A First Nations Diabetes Report Card

Part 1: Marking a Path to Community Wellness

Assembly of First Nations • June 2006

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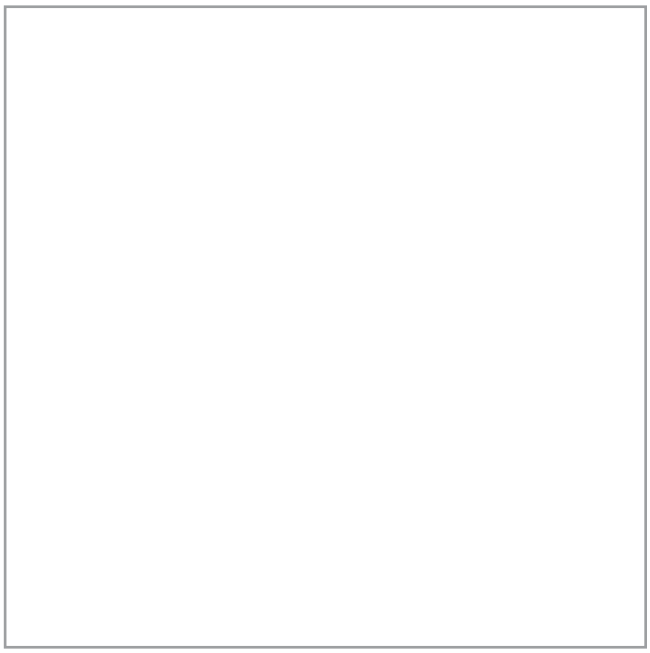
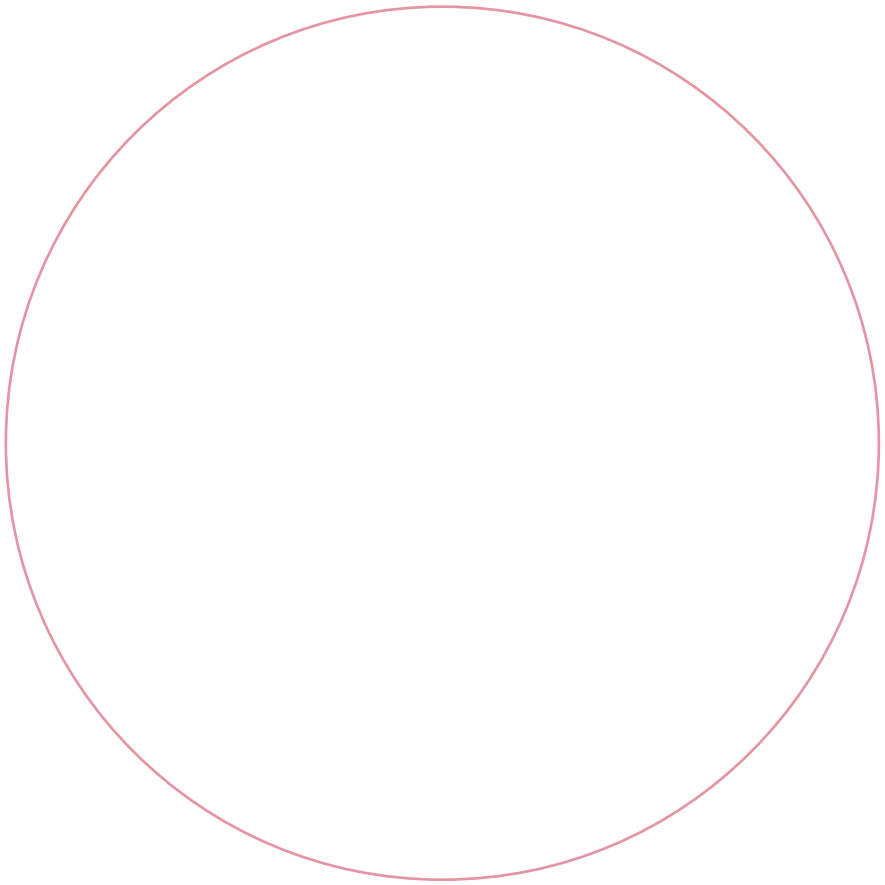




Acknowledgements

This inaugural issue of A First Nations Diabetes Report Card is dedicated in memory of Kevin Armstrong whose passion for life and for his work inspired us all. It is in the spirit of this passion that this report is written in furthering the work that he started in improving the health and well-being of First Nations people.

The Assembly of First Nations (AFN) wishes to thank the program leads of the many inspiring diabetes programs across this land for sharing their program knowledge with us and the many committees and volunteers of the Assembly of First Nations who have contributed their time and wisdom to this report by providing information and in sharing their own personal journeys with diabetes. We also wish to thank the leadership of federal, provincial and territorial governments and Aboriginal organizations in assisting in the development of the first issue of the First Nations Diabetes Report Card.

The information in this report would not have been possible without the research work of Dr. L. Fischer and Andrea L.K. Johnston, who pulled together a detailed account of policy and programs for the prevention and treatment of diabetes among First Nations People, or without the work of Katherine Gray-Donald who identified the key indicators for Type 2 diabetes in First Nation communities included in this report. Thank you to Karen Philps of the Canadian Diabetes Association whose advice was invaluable in the support of this project and to Carol Seto, Carol Seto and Associates, for providing a synthesis of the information gathered and in the writing of this report.

Executive Summary

Diabetes has become a disabling and deadly disease with First Nations suffering at a rate three to five times that of the general Canadian population.

In November 2005, the First Ministers Meeting on Aboriginal Issues committed more than $5 billion over the following five years to close the gap between Aboriginal people and other Canadians in education, health, housing and economic opportunities. The Kelowna Accord addressed commitments to health including setting down targets to reduce diabetes by 20% in five years and 50% in 10 years and doubling the number of Aboriginal health professionals in 10 years from the present 150 physicians and 1200 nurses.

According to the Assembly of First Nation's 2005 "Agenda for Restoring and Improving First Nations Health", the health of First Nations people is as important as the health of the individual. Promoting health, preventing disease, and protecting the health of communities is pivotal in any collective action.

Community health planning and the understanding of the broader determinants of health must be led by the very communities who know intimately the problems of food security, safe water, overcrowding and other issues facing their people. Only then will chronic disease prevention, including injuries and substance abuse, as well as other urgent public health problems facing communities, be successfully tackled.

The AFN is taking the next steps needed to plan out what this will mean for the health of First Nations in Canada by developing A First Nations Diabetes Report Card. The Report Card has three objectives:

- To provide information in improving knowledge and research capacity;
- To enhance relationships between different federal, provincial and territorial health authorities, jurisdictions and organizations and people involved in diabetes and prevention; and,
- To raise awareness of key decision-makers to the challenges faced by First Nations people with diabetes, their families and communities while sharing practices which effectively address these.

A First Nations Diabetes Report Card is the first of its kind and will consist of three parts, the first of which will lay down the groundwork in six key areas of diabetes: prevention, treatment, education, policy development, research and surveillance. It begins to discuss broad indicators for Type 2 diabetes and health that can be used to compare progress in the six key areas across the nation. Parts 2 and 3 of the First Nations Diabetes Report Card will look at collecting more empirical data from provinces and territories and across the entire lifespan … from womb to tomb.

The Assembly of First Nations Wholistic Policy and Planning Model is used as the foundation for building the Report Card and is aligned with the principles and policies of the First Nations Health Action Plan.

Eleven evidence-based recommendations are put forward in marking a path to improved First Nations health and well-being supported by research evidence and policy and program work done to date. The First Nations Diabetes Report Card closes with community stories of challenges faced and successes celebrated in addressing diabetes prevention, treatment, education, policy development, research and surveillance in First Nations communities.

Introduction

The Assembly of First Nations

The National Indian Brotherhood was founded in 1968 and became the Assembly of First Nations (AFN) in 1982. The AFN is the national representative organization of more than 630 First Nations in Canada. Historically, First Nations have a unique and special relationship with the Crown and the people of Canada, as manifested in Treaties and other historical documents and the Canadian Constitution. This special relationship is one of negotiated agreement with a view toward peaceful coexistence based on equitable sharing of lands and resources, and ultimately on respect, recognition and enforcement of our right to govern ourselves. As the national lobby organization working to support the efforts of First Nations leaders, the AFN exists to promote the "restoration and enhancement" of this relationship and to ensure that it is beneficial to First Nations, including health care for First Nations people in Canada.

A First Nations Report Card

This report is the first of AFN's three-part First Nations Diabetes Report Card based on the Canadian Diabetes Association's (CDA) model. It lays down the groundwork in six key areas: prevention, treatment, education, policy development, research and surveillance. It begins to discuss diabetes health indicators in each of these areas with a focus on adult health from a national perspective. These diabetes health indicators are the policy tools which will help to identify the gaps, priorities, opportunities and promising strategies that will help to inform decisions about how to best allocate resources in reducing the burden of diabetes among First Nations.

AFN's First Nations Diabetes Report Card has three objectives:

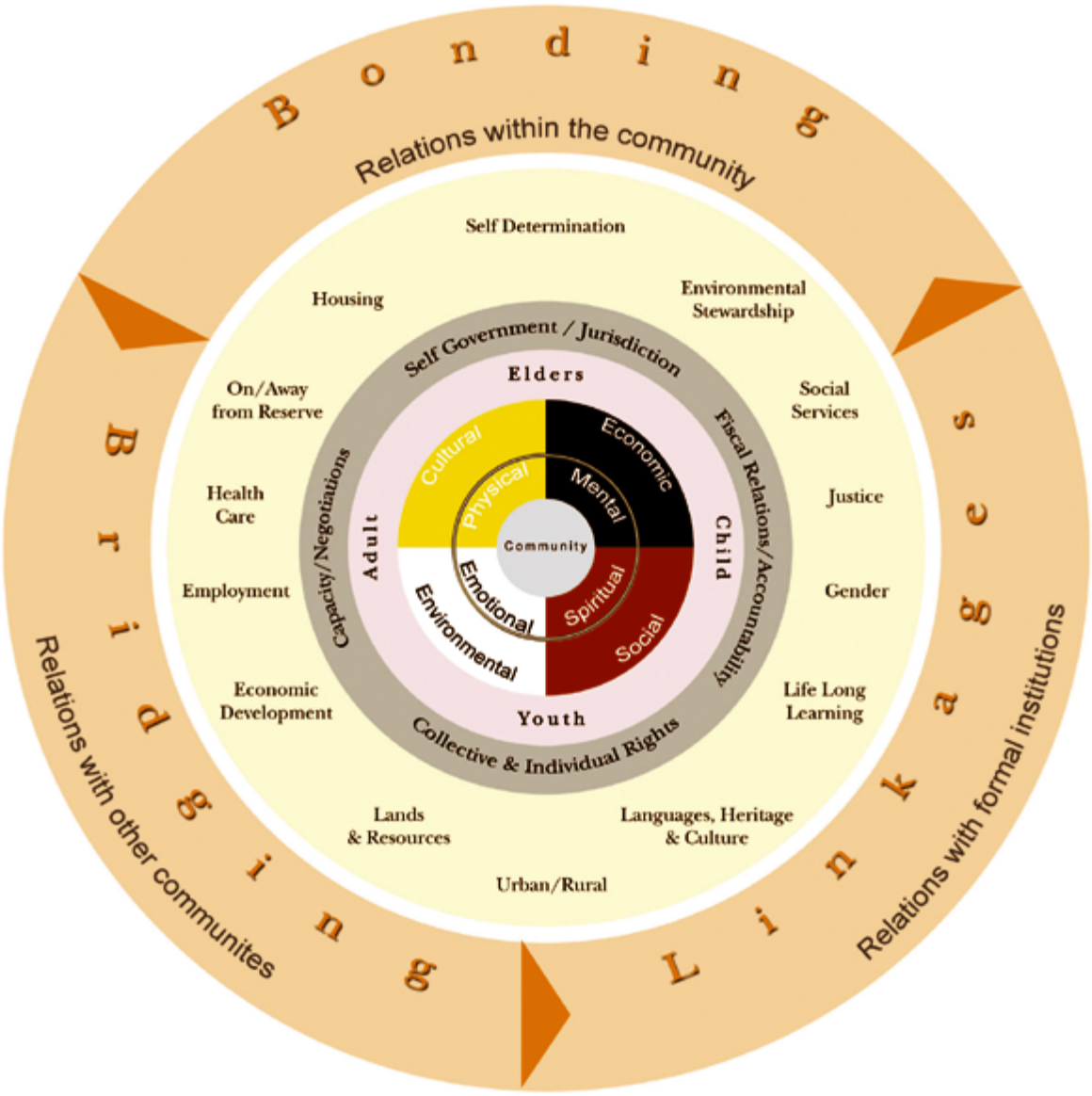
- To provide information in improving knowledge and research capacity;
- To enhance relationships between different federal, provincial and territorial health authorities, jurisdictions and organizations and people involved in diabetes and prevention; and,
- To raise awareness of key decision-makers to the challenges faced by First Nations people with diabetes, their families and communities while sharing practices which effectively address these.

The first part of the Report Card draws largely on research literature using three main sources of research to build the picture of diabetes in First Nations communities: the First Nations Centre's First Nations Regional Longitudinal Health Survey (RHS), the AFN's Report on Policy and Programs for the Prevention and Treatment of Diabetes Among First Nations People prepared by Johnston Research Inc. and the CDA's Diabetes Report Card. It will set the stage for Parts 2 and 3 of the Report Card which will probe empirical research to elaborate on the status of health indicators for Type 2 diabetes across each province and territory and across the life cycle in First Nations communities.

A Wholistic Approach to Health

It is not enough to focus on a few determinants of health in describing the foundational elements of First Nations' health and well-being. A wholistic model of health is needed to map out the intertwining relationships that are needed to achieve community wellness. Figure 1 provides a proposed model for diabetes based on AFN's First Nations Wholistic Policy and Planning Model (AFN, July 2005):

First Nations Wholistic Policy and Planning Model



Legend

- Medecine Wheel
- Lifespan
- First Nations Self-Government
- Health Determinants
- Social Capital

The model places community at its centre with the prominence of the Medicine Wheel marking the four directions of spiritual, physical, mental and emotional health. The model depicts the role of cultural, economic, social and environmental factors in impacting the health of individuals throughout their lifecycle and the importance of First Nations self-government in achieving optimal health. These relationships affect and are affected by the six key areas of diabetes: prevention, treatment, education, policy development, research and surveillance in determining health.

> *"By far the greatest share of health problems is attributable to broad social conditions. Yet health policies have been dominated by disease-focused solutions that largely ignore the social environments. As a result, health problems persist, inequalities have widened and health interventions have obtained less than optimal results."*
>
> *– World Health Organization, 2005*

Aligned with the AFN's First Nations Health Action Plan (AFN, September 2004), the AFN's First Nations Diabetes Report Card explores the elements needed to create a sustainable and coordinated health system which services First Nations communities affected by diabetes, a system which provides:

- Stable and sustainable program and capital funding in attaining and maintaining the health of First Nations people.
- Coordinated health care without borders for all First Nations people.

Marking the Way to Community Wellness

Painting the Landscape

Diabetes has become a disabling and deadly disease for many Canadians, but First Nations continue to suffer with a level that is three to five times higher. First Nations adults have higher age-standardized prevalence rates than Inuit people and comparable or higher than Métis people (Bruce GB, Kliewer Ev, Young TK et al, 2003).

Diabetes prevalence among First Nations people is shaped by the challenges and realities, or determinants of health that First Nations people face. A higher prevalence of diabetes in First Nations adults has been linked to attaining a less than high school education level, greater degrees of isolation and understanding or speaking one or more First Nations languages (First Nations Centre, November 2005). The burden of diabetes not only weighs heavily on individuals but also on their families. About 3 in 10 adults with diabetes receive care from their families (First Nations Centre, November 2005).

These statistics must be painted against a current backdrop of chronic under-funding of health services for First Nations people. Over the next 5 years, the AFN forecasts a shortfall of $2.85 billion without a much needed 11.3% growth in the health budget (AFN Facts on First Nations Health Services, March 2006). First Nations people are already experiencing gaps in needed health care in comparison to the Canadian population. Waiting time is shared by First Nations as the most common reason for not accessing the health care they need (First Nations Centre, July 2003).

The 2004 First Ministers 'Ten Year Health Plan" provides $4.5 billion over six years, beginning in 2004-05, for a Wait Times Reduction Fund. Benchmarks for radiation therapy, screening for cancer and various orthopedic procedures have been established (Ministry of Health and Long-Term Care, December 2005). A

strategy for addressing wait time issues experienced by First Nations people has not been discussed. First Nations do not support a pan-Aboriginal approach to health service delivery, including strategies to reduce wait times, as this does not recognize the unique needs of First Nations communities and conflicts with First Nations' jurisdictions, rights to health benefits and the federally-recognized inherent right to self-government.

Benchmarking for Improved Diabetes Care

Health indicators provide the markers to support the monitoring of progress in improving and maintaining the health of populations and in assessing the health of the system itself. Health indicators ideally provide evidence-based, comparative information on:

- The overall health of the population and how it compares to other regions in the province and country and how it changes over time;
- The major non-medical determinants of health in the region;
- The health services received by the region's residents; and
- Characteristics of the community or the health system that provide useful background information (Statistics Canada, November 2003).

This report considers potential broad health indicators for Type 2 diabetes prevention, treatment, education, policy development, research and surveillance which are modifiable in the short- to medium-term towards reducing the burden of this disease and changing the face of diabetes in First Nations communities. AFN's Wholistic Policy and Planning Model is instrumental in guiding the development of these health indicators and in looking through a determinants of health lens which takes into account the barriers faced by First Nations individuals, their families and their communities.

Subsequent reports will refine and expand on this initial set of diabetes health indicators, providing comparisons between provinces, territories and across the span of the life cycle … from womb to tomb.

Type 2 Diabetes Health Indicators

Potential health indicators from a broad perspective are presented in each of the six key diabetes areas of: prevention, treatment, education, policy development, research and surveillance. Based on a review of health indicator work conducted by Gray-Donald, these indicators set the stage for long-term monitoring of progress and comparison of initiatives across provinces, territories and the lifecycle … from womb to tomb (Gray-Donald, 2005).

A. Prevention

> *"First Nations people who considered their health status as excellent or very good identified regular exercise and a balanced diet as practices contributing most to good health."*
>
> *- First Nations Centre, November 2005*

Access to Healthy Foods: Traditional food accessibility/hunting/fishing

Growth and migration to large urban centres, changing work habits, better food packaging, access to store bought foods, and the legacy of colonization and residential schools have all impacted the food choices and health of First Nations people. Despite the benefits of traditional foods, only half of First Nations adults often consume traditional protein-based foods (First Nations Centre, November 2005). Gender, age, income and level of education are not related to consumption of traditional or First Nation foods but the size of a community can be used as a predictor of traditional food consumption (First Nations Centre, November 2005). Adults in small communities (< 300 residents) are more likely than residents in larger communities (> 1500 residents) to consume protein-based traditional foods and berries and other vegetation foods (First Nations Centre, November 2005).

Access to nutritious foods, including traditional foods is inequitable. All First Nations communities should have access to nutritious foods sources which provide a protective effect from diabetes as a result of the combined effect of an increase in physical activity through hunting and gathering and reduced fat intake related to the consumption of traditional meats (Gray-Donald, 2005).

There are few programs which have arisen out of policy to address access to both nutritious and traditional foods. While limited in budget and scope, Indian and Northern Affairs Canada's (INAC) Food Mail Program is one example intended to provide reduced freight charges for shipping nutritious perishable food to northern communities not accessible year round by surface travel. It has resulted in reduced cost for food and includes an educational component around the reading of food labels. Another example is the Yukon First Nations Traditional Diet Program at Whitehorse General Hospital, which offers a Traditional Diet Coordinator who oversees and ensures the safety of traditional foods served at the hospital.

Recommendation 1

Ensure a process through which First Nations people have reasonable access to a safe, secure and nutritionally adequate food supply, including traditional foods.

Access to Physical Activity: Recreational opportunities for adults, youth and children.

Traditional lifestyles of First Nations are physically active. In some First Nations communities in Canada, traditional activities such as hunting, trapping, fishing and gathering provided the main source of physical activity up until the 1960s. A combination of decreased reliance on traditional foods, increased reliance on government subsidies and purchase of more store-bought foods significantly changed the physical pattern of these First Nations communities (Warry W, 1998).

Healthy lifestyle, including regular physical activity, has been shown to contribute to the prevention of diabetes. Yet, the means to access recreational opportunities can be limited by a number of factors including: a lack of awareness of existing programs or facilities, an inability to afford equipment or registration fees, a lack of cultural appropriateness, the remoteness of communities or the absence of a safe environment to exercise.

Using physical activity as a proxy for recreational opportunities, less than a quarter of First Nations people are active at a level that would be beneficial to health, with men more likely than women to report sufficient activity (First Nations Centre, November 2005). Most First Nations people choose walking for their physical activity but also participate frequently in activities including fishing, swimming, berry picking or other food gathering, bicycling and hunting or trapping (First Nations Centre, November 2005).

The opportunity to participate in regular physical activity should be consistently available to First Nations. Low physical activity is a risk factor for diabetes, other chronic diseases and mental health. Traditional activities such as hunting and fishing contribute to physical activity levels. Yet, federal, provincial and territorial laws and policies make it difficult to engage in these activities outside First Nations communities despite Aboriginal and treaty rights in hunting, fishing and gathering. Access to recreational facilities or physical spaces where First Nations people can be active will depend on many factors including safety, affordability and availability.

Federal, provincial and territorial policies related to hunting, fishing, trapping and gathering are evolving and will continue to be the subject of heated debate over Aboriginal and treaty rights to these activities. Some promise is provided by Sport Canada's Policy on Aboriginal Peoples' Participation in Sport which aims to enhance Aboriginal people involvement in sports; improve opportunities to reach high performance levels; build the capacity of individuals, communities and organizations to support Aboriginal sport in Canada; and, develop and strengthen cooperation and collaboration in sport among governments.

Recommendation 2

Develop comprehensive physical activity strategies for First Nations living in and away from their communities that include environment and policy initiatives to reduce barriers to accessing enjoyable, safe opportunities for physical activity.

Access to Education and Support: Number of community wellness centres as a percentage of the population (by community) with access to these centres

Diabetes education enhances knowledge, skills and changes in behaviour. It improves self-care and clinical outcomes. Community wellness goes beyond the biomedical model of diabetes care and considers, not only the physical, but also the mental, emotional and spiritual wellness of individuals, their families and their communities.

A sampling of the type and scope of available diabetes programming for Aboriginal people is used as a proxy for the number of community wellness centres. Four in ten First Nations people afflicted with diabetes currently attend a diabetes clinic or see someone for diabetes education. Among the 6 in 10 who do not attend, half said they did not require diabetes education and over a third did not state a reason. Access (22.2%) is the main reason cited for those needing diabetes education and not receiving it. This was more apparent for isolated as opposed to non-isolated areas (First Nations Centre, November 2005).

Over the past five years, the Aboriginal Diabetes Initiative (ADI) has funded care and treatment costs for First Nations living on reserve and culturally appropriate approaches to diabetes prevention and health promotion activities for Aboriginal people across Canada, including Métis and individuals living way from their communities. As of January 2006, Health Canada, First Nations and Inuit Health Branch (FNIHB) reported a total of 458 programs across the nation servicing Aboriginal People, many of which service First Nations through Friendship Centres or Aboriginal Health Access Centres (ADI, January 2006).

The 2005 federal budget confirmed the investment of $190 million over the next 5 years to maintain and enhance the ADI. Federal prevention and health programs service most First Nations communities and often supplement provincial treatment programs. Non-status First Nations generally do not have access to these programs. Provincial programs are dependent on many factors including resources and the predominance and degree of isolation of First Nations (AFN, January 2006).

Diabetes programming falls into one of four programming categories: Risk Awareness and Healthy Lifestyle Education programs, Healthy Lifestyle Participation Support Programs, Early Detection and Screening programs and Treatment programs and services (AFN, January 2006).

- **Education Programs**: provide diabetes risk awareness and healthy lifestyle information grounded in First Nations teachings utilizing a variety of settings including health fairs, established gatherings, friendship centre programs, cultural events and other healthcare settings.

- **Participatory Programs**: include programs such as community kitchens, walking programs, school diabetes prevention programs which help to improve access to healthy food at affordable prices and exercise venues that are healthy, safe and affordable and have built-in incentives to participation such as take-home meals or food vouchers.

- **Early Detection and Screening Programs**: which exist in collaboration with research initiatives in screening for diabetes and its complications.

- **Treatment Programs and Services**: screening and treatment in the mainstream system while providing culturally sensitive services.

A wide variety of diabetes prevention and management programs exist across the country. However, funding is often time limited and constrained in how it is applied. For example, the ADI provides funding for health promotion and primary prevention activities off-reserve. Some health providers have interpreted this to mean that they cannot provide services on-reserve or to people who have diabetes (AFN, January 2006). In addition, annual renewal of funding

arrangements is required to sustain programming. First Nations' inherent Aboriginal and Treaty rights to health support the provision of health services regardless of First Nations citizens' residency, on or away from their communities. Improvements and growth in the system are required with consideration of multi-year, regularized and adequate funding to support diabetes prevention and management (AFN, November 2005).

Recommendation 3

Ensure that First Nations people have timely, affordable and ongoing access to community wellness programs which provide diabetes education and support and which respect the unique language, culture and geography of each community.

B. Treatment

Access to Professionals and Diabetes Services: First Nations diabetes care follows the CDA Guidelines

The CDA 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada are widely recognized by provinces/territories as the standard for diabetes prevention and management in Canada (Johnson JA and Bowker S, September 2005). Effective standards for diabetes care in the diagnosis, prevention and treatment of diabetes have been shown to reduce the risk of diabetes and its associated complications.

Some recommendations are made in the diabetes clinical practice guidelines for Aboriginal populations: the need for community-based screening and primary prevention programs and a need for respect of the culture, language and geography diversities among Aboriginal communities. Almost all First Nations people with diabetes receive some form of diabetes treatment but only half monitor their blood sugars regularly (First Nations Centre, November 2005). Current guidelines recommend blood glucose testing at least once a day if managed by insulin or diabetes medication. Research suggests that this is not unique to First Nations and that there exist treatment gaps and opportunities for improvement in the use of CDA's CPGs for the clinical management of all people at risk or with diabetes (Clark HD et al, 2003; Toth EL et al, 2003).

Diabetes is not always a priority for the individual or community. Loss of traditional ways, psychosocial issues, substance abuse, sedentary lifestyles and poor eating habits can affect the decision to seek diabetes care or not (CDA, 2003). Systemic barriers such as long waiting lists, cost of services and availability of a health care professional also impact access to treatment for about one fifth of First Nations people (First Nations Centre, November 2005).

The Screening for Limbs, Eyes, Cardiovascular and Kidney Complications (SLICK) is one example of a coordinated effort between Alberta First Nations, FNIHB and the University of Alberta in Edmonton to address these barriers to treatment. SLICK offers a mobile service to First Nations communities providing access to a comprehensive screening program for limb, eye, cardiovascular and renal complications based on the CDA's diabetes guidelines.

Recommendation 4

Establish a strategy to improve the level of diabetes care and management delivered to First Nations People using the CDA's 2003 Clinical Practice Guidelines by involving Federal, Provincial and Territorial key stakeholders including community leaders, healthcare professionals and funding agencies.

Access to Professionals and Diabetes Service: Availability of traditional healing

Traditional healing practice promotes mental, physical and spiritual well-being through a variety of activities including physical cures using herbal medicines, ceremony, counseling and the wisdom of the Elders (RCAP, 1996). Traditional healing practices are a part of the integral fabric of the First Nations way of life and, as such, are tied to First Nations culture and health.

First Nations believe that a return to Aboriginal healing practices would improve Aboriginal Health (First Nations Centre, July 2003). Six percent see a traditional healer or take part in traditional ceremonies as part of their treatment for diabetes (First Nations Centre, November 2005). More First Nations people would access traditional care if they knew where and if it was covered by the health system (First Nations Centre, July 2003).

The report of the Royal Commission on Aboriginal People of 1996 called for an extended role for traditional medicine and healing practices to address the mental, spiritual, emotional and physical aspects of health (RCAP, 1996). Yet, there is little flexibility in current funding agreements to support traditional healers at par with practitioners in the mainstream system. Moreover, protection of traditional medicines from modification, bio-piracy, outside patenting and other forms of misuse is needed as well as full exemption from federal, provincial and territorial legislation, licensing and other regulations. (AFN, November 2005).

Recommendation 5

Support the development of a First Nations Wholistic Health Strategy for diabetes that recognizes community and regional diversities and which is characterized by complementary traditional knowledge and western approaches, including an expanded and protected role for traditional medicine and healing practices.

Access to Treatment: Direct costs for diabetes medications and supplies

A person with diabetes typically incurs medical costs that are 2-5 times higher than those of a person without diabetes (Public Health Agency of Canada, 2005). Current estimates predict that if the increase in the prevalence of diabetes follows the current pattern, direct healthcare costs for people with diabetes in Canada will increase by 75 % between 2000 and 2016 (Ohinmaa A, Jacobs P, Simpson S et al, 2004).

Registered First Nations people are covered under the federal Non-insured Health Benefits (NIHB) Plan, while those without status are covered by provincial or territorial drug plans for their diabetes medications, supplies and devices. The "formulary" lists medications and medical supplies that are covered by federal, provincial or territorial drug plans. However, newer diabetes medications, devices or supplies are not always listed on the formulary restricting access for those with diabetes and who are on limited incomes. For more information on federal, provincial and territorial formularies, consult the 2005 CDA Diabetes Report Card (CDA, December 2005).

The CDA's 2005 Online Membership Survey revealed that over half of Association members pay out-of-pocket expenses that amounted to between $50-$200/month. Almost half were not covered by any health insurance plan causing financial hardship for them and their family (CDA, December 2005). First Nations people are often not able to afford to purchase or access needed diabetes drugs or equipment because they do not have the money and do not have supplemental coverage to the NIHB Plan.

Recommendation 6

Commit to a strategy for First Nations people to sustain a financial base that will cover the cost to the individual for diabetes medications and supplies enabling appropriate management of their diabetes.

Access to Treatment: Coverage by NIHB

The NIHB program represents close to half of Health Canada's total expenditures in First Nations and Inuit Health. The original intent of NIHB was to improve the health of First Nations people to that enjoyed by the rest of Canada. Registered First Nations people and Inuit can access health-related goods and services through NIHB such as diabetes medications, diabetes medical supplies and equipment and medical transportation services that are not insured by provinces and territories or other private insurance plans.

NIHB program funding levels are currently based on an estimated annual population growth rate and do not take into account health needs and cost drivers (AFN, April 2005). Diabetes is one cost driver where there are clear indications of increasing prevalence and accompanying higher costs. The numbers of people with diabetes is currently increasing at a greater rate than population growth. A two-fold increase in NIHB claims for diabetes medication and supplies was seen in the four-year period between 1995-2000. Diabetes also impacted vision benefits, medical transportation to access specialists, renal dialysis services and dental services (NIHB, 2002).

If the original intent for NIHB was to bring equity in health for First Nations people as the rest of Canada, this is not what is being experienced today. Just under one-third of First Nations people lack access to NIHB and one-fifth has reported denial of approval for NIHB (First Nations, November 2005). The First Nations Action Plan for NIHB is comprised of six key elements:

- Clear mandate and policies of the NIHB Program;
- Reasonable rate of annual growth;
- Ensuring needs-based eligibility criteria;
- Transparency in federal corporate administration;
- Tri-partite service agreements;
- First Nation Charter of Rights and Responsibilities;
- Linkages with community-based programming; and,
- First Nations Health Reporting Framework.

Recommendation 7

Set a sustainable financial base for First Nations health services that takes into account health needs and cost drivers and at an estimated annual growth rate of 10-12% (AFN, April 2005).

C. Policy Development

Address of Diabetes in First Nations Communities: Federal, provincial and territorial strategies developed for the prevention and treatment of diabetes in First Nations people.

In 1999, the Canadian Diabetes Strategy allocated over half of the $115M to address diabetes among Aboriginal people. The $58M commitment to the ADI was made in November 1999 to create a comprehensive, collaborative and coordinated approach to reducing diabetes and its complications in Aboriginal people. The ADI is made up of two components. The First Nations On-Reserve and Inuit in Inuit Communities component makes up 75 % of the program and

focuses on care and treatment, prevention and promotion and lifestyle support with funding distributed through regional FNIHB offices. The Métis, off-Reserve Aboriginal and Urban Inuit Prevention and Promotion component focuses primarily on primary prevention and health promotion and is administered through a proposal driven process within FNIHB's national office. In the 2005 Budget announcement, the Government of Canada announced a commitment of $190M over five years to make permanent and enhance the ADI.

On the provincial and territorial front, Aboriginal diabetes strategies can be found in some, but not all, regions. Alberta, Saskatchewan, Manitoba and Ontario are examples where First Nations diabetes needs have been addressed as part of a provincial or Aboriginal plan. Part 2 of the First Nations Diabetes Report will take a closer look at these initiatives to determine what is being done to close the gap and reduce the burden of diabetes among First Nations in Canada.

Recommendation 8

Each province and territory commit to developing First Nations-specific and First Nations-led diabetes strategies to reduce the prevalence of diabetes and its complications among First Nations citizens living in and away from their communities across Canada.

D. Education

Access to Education: First Nations Health Professionals

First Nations who rate their health as being very good or excellent also see their access to health services as being better or the same as Canadians (First Nations Centre, November 2005). Almost half of First Nations people say that they would prefer to visit an Aboriginal health provider than a non-Aboriginal Health Provider (First Nations Centre, July 2003). Yet all Canadians are facing a shortage of health care providers, particularly in remote and northern communities. One fifth of First Nations believe that the lack of a physician or nurse in their area is a significant barrier to accessing health care. In addition, the responsibility for diabetes care often falls to community health representatives who are already overwhelmed in fulfilling the role of primary health workers in First Nations communities.

The Royal Commission on Aboriginal people identified the need for federal, provincial and territorial governments to build health human resource capacity in Aboriginal communities by committing to training 10,000 Aboriginal health professionals in health and social services over a ten-year period. Eight years later, the Government of Canada acknowledged its responsibility by announcing $700M in Aboriginal health including $100M for human health resources development. At the First Ministers' Meeting on Aboriginal Issues in November 2005, the federal government committed to doubling the number of Aboriginal health professionals in Canada from the current numbers of 150 physicians and 1200 nurses by 2015.

Recommendation 9

Develop a stand-alone First Nations Health Human Resources Strategy to address current gaps in health capacity and sustain the number of Aboriginal health care professionals and health workers at a level minimally equitable to current practitioner to Canadian population ratios.

E. Research

"Research is being translated into new treatments and approaches to health care which are, in turn, improving health"
- Dr Alan Bernstein

Advances in First Nations Research: Research funding devoted to First Nations diabetes

Research is important to understanding the nature of diabetes, reducing the burden of the disease and its complications. However, in 2001/02 only $4.6M (about 5 %) in research funding was directed towards Aboriginal people (Public Health Agency of Canada, 2005). There is currently no single source or central registry that shares information about new and updated knowledge from Aboriginal diabetes research collected across the country.

Funding for Aboriginal diabetes research originates from many different sources including municipal and provincial governments, federal government agencies such as the Canadian Institute of Health Research's Institute for Aboriginal Peoples' Health and non-government organizations such as the CDA. These combined do not have sufficient funds to respond to current diabetes research needs. An increase of research dollars to $75M by 2005 was recommended by the Coordinating Committee for the National Diabetes Strategy at a national diabetes symposium held in May 2003 to address research priorities including: effective mechanisms and prevention strategies for Type 2 diabetes, urban Aboriginal lifestyles and diabetes and challenges of diabetes care in remote and rural Aboriginal populations (Public Health Agency of Canada, 2005).

Research needs to be participatory, involve First Nations organizations and communities and be relevant and useful to those communities in improving health. A cultural context for data collection and interpretation is needed and research findings should be shared with communities for the work to have a benefit for the community. The four principles of Ownership, Control, Access and Possession developed by the First Nations Information Governance Committee provide a standard for conducting research processes in First Nations communities.

The First Nations OCAP Principles for Research and Information

Ownership First Nations communities or groups own their cultural knowledge, data and information collectively.

Control First Nations, their communities and representative bodies have the right to seek control over all aspects of research in which they are involved.

Access First Nations communities and people should have access to data that has been collected about them.

Possession First Nations communities and people should have physical control of data that has been collected about them.

Recommendation 10

Funding should be increased to improve knowledge about diabetes among First Nations using the OCAP Principles for Research, and to support establishment of First Nations Health Information Institutions in the collection of First Nations' longitudinal health data, including diabetes, and to enhance First Nations' capacity to participate and benefit from health research initiatives.

F. Surveillance

Monitoring First Nations Health: First Nations-specific diabetes surveillance

Health surveillance involves the collecting, interpreting and communicating of health data for the purpose of describing the magnitude of a health problem, describing health outcomes, detection of epidemics, documenting health events, evaluating prevention or control measures or monitoring changes in a health event over time (AFN, 2006). The National Diabetes Surveillance System is an example of one system which funds provinces and territories to provide diabetes information from their databases directly to a central repository for national analyses. The project is guided by federal, provincial and territorial governments, academic institutions, non-government organizations and national Aboriginal organizations.

However, the National Diabetes Surveillance System has not engaged First Nations in the design of its reporting format and has not been inclusive of the OCAP Principles, particularly with respect to enhancement of First Nations capacity. First Nations are not targeted recipients of NDSS funding. For this reason, the AFN has withdrawn its participation in the National Diabetes Surveillance System and turned its efforts into development of a First Nations specific, comprehensive public health strategy which will be responsive to the needs of First Nations communities.

Federal, provincial and territorial governments currently control most of First Nations health data. First Nations persons are identified in provincial data bases by three main methods: identification of health card numbers, use of a postal or residency code or information extracted from the FNIHB Status Verification System (AFN, 2006). No one method is perfect in drawing a picture of First Nations health and there are provinces without any systems in place to uniquely identify First Nations and the health care that they have received.

The current transfer of resources to support a First Nations public health surveillance strategy will require establishing First Nations sub regional centres for health information and public health surveillance under control of and in collaboration with First Nations authorities, federal and provincial agencies and relevant University centres to leverage existing infrastructure (AFN, 2006). Training and First Nations management of the process are crucial if data is to be relevant to the needs of the community and if information about health and community health planning is to be shared with the community in improving health.

The First Nations Regional Longitudinal Health Survey process is one example of a successful model of collaboration between researchers, epidemiologists and other key stakeholders in which data collection and analysis fully respect the OCAP principles and where data are managed and controlled by First Nations communities.

Recommendation 11

Work with federal, provincial and territorial governments to establish First Nations-controlled Health Information Centres across Canada to integrate health information activities, including diabetes-related data, with appropriate funding to address training needs and build health information capacities at a regional and community level.

Community Speak

Marion Schafer,

ADI Coordinator, Yukon

"Aboriginal people deny diabetes in my community. When we hold events, no one comes. So we decided to focus on teaching the children." As an ADI Worker in a small community in Whitehorse, Marion teaches children in Grades 5 and 6 in the community how to eat healthy and keep active to prevent diabetes. She brings in her blender and makes fresh juice for students and shows them how to make smoothies.

Marion invites people from the community like "Dave" who can share their experiences and tell the children what it's like to have diabetes. Dave tells the children that he got diabetes 20-30 years ago and tells students that it is all about eating right and exercising regularly. Students are riveted as he pulls out his insulin and needle and shows them how he must inject every day … his life depends on it.

"Marissa" is 22 years old and tells students she got really sick when she was very young and blacked out … it was about the time she was around their age. She didn't know she had diabetes and kept on eating junk food. She pulls out her blood testing equipment and the children watch as she tests her blood sugars … 7.0 mmol/l … her blood sugars are not bad today. She tells them it's not easy to cut junk food out of your life but it's important to read food labels and make healthy food choices if you want to be healthy.

Today as everyday that she comes in, Marion provides a healthy lunch for the students. She knows it's not easy to eat healthy at home because foods are expensive in her community. Special arrangements must be made to fly in food. She tries to help students make healthy choices so that's why she sometimes gives out water bottles instead of juice containers. Marion knows that she is helping her community because her lessons have made a difference to what the students know about diabetes and living healthy.

Cathy Woodhurst, *RN, MA*

Site Leader Sh'ulh-etun Health
Vancouver Island, British Columbia

Cathy has been working as a diabetes educator with First Nations for the last five years and has seen four teens diagnosed with diabetes in the Cheatings First Nations last year. This has been a traumatic event for the individual, the family and the community. "I believe this has been a catalyst for the community to pull together and support a chronic illness initiative for diabetes," says Cathy. Community members know that these young people will live long enough to get the complications of diabetes and die early if health issues are not addressed. They believe that diabetes in their community is inevitable.

"The stories I hear from young people with diabetes are that they got diabetes because they drank too much pop. They feel shame and guilt because they think that it is their fault they have diabetes," says Cathy. Teens also deal with the effects of second-generation residential school abuse … low self worth, lack of motivation to adopt healthy behaviors, denial of their diabetes and isolation can all result. "It's heartbreaking," admits Cathy.

Chips and pop can be the norm with fast food filling a "spiritual hole" for youth and a nation that has lost its culture. Chemainus First Nation is another community touched by diabetes but who is taking action to steer the course of future generations towards health.

Evelyn Weenusk, *RN*

Program Advisor, Keewatin Tribal Council Home & Community Care Program, Manitoba

Evelyn is part of the Manitoba First Nations Diabetes Committee which is working on a Diabetes Integration project to improve the way First Nations people in Manitoba receive diabetes care and treatment. Keewatin Tribal Council serves 11 northern communities which are mostly fly-in and who rely greatly on FNIHB Nursing stations to access diabetes care. She hears stories of many who cannot access these services because of distance and who do not get diagnosed and treated for their diabetes. Unfortunately, most of those who finally reach the nursing stations also arrive to find out, not only that they have diabetes, but that they already have started to develop or have advanced complications from diabetes.

Sheradon (Kekota) Roberts

Cultus Lake, British Columbia

Kekota's journey with diabetes began on January 30, 2004 when her four year-old son Brendan was diagnosed with type 1 diabetes. "I didn't know anything about diabetes but we never would've thought that it would hit one of our children, especially at such a young age," recounts Kekota, "We were in shock … questions ran through our heads of why?"

The hospital in Abbotsford kept the family there for five days as they helped them to learn about caring for their son's new way of life, as well as their new way of family life. They learned about how to draw up insulin, how and where to inject the shot, how to watch for signs of low and high blood sugars and what that meant, how to plan his meals and snacks and how to manage sick days. "It was very difficult for us as we were overwhelmed with the fact that our son was now diabetic," said Kekota.

On the long drive home from Abbotsford to Cultus Lake, Kekota worried about her son and kept checking to make sure that he was "ok". This was only the beginning of her learning as Kekota arrived home to face taking care of her son at home. Even shopping, which she used to always enjoy, became a huge chore as she searched the shelves trying to find the right snacks and meals for her son.

"There is not enough support and information for parents after their children first become diagnosed," shared Kekota. "We made it into the BC Children's Hospital in September of that year … they were very informative and he got to meet a couple of other children with diabetes," recalled Kekota.

After Brendan's first year of living with diabetes, he fell into a depression and wanted to stop eating. He was tired of being left out and feeling different when a special snack was brought into class and he was not allowed to eat it. Kekota's husband sat down and told him that God chose him to have diabetes because he knew that Brendan had a strong spirit and that his parents were capable and strong enough to know how to look after him. After his talk with his dad, Brendan felt much better.

Brendan's day starts with a finger poke at 6:30 a.m. and if he's higher than 6 mmol/l, he gets to sleep in until 7:15 a.m. Then he has breakfast and his 2 insulin shots. At 10 a.m., he has his first snack of the day and when noon comes, he has a finger poke and lunch. At 2 pm, he has another snack and by 4:30-5:00 p.m., he has another finger poke and dinner. After dinner, he has 1 insulin shot and then, between 7:30-8:00 p.m., he has a finger poke and a bedtime snack with his last insulin shot of the day. At about 1-2 a.m. Kekota does another finger poke check to see if his sugar levels are ok to keep him controlled until morning. Brendan and his family are fortunate; Brendan's diabetes medications and supplies are covered.

"Brendan's Power Rangers Team" walks annually in the Juvenile Diabetes Research Foundation's walk. This year, they're hoping to reach a goal of $5000 towards the Juvenile Diabetes Research Foundation's 2006 campaign. Kekota and her family are proud supporters of this event and believe that they will continue to be for all their years ahead, until there is a cure for diabetes.

References

ADI. Personal Communication. January 17, 2006.

AFN. Fact Sheet: The Facts on First Nations Health Services. Ottawa. March 2006. http://www.afn.ca/cmslib/general/FS-FNH.pdf. Accessed April 10 06.

AFN. Final Report: Policy and Programs for Prevention and Treatment of Diabetes among First Nations People. Ottawa. January 2006.

AFN. Agenda for restoring and improving First Nations health. Ottawa. November 2005. Available at: http:www.afn.ca/cmslib/general/AgendaRestoringImprovingFNsHealth.pdf. Accessed April 10 06.

AFN, A First Nations holistic policy and planning model: health determinants perspective. July 2005.

AFN. First Nations action plan for non-insured health benefits. Ottawa. April 2005.

AFN. First Nations Health Action Plan. Ottawa. September 2004. Available at: http://www.afn.ca/cmslib/general/Action-Plan-1.pdf. Accessed April 12 06.

AFN, First Nations Public Health Framework. Barker, K. et al. 2006

Bruce GB, Kliewer EV, Young TK et al. Diabetes among the Métis of Canada: defining the population, estimating the disease. Can J Diabetes. 2003; 27(4):442-448.

CDA. Diabetes report 2005. Toronto. December 2005. Available at: http://www.diabetes.ca/section_advocacy/index.asp. Accessed April 10 06.

CDA Clinical Practice Guidelines Expert Committee. CDA 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. Can J Diabetes. 2003;27(suppl 2):S110-112.

Clark HD, van Walraven C, Code C et al. Did publication of clinical practice guideline recommendation to screen for Type 2 diabetes in women with gestational diabetes change practice? Diabetes Care 2003; 26(2):265-8.]

First Nations Centre. First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities. Ottawa. November 2005. Available: http://www.naho.ca/firstnations/english/regional_health.php. Accessed April 10 06.

First Nations Centre. National Aboriginal Health Organization. Summary of findings: National Aboriginal Health Organization public opinion poll on Aboriginal health and health care in Canada. Ottawa. July 2003. Available at: http://www.naho.ca/firstnations/english/opinion_poll.php?print=1. Accessed April 25 06.

Gray-Donald K. Health indicators to examine prevention and treatment of Type 2 diabetes mellitus in Aboriginal peoples in Canada. Ottawa. 2005.

Johnson JA and Bowker S. Appendix S: A review of Canadian policies and programs for diabetes 2004/05. Edmonton. September 2005. Available at: http://www.diabetes.ca/files/diabetesreport2005/Appendixadiabetesreport.pdf. Accessed Apr 10 06.

Ministry of Health and Long-Term Care Backgrounder. Backgrounder: First ever common benchmarks will allow Canadians to measure progress in reducing wait times. Toronto. December 2005. Available: http://www.newswire.ca/en/releases/archive/December2005/12/c5919.htm?view-print. Accessed May 10 06.

NIHB Sustainability Working Group. Non-insured health benefits sustainability document. Ottawa. 2002.

Ohinmaa A, Jacobs P, Simpson S et al. The projection of prevalence and cost of diabetes in Canada: 2000 to 2016. C J Diabetes 2004;28:116-123.

Public Health Agency of Canada. Building a national diabetes strategy : synthesis of research and collaborations : consultation findings, Volume 1. Ottawa. 2005.

Royal Commission on Aboriginal peoples. Gathering Strength, Volume III. Ottawa. 1996. Available : http://www.ainc-inac.gc.ca/ch/rcap/sg/sia3a_e.html. Accessed April 10 06.

Statistics Canada. Health Indicators. Volume 203, No. 2. Catalogue no. 82-221-XIE. Ottawa. November 2003.

Toth EL, Majumdar Sr, Guirguis LM et al. Compliance with clinical practice guidelines for Type 2 diabetes in rural patients : treatment gaps and opportunities for improvement. Pharmacotherapy 2003; 23(5):659-65.

Warry W. Unfinished dreams : community healing and the reality of Aboriginal self-government. Toronto. 1998. P65.

World Health Organization Commission on Social Determinants of Health. Report of First Meeting. Geneva. March, 2005.

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