Trends in Alzheimer’s disease and related dementias among First Nations and Inuit

Final Report
March 27th, 2012

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Contract Reference 4500268919
Acknowledgments

We would like to thank all of the people who provided guidance during the planning, preparation and review of this report. In particular, we thank the following organizations:

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<td>Assembly Of First Nations (AFN)</td>
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Executive Summary

In Canada, the number of people with Alzheimer’s disease and related dementias (ADRD) is projected to more than double over the next 30 years. Little is currently known about the prevalence and incidence of ADRD among First Nations and Inuit but ADRD is expected to be an increasing challenge for home care services in First Nations and Inuit communities. The current lack of essential information makes planning for, and responding to, this emerging issue difficult for communities and those who provide services.

This report was undertaken to provide information to the First Nations and Inuit Home and Community Care programs to assist in their planning. The report draws on published information through a literature review. Based on the limited data available, estimates for current and future prevalence of ADRD among First Nations and Inuit are provided.

The conceptual framework used for the report takes into account social determinants of Aboriginal health over the life course.

A Note on Terminology

Throughout this report, we have used consistent terminology when referring to Indigenous peoples in Canada and internationally.

The term “Indigenous” is used when we refer to groups across several countries.

The term “Aboriginal” is used when we refer collectively to the three constitutionally recognized groups in Canada: First Nations, Inuit and Métis. Where possible, we avoid this collective term and use the terms “First Nations”, “Inuit” and “Métis” specifically. For this report, the term “First Nations” refers to individual people and not to individual Nations. The term also may include individuals living off reserve and/or who are not registered through the Indian Act. Where relevant, we distinguish these populations and, where possible, we refer to individual Nations.

In international contexts, we use the accepted ethnic identifiers and terms most often used in those countries. For example, we use “Aboriginal” in Australia and “American Indian”/“Alaskan Native” and “Blacks” in the United States.
Key Findings

1. The limited published information available indicates that the prevalence of treated dementia is increasing more quickly in First Nations than in the general Canadian population and that the age of onset is younger for First Nations.

2. No validated cognitive screening tool has been developed that is sensitive to First Nation or Inuit culture or that takes into account the broader social determinants of health (income, education, geography, history, etc.), which are known to affect the reliability of mainstream screening tools.

3. First Nations and Inuit are likely underdiagnosed for ADRD, with a greater degree of underdiagnoses likely in more rural and remote communities.

4. First Nations and Inuit may be at greater risk of developing ADRD than the mainstream population for the following reasons:
   a. First Nations and Inuit are known to have higher rates of medical conditions known to increase the risk for developing ADRD: stroke, high cholesterol, hypertension, diabetes mellitus, depression, major head injury, obesity, periodontal disease, psycho-social stress; and, have reduced opportunities for potential protective factors such as education, vaccinations, and physical activity; and,
   b. First Nations and Inuit are more affected by other social and environmental factors that increase the risk of developing ADRD: lower levels of education; poverty; high rates of smoking; alcohol and drug abuse; and, greater exposure to environmental toxins.

5. Research from Canada and the United States suggests that Indigenous peoples may hold many different understandings of dementia ranging from a western disease perspective to an Indigenous framework of aging through the lifecycle. Varying cultural understandings also influence the interpretation and experience of dementia symptoms.

6. Cognition is culturally constructed (how we understand the world influences how we process knowledge about it), therefore cognitive stimulation must be culturally relevant. Cultural systems within and among Aboriginal communities that may potentially improve or sustain cognitive function in old age include: Aboriginal language use, the traditional role of elders as story tellers and knowledge keepers, and participation in ceremony.

7. Caregiving for older First Nations and Inuit is more complex and difficult in comparison to the overall Canadian population. The relative burden of illness experienced by older Aboriginal people in Canada is much greater than the general population. First Nations and Inuit are more likely to suffer from chronic disease in old age, more likely to have several co-morbid conditions, are less likely to have access to care that is equivalent to care for the general population, and are more likely to be negatively affected by social determinants of health.
8. Informal caregivers in Aboriginal communities generally share a positive view of their role and accept responsibility with few questions. **Cultural values** play a large role in sustaining informal caregiving in these communities.

9. **Informal caregivers** in tribal communities in the United States appear to exhibit less stress associated with their role but do report significant burdens. There is a strong desire on the part of these caregivers to do a good job and make good decisions regarding care. Caution should be exercised in viewing informal caregiving traditions in First Nations and Inuit as a panacea for increasing pressures on public spending. The evidence reviewed suggests there are optimal conditions under which informal care giving is appropriate for Aboriginal people.

10. **Formal institutionalized caregiving** is viewed as problematic for many Aboriginal communities participating in research. Aboriginal people prefer to age in their communities even when physical or cognitive limitations are present. Institutions (nursing homes) especially when located outside of the communities are viewed a mechanism by which the transmission of knowledge is interrupted and Elders’ important role in the community is undermined. Nursing homes are described by some as a ‘death sentence’ to be used only as a last resort. Research from the United States suggests that nursing home or alternate level care models **may** be acceptable where the tribal/band authority controls, staffs and runs the facility using culturally appropriate methods.

11. There is limited but promising evidence that the use of **Indigenous language** in the care of people with dementia may have benefits to the quality of care and the quality of life experienced by the patient. Use of Indigenous language may also prove to be an important prevention tool. Both of these findings suggest that provision of services locally, by local people, is an important part of Inuit and First Nation dementia care.

12. Dementia is a word that is not easily translated into Indigenous languages. Dementia as a **biomedical construct** did not exist in these communities. Words used to describe forgetfulness or confusion exist, but these are distinct from describing dementia as an illness or disease.

13. The **provision of services** for people with dementia are best delivered locally. There is a widespread desire to have services available close to home so that culture and language barriers may be minimized and so that Elders’ role within the community is not disrupted. The provision of local services can be enhanced and made more effective by improved training for local staff, the provision of community information sessions, support services for family, and cultural sensitively training for all health care professionals. **Telemedicine** (videoconferencing) may be an appropriate way to improve specialist service coverage to First Nations and Inuit but research into its effectiveness and acceptability for First Nation and Inuit dementia care is currently lacking.

14. As a direct result of population aging, our **projections** indicate that the rate of increase in the number of First Nations with ADRD will be nearly double the increase in the general Canadian population. Between 2006 and 2031, ADRD will likely increase by 4.2 times in First Nations. The increase will be highest on-reserve, where a 4.8-fold increase is expected. Accurate projections are not possible for Inuit due to lack of baseline prevalence data. If First
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15. The use of cholinesterase inhibitors is expanding among First Nations and Inuit beneficiaries of Health Canada’s Non-Insured Health Benefits program. Over one year, the number of claimants increased by 11% and the number of claims by 25% between 2009-10 and 2010-11, indicating a likely increase in both spread and intensity of use, particularly in Quebec and Atlantic regions. Females accounted for 67% of the claims and associated costs. Ninety percent of claims were for those aged 65 and older. However, a notable 15% of the total amount that NIHB paid for cholinesterase inhibitors were for those younger than 65.

16. Several limitations concerning the available data (type and coverage) restricted the projection methodologies. It is likely that actual number of people with ADRD could be twice as high as the treated prevalence estimated in this report. As a result of the changing profile of diabetes prevalence and the relationship between diabetes and ADRD, the projected prevalence of ADRD among First Nations and Inuit may be underestimated.

17. Diabetes and ADRD are associated. Left unchecked, increasing rates of diabetes will be associated with increasing rates of ADRD for First Nations and Inuit. Diabetes interventions focused at two stages may be effective in reducing the future burden of ADRD in First Nations and Inuit: 1) Diabetes prevention programs for people throughout the lifecycle, and 2) diabetes interventions that seek to improve blood glucose levels in those already diagnosed with diabetes.

18. Beyond the discussion of reducing risk, very little information is available to date that evaluates the effectiveness of prevention and intervention activities concerning ADRD. There do not appear to be any Aboriginal-focused ADRD interventions or evaluations of intervention or prevention strategies. Based on mainstream research, it is likely that strategic and appropriate interventions may mitigate some of the expected increase in ADRD in First Nations and Inuit. It is projected that programs that seek to increase physical activity levels could result in 8.6% fewer cases of ADRD over 30 years.

Potential Impacts on First Nations and Inuit Home and Community Care Programming

With some limitations noted, the results suggest an increased demand for ADRD-specific care will be placed on First Nations and Inuit communities and on the Home and Community Care Program over 25 years. Our conservative estimates suggest an almost 5 fold increase in First Nation ADRD care patients and nearly a 3 fold increase in Inuit dementia care patients. While the data should be interpreted with caution at this point, the ADRD gender distribution from British Columbia First Nations suggests that FNIHCC may expect to see an increase in the number of males requiring services - currently, more females require (or access) services (Johnston Research Inc., 2011).
Enabling First Nation and Inuit people to remain in their communities is the most appropriate approach to caring for those with dementia. This will result in increased demands for ADRD specific care that will impact on expenditures in many of the mandatory and non-mandatory programs supported by FNIHCC, most critically:

- assessment (screening and specialist care),
- case management,
- home care support (RN and personal support worker),
- training (nurses, community health workers, informal caregivers, community),
- respite care, and
- data/research.

Programs that support families caring for persons with ADRD will also be impacted. First Nations and Inuit in most cases do not “fit” mainstream care models that focus on dyad care-giving relationships because multiple family and community members can be involved in care for the person with ADRD. This will increase community and informal caregiver training needs (more individuals will require training) which must be made specific for ADRD care.

**Recommendations**

1. At a systemic level, we recommend that FNIHCC consider consulting on the development of national, comprehensive First Nations and Inuit ADRD Strategy in partnership with First Nations and Inuit organizations and other invested parties such as the Alzheimer’s Society of Canada, the long-term, acute and primary care sectors and academic partners. This strategy should include:
   a. The development of ADRD research agenda in collaboration with First Nations and Inuit organizations
   b. Appropriate support to informal caregivers
   c. Emphasis on prevention and early intervention
   d. Integrated systems of care
   e. Strengthening the ADRD workforce

2. At the FNIHCC program level, we recommend that the program support collaborative research that leads to the development of best practices for screening First Nations and Inuit for cognitive impairment and dementia. In the short term, work should focus on:
   a. the development of culturally appropriate screening instruments that reflect the Aboriginal social determinants of health, the diversity of First Nations and Inuit culture, and local/community access to physician care, specialist care and follow-up care;
   b. the assessment of the appropriateness and effectiveness of the use of telemedicine in dementia screening; and,
   c. training of physicians and health care workers in the use of culturally meaningful screening instruments.
3. We recommend the development of a **Cultural Safety Training Program** for First Nation and Inuit Dementia Care in consultation with communities, Elders, researchers, program staff and front-line health care workers. The training should build on the themes identified in the literature review:
   a. Should reflect First Nation and Inuit understandings of and experiences with dementia (cultural understandings of the illness/process, causes, expectations, symptoms, appropriate care and treatment),
   b. Should be directed at non-Aboriginal health care providers but available to all Aboriginal and non-Aboriginal providers; especially nurses, physicians, partner organizations such as Aboriginal Affairs and Northern Development Canada staff and Alzheimer society staff,
   c. Should include training on the integration of traditional and western medicine in treatment and prevention of dementia and should facilitate relationship building between physicians and local healers,
   d. Should include the development of a common local language and terminology guide specific to the region.

4. We recommend that the FNIHCC program support and encourage community-led culturally relevant initiatives that provide opportunities for both **intervention in and prevention of dementia** in First Nation and Inuit communities, for example, programs that connect elders and youth, elders with each other, and that increase elder participation in traditional language and ceremonial events. Such activities could be supported through enhancements modifications or additions to current programming and through programming combined with pilot testing new initiatives. In either case we further recommend clear appropriate **evaluation** processes be incorporated so that best practices can be developed and shared.

5. We recommend FNIHCC proceed with great sensitivity in relation to expectations concerning the role of **informal and community caring models**. Caution should be exercised in viewing informal caregiving traditions in First Nations and Inuit as a panacea for increasing pressures on public spending. While informal caregiving can be appropriate and effective, the evidence reviewed suggests there are optimal conditions under which informal care giving is safe and effective for Aboriginal people:
   - When enough financial resources are in place for the family,
   - When families/households are healthy themselves,
   - When supported by well-trained and culturally safe community health care staff and professional expertise,
   - When information and training is available for the career(s) and community at large
   - When in-home respite services are available,
   - When cultural healing resources are available for the patient and career,
   - When communities are part of the care support.
6. We recommend the development of **Local Care Models** that are reflective and supportive of local culture, geography, resources, community assets, and community health services. Working within its’ mandate, we recommend that FNIHCC coordinate the development Local Care Models by:
   a. Enhancing in-home respite care and working with communities to determine how they might work to prioritize respite in their delivery of the FNIHCC program over the next 10 years.
   b. Provide culturally appropriate training and support for ADRD to informal and formal community caregivers
   c. Provide culturally safe information sessions on ADRD for community members at large
   d. Support “adult day care” that is grounded in the local culture and values and is focused on culturally appropriate interventions and dementia prevention (see Recommendation #4)
   e. Support financially the integration of traditional Indigenous medicine and ceremony into care plans for clients and care-givers.

7. We recommend that the FNIHCC respond to the immediate and ongoing need for **data and information on ADRD** among First Nations and Inuit and specifically FNIHCC clients.
   a. Short term strategies:
      i. Continue to monitor NIHB claims for cholinesterase inhibitors, including sex, age, and regional breakdowns.
      ii. Investigate the possibility of using the RHS (memory variable) for on-reserve and CCHS (reported dementia diagnosis) for off-reserve First Nations as a proxy for determining incidence of dementia.
      iii. Immediately include ADRD as one of the conditions tracked in existing information system OR conduct a special study to determine the current proportion of clients with an ADRD diagnosis.
      iv. Encourage survey and information system development that would allow for research of ADRD among First Nations and Inuit. This minimally requires collection of both Aboriginal identity and ADRD – or the ability to link the two data elements. An enhancement would be the collection of risk factors and comorbid conditions. Ideally, longitudinal data would be available that takes into account social determinants of health from an Aboriginal perspective.
      v. Ensure that cognitive assessment tools embedded in current and potential future information systems (e.g., Resident Assessment Instrument – Home Care (RAI-HC)) are culturally relevant.
      vi. Consider undertaking a longitudinal ADRD research study in partnership with First Nations and Inuit organizations and other invested parties such as the Alzheimer’s Society of Canada, the long-term, acute and primary care sectors and academic partners.
b. Long term strategies:
   i. Embed mechanisms to monitor ADRD clients into existing systems. Consider longitudinal assessment of cognition, informal caregiving, care needs, comorbid conditions, medication use, and adverse outcomes.
   ii. Invest or participate in pan-Canadian efforts to develop/use existing databases or to conduct primary research on ADRD in First Nations and Inuit.

8. In addition to the recommendations we have made program-wide, we recommend that service provision for remote First Nation and Inuit communities focus as much as possible on improving and sustaining locally available resources for people with dementia. Strategies should include but not be limited to:
   a. The development and implementation of dementia specific training for all community health care workers that is prepared and presented within a cultural safety framework.
   b. Exploration and research into the use of telemedicine in dementia diagnosis and ongoing dementia care.
   c. Enhanced homecare services for people in the late stages of dementia to enable people with dementia to remain in their communities until their passing if they should desire it.
   d. Community development work to enhance community and family participation in care of people with dementia.
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Final Report

1. Introduction and Background
Alzheimer’s disease and related dementias (ADRD) is emerging as a significant health concern globally and in Canada. In Canada, approximately 500,000 people have ADRD. This number is projected to more than double to 1,125,184 over the next 30 years (Alzheimer Society of Canada, 2010). Little is currently known about the prevalence and incidence of ADRD among First Nations and Inuit. Concerns have been raised regarding a perceived increase in the rate of ADRD in Aboriginal communities, a lack of adequate planning for ADRD in Aboriginal communities, and a lack of Aboriginal-specific data on ADRD and ADRD risk factors (Sutherland, 2007). Alzheimer’s disease and related dementias are expected to be an increasing challenge for home care services in First Nations and Inuit communities. In a public opinion research survey done for the First Nations and Inuit Home and Community Care Program, participants rated the priority of Alzheimer’s and related dementias at 96% in terms of the strategy for the next ten years and at 94% in terms of research plans. However, the current lack of essential information makes planning and responding to this emerging issue difficult for communities and for those who provide services.

The research for this report was undertaken to provide information relevant to ADRD to the First Nations and Inuit Home and Community Care (FNIHCC) programs to assist in their development of a 10-Year Strategy. The objectives of the study are twofold. First, we aim to summarize information from the published literature to inform future planning for ADRD among First Nations and Inuit. Second, we seek to provide estimates for current and future prevalence of ADRD among First Nations and Inuit, given the limited data available.

Recommendations that reflect the evidence presented are provided at the conclusion the report following a discussion of the potential impact of ADRD on the FNIHCC program.

1.1 Defining Alzheimer’s Disease and Related Dementias
Alzheimer’s disease and related dementias (ADRD) is a term used to refer to a group of brain disorders that lead to cognitive impairment. There are many types of dementia including Alzheimer’s disease, vascular dementia, mixed dementia, Lewy Body dementia, frontotemporal dementia, and Wernicke-Korsakoff syndrome. A diagnosis of dementia is also commonly associated with other diseases affecting the brain; for example, dementia due to: HIV disease, head trauma, Parkinson’s disease, Huntington’s Disease, Pick’s disease, Creutzfeldt-Jakob Disease, and those that are “substance related” (alcohol, drugs and medications). Dementia is commonly categorized as reversible or irreversible. Reversible dementias are often secondary to another primary illness (depression, thyroid disease, kidney disease) but also include dementia caused by excessive short term alcohol use, drugs and medications. The term ADRD is used to refer to those dementias that are irreversible and progressive: Alzheimer’s disease, vascular dementia, mixed dementia, Lewy

Alzheimer’s disease (AD) is the most common form of dementia. It is irreversible, progressive, degenerative and fatal. It accounts for 63% of dementia cases in the general population. Alzheimer’s disease cases are most often ‘sporadic’ (late-onset); however, between 5-7% of AD cases are categorized as Familial Alzheimer’s Disease, which have an earlier onset. Vascular dementia is the second most common form, accounting for 20% of all dementias in the general population. Vascular dementia is caused by a decrease in the supply of blood to the brain caused by diseases of the vascular system, such as high blood pressure, heart problems, high cholesterol and diabetes. Many individuals with Alzheimer’s disease also have vascular dementia producing a diagnosis of ‘mixed dementia.” (Alzheimer Society of Canada, 2010).

Symptoms of ADRD include loss of memory, judgment and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person’s ability to function at work, in relationships or in everyday activities (Alzheimer Society of Canada, 2010).

1.1.1 Diagnosing Alzheimer’s Disease and Related Dementias
Diagnosis of dementia is largely “a clinical exercise”; that is, there are no biological or radiological markers of dementia that allow for a simple test (3rd Canadian Consensus Conference on Diagnosis and Treatment of Dementia Steering Committee, 2006; Robillard, 2007). Because there is no accepted definitive test for Alzheimer’s disease (except autopsy after death), the process of diagnosis is one that involves an integrative approach (various assessments) and most often a diagnosis of exclusion (a diagnosis in which all other probable causes have been ruled out by laboratory tests and/or imaging tests).

Typically, patients presenting with dementia are evaluated based on their symptoms during a clinical visit with their physician. Physicians evaluate patients based on presenting symptoms as reported by them or their family members, their functioning, and any changes over time (Myron F. Weiner & Lipton, 2012). Based on the current Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2006) the recommended examination when a patient presents with dementia follows (3rd Canadian Consensus Conference on Diagnosis and Treatment of Dementia Steering Committee, 2006; Robillard, 2007; Myron F. Weiner & Lipton, 2012):
1.2. Conceptual Framework: Social Determinants of Aboriginal Health over the Life Course

The health of First Nations and Inuit is affected by a complex interplay of historic, environmental, social, political, cultural, economic, and behavioral factors over each individual’s life course (Loppie Reading & Wein, 2009). In this report, we have taken a determinants of health approach over the life course to understand and describe what influences ADRD in First Nations and Inuit populations. Social determinants of health are made up of proximal, intermediate and distal determinants of health (Loppie Reading & Wein, 2009). Distal determinants include historic, political, social and economic contexts, such as the effects of residential schools and the Indian Act. Intermediate determinants include community infrastructure, resources, systems and capacities. Proximal determinants are more immediate factors like health behaviours, physical and social environments (Loppie Reading & Wein, 2009). The Public Health Agency of Canada has developed 12 determinants of health categories, including: income and social status, social support networks, education and literacy, employment / working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, culture (Public Health Agency of Canada, 2011).

Specific social determinants of health that are most relevant to different populations depend on context. In a 2007 discussion paper, Inuit Tapiriit Kanatami put forth the key health determinants that are most relevant to Inuit health (Inuit Tapiriit Kanatami, 2007):
Understanding the role of social determinants is one important part of understanding health. While the above social determinants of health are widely known to influence health and wellbeing, additional context is required to understand how those determinants affect the health of Aboriginal peoples. Figure 1 presents a helpful model for understanding how health is affected by the interplay between social determinants of health, Aboriginal conceptions of health, and the socio-political context over the life course. In this model, it is clear that the social determinants of health are filtered through the socio-political context of First Nations, Inuit and Métis as well as through the life course stages.

**Figure 1: Integrated Life Course and Social Determinants Model of Aboriginal Health**

Source: Loppie Reading and Wein 2009
1.3. Report Format and Limitations

This report and analysis of trends in ADRD in First Nations and Inuit is presented in three broad parts: a literature review including academic and non-academic sources (Section 2), novel analysis of ADRD prevalence and related pharmaceutical use using available data (Sections 3 and 4), and a discussion of implications and recommendations for consideration by FNIHCC (Section 5).

Where possible, findings and discussion focus on First Nations and Inuit as distinct populations. One key limitation throughout this report is the lack of available information on ADRD in Inuit. While the literature review focused on findings from Canada, the search was expanded to international sources reporting on Indigenous populations due to a lack of published Canadian research on ADRD in First Nations and Inuit. This may limit the applicability to the Canadian context.

The novel analyses presented in this report were limited by the data available. To estimate current and projected prevalence of ADRD, baseline age-specific prevalence rates from BC First Nations were applied to First Nations across Canada. Using this approach, the resulting current and projected numbers of individuals with ADRD are likely to be substantially underestimated because they rely on diagnosis of ADRD in physician and hospital data. Because there are no published sources for ADRD prevalence among Inuit, we applied the baseline prevalence from BC First Nations in our cursory projection for Inuit. For this reason, the Inuit projection must be interpreted with particular caution. We assumed that the prevalence of ADRD applied evenly on-reserve and off-reserve for First Nations and in Inuit Nunangat and elsewhere for Inuit. The projections relied on the Aboriginal population projection methodology developed by Statistics Canada, with the inherent limitations and assumptions therein. Using this methodology, the projected increases in ADRD over time account only for the effect of population aging and not for other exacerbating influences such as increasing prevalence of diabetes and other conditions that impact ADRD.

In the section on AD-related pharmaceutical use, the results provide a high-level indication of the magnitude of pharmaceutical use but cannot provide conclusive information on coverage or intensity of use. We were not able to calculate population utilization rates because the total number of First Nations and Inuit who have mild to moderate AD and who receive NIHB coverage was not known. We were not able to draw implications from the number of claims because the dose and frequency of prescribing was not known.

Despite the above limitations, the report summarizes the information that has been published on ADRD in First Nations and Inuit and takes an important next step in providing estimated current and projected prevalence. The findings provide a foundation on which decisions can be made regarding programming and further research.
2. Alzheimer’s Disease and Related Dementias in First Nations and Inuit: Literature Review

We undertook a review of published academic and grey literature on Alzheimer’s disease and related dementias (ADRD) in First Nations and Inuit in Canada. The findings confirmed our initial impressions that little has been published about ADRD in these groups. As a result, we included academic literature from outside of Canada in our search.

2.1. Search Methods

We undertook two separate search strategies: one for academic (peer-reviewed) literature and one for grey literature.

The academic literature was searched in the following topic areas:

- Incidence, prevalence and rates of Alzheimer’s disease and/or related dementias (ADRD) in Aboriginal peoples
- ADRD detection, screening, diagnosis in Aboriginal peoples
- Co-morbidity, social determinants of health, and risk factors in Aboriginal peoples
- Cultural considerations in diagnosis and care

Articles on the above topics were identified through a search of the following databases: MEDLINE, Native Health Database PsychINFO, Social Sciences Citation Index and WorldCat. Key words searched included: “Aboriginal”, “First Nations”, “Inuit”, “Métis”, and “Indigenous”. We also included some non-Indigenous references relevant to the topic. Primacy was given to Canadian references but when necessary searches are repeated for the United States, Australia and New Zealand.

The grey literature search was limited to Canada. A list of relevant organizations, websites, databases and search engines was generated following the model outlined in Grey Matters: A Practical Search Tool for Evidence-Based Medicine produced by the Canadian Agency for Drugs and Technologies in Health. The list of searched sources is included as Appendix A.

In cases where the website had an effective embedded search engine, we used the following sets of search terms, as appropriate:

- Set 2: “dementia”, “Alzheimer”, “memory”.

In cases where the website did not have a search engine or the above search generated no results, we browsed the site for related reports, news items, projects, etc.

After identified academic or grey literature sources were reviewed for relevance and validity, they were entered into “Endnote” bibliographic software management software with a summary and tags.

2.2. Incidence and Prevalence of ADRD among Indigenous Populations

Despite increasing interest and some key early work done to estimate the prevalence of ADRD in First Nations in Canada, we found no First Nations or Inuit-specific incidence estimates and very little published on prevalence among First Nations. In the academic literature, most of the relevant papers cited three key articles that described primary research on prevalence in Indigenous
Hendrie, Hall et al. (1993) was the only academic source for ADRD prevalence estimates in First Nations in Canada. In this small study, the authors surveyed and assessed 192 Cree seniors from Norway House and Nelson House in Northern Manitoba. They found, for those over aged 65, the age-adjusted prevalence of AD was 0.5% compared to 3.5% for non-Aboriginal Manitobans. However, age-adjusted prevalence for all dementia was 4.2% for both populations. This and other early work in this field in North America suggested that AD may be less prevalent in Indigenous communities compared to non-Indigenous, partially owing to genetic influences (Henderson et al., 2002; Hendrie et al., 1993), and that vascular dementia may be more common than other forms due to high rates of vascular risk factors (Hendrie et al., 1993).

We found only one other Canadian population-based estimate of ADRD prevalence for First Nations. This was an annual report from the British Columbia Provincial Health Officer from 2007 entitled Pathways To Health (British Columbia Provincial Health Officer, 2009). This report indicates that the prevalence of ADRD in First Nations is increasing (Figure 2). As of 2006-07 the age-adjusted rates of dementia had risen to similar levels as non-First Nations populations in BC. The results presented suggest younger age profile for First Nations ADRD patients and potentially a higher proportion of males with dementia compared to the general population.

**Figure 2: Treated ADRD Prevalence rates for First Nations and non-First Nations in BC, modification of figure presented in Pathways to Health Report 2007**

<table>
<thead>
<tr>
<th>Year</th>
<th>Status Indians</th>
<th>Other Residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997/98</td>
<td>3.6</td>
<td>4.3</td>
</tr>
<tr>
<td>1998/99</td>
<td>4.1</td>
<td>4.6</td>
</tr>
<tr>
<td>1999/00</td>
<td>4.1</td>
<td>4.8</td>
</tr>
<tr>
<td>2000/01</td>
<td>4.4</td>
<td>5.0</td>
</tr>
<tr>
<td>2001/02</td>
<td>4.2</td>
<td>5.1</td>
</tr>
<tr>
<td>2002/03</td>
<td>4.5</td>
<td>5.2</td>
</tr>
<tr>
<td>2003/04</td>
<td>4.8</td>
<td>5.4</td>
</tr>
<tr>
<td>2004/05</td>
<td>5.1</td>
<td>5.6</td>
</tr>
<tr>
<td>2005/06</td>
<td>5.3</td>
<td>5.8</td>
</tr>
<tr>
<td>2006/07</td>
<td>5.8</td>
<td>6.0</td>
</tr>
</tbody>
</table>

Source: Population Health Surveillance and Epidemiology, Ministry of Health, 2008
While these preliminary Canadian estimates show that First Nations have similar (yet increasing) rates of dementia compared with non-First Nations populations, there may be wide variability in the experiences of Aboriginal communities. There are some documented cases where specific First Nations communities in BC are experiencing high rates of AD due to genetic mutations that lead to early onset Alzheimer’s disease, such as a novel PS-1 gene mutation (Lombera, Butler, Beattie, & Illes, 2009). In addition, a report on the Métis population of Manitoba showed that Métis aged 55 and older had a higher prevalence of ADRD (12.4%) compared with the general Manitoba population (10.6%) (Patricia Martens et al., 2010). Of note, the report revealed substantial regional variation in ADRD rates throughout the province. One Regional Health Authority (Brandon) had rates of 18.7% for Métis compared with 8.6% for other Manitobans. The significantly higher prevalence among Métis was present in the southern and middle-regions of the province but not the north.

In other parts of the world, Indigenous populations are experiencing markedly higher ADRD prevalence than non-Indigenous populations. Recent research in Australia suggests the age-standardized prevalence of dementia over age 45 is 5.2 times higher among the Indigenous peoples in Kimberly, Australia than for the overall Australian population (12.4% compared to 2.4%) (Smith et al., 2008).

### 2.3. Screening and Diagnosis of ADRD in Indigenous Populations

Screening and diagnosis are impacted by access to physicians, physician’s attitudes towards ADRD, history of relations between Aboriginal people and the health care system, cultural fairness and appropriateness of screening instruments, cultural values and meanings placed on the symptoms, and care-givers’ cultural understandings of dementia.

Standardization of valid diagnostic and screening tools allows for common approaches to treatment and comparative analyses. However, achieving a high level of validity for screening and diagnostic tools often requires cultural adaptation of the tools and may impact the ability to standardize the tools. Decisions about screening and diagnostic approaches must be made in an effort to achieve the optimal balance between validity and standardization.

#### 2.3.1. Diagnosis

The introduction to the report provides a summary of the current recommendations for ADRD diagnosis. Accurate diagnosis of dementia is crucial for preventative and therapeutic strategies, epidemiological purposes and to prevent medication errors (Rankin et al., 2008; Zekry & Gold, 2010). In addition, given high rates of chronic disease resulting in multiple prescription medication use, the potential for alcohol misuse, and depression affecting many Aboriginal groups, it is important to monitor and distinguish between potential causes of cognitive impairment so that treatment plans can be adjusted (McCole, 2003).

Research on the diagnosis of dementia in Indigenous peoples in North America suggest that underdiagnosis may be a considerable issue (Hendrie, 2006; Lori L.; Jervis & Manson, 2007; L. L. Jervis & S. M. Manson, 2002; Morgan et al., 2009). A study in the United States has shown that American Indians experience symptoms on average five years before seeking a diagnosis; compared to two years for Euro-Americans (P. Dilworth-Anderson, 2010). Late and under-diagnosis of dementia is believed to be related to: a ‘naturalized’ explanatory model of illness held by some Indigenous peoples where the early stages of dementia are not viewed as a disease or health issue.
(Griffin-Pierce et al., 2008), the avoidance of health care systems based on mistrust and poor past relations between physicians and Indigenous peoples (Griffin-Pierce et al., 2008) as well as poor access to diagnostic services (Morgan et al., 2009; M.F. Weiner, Rossetti, & Harrah, 2011).

It has also been noted that screening for AD is often not viewed as a priority for physicians. There has been an attitude that “it doesn’t really matter since AD is the most common cause of dementia and there’s nothing you can really do for it” (Powell, 2002). Similarly, a diagnosis may not always be a priority or be valued by an Indigenous person who may hold differing views on the meaning of the illness or for which other social inequalities may take precedence (Pollitt, 1997).

There is limited evidence that telemedicine/videoconference diagnosis may be acceptable and effective for Indigenous peoples based on a study in the United States (M.F. Weiner et al., 2011). A study in Canada found that a combined telemedicine (videoconference) and memory clinic design was acceptable for dementia diagnosis in rural and remote Saskatchewan; however, the team noted that there was limited success with this model in remote First Nations and Métis communities where the cost of travel to the memory clinic was too high (Morgan et al., 2009). Although telemedicine is a promising approach, evaluation of existing models or new research is necessary to validate its appropriateness and effectiveness in the First Nation and Inuit context.

### 2.3.2. Screening

Screening for cognitive impairment and dementia is normally carried out by a physician. Most of the literature concerning cognitive screening of Indigenous people has focused on the appropriateness of the mental status exams; especially those considered “Brief Cognitive Assessments.” Common assessments included in this category are the mini-mental state exam (MMSE), the mini-cog, short portable mental status questionnaire, the Montreal Cognitive Assessment (MoCA/MOCA), Cognitive Capacity Screening Examination (CCSE), Dem-Tect, combined MMSE and CCSE (CMC), and the Clock Drawing test. These tests allow for an initial assessment as well as establishing a baseline for memory loss over time.

The literature concerning cross-cultural screening and diagnosis in general suggests that certain screening tests are more relevant cross-culturally than others (S. Borson et al., 1999); however, the validity of screening instruments cross-culturally is a long recognized problem. Issues include the fairness of the tests when translated into other languages (for example, words can be more or less complex in other languages); relevance of the items on the tests (e.g., the name of the Prime Minister, familiarity with animal symbols); educational history; and, cross-cultural meanings of test items (Cattarinich, Gibson, & Cave, 2001; Griffin-Pierce et al., 2008; Kaufert & Shapiro, 1996). In controlled studies, many of these factors have been shown to produce an over-diagnosis for ethnic minorities because they perform poorly (L. L. Jervis, Beals, Fickenscher, & Arciniegas, 2007; Parker & Philip, 2004; Pollitt, 1996; Teng, 2002). Other studies have shown that for American Indians in particular, greater exposure to western health care systems and knowledge, boarding school experience, and more education have all been found to predict higher (better) scores on the MMSE and DRS2 when compared to American Indians who have less acculturative stress (L. L. Jervis et al., 2010).

In Canada, however, other moderating factors such as cultural interpretations of symptoms and access to services means that Aboriginal peoples, and those people living in remote locations are more likely to be under-diagnosed (Hendrie, 2006; Morgan et al., 2009).
Cross-cultural controlled research studies have shown that the MMSE, while one of the most widely used screening tests is more affected by culture, language and level of education than other screens (S. Borson et al., 1999; S. Borson, Scanlan, Watanabe, Tu, & Lessig, 2005). One study found the MMSE failed to identify five times as many cases in and American Indian population as other tests (i.e., Alzheimer’s disease screen for primary care [ADS-PC]) and misclassified five times as many non-cases (Grober, Hall, Lipton, & Teresi, 2008). It has also been interpreted as disrespectful to elders, with “seemingly random and inconsequential questions being asked by a person who is younger than the patient” (Finke, 2003). Attempts to make the MMSE culturally appropriate have not been successful in the American Indian population and instead it is suggested that caregivers begin with tests that are sensitive to functional decline and interview clients further paying attention to speech fluency, attention span, short term memory and memory during the clinical interaction (Finke, 2003). Certain screening tests appear to be more sensitive to cross-cultural applications. Researchers suggest that short tests that are sensitive to literacy and language are the most reliable cross-culturally, for example, these include the ADS-PC (Grober et al., 2008) and the mini-COG (S. Borson et al., 1999; S. Borson et al., 2005); as well as, those that use appropriate vocabulary and functional inventories that are meaningful in the cultural context. Validation is a key step to cross-cultural application of screening tests (Kaufert & Shapiro, 1996).

Screening tests developed with particular communities or the adaptation of existing screening tools aided by community members are viewed as necessary for accuracy in diagnosing ADRD (Cattarinich et al., 2001; Parker & Philp, 2004). Many tests have been adapted and/or developed to more accurately diagnose elderly who are not from the dominant euro-North American background; including the Clock Drawing Test, Mini-Cog, the 7-minutes screening battery, and the Time and Change Test. Other tests have adapted the cut-off points to adjust for language, culture and educational levels (e.g., MMSE, Short Portable Mental Status Questionnaire and Abbreviated Mental Test Score) (Parker & Philp, 2004).

An Indigenous screening tool has been developed with Aboriginal people in Australia, the Kimberly Indigenous Cognitive Assessment (KICA). This test includes three components, the cognitive test, an informant interview and a functional test (LoGiudice et al., 2006). This tool has been tested and validated with different Aboriginal communities in Kimberly and the Northern Territory and is currently undergoing validation for more diverse and urban Indigenous communities.

Similar initiatives have been undertaken in Canada; however these tools have not been adequately validated at this time. Hall et al. (Hall et al., 2000) developed and tested the Community Screening Interview for Dementia (CSI’D) to be used on multiple ethic groups including Cree in Canada. The test included two parts, a cognitive test sensitive to literacy levels and an interview on performance in everyday life. The test was not specific to the Cree and was not successful in eliminating educational level bias. After developing and testing the Community Screening Instrument for Dementia for Cree in Manitoba, Blacks from Indianapolis, Yoruba from Ibadan and residents of Chinese villages, Hendrie concluded that no existing instrument can be used in all cultures without a process of translation, harmonization and pilot testing; he found this to be true even between Cree villages in Manitoba (Hendrie, 2006). Recently, Crossley worked with Grandmothers in Saskatchewan to adapt the cognitive abilities screening instrument (CASI) and community screening interview (CSI’D) to produce the N-CAM (Northern Cultural Assessment of Memory). Preliminary results suggest the test is acceptable to participants and is sensitive to cognitive impairment (Crossley, 2011). However,
Earlier studies have found the CASI and the CSI'D to be affected by level of education (S. Borson et al., 1999; Hall et al., 2000). In Ontario, the Alzheimer Society of London and Middlesex and the Oneida Nation of the Thames partnered to develop the First Nations First Link program in London (Alzheimer Society of London and Middlesex, January 27, 2010). One project they have undertaken is the integration of cultural elements into the Montreal Cognitive Assessment (MoCA) screening test to make it more culturally appropriate. The MoCA has been found to be highly reliable to detect mild cognitive impairment in non-ethnic populations (Nasreddine et al., 2005). The First Nations First Link program adapted the tool by replacing pictures of lions and camels with bears, turtles, and wolves; and the 3D cube with a 3D circle representing the medicine wheel (The Canadian Press, 2010). Although this is a positive development and may prove to be effective, to date there has been no evaluation of this adaptation. The MoCA has not been evaluated positively as a cross-cultural measure of cognitive performance. It has been found to be affected by level of education (even with an adjusted cut-off point) and has not been found to be applicable to ethnically diverse populations in the United States (Lombera et al., 2009).

2.4. Risk Factors Related to ADRD

In general, risk factors for ADRD are beginning to be better understood. There are two categories of risk factors: potentially modifiable and non-modifiable. Non-modifiable risk factors include things like age, sex, and genetics. Potentially modifiable risk factors are those that could possibly be prevented or modified, such as behaviours, some health conditions, medication use, early life experiences and education level, to name a few. To best understand risk factors, it is helpful to take a life-course approach (J. Reading, 2009). This approach appreciates the impact of life events and key transition points along the life-cycle on neuro-cognitive growth and decline and the overall aging (Arkles et al., 2010). While few studies embody a life-course longitudinal approach to the study of ADRD, in our analysis we attempted to separate the factors associated with ADRD risk into those that occur in early, mid and later life.

While there has been markedly less research conducted specifically regarding ADRD risk in First Nations and Inuit, there is cursory evidence of some differences in the ADRD risk profile in these populations compared with the general population. In one group of American Indians, non-modifiable risk factors have been shown to play a stronger role in AD prevalence than among non-indigenous people (M. F. Weiner et al., 2010). Some of the known modifiable risk factors for ADRD are more common among First Nations and Inuit, which may further increase the risk of ADRD in these populations.

2.4.1. Risk and Protective Factors for ADRD over the Life-Cycle

There is no single cause of ADRD. While genetic factors play an important role, only 5-7% of Alzheimer’s disease patients have a clear diagnosis of the genetic Familial Alzheimer’s Disease. In rare situations, there are some First Nations in Canada that exhibit specific familial AD (Butler et al., 2011). More commonly, ADRD arises from a combination of genetic and environmental risk factors. While increasing age is the most predictive factor in assessing risk for ADRD, research into other risk and protective factors for ADRD has helped to shape an understanding of overall ADRD risk (Diamond, 2008).
Table 1 displays a summary of recognized risk factors according to when in an individual’s life cycle they occur. Because this is an area of study that is still in development, some of the risk factors listed have less conclusive causal evidence than others. However, these risk factors are those with sufficient evidence supporting an association with ADRD. This summary builds on previously published systematic literature reviews, primarily from Arkles et al. 2010 and Patterson et al. 2007, as well as the risk factors recognized by the Alzheimer Society of Canada (Diamond, 2008).

Table 1: A cursory life-cycle analysis of factors associated with ADRD

<table>
<thead>
<tr>
<th>Possibly modifiable Protective factors</th>
<th>Early life</th>
<th>Mid-life</th>
<th>Later life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccinations</td>
<td>Men – high testosterone</td>
<td>Physical activity</td>
<td>Physical activity</td>
</tr>
<tr>
<td>Education</td>
<td>Physical activity</td>
<td>Mental activity</td>
<td>Mental activity</td>
</tr>
<tr>
<td>Physical activity</td>
<td>Men – high testosterone</td>
<td>Physical activity</td>
<td>Physical activity</td>
</tr>
<tr>
<td>Mental activity</td>
<td>Physical activity</td>
<td>Mental activity</td>
<td>Mental activity</td>
</tr>
<tr>
<td>Non-steroidal anti-inflammatory drug use</td>
<td>High fish and seafood consumption</td>
<td>Moderate wine consumption</td>
<td>Moderate wine consumption</td>
</tr>
<tr>
<td>High fish and seafood consumption</td>
<td>Depression</td>
<td>Smoking</td>
<td>Smoking</td>
</tr>
<tr>
<td>Moderate wine consumption</td>
<td>Exposure to toxins</td>
<td>Obesity</td>
<td>Obesity</td>
</tr>
<tr>
<td>Physical activity</td>
<td>Women – high estrogen</td>
<td>Psycho-social stressors</td>
<td>Psycho-social stressors</td>
</tr>
<tr>
<td>Mental activity</td>
<td>Major head injury</td>
<td>Major head injury</td>
<td>Major head injury</td>
</tr>
<tr>
<td>Non-modifiable Risk Factors</td>
<td>Increasing age</td>
<td>Depression</td>
<td>Depression</td>
</tr>
<tr>
<td>Increasing age</td>
<td>Suicide</td>
<td>Exposure to toxins</td>
<td>Exposure to toxins</td>
</tr>
<tr>
<td>Family history of ADRD</td>
<td>Smoking</td>
<td>Obesity</td>
<td>Obesity</td>
</tr>
<tr>
<td>ApoE4 allele (for Alzheimer’s disease)</td>
<td>Exposure to toxins</td>
<td>Psycho-social stressors</td>
<td>Psycho-social stressors</td>
</tr>
<tr>
<td>Low cognitive capacity</td>
<td>Depression</td>
<td>Major head injury</td>
<td>Major head injury</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>Major head injury</td>
<td>Cerebrovascular disease</td>
<td>Cerebrovascular disease</td>
</tr>
</tbody>
</table>

Please note: factors listed are those for which an association with ADRD has been observed. Most of these factors cannot be considered causes of ADRD but they indicate an elevated or decreased risk for ADRD.
2.4.2. Risk Factors in First Nations and Inuit

The key factors affecting First Nations and Inuit risk for ADRD are summarized in Figure 3 and in the discussion below.

The most important risk factor for ADRD is increasing age. The number of First Nations in Canada is expected to increase by 1.4 times between 2006 and 2031 and the number of Inuit by 1.9 times. A disproportional amount of the growth will be among those aged 60 and older, who are expected to increase in number by 3.4 times for both First Nations and Inuit. The number of First Nations aged 60 and older will increase from 54,165 in 2006 to 184,334 in 2031 (Caron Malenfant & Morency, 2011). The number of Inuit aged 60 and older will increase from 2,883 to 9,833 (Caron Malenfant & Morency, 2011). This shifting population age structure for First Nations and Inuit will likely have a large impact on the prevalence of ADRD in those groups. This will be explored further in Chapter 3 of this report.

Exposure to risk factors for many chronic diseases begins in the prenatal and natal environments. While the existing prenatal and natal research in the context of ADRD is limited, a compromised intrauterine environment appears to be associated with ADRD (Arkles et al., 2010). The mother’s exposure to poverty, abusive situations, stress and health conditions largely determine the prenatal exposures experienced. For example, high rates of gestational diabetes and maternal smoking, maternal alcohol use, and higher than average birth weights have been documented among First Nations and Inuit (J. Reading, 2009). However, clear linkages between these factors and ADRD are not established.

Childhood vaccinations and inoculations throughout life have been observed to be protective for ADRD (Patterson, Feightner, Garcia, & MacNight, 2007). Immunization rates are reportedly approximately 20% lower among First Nations children than the general population (NAHO website). In Manitoba, documented rates are 62% versus 89% at one year of age and 45% versus 77% at two years of age (Patricia Martens et al., 2002).

Inflammatory conditions in childhood and mid-life have been linked to later ADRD. Notably, a link between periodontal disease/tooth loss in childhood and ADRD has been observed (Gatz et al., 2006). In Canada, the number of First Nations children who receive regular dental care is increasing but there remains a disparity in dental treatment on-reserve (The First Nations Information Governance Centre, 2011). Among 6 to 11 year old First Nations children on-reserve, 83.8% received dental care in the 2008/09. Many Inuit communities do not have a regular dentist, but rather receive irregular visits from southern dentists. In the 2006 Aboriginal Peoples Survey, only 63% of Inuit children aged 6 to 14 reported receiving dental care in the past 12 months (Tait, 2008). The situation was worst in Nunatsiavut where only 38% had received care and best in Inuvialuit (79%). The First Nations and Inuit rates are markedly lower than the 91.3% of children aged 6 to 11 in the general Canadian population who see a dentist each year (Health Canada, 2010).

Psycho-social stressors and low socioeconomic status, in childhood and over the lifetime, have been associated with higher risk of ADRD (Arkles et al., 2010; Johansson et al., 2010; Ohanna, Golander, & Barak, 2011; Peavy et al., 2011). Socio-economic status may be measured in different ways: family income, education, employment status, housing status (including ownership, crowding and need for repair), or by using a composite index, such as the Human Development Index. On all
measures of socioeconomic status and poverty, First Nations and Inuit outcomes are worse than the general Canadian population (J. Reading, 2009). The most recent First Nations Regional Health Survey found that only 47.2% of First Nations adults on reserve were working for pay and that 70.8% reported that the home was in need of repair (compared to 25.7% of the general Canadian population) (The First Nations Information Governance Centre, 2011).

An increased risk of Post-Traumatic Stress Disorder (PTSD) related to experiences of historical trauma (especially residential schools) (Yellow-Horse Braveheart, 2003; Yellow Horse Brave Heart & DeBruyn, 1998) may also contribute to ADRD risk in First Nations and Inuit. Recent studies with veterans suggest that sufferers of PTSD are at an increased risk of ADRD (Qureshi et al., 2010; Yaffe et al., 2010).

Many studies have shown an association between lower levels of formal education and higher risk of ADRD. The mechanism of this association is currently being debated (i.e., is it actually education level that matters, or is it socio-economic status or cognitive capacity?). Historically, formal education in First Nations and Inuit was carried out with the goal to “civilize” and “assimilate” without due regard and respect for First Nations and Inuit knowledge and culture (St. Germain & Dyck, 2011). Generations of First Nations and Inuit experienced residential schools and federally-run day schools, the effects of which are echoing through contemporary generations. Currently, First Nations and Inuit are leading initiatives to improve the education system for children now and into the future (Haldane, Lafond, & Krause, 2012; National Committee on Inuit Education, 2011). Inuit teachers and Inuit language are increasingly part of the formal education experience for Inuit students (Tait, 2008). While this is, indeed, promising, current educational attainment outcomes show a wide disparity when the general Canadian population is compared with First Nations and Inuit. High school non-completion rates among those aged 25 to 34 in 2006 were 51% for First Nations on reserve, 29% for First Nations off reserve, and 10% for the general Canadian population (St. Germain & Dyck, 2011). Half of all Inuit adults aged 25-64 had not completed high school in 2006 (Tait, 2008).

There is substantial evidence linking head trauma to ADRD risk, though findings have been inconsistent (Cooper, 2002; Patterson, Feightner, Garcia, & MacNight, 2007). In general, minor head injuries do not appear to increase risk, but moderate and severe head injuries do (Arkles et al., 2010). Among First Nations youth living on-reserve, 4.4% reported having a concussion in the past 12 months (The First Nations Information Governance Centre, 2011). Among Canadian youth, in general, the percentage reporting a head injury was 2.7% (Billette & Janz, 2011).

“Lifestyle” factors in mid and late life, such as low physical activity levels, smoking, drug abuse, and alcohol-related disorders, have been associated with ADRD (Arkles et al., 2010; Patterson, Feightner, Garcia, & MacNight, 2007). Many of these factors are related to poverty, community-level risk factors, and the effects of intergenerational trauma. All are more common in First Nations and Inuit than the general population. Over half (58%) of Inuit adults and 43% of First Nations adults smoke daily, compared with 17% of the general Canadian adult population (Tait, 2008). Compared with the general population, First Nations are more likely to abstain from alcohol and drink less frequently on average (J. Reading, 2009). However, they are more likely to be considered heavy alcohol drinkers (five or more drinks on a single occasion) (J. Reading, 2009). Exercise and physical activity is key to prevention and delay of cognitive decline (Denkinger, Nikolaus, Denkinger, & Lukas, 2012). While many First Nations report that they walk regularly (over 80%), almost half of First Nations children
(45%) and youth (44%) are considered inactive (The First Nations Information Governance Centre, 2011).

Cerebrovascular disease and the interrelated risk factors associated with it, such as high cholesterol, hypertension, obesity, smoking and diabetes, also increase the risk for ADRD (Luchsinger et al., 2005). One of the diagnostic criteria for vascular dementia is history of a cerebrovascular event. In addition, CVD and its associated risk factors are also associated with increased risk for other types of dementia (Honig et al., 2003). Many of these risk factors are elevated in First Nations populations. The prevalence of high blood pressure among First Nations aged 18 and older on reserve is 22% (The First Nations Information Governance Centre, 2011). The rate for the general Canadian population is 17% among those aged 12 and older (Statistics Canada, 2011). Compared with the general population, Inuit do not appear to have an elevated prevalence of high blood pressure (Tait, 2008). Obesity is also independently related to AD risk (Profenno, Porsteinsson, & Faraone, 2010). Obesity is much more prevalent among First Nations adults (approximately 40%) than the general population (17%) aged 18 and older (Statistics Canada, 2011; The First Nations Information Governance Centre, 2011).

Diabetes has been shown to be associated with increased ADRD risk (Ahtiluoto et al., 2010; Akomolafe et al., 2006; Irie et al., 2008; Profenno et al., 2010). Recent research has demonstrated a 75% increased risk of ADRD among those with diabetes compared with those with normal glucose tolerance (Ohara et al., 2011). The presence of diabetes in new AD cases also appears to accelerate functional decline (Sanz et al., 2011). The estimated prevalence of diabetes is 21% among First Nations adults on-reserve (The First Nations Information Governance Centre, 2011) and 4% among Inuit adults (Tait, 2008). However, the Inuit-specific rate is rapidly increasing and jumped from 2% in 2001 to 4% in 2006 (Tait, 2008). First Nations women represent two thirds of all First Nations people with diabetes. For the general population, the reverse is true (J. Reading, 2009; The First Nations Information Governance Centre, 2011). The epidemiology of diabetes among First Nations has been documented (Dyck, Osgood, Hsiang, Gao, & Stang, 2010; Green, Blanchard, Young, & Griffith, 2003) and rates are expected in increase among First Nations and all Canadians (Canadian Diabetes Association, 2009).

If diabetic patients also experience depression, the risk of ADRD appears to be even further increased (Katon et al., 2011). Depression is known to be interrelated with ADRD and each exacerbates the other (Enache, Winblad, & Aarsland, 2011; R. C. Green et al., 2003; Modrego & Ferrández, 2004; Ownby, Crocco, Acevedo, John, & Loewenstein, 2006). Evidence shows that the number of past depressive episodes predicts later ADRD (Kessing & Andersen, 2004). Rather than a causal relationship, it is possible that depression and ADRD share a set of risk factors, such as stress, inflammation and cerebrovascular factors, that make the two conditions more likely to appear in the same individuals (Aznar & Knudsen, 2011; Enache et al., 2011). In First Nations and Inuit, the risk of depression is increased among those who attended residential and federal day schools and among their offspring (Bombay, Matheson, & Anisman, 2011).

Two Canadian studies found evidence that exposure to toxins increased the risk of ADRD. The toxins under study were pesticides, fertilizers, defoliants and fumigants (Patterson, Feighner, Garcia, & MacNight, 2007). While this has not been studied in the context of ADRD, environmental toxin exposure has been suggested as a potential explanatory variable for the high rates of diabetes in First Nations, Inuit and Métis (Sharp, 2009). Significant exposure to toxins through traditional foods
in the Arctic among the Inuit has been documented (Van Oostdam et al., 2005; Wormworth, 1995). At the same time, much of the traditional Inuit diet is fish and seafood-based, which may protect against ADRD.

While the omega-3 fatty acids present in a fish-based diet are likely to impact cognition in the developmental stages, the existing literature is not clear about the relationship between this type of diet and the prevention of cognitive decline over the lifespan (Karr, Alexander, & Winningham, 2011). The diets of First Nations and Inuit have shifted away from traditional sources and are now more reliant on externally influenced nutritional choices (J. Reading, 2009), including more processed foods, increased dairy consumption and lower fiber intake. The direct effect of this shift on an increased risk for ADRD is not understood; however, the well-documented relationships between nutrition and other ADRD risk factors, such as inflammatory conditions, diabetes and CVD, are possible ways that the contemporary typical First Nations and Inuit diet may contribute to an elevated risk of ADRD. Likewise, food allergies and intolerances that have arisen from this shift, such as lactose and gluten intolerances, may contribute to increased autoimmune diseases and inflammatory conditions in First Nations and Inuit (Yoshida, Riley, & T, 2006). While the contribution of this to an increased risk of ADRD is not established, this is an area for further investigation, particularly given the previously discussed link between inflammation and dementia.

**Figure 3: Key Risk Factors and Determinants of ADRD over the Life Course for First Nations and Inuit**
2.4.3. Biomedical Approaches to Prevention of ADRD

Substantial societal and programmatic benefit can be realized through the prevention of ADRD. The Rising Tide report of the Alzheimer Society of Canada reported that by delaying the onset of ADRD by two years, there would be 35% fewer people living with ADRD in community and long-term care after 30 years (Alzheimer Society of Canada, 2010).

Chief among the key prevention measures for ADRD is maintaining cardiovascular health through regular physical exercise (Ahlskog, Geda, Graff-Radford, & Petersen, 2011; Barak & Aizenberg, 2010; Hughes & Ganguli, 2009; Larson et al., 2006) and the management of hypertension using pharmacologic and other approaches (Barak & Aizenberg, 2010; Cooper, 2002).

Cognitive engagement also appears to prevent or delay ADRD (Barak & Aizenberg, 2010; Hughes & Ganguli, 2009). Other promising measures for the prevention of ADRD include promoting moderation in alcohol use, abstinence from smoking and healthy eating (Hughes & Ganguli, 2009).

In the mild to moderate stages of AD, the use of cholinesterase inhibitors can assist in the management of symptoms and potentially slow the progression of disease (Cooper, 2002). The data analysis in Chapter 4 demonstrates that a very small, but quickly growing, number of First Nations and Inuit are using anti-dementia drugs. In later stages of ADRD, improvements in community support services and nursing home care can help to mitigate ADRD (Cooper, 2002).
2.5. Cultural Considerations in ADRD Care

It is now well established that culture influences a person’s understandings and behaviours around illness. This includes what a person believes has caused their illness, how they think it should be treated, health care seeking behaviours, decision making models, and what are considered appropriate models of care (Kane, 2000; Kleinman, Eisenberg, & Good, 1978). In dementia care, culture has been shown to influence individual and families experiences with the illness (Kane, 2000). Understanding patients in the context of their culture and history is considered vital to implementing cultural safety in healthcare and improving health outcomes. Without this understanding of culture, it is not possible to develop appropriate mechanisms for diagnosis, treatment and care and, therefore, not possible to achieve health equity for First Nations and Inuit.

When discussing culture it is important to remember that culture is different among First Nations; between First Nations, Inuit and Métis; between communities who are urban, rural and remote; between those in the north, south, west and those in the east; and so on. Even within these communities, there exists diversity in beliefs and practices (Hendrie, 2006; John, Hennessy, Dyeson, & Garrett, 2001). In dementia studies, researchers have found that external pressures resulting from colonialism and increased experiences with and exposure to western biomedical models and western culture can impact Indigenous traditional frameworks for understanding dementia (Henderson & Henderson, 2002; L. L. Jervis & S. M. Manson, 2002; Long Feather, 2007). That is to say, that each person’s view of dementia reflects biomedical/western information and cultural understandings framed within that persons own history, circumstances and context (Henderson & Henderson, 2002). Therefore, it is important during this review to remember that the cultural beliefs and practices presented here are specific to a time and place and are useful to help us understand some common cultural values and understandings concerning ADRD in Indigenous peoples but they should not be used to essentialize the First Nations and Inuit experience with dementia. It is widely recognized now that assigning general cultural attributes or traits to populations comes with many risks to patient care (Botsford, Clarke, & Gidgg, 2011).

2.5.1. Aboriginal Understandings of ADRD

Certainly, most research with Indigenous peoples to date have found that the biomedical construct of dementia (dementia as a disease) is not well understood and the illness is not viewed as problematic. Those studies and reports that discussed ADRD in a traditional Aboriginal framework included participants who describe dementia as a “natural” part of the circle of life. This was the case for the Secwepemc in British Columbia (Hulko et al., 2010), in rural Northern Saskatchewan (Lanting, Crossley, Morgan, & Cammer, 2011) and Ontario (Jacklin & Warry, 2011). A study with Secwepemc communities in British Columbia found that community elders held differing perceptions of dementia and that these understandings have changed over time (Hulko et al., 2010). Understandings included Secwepemc beliefs that dementia was a part of “going through the full circle of life” (described by the authors as “traditional”). In Saskatchewan Grandmothers described dementia as going “back to the baby stage” and part of the “circle of life” (Lanting et al., 2011). During a roundtable gathering in Ontario, diverse Aboriginal participants described dementia as part of the natural life cycle and a return to the stage of infancy (Sutherland, 2007). Also in Ontario, preliminary results from a large multi-site study with diverse Aboriginal people suggest that the cultural understanding of dementia as ‘normal’ and as part of “the circle of life” was consistent among diverse Aboriginal communities (Jacklin & Warry, 2011). The view of dementia as ‘normal’ is
widespread across many non-western cultures (Botsford et al., 2011); however, the nuances of how ‘natural’ is defined and understood vary considerably. In the studies from Canada cited above, the cultural framework of the medicine wheel and circle of life provide the context for the Aboriginal understanding. The understanding of the connections between the Spirit world and the physical world at the intersection of old age, death, birth and infancy help explain ‘childlike’ behaviour and communication with the deceased.

The view of dementia as ‘normal’ was also found by some to be related to how the illness was perceived by others the community. Aboriginal participants at the Ontario roundtable suggested that because people are described as being ‘closer to the creator’ there may be less stigma associated with mental illness, including dementia, in Ojibwa communities (Sutherland, 2007). Other studies have also found a general lack of shame associated with ADRD in Indigenous cultures when compared to western cultures (Hulko et al., 2010; Kane, 2000). Each of these studies referenced also included participants who identified dementia and/or Alzheimer’s disease as a biomedical disease process. Among the Secwepemc it was reported that the changing perception that dementia is “your dementia” (a white disease) has been increasing over the past century (Hulko et al., 2010). Focus group participants in this study agreed to use the term “your dementia” to identify the biomedical disease of dementia. More research is needed to better understand how and when individuals employ the biomedical framework for understanding the illness versus the traditional framework that provides an understanding of the symptoms.

Certainly, even for those who view dementia as normal (or as having been normal prior to colonization), dementia is still feared by many and caring for someone with dementia is viewed as extremely difficult (Hulko et al., 2010). Communities feel unprepared and poorly equipped to deal with someone in the later stages of the illness (Hulko et al., 2010; Sutherland, 2007).

We found no research on understandings of dementia among the Inuit but did find some limited information on perceptions of aging and conceptions of mental health. One research study with the Inuit community of Holman investigated Inuit conceptions of healthy aging and found linkages to mental and physical capacities (Collings, 2001). Continuation of a physically active life on the land was highly regarded among men, and continued social engagement and domestic roles were valued for women. Interestingly, there was no mention of dementia, memory loss, or forgetfulness that emerged from this study. However, there was frequent mention of ‘mind changes’ being related to aging poorly that would fall into the categories of apathy and depression which are symptoms of Alzheimer’s disease. Further, ‘wisdom’ was a highly valued aspect of healthy aging (relating to the role in passing on knowledge) but not having ‘wisdom’ was never cited as a contributor to ‘unhealthy aging’. This limited evidence suggests that the primary symptoms of dementia (forgetfulness, memory loss, confusion, inability to recall knowledge) may not be viewed as problematic throughout the aging process but related symptoms of depression and apathy (social withdrawal) are viewed as problematic, especially for women.

In a review of the literature, Kirmayer et al. (2009) cite earlier work (Vallee 1966), which also described “withdrawal and melancholy” as one of the patterns of mental illness’ as well as an additional behaviour called quajimaillituq: “a term applied to rabid dogs and, in this context, conveying the sense “he does foolish things and he does not know what he does.”” These categories of behaviours were generally used to describe acute episodes but there was also recognition that they could become chronic. In their own research Kirmayer et al. (1994) were made aware of
**isumaqanngituq** “he has no mind/brain”, “crazy” “doesn’t know what is going on around him” with the literal translation in English being “she/he is without thoughts”. Kirmayer et al. (2009) suggest that the same term can be applied for someone who is profoundly intellectually disabled or demented (Kirmayer, Fletcher, & Watt, 2009).

While little is known about the biomedical construct of Alzheimer’s disease or dementia in Inuit the diagram below reproduced from Kirmayer et al (2009) suggests that there is a specific cultural interpretation of symptoms related to dementia for the Inuit which warrants further work focused more specifically on dementia.

**Figure 4: Inuit interpretation of mental health related symptoms**

**Causes**

The most widely held view found to date is that dementia is a natural part of the lifecycle. Yet, in most studies the participants also held alternative views of dementia as a disease caused by external determinants such as western foods, changes in life styles, drugs and alcohol, environmental toxins and more (Butler et al., 2011; Hulko et al., 2010; Jacklin & Warry, 2011).

Those studies that investigated Aboriginal peoples’ views of the causes of dementia found that there is generally a much greater emphasis placed on social and environmental factors compared to biomedical (disease or genetics) (Butler et al., 2011; Hulko et al., 2010; Jacklin & Warry, 2011). Secwepemc participants discussed changes in diet, the transition off the land, chemicals in the food, accidents, alcohol, drugs, age, medications, pollutants, loss of oral cultural traditions, and trauma.
(residential schools included). The authors note that participants created complex interconnected webs of causation that could include a multitude of the above mentioned causes (Hulko et al., 2010). Participants in a study in a remote community in British Columbia with a unique genetic form of AD attributed the disease to the environment, changes in diet, industry and alcohol and drug misuse as well as to the hereditary genetic factor (Butler et al., 2011).

Preliminary results in Ontario suggest that Aboriginal peoples explanations of what causes dementia can be categorized into three frameworks: physiological (genetics, aging, side effects of prescription drug use, co-morbid conditions); psychosocial (trauma, stress, unresolved grief, drug and alcohol abuse); and, Indigenous (disruptions to traditional activities and relationships, bad medicine). These three explanatory models were not always discrete categories (Jacklin & Warry, 2011).

**Interpretation of Symptoms**
A detailed case-study of an American Indian woman described by Henderson and Henderson (2002) demonstrates how an American Indian family living on reserve interprets their mother’s Alzheimer’s disease. For this family, the hallucinations associated with the illness are viewed as a mechanism by which their mother is able to communicate with the ‘other side’. In this case, her illness was not normalized, rather it was viewed as ‘supernormal’. The interpretation of symptoms as expressions of culture and part of the life cycle was also found in Ontario where some Aboriginal research participants expressed great concern, if not anger, that physicians and others labeled these behaviours as being associated with a disease (Jacklin & Warry, 2011).

2.5.2. Culture and Prevention
Very few studies mention cultural mechanisms that maintain or enhance brain health. The majority of prevention discussions are dominated by western educational methods. There is no doubt that many of the western methods used to stimulate the mind are effective cross-culturally, especially activities that include social interactions, puzzles, music, and exercise. However, much more has to be done to understand if there are particular mechanisms to stimulate brain health for Aboriginal people. In British Columbia, Secwepemc elders suggested that living healthy (eating right, sleeping) and keeping the mind busy were key to preventing dementia. These are very much akin to the messages provided by the local Alzheimer’s Society (Hulko et al., 2010). However, the cultural nuance of how to keep your mind active should not be overlooked. An elder cited in this article suggested that the cultural role of elders as story tellers to the youth kept the minds of elders “going”. Citing a very specific case of an elder in this role, one participant noted “he never had the problem with memory” (Hulko et al., 2010).

Although not a focus of their research an Elder speaking about intergenerational relationships told Hulko et al. (2010) that when the elders were involved in caring for their grandchildren ‘they didn’t have time to lose their minds’. In the same study, an Elder spoke about the oral tradition of elders telling the stories to the younger generations, which kept the mind healthy (Hulko et al., 2010). This notion that the changing role of elders in Aboriginal cultures is linked to a decline in cognitive health was also a feature in the preliminary results from the Ontario study (Jacklin & Warry, 2011). This study supports the notion that changing roles of elders may be reducing culturally relevant opportunities for cognitive stimulation. The Ontario research suggests that Aboriginal people from many communities believe that, because of the intellectual complexity involved in their language and
ceremonies, participation in these ceremonies has had a positive effect on brain health (Jacklin & Warry, 2011).

2.5.3. Treatment and Care
A recent report commissioned by FNHI “10-Year First Nations and Inuit Home and Community Care Strategy – literature review” provides a systematic overview of home care and LTC related to First Nation and Inuit (Johnston Research Inc., 2011). Many of the recommendations found in that report are relevant to dementia. The summary here is intended to provide as much dementia specific information as possible to enhance the original recommendations in the Johnston report.

Culture affects the experiences of the caregivers (family and formal) and those experiences affect the amount of care that is provided, who is responsible for care giving (including gender roles), coping strategies, self-care strategies, the type of care and the use of social supports (Peggye Dilworth-Anderson & Gibson, 2002; Hinton, 2002). Research in Saskatchewan has shown that although the needs are much greater, there is significant underutilization of mainstream services by Aboriginal people due to poor access to services, much higher rates of informal caregiving in their communities and institutional barriers (Buchignani & Armstrong-Esther, 1999).

Informal Caregiving
Caring for someone with dementia is difficult for anyone from anywhere. Caring for someone with dementia who is First Nation or Inuit presents unique challenges and difficulties. High rates of diabetes, cardiovascular disease, arthritis and other musculoskeletal disorders and many other disease and disabilities are often co-morbid with dementia in these populations. First Nation and Inuit caregiving also occurs in a unique set of policies impacting access to care and medications and, in many cases, caregiving occurs in isolated communities.

Studies have found that upwards of 80% of caregiving for the elderly in Aboriginal communities is informal care provided by spouses, siblings and children (Buchignani & Armstrong-Esther, 1999). Aboriginal seniors are also more likely to be living in larger family structures and households and are often providing care to young children (Buchignani & Armstrong-Esther, 1999). American Indian careers providing dementia care are known to experience a greater degree of care-giver burden than those who care for someone with solely a physical impairment (John, Hennessey, Roy, & Salvini, 1996). Informal and formal caregiving in this context needs to be understood as having unique needs when compared to the non-Aboriginal population due to the complex interplay of socio-economic factors and the high illness burden.

Readers of this report are urged to be cognizant that although the traditional care models described below may be the most appropriate and effective within this cultural context, one cannot assume that that informal caregiving in Aboriginal communities is not difficult, unproblematic or does not require support. Informal caregivers in Aboriginal communities are reported to find caregiving rewarding but also experience stress in the form of anxiety related to the quality of care they are providing (L. Jervis, Boland, & Fickenscher, 2010), the psychosocial aspects of care, strains on family relations, and negative effects on personal well-being (Hennessey & John, 1996).

Limited research has been undertaken that addresses caregiving and dementia in Indigenous populations. The majority of the few studies that have been published concern American Indian and Alaskan Native communities in the United States. Due to a scarcity of studies concerning First
Nations and Inuit in Canada, we have incorporated a review of the literature from the United States, which is helpful in understanding larger cultural patterns of informal caregiving, and then we highlight some specific emerging research from Canada.

In Indigenous communities, the family is often viewed as the primary or sole provider of care (Buchignani & Armstrong-Esther, 1999; Cammer, 2006; Chapleski, Sobeck, & Fisher, 2003; Hennessy & John, 1996; L. L. Jervis & S. M. Manson, 2002; John et al., 1996). This stems from necessity in some cases, but more often because of a cultural emphasis familial interdependence (Hennessy & John, 1995; L. L. Jervis & Manson, 1999), and the cultural value placed on reciprocity (L. Jervis et al., 2010). Studies in the United States among the Pueblo have found that care-giving is most often provided by females. These studies have found that care-giver burden in these communities is exceptionally high but that the Pueblo caregivers rarely express any negative emotions. It was reported that the Pueblo strategy for coping was similar to other tribes which emphasized acceptance and adaptation rather than control (Hennessy & John, 1995; L. L. Jervis & S. M. Manson, 2002), and that care-givers rely heavily on cultural resources to cope (e.g., beliefs, extended family, traditional and religious practices) (L. L. Jervis & S. M. Manson, 2002). There is some suggestion as well that cultural attitudes of reciprocity were related to low levels of career stress and strain (Botsford et al., 2011; L. Jervis et al., 2010) and that Indigenous caregivers feel rewarded in their role due to the development of strong relationships with elders (L. Jervis et al., 2010).

Caregiver burden is also a consideration. Work with the Pueblo Indians suggests that role conflict, negative feelings, doubt concerning caregiving abilities and guilt are common burdens experienced by Pueblo caregivers. Other significant burdens experienced by this group included financial stress and fear about the elder’s future (John et al., 2001). A recent study suggests that caregiver stress in American Indians is most commonly related to the career’s perception that they are not doing a good enough job (L. Jervis et al., 2010). Mainstream research demonstrates that careers who have not received adequate training and support regarding dementia are at a higher risk for adverse effects (burnout and health problems) related to caregiving and provide lower quality of care (Williamson, Shaffer, & Family Relationship in Late Life Project, 2001); and, that the most effective interventions to enhance caregivers knowledge and skills are delivered in the early stages of the caregiver to career relationship (McClendon, Symth, & Neundorfer, 2006).

In Canada, Aboriginal communities in Ontario have emphasized the importance of family and community in caregiving. Here is has been expressed that the family is the appropriate caregiver whenever possible. There is also recognition that this needs to occur with the support of the local health care system and community (Jacklin & Warry, 2011).

**Community Caregiving**

An underdeveloped theme that emerged from the Canadian literature is the role of the community in dementia caregiving.

Research with a remote First Nation in British Columbia found that the community participated in dementia caregiving in two distinct ways; first, Elders from the community became involved in decision making in cases where the person with dementia had no family; and second, community members participated in monitoring people with dementia who were known to wander. In the latter case, caregivers sent letters to other community members to alert them to the person’s behaviour (Lombera et al., 2009). Among the Secwepemc it was suggested that community caring is
appropriate: “community members support one another throughout the lifecourse, an Elder would continue to be supported and to support others while completing their journey through the full circle of life” (Hulko et al., 2010). This group suggested that the words “Supporting one another” best reflected the participant’s ideals concerning caregiving for dementia such as family relationships, wholistic health and community. Explicitly “supporting one another” is meant to convey that there is a growing disconnect between the vision of the health care system and the vision of the community (Hulko et al., 2010).

**Formal Caregiving**
Grandmothers in Saskatchewan talked about the ‘big change in culture’ that has been occurring in their communities. They discussed the increased pace of life and changing family structures as being related to less community helping and more isolation for elders (Lanting et al., 2011). In Ontario, Aboriginal people shared how specific historical policies of the federal government, such as the residential school policy, have led to post traumatic stress in the elder Aboriginal population and inter-generational trauma in the younger generations which greatly affects the ability of families to function in a care giving role without a healing process (Sutherland, 2007). Yet, enabling community and family care giving is viewed as culturally appropriate whereas, long-term care facilities are viewed as a ‘death sentence’ (Sutherland, 2007).

Institutionalization can double the mortality rates for person with dementia (McClendon et al., 2006). Nursing homes are often viewed as inappropriate and as a last resort. Removal from a community to obtain care at a nursing home or hospital is viewed as inappropriate and undesirable. Very specifically, removal of Elders from the community is seen to further disrupt traditional modalities for the passing on of knowledge, i.e., preventing the teaching and learning of culture and the passing on of Indigenous knowledge, and has been described as “forced disengagement” (Easley & Kanaqlak, 2004). From the limited studies available, the suggested alternatives to a nursing home include improved home care supporting traditional caregiving values; more culturally congruent and safe care from service providers; and nursing homes that more closely resemble assisted living facilities (ALF) under the ownership and operation of the tribe or band which better reflect Aboriginal culture, language and values (Brown & Gibbons, 2008; Chapleski et al., 2003; Easley & Kanaqlak, 2004). In order to better support caregivers, studies recommend caregiver training, support groups, enhanced care coordination, adult daycare, and respite (Hennessey & John, 1996).

**Traditional Medicine**
Aboriginal peoples with ADRD may be incorporating Indigenous medicines into their treatment plans. Herbal remedies and ceremonies are important aspect of healing from past traumas and medical conditions (Sutherland, 2007). The inclusion of traditional healers and ceremony in care is a re-occurring theme in the literature (Henderson & Henderson, 2002; Hulko et al., 2010; Lori L. Jervis & Spero M. Manson, 2002; Keightley et al., 2011; Segal & Smith, 2004). These studies suggest that the incorporation of Indigenous medicine is an important part of providing culturally appropriate care and improving outcomes. In Northwestern Ontario, a study that included AD in its categorization of “acquired brain injury” found that spirituality and access to traditional care were deemed essential (Keightley et al., 2011). It was emphasized that the Ojibwa approach to wellness does not focus on fixing the illness. Wellness is wholistic and improvements in cognitive function can be best accomplished when biomedical health care teams work with traditional healers to promote wellness.
This theme was linked to a discussion about the lack of financial resources for traditional healing which is viewed as a barrier to good health.

Considerations for Cross Cultural Dementia Care for First Nations and Inuit

Several studies have been conducted that look at cultural safety, cultural competence and culturally appropriate care for Indigenous peoples. It is beyond the scope of this review to discuss the various models of cross-cultural care or to propose a culturally safe model of dementia care. We note however, that research with Indigenous peoples in Australia has suggested that the dominant Euro-Western models of person-centeredness and personhood in dementia care are not appropriate for Indigenous people who view health wholistically, have deep connections to land and place, whose social organization is not focused on self but on family and community, and for whom personal agency is less valued than community agency (McMillan, Kampaes, Traynor, & Dewing, 2010). We assume in our review that cultural safety and the provision of culturally appropriate care are the mechanisms through which health equity may be achieved in relation to dementia care. In this section we have extracted from the literature considerations that have been deemed important for dementia care for First Nations and Inuit.

There are several possible approaches to culturally safe and appropriate care. The data gathered from this literature review suggests that the diversity of health care access, culture and geography will necessitate regionally specific approaches to improving the cultural safety of dementia care for First Nations and Inuit.

One Canadian study in Alberta suggested that more ethical and appropriate care could be achieved by a focus on increasing the number of community-based staff and community run programs that could provide culturally appropriate health care to complement traditional and informal caregiving in the community (Buchignani & Armstrong-Esther, 1999). In this scenario culturally appropriate care is thought to be achievable by “same-culture care”. In discussing care of Aboriginal people with dementia in Saskatchewan, grandmothers suggested that there is a need for “culturally grounded health care.” By this they meant that there should be sensitivity in communication, respect for Aboriginal languages (especially an understanding of the role of humour) and translation services, and rich visual images should be used to aid communication (Lanting et al., 2011). In this scenario culturally appropriate/grounded care is linked to increased sensitivity, respect and cooperation in the care model. In Ontario, it was noted that different communication styles and language barriers make mainstream health care services and approaches to care inappropriate and poorly understood. Teachings have to occur at the appropriate time, be at the right pace and be done with respect for cultural beliefs and boundaries (Sutherland, 2007). Like the Grandmothers in Saskatchewan, Ontario participants viewed improved communication as a mechanism for improved care but the comments also highlight that training and respect for Aboriginal culture is important in culturally appropriate care.

Very little is yet known about the appropriate and respectful language to use when discussing dementia with First Nations and Inuit. The word dementia is often not known or used (Hendrix and Swift Cloud-Lebeau 2006 cited in Hulko 2010). An Inuit advisor to this literature review indicated that there is no Inuit word for dementia. Researchers working with the Secwepemc in British Columbia were unable to find a word in the Secwepemtsin language for dementia. The closest translations was “the lights went out”, although ‘forgetting’ was translated as “you forgot” or
“slepe” in Secwepemc which indicates forgetfulness with a cause (not natural) but not caused by dementia (Hulko et al., 2010). In a northern region of Saskatchewan where experiences with dementia are limited, it was reported that participants in research could not think of a word for dementia in Cree (M.E. Andrews, Morgan, & Stewart, 2010). Among the Choctaw, researchers had great difficulty finding an appropriate translation finding that meanings of individual words often differed significantly when they were back-translated (Henderson & Henderson, 2002). The provision of cross-cultural care requires not only translation of the words but also the concepts. The evidence to date suggests the need for the development of ethical, respectful and safe ways for health care practitioners to speak to elders about dementia in a way that facilitates a common understanding even when back translated.

Aside from direct translation, having caregivers and health practitioners available who speak local First Nations and Inuit languages may be a significant part of providing culturally safe and effective care. In a tribal nursing home setting in the US, staff believed that their ability to speak the tribal language was very helpful as they found residents became increasingly cultural and monolingual in their tribal language as dementia progressed. The staff also noted that the tribal language had the effect of calming down confused patients (Lori L.; Jervis & Manson, 2007). A similar phenomenon was reported in the preliminary findings in the Ontario study where having a visiting personal support worker speak to a dementia patient in “the language” resulted in an immediate improvement in mood and functioning (Jacklin & Warry, 2011). In northern Saskatchewan, the inability of nurses to speak the language was reported to have had the largest impact on providing dementia awareness training and caring effectively for Cree with dementia (M.E. Andrews et al., 2010)

Geographic Considerations
The unique geography of rural, remote First Nation and Inuit communities presents particular challenges for care of the elderly. Research drawing on the Aboriginal Peoples Survey in Canada found that older Aboriginal people living in rural, arctic and reserve settings are more likely to contact a nurse for medical care than a physician; and, those living on-reserve are more likely to have contacted a traditional healer (Wilson, Rosenberg, & Abonyi, 2010).

A study focusing on dementia care in rural and remote Canada found that in general there was a noted lack of culturally appropriate care, a need for caregiver and public education, and a need for more research on the value of telemedicine in these contexts (Morgan, Innes, & Kostensiuk, 2011). More specifically, research has found that travel for diagnosis and care is costly and may be undesirable to some families. The distance to care, physical challenges of travel, financial burden of travel and stress of travel are considered significant burdens. In addition, fear of services in larger southern centres and lack of appropriate services (e.g., English only care) have also been reported as significant issues associated with traveling for care (Cammer, 2006). In relation to knowledge and training, research with nurses in northern Saskatchewan found that nurses working in northern rural and remote First Nations had much less experience working in long term care facilities and specifically with people with dementia (Mary Ellen Andrews, 2008; M.E. Andrews et al., 2010). Nurses living and working in northern First Nations suggest that northern specific dementia care policies be considered including the provision of resources for care that currently do not exist and continuing educational training for RNs. The study also suggested that nurses had limited capabilities to interact with clients in a culturally appropriate way, citing both language and cultural barriers to understanding local needs (M.E. Andrews et al., 2010).
2.5.4. Summary

The literature review revealed several re-occurring themes in relation to culture.

- There is currently a lack of access to culturally appropriate care and resources that could foster traditional care models.

- There is diversity in beliefs and experiences with dementia among Aboriginal people in North America which are partly attributed to “acculturation” and “assimilation” and increasing exposure to biomedical information. Indigenous peoples may hold many different understandings of dementia ranging from a western disease perspective to an Indigenous framework of aging through the lifecycle (natural). Varying cultural understandings were also found in relation to the interpretation and experience of dementia symptoms.

- Cultural systems within and among Aboriginal communities that may potentially improve or sustain cognitive function in old age include: Aboriginal language use, the traditional role of elders as story tellers and knowledge keepers, and participation in ceremony.

- Caregiving for older First Nations and Inuit is more complex and difficult in comparison to the overall Canadian population. Informal caregivers in Aboriginal communities generally share a positive view of their role and accept responsibility with few questions. Cultural values play a large role in sustaining informal caregiving in these communities.

- Formal institutionalized caregiving, i.e., nursing homes are viewed as problematic for many Aboriginal communities. There is a desire to age in home communities even when physical or cognitive limitations are present. Institutions (nursing homes) especially when located outside of the communities are viewed as a mechanism by which the transmission of knowledge is interrupted and Elders’ important role in the community is undermined. Nursing homes are described by some as a ‘death sentence’ to be used only as a last resort.

- The use of Indigenous language in the care of people with dementia may have benefits to the quality of care and the quality of life experienced by the patient. Use of Indigenous language may also prove to be an important prevention tool.

- Dementia is a word that is not easily translated into Indigenous languages. Dementia as a biomedical construct did not exist in these communities. Words used to describe forgetfulness or confusion exist but are distinct from dementia as understood as an illness or disease.
2.6. Remaining Knowledge Gaps

Inuit
- The research did not uncover any information concerning dementia in the Inuit; this includes information on prevalence, screening or diagnosis, cultural understandings or historical experiences, caregiving, service use or service provision, or risk factors. There is much work to be done with Inuit communities to determine how their information and service needs will be best met.

Epidemiological Trends
- Limited reliable data is available that allows for accurate estimates of ADRD in First Nations and Inuit. There is no published information on the incidence of ADRD in either population.
- There is currently only one source of published treated prevalence estimates in First Nations in one province (BC).

Screening and Diagnosis
- The use of telemedicine (videoconferencing) for screening, diagnosis and on-going assessment and care has not been fully explored as an effective care model for rural and remote First Nations and Inuit communities in Canada.
- There are no validated culturally appropriate and sensitive screening mechanisms/tools for ADRD for First Nations and Inuit.
- There are no culturally appropriate assessments to determine First Nations or Inuit caregiver needs or level of burden.

Caregiving
- Community caregiving has been mentioned as part of the appropriate circle of care for First Nations. There is very little information on how communities cooperate in caregiving or how formal structures could or do facilitate the community’s role in caregiving (e.g., training, support, infrastructure) and/or what barriers exist in fulfilling this role.

Gender
- Very little information was presented in the literature concerning gender.
- The prevalence data from British Columbia suggests males may have a slightly higher prevalence of dementia than females, which is contrary to mainstream estimates.
- Some of the caregiving literature suggests that female daughters are more likely to provide care to elderly parents and relatives, and wives to their husbands, but there is no evidence to suggest this is a pattern that is applicable to all Indigenous cultures.

Risk
- No Canadian study has examined the risk factors for ADRD in First Nations and Inuit. As such, none have examined risk factors with an Aboriginal perspective on health and in the context of First Nations and Inuit socio-political conditions.
- Very few of the published studies examining risk of ADRD employ a life course approach, which is particularly important for understanding the cumulative impact of many different risk factors over a lifetime. Because First Nations and Inuit have a higher exposure to most of the documented risk factors, a life course approach is necessary.
- Particular attention must be given to the long-term and intergenerational effects of emotional trauma on ADRD in First Nations and Inuit.
2.6.1. Assessment of existing data sources
In general, few population-based data sources are currently being used to report on ADRD among First Nations, Inuit and Métis populations. However, the potential for such examination exists. Increasing amounts of information are available on the health of First Nations and Métis people using health services data linked with First Nations status or Métis membership lists or other identifiers, particularly in Ontario and the Western Provinces. This has been done in BC and Alberta. It could be done in Saskatchewan where a similar study was undertaken looking at diabetes. It could also be done in Manitoba where the Manitoba Centre for Health Policy has strong relationships and agreements with the Assembly of Manitoba Chiefs as well as advanced methods for identifying First Nations in healthcare databases.

In addition, several health services databases present potential for use without the need for data linkages if they include a First Nations/Inuit identifier. For example, the national Home Care Reporting System, held by the Canadian Institute for Health Information, includes an Aboriginal identifier. However, at present this identifier cannot be used to break out the First Nations and Inuit populations specifically.

Several surveys currently exist that could be potential sources of information on ADRD in First Nations and Inuit populations. These include:

- The First Nations Longitudinal Regional Health Survey (RHS)
- The Inuit Health Survey
- The Aboriginal Peoples Survey (APS)
- The Canadian Longitudinal Study of Aging (CLSA)
- The Canadian Community Health Survey (CCHS)

No existing survey is currently able to provide accurate prevalence estimates of the prevalence of Alzheimer’s disease and dementia among First Nations or Inuit populations. However, several of these surveys could be developed to include additional questions (e.g., APS and the Inuit Health Survey) or used in their current format for cursory analyses. For example, the RHS includes a question about memory. The CCHS contains both Aboriginal identity and dementia diagnosis questions, but may present sample size challenges. The possibility of using the CCHS to obtain national estimates for the off-reserve population should be further investigated.

Over the next several decades, the impact of dementia in First Nations and Inuit communities is likely to change. Given several key findings (below) of the literature review, we undertook an exercise to model the projected increase in demand for culturally competent dementia care.

- The limited evidence available on dementia prevalence in First Nations shows that dementia is occurring at younger ages than expected (British Columbia Provincial Health Officer, 2009). Similar to the pattern for the non-dementia population, the proportion of First Nations adults with dementia who are in the younger age groups is higher than that for the general Canadian population (British Columbia Provincial Health Officer, 2009). This, coupled with an anticipated increase in the number of people falling in the middle to late age groups (Caron Malenfant & Morency, 2011), will likely result in an increase in the prevalence of dementia and an accompanying need for increased culturally competent dementia care.

- A further exacerbation of this trend may arise from the higher than average incidence and prevalence of risk factors, such as Type II Diabetes, among First Nations (Dyck et al., 2010). Recent evidence indicates that those with diabetes have a higher risk of developing ADRD later in life (Ohara et al., 2011).

- Projected ADRD-related societal costs for Canada overall can be substantially reduced in the long-term with key interventions that either prevent ADRD, such as increased physical activity, or that provide targeted support, such as introducing system navigators (similar to those being used in the First Link program in Oneida) (Alzheimer Society of Canada, 2010).

3.1. Methods

3.1.1. Data Sources, Case Definition and Assumptions

Two key data sources were used to estimate the future impact of ADRD on First Nation communities and the Home and Community Care program. First, 2006/07 ADRD treated prevalence rates were obtained from the only published population-based estimates of ADRD prevalence specific to First Nations (British Columbia Provincial Health Officer, 2009). The case definition for ADRD was: two doctor visits or one hospital visit within the year for the following International Classification of Disease (ICD) codes: ICD-version 10 ‘F00’, ‘F01’, ‘F02’, ‘F03’, ‘G30’ or ICD-version 9 ‘290’, ‘294’, ‘331’. Because this refers to the proportion of people with documented treatment for ADRD but does not necessarily capture the total disease prevalence, we term this “treated prevalence”. Though these estimates were for BC First Nations, we assumed that they applied to First Nations across Canada. While there was one other prevalence estimate for one First Nation community in Canada, it was constructed approximately 20 years ago and was based on a small number of people in only one community (Hendrie et al., 1993). Because there were no published sources for ADRD prevalence among Inuit, we also used the same baseline prevalence in our cursory projection for Inuit. For this reason, the Inuit projection must be interpreted with caution. We assumed that the prevalence of ADRD applied evenly on-reserve and off-reserve for First Nations and in Inuit Nunangat and elsewhere for Inuit. For our comparison analysis of the general Canadian population, we used the ADRD treated prevalence estimates from this same report.
The second key data source was the recently released population projections from Statistics Canada for First Nations, Inuit and Métis (Caron Malenfant & Morency, 2011). The projections were based on the 2006 census and project out to 2031. They assume no ethnic migration, constant fertility rates and internal migration rates similar to the past decade. For more details on Statistics Canada’s projection methodology, please see: (Caron Malenfant & Morency, 2011). To obtain comparative projections for the general Canadian population, we combined information from other Statistics Canada reports, assuming a medium growth scenario (which assumes fertility and immigration similar to recent years and moderate growth in life expectancy)(Statistics Canada - CANSIM, 2010; Statistics Canada, 2010).

For the purposes of the numeric projection results, we employed a conservative assumption that the age-specific prevalence of ADRD among First Nations and Inuit would not change between 2006 and 2031. Thus, the projected numbers primarily account for the effect of population aging, which remains the most important driver of ADRD rates, and not for any increase in age-specific prevalence that may arise from increased risk factor exposure, such as diabetes. We also assume no change over time in the likelihood of recognition and diagnosis of ADRD and the accuracy of diagnostic coding for ADRD by hospitals and physicians for First Nations and Inuit.

3.1.2. Data Analysis
First Nation-specific treated ADRD rates were available for the following age groups: 60-69, 70-79, 80 and older. The age-specific treated prevalence rates used were as follows: 0.4% for age 60-69, 4.6% for ages 70-79, 12.8% for ages 80 and older.

We calculated the 2006 observed and 2031 expected number of First Nations, Inuit, and Canadians overall for each of the above age groups. The estimated proportion of First Nations living on-reserve in 2006 and 2031 were used to calculate the current and projected number of ADRD cases on-reserve. Similarly, the proportion of Inuit residing in Inuit Nunangat was used to estimate the number of Inuit cases in the north.

We applied the BC First Nations age-specific prevalence estimates to both time periods to determine the estimated number of ADRD cases in each age group and time period for First Nations and Inuit. We used the overall BC prevalence estimates to calculate the number of ADRD cases in the general Canadian population.

The potential effects of increased risk factor exposure over time were not accounted for in the data analysis but will be discussed in Section 5.3.

3.2. Results and Discussion
3.2.1. First Nations
We estimate that, in 2006, there were approximately 1,606 First Nations in Canada being treated for ADRD through physicians and hospitals. Approximately 735 of these people were living on-reserve (Table 1).

The number of First Nations in Canada is expected to increase from approximately 785,000 to 1.1 million, an increase of 1.4 times. Much of this growth will be among First Nations aged 60 and older, who are expected to increase in number by 3.4 times from 54,165 in 2006 to 184,334 in 2031 (Caron Malenfant & Morency, 2011). This population aging will contribute to a 4.2 times increase in
the number of First Nations with ADRD from 1,606 to 6,778 (Table 1). The increase will be highest on-reserve, where a 4.8 fold increase is expected.

**Table 2: Estimated treated Alzheimer’s disease and related dementias among First Nations, 2006 and 2031**

<table>
<thead>
<tr>
<th>Estimated treated ADRD 2006 (#)</th>
<th>Estimated treated ADRD 2031 (#)</th>
<th>Projected increase: 2006 to 2031</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-69 years</td>
<td>130</td>
<td>378</td>
</tr>
<tr>
<td>70-79 years</td>
<td>733</td>
<td>2,856</td>
</tr>
<tr>
<td>80 years and older</td>
<td>744</td>
<td>3,544</td>
</tr>
<tr>
<td>Total age 60 and older</td>
<td>1,607</td>
<td>6,778</td>
</tr>
<tr>
<td>On-reserve age 60 and older</td>
<td>735</td>
<td>3,550</td>
</tr>
</tbody>
</table>

**3.2.2. Inuit**

Using treated prevalence of First Nations in BC to estimate prevalence of ADRD in Inuit, we estimate that, in 2006, there were approximately 83 Inuit in Canada being treated for ADRD (Table 2).

If the assumed First Nation prevalence numbers are a reasonable reflection of reality for Inuit, we project a 3.3 times increase in the number of Inuit with ADRD by 2031.

**Table 3: Estimated treated Alzheimer’s disease and related dementias among Inuit, 2006 and 2031**

<table>
<thead>
<tr>
<th>Estimated treated ADRD 2006 (#)</th>
<th>Estimated treated ADRD 2031 (#)</th>
<th>Projected increase: 2006 to 2031</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-69 years</td>
<td>7</td>
<td>24</td>
</tr>
<tr>
<td>70-79 years</td>
<td>40</td>
<td>133</td>
</tr>
<tr>
<td>80 years and older</td>
<td>36</td>
<td>121</td>
</tr>
<tr>
<td>Total age 60 and older</td>
<td>83</td>
<td>278</td>
</tr>
<tr>
<td>Within Inuit Nunangat age 60 and older</td>
<td>65</td>
<td>222</td>
</tr>
</tbody>
</table>
3.2.3. General Canadian Population

Estimates have been published elsewhere for the prevalence of ADRD in Canada, projected out to 2038 (Alzheimer Society of Canada, 2010). The report showed that an increase of 2.3 times was expected (from 480,000 to 1.1 million). However, the estimates were based on a different case definition for ADRD than the one based on physician and hospital records that we have used above. Therefore, to provide a general population comparison and to validate our approach, we calculated similar estimates for the general Canadian population.

As Table 3 shows, our projected increase in treated ADRD in the general Canadian population mirrors that reported by the Alzheimer Society of Canada: 2.3 times. However, the actual number of people captured by our definition was approximately half that of the more comprehensive definition used in the Rising Tide report.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Estimated treated ADRD 2006 (#)</th>
<th>Estimated treated ADRD 2031 (#)</th>
<th>Projected increase: 2006 to 2031</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-69 years</td>
<td>8,473</td>
<td>15,035</td>
<td>1.8 times</td>
</tr>
<tr>
<td>70-79 years</td>
<td>71,534</td>
<td>159,548</td>
<td>2.2 times</td>
</tr>
<tr>
<td>80 years and older</td>
<td>182,101</td>
<td>419,671</td>
<td>2.3 times</td>
</tr>
<tr>
<td>Total age 60 and older</td>
<td>262,109</td>
<td>594,253</td>
<td>2.3 times</td>
</tr>
</tbody>
</table>

The above results validate our approach to estimating a measure of the increased demand that will be placed on First Nations and Inuit communities and on the Home and Community Care Program over 25 years. However, the actual numbers of individuals living with ADRD is likely underestimated as a result of using a treated prevalence case definition and could be up to twice as high as shown above for First Nations and Inuit.
3.2.4. Summary Points

- Between 2006 and 2031, ADRD will likely increase by 4.2 times in First Nations. The increase will be highest on-reserve, where a 4.8 fold increase is expected.
- Accurate projections are not possible for Inuit due to lack of baseline prevalence data. If First Nations prevalence rates are assumed to apply in Inuit, ADRD may increase in Inuit by 3.3 times between 2006 and 2031.
- The rate of increase in the number of people with ADRD among First Nations will be nearly double that of the general Canadian population, and will be about 1.5 times higher in Inuit.

3.3. Discussion of Alternate Scenarios

3.3.1. Potential Impact of Diabetes and other Risk Factors

The above calculations do not take into account a possible changing prevalence profile for First Nations and Inuit due to the potential increased prevalence of relevant risk factors, such as diabetes. Recent evidence indicates that those with diabetes have up to nearly 2 times higher risk of developing ADRD later in life (Ohara et al., 2011). Population-based researchers have observed that First Nations have an age-adjusted prevalence rate that is approximately four times higher than the general population (Dyck et al., 2010; C. Green et al., 2003); in some age and sex groups, this ratio is up to 7 times higher in First Nations (C. Green et al., 2003). Even with hypothetical interventions that decrease the incidence of diabetes over the next several decades, diabetes prevalence is still expected to grow at a faster rate among First Nations as the population growth outpaces mortality in the middle and late age groups (C. Green et al., 2003).

As a result of this changing profile of diabetes prevalence and the relationship between diabetes and ADRD, the above projections for ADRD among First Nations and Inuit may be underestimated. Likewise, interventions to reduce diabetes incidence and better manage pre-diabetes have the potential to mitigate some of the projected increase in ADRD in First Nations populations.

3.3.2. Potential Impact of Select Interventions

The Rising Tide report from the Alzheimer Society of Canada outlines the potential effects of four intervention scenarios on nation-wide rates of ADRD over time (Alzheimer Society of Canada, 2010). These interventions include:

1. Increase in physical activity levels
2. Hypothetical program to delay onset of dementia by 2 years
3. Caregiver development and support program
4. System navigator / Case management approach

In-depth description of the scenarios, including the evidence supporting the selected interventions, is available in the Rising Tide report at http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Rising-Tide.

The report projected substantial reductions in incidence, prevalence, health care utilization and economic impact of ADRD for the first two intervention scenarios. We can apply the percentage decreases in prevalence to the analysis above to obtain an approximation of the expected decrease
in the number of First Nations and Inuit living with ADRD in 2031. While our projection is for 25 years, and the Rising Tide projections are for 30 years, this rough calculation is still likely to be an underestimate of the full effect of the interventions because it does not account for the different age structure for First Nations and Inuit compared with the rest of the Canadian population.

**Increased activity levels:** With a 50% increase in physical activity levels among Canadians aged 65 and older without dementia who are already moderately to highly active, there is projected to be a 5.1% decrease in prevalence of ADRD over 10 years and an 8.6% reduction over 30 years (Alzheimer Society of Canada, 2010).

- This would approximate to 583 fewer First Nations and 24 fewer Inuit aged 60 and older living with ADRD in 2031.

**Delayed onset of ADRD:** A hypothetical delay of two years in the onset of ADRD would result in 21.6% fewer Canadians with ADRD over 10 years and 36.4% over 30 years (Alzheimer Society of Canada, 2010).

- This would approximate to 2467 fewer First Nations and 101 fewer Inuit aged 60 and older living with ADRD in 2031.

The third and fourth intervention scenarios showed marked reductions in the prevalence of ADRD in long-term care and the economic impact of ADRD. While we do not have sufficient data to estimate these impacts in First Nations and Inuit, one would expect to see similar benefits in First Nations and Inuit resulting from programs that provide enhanced caregiver support and system navigation.
4. Drugs used to Treat Alzheimer’s Disease among First Nations and Inuit: Analysis of Data from the Non-Insured Health Benefits Program

In Canada, there are three drugs that are approved for use in the treatment of mild to moderate Alzheimer’s disease: Aricept, Excelon and Reminyl (and their generic versions) (Lee, Hsiung, Seitz, Gill, & Rochon, 2011). These drugs do not cure or reverse the progression of Alzheimer’s disease, but they reduce the symptoms by inhibiting cholinesterase.

Health Canada’s Non-Insured Health Benefits (NIHB) program pays for prescription medications for Registered First Nation and Inuit beneficiaries if they are not covered under other drug programs. The three approved cholinesterase inhibitors were added to the NIHB Drug Benefit List on December 22, 2008. Prior to this, they were “exception drugs”, which are covered on a case by case basis after a pharmacy and physician applies to the Drug Exception Centre.

4.1 Methods
Aggregate NIHB data for approved cholinesterase inhibitors and their generic equivalents was provided by the NIHB program for three fiscal years: 2008-09, 2009-10 and 2010-11. Data were aggregated by “Item Name” (includes the drug name and dose), 5-year age group, sex and region. Aggregate costs were provided for 2010-11. Small cell sizes were suppressed by NIHB for 2010-11, limiting some aspects of the analysis.

4.2. Results
In 2010-11, the NIHB paid a total $242,282.62 in 3,574 claims for cholinesterase inhibitors to 320 distinct First Nations and Inuit clients (Table 5). This was 25% more claims for 11% more claimants compared with 2009-10.

Because cholinesterase inhibitors were only covered by exception until December of 2008, the 2008-09 data were not included in the analysis. However, for reference, the number of claims made when cholinesterase inhibitors were “exception drugs” was 512 for 112 clients. The effect of adding the drugs to the formulary was a more than twofold increase in the number of clients and a fivefold increase in the number of claims.

<table>
<thead>
<tr>
<th>Table 5: Overall use of cholinesterase inhibitors as paid by NIHB, 2009-10 and 2010-11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2009-10</strong></td>
</tr>
<tr>
<td>Total number of Claims</td>
</tr>
<tr>
<td>Total number of Distinct Clients</td>
</tr>
<tr>
<td>Average Number of Claims per Client</td>
</tr>
<tr>
<td>Average Payment per Claim</td>
</tr>
<tr>
<td>Average Payment per Client</td>
</tr>
</tbody>
</table>
Overall, 66% of claims for cholinesterase inhibitors were made by female claimants (67% in 2009-10 and 65% in 2010-11). In 2010-11, females accounted for 67% of the amount paid out to First Nations and Inuit claimants for cholinesterase inhibitors.

The use and associated cost of cholinesterase inhibitors was higher in older age groups. The combined total number of claims for 2009-10 and 2010-11 by age group is presented in Table 6. Also included in the table are the total amounts paid to claimants in 2010-11 by age group.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total Number of Claims (2009-10 and 2010-11)</th>
<th>Amount Paid by NIHB (2010-11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-49</td>
<td>23</td>
<td>$1,707.30</td>
</tr>
<tr>
<td>50-54</td>
<td>28</td>
<td>$4,112.78</td>
</tr>
<tr>
<td>55-59</td>
<td>167</td>
<td>$9,001.04</td>
</tr>
<tr>
<td>60-64</td>
<td>381</td>
<td>$23,135.70</td>
</tr>
<tr>
<td>65+</td>
<td>5,826</td>
<td>$206,420.60</td>
</tr>
</tbody>
</table>

The use of cholinesterase inhibitors between 2009-10 and 2010-11 varied by region. Please see Appendix B for a detailed regional breakdown. Ontario accounted for the largest number of claims and claimants in both years. However, the numbers dropped just slightly from one year to the next. This stability offset the large increases in several other regions, including Quebec, Atlantic, Manitoba.

In 2009-10, the most commonly claimed type of cholinesterase inhibitor was Aricept (70.0%), followed by Reminyl (24.5%) and then Excelon (5.5%), including the related generics. Analysis of drug type was not possible for 2010-11 due to cell suppression in the data provided by NIHB.

4.3. Discussion

In Canada overall, public spending for cholinesterase inhibitors is among top 10 drug classes for seniors (Canadian Institute for Health Information, 2010). In 2008, $20.5 million was spent in six provinces (Alberta, Saskatchewan, Manitoba, New Brunswick, Nova Scotia and Prince Edward Island), accounting for 2% of total drug spending in those provinces. From 2002 to 2008, total spending on cholinesterase inhibitors in the above provinces increased by 19.6%. It was the fourth fastest growing drug category for spending on seniors (Canadian Institute for Health Information, 2010).

While we were not able to conduct a similar analysis on the increase in spending on cholinesterase inhibitors by NIHB, the increase in the number of claims and clients among First Nations and Inuit beneficiaries suggests that a similar or steeper increase in spending would be observed.

The analysis of the data provided indicates two drivers of the increased use and accompanying spending. We observed likely increases in both the spread of use and in the intensity of use of cholinesterase inhibitors. In most provinces there was an increase of 50% in the number of First Nations and Inuit who submitted claims in 2010-11 compared with 2009-10. This indicates increased coverage of the First Nations and Inuit AD patients for whom cholinesterase inhibitors would likely be helpful. The observed increase in coverage may be a result of improved screening and detection of AD, increased awareness of the effectiveness and availability of cholinesterase...
inhibitors and increased prevalence of AD over the study period. We are limited in our ability to draw a firm conclusion because we do not have a valid estimate on the total number of First Nations and Inuit who have mild to moderate Alzheimer’s disease and who receive NIHB coverage in each region and in Canada overall.

In addition to a greater number of First Nations and Inuit receiving cholinesterase inhibitors, there were 25% more claims submitted in 2010-11 compared with 2009-10. There are several reasons why this might be the case. Individual claimants may actually be using more cholinesterase inhibitors at higher doses. However, more likely, we observed a ramp-up phase in 2009-10 following the introduction of cholinesterase inhibitors on the Drug Benefits List in December 2008. We are limited by the lack of adequate longitudinal data. The numbers may stabilize in the coming years. It will be important to continue to monitor the use. Conversely, the prescribing practice may have shifted to more frequent prescriptions with no accompanying change in dose. Due to limitations of the data provided, (for example, we did not have individual client data with date of prescription), a deeper client-level analysis employing a defined daily dose (DDD) methodology would be required to conclude whether the intensity of use actually increased disproportionally over the study period, or whether this is an artifact of prescribing practice.

While the large majority of claims and associated costs are associated with First Nations and Inuit aged 65 and older, a notable proportion was for younger claimants. Approximately 10% of the claims and 15% of the costs were associated with claimants under the age of 65.

Though, overall, a very small proportion of the estimated number of First Nations and Inuit who are living with ADRD are receiving pharmaceutical treatment, the numbers are increasing and are likely to account for a greater proportion of the direct costs associated with ADRD in First Nations and Inuit. However, without a fulsome economic analysis, we cannot conclude that the increased cost of cholinesterase inhibitors are not outweighed by the economic benefits of improved functioning among those taking cholinesterase inhibitors.
5. Looking Forward: Implications for First Nations and Inuit Health

Widespread and comprehensive efforts are needed to address the disparities in social determinants of health and the related outcomes in First Nations and Inuit. The impact that these continued disparities have on the incidence and prevalence of many chronic diseases is complex and sobering. Within this broad context, individual programs, such as the FNIHCC program, must also anticipate and prepare for increased numbers of First Nations and Inuit seniors. One aspect of this is the need for programs and communities to allocate effort, training and resources to ADRD prevention and care.

With some limitations noted, the results suggest an increased demand for ADRD specific care will be placed on First Nations and Inuit communities and on the Home and Community Care Program over 25 years. Our conservative estimates suggest an almost 5 fold increase in First Nation ADRD care patients and nearly 3 fold increase in Inuit dementia care patients. While the data should be interpreted with caution at this point, the ADRD gender distribution from British Columbia First Nations suggests that FNIHCC may expect to see an increase in the number of males requiring services - currently, more females require (or access) services (Johnston Research Inc., 2011).

The primary focus for FNIHCC program is to enable those with disabilities, chronic or acute illnesses and the elderly to receive the care they need in their communities. This is consistent with the desire of First Nations and Inuit to have their elders remain in their communities and to continue to contribute through their lifecycle. It is also consistent with literature that suggests poorer health outcomes when elderly or chronically ill are institutionalized. There is nothing in the dementia care literature or the Aboriginal dementia literature to suggest the model of enabling people to remain in their communities is not the most appropriate. The reality of this model will be increased demands for dementia-specific care that will impact on expenditures in the many of the mandatory and non-mandatory programs supported by FNIHCC, most critically, assessment (screening and specialist care), case management, home care support (RN and personal support worker), training (nurses, community health workers, informal caregivers, community), respite care, and data/research. At the same time, it will be vital to stay committed to FNIHCC program principles of providing culturally appropriate care, respecting First Nations and Inuit approaches to healing, and ensuring the services are effective and equivalent to those received by the general population (Johnston Research Inc., 2011).

From a programmatic point of view, ADRD care is complex and requires excellent coordination of several services: home support (meals, housework), personal support, nursing support, day programs, specialist referrals and monitoring, medication, Indigenous healing, safety monitoring, and respite. In addition, in the case of First Nation and Inuit seniors, ADRD is often, if not always, co-morbid with one or more other chronic conditions such as diabetes, heart disease, arthritis, cerebrovascular disease and more, which elevates the care needs.

Programs that support families caring for persons with ADRD will also be impacted. First Nations and Inuit in most cases do not “fit” mainstream care models that focus on dyad care-giving relationships because multiple family and community members can be involved in care for the person with ADRD. This will increase community and informal caregiver training needs (more individuals will require training) which must be made specific for ADRD care.
Caregiving for persons with ADRD is considered more difficult and burdensome when compared to caring for a person with a physical condition alone. Caregiver burnout is a central concern, as is the potential for related adverse effects on the caregiver (increasing their own risk of poor health outcomes) and the person with ADRD (abuse, neglect). Respite in conjunction with training for informal caregivers is the only proven effective method to mitigate these effects. Mainstream research demonstrates that careers who have not received adequate training and support regarding ADRD are at a higher risk for adverse effects (burnout and health problems) related to caregiving and provide lower quality of care (Williamson et al., 2001); and, that the most effective interventions to enhance caregivers knowledge and skills are delivered in the early stages of the caregiver to career relationship (McClendon et al., 2006).

5.1. Recommendations for FNIHCC Program First Nations and Inuit ADRD Strategies

When discussing comprehensive First Nations and Inuit ADRD strategies, it may be helpful to draw on culturally relevant frameworks. These frameworks recognize a holistic view of a person’s health in the context of First Nations and Inuit communities and their complex historic and contemporary social realities. The conceptual framework used in this report, Aboriginal Social Determinants of Health (Loppie Reading & Wein, 2009), provides one such opportunity. In addition, the Assembly of First Nations has produced a community planning framework for First Nations that would be helpful in framing a First Nations ADRD strategy (J. L. Reading, Kmetic, & Gideon, 2007). Inuit Tapiriit Kanatami has published a discussion paper on Social Determinants of Inuit Health in Canada that may help to facilitate Inuit-specific planning and strategy development (Inuit Tapiriit Kanatami, 2007).

Decisions to advance specific recommendations must be made in an environment where finite fiscal resources are available. These decisions will likely require efforts to prioritize and assess the costs of implementing recommendations in order to best allocate resources. Where possible, some recommendations could be incorporated through modifications to existing services.

With this context in mind, the following recommendations are presented:

1. At a systemic level, we recommend that FNIHCC consider consulting on the development of national, comprehensive First Nations and Inuit ADRD Strategy in partnership with First Nations and Inuit organizations and other invested parties such as the Alzheimer’s Society of Canada, the long-term, acute and primary care sectors and academic partners. This strategy should include:
   a. The development of ADRD research agenda in collaboration with First Nations and Inuit organizations
   b. Appropriate support to informal caregivers
   c. Emphasis on prevention and early intervention
   d. Integrated systems of care
   e. Strengthening the ADRD workforce
2. At the FNIHCC program level, we recommend that the program support collaborative research that leads to the development of **best practices for screening** First Nations and Inuit for cognitive impairment and dementia. In the short term, work should focus on:
   f. the development of culturally appropriate screening instruments that reflect the Aboriginal social determinants of health, the diversity of First Nations and Inuit culture, and local/community access to physician care, specialist care and follow-up care;
   g. the assessment of the appropriateness and effectiveness of the use of telemedicine in dementia screening; and,
   h. training of physicians and health care workers in the use of culturally meaningful screening instruments.

3. We recommend the development of a **Cultural Safety Training Program** for First Nation and Inuit Dementia Care in consultation with communities, Elders, researchers, program staff and front-line health care workers. The training should build on the themes identified in the literature review:
   i. Should reflect First Nation and Inuit understandings of and experiences with dementia (cultural understandings of the illness/process, causes, expectations, symptoms, appropriate care and treatment),
   j. Should be directed at non-Aboriginal health care providers but available to all Aboriginal and non-Aboriginal providers; especially nurses, physicians, partner organizations such as Aboriginal Affairs and Northern Development Canada staff and Alzheimer society staff,
   k. Should include training on the integration of traditional and western medicine in treatment and prevention of dementia and should facilitate relationship building between physicians and local healers,
   l. Should include the development of a common local language and terminology guide specific to the region.

4. We recommend that the FNIHCC program support and encourage community-led culturally relevant initiatives that provide opportunities for both **intervention in and prevention of dementia** in First Nation and Inuit communities, for example, programs that connect elders and youth, elders with each other, and that increase elder participation in traditional language and ceremonial events. Such activities could be supported through enhancements modifications or additions to current programming and through programming combined with pilot testing new initiatives. In either case we further recommend clear appropriate **evaluation** processes be incorporated so that best practices can be developed and shared.

5. We recommend FNIHCC proceed with great sensitivity in relation to expectations concerning the role of **informal and community caring models**. Caution should be exercised in viewing informal caregiving traditions in First Nations and Inuit as a panacea for increasing pressures on public spending. While informal caregiving can be appropriate and effective, the evidence reviewed suggests there are optimal conditions under which informal care giving is safe and effective for Aboriginal people:
6. We recommend the development of **Local Care Models** that are reflective and supportive of local culture, geography, resources, community assets, and community health services. Working within its’ mandate, we recommend that FNIHCC coordinate the development Local Care Models by:

   m. Enhancing in-home respite care and working with communities to determine how they might work to prioritize respite in their delivery of the FNIHCC program over the next 10 years.

   n. Provide culturally appropriate training and support for ADRD to informal and formal community caregivers

   o. Provide culturally safe information sessions on ADRD for community members at large

   p. Support “adult day care” that is grounded in the local culture and values and is focused on culturally appropriate interventions and dementia prevention (see Recommendation #4)

   q. Support financially the integration of traditional Indigenous medicine and ceremony into care plans for clients and caregivers.

7. We recommend that the FNIHCC respond to the immediate and ongoing need for **data and information on ADRD** among First Nations and Inuit and specifically FNIHCC clients.

   r. Short term strategies:

      i. Continue to monitor NIHB claims for cholinesterase inhibitors, including sex, age, and regional breakdowns.

      ii. Investigate the possibility of using the RHS (memory variable) for on-reserve and CCHS (reported dementia diagnosis) for off-reserve First Nations as a proxy for determining incidence of dementia.

      iii. Immediately include ADRD as one of the conditions tracked in existing information system OR conduct a special study to determine the current proportion of clients with an ADRD diagnosis.

      iv. Encourage survey and information system development that would allow for research of ADRD among First Nations and Inuit. This minimally requires collection of both Aboriginal identity and ADRD – or the ability to link the two data elements. An enhancement would be the collection of risk factors and comorbid conditions. Ideally, longitudinal data would be available that takes into account social determinants of health from an Aboriginal perspective.
v. Ensure that cognitive assessment tools embedded in current and potential future information systems (e.g., Resident Assessment Instrument – Home Care (RAI-HC)) are culturally relevant.

vi. Consider undertaking a longitudinal ADRD research study in partnership with First Nations and Inuit organizations and other invested parties such as the Alzheimer’s Society of Canada, the long-term, acute and primary care sectors and academic partners.

s. Long term strategies:
   i. Embed mechanisms to monitor ADRD clients into existing systems. Consider longitudinal assessment of cognition, informal caregiving, care needs, comorbid conditions, medication use, and adverse outcomes.
   ii. Invest or participate in pan-Canadian efforts to develop/use existing databases or to conduct primary research on ADRD in First Nations and Inuit.

8. In addition to the recommendations we have made program-wide, we recommend that service provision for remote First Nation and Inuit communities focus as much as possible on improving and sustaining locally available resources for people with dementia. Strategies should include but not be limited to:
   t. The development and implementation of dementia specific training for all community health care workers that is prepared and presented within a cultural safety framework.
   u. Exploration and research into the use of telemedicine in dementia diagnosis and ongoing dementia care.
   v. Enhanced homecare services for people in the later stages of dementia to enable people with dementia to remain in their communities until their passing if they should desire it.
   w. Community development work to enhance community and family participation in care of people with dementia.
6. References


Finke, B. (2003). How Do We Screen for and Diagnose Dementia in Al/AN Elders? *The IHS Primary Care Provider, 28*(1), 7-8.


Kessing, L. V., & Andersen, P. K. (2004). Does the risk of developing dementia increase with the number of episodes in patients with depressive disorder and in patients with bipolar disorder? *Journal of neurology, neurosurgery, and psychiatry, 75*(12), 1662. doi: 10.1136/jnnp.2003.031773


Statistics Canada.
Trends in Alzheimer’s disease and related dementias among First Nations and Inuit


Williamson, G. M., Shaffer, D. R., & Family Relationship in Late Life Project. (2001). Relationship quality and potentially harmful behaviours by spousal caregivers: How we were then, how we are now. . Psychology and Aging, 16, 217-226.


### Appendix A: List of Source Organizations for Grey Literature Search

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<thead>
<tr>
<th>Source Organization</th>
<th>Website</th>
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<td><strong>Search engines</strong></td>
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<tr>
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<td><a href="http://www.google.com">www.google.com</a></td>
</tr>
<tr>
<td><strong>Alzheimer’s disease and dementia-related organizations</strong></td>
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</tr>
<tr>
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<td><a href="http://www.alzheimer.ca">www.alzheimer.ca</a></td>
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<tr>
<td>Alzheimer Disease International</td>
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<td>Alzheimer Society of New Brunswick</td>
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<td>Alzheimer Society of Ontario</td>
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<td>Alzheimer Society of PEI</td>
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**Relevant Canadian Research Centres and Institutes**

<p>| University of Manitoba Centre on Aging   | umanitoba.ca/centres/aging/  |</p>
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<th>mchp-appserv.cpe.umanitoba.ca</th>
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<td>Saskatchewan Health Quality Council</td>
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<tr>
<td>Institute for Clinical and Evaluative Sciences</td>
<td><a href="http://www.ices.on.ca">www.ices.on.ca</a></td>
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<tr>
<td>L'Institut national de santé publique du Québec</td>
<td><a href="http://www.inspq.qc.ca">www.inspq.qc.ca</a></td>
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<td>Networks Environments for Aboriginal Health Research</td>
<td>akneahr.ciet.org</td>
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<td><a href="http://www.neahr.ualberta.ca">www.neahr.ualberta.ca</a></td>
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<td>aahrp.socialwork.dal.ca/research_programs/AAHRP_funded_projects.html</td>
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<td></td>
<td>kloshetillicum.ca</td>
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<tr>
<td></td>
<td>umanitoba.ca/centres/cahr/</td>
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<td><a href="http://www.iphrc.ca">www.iphrc.ca</a></td>
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<td><a href="http://www.nasivvik.ulaval.ca">www.nasivvik.ulaval.ca</a></td>
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**Provincial Governments and Ministries of Health**

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<td>Ministère de la Santé et des Services</td>
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<td>Organization</td>
<td>Website</td>
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<td>------------------------------------------------</td>
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</tr>
<tr>
<td>Sociaux de Québec</td>
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<tr>
<td>Government of New Brunswick</td>
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**Aboriginal Organizations**

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<td>Makivik Corporation</td>
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<td>Metis Nation of BC</td>
<td>mnbca.ca</td>
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<tr>
<td>Native Women’s Association of Canada</td>
<td><a href="http://www.nwac.ca">www.nwac.ca</a></td>
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<tr>
<td>Congress of Aboriginal Peoples</td>
<td><a href="http://www.abo-peoples.org">www.abo-peoples.org</a></td>
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<td>National Association of Friendship Centres</td>
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**Surveys**

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Appendix B: Regional Breakdown of Cholinesterase Inhibitor Claims from the Non-Insured Health Benefits program (NIHB)

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<th>2009-10</th>
<th>2010-11</th>
<th>Percent Change</th>
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<tr>
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<tr>
<td>Atlantic</td>
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<td>222</td>
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<td>Pacific</td>
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<td><strong>Total</strong></td>
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<tr>
<td><strong>Total</strong></td>
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