by First Nations and Inuit Health Branch (FNIHB) in many First Nation communities.

CHN: Community health nurse.

Cultural Awareness: The acknowledgement of differences between cultures.

Cultural Competence: Focuses on the skills, knowledge, and attitudes of practitioners.

Cultural Safety: Cultural safety was first introduced by Irihapeti Ramsden, a Maori nurse in Aotearoa (New Zealand), in 1990. Her description of the term explained that cultural safety moves beyond cultural sensitivity and cultural competence (i.e., having knowledge about the culture of “the other”) in that it analyzes power imbalances in society as well as political ideals of self-determination and de-colonization. Cultural safety involves self-reflection and an understanding that cultural values and norms of the client may be different due to unique socio-political histories. Self-reflection leads to empathy, the capability to share another being's emotions and feelings, which in turn improves the therapeutic encounter with clients and their communities, leading to better health outcomes. Empathy could also lead to advocacy and social justice work on behalf of clients and their communities (adapted from Anishnawbe Health Toronto Website, accessible at <http://www.aht.ca/aboriginal-culture-safety>).

Cultural Sensitivity: The recognition of the importance of respecting difference.

EMR: Electronic medical record.

First Nations Community: Many communities use the term "First Nation" in the name of their community. Currently, there are 617 First Nation communities in Canada, which represent more than 50 nations or cultural groups and 50 Aboriginal languages.

First Nations People: The term "Indian," is considered to be offensive by many Aboriginal people, when used by non-Aboriginal people. It is replaced by “First Nation,” a term not legally defined. However, it commonly refers to both Status and Non-Status Indian people in Canada.

FNIHB: First Nations and Inuit Health Branch is a department of Health Canada. The branch provides some direct services or transfer payments to First Nations and Inuit communities to cover specific health care.

Health Council of Canada: The Health Council of Canada is an independent, non-profit organization that receives funding from Health Canada.

Indian Status: A First Nations person individually recognized by the federal government as being registered under the Indian Act is referred to as a Registered Indian (commonly referred to as a Status Indian). Status Indians are entitled to specific health programs and services offered by federal agencies and provincial governments.

NIICHRO: National Indian and Inuit Health Representatives Organization.

NOSM: Northern Ontario School of Medicine.

OCAP: Ownership, control, access and possession, it constitutes a self-determination approach to First Nations relevant research and data.

PAR: Participatory Action Research.

PTO: Provincial/Territorial Organization such as the Nishnabe Aski Nation (NAN) and the Union of Ontario Indians (UOI).

NIHB: Non-Insured Health Benefits program provides coverage for a limited range of these goods and services for First Nations and Inuit people when these services or goods are not insured elsewhere.

TH/M: Traditional Aboriginal health or medicine approaches, which are distinguished from western clinical approaches.

Wholistic: Variant spelling of holistic often used by Aboriginal people to underscore the importance of addressing the whole body or person. It stands in contrast to the Western scientific reductionist approach to health.

Wholistic Health: Approach to health that considers the physical, mental, emotional and spiritual aspects of health.

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