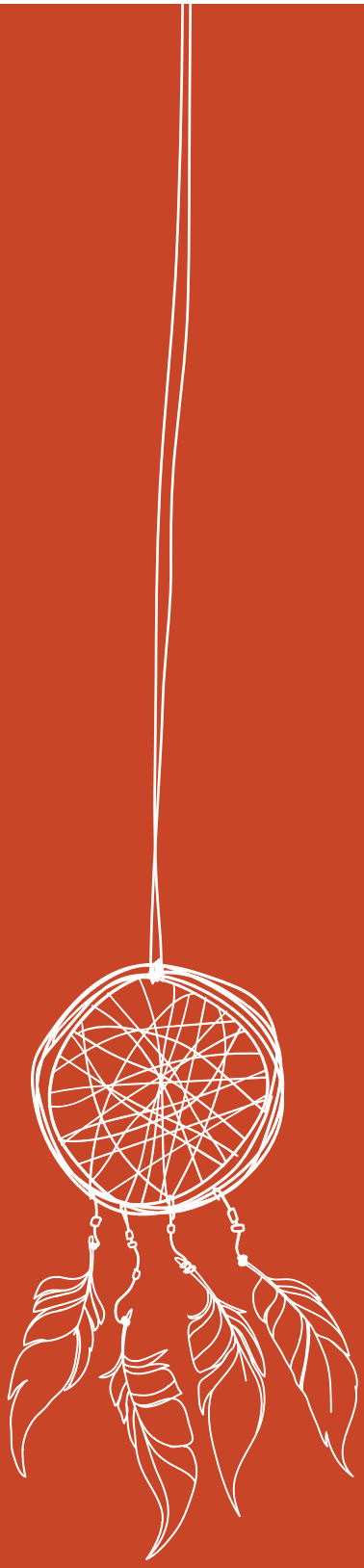

# Preventing and Managing Chronic Disease in First Nations Communities:

## A GUIDANCE FRAMEWORK (SUMMARY VERSION)

Indigenous Services Canada
Services aux Autochtones Canada
Canada

Également disponible en français sous le titre :
*Prévention et gestion des maladies chroniques dans les communautés des Premières Nations : Un cadre d'orientation(Version sommaire)*

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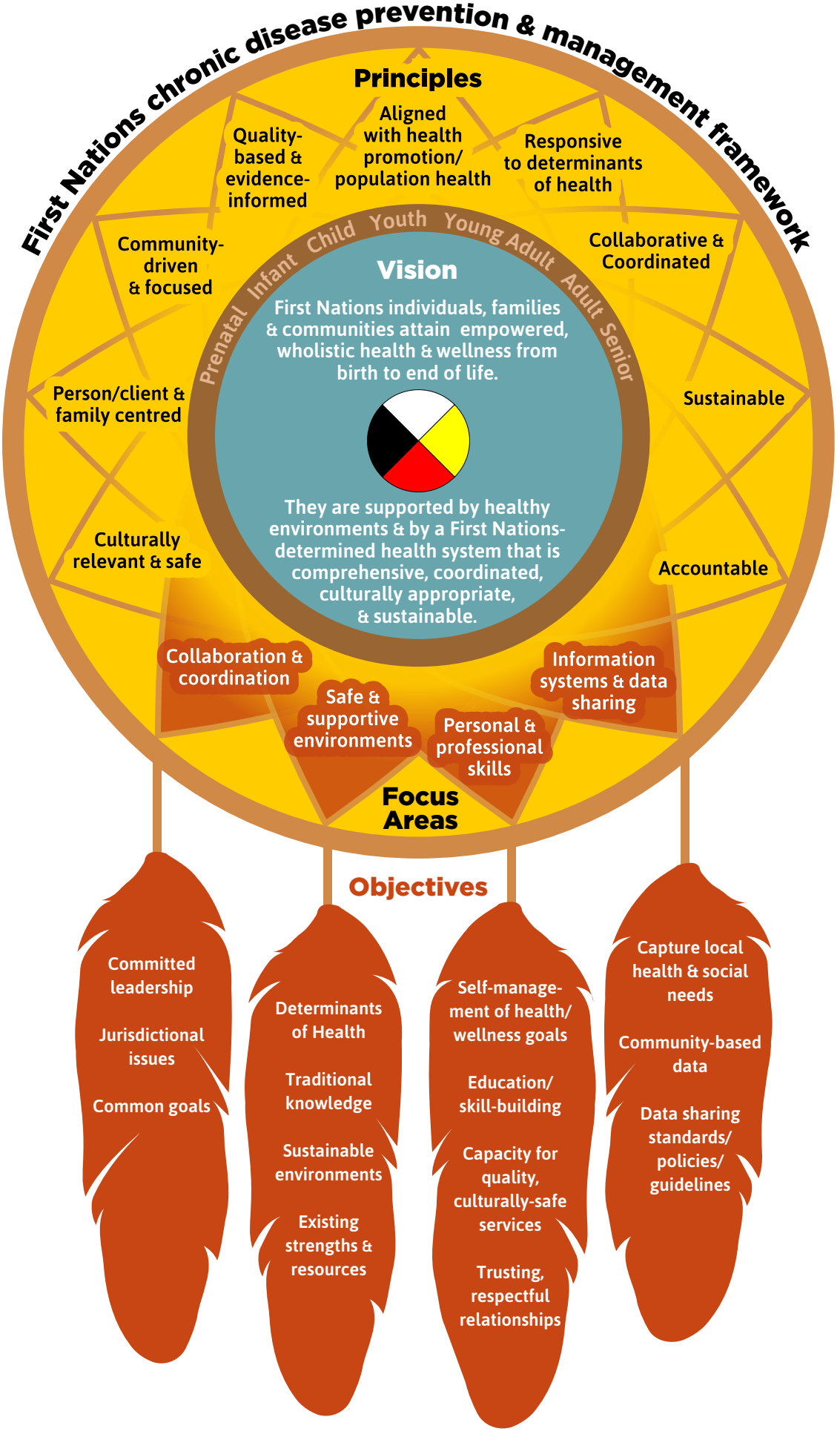
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# 1.0 Introduction

## 1.1 Background

As of 2011, there were 630 First Nations communities in Canada. These communities vary considerably in terms of size, locations and challenges they face. As a whole, First Nations in Canada experience disproportionately higher rates of chronic disease* when compared to the general population. This is attributed to a range of social, geographic and physical factors which are embodied as the social determinants of health[1]. In fact, chronic diseases now constitute the major causes of morbidity, mortality and disability among First Nations. This trend reflects the broader issue of health disparities between First Nations and non-Indigenous populations in Canada.

The First Nations and Inuit Health Branch (FNIHB) within Indigenous Services Canada supports a number of community services to prevent and manage chronic disease within First Nations communities. These programs are funded independently, which can be a challenge when trying to link with provincial/territorial systems and to support communication or teamwork between health providers and clients. These challenges reinforce siloed and disease focussed approaches and serve as a barrier to providing client and community focussed services[2345678].

It was with these factors in mind that work on this resource, *Preventing and Managing Chronic Disease in First Nations Communities: A Guidance Framework*, was initiated. This *Framework* provides direction on objectives and actions to improve health outcomes. It identifies opportunities to improve the access of individuals, families, and communities to appropriate, culturally-relevant services and supports, based on their needs, at any point along the wellness to chronic disease health continuum.

To be successful, these efforts need to respect and leverage the strengths of First Nations, including culture, language, values, and ways of knowing.

## 1.2 First Nations health, wellness and culture

Throughout the development of this *Framework*, culture was consistently identified by First Nations stakeholders as the foundational component of health and wellness. The cultural values, sacred knowledge, language, and practices of First Nations are essential determinants of individual, family, and community health and wellness. These are unique for respective First Nations.

The promotion of wellness, through to the prevention and management of chronic disease, needs to be contextualized to a First Nations environment. First Nations have identified the importance of culturally relevant and culturally safe community-based services and supports.

Unfortunately, in many communities, forces of colonization and other determinants have displaced the First Nations worldview, culture and their traditional ways of healthy living. These communities face major challenges that continue to impact their health and wellness.

* While often referenced in the singular, the term *chronic disease* represents a *group* of conditions that develop slowly, are of long duration and of generally slow progression. The expressions *chronic disease* and *chronic diseases* are used interchangeably in this document. See **Section 1.3** for further details.

## 1.3 What is chronic disease?

*Chronic diseases* can significantly affect quality of life and limit daily activities. The term represents a group of conditions that develop slowly, are of long duration and of generally slow progression. Because of this, they are more common later in life, although they can occur at any age. Chronic diseases are sometimes referred to as non-communicable diseases (NCDs), because they are not transmitted from person to person. They generally cannot be prevented by vaccines or cured by medication, although some can be managed[9].

Despite their prevalence, chronic diseases are often silent. They also tend to be cumulative - as such, the importance of health promotion, disease prevention, and early detection cannot be underestimated. Lastly, while they are all very different in many ways, chronic diseases often share a similar set of risk factors.

According to the Public Health Agency of Canada, the common risk factors for chronic disease for any population involve factors that can be modified. These include: smoking (non-traditional tobacco use); the harmful use of alcohol; raised blood pressure (or hypertension); physical inactivity; raised cholesterol; overweight/obesity; poor nutrition or an unhealthy diet; and raised blood glucose[10].

The prevalence in today's society of these major modifiable risk factors, in combination with non-modifiable risk factors such as age and heredity, contribute to the majority of new occurrences of heart disease, stroke, chronic respiratory diseases, and some cancers[12]. The relationship between these risk factors and the most common chronic diseases is similar throughout the world.

## 1.4 Determinants of health

It is well recognized that modifiable risk factors (lifestyle behaviours), such as physical activity and smoking, are influenced not only by individual choice, but also by a variety of social, economic and cultural factors inherent in the environments where people live, learn, work, and play. These *social determinants of health* affect all aspects of health, and provide a more complete understanding of the factors that lead to disparities in the health status of First Nations[11].

Successful efforts to improve health outcomes of First Nations need to take into account the broader socio-political environment, economic and historical events that have strongly influenced the current health and social realities of First Nations individuals and communities.

Such *Indigenous-specific determinants of health*[12] extend beyond issues of health care and service delivery. Many First Nations face critical housing shortages, high rates of unemployment and low levels of education. By extension, the underlying causes of illness and disease for many Indigenous peoples in Canada are linked to factors such as poverty, substandard housing, barriers to education, and food insecurity.

These additional determinants are rooted in a history of colonization and forced assimilation, which has affected First Nations culture, languages, land rights and self-determination. Taking into account this legacy of colonization, a process of *decolonization* has emerged as a priority for First Nations communities and leadership. This refers to a process where First Nations people reclaim their traditional culture, redefine themselves as a people, and reassert their distinct identity[13].

There have also been calls for a parallel process of raising consciousness within Canadian society, aimed at eliminating stigma and discrimination against First Nations people, both on the personal and the structural levels of society. These efforts to provide effective healing programming and to reclaim cultural identity are recognized as keys to revitalizing communities and reducing the impact of chronic diseases.

## 1.5 Purpose of the *Framework*

This *Framework* is not meant to be an implementation plan. Rather, it serves as a non-prescriptive guidance document to help individuals and organizations reflect on their own efforts, consider where improvements could be made, and determine next steps that are relevant for their own contexts. The intent is to assist communities in responding to new opportunities as they arise, as well as in reforming and realigning their existing chronic disease programs and services (both prevention and management) according to their own priorities.

## 1.6 Who is the *Framework* for?

This *Framework* is intended for First Nations communities. Within communities, it is intended for those who plan and deliver services. The *Framework* can also be used to inform future services that are guided by First Nations.

The guidance and interventions proposed within this *Framework* cannot be the responsibility of any one party or jurisdiction. Rather, a positive outcome will require that all partners, which can include, but are not limited to – First Nations leadership and communities, Indigenous Services Canada, other federal government departments, as well as provincial/territorial, regional and non-governmental health organizations – collaborate and coordinate their efforts.

Like chronic disease, this *Framework* should not be viewed in isolation, but should be referenced alongside other First Nations-specific resources related to health and wellness.

# 2.0 A Guidance Framework

## 2.1 Developing the *Framework*

This *Framework* was developed using two primary sources: 1) evidence in the chronic disease literature, and 2) Indigenous knowledge gathered through active engagement.

One model in particular, the *Expanded Chronic Care Model* (ECCM)[14], emerged from the literature review and provided a primary frame of reference that informed the engagement sessions with First Nations. The model encourages the creation of broader, interdisciplinary, and inclusive teams that work directly with community supports and leadership, and places clients at the centre of care.

While not as central to the engagement process as the ECCM, two additional models, the *wellness to chronic disease continuum*[15] and *the life course approach*[16] were also sourced from the evidence base and contributed helpful concepts to the *Framework*.

Supported with this frame of reference, engagement sessions were held across Canada from March to October 2013. The purpose was to gather input from First Nations regional and community-based health representatives, FNIHB regional health professionals and provincial/territorial health departments.

Ten sessions were held with a total of 325 participants, which included more than 225 community-based participants. All but one of the sessions was organized by a host First Nation organization. Following each engagement session, reports were developed based on the outcomes of discussions specific to that region.

Engagement focused on three priorities to develop the First Nations-specific *Framework*: 1) defining a shared *vision*; 2) identifying and describing key *principles*; and 3) exchanging ideas and knowledge on effective *community-based approaches* for promoting health and preventing and managing chronic disease.

The results of this engagement formed the ***vision,*** nine ***guiding principles***, four ***focus areas***, and associated ***objectives*** and ***activities*** (distilled from the input on community approaches) for improved wellness and chronic disease outcomes for First Nations.

## 2.2 Vision Statement

For the purposes of the First Nations engagement sessions, ***vision*** was defined as an aspirational statement that communicates both the purpose and value of an approach to chronic disease prevention and management for First Nations communities. It answers the question "*Where do we want to go?*" The vision for improved chronic disease prevention and management outcomes for First Nation is:

**"First Nations individuals, families and communities attain empowered, wholistic health and wellness from birth to the end of life. In so doing, they are supported by healthy environments and by a First Nations-determined health system that is comprehensive, coordinated, culturally appropriate, and sustainable."**

## 2.3 Guiding Principles

This *Framework* is grounded in nine *principles*. These represent fundamental, shared values that provide direction, set standards, guide efforts and underpin all the chronic health decisions that First Nations partners in health make going forward. *To be successful, policies, programs, and services aimed at addressing chronic disease in a First Nations setting need to be:*

1. Culturally relevant and safe
2. Person/client and family centred
3. Community-driven and focused
4. Quality-based and evidence-informed
5. Aligned with health promotion and population health approaches
6. Responsive to the impact of Indigenous-specific determinants of health
7. Collaborative and coordinated
8. Sustainable
9. Accountable

## 2.4 Focus Areas

The engagement sessions identified four primary *focus areas* within the continuum of chronic disease prevention and management where improvements could have the greatest positive impact on the health and wellness of First Nations people, families and communities:

1. Collaboration and coordination
2. Safe and supportive environments
3. Personal and professional skills
4. Information systems and data sharing

Specific *objectives* for each area were formulated based on collective input from the engagement sessions. These objectives identify and consolidate a discreet set of strategic considerations and suggested activities most relevant to each area. Examples of these *activities* were offered during engagement that could be taken, or were already being taken, to move toward system transformation, and demonstrate how the respective objective might be achieved.

# 1. COLLABORATION AND COORDINATION

Many health agencies – regional/provincial/territorial and federal – are responsible for delivering programs and services along the continuum of health, from promotion and prevention to management and care. Successful delivery requires a firm commitment at the leadership levels of all partners in health to cooperate, coordinate and collaborate among themselves and with other First Nations to define common goals and address jurisdictional issues. This committed leadership – in conjunction with sufficient, needs-based funding of programs and services – is critical to ensuring that First Nations individuals, families and communities receive services when and where they are needed.

**OBJECTIVE 1**

Leadership at all levels is committed to improving the current health system, creating effective partnerships, encouraging ongoing learning, and maximizing internal and external resources.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Leadership at all levels fully supports chronic disease prevention and management as a community priority** | ▸ Develop a community vision for community health and wellness.<br>▸ Develop a plan for implementing the community vision through various logistics, funding and training.<br>▸ Adapt budgeting and funding to meet community priorities based on quality, long-term sustainability, and consistency in support.<br>▸ Make/enhance connections with the provincial/territorial health system in order to collaborate and support seamless chronic disease prevention and management services.<br>▸ Support local community groups, networks, and activities that focus on health and well-being. |
| **Support the integration of similar community-based programs (e.g., home care services) to improve the delivery of chronic disease prevention and management programs** | ▸ Establish and maintain relationships with health providers based on an inter-disciplinary approach that promotes team building and care coordination.<br>▸ House all health care programs/services in the same building in communities to improve teamwork and to give clients easier access to services.<br>▸ Work with community Elders and/or traditional healers to provide integrative and culturally appropriate care. |
| **Collaborate with other strategies and initiatives relevant to chronic disease** | ▸ Coordinate with the health promotion and disease prevention/care aspects of existing Frameworks, strategies, initiatives, and programs. |

## OBJECTIVE 2

Partners in First Nations health identify and address jurisdictional issues so that clients can have seamless access to services that prevent and manage chronic disease.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Collaborate with other First Nation communities, as well as with regional, provincial/territorial and federal health agencies, to *identify* jurisdictional issues** | ▸ Create agreements with provinces/territories to clearly outline the kinds of services available to First Nations, and clearly outline federal and provincial/territorial jurisdictional responsibilities for First Nations health service delivery, and accountability for First Nations health outcomes. |
| **Collaborate with other First Nation communities, as well as with regional, provincial/territorial and federal health agencies, to *address* jurisdictional issues** | ▸ Reduce the impact of barriers on accessing services (such as remoteness, availability of professionals, limited funding, and low access to specialized services like cancer screening and FASD diagnostic clinics).<br>▸ Establish collaborative practices (a client sees more than one professional at the same visit) in conjunction with the provincial/territorial system, and ensure that cultural supports are available as needed.<br>▸ Provide timely access to provincial/territorial health and social services, while ensuring that cultural sensitivity, culturally safe and appropriate care, and traditional health and language support are part of this access. |

## OBJECTIVE 3

Partners and stakeholders in health work together to define common goals and commit to accountability in their efforts to prevent and manage chronic disease.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Set up fair and effective service partnerships and protocols between the community and the provincial/ territorial service structures, in order to establish inter-disciplinary team approaches with clear roles and responsibilities** | ▸ Put in place the position of case management/care coordinator to ensure continuity of care and clarity of roles and responsibilities.<br>▸ Develop integrated care teams and integrated workplans with community-based workers (such as community health nurses, home care nurses, personal and home support workers, including spiritual advisors and traditional healers). |
| **Make adjustments to health care practice using quality improvement methods** | ▸ Apply clinical practice guidelines, standards, policies and procedures and put in place planned interactions and active follow ups (e.g. care pathways and processes).<br>▸ Integrate programs (ranging from health promotion, disease prevention, and care management), with a focus on wholistic wellness rather than illness.<br>▸ Provide local community health centres with the funding necessary to pursue accreditation and enable integration and quality of care. |

# 2. SAFE AND SUPPORTIVE ENVIRONMENTS

The natural, social and physical environments in which people live, learn, work, and play have a major impact on people's health and quality of life. Inequities in these environments are a root cause of health gaps among First Nations. Supportive environments are safe and respectful for all who use or inhabit them. They serve a variety of functions. These include:

- Providing access to needed services and promoting healthy and safe physical activities;
- Ensuring access to affordable healthy food and basic necessities;
- Supporting healthy nutrition and lifestyle choices in the workplace and schools; and
- Providing safe places to care for and support seniors, persons with disabilities, and victims of violence.

Supportive environments include the natural world and traditional land in and around communities. Sustaining spiritual links with ancestral lands through traditional languages, knowledge, teachings, practices, and environmental stewardship, are important ways in which First Nations work to create and maintain supportive environments.

**OBJECTIVE 1**

The social and Indigenous-specific *determinants of health* have been addressed.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **First Nations work with inter-disciplinary and multi-jurisdictional partners on issues related to housing, safe water supply, job opportunities, food security and infrastructure** | ▸ Create a plan or program, when required or as appropriate, that responds to the housing shortage crisis, environmental hazards to health such as mold, radon, and rodent infestations, as well as needed repairs resulting from the deterioration of housing infrastructure.<br>▸ Work with retailers, Elders, and other partners to develop/strengthen traditional food access programs (could include community gardening, food preparation, and land-based activities such as harvesting traditional foods through hunting, fishing, and gathering).<br>▸ Develop and share best practices (as defined by First Nations) that respond to the social and Indigenous-specific determinants of health.<br>▸ Develop policies that support healthy choices, as well as healthy and safe environments.<br>▸ Improve collaboration/coordination on these issues between federal government departments. |

## OBJECTIVE 2

Traditional worldviews, knowledge, and language support positive links to the natural, social, and physical environments.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Establish practices that protect, preserve, and enhance traditional worldviews, knowledge, and language to support positive links to environments** | ▸ Develop and implement appropriate curricula and learning resources (in primary, secondary and post-secondary schools) on the historical relationship between First Nations and Canada, colonization and acts of forced assimilation (including the history and legacy of residential schools).<br>▸ Develop and implement school curriculums which fully respect, protect and preserve traditional teachings and traditional Indigenous languages.<br>▸ Work with Elders and/or traditional knowledge keepers to provide teachings of traditional knowledge, medicine, healing, languages and cultural practices, both within and outside of school settings.<br>▸ Host traditional social gatherings (i.e. traditional feasts) and culture camps (to teach traditional languages and traditional ways of living and knowing). |

## OBJECTIVE 3

Sustainable environments promote healthy lifestyles, and access to healthy choices.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **All partners collaborate to develop public policies that support healthy and sustainable environments** | ▸ Improve the safety of community infrastructure (sidewalks, playgrounds, fences, buildings, etc.).<br>▸ Enforce by-laws that promote safe outdoor spaces (e.g. prohibiting dogs from roaming around without a leash).<br>▸ Modify community infrastructure to support more outdoor physical activity (walking paths, bike parks, better lighting, etc.).<br>▸ Improve access to living spaces for persons with a disability or chronic disease (residential care or group homes), including support for those with mental health challenges.<br>▸ Develop an Elders-at-home strategy.<br>▸ Design and implement campaigns to promote smoke-free homes, workplaces and public spaces.<br>▸ Designate breastfeeding friendly sites and smoke-free spaces within communities. |

## OBJECTIVE 4

The community's existing strengths and resources serve as the foundation for progress.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Encourage all community resources and stakeholders to collectively engage in the self-determination of community health planning** | ▸ Create a community health committee (representing, among others, day-cares, schools, social services).<br>▸ Encourage volunteerism by instituting a volunteer recognition program.<br>▸ Leverage role models and strengthen cultural values through inter-generational sharing and activities.<br>▸ Implement an awareness campaign on the importance of healthy public policies.<br>▸ Develop and implement healthy public policies within the community (e.g. training on how to apply animal control by-laws).<br>▸ Encourage the creation and expansion of youth clubs (such as drumming, singing/dancing groups), in order to develop leadership skills among youth and nurture their self-confidence. |

# 3. PERSONAL AND PROFESSIONAL SKILLS

The right kind of resources, learning opportunities, and support (from health providers, family, community members, and/or respected others, such as Elders and peers), are important for self-management. All community members can benefit from chronic disease health/wellness information, self-management resources, and community-based group programs that are accessible and culturally-responsive.

Enhancing professional skills involves equipping health workers with better tools for health promotion, for the prevention and management of chronic disease, and strengthening their ability to support clients in a culturally safe and appropriate manner.

**OBJECTIVE 1**

Individuals and families develop their own personal health and wellness goals, grounded in traditional knowledge and wholistic health.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Support individuals and families in their wellness and chronic disease self-management efforts in a culturally safe way** | ▸ Involve individuals and families, and informal care-givers in shared decision-making, care planning and goal-setting.<br>▸ Provide clients and their families with access to culturally safe education programs and health information.<br>▸ Work with Elders to translate western health and wellness, and medication information into a traditional language.<br>▸ Organize or encourage peer support groups for those experiencing health challenges and/or living with a chronic disease.<br>▸ Provide individual and family follow-up, using a coordinated inter-disciplinary approach. |

| **OBJECTIVE 2**<br>Appropriate education and skill-building activities are in place to promote health and wellness. | |
|---|---|
| **STRATEGIES FOR CHANGE** | **POTENTIAL/SUGGESTED ACTIVITIES** |
| **Encourage use of a community-based approach to health and wellness** | ▸ Integrate healthy living lessons into the school curriculum, with classes focused on home economics, cooking, health, and physical education.<br>▸ Provide educational opportunities for youth and children to learn about culturally grounded healthy living and chronic disease self-management practices.<br>▸ Organize groups for parents to support positive approaches to parenting that are grounded in tradition and culturally-driven.<br>▸ Identify community champions and role models who demonstrate healthy living practices and inspire others to make healthier choices.<br>▸ Promote population-specific and culturally-safe healthy living and disease prevention activities through social media, radio, Internet, and community bulletin boards.<br>▸ Undertake community awareness campaigns to dispel misconceptions about common chronic conditions and diseases. |

## OBJECTIVE 3

Health providers have the capacity to provide high quality, culturally safe services.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Equip health providers with the training, skills, competencies, and knowledge necessary to deliver high quality, culturally safe chronic disease prevention and management activities** | ▸ Provide frontline services with sufficient funding and staffing to:<br>  ▸ Ensure health professionals complete mandatory training courses;<br>  ▸ Allow for and promote supports for self-care to prevent burnout in the workplace.<br>▸ Create a healthy work environment that incorporates leadership, cultural safety, effective teamwork, standardized processes of care, ongoing learning, and measures for improvement.<br>▸ Provide regular orientation to health providers on what services/programs and resources are available, and training in how to help clients access needed supports and services ('navigate the system').<br>▸ Develop protocols for information and knowledge sharing (i.e. telemedicine) and form linkages to support the facilitation of improved communication, relationship building, and networking among partners.<br>▸ Train health workers in cultural safety, communication, motivational interviewing techniques, and chronic disease self-management education techniques. |

## OBJECTIVE 4

Health providers work with their clients within a relationship based on trust, respect, and open communication.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Develop the capability of health providers to work with their clients within a relationship based on trust, respect, and open communication** | ▸ Train health providers in relationship-building, cultural competency and cultural safety.<br>▸ Train health providers to become coaches, mentors, and facilitators.<br>▸ Implement cross-training of roles and responsibilities for health providers working in a team to broaden their knowledge and expertise, and to ensure scope of practice is articulated for each health care provider. |

# 4. INFORMATION SYSTEMS AND DATA SHARING

The use of information systems is key to support processes for change. Information systems capture details on the health and social needs of a community. This data can be used for planning, coordination, decision-making and communicating with health providers. In an ideal situation, information about demographics; health of the community; and cultural, social and economic trends are combined with needs and strengths assessments that are led by community groups.

In order for this to work, information systems used by community-based services (including surveillance reporting and client registries) and those at the provincial/territorial level need to be compatible, efficient, and appropriately integrated. Clear guidelines and data sharing need to be established to ensure that client information is shared in acceptable and safe ways which work towards OCAP® principles.

OCAP® stands for ownership, control, access and possession. It "was created by the First Nations Information Governance Centre (FNIGC) and provides guidance to communities about why, how, and by whom their information is collected, used, or shared. OCAP® reflects First Nation commitments to use and share information in a way that brings benefit to the community, while minimizing harm." (FNIGC, 2014). For more information on OCAP®, go to: http://ir.lib.uwo.ca/iipj/vol5/iss2/3

"Because of the federal Crown's relationship with, and responsibilities to First Nations, Canada collects and holds more information on First Nations people than perhaps any other group in Canada. The collection, use, and disclosure of this information is regulated by the *Privacy Act* (Government of Canada, 1985b), the *Access to Information Act* (Government of Canada, 1985a), and the *Library and Archives of Canada Act* (LACA), all of which apply exclusively to federal government institutions (see Banks & Hébert, 2004). While the *Privacy Act* protects personal information, the *Access to Information Act* and the *Library and Archives of Canada Act* present legislative obstacles to OCAP®..." (http://fnigc.ca/sites/default/files/docs/ocap_path_to_fn_information_governance_en_final.pdf, 2014, p. 2)

## OBJECTIVE 1

Community information systems are designed to capture local health and social needs.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **First Nations leaders and First Nation data experts work together so that communities are able to collect, possess and protect their own health data** | ▸ Develop community Electronic Medical Records (EMR) system and ensure its compatibility with provincial/ territorial and hospital systems.<br>▸ Train community staff and provide ongoing support in using the information system to ensure data quality and skilled analysis.<br>▸ Ensure the system allows ongoing back up and archiving of information. |

## OBJECTIVE 2

Community-based data is used to promote quality improvement for First Nations programs and services.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Develop appropriate community-based health indicators within information systems** | ▸ Include indicators in information systems that are evidence-based, relevant to communities, and promote quality improvement of programs and services.<br>▸ Develop a comprehensive and community driven public health surveillance system, including appropriate indicators, as well as systematic and timely collection methods.<br>▸ Use evidence based indicators to promote quality improvement.<br>▸ Develop client registries within community information systems. |

## OBJECTIVE 3

Clear standards, policies, and guidelines on data sharing are in place to ensure client privacy, as well as system safety and security.

| STRATEGIES FOR CHANGE | POTENTIAL/SUGGESTED ACTIVITIES |
|---|---|
| **Develop clear standards, policies, guidelines and data sharing protocols** | ▸ Ensure early, frequent and continuous community engagement in the process to develop standards, policies and guidelines.<br>▸ Share best practices about system performance, success stories and challenges to help other communities develop their information systems.<br>▸ Develop a plan on how people (and systems) will work together; clarify roles and access to the system to ensure client health needs and health data remain private, confidential and closely guarded from misuse.<br>▸ Create data collection systems which would be owned, controlled, managed and housed within communities, and work towards being fully OCAP® compliant.<br>▸ Formalize standards, policies and guidelines via appropriate agreements between partners. |

# 3.0 Conclusion

The suggestions provided in this document, by First Nations, are examples of what is required to respond to the increasing rates of chronic disease in order to promote a better quality of life for individuals and families and, ultimately, to improve the health of communities.

Partners and stakeholders who took part in engagement sessions wanted the *Framework* to create an *enabling environment* that would guide effective disease prevention and management. The *Framework* development process reflected this request. For the first time, the challenges were addressed according to what communities articulated as their actual needs, using their strengths as a foundation, with a goal of empowering them for the future.

Indeed, one of the pivotal benefits of the *Framework* is that it can be used to support planning at the community level. How this *Framework* is implemented by First Nations is at the full discretion of communities, according to each community's needs and priorities and within the limits of the fiscal and human resource realities that exist within Indigenous communities.

It can also be used at the regional and national levels to strengthen federal chronic disease prevention and management programming and services, as well as to inform policy development.

Effective responses in First Nations communities require new and innovative ways of approaching the prevention and management of chronic disease. As such, this *Framework* will prove most effective as a *living* process that looks forward and evolves over time in response to actual community experiences as they work with the stated *objectives* and suggested *activities*.

The ultimate aspiration is that actions taken now in response to the *Framework* will pay off with health, economic, and quality of life dividends for First Nations in the future, as communities make steady progress towards achieving the ***vision***:

**"First Nations individuals, families and communities attain empowered, wholistic health and wellness from birth to end of life. In so doing, they are supported by healthy environments and by a First Nations-determined health system that is comprehensive, coordinated, culturally appropriate, and sustainable."**

# Endnotes


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