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Executive Summary

The National Aboriginal Health Organization (NAHO) is dedicated to improving the physical, mental, emotional, social, and spiritual health of Aboriginal Peoples. NAHO believes that the advancement and sharing of knowledge in the field of Aboriginal health are a key to the empowerment of Aboriginal Peoples. And since research is one way to create knowledge, NAHO has developed this framework in order to provide guidance and direction in setting NAHO's current research role and agenda, and to help determine the type of research that NAHO will support or endorse.

The framework also offers a general guide to culturally appropriate research for Aboriginal communities and researchers, and non-Aboriginal researchers and research organizations. We hope it will contribute to developing a standard of excellence for research on or by Aboriginal Peoples.

Guiding principles for Aboriginal health research identified in the framework are:

- Research will be focused on community priorities and needs.
- Methods will be culturally appropriate and respectful of diversity.
- The research process will be transparent and inclusive.
- Research designs will be credible and of high quality.
- Research will respect the principles of Aboriginal ownership, control, access, and possession (OCAP).

Key health challenges facing Aboriginal communities are grouped under the following broad headings:

- self-determination
- physical and human environments
- emotional and mental health
- chronic diseases and disabilities
- healthy childhoods
- access to effective and appropriate services.

NAHO's research directions for the immediate future are to:

- support research that builds upon Indigenous knowledge
- promote better ways of doing research
- address the inequities in research on Aboriginal Peoples
- contribute to more effective programs and services
- build capacity for research in the Aboriginal community.

NAHO intends the research framework to be a living document that changes and evolves. Your comments and insights are welcome.

Introduction

...Wellness is a community issue, a national issue, a women's issue. It touches youth concerns, family considerations, even self-government and historical concerns. I firmly believe that no other issue so fundamentally relates to the survival of our people as that of health.

(Tom Iron, Federation of Saskatchewan Indian Nations, quoted in Royal Commission on Aboriginal Peoples, 1996, Vol. 3, Chapter 3, p.107)

Being healthy is both a goal, and a means for a people who want to return to their historical self-sufficiency and prosperity built on mutual support, and harmony with the natural world. Better health for individuals will contribute to stronger families and communities, and healthy citizens can more easily build healthy communities and nations.

Good health involves more than being free of disease or living longer. It includes having a strong physical body, a mind able to learn and embrace change, a heart that is open and caring and a spirit that is clear and connected to all that is around us. Achieving health is a lifelong journey.

Vision

The National Aboriginal Health Organization (NAHO) is dedicated to improving the physical, mental, emotional, social, and spiritual health of Aboriginal Peoples. NAHO believes that the advancement and sharing of knowledge in the field of Aboriginal health are a key to the empowerment of Aboriginal Peoples.

The NAHO Research Framework

For research to be useful and empowering for Aboriginal Peoples, it must begin with a common vision, be guided by values and principles, identify priorities, and set a clear direction.

A framework is a guiding document that describes how certain work will be done or an issue addressed. It answers the questions: What are we trying to do? What do we believe? What are our priorities? How will we do this task? The purpose of this health research framework is to:

- provide guidance and direction in setting NAHO's current research role and agenda
- help determine the type of research that NAHO will support or endorse
- offer a general guide to culturally appropriate research for Aboriginal communities and researchers, and non-Aboriginal researchers and research organizations
- begin the process of developing a standard of excellence for research on or by Aboriginal Peoples.

This framework is intended for use by NAHO and by others who want to improve their research practices. It is a guiding document that applies to a wide range of research inquiries: policy research and analysis; research syntheses and reviews; original research at the national, provincial, territorial, regional, and community levels; and applied medical research.

The remainder of this document addresses:

- the central role of Indigenous knowledge in Aboriginal research
- some common values and the diverse history and experiences among Métis, Inuit and First Nations groups in Canada
- guiding principles for health research on or by Aboriginal people
- key Aboriginal health challenges as identified by NAHO
- specific research directions for NAHO
- thoughts for the future.

The Central Role of Indigenous Knowledge

For research to be useful and empowering for Aboriginal Peoples, the central role of Indigenous knowledge must be acknowledged and respected.

First Nations, Inuit and Métis people comprise the Aboriginal, or Indigenous, population in Canada. Indigenous Peoples throughout the world have been described as those with

... a social and cultural identity distinct from the dominant society where they live, who have a close attachment to their ancestral lands...

Indigenous societies represent cohesive systems of life, imbued with a shared world view. Every aspect of indigenous life is governed by sets of rules and values, and sustained by a sound knowledge base. Indigenous peoples have achieved harmonious integration with the environment and have sustained this relationship over the centuries.

(Alderete, 1999, p.7)

Indigenous health knowledge is part of a complex knowledge system passed from generation to generation for thousands of years. However, colonialism, the suppression of language and culture, and epidemics of disease and death have resulted in the permanent loss of some knowledge, and the need to rebuild, protect and transmit community Indigenous knowledge throughout Canada.

The need to preserve and use Indigenous knowledge has never been greater. Canadian Aboriginal communities are facing rapid change and daunting symptoms of ill health such as community and family violence, suicide, high levels of infectious and chronic diseases and tragic levels of childhood deaths, youth injuries and adult disabilities (First Nations and Inuit Regional Health Survey National Steering Committee, 1999; Health Canada, 1999; Statistics Canada, 1996; National Aboriginal Health Organization, 2001b;

Kinnon, 2002; Smylie, 2001). While Aboriginal communities are gaining greater control over social and economic development and health programs, they are often based on non-Indigenous values, approaches, structures, and methods. By and large, research on Aboriginal health concerns has been grounded in European values and Western scientific principles, rather than upon those of the people themselves.

However, there is now great opportunity for change as Aboriginal communities work to exercise more control over our present and our future. Many communities and organizations are working to ensure that Indigenous knowledge and appropriate non-Indigenous approaches are given equal respect in addressing the needs of Aboriginal communities. According to participants in a roundtable on Aboriginal health policy

Aboriginal people must maintain the integrity of their traditional knowledge, but also they should draw on it as a powerful lens through which to promote health and well-being.

(Dion Stout, Stout and Rojas, 2001, p.2-3)

Building Better Research Relationships

For research to be useful and empowering for Aboriginal Peoples, existing research relationships and methods must change.

Research is a systematic way of building knowledge. Research methods can range from simply observing the world, drawing conclusions from what is seen, testing them out and confirming what is learned, to developing and using methods and technology able to collect, analyze and compare large amounts of data. The value of a research method is not measured by its complexity, but by its ability to contribute to better knowledge in the most appropriate way. Good research uses the best available technology to analyze data, accurately interpret the results, validate them with research participants, and communicate these results to others.

Unfortunately, many Aboriginal people have been the subjects of research that they had little say in or control over, that misrepresented or misinterpreted their experiences, and failed to create knowledge that was useful to the community. Rather than having a positive affect on their lives, it resulted in either inaction or poorly designed policy or programs (Dion Stout, 2001; Dion Stout, Stout and Rojas, 2001).

Much needs to be done to restore Aboriginal people's trust in research. Some critical issues to address include: the need to embrace "different ways of knowing" based on Indigenous values, principles and beliefs; shifting control over research to the Aboriginal community; building equitable partnerships between researchers and those researched; and developing high ethical standards that are culturally appropriate.

Common Values, and the Strength of Diversity

For research to be useful and empowering for Aboriginal Peoples, it must be guided by the values, beliefs and experiences of Aboriginal Peoples.

Balance and Respect

There are as many different visions of health and wellness as there are different Aboriginal cultures in Canada. There are, however, some common themes that can be found throughout these diverse experiences that provide a view of health and wellness that is distinctly Aboriginal. Two key principles are balance and respect, and it is the Elders and Aboriginal scholars whom we need to look to as authoritative voices concerning these fundamental beliefs.

Health, from an Indigenous perspective, is not seen as separate and distinct from other aspects of life or a person. A person is not just a physical being – equally important are the mental, emotional, social, and spiritual aspects of that person. Individuals are a part of, and are greatly affected by, the natural and built environments in which they live, as well as by the spirit world, their families, their communities, and their nations. Maintaining health requires keeping or regaining a balance in the different aspects. Treatment of illness involves an understanding of all the factors, inside the person and in the world, that disturb balance. Methods used to restore this balance will vary according to the healer or community. Traditionally, these methods have included healing circles, sweat lodges, traditional medicines, songs, dancing, feasts, and other ceremonies. At present, Aboriginal communities consider efforts toward self-determination, community and economic development, family healing, and personal change as ways of restoring balance and health.

In order for healing to take effect, we must foster the principle of respect. For changes to take place in people's health, they must have respect for themselves and their place in the world. This respect will form the foundation of all interactions and will also direct or guide any attempts to make changes in order to improve or restore health. Again, the methods and means will be as diverse as the cultures that developed them (Smylie, 2001; Dion Stout and Kipling, 2001).

There are three distinct groups of Aboriginal Peoples in Canada, namely, Inuit, Métis, and First Nations. While a great deal of diversity exists within these three groupings, the groupings themselves can be useful in examining shared experiences, as well as in identifying distinct realities and needs.

Inuit Culture, History and Environment

For Inuit, health is about non-interference, and the ability to enjoy a spiritually and culturally fulfilling relationship with the land, based on Inuit traditions, practices, and beliefs. For Inuit, health problems result from interference with the smooth functioning of this relationship (Pauktuutit, no date; Hanrahan, 2000).

Inuit history and geography give rise to unique health conditions and issues. The cost of living in the North is 50 to 70 per cent higher than in urban centres in the South. Inadequate housing and homelessness are growing problems: one in six residents of Iqaluit lacks proper shelter (Inuit Tapiriit Kanatami, 2002). More than any other Aboriginal group, Inuit must travel far to access many health services, especially specialized services. Removal from home communities and family support is emotionally stressful (Hanrahan, 2002). For those Inuit who do not speak English or French, language can be a barrier, to the point that some Inuit may not seek the medical help they need. Interpretation services are not always available.

The Inuit population is also very young, with a mean age of 15 years, and it is growing quickly: by 2016, the Inuit population is expected to reach 60,000, a 48 per cent increase over the 1996 population (Inuit Tapiriit Kanatami, 2002). Meanwhile, life expectancy in Nunavik (Northern Quebec) is 64 years, 14 years lower than the national average. (Archibald and Grey, 2000).

During recent regional health meetings, NAHO's Inuit Centre was told of many health concerns including high suicide rates, gambling and other addictions, chronic diseases and cancer, fetal alcohol syndrome and fetal alcohol effects, marital breakdown, and environmental contaminants. Participants also reported many sources of strength in Inuit communities, including living "on the land," food and nutrition programs, as well as the longstanding Inuit tradition of self-sufficiency.

Inuit now demand that health care in the North incorporate Inuit values, beliefs, and practices (Pauktuutit, 2000; Gray, 1996). Accordingly, Inuit organizations like Inuit Tapiriit Kanatami, Pauktuutit Inuit Women's Association and NAHO's Inuit Centre call for Inuit-specific programs, a focus on prevention and population health, and the incorporation of Inuit knowledge (Qaujimagajatuqangit) into health service delivery. Health researchers echo these goals and call for the use of a social policy approach to promote Inuit health (see Bjerregaard and Young, 1998). Such an approach would be consistent with Inuit culture.

Métis Origins, Experience and Needs

According to census data, in 1996, 26 per cent of the Aboriginal population self-identified as Métis. An infinity symbol on the Métis flag represents the Métis as the "joining of two cultures together, forever." Métis are said to be

a people set apart. With one foot planted in our white European ancestry and the other foot planted in the timeless, tribal customs of the Indians, we belong wholly to neither and, as a result, hold on to each other and our traditions all the more tightly.

(Senator John Boucher, quoted in Métis National Council, 2002)

Métis are accorded legal status under Section 35 of the *Constitution Act* of 1982 where the term Aboriginal is defined to include Métis, along with Indian and Inuit people. However, the federal government has not accepted jurisdiction on behalf of Métis as

Aboriginal Peoples. Neither the federal nor provincial governments have assumed responsibility for Métis health services, nor has a comprehensive government policy or strategy been developed to address Métis health issues.

Métis are, for the most part, a people without a land base, with exceptions such as Métis Settlements in Alberta, and Métis who are beneficiaries of land claims agreements in the Northwest Territories and Yukon Territory (other land claims negotiations are currently in progress). More than half the population resides in urban centres; the remainder are geographically dispersed among smaller communities. The Royal Commission on Aboriginal Peoples notes the life experiences of Métis have been

markedly different than that of First Nations or Inuit. Their rights, ignored and abused for generations, are in urgent need of recognition and restoration. As one of the Aboriginal Peoples of Canada, Métis people want to be recognized as having their own unique cultural and political traditions. They are seeking a nation-to-nation relationship with Canada. As with other Aboriginal peoples, land and self-determination are central issues. Métis people are seeking to build their own institutions and organizations based on the foundation of their culture.

(Royal Commission on Aboriginal Peoples, 1996, Vol. 4, Chapter 3, p.4)

There is at present an almost total lack of national Métis-specific health information. Census data remain the primary source of information. Métis-specific health information is needed to support capacity building and community development towards the enhancement of Métis community health and wellness.

The NAHO Métis Centre recently co-hosted a Métis Health Policy Forum, bringing together for the first time Métis leaders, health professionals and practitioners, educators and researchers, Elders and youth, and community members. Forum participants stressed the need to conduct Métis-specific health research and to gather Métis traditional health knowledge. Madeleine Dion Stout, a Forum presenter, urged that Métis be “researched to life” using everyday forms of knowing, including stories that are basic to informing Aboriginal people’s health and instructive in informing Métis health policy (Métis Centre, National Aboriginal Health Organization, 2002).

First Nations Issues and Priorities

For a person to be healthy, [he or she] must be adequately fed, be educated, have access to medical facilities, have access to spiritual comfort, live in a warm and comfortable house with clean water and safe sewage disposal, be secure in cultural identity, have an opportunity to excel in meaningful endeavor, and so on. These are not separate needs; they are all aspects of the whole.

(Henry Zoe, Yellowknife, Northwest Territories, quoted in Royal Commission on Aboriginal Peoples, 1996, Volume 3, Chapter 2, p.206)

First Nations, as the original inhabitants of this land, live in all parts of Canada and comprise over 50 distinct cultural groups. While many First Nations continue to live

close to the land and maintain at least some traditional activities such as hunting, fishing and trapping, an increasing number are moving to urban centres to seek better housing, employment and health care.

Current issues of importance to First Nations communities include disparities between on- and off-reserve populations, the exercise of self-government, and addressing the overwhelming needs of a population that has not been particularly well served by a myriad of programs and services in the past. Barriers to effective health programs include jurisdictional disputes and divisions of powers between the federal, provincial and territorial governments. In 2001, the Assembly of First Nations identified these seven health priorities for First Nations communities:

- building and sustaining health and health care systems
- human resources, capacity building and training
- a comprehensive health research and infostructure
- resolution of existing jurisdictional matters
- establishment of a national mental health program, community-based suicide prevention and training
- a comprehensive child health policy
- early screening for cancers
- smoking prevention and health promotion related to second-hand smoke
- greater awareness of the state of water systems and recognition of mould as a public health crisis (Assembly of First Nations, 2001b).

The need for accurate and accessible health information has led to new ways of doing research. First Nations, through the Assembly of First Nations' Chiefs' Committee on Health and its standing committee, the First Nations Information Governance Committee, have given a mandate to the First Nations Centre of NAHO to co-ordinate and serve as data steward for the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS). This extensive health survey builds on the *First Nations and Inuit Regional Health Survey National Report* published in 1999. The NAHO First Nations Centre has been entrusted to protect First Nations data and uphold the principles of ownership, control, access, and possession of data (OCAP), which are discussed in more detail in the research principles section of this document.

Guiding Principles for Health Research

For research to be useful and empowering for Aboriginal Peoples, it must be based on sound, ethical principles.

Principles serve as a guide in how we live and work, and describe the essence of what we believe to be important. Just as research continues to evolve with every advance in knowledge, research principles are intended to be dynamic and adaptable to change as we learn better ways of working toward meaningful research. Ideas in this section build upon those presented by Aboriginal Healing Foundation (2000), Dion Stout and Kipling (2001), Health Canada (2001) and Piquemal (2000).

The five main principles guiding NAHO's research activities are:

1. Research will be focused on community priorities and needs.
2. Methods will be culturally appropriate and respectful of diversity.
3. The research process will be transparent and inclusive.
4. Research designs will be credible and of high quality.
5. Research will respect the principles of Aboriginal ownership, control, access, and possession.

1. Research will be focused on community priorities and needs

As a guiding principle, it is important that health research projects be based on population and community needs and have a direct and immediate application to improving health status. Some ways to ensure that research is focused on community priorities, needs and realities include:

- using community-based research and participatory research methods
- addressing root causes, rather than symptoms of ill health, and the requirements for optimal health that are particular to the experiences and history of Aboriginal Peoples
- providing new insight into key health issues, and offering potential to improve promotion, prevention, treatment, rehabilitation, and individual, family and community support
- addressing specific issues within the context of the long-term aspirations of Aboriginal communities to be self-sustaining, healthy and prosperous.

2. Methods will be culturally appropriate and respectful of diversity

As a second principle, research methods need to be grounded in the values, beliefs, experiences, and approaches of those under study. As noted in *People to People, Nation to Nation: Report of the Royal Commission on Aboriginal Peoples*, researchers must demonstrate greater competence in selecting methodologies that are appropriate to the inquiry and the community, while being sensitive to negative experiences of the past. This can be achieved by:

- incorporating an understanding of, and respect for, a diversity of Indigenous knowledge and Aboriginal healing practices found in First Nations, Métis and Inuit communities
- thinking of Indigenous and Western approaches as equally meaningful
- reflecting the values and beliefs of Aboriginal cultures related to connectedness, respect, balance, and the equal importance of physical, emotional, social, mental, and spiritual health
- considering a variety of different types of information gathering and knowledge creation, including, for example, qualitative research, quantitative research, participatory research, and storytelling

- addressing ethical issues such as collective rights versus individual rights, conflict of interest, consent to research, privacy, confidentiality, and the need to preserve human dignity from an Indigenous perspective.

A number of examples of ethics guidelines can serve as models for further development. The Kahnawake Schools Diabetes Prevention Project adopted a Code of Research Ethics in 1996 to guide collaboration between the Mohawk community of Kahnawake in Quebec, community-based researchers and academic institutions. In 1999 the Grand Council of the Mi'kmaq in Nova Scotia ratified a Mi'kmaq Ethics Watch, setting out Principles and Guidelines for Researchers Conducting Research With and/or Among Mi'kmaq People. Saskatchewan Indian Federated College has established an ethics review process to reflect First Nations ethical standards.

As well, ethical considerations noted in the Tri-Council Policy Statement, Section 6, Research Involving Aboriginal Peoples (Medical Research Council of Canada, Natural Sciences Research Council of Canada and Social Sciences and Humanities Research Council of Canada, 2000), and those raised by the Royal Commission on Aboriginal Peoples (1996) and the First Nations and Inuit Regional Health Survey National Steering Committee (1999), also should be considered.

3. The research process will be transparent and inclusive

At all stages of the research process, from initial consultation to use of the results, researchers must strive for an open and participatory process. Research participants, or their representatives, will be involved in the design, development, implementation, and follow-up to the research. This includes:

- establishing clear policies that outline granting and contracting terms, as well as the nature of partnerships, sponsorships and endorsements
- creating written research agreements that outline roles and responsibilities, methods of accountability, publication protocols, and decisions on storage, retention and destruction of data, etc.
- clearly stating and continually clarifying expectations of all parties (researchers, research participants, host communities, funding agencies, etc.)
- ensuring that involvement in the research process includes representation from all ages and both genders, and takes positive action to ensure the voices of sometimes forgotten groups are heard, such as youth, women, older adults, urban populations, etc.
- identifying and addressing any barriers to full participation in research processes, such as cultural and language barriers, educational differences, and time and resource constraints
- allocating resources to develop long-term Aboriginal research capacity.

4. Research designs will be credible and of high quality

For health research to be of benefit to the Aboriginal and the research communities, it needs to be credible to both communities, and of the highest quality. Research designs need to be carefully designed and methodologically sound, yet flexible and adaptable. This might involve:

- developing different methodologies for different communities and specific populations
- drawing on international Indigenous research and experiences
- finding ways to reduce the time needed, the financial burden and negative emotional effects of research on individual participants and the community
- ensuring research results are returned to the community in a language and format that is appropriate and accessible.

5. Research will respect the principles of Aboriginal ownership, control, access, and possession

Also known as OCAP, the principles of “ownership, control, access, and possession” relate to the need to balance the rights and responsibilities of individuals and the community with those of researchers. In addressing the interests of a community, OCAP encourages health researchers to consider Aboriginal people as equal partners in any research that includes them. Along with incorporating community Indigenous knowledge in the research design, OCAP emphasizes the importance of:

- supporting collective community ownership of cultural knowledge, data and information
- developing better means for Aboriginal communities to undertake their own research and therefore owning their own data and the resulting knowledge
- ensuring Aboriginal access to the data collected
- planning for Aboriginal communities to remain in possession of data on their members.

Key Health Challenges

For research to be useful and empowering for Aboriginal Peoples, it needs to address the highest priorities and most critical issues facing Aboriginal Peoples.

Aboriginal Peoples face many daunting health challenges, and the health inequities between Aboriginal and non-Aboriginal Canadians are well documented (First Nations and Inuit Regional Health Survey National Steering Committee, 1999; Health Canada, 1999; Statistics Canada, 1996; National Aboriginal Health Organization, 2001b; Kinnon, 2002; Smylie, 2001).

Just as each Aboriginal community and organization needs to set its own health research priorities, the six challenges listed below suggest themes for NAHO’s immediate research activities. Two themes address determinants of health, three deal with poor health outcomes and another relates to the health system.

It is becoming increasingly clear in the health field in general that health research must go beyond studying diseases and the shortcomings of the health services system, pressing as these issues are. Research must also address the broader factors that lead to ill health, and the interconnections among these factors. For Aboriginal Peoples, ill health is directly linked to colonization, cultural suppression, family and community dislocation, chronic unemployment, poverty, lower education attainment, and unhealthy environments. Solutions to these problems need to be community-based and grounded in Indigenous knowledge.

From NAHO's perspective, the key health challenges currently facing Aboriginal Peoples relate to:

1. self-determination
2. physical and human environments
3. emotional and mental health
4. chronic diseases and disabilities
5. healthy childhoods
6. access to effective and appropriate services.

1. Self-Determination

Self-determination is the opportunity and ability to direct one's own life. For an individual, it includes the freedom and the resources to make economic, health and personal decisions in one's own best interests; for communities, it is the ability to create an environment that supports the well-being of its citizens; and for nations and peoples, it is sovereignty over the land and its inhabitants; in other words, independence in exercising power and the authority to govern. It is well known that populations who have more direct control over their own lives and the resources for meaningful participation in decision-making processes tend to have better health outcomes than those who have little control (Federal, Provincial and Territorial Advisory Committee on Population Health, 1994).

Over the course of history, Indigenous Peoples throughout the world have been denied self-determination as nations, communities and individuals. A return to self-determination and self-sufficiency, including the exercise of inherent rights, self-government, economic stability, sound community infrastructure, and removal of barriers to empowerment are central to improving the health status of Aboriginal Peoples in Canada (Alderete, 1999; Barsh, 1993; Gray et al., 1995, cited in Smylie, 2001; Royal Commission on Aboriginal Peoples, 1996).

Research is required to further explore the relationship between Aboriginal social, political and economic self-determination and health, effective ways to foster better understanding of the inherent right to and value of self-government for Aboriginal Peoples, and ways to remove barriers to personal empowerment, and effective leadership and participation in decision making.

2. Physical and Human Environments

Environmental health is of increasing concern in Canada (Canadian Public Health Association, 2002; Canadian Institute of Child Health, 1997). Aboriginal Peoples' health is particularly affected by contaminants in the air, soil and water, because of their close relationship to the land, conditions in Canada's North and Aboriginal people's work in occupations such as forestry and mining. Individuals and communities which rely on hunting or fishing for a major food source have increased levels of contaminants in their bodies. Children are especially sensitive to environmental contamination (Ship, 1998; Bethunes, 1998). International threats to biodiversity and the destruction or appropriation of medicinal plants are also significant environmental concerns.

Built environments such as homes, schools, workplaces, neighbourhoods, and urban landscapes also have their effect on health outcomes. Aboriginal people often live in both poor-quality and overcrowded housing, resulting in high levels of respiratory ailments and communicable diseases (Assembly of First Nations, 2001a; Indian and Northern Affairs Canada, 2001). Because of high levels of poverty and living in the North, Aboriginal people are also exposed to poorly constructed and often unsafe buildings. There is also increasing awareness and concern about the negative health effects of subtle and overt racism and discrimination that Aboriginal people face in their human environments (Royal Commission on Aboriginal Peoples, 1996; Bartlett, 2001).

There is a need for research to explore and document the links between, and the long- and short-term health outcomes of, environmental contaminants, unhealthy buildings, and high levels of racism and discrimination, as well as effective ways of preventing and responding to these conditions. Knowledge that contributes to preservation of biodiversity and traditional medicines and practices, and prevents further damage to the physical environment, is also needed.

3. Emotional and Mental Health

For Aboriginal Peoples, culture is critically important for feelings of self-worth and identity. The loss of culture and language has resulted in profound feelings of despair, grief and depression, which have been linked to alcohol and drug abuse, violence and family breakdown. As well, many communities and families support a significant number of children and adults with learning disabilities and mental health disorders, often in conditions of poverty and a dearth of services (Royal Commission on Aboriginal Peoples, 1996). The emotional and mental health problems among Aboriginal Peoples are typical of Indigenous populations worldwide who have been repressed in the expression of their culture or the governance of their institutions. Recent research has shown a connection between cultural discontinuity and youth suicide (Chandler and Lalonde, 1998, cited in Dion Stout, 2001).

The longer this imbalance remains "unhealed," the more far-reaching the immediate and long-term effects on individuals, families and communities. Research is required to better understand the root causes of mental and emotional ill health, the interconnections with

physical and spiritual health, and effective means of addressing these issues within Indigenous models of healing.

4. Chronic Diseases and Disabilities

Chronic conditions such as diabetes, cardiovascular disease, cancer, hypertension and arthritis/rheumatism are relatively new diseases among Aboriginal Peoples that are rapidly becoming more prevalent (Statistics Canada, 1996; First Nations and Inuit Regional Health Survey National Steering Committee, 1999; Smylie, 2001). The rise in chronic diseases has been linked to rapid social change and cultural loss, chronic stress, residential school trauma, and changes in diet and activity levels resulting from poverty and an inactive lifestyle. Chronic diseases contribute to poor overall health and vitality (so necessary for family healing, the renewal of cultures and the development of communities), premature death, and dramatic increases in health and home care costs, especially as the population ages. Disabilities further limit mobility and activity levels, and the ability to participate in cultural activities and in community life. Disabilities also increase personal isolation and the burden on families. There are urgent needs for research into the underlying factors related to chronic diseases and disabilities, and the interrelatedness of these factors, as well as effective prevention through adequate and healthy diet and increased physical activity, early disease detection and treatment, and ongoing support for those affected.

5. Healthy Childhoods

The conditions in which a great number of Aboriginal children live have been compared to those in developing countries, and contrast with the active and vigorous life of centuries ago. Aboriginal children are at high risk of poor health in general, high birth weight, infant death, infectious diseases, and deaths due to injuries and suicide (Smylie, 2001; Statistics Canada, 1996; First Nations and Inuit Regional Health Survey National Steering Committee, 1999). Healthy child development has been identified as a priority of many governments at various levels and has resulted in initiatives such as Aboriginal Headstart, prenatal nutrition programs and community development funding programs.

While programs and initiatives that deal specifically with childhood development are immediately useful, new knowledge is needed in ways to promote the health and well-being of Aboriginal children and their families, taking into account their particular values, cultures and environments. More attention needs to be paid to effective ways of reducing poverty, improving education and ensuring adequate housing for all Aboriginal children. The issues that affect childhood development cut across all categories of research and investigation.

6. Access to Effective and Appropriate Services

In spite of considerable improvements over recent decades, most Aboriginal people do not yet have equitable access to the full range of disease prevention, health protection, primary health care and specialist services, and home and community care taken for

granted by other Canadians. Barriers to care are numerous and well documented, and include Métis jurisdictional issues, geographic isolation, shortages of Aboriginal and non-Aboriginal health care providers, cultural and language barriers, administrative problems and competition for funding (Statistics Canada, 1996; Archibald and Grey, 2000; First Nations and Inuit Regional Health Survey National Steering Committee, 1999; Hanrahan, 2002; Kinnon, 2001; National Aboriginal Health Organization, 2001b; Métis Centre, National Aboriginal Health Organization, 2002).

Research is needed on ways to effectively address barriers to services, balance disease prevention, health protection and acute health care services, community-based and distant health interventions, Indigenous and Western healing approaches, and Aboriginal-specific and culturally appropriate mainstream services that are proven effective in serving a distinct yet diverse population.

Research Directions

For research to be useful and empowering for Aboriginal Peoples, it needs a clear direction.

In its research framework, NAHO has explored the need for knowledge in order to improve the health of Aboriginal Peoples, described an Aboriginal vision for health and wellness based on the values and perspectives of Métis, Inuit and First Nations, proposed guiding principles for research, and highlighted six key health challenges. Finally, NAHO presents five specific research directions for the organization.

Research directions are broad aims that NAHO intends to pursue in its future research activities, as a means of improving the physical, mental, emotional, social, and spiritual health of Aboriginal Peoples. Used together with key health challenges, these directions will help in setting research priorities and selecting research topics for the organization. NAHO's current research directions are:

1. support research that builds upon Indigenous knowledge
2. promote better ways of doing research
3. address the inequities in research on Aboriginal Peoples
4. contribute to more effective programs and services
5. build capacity in the Aboriginal community.

1. Support research that builds upon Indigenous knowledge

NAHO will support research that builds upon Indigenous knowledge. Such research will be grounded in Indigenous values, principles and methods, and provide analysis and interpretation grounded in Aboriginal experiences and cultural knowledge. Indigenous knowledge has much to contribute, both in and outside the Aboriginal community, particularly to population health, environmental health and health system renewal. Research activities might include documenting Indigenous research practices and

principles, cultural values and Elders' teachings, promoting inclusion of traditional medicine and healing in health programs, and evaluating programs and services from an Indigenous perspective.

2. Promote better ways of doing research

Growing interest in the Aboriginal and the broader research community in creating high quality, ethical research is leading to new models such as the First Nations and Inuit Regional Longitudinal Health Survey and other initiatives based on the principles of Aboriginal ownership, control, access, and possession of research data (OCAP). As well, NAHO is involved in research ethics development projects such as Health Canada's Governance of Research Involving Human Subjects and the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans. NAHO will continue to promote more effective and appropriate ways of doing research, and work toward new standards of excellence for research by and on Aboriginal people.

3. Address the inequities in research on Aboriginal Peoples

NAHO will adopt a proactive approach that addresses the disparities in current research on Aboriginal Peoples. For example, research on Métis populations will be a priority because so little information is available. Other priority groups include urban Aboriginal people, older adults, and groups that often have poor access to resources for research. NAHO will undertake and support research that addresses current gaps in national, provincial, territorial and community knowledge, and ensure there is gender equity in research, as well as inclusion of youth and Elders' needs and perspectives.

4. Contribute to more effective programs and services

NAHO will participate in research intended to have a direct and immediate impact on the development and delivery of Aboriginal-specific programs and services at all levels and inclusive of First Nations, Métis and Inuit. It will document successful approaches and best practices, address capacity development and increase knowledge among community leaders and service providers. NAHO will examine Aboriginal determinants of health, investigate emerging issues, and pursue integrated and holistic solutions.

5. Build Capacity in the Aboriginal Community

NAHO will participate in research that contributes to knowledge of capacity building, and ensures that this research builds sustained skills and knowledge among Aboriginal Peoples. Capacity development is an area that should be further explored and defined by Aboriginal Peoples. Research might include priorities and strategies for knowledge and skill development, how efforts to recruit and retain Aboriginal health care providers can be improved, and how well health infrastructure needs are being addressed. NAHO intends to be a leader in knowledge development technologies that are transferable to other communities and bodies.

Aboriginal Health Research: Into the Future

Finally, for research to be useful and empowering for Aboriginal Peoples, it needs to evolve and change.

Knowledge is a community resource. It defines and drives the community. It's interconnectedness, it's multifaceted and multidimensional, it's revered, it's language, communication and history. It's collective memory. It's captured and maintained for future generations. It's a reflection of life experience. It's acquired through listening and being empathetic. It's wisdom, strength and leadership. It's a strategic resource. It's the power of a good mind. It's imperfect. It's a gift bestowed by the Creator.

(Thomas Maracle, quoted in Dion Stout and Kipling, 2001, p.4)

It is an exciting time for those in the Aboriginal health research field. Researchers have the opportunity to change in very fundamental ways the manner in which research is conceived and carried out, and how knowledge is defined and created. We have the potential to contribute to a new awareness that makes a difference in peoples' lives and provides a basis for the growth of healthy communities and populations. By drawing on the wisdom of ancient Indigenous Peoples and the possibilities of science and technology, wisely used, we can undertake research that is meaningful, useful, ethical, and honourable. The opportunity to redress the misuse of information and the exploitation of research subjects and communities in the past has never been better. Research itself can become more "healthy," through balance and respect.

The Last Word is Yours

Finally, this research framework is intended as a living document, one that changes and evolves as research practice improves. We invite your comments and insight into continuing efforts to create new standards of excellence for Aboriginal health research.

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Glossary

Aboriginal healing practices

Promotion of wellness, prevention of disease, and treatment of illness that are based on Indigenous knowledge, and designed to restore balance and physical, mental, emotional, social, and spiritual well-being. Aboriginal healing practices vary from culture to culture and include a wide range of activities, from physical cures using herbal medicines and other remedies to the promotion of psychological and spiritual well-being using ceremony, counselling and the accumulated wisdom of Elders (Adapted from Royal Commission on Aboriginal Peoples, 1996, Vol. 3, Appendix 3A, p.348).

Aboriginal Peoples

The collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups – Indians, Inuit and Métis.

Acute health care

The care delivered to patients who are in the acute phase of an illness. Acute illness requires immediate attention to avoid complications, and is the phase of care in which the greatest amount of medical and nursing intervention is required (Edmonds, 2000, p.4).

Biodiversity

The range of organisms in the environment, and the numbers and types of different species, or the genetic variations within and between species, that can be found on Earth (also referred to as biological diversity). The loss of biodiversity is at the forefront of discussion concerning the effect of human activities on the environment (National Aboriginal Health Organization, no date, p.1).

Capacity building

Increasing the ability of individuals, communities and organizations to learn and to do. Capacity building for self-determination in health services involves building upon an individual and community development process. It is developing and applying abilities to govern and manage, make informed evidence-based decisions, plan strategically, identify and set priorities, evaluate, manage human and fiscal resources effectively and efficiently, and take responsibility for the success and failures of health interventions. Capacity building also implies the capacity for working with external agencies, organizations, institutions, and departments to share knowledge and experiences (Adapted from Mailloux and Gillies, 2001, p.24).

Collective rights

The idea that the members of a community or group have rights as a collective in addition to their rights as individuals. These rights might include ownership, control, access, and possession of research and community and cultural knowledge, and intellectual property rights. Collective rights are an important value in many Aboriginal cultures.

Community-based research

Research that is conceived and conducted by a community. Community members, usually through community organizations, service agencies or coalitions, undertake or direct research in order to provide information and analysis on issues that are of concern to them, and use the results to develop effective responses or influence change.

Cultural discontinuity

Culture is everything – tangible and intangible – that people learn and share in coming to terms with their environment (Royal Commission on Aboriginal Peoples, 1996, Vol. 4, p.423). Aboriginal cultures that remained strong for thousands of years have been disrupted and harmed by European cultural dominance, assimilation, and community and family breakdown. The resulting loss of cultural traditions, values and knowledge has had profound negative effects on all aspects of health.

Culturally appropriate

Programs, services or activities that are grounded in the culture in which they operate. Aboriginal initiatives that are culturally appropriate have been developed from a base of local Indigenous knowledge and incorporate the values and traditions of the culture or cultures represented. They are holistic and integrated within the community, and delivered by individuals who are both respectful of cultural differences and skilled in working with people in a way that strengthens cultural identity and builds cross-cultural understanding.

Determinants of health

The factors and conditions that are known to have an influence on health and which determine the health status of individuals and populations. Commonly used categories include income and social status, education, employment and working conditions, social environments, physical environments, gender, culture, biology, and health services (Federal, Provincial and Territorial Advisory Committee on Population Health, 1994).

Disease prevention

Measures not only to prevent the occurrence of disease, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established. Primary prevention is directed towards preventing the initial occurrence of a disorder. Secondary

and tertiary prevention seek to arrest or retard existing diseases and their effects through early detection and appropriate treatment (World Health Organization, 1998, p.4).

Empowerment

A process through which people gain greater control over decisions and actions affecting their health (Nutbeam, 1998, p.354).

First Nations

One of the three recognized Aboriginal Peoples of Canada. First Nations live in all parts of Canada and comprise over 50 distinct cultural groups.

First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS)

The first nationally co-ordinated, regionally administered survey of First Nations and Inuit that was carried out by an Aboriginally controlled body. The initial survey was conducted in 1997 and results were published in 1999. The First Nations Centre (FNC) of the National Aboriginal Health Organization (NAHO) has been mandated to co-ordinate and serve as data steward for the second cycle of the survey being completed in 2002. FNIRLHS operates using the principles of Aboriginal ownership, control, access, and possession (OCAP).

Health infostructure

The application of communications and information technology in the health sector to allow the people of Canada (the general public, patients and caregivers, as well as health care providers, health managers, health policy makers and health researchers) to communicate with each other and make informed decisions about their own health, the health of others, and Canada's health system (Office of Health and the Information Highway, Health Canada, 2002).

Health outcome

A change in health status of an individual, group or population which is attributable to a planned intervention or series of interventions, regardless of whether such an intervention was intended to change health status (World Health Organization, 1998, p.10).

Health policy

A formal statement or procedure within institutions (notably government) which defines priorities and the parameters for action in response to health needs, available resources and other political pressures (World Health Organization, 1998, p.10).

Health promotion

The process of enabling people to increase control over, and improve their health (World Health Organization, Health and Welfare Canada and Canadian Public Health Association, 1986, p.1).

Holistic

A central belief among Aboriginal people that all things are interrelated. Everything in the universe is a part of a single whole. Everything is connected in some way to everything else. Health is an interaction of physical, mental, emotional, and spiritual dimensions of the person, and people are healthy in relation to the environment in which they live.

Indigenous knowledge

An ancient, communal, holistic, and spiritual body of information and understanding that encompasses every aspect of human existence. Indigenous knowledge is unique to a culture and territory. Knowledge is passed on through traditional teachings, ceremonies, healing practices, and everyday living. In Canada, Indigenous knowledge is being applied in scientific, genetic and medical research, resource management and environmental monitoring (Adapted from Brascoupé and Mann, 2001, p.3).

Indigenous people

The original inhabitants of a geographic area, who have a social and cultural identity distinct from the dominant society where they live, and who have a close attachment to their ancestral lands (Adapted from Alderete, 1999, p.7).

Inherent right

A right which abides in a person and is not given from something or someone outside itself. An inherent right is one which a person has because he or she is a person (Garner, 1979, p.704). Refers to the right of Aboriginal people to self-government, which cannot be given or taken away by someone else.

Inuit

One of the three recognized Aboriginal Peoples of Canada. They are the Indigenous people of Canada's Arctic.

Métis

One of the three recognized Aboriginal Peoples of Canada. Every person who (a) identifies as Métis and (b) is accepted as such by the nation of Métis people with which that person wishes to be associated, on the basis of criteria and procedures determined by that nation to be recognized as a member of that nation for the purposes of nation-to-

nation negotiations and as Métis for that purpose (Royal Commission on Aboriginal Peoples, 1996, Vol. 4, Chapter 5, p.203).

Ownership, control, access, and possession of research data (OCAP)

A set of principles currently being developed in the Aboriginal research community to apply to all aspects of the research process including data collection, monitoring and surveillance, health surveys, and statistical analysis. *Ownership* refers to the relationship of an Aboriginal community to its cultural knowledge, data and information, which are considered to be collectively owned. Aboriginal people, their communities and representative bodies seek to *control* all aspects of the research and information management processes which impact them. Aboriginal people want to ensure full *access* to information and data on Aboriginal people. *Possession* of data is a mechanism by which ownership can be asserted and protected. OCAP is part of the broader self-determination aspirations of Aboriginal Peoples (First Nations Centre, National Aboriginal Health Organization).

Participatory research

Participatory research is a systematic inquiry with the active involvement of those being studied. Participatory research is usually action-oriented, where those involved in the research process work together to define the research, collect and analyse the data, produce a final product, and then act on the results.

Primary health care

The first point of contact individuals have with the health system and the first element of a continuing health care process. Primary health care includes prevention, diagnosis and treatment of common illness and injury, support for emotional and mental health, ongoing management of chronic conditions, protection from infection, advice on self-care, ensuring healthy environments and communities, and co-ordination for access to other health care services and providers (Primary Health Care Transition Fund, Health Canada, 2002).

Qualitative research

Research that uses descriptive information to examine and interpret an issue, in order to discover underlying meanings and patterns.

Quantitative research

Research that uses numerical information to quantify an issue, in order to describe its nature and magnitude.

Research ethics

A system of rules or standards that distinguishes between acceptable and unacceptable research practices. Health research ethics guidelines usually deal with issues such as the nature of the relationship between researchers and subjects, ownership of and access to data, conflict of interest, consent to research, privacy, confidentiality, and measures to preserve human dignity.

Residential schools

The boarding schools that many Aboriginal children attended between 1800-1990. Children were forcibly removed from their families for extended periods and culturally assimilated. Many experienced physical, sexual, spiritual and cultural abuse. The inter-generational and community-wide effects of the residential schools have had a devastating affect on Aboriginal Peoples' health (Adapted from Aboriginal Healing Foundation, 2002).

Royal Commission on Aboriginal Peoples (RCAP)

The national commission that was established in 1991 to investigate and recommend action on a broad range of issues affecting Aboriginal people, including the relationship between Aboriginal and non-Aboriginal peoples in Canada. After extensive consultations and research, the Commission presented its final report, *People to People, Nation to Nation, Report of the Royal Commission on Aboriginal Peoples*, to the House of Commons in 1996. The report contained 440 recommendations, many of which have influenced federal government policy and programs.

Self-determination

The opportunity and ability to direct one's own life. For an individual, it includes the freedom and the resources to make economic, health and personal decisions in one's own best interests; for communities, it is the ability to create an environment that supports the well-being of its citizens; and for nations, it is sovereignty over the land and its people. Evidence suggests that self-determination, or locus of control, is a determinant of health. Empowerment is a means to greater self-determination.

Sovereignty

Supreme power or authority of a people over their interests and territory, independent of the control of other governments (de Wolfe, Gregg, Harris et al., 2000).

Self-government

Results when a people or nation govern themselves. Self-government for Aboriginal communities requires the power, the resources and the legitimacy to make collective decisions affecting the economic, social and political future of their members. Aboriginal Peoples trace their existence and their systems of government to long before contact with Europeans, and their right to self-government was never given up. As a result, Aboriginal

people have a constitutionally protected and internationally recognized right to govern themselves. Aboriginal visions of self-government are as varied as the people's traditions, circumstances and aspirations (Adapted from Barsh, 1993; Royal Commission on Aboriginal Peoples, 1996).

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

Describes the standards and procedures for governing research involving human subjects and represents the policies of three major Canadian research bodies: Medical Research Council (M.C.), Natural Sciences and Engineering Research Council (NSEC), and Social Sciences and Humanities Research Council (SSRC). "Section 6: Research Involving Aboriginal Peoples" raises issues specific to Aboriginal research, but does not propose policy in this area as yet, in the absence of sufficient consultation with Aboriginal people (Medical Research Council, Natural Sciences and Engineering Research Council and Social Sciences and Humanities Research Council, 2000).

List of Acronyms

FNIRLHS	First Nations and Inuit Regional Longitudinal Health Survey
MAC	Medical Research Council
NAHO	National Aboriginal Health Organization
NSEC	Natural Sciences and Engineering Research Council
OCAP	Ownership, control, access, and possession of data
OCAP	Royal Commission on Aboriginal Peoples
SSRC	Social Sciences and Humanities Research Council