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with contributions by

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Melissa Ricciuti, Nancy Sagmeister and Ernie Sandy

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Foreword

By the Toronto Central Local Health Integration Network

“Diabetes care and treatment involves providing Aboriginal-specific programs and services that will help individuals living on- and off-reserve to manage their diabetes, prevent complications and promote well-being.” (Ontario Aboriginal Diabetes Strategy, MOHLTC 2006)

In January 2009 the Toronto Central Local Health Integration Network (TC LHIN) was asked by the Ministry of Health and Long-Term Care (MOHLTC) to design a project for a population at high risk of having diabetes as part of the Provincial Diabetes Strategy. With the guidance from the TC LHIN Diabetes Steering Committee, the LHIN identified the urban Aboriginal community as a high-risk and vulnerable population with diabetes rates three to five times greater than the general population. Beyond the high rate of disease, diabetes is a significant concern within this community given that they generally experience an earlier onset, greater severity at diagnosis, high rates of complications, lack of accessible services and an increased prevalence of risk factors.

In Toronto, Aboriginal persons with diabetes can access services for care and management of their disease through a range of health and social services providers from both Aboriginal and non-Aboriginal service providers. While Toronto’s Aboriginal health providers predominantly serve a downtown, high-needs part of the Aboriginal community, their service reach extends beyond TC LHIN boundaries (Greater Toronto Area – GTA). Provincial health administrative data lacks Aboriginal/ethnic identifiers; thus there is lack of information on Aboriginal specific service usage.

A time-limited TC LHIN Aboriginal Working Group was formed to discuss and scope the issues around diabetes in the Toronto Aboriginal community as well as to develop a work plan for the scope of this Pilot project. A gap analysis was conducted through this Working Group, and it was found that:

- The Aboriginal population have poorer access to health services than non-Aboriginal population
- Identifying members of GTA Aboriginal community with diabetes is a challenge
- The “Reactive” health delivery model is currently preferred and this may not be suited for Aboriginal at-risk populations
- “Poverty not conducive to healthy lifestyle”
- Fear/distrust of health professionals: lack of caregiver cultural sensitivity
- Lack of access to traditional Aboriginal practices and approaches
- Complications associated with multiple health issues
- Lack of acceptance and understanding of diagnosis: stigma associated with the disease

Based on this knowledge and the recommendations of the Working Group, along with key informant interviews conducted with Aboriginal leaders, health service providers and diabetes experts in Toronto, it was identified that there are two areas which require further research and exploration in order to develop a planning model for the delivery of services to this unique population:

a) there is a great need to understand the particular characteristics and needs of Aboriginal populations with diabetes for successful outcomes; and

b) formulate a better understanding of the modes and ease of access to services and supports available in Toronto to Aboriginal persons with diabetes.
Based on the recommendations of the Aboriginal Working Group and the TC LHIN Diabetes Steering Committee, a decision was made to focus on gathering further evidence through a culturally respectful, community based participatory research study as the focus of the Pilot Project. The goal of this research is to equip the health care system with tools and appropriate knowledge to develop interventions and more relevant services that will help improve access to diabetes supports for Toronto’s Aboriginal community and reduce the number of preventable interventions, and unnecessary emergency room visits.

To ensure success, a partnership was developed with an Aboriginal health service provider - Anishnawbe Health Toronto that was to lead the development of an Aboriginal community led research model and to conduct the research.

Prior to this partnership, the TC LHIN was able to collaborate with the Aboriginal Research Team, led by Dr. Janet Smylie, and the Centre for Research on Inner City Health, St. Michael’s Hospital. The TC LHIN would like to thank Dr. Smylie for her leadership, guidance and work on the early stages of this research.

The TC LHIN is also grateful and humbled by the tremendous work led by the Co-Investigators, Lynn Lavallée and Heather Howard, as well as the leadership and guidance provided by the Governing Circle, who maintained the utmost respect and integrity for the research. The TC LHIN is also grateful to the members of the Working Group and the Diabetes Steering Committee for their hard work in identifying the scope of this project. Finally, TC LHIN is grateful to Anishnawbe Health Toronto for community leadership in this initiative.
Acknowledgements

We are extremely grateful to the 138 participants who candidly shared their stories, challenges and hopes with us. Without them this research would not have been possible. It is for the community that research should be conducted and we hope that your lives will be forever changed as a result of participating in the project. We want to thank you from the bottom of our hearts.

We would like to acknowledge the working group that worked for almost two years to develop the focus of this project.

The research team would like to acknowledge and thank Anishnawbe Health Toronto (AHT), specifically Joe Hester, Executive Director who took responsibility for this project for the betterment of the Aboriginal community in Toronto. There are tremendous responsibilities that come with administering a research grant. Particularly within the Aboriginal community, research can be challenging and may conjure up memories of past research gone wrong. Aboriginal communities are not particularly fond of research and for an Aboriginal agency to take on this role speaks to AHT’s resolve in wanting to help the community. We also thank Dr. Shah for his commitment to the Aboriginal community. Chi miigwetch!

There were many people at AHT who worked closely with the research team ensuring that we had everything we needed to be successful. Chi miigwetch to Jane Harrison, Manager Waash-Keshuu-Yaan (Health Unit) for providing continual guidance and direction to the project and the research team. Miigwetch to Rod Michano, Patrick Carpenter, Joan Lee, Yan Jin, Bill Waboose, Phyllis Hernandez and the reception staff at 179 Gerrard Street East. We would like to thank the Diabetes Education Team at AHT; Teresa Salzmann, Lauren Tribe, Janet Killick, Alana Grosbeck, Melissa Stevenson and Jennifer Otley who partnered with us to help recruit participants and were part of the consultation group at the end of the project.

To the Governing Circle members, we want to say chi miigwetch for agreeing to be part of this project and for your continual feedback throughout the entire process.

We would like to thank the many agencies and individuals who helped spread the word of this important research, particularly the Oshawa Community Health Centre, Peel Aboriginal Network, Na-Me-Res, Native Women’s Resource Centre and the Native Canadian Centre of Toronto.

Miigwetch to Dr. Janet Smylie who provided initial direction on the project and the research design, specifically the Concept Mapping.

The co-principal researchers would like to say Chi Miigwetch to the entire research team for their hard work and commitment to the community. It was very clear that this was much more than a job for each of the team members and Heather and Lynn are sincerely grateful for all of your contributions.

Finally, we would like to acknowledge the funder of this project, the Toronto Central Local Health Integration Network, specifically Vanessa Ambtman and Camille Orridge.
At the beginning of the project the team discussed the importance of naming the project so the team would have vision and focus in the Urban Aboriginal Diabetes Research Project. The naming underscores the process of the research versus the product, speaking to the Aboriginal leadership and capacity building that was foundational to the project. Drawing upon their respective cultural background and experience, the research team (Krystine Abel, Jessica Keeshig-Martin, Melissa Ricciuti, Carolyn Akiwenzie, and Nancy Sagmeister) collaborated in bestowing an appropriate cultural name upon the project. The name Kina go Gmushkiimnaan embodies time-honoured ancestral teachings of healing.

All of our Medicines was the English name that would describe the project. Research team member Ernie Sandy was asked to provide the translation into Ojibway. Ernie provides this story that describes Kina go Gmushkiimnaan:

The name of the research project has a very special history. Before the arrival of the Europeans to Turtle Island (North America) a little over five hundred years ago, my ancestors, the Anishnaabeg and other nations practiced healing and wellness for thousands of years. Our healers walked and talked Kina go Gmushkiimnaan when it came to restoring a balance and harmony within an individual or community. As nations, we had our own health care-systems that were based on preventative measures. Our active lifestyle was complimented by eating natural foods and wild game in moderation. Diseases such as cancer, small pox, heart, kidney and diabetes were virtually unheard of until recently.

When someone became ill in the community, it was in the forests with its various plants that were our pharmacy. And those who knew of the medicinal qualities of the leaves, bark and root were the medicine men and women. These terms are used to describe traditional healers and spiritual leaders. Their role in the community was to call upon all our medicines in the event that someone became ill or was about to pass onto the spirit world. The practice of traditional was not taken lightly. It took several years as an apprentice before the community recognized someone as the carrier of the time honoured healing ceremonies.

Kina go Gmushkiimnaan involved restoring the balance and harmony with the person wholistically, that is, the mind, body, emotion and spirit. Knowledge about Kina go Gmushkiimnaan or All Our Medicines was passed down from one generation to the next. One or two members of the community served as the medicine man or woman. He or she always had someone under their wing as their successor, thus assuring the transmission of skills and knowledge in Kina go Gmushkiimnaan. It was an honour to be looked upon by the community as the Traditional healer. It is the spirit of our ancestors that lives within the name of the project.

Therefore, the name is much more than a collection of letters. It provides teachings of Native spirituality. It was a name developed in collaboration between the Research Team and Governing Circle for the Urban Aboriginal Diabetes Research Project.

Kina go Gmushkiimnaan or All Our Medicines is a worldview that not only refers to our sacred medicines, tobacco, sweet grass, sage and cedar. As part of the healing journey the name embodies the very essence of all life, wind, fire, water and our Mother the Earth.
The Research Team Biographies

As is traditional in our culture we begin by introducing ourselves and our ancestors.

Co-Principal Researchers

**Heather Howard** – Heather is of Irish descent, born and raised in rural Quebec. She moved to Toronto in 1995 when she began graduate studies at the University of Toronto and work as a program coordinator at the Native Canadian Centre of Toronto whose history became the focus of her Ph.D. dissertation (completed in 2005). In addition to the Native Canadian Newsletter and the Toronto Native Community History Project, Heather coordinated a project funded by the Aboriginal Healing Foundation for the Native Centre, which examined the impact of residential school experience on contemporary barriers to diabetes management. More personally, her dedication to the eradication of diabetes in the Aboriginal community has been inspired by the life and loss of her first husband, Rodney Bobiwash, Wacoquaakmik (Anishnaabe, Bear Clan) to complications from diabetes when he was 42 years old. Heather’s research has primarily utilized community-based participatory methods and revolves around research capacity-building, promoting the value of Indigenous knowledge frameworks to scholarship, and research which is meaningful to the community. She recently completed a project with an all-Aboriginal student team, which gathered perspectives on diabetes education and support services from service providers and Aboriginal person with diabetes in Toronto. Heather is an assistant professor in the Department of Anthropology at Michigan State University. She also holds a research faculty affiliation with the Centre for Aboriginal Initiatives at the University of Toronto. Her most recent publication is *Aboriginal Peoples in Canadian Cities: Transformations and Continuities*, released in 2011 by Wilfrid Laurier University Press.

**Lynn Lavallée** – Manitou Nibi Kwe (Deer clan) - Born in Sudbury, Ontario, Lynn moved to Toronto's Regent Park when she was eight years old. She has lived in Toronto (for the most part) since that time. Lynn's father (Oscar Lavallée) and his many generations (Gauthier, Pepin, Taylor) were from Temiscaming, Quebec. Her mother (Frances Labelle) was born in Timmins, Ontario. Lynn's maternal grandmother was Annonciade Labelle (nee Lafont) from Maniwaki, Quebec and her grandfather was Norman Godon/McIvor from Mariapolis (Swan Lake) in Manitoba. Lynn is proudly registered with the Métis Nation of Ontario. Lynn completed a double major, Bachelor of Arts (BA) in Kinesiology and Psychology from York University; Master of Science (MSc) in Community Health (Sport Psychology) at the University of Toronto; and Doctorate of Philosophy (PhD) in Social Work at the University of Toronto. Lynn is currently an Associate Professor at Ryerson University. Her work focuses on the social determinants of health and psychophysiology of stress. This interest comes from her personal journey of dealing with early mortality and morbidity in her own family. The epistemological framework that guides Lynn’s work is the Anishinaabe teaching of the medicine wheel with particular emphasis on the physical, mental, emotional and spiritual impacts of sport and recreation, Indigenous health and well-being, Indigenous research ethics and methods, diabetes, and mental health. Lynn is actively involved in the Aboriginal community with past and current work on the Aboriginal Sport & Wellness Council of Ontario, Toronto Kiwanis Boys and Girls Club, Native Canadian Centre of Toronto, Community Campus Partnerships for Health, and Active Healthy Kids Canada.
Research Co-ordinator

Nancy Sagmeister is from Toronto and is a member of the Chippewas of Nawash First Nation (Cape Croker). Nancy graduated with an honours Bachelor of Commerce degree and a diploma in journalism. She worked for the Ontario government and eventually moved to the Aboriginal Health Office at the Ontario Ministry of Health and Long Term Care where she participated in developing the Aboriginal Healing and Wellness Strategy. She has worked as a consultant on a variety of projects for First Nation and other organizations. Nancy also worked in Ecuador for about 18 months, as a health promotion facilitator with marginalized communities. She credits her interest in health promotion to her mother, who showed Nancy the importance of healthy eating and healthy living in her words and actions.

Indigenous Research Integrity Advisor (Waaseyaagiishig nini bemset)

Ernie Sandy is a 62-year-old fluent speaking Ojibway who walks in two worlds, that of the academia and in the footsteps of his ancestors, the Ojibway people. He was born on Christian Island in the late forties where he spent his childhood years. He is proud of his ancestral roots in Cape Croker, also known as Neyaashiinigmiing.

Since 1969, he has been closely affiliated with the Chippewas of Rama First Nation where he lives with his family. He is from the Bear Clan and a proud member of the Taamgaadnakiijik (pronounced Tum god nuh keejik) or TAAM at the Native Canadian Centre of Toronto. The name refers to the first urban Aboriginal peoples to work in Toronto. As a Traditional Teacher at the Native Canadian Centre of Toronto, he is always in demand to share the history, culture and customs of his ancestors. His Anishnaabe name is Waaseyaagiishig nini bemset (A man who walks with the breaking of dawn). His earlier life involved working at a factory for 11 years during the 1970’s and early 1980’s while raising his children with his wife Stephanie.

Recognizing that there was more to life than working at a factory, he applied to a number of universities as a mature student and was accepted at the University of Western Ontario (UWO) where he received degrees in Canadian History, Political Science and Journalism. He also attended Teachers’ College at Nipissing University, North Bay. The majority of his positions since graduating from UWO in 1986 have been with Aboriginal political organizations, and more recently in teaching.

As a gifted speaker and with an extensive knowledge about Aboriginal history, economic and social issues, politics and culture, he was well suited for the academia as a lecturer on Native issues and concerns. Drawing from experiences in having lived on a First Nation most of his life, he speaks passionately about the plight and advancement of his people. During the last fifteen years, he has been teaching part time in Indigenous philosophy, culture, history and natural law at the university and college level.

On a more current note, as a diabetic, he has contributed to the research process and results of the Urban Aboriginal Diabetes Research Project. As an advisor, he provided valuable insight into the disease as a diabetic as well as establishing a rapport with the Aboriginal participants in the sharing circles on diabetes.
Research Assistants

Krystine Abel is an Anishinabe Kwe born and raised in Toronto and she is a member of the M’Chigeeng First Nation. Krystine is Majoring in Social and Cultural Anthropology, with a Minor in Aboriginal Studies at the University of Toronto. Having the opportunity to work on the ‘Transformation in Diabetes’ health research project in her first year, and work on the Urban Aboriginal Diabetes Research Project in her second year has complimented her studies but also provided her with a wealth of knowledge about Aboriginal health issues and how the disease directly affects her family. The opportunity to work with the community has been a wonderful experience and having Ernie Sandy as our Indigenous Research Integrity Advisor was an honour in sharing his knowledge throughout the project with the team.

Carolyn Akiwenzie is an Ojibway Anishnabe Kwe born and raised on the Chippewas of Nawash First Nation Reserve (Cape Croker). While completing her final year in her schooling she got hired to work at the University of Toronto on a project titled “Transformations in Diabetes Education”. The project was an all-Aboriginal student team which gathered perspectives on diabetes education and support services from service providers and Aboriginal persons with diabetes in Toronto and is very happy to continue this journey of learning on a new project “Urban Aboriginal Diabetes Project named Kina Go Gmushkiimnon with Anishnawbe Health Toronto. This project will explore how Aboriginal people in Greater Toronto Area deal with their diabetes as well as what people understand to be the cultural-based treatment of diabetes. Carolyn has just recently graduated from the Child and Youth Worker and Assaulted Women’s and Children’s Counsellor/Advocate Programs at George Brown College.

Jessica Keeshig-Martin –Biidaabno kwe-is a Research Assistant on the Kina Go Gmushkiimnon Urban Aboriginal Diabetes Research Project. Jessica considers herself to be an Urban Aboriginal having spent a majority of her life living in the cities of Toronto and Ottawa, and yet she remains close to the community and land of her ancestors in Neyashiinigming (Cape Croker). She is graduating this year with a double major Honours B.A. in Aboriginal Studies and Sociology at the University of Toronto. Researching Aboriginal health and education is important to Jessica and has been the inspiration for her work in the area of diabetes research over the last two years. Jessica says that this project has been immensely fulfilling for her because it has enabled her to gain invaluable experiences from working within the Urban Aboriginal community of Traditional Healers and Elders, Scholars, Activists, Community Members and Agencies.

Hello, my name is Melissa Ricciuti (Gilbezigwii mashkwazii kwe), and I am a Research Assistant on the Kina Go Gmushkiimnon Urban Aboriginal Diabetes Project. I am Italian and Ojibway - from the Wikwemikong First Nation on Manitoulin Island. I grew up off-reserve, in Stoney Creek, ON, and have been living in downtown Toronto for 4 ½ years. I am Marten clan, and my spirit name is ‘When the Fire Stands Up’. I am in my third year of study in the Social Work program at Ryerson University. Upon graduation I am interested in pursuing a law degree. I am committed to helping facilitate the well being and success of all Aboriginal Peoples, but I have a particular interest in working with children, youth, and families in the City of Toronto. Diabetes and the issues surrounding the onset and management of diabetes are of particular importance to me, as my father is diabetic and continually struggles to maintain a healthy lifestyle in the face of diabetes.
Governing Circle

Approaches to Indigenous research include ensuring that community feedback is continuous throughout the project. A Governing Circle comprised of Elders, Traditional Healers and people living with diabetes was developed at the beginning of the project to continue the process of consultation with community. Monthly meetings with the Governing Circle allowed for regular feedback from the research team to the Governing Circle, as well as feedback on knowledge sharing activities and this final report.

The Governing Circle members are:

**James Carpenter** is from Alderville First Nation. James works with the pipe, spirits, and medicine ceremonies. He is a Healer at Anishnawbe Health Toronto.

**Dolores Esquimaux** - My name is Dolores Esquimaux. My spirit name is (Wa-we-bez-dum) which means good listener. I am deer clan. I am an Ojibway from Manitoulin Island. I stayed on the rez until my early teens and since have always lived in Toronto. I have been working at Anishnawbe Health for the past 16 years as a Traditional Counsellor/Traditional Healer.

**Marie Gaudet**, Ojibwe, Turtle Clan, is accomplished in many areas. She is a writer, visual artist, publisher, cultural teacher, and a mother. Marie has worked in the educational system in Toronto at the elementary and day care levels. She is actively involved with the Eagle Heart Drummers and Dancers for several years, promoting Traditional dance and song in both the Native and non-Native communities. Marie is a jingle dress dancer. She presently teaches at First Nations School as the Tradition and Culture Teacher. Marie currently runs an Aboriginal Stay in School Project for youth. They have created and published many books written in the Ojibwe Language, music CD's, music videos and short films. She also assists the youth in many theatrical productions as well as choreographing dance projects such as hoop and hip hop. She presently lives in Toronto with her partner and they have 7 children, five boys and two girls.

**Vern Harper**'s name in Cree is Asini which means "stone." Born in Toronto, he is a Canadian First Nations Cree Elder, medicine man, a Sundancer, Aboriginal rights dissident, and Korean War veteran. This "Urban Elder" as he has been called, is a fifth generation grandson of Mistawasis, a hereditary Cree chief, and a sixth generation grandson of Big Bear. After facing challenges early in his life, Vern became politically active as vice-president of the Ontario Métis and Non-Status Indian Association (1972-74). He is one of a few First Nations Elders with Chaplain Status recognized by the Correctional Service of Canada. With his former wife Pauline Shirt Harper, Vern organized the cross Canada Native Peoples' Caravan ending in a lengthy encampment in Ottawa (1974-75). Built upon Traditional and spiritual teachings, this demonstration was successful in bringing together native organizations to publicize native grievances. This demonstration opened the door to the first face-to-face meetings between Native leaders and political leaders. In 1979, he wrote about the trek in "Following the Red Path: The Native Peoples' Caravan, 1974." Continuing their commitment to Traditional teaching, Pauline and Vern Harper went on to establish the Wandering Spirit Survival School of Toronto in 1976, now known as the First Nations School. Vern Harper was the subject of the documentary "Urban Elder," which chronicled his life and role as community leader and Traditional Elder in an urban setting. Presently, Vern Harper serves as Resident Elder at the Centre for Addiction and Mental Health (CAMH) in Toronto, further promoting the role of First Nations spirituality in the treatment of mental health and addiction.
Brian Marion was a Canadian Aboriginal artist, born October 6, 1960 in Kamsack, Saskatchewan and passed to the spirit world in Toronto, Ontario in December, 2011. He has returned to his home community in Saskatchewan. Growing up amongst the Saulteaux and Cree of the Prairies until he was fifteen, Brian then moved to Ontario to live with the Ojibway of the Northern Woodland region. At the age of 15, Brian began a nine-year apprenticeship with Norval Morrisseau, considered to be the Father of the Canadian Woodland Aboriginal style of art. According to Morrrisseau, "during those years of training, Brian learned both the spiritualism of the Ojibway culture and the techniques of Shaman art." While he developed his artistic talents, he was taught to use the meanings of the legends as a basis for the composition of his paintings. He acquired the knowledge from the visions of our people and came to understand our close ties with nature. He was able to get inspiration from his native spirituality and with the blessing of the Creator, add his own emotional and intuitive interpretations to produce beautiful art. Brian Marion’s many achievements include a show with Norval Morrisseau at First Canadian Place, a mural commissioned by the African National Congress "Mandela Free Leonard Peltier next?" and a mural "Rainbow World" for the Young People’s Theatre. Other accomplishments include his artwork featured in a music video with Robby Robertson, John Trudell and Buffy Ste. Marie, three books published by Prentice Hall/Ginn Publishing and a poster commissioned by IKEA Canada. In 1994 Brian was chosen to represent Canada at the 50th Anniversary D-Day Celebrations in Normandy, France. His work has been shown in Milan and at the Canadian embassy in Chicago, promoting Aboriginal art as part of Canadian trade missions to these countries. His work is featured in many private and corporate collections around the world including that of the Prime Minister of Canada.

Pauline Shirt was born and raised in Saddle Lake Reserve, Alberta. Pauline is greatly recognized for her commitment to the Toronto Native community and for her dedication as a teacher and lecturer since the late sixties. She is a member of the Three Fires Society and the Buffalo Dance Society. Pauline Shirt, a Founder of the First Nations School and the Red Willow, are just two examples of her hard work ethic and perseverance to enhancing the betterment of the Toronto Aboriginal community. Today, Pauline serves as a mentor to many Aboriginal youth and young families as an experienced and trusted Grandmother. She also works in all levels of government conducting Opening Prayers and attending meetings, making sure the Aboriginal community is positively recognized as she offers a voice for her people.
Dedication

It is with incredible sadness in our hearts that we learned of the passing of Brian Marion as we were writing this report. As a member of the Governing Circle of the Urban Aboriginal Diabetes Research Project Brian was a tremendous inspiration to us and everyone he met. He provided the team with guidance, encouragement, and the wisdom of his experience with the disease. He was a person of amazing bravery and love. We acknowledge Brian’s contribution to this project with the deepest, heartfelt appreciation, and hope we are able to represent his words and spirit within these pages well.

The Creator saw that he was suffering and knew it was time to take him to the spirit world. The Urban Aboriginal Diabetes Research Project’s Research Team thanks the Creator for the time we had with Brian. There is no question that Brian must have lived a challenging life as a diabetic. Even though he took his deteriorating body in stride, it was only a matter of time before he would succumb to diabetes. In his passing we thank him for being there for us as a teacher and as an Elder.

Brian was inspirational in his teachings and words of wisdom. He strongly believed that people needed to continue learning about diabetes. He shared his struggle with diabetes when it came to cooking his meals. He was also very aware that he needed his medication to help him manage the diabetes.

He was a fatherly figure for the Research Team. We regarded him as an Anishnawbe with a very clear message on the impact of diabetes. They say that a picture and person is worth a thousand words. His amputated leg told us, and other people with diabetes, a clear and undeniable story of diabetes at a later stage. In his unselfish ways, he used his body as a teaching tool for diabetes management and struggles. He didn’t have to tell us that his stage of diabetes was the end result of neglecting the diabetes. We saw it for ourselves and admired his courage in sharing his condition with us. He could have stayed at home and suffered quietly, but he chose not to. His story of his struggles and frustrations in not healing came out loud and clear by his continued presence at Governing Circle meetings.

By his own admission, he told us during one of the Council meetings that he is the amputation stage of diabetes, and that it was too late for him for recovery. With the courage of a warrior, he also acknowledged his long time denial of the disease in a recent interview with members of the research team. Even though his one leg was amputated, it did not slow him down. He still drove himself around to meetings and gatherings. His commitment to the Urban Aboriginal Diabetes Research Project was amazing. He was there when called upon and he shared openly about his disease.

Brian’s passing into the spirit world at a time when we were wrapping up this diabetes research project brought a sense of urgency and need to tackle the issues related to having this disease, as well as prevent further cases within our community. Brian knew that he set an example that others may learn from and not only did we learn from his deteriorating body due to complications of having diabetes, we learned from his strength and perseverance as a man with incredible kindness and passion for his work and culture. From Brian we learned that no matter what happens in life you must remain grounded and remain close to who you are. In a feedback session with Brian, he repeated, “Keep this going, just keep it going.” Now that we have completed the work we set out to do his words will remain with us always and we hope that those that read this report will learn from Brian’s experience as well as the experiences of all of our participants that have diabetes and that deal with the many issues related to managing it.

Baamaapii miinwaa Brian.
Introduction

Background to This Project

Since 2008, the Ontario Minister of Health and Long-Term Care has been implementing a comprehensive four-year provincial diabetes strategy that aims to prevent, manage and treat diabetes care across the province. Toronto is home to a concentration of “high-needs” populations (those with a high prevalence of diabetes and high proportion of “at-risk” communities) including Aboriginal peoples (Toronto Central LHINS Diabetes Strategy, 2008). The Toronto Central Local Health Integration Network (TCLHIN) launched efforts to advance the provincial strategy with increased focus on Aboriginal engagement, and the risks and needs of this community related to diabetes in the Greater Toronto Area (GTA).

The TCLHIN initiated consultations and planning with Aboriginal agencies, health services providers (Aboriginal and non-Aboriginal), and researchers through a Working Group advisory process. This group provided advice and guidance for the development of research aimed at understanding the needs of Aboriginal persons living in Toronto with diabetes, with particular attention to their experiences with diabetes management and culture-based approaches to care. The results of this research will inform strategies and interventions to effectively address diabetes management, care and prevention of complications, and improve access to appropriate, coordinated diabetes care utilizing a culture-based model of care for Aboriginal people in Toronto.

The research planning and development process took place between 2009 and 2010 during which discussions emerged around the vital importance of Aboriginal community sovereignty in strengthening community leadership and capacity in health research. These discussions spoke to the principles of OCAP, which stands for Ownership, Control, Access and Possession of the data and refers to “all aspects of research (including funding and review), monitoring, statistics, cultural knowledge and so on” and asserts Aboriginal community authority over research. This includes the right to make decisions about what, why, how and by whom information is collected, as well as how it will be used and shared (Schnarch, 2004). These meetings signified a momentous and positive shift in Aboriginal inter-governmental communications and research relations, which resulted in Anishnawbe Health Toronto (AHT) assuming autonomous control of the research project. This included: recruitment of the lead University-based researchers and Aboriginal research team, administration and location of the project within AHT (thus within Aboriginal community space), and providing foundations for a research process grounded in Indigenous community-based methods and philosophy.

Mandate and Objectives of the Research

The objectives of this research project were:

1. To gather information regarding Aboriginal cultural perspectives about diabetes and barriers to diabetes management.
2. To identify challenges that Aboriginal people living with diabetes in the GTA experience.

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1 Aboriginal refers to First Nations, Indian (status and non-status), Inuit and Métis (registered and not registered) peoples, and is used with respect for the diversity of the cultures, languages, knowledge, values, and right to self-determination of individuals and groups.
3. To uncover misconceptions and cultural nuances in order to identify barriers and interventions that will enable positive health outcomes in Aboriginal people with diabetes. The research project is also aimed at assisting in planning, advocacy, determining health priorities and identifying trends with the intent of improving the health status of members of the Toronto Aboriginal community.

One of the key outcomes of this research is the importance of understanding the range of perspectives on what diabetes is and means to Aboriginal people living with diabetes, based on their own experiences. As this report will emphasize, their voices are diverse while also affirming a wholistic vision of Aboriginal health. Diabetes is not only a physical illness, but also one interdependent with mental, emotional, and spiritual conditions, themselves connected with Aboriginal family, community and cultural health and well being. Challenges to managing diabetes identified by participants in this study may also be better understood and addressed by taking into account broader socio-cultural, historical, and economic issues, in addition to other aspects of the whole lives of persons with diabetes. This research suggests that this wholistic understanding of diabetes should be prevalent in efforts aimed at improving the health of individual persons living with diabetes and preventing diabetes in the Aboriginal community. Intervention, which already uses community-based Aboriginal culture-based approaches, would benefit from increased support to further this framework in work at the individual patient and community levels, as well as in collaborations with non-Aboriginal practitioners who help Aboriginal people manage diabetes. Specific recommendations for future policy, intervention, and community action are made at the end of this report.

The findings in this report are particularly instructive and meaningful because the voices of Aboriginal people living with diabetes are at the center. This was made possible because the project was directed by the principles of Aboriginal governance of Aboriginal health research, with the incorporation of Aboriginal values to research. This ensured that the project built capacity within the Aboriginal community, directly involved the Aboriginal community, and provided outcomes that will be of immediate help to the community, including recommendations for programme and policy development. These were specifically outlined in a statement of research principles established before research began (See Appendix A for Statement of Principles in excerpts from Research Agreement). In keeping with the values of Aboriginal research, the project also began with the establishment of the Governing Circle described in the preliminary pages of this report, which included: a male and female Elder, two Aboriginal people living with diabetes (male and female), and two Traditional Healers (male and female). Capacity building components of the project included co-mentorship among the project research scientists, the hiring and training of Aboriginal research staff, and training of the researchers and staff with the research methods adopted for the project. Community-based participatory research methods ensured continuous engagement between the research team and participants, as well as with the Governing Circle and Anishnawbe Health Toronto throughout the research process from design through dissemination of the findings.

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2 Wholistic is spelled with a “w” to reflect the concept of wholeness when the four areas of health: physical, emotional, mental, and spiritual, are in balance as per the definition provided by Antone, Gamlin, & Provost-Turchetti (2003).
Timeline of the Research Project

This project unfolded between May and December 2011.

In May, the research office was established at Anishnawbe Health Toronto’s Gerrard Street location, and the research team was recruited. Ethics review within the three universities where the lead researchers are affiliated took place over the course of the month of June. During this time, the research team received training and certification in research ethics, and engaged in a comprehensive literature review, which is summarized in this report.

July was a particularly intensive month. The team was prepared in a two-day workshop to carry out one of the key methods used in this research, Concept Mapping, outlined below and detailed later in this report. We also worked together to develop the format for sharing circles and a questionnaire that were the basis of this method. An in-depth and far-reaching strategy to recruit participation from the Aboriginal community for the research was also formulated and carried out by the end of July.

During the month of August, four sharing circles were held. Statements collected during these sharing circles were compiled and prepared for the second phase of the Concept Mapping process, which took place over the course of September and October and included further gatherings of participants and completion of the questionnaires.

Also in October, Anishnaabe Symbol-Based Reflection and Photovoice (the second method used in this research), was carried out. In this method, participants were asked to create a visual representation of what it means to them to live with diabetes, either through the production of art or a photograph. Participants then presented their artwork among themselves and a selected group of observers on November 1.

The month of November was spent analyzing all the data collected and preparing it for presentation in this report and for feedback and input collected in late November and early December from the project’s Governing Circle, AHT Healers, staff physician Dr. C.P. Shah, and the AHT Diabetes Education Team. Members of the community who had participated in the research were invited back to review the results with the team in early December, as drafting of this report was underway.

Overview of This Report

This report begins with a review of relevant literature to provide context for the findings of this research project. It provides a basic overview of diabetes as a disease and illness, examines challenges in Aboriginal communities to diabetes management, and of historical, social and culture-based approaches to diabetes with emphasis on community-based and capacity building perspectives in Aboriginal health research.

The next section of this report describes the methods and approaches used to carry out our research. It begins by framing our methods within the context of ethical research practice with Aboriginal communities and Indigenous approaches to research. This includes the requirement and value of addressing Chapter 9 of the TriCouncil Policy Statement Guidelines 2 (TCPS2). The TCPS2 provides the federal guidelines for conducting research involving humans. Chapter 9 details the guidelines for research with Aboriginal communities. These are quite detailed and include:
• respect for the governing authorities, engaging organizations and recognition of the complex authority structures and diversity within communities,
• research that is mutually beneficial and collaborative in nature
• research that critically examines how colonial structures and systems can exercise authority over Aboriginal peoples
• the importance of ensuring community representatives are part of the interpretation and dissemination of research results
• that research be respectful of community customs and codes of practice
• that a research agreement be in place to ensure clarity on roles, responsibilities, and intellectual property in line with the principles of OCAP described above
• that Aboriginal research capacity be strengthened by enhancing the skills of community in research methods, project management and ethical review and oversight
• that the role of Elders and knowledge holders be recognized

This section explains specifically how this research project is grounded in all of these principles and guidelines of Chapter 9.

Also detailed in this section of the report are the three methods we used to gather the information needed to answer our research questions and meet the objectives noted above regarding the management and understandings of cultural-based approaches to diabetes within the Toronto Aboriginal community. These were Concept Mapping and Anishnaabe Symbol-Based Reflection and Photovoice.

Concept mapping is a consultative and participatory method of gathering information, which uses a computer software programme (Concept Systems©) to represent research results in a visual “map” which can then be used to focus practical recommendations and actions. It is consistent with an Indigenous approach to research because it actively engages participants in the brainstorming of ideas, and in analyzing and interpreting results. This method involved a series of sharing circles where participants were asked to reflect on a specific issue, feeling or thought, which occurred to them about living with diabetes. The statements made during these sessions were then compiled and used in two additional activities detailed in this section of the report.

Anishnaabe Symbol-Based Reflection and Photovoice are methods that involve participants developing symbols/artistic pieces or taking pictures that represent a concept and writing a brief statement describing their work. We had participants share their projects with each other in a closing sharing circle. Anishnaabe Symbol-Based Reflection and Photovoice are catalysts for change within the individual and, when shared with the broader community and/or policy makers, can contribute to significant systemic change. With each of these methods, the results were interpreted collaboratively by the research team, a group of research participants, members of the project’s Governing Circle, the Anishnawbe Health Diabetes Education Team, healers, and staff physician Dr. C.P. Shah. The results section details our findings with particular attention to their meaning for the Aboriginal community participant and practitioner insights gleaned from this participatory interpretive process.

Finally, the report concludes with a set of recommendations aimed at the various levels of government responsible for Aboriginal health, policy-making, and funding: Aboriginal community leaders, organizations, and programmes, as well as non-Aboriginal health care and service providers. We hope the powerful spirits and voices of people expressed in this report and translated in these recommendations will help transform and support the lives of Aboriginal people living with diabetes in
Toronto. These voices were diverse and conveyed fear, frustration and stress, as well as hope, resourcefulness, and positivity. The recommendations at the end of this report revolve around several themes including the diversity and the commonalities shared by participants, the value of the process engaged by this research, wholistic approaches to programming and evaluation.

We are very proud of this research project on multiple levels. As Jessica Keeshig-Martin remarked one day, “the healing doesn’t start after the report is published but was a part of the research throughout” (Keeshig-Martin, personal communication, November 3, 2011). This has been evident in the sense of respect and responsibility for Aboriginal ethical practice, leadership and capacity-building which continuously guided the project, in the careful and attentive engagement with community members who participated in the research, and in our plans to share the knowledge gained. Beyond this report, these results will be shared with community, policy-makers, as well as academic audiences through meetings, web-based resources, and publications. Further information will be posted at the website of Anishnawbe Health Toronto at www.aht.ca.
Review of Literature

In this section we provide a brief review of some of the existing literature and research relevant to this project. Early in the project, the research team conducted a comprehensive search of articles, books, reports, websites, and gray literature and assembled these with abstracts in a database. This material includes demographic and statistical reports on the prevalence and severity of diabetes in the Aboriginal population, community-based and government studies, academic research on focused topics including Aboriginal people and the health care system, contributing factors to diabetes such as colonization, moving away from traditional diets, poverty, stress, sedentary lifestyles and obesity. Other material included identified gaps in the literature and studies of barriers to diabetes management and culture-based care of diabetes, including a few examples of non-Aboriginal cultural approaches.

Over the last three decades there has been a tremendous amount of research conducted on diabetes in Indigenous populations in both Canada and the United States. A full review of this literature is beyond the scope of this report. While the majority of Aboriginal people reside off-reserve, research has tended to privilege reserve-based studies to the neglect of urban Aboriginal communities and the significance of urbanization for Aboriginal health. A great deal of research has also focused on the biology and genetics of diabetes, or has been restricted to epidemiological, population health and promotion perspectives, which also favor biological and individuated behavioural approaches.

While all of those analyses are important, in this research, the voices of Aboriginal people living with diabetes in Canada’s largest city are at the center of our findings, and the literature reviewed in this report focuses on concerns and approaches comparative to those in this study. We begin with a basic overview of diabetes as a disease and illness, which we hope will clarify some questions we heard from participants in the course of the research. As described in the rest of this report, community-based, capacity building research and Indigenous frameworks of analysis were fundamental to providing meaning to the results of this project (Lavallée, 2011). With this framework in mind, we focus here on the work of other researchers who have examined questions similar to the ones at the root of this project on culture-based approaches and challenges to diabetes management in Aboriginal communities.

Diabetes and Resources

Diabetes is a complex condition. From a strictly biological perspective, it is a disease which prevents the body from converting the sugars from food into energy, as it should. All the food we eat is converted by the body into energy. It is important to balance the food we need for energy with the exercise require to expend energy. The main source of energy is glucose, a type of sugar that is in many of the foods we eat. This includes rice, pasta, grains, potatoes, fruits and some vegetables, as well as candies and desserts. Persons with diabetes are usually advised to avoid these foods because they are high in carbohydrates and starch, and glucose is made when we digest these. Insulin, produced by the pancreas, is the tool the body uses to change glucose into energy.

There is a standard range of glucose levels in our bloodstream we should maintain to be in good health. Diabetes is a condition in which the body does not process glucose well. In Type 1 diabetes, the pancreas produces little to no insulin. In Type 2 diabetes, which is more common, insufficient amounts of insulin are released from the pancreas, or the insulin produced does not work as it should. There may be a variety of reasons the insulin is not doing what it should and these reasons may change over time.
This can be frustrating for persons living with diabetes, who must adjust their medications, diet and exercise frequently to maintain the balance needed in order to manage their diabetes. There is no cure for diabetes, thus balanced management is crucial to successfully living with diabetes.

During pregnancy, a woman’s body produces many hormones that can interfere with its proper use of insulin, which can result in gestational diabetes. For the most part, gestational diabetes can be controlled and goes away when the baby is born. However, women who have had gestational diabetes have up to a 50% increased chance of developing Type 2 diabetes (Houlden, 2004). Some studies also show that babies born to women who had gestational diabetes are also at higher risk of developing diabetes (Dabalea, 2007). With “prediabetes,” a person may have elevated glucose levels in their blood that are not high enough on a consistent basis to be classified as type 2 diabetes. Because prediabetes has been associated with increased risk for heart disease or stroke an early diagnosis is important. It is also important because it does not always lead to the development of Type 2 diabetes, and provides for an early opportunity to make dietary or lifestyle change (Chiasson & Bernard, 2011).

There are many resources available online which explain the biological processes involved in diabetes in easy-to-understand terms. The Canadian Diabetes Association website includes a diabetes dictionary and many resources for persons living with diabetes (Canadian Diabetes Association, n.d.). Links to this and other websites included in this review can be found in the references section at the end of this report. This website also provides information about the latest research on diabetes in Canada, taking into account special populations which include women, children and teens, as well as “high-risk” populations in which Aboriginal people are included.

The National Aboriginal Diabetes Association is an advocacy organization whose website also has useful information focused on the particular issues faced by Aboriginal peoples with diabetes (National Aboriginal Diabetes Association, n.d.). The National Aboriginal Health Organization produces knowledge aimed at overall health promotion, and recently released a toolkit focused on diabetes (National Aboriginal Health Organization, 2011). Health Canada’s website provides fact sheets and information about the national Aboriginal Diabetes Initiative including a report on Aboriginal communities in action, which summarizes the work of First Nations and Inuit communities who have developed creative ways to promote healthy lifestyles and reduce the incidence of Type 2 diabetes (Health Canada, 2008; Health Canada, n.d.).

More about the Ontario Aboriginal Diabetes Strategy can be found in a publication available online (Ontario Ministry of Health and Long-term Care, 2010). The mission of the Southern Ontario Aboriginal Diabetes Initiative (SOADI) is “the development, and enhancement of programmes and services focusing on the education, prevention, and management of diabetes in Aboriginal communities, both on and off-reserve” (SOADI, n.d.). SOADI has generated a vast array of resources, including a variety of prevention workshop materials, toolkits, videos, personal care items, and games provided by their staff that travels throughout the organization’s vast service area, which includes Toronto. There is free access to videos they have produced with Aboriginal community members available at the SOADI website, and a number of other items can be purchased online. Within the City of Toronto, Anishnawbe Health Toronto’s Diabetes Education Team provides a “traditional culture based programme for the prevention of complications of diabetes. The programme provides diabetic clients, family and supports with access to traditional, western and complimentary care” (Anishnawbe Health Toronto, n.d.). The goal of the programme is to prevent complications of diabetes. AHT has produced a series of information pamphlets and distributes information about diabetes, some of which is available in Aboriginal languages.
Issues of Specific Concern to Aboriginal People with Diabetes

Diabetes affects Aboriginal peoples in greater numbers compared with mainstream and multicultural Canadian populations (Dyck et al., 2010; Reading et al., 2009). It is a disease that was virtually unknown in the Aboriginal population until the 1940s, and has now reached epidemic proportions. This is true of the global experience of Indigenous peoples (Wild et al., 2004). A recent study confirms that the rate of diabetes among status Aboriginal adults is two to five times higher than in the general Canadian population (Oster et al., 2011). A study of the prevalence of diabetes in First Nations people in Ontario found three to five times higher rates than in the general population (Bobet, 1998). The onset of diabetes occurs much younger in the First Nations population, and complications are more severe (Shah, 2005). In 2010, the Canadian Diabetes Association reported that 20% of the Aboriginal population overall in Canada has diabetes (Canadian Diabetes Association, 2010).

Generally, research does not account sufficiently for off-reserve, Métis, Inuit and non-status First Nations peoples. Although diabetes has been repeatedly identified as a top health concern of Aboriginal people, there is very little understanding of its impact in urban Aboriginal communities (Green, et al., 2003; McKee, et al., 2009; Young, et al., 2000). The Aboriginal Peoples Survey, conducted by the Canadian government in conjunction with the 2001 census, indicated that 30% of the off-reservation population reported having a disability, and 60% reported at least one chronic condition such as arthritis, high blood pressure, or diabetes. The survey identified 24,910 Aboriginal people in Toronto of which 51.5% reported a chronic condition. Nearly 12% reported diabetes, higher than the 9% diabetes rate reported for Aboriginal people overall in the province of Ontario (Statistics Canada, 2002).

These figures are problematic because the census does not account for residence patterns, mobility, social organization and other factors that lead to undercounts (Howard & Lobo, in press). A recent study commissioned by the Toronto Aboriginal Social Services Council estimated that 70,000 Aboriginal people live in the Greater Toronto Area, while the 2006 census counted only 26,565 (McCaskill, FitzMaurice & Cidro, 2011). Studies focused on the residential patterns of particular populations, such as Inuit, suggest that rates of diabetes increase as the “North comes into greater contact with the South” and people lose the protection of geographic isolation and traditional ways of life (Reading et al., 2009, p. 82; Young et al., 2000). That is, increased rates of diabetes are associated with the loss of the activity, exercise, and nutrition associated with traditional food gathering, preparation, and consumption.

More recent and accurate data on the frequency of diabetes in urban Aboriginal populations is needed. Complications from diabetes, including blindness, limb amputation, and organ failure, are also more frequent and severe for Aboriginal peoples (Bobet, 1998). The visibility of complications and living with, or caring for, a person with diabetes are experiences to which many Aboriginal people can relate, and makes diabetes a predominant feature of urban Aboriginal community life. The growing population of Aboriginal peoples in urban centers makes it urgent to begin examining these experiences from the urban Aboriginal point of view.

Wholistic Approaches to Diabetes Research

It is obviously important to understand the physical aspects of diabetes outlined above, however these need to be situated within a wholistic framework. Physical aspects measured in terms of “risk factors” such as being over the age of 40, overweight, and having high blood pressure and cholesterol, tend to dominate the way diabetes is framed. Having a parent or sibling with diabetes and being a member of a
“high risk” group, which includes Aboriginal people, are also risk factors (Canadian Diabetes Association). According to Bobet (1997), two-thirds of the First Nations persons diagnosed with diabetes in the mid-1990s were women. Although based on data from the same time period, Shah (2005) reported smaller differences between men and women, ranging from 5% higher to 8% higher rates for women than men across different age groups.

Rates may be higher for women due to gestational diabetes and its increased risks for the development of type 2 diabetes (First Nations Centre, 2011; Dyck et al., 2010). Women also tend to be within the health care system more (partly because they are giving birth and attending clinics with children) and may be diagnosed sooner and more often than men for these reasons. According to a recent study in the Atlantic region, Aboriginal men, more than women, tend to avoid the diabetes clinic (Martin, 2011). Interviews with persons with diabetes who missed their appointments, and with service providers revealed that a lack of personal and/or cultural fit, personal perceptions of diabetes, and issues regarding diabetes care were among the reasons cited for not going to the diabetes clinic (Patterson et al., 2011). Stigma associated with having diabetes may also prevent Aboriginal people from seeking care or taking steps to manage their diabetes (Iwasaki, Barlett & O’Neill, 2004). Diabetes is also being diagnosed in Aboriginal people at younger ages than in the non-Aboriginal population, and complications occur earlier and are more severe (Simpson, Corabian, Jacobs, & Johnson, 2003). This trend is cause for considerable concern. If they remain unchanged, Jin, Martin and Sarin predicted in 2002 that the rates of diabetes in the Aboriginal population could triple by the year 2016 (Reading, 2009).

Social and historical inequities and disparities, which contribute to these risk factors, are well documented in relation to health status in Aboriginal communities (Adelson, 2005). In their study of chronic disease in the Aboriginal population, Reading and colleagues advocate for a life-course approach, which they align with the wholistic framework often described for Aboriginal perspectives on health, arguing that “an adult risk factors approach alone is not enough” (Reading et al., 2009, p. 5). They integrate research on the social determinants of health such as gender, socio-economic and housing status, geographic location and access to health care, with life stages as described in the First Nations Regional Longitudinal Health Survey as visualized in the medicine wheel in which the life cycle connects the experiences and wellness of infants to the experiences and wellness of children, youth, young adults, parents, grandparents, and elders, again from an individual, family, community, and First Nations perspective (First Nations Centre, 2005, Reading et al., 2009, pp. 7-8).

Moreover, in a wholistic framework, the inseparability of the physical from the emotional, mental and spiritual determinants, which shape the specific ways Aboriginal people are impacted by diabetes, is significant (Bartlett, 1998; Isaak & Marchessault, 2008). Focused around nursing practice, Sylvia Barton’s (2008) review of the literature on Aboriginal diabetes in Canada from 1997 through 2007 reveals the positive impact of the incorporation of wholistic principles in diabetes research. Based on her close examination of twenty-six community-based studies, she concludes “Aboriginal values and practices must be widely promoted among practitioners and researchers working with Aboriginal communities” (Barton, 2008, p. 48). These include being centred on respect, relevance, responsibility, and reciprocity, as well as inclusive of Aboriginal perspectives in design and conduct. Barton suggests that mixed-method approaches, which are informed by ethical guidelines considerate of “indigenous ways of being, knowing, and doing... are vital to the exploration of diabetes among Aboriginal people” (Barton, 2008, pp. 48-49).
Some examples of best practices in this regard include the following:

- In British Columbia, King-Hooper, Schulz and Watts (1995) made their research meaningful and productive of positive outcomes by combining several quantitative and qualitative methods to design a culturally appropriate diabetes prevention strategy which privileged the perspectives of the Nuu-chah-nulth experience in a community-based programme.

- The Kahnawake Schools Diabetes Prevention Project focused on broad community participation in research over a long period of time to change diet and exercise, and had good participation not so much because people were physically better as a result, but because the project was grounded in the goals of achieving overall well being from the Mohawk perspective (McComber et al. 1996).

- The collaborative research of Boston et al. (1997) with James Bay Cree started from the understanding that Cree knowledge and experience had to be the basis for successful diabetes intervention. Their research found that the decrease in bush living and colonial influences were seen as the main causes of diabetes, and therefore this meaning of diabetes was important to the way interventions were designed.

As noted above, examples of research addressing diabetes in urban Aboriginal communities are far and few between. Fewer are those implementing Indigenous, community-based, and wholistic approaches along the lines of those reviewed by Barton. Interestingly, it is in Toronto that we find the earliest examples in the literature of this type of research. The collaborative work of Rebecca Hagey (an anthropologist and nursing professor at the University of Toronto) with Aboriginal community leaders on the development of the Native Diabetes Program at the Native Canadian Centre of Toronto in 1980 is often cited as an exemplary model of community empowerment (Hagey, 1984; 1989). Hagey worked with Joe Sylvester, and other community members and leaders to develop a programme in which preventative, recovery, and disease management strategies were framed within decolonizing discourses. That is, as Joe and Young (1993) have described, diabetes is explained as a “disease of civilization,” in which the oppressive historical processes of land dispossession, non-Aboriginal settlement and policies aimed at cultural destruction and assimilation are seen as key to processes of culture change that brought about important transformations in dietary and physical activity, and therefore generated the conditions that have resulted in high prevalence rates of Type 2 diabetes in the Aboriginal population.

The Native Diabetes Program included several forms of interventions paired with research. It delivered individual counselling and a series of full-day workshops open to persons with diabetes and interested family members. The workshops were led by Sylvester, and involved ceremony, storytelling, and activities offered by other “resource people,” which included “nutritionists, nurses, student volunteers, Native diabetics” (Hagey, 1984, p. 266). Material resources, such as pamphlets and other hand-outs emerged in the programme, in which Anishnawbe (Ojibway) traditional knowledge was privileged in the explanatory model for understanding, preventing, and managing diabetes. Howard (in press) situates Hagey’s work with the Diabetes Project in the 1980s in relation to the history of Aboriginal community-based approaches to Type 2 diabetes in Toronto where such initiatives have been in place for over three decades. The Native Diabetes Program was the predecessor for the establishment of Anishnawbe Health Toronto.

Howard illustrates the value of pairing social research with the development of Aboriginal diabetes interventions. She considers how the politics of Aboriginal multi-cultural and socio-economically diverse dynamics of contemporary urban Aboriginal communities are significant considerations for present and future community-based diabetes initiatives. More recently, Howard-Bobiwash et al. (2011) conducted a
study in which a team of youth researchers engaged in the training, development and execution of a research project. This project included research ethics, design, methods, and analysis with representatives of agencies serving Aboriginal people and non-Aboriginal diabetes programmes, as well as Aboriginal persons living with diabetes. Diabetes programme and agency representatives identified challenges in the coordination and maintenance of consistency of programme delivery, particularly in relation to potential partnerships and Aboriginal participation in programmes across the spectrum. Individual interviews and focus groups identified broader social and structural challenges for Aboriginal persons living with diabetes, specific to urban Aboriginal community life, and successful strategies for managing illness and living a good life despite considerable challenges.

Finally, two other urban diabetes research initiatives in Winnipeg and Vancouver respectively provide comparative value to the research presented in this report. Judith Bartlett and her colleagues have innovated interesting methodologies for capturing the experiences of Aboriginal persons living with diabetes in Winnipeg (Bartlett et al., 2007; Iwasaki & Bartlett, 2006; Iwasaki, Barlett & O’Neill, 2004). Jennifer Eskes’ recent Master’s thesis in human nutrition at the University of British Columbia uses critical and postcolonial theory to examine an Aboriginal diabetes programme on the downtown east side of Vancouver (Eskes, 2010).

In summary, the rate of diabetes for Aboriginal people is 2-5 times higher than for the overall Canadian population (Oster et al., 2011), and those Aboriginal people who have diabetes tend to have more complications. Past literature has privileged First Nations on-reserve. In addition, the literature has focused on biology and genetics. However, there is increasing recognition of the importance of culturally-based, wholistic programmes that incorporate physical, mental, emotional and spiritual well-being. This research addresses the caveats of past literature, focusing on urban Aboriginal peoples (First Nations, Métis and Inuit) with diabetes and explores how to support people in better managing diabetes.
Methods

This methods section describes how the research was carried out. It discusses the process that was required to obtain ethics approval from the research institutions, selection criteria for participants, how participants were recruited, the consent process, and the research activities specifically an explanation of the methods; Concept Mapping, further quantitative analysis with a statistical software programme, Anishnaabe Symbol-Based Reflection and Photovoice.

Research Ethics

All universities in Canada and the United States are bound by ethical guidelines and must have research ethics boards that review all research done with human subjects, biohazards and animals. These research ethics boards review all research proposals to ensure the risks of research do not outweigh the benefits. As university researchers, the co-principal researchers on the project were required to obtain ethical approval from their university institutions before any contact with potential participants could commence. The project underwent research ethics review at three universities, Ryerson University (Lynn Lavallée), University of Toronto and Michigan State University (Heather Howard).

In Canada, all university ethics boards must address the TriCouncil Policy Statement Guidelines 2 (TCPS2). Chapter 9 of these guidelines relates to research with First Nations, Métis and Inuit (Canadian Institutes of Health Research, et al., 2010). While the Articles in the chapter serve to guide people working with Aboriginal peoples when conducting research, many Aboriginal peoples and agencies already recognize the need for substantial community engagement. The TCPS2 now puts what Aboriginal people already know into a process that must be adhered to by any university affiliated researchers in Canada wanting to conduct research with First Nations, Métis or Inuit.

Article 9.1 and 9.2 of the TCPS2 requires engagement with the community and discusses the nature and extent of the engagement. As noted in the Introduction, this research topic developed as a result of over 1.5 years of consultation with the Aboriginal community. As a continuation of this engagement requirement, this project involved the development of a Governing Circle whereby the research team continually shared the progress of the research with a group of people from the community. The Governing Circle was comprised of an equal number of males and females, Elders, Traditional Healers and Aboriginal people living with diabetes. In addition, the delivery of this project through a community agency, Anishnawbe Health Toronto, ensured on-going engagement.

Article 9.3 – 9.6 and 9.12-9.13 focuses on respect for the governing authorities of Aboriginal communities and engagement with organizations while recognizing the complex authority structures and diversity within communities. It also emphasizes that research is mutually beneficial and collaborative in nature. Past research has indicated that Aboriginal people in Toronto do not feel that there is one authority figure or agency that can address all Aboriginal people in Toronto on all matters (Environics Institute, 2010). However, this research was born from the community after almost two years of consultation and Anishnawbe Health Toronto took the responsibility of administering the research on behalf of the community. Funding for the project flowed directly to the community agency and a research agreement was signed between the community agency and the researchers (See Appendix A for excerpts of the agreement). Recognizing that the urban Aboriginal community is extremely diverse, and that there is not one single authority structure, the research aimed to be inclusive of all Aboriginal and non-Aboriginal agencies that deal with people who have diabetes, either
directly or indirectly. These agencies were involved in the recruitment and invited to the community forum where the results of the project were shared.

Article 9.7 of the TCPS2 relates to critical inquiry ensuring that the research critically examine how colonial structures and systems can exercise authority over First Nations, Métis and Inuit. Related, Article 9.17 discusses the importance of ensuring community representatives are part of the interpretation and dissemination of research results. We dealt with this in many ways and on various levels. The entire research team was important with respect to critical inquiry. The research team was involved in the interpretation of the research and ensured ethical and respectful interactions with participants. It was important that the research team understand the lived experiences of First Nations, Métis and Inuit, so the hiring process met this criterion. All staff identified as First Nations or Métis; the one non-Aboriginal, co-investigator, Dr. Heather Howard has been personally and professionally involved in the Toronto Aboriginal community for nearly 20 years. One of the Governing Circle members noted that Heather “has been adopted by the Toronto Aboriginal community”. Other steps were put in place to ensure critical inquiry, such as sharing the results and interpretation of the research with the Governing Circle, Anishnawbe Health Toronto Diabetes Education Team and other staff, Traditional Healers, and the entire research team.

Article 9.8 of the TCPS2 discusses the importance of being respectful of community customs and codes of practice. Again, this was done throughout the project. At all group gatherings an Elder was present, traditional openings and closings and purification ceremonies were conducted. Tobacco was offered as a form of consent and food was part of every gathering. Although not a community custom or code of practice, it was important for us to recognize the challenges one might face in participating in the research. Thus childcare, transit and compensation (by way of Loblaws’ gift certificates) were provided.

Articles 9.9 and 9.10 speak to the need for ethical approval, which was obtained prior to commencing this research. Article 9.11 recommends a research agreement serve to ensure clarity and confirm roles and responsibilities. As noted above, this research began with a research agreement between Anishnawbe Health Toronto and the two co-principal researchers. Within this research agreement the notion of intellectual property (Article 9.18) should be addressed. As noted in the Introduction, the principles of ownership, control, access and possession (OCAP) are commonly discussed from a First Nations, Métis and Inuit perspective. Provisions for the OCAP principles should be clear before research begins. The research agreement for this project states that Anishnawbe Health Toronto is the sole and rightful owner of the data, and controls how the findings will be shared; for example in publications.

Article 9.14 emphasizes the importance of strengthening research capacity through enhancing the skills of community in research methods, project management and ethical review and oversight. This article allows for the specific targeting and hiring of Aboriginal people. The principle of capacity building was at the forefront of this project and imbedded in the Charter agreement between the funder and Anishnawbe Health Toronto and the research agreement between Anishnawbe Health Toronto and the co-principal researchers. The co-investigators addressed capacity building by hiring seven Aboriginal people, two part-time research co-ordinators, one Indigenous research integrity advisor, and four research assistants. The training opportunities of this project included formal training and obtaining a certificate on the Concept Mapping process through Concept Systems, training and experience with the Anishnaabe Symbol-Based Reflection and Photovoice methods, experience with the ethical protocol of universities, including the TCPS2 guidelines and the ethics certification required by Michigan State University, and shown how to analyze data with the statistical software programme, SPSS. One part-time research co-ordinator was unable to remain on the project but before leaving was able to
participate in the ethics and concept map certification. For more details on the capacity building experiences of the research team please see the Reflections by the Research Team section of report.

Article 9.15 of the TCPS2 notes the importance of recognizing the role of Elders and knowledge holders. As mentioned above in Article 9.1 and 9.2, the project involved the development of a Governing Circle, as well as sharing and getting feedback on the results from Traditional Healers and other members of the community.

As with any ethical component of research, privacy and confidentiality (Article 9.16) are critical. However, for the arts-based methods in this research participants were given the opportunity to be identified by name with their work. The remainder of the Articles of the TCPS2 (9.19-9.22) relates to collecting biological data or secondary data and was not applicable to this project.

While addressing the Articles of the TCPS2 may seem a bit challenging, it provides an excellent framework from which to begin, conduct and complete research that will ensure no harm is done by research, and that community benefits from research. Researchers not affiliated with universities are not required to address the TCPS2 guidelines or undergo ethical review. However, many communities and organizations are developing their own research ethics guidelines. For instance, research conducted at the 2008 North American Indigenous Games underwent review by the host society, Cowichan Tribes (Lavallee, 2010a) and research conducted on Manitoulin Island must undergo ethical review by the Manitoulin Anishinabek Research Review (Lavallee, 2010b). These guidelines were developed with the Aboriginal community and the TCPS2 simply reinforces what Indigenous peoples already know, including Anishnawbe Health Toronto. As a result of this research project, Anishnawbe Health Toronto is now incorporating many of the TCPS2 guidelines into their own policy document that will be given to any researchers wanting to conduct projects with their organization.

Selection and Recruitment of Participants

Recruitment of participants began after ethical review was completed in July 2011.

The focus of this research project was to find out about how to better meet the needs of Aboriginal people who have diabetes. The selection criteria were limited to people:

- who self-identified as Aboriginal (First Nations status, First Nations non-status, Métis registered, Métis unregistered, and Inuit);
- who self-identified as having Type 1 or Type 2 diabetes, had or have gestational diabetes, or have been told they had pre-diabetes or elevated sugar levels;
- who were 18 years of age and older.

The justification for involving people who were told they had pre-diabetes or had elevated blood sugar levels was that pre-diabetes is now considered a diagnosis. These are persons who are under medical monitoring similar to persons with a diabetes diagnosis, and may even be taking diabetes medicine. It also relates to reciprocity or ensuring the research gave back to the participants. It was expected that people who participated in the project would benefit from having their voice heard and hearing others. The justification for involving only adults age 18 years of age and older related to the required maturity level to complete the activities related to the project.

Participants were recruited through the circulation of flyers via email lists, posted at agencies in the Greater Toronto Area, universities and colleges, contacting service providers to people with diabetes,
word of mouth, attending events such as powwows and socials, and media sources such as Aboriginal Peoples’ Television Network and Aboriginal radio.

The flyer indicated the expectations as well as compensation which included a $50 Loblaws’ card to honour the participants for their work, provided money for child care and transit tokens. Some of the initial sharing circles compensated participants with $30 Loblaws’ cards but this was changed to $50 after reflecting on the amount of work involved in subsequent activities. At each group event food and beverages were also provided.

**Participant Consent**

Obtaining prior and informed consent is a requirement of research being conducted by university researchers. The consent form must indicate all risks and benefits of the research, compensation, and intention of the research. Typically participants sign a consent form but in this case we used sacred tobacco as a method of consent. Increasingly, researchers conducting research with Indigenous communities who understand tobacco to be a sacred medicine are using tobacco as a means of obtaining consent versus signing a consent form (Davidson, Brown, & Moffit, 2006; Ellis & Early, 2006). Participants were able to decide if they wanted to use tobacco as a form of consent or sign the consent form. The majority of participants accepted tobacco as a form of consent.

After consent was obtained, either through signature or tobacco, the participants engaged in the research activities.

**Research Activities**

Using more than one research method allows for something called triangulation, where in order to answer a question, you approach it in various ways to get a better and more accurate picture of what people are experiencing. Three research methods were used to explore the research question identified by the community; 1) What are the challenges for urban Aboriginal peoples in managing their diabetes?; and 2) Does culture play a role in managing diabetes? Concept Mapping, Anishnaabe Symbol-Based Reflection and Photovoice methods are described below.

**Concept Mapping – Explanation of the Method**

Concept mapping emerged in the 1980s as a research method to guide social and health service evaluation and program development. It uses the language of participants and produces a visual display of the interrelationships among their ideas (Trochim, 1989). Based on these principles of concept mapping, Concept Systems (www.concepts.com) developed a software programme and related process that involves talking with participants and getting their ideas about a topic. It is classified as a qualitative research method, meaning it allows people involved in research to freely share their ideas about a topic but is also quantitative, in that it takes the information shared by people and can provide some overall measurement of people’s perspectives. Concept Mapping involves three main steps that fully engage participants in the research: 1) generating ideas through brainstorming; 2) structuring ideas through sorting and rating of statements; and 3) Concept Mapping analysis.
The first step to Concept Mapping is generating ideas by holding brainstorming sessions with people to establish statements that answer a specific research focus. The research focus is put into a ‘focus prompt’. The focus prompt for this research was, “A specific issue, feeling or thought that occurs to me about living with diabetes is...” which participants were asked to complete in a sharing circle format.

It is possible that hundreds of statements are made during the brainstorming sessions, so afterwards they have to be cleaned up by removing duplicate statements, combining statements that have the same meaning, including only those statements that can be used in the rating part of the process and narrowing down the statements to a more manageable number for the sorting and rating phase. Concept Systems recommends that 80-100 statements be used for the sorting and rating because the sorting and rating can be a lengthy process for participants.

The second step of Concept Mapping is the structuring of ideas, which involves two processes, sorting and rating the statements made in the brainstorming session. The 80-100 statements are typed onto individual cards and participants are asked to sit down and sort the cards based on themes that make sense to them. For instance, in this project some of the themes that people identified regarding the statements made about living with diabetes were financial challenges, physical issues, culture and community. After everyone completes their sorting the information is entered into the Concept Mapping software.

The rating process involves taking the same 80-100 statements and developing a survey asking participants questions about each statement, such as whether or not he/she agrees with the statement. In the case of this research we asked participants to rate the degree to which they felt they agreed with the statement, and the degree to which they felt they had control over the statement.

After everyone completes his or her sorting and rating, the information is entered into the Concept Mapping software. The software analyzes the data with a statistical process similar to factor analysis – identifying factors that people identify in similar ways. Basically, the software looks at each individual’s sort in relation to everyone else’s according to similarities in the ways each statement was sorted. This is called a “similarity matrix” which allows the software to calculate the number of times participants sorted the same items together. The more participants sort items together, the more we can say with confidence that there is a meaningful relationship between the ideas. The software then plots these relationships onto a map so that they can be examined visually in terms of how close or distant they are from each other. The software also plots the rating information in a non-overlapping way so that statements fall into clusters across the spectrum without obscuring each other. “Clusters arrayed in close proximity to each other have a stronger meaning relationship than those situated farther apart” (Risisky et al., 2008, p. 79). This allows for the analysis to be applied to recommendations for action effectively by focusing on the relationships participants generated between ideas.

The final step of Concept Mapping, called Concept Mapping Analysis, involves analyzing the data that was entered into the computer programme. This process involves looking at how many themes make the most sense to report, whether all the statements in each theme fit well, and exploring which themes were most and least important based on the rating. The final product of the Concept Mapping process is a visual map of all of the themes identified, as well as how they were rated by the participants. The cluster map is visual and resembles a circle with clusters that are interrelated and interdependent much like the Anishnawbe teachings of the Medicine Wheel.
How We Used Concept Mapping in this Project

We held five brain-storming sharing circles with a total of 28 participants during the month of August 2011. These sharing circles focused on participants responding to the focus prompt, “A specific issue, feeling or thought that occurs to me about living with diabetes is...” The research assistants took detailed notes, and after compiling all of the data over 600 statements were recorded. These were narrowed down to approximately 400 after deleting duplicate statements. The Concept Mapping process recommends that only 80-100 statements be used in the subsequent stages of the process so the statements were further narrowed down with the assistance of the Concept Systems expert staff. This process involved maintaining the integrity of what people said while collapsing similar statements and removing statements that could not be used for the subsequent steps (sorting and rating). The end product was 79 statements that were then used in the sorting and rating steps (See Appendix B for rating sheet listing 79 statements).

Through sharing circles held at various locations throughout the Greater Toronto Area, attending various events and through one-on-one meetings, we had a total of 59 participants sort the statements and 123 complete the rating of the statements. On average, participants sorted the statements into 5 or 6 different themes, such as financial difficulties, emotional, spiritual, physical, mental, western medicine, health care system, need help, personal difficulties, exercise, and stereotyping.

After all the data was entered into the Concept Mapping software the research team met to analyze the data. The team ran the cluster map to see how many clusters made the most sense. We decided that seven clusters were ideal and allowed for the best representation of the cluster with the statements in that cluster. In addition, the cluster map and the statements were shared with a smaller random sample of participants, diabetes practitioners and experts at Anishnawbe Health Toronto, Traditional Healers and the Governing Circle members. They provided valuable feedback on the interpretation of the cluster map and recommendations that have been incorporated in this report.

The cluster map and result of the Concept Mapping are reported in the Results section of this report.

Anishnaabe Symbol-Based Reflection - Explanation of the Method

Anishnaabe Symbol-Based Reflection (ASBR) is a method developed in 2005 by Lynn Lavallée and a group of research participants in Toronto (Lavallée, 2007, 2008, 2009). The method was named by the participants of the research. Anishnaabe (spelled as the participants wished) is to honour the traditional territory and people from which the method was born.

ASBR directly involves the participants in the research process by having them create symbols that represent the concept or research question being explored. For instance, in this research participants were asked to make a symbol that reflected how they managed their diabetes. When an artist makes something such as a painting, jewellery, medicine wheel or dream catcher their energy is said to be placed into that object, and the process of making something also allows for a wholistic experience; physically, mentally, emotionally and spiritually. This is the premise behind ASBR. It allows for the creation of a symbol that answers a research question but at the same time allows participants to be wholistically engaged in the research process. There have been other similar arts-based approaches to research; however, this method engages an Indigenous approach.
Further principles behind the ASBR method are to allow participants time to make their symbols and returning to share their symbols with one another. This sharing circle is critical to the ASBR method. It allows for the research to give back to the participants, a form or reciprocity so that the research is not simply taking from participants but leaving the participants in a good way. Participants of this method have shared that the sharing circle was inspiring because they did not realize how other people felt about the same issue, they did not feel as alone, and benefited spiritually from making the symbol. The participants are also asked to write a brief summary of what their symbol means. This helps in the creation of a written report or document about the research. Finally, in keeping with an Indigenous approach to research participants are asked to be involved in any knowledge sharing or dissemination activities, like presentations in the community or at conferences so they are directly involved in sharing the results of the research.

Photovoice – Explanation of the Method

Photovoice is a participatory action research method that involves giving participants cameras to take pictures of a specific topic related to research. This process allows participants to act as recorders, and potential catalysts for social action and change in their own communities. Participants take pictures that help tell their story regarding a particular concern. The individual’s story typically accompanies the pictures to promote an effective, participatory means of sharing expertise (Wang, Yuan, & Feng, 1996). The three main goals of Photovoice are a) to enable people to record and reflect their community's strengths and concerns; b) to promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs; and c) to reach policy makers. Photovoice is based on health promotion principles and the theoretical literature on education for critical consciousness, feminist theory, and a community-based approach.

How We Used Anishnaabe Symbol-Based Reflection and Photovoice in this Project

We recruited participants for the ASBR and Photovoice through our interaction with participants of the Concept Mapping, as well as through flyers circulated throughout the community and word of mouth. A total of 28 participants came forward for the initial orientation session on October 3, 2011. The methods were explained and people identified if they were interested in participating. Participants who were interested in Photovoice were provided with cameras if they did not have their own. The cameras that were given to participants valued at $40 were given as a gift for their participation at the end of the project. Participants who were interested in the ASBR were compensated for their materials to a maximum of $60.

The research team maintained contact with the participants over the next month to ensure individuals had everything they needed and would be ready for the sharing circle in one month’s time.

Twenty-three participants completed the ASBR and Photovoice (14 ASBR, 9 Photovoice) and attended the final sharing circle on November 1st. One participant was unable to attend the sharing circle and brought his artwork directly to the research office.
Results and Discussion

This section provides an overview of the participants, results of the Concept Mapping, statistical analysis of the statements, and results of the Anishnaabe Symbol-Based Reflection and Photovoice.

The Participants

In total, 138 individuals participated in the research project with a total of 275 separate interactions. As noted in the Methods section, triangulation involves taking multiple forms of assessment or measurement that can involve the same or different participants. Our total of 275 interactions indicates a strong representation of our findings. In addition, we were able to build trust amongst the participants and the community, allowing individuals to return for future activities. Elder Vern Harper stated that he saw the participants of this project treated with dignity and in turn, that people wanted to participate more because their trust had been earned. In fact, as the project ended we had new individuals approach us because they had heard about the project and wanted to become involved. Unfortunately, we had to turn people away due to the restricted timeline of the project.

<table>
<thead>
<tr>
<th>Research Activity</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain storming sharing circles for Concept Mapping</td>
<td>28</td>
</tr>
<tr>
<td>Sorting for Concept Mapping</td>
<td>59</td>
</tr>
<tr>
<td>Rating for Concept Mapping</td>
<td>123</td>
</tr>
<tr>
<td>Orientation session for ASBR and Photovoice</td>
<td>28</td>
</tr>
<tr>
<td>Final sharing circle for ASBR and Photovoice</td>
<td>23</td>
</tr>
<tr>
<td>Sharing circle to get feedback on the Concept Mapping</td>
<td>14</td>
</tr>
<tr>
<td>TOTAL</td>
<td>275</td>
</tr>
</tbody>
</table>
Gender

Of the 138 participants, 106 (76.8%) were female, 30 (21.7%) were male, and 2 (1.4%) were two-spirited. We recognized early on in the project that more females were coming forward for the research, possibly due to some of the reasons cited in the literature review with regard to gender and diabetes. Unfortunately, research literature reporting the prevalence of diabetes for two-spirited people is absent. We suspected that the reason we may have had fewer men and two-spirited come forward may be due to the nature of the activities (sharing circles) and that men and/or two-spirited may not be as comfortable with the process. We specifically targeted agencies in Toronto that serve men and two-spirited people and asked male and two-spirited participants if they knew someone who might fit the criteria and would want to participate (i.e. snowball method of sampling for research participants).

A recommendation for service providers is to establish special programmes and recruitment strategies that address the needs of males and two-spirit people.

Self-Identification

A selection criterion for involvement in this research was self-identification as First Nations, Métis or Inuit. We wanted to ensure that individuals who may not have Indian status, or be registered with the Métis Nations, would feel inclined to come forward. In order for all people who identify as Aboriginal to participate, we ensured that our flyers and all information given to participants allowed them to self-identify in whatever way was best for them. Therefore we used wording that would welcome all, First Nations status or non-status, Métis registered or unregistered and Inuit. 127 (92%) identified as First Nations (status or non-status), 9 (6.5%) identified as Métis (registered or not registered) and 2 (1.4%) identified as having multiple Indigenous identities.

A recommendation of this project is to develop stronger partnerships with the Métis Nation and that the Métis be included in the planning of future research and programmes for Aboriginal peoples. Targeted outreach to the Inuit community is recommended.

While it is recognized that the Canadian Census does not accurately capture the representation of Aboriginal people in Toronto (Guimond, 2003), it is the best statistical data that can be used. The 2011 Canadian Census Aboriginal population data will be released in February 2012 so the 2006 data is cited to
draw a comparison with the data found in this project. In 2006, 65% of the Aboriginal population who completed the census reported being First Nations, 29% Métis, 1% Inuit, and 5% multiple identities. Our project significantly under-represented the Métis with only 6.5% identifying as Métis while the 2006 census reported 29% identifying as Métis (Statistics Canada, 2010). Our study included no one who identified as Inuit. Although the population of Inuit in the city of Toronto is quite small it would be worthwhile for programmes and researchers to conduct targeted outreach to be inclusive of the Inuit.

Specific focus was made to attract more Métis to the project. One of the research team members met with a staff person at the Métis Nation of Ontario (Toronto York Community Council). We were informed that the Métis Nation of Ontario was conducting a study related to diabetes and that this may have been one of the reasons we had few Métis come forward.

Age

The age of participants ranged from 18 to 79. Participants were required to be 18 years of age or older given the nature of the expected activities. There was no restriction to the upper limit of age. Ten participants (7.4%) were classified as youth between the ages of 18 and 29, 18 (13.2%) were between the ages of 30 and 39, 35 (25.7%) were between the ages of 40 and 49, 36 (26.5%) were between the ages of 50 and 59, 28 (20.6%) were between the ages of 60 and 69, and 9 (6.5%) were between the ages of 70 to 79.

Almost half of the participants were 49 years of age or younger and almost one quarter were 39 years of age or younger. While this study did not involve a random sample of individuals and cannot state that this composition of Aboriginal peoples in Toronto represents the whole of people living with diabetes, it reflects that the individuals who came forward for this project were fairly young. In discussions with the Diabetes Education Team at Anishnawbe Health Toronto and other health practitioners, it was identified that funding for programmes tend to target older individuals. An observation of the research team was that some of the younger females had gestational diabetes. Consistent with other research literature that demonstrates Aboriginal people have diabetes at a younger age (Shah, 2005), this study indicates that programmes need to meet the diverse demographics of Aboriginal peoples.

It is recommended that policy makers broaden criteria for diabetes programmes for urban Aboriginal peoples in Toronto, particularly related to younger age groups and females with gestational diabetes or of child-bearing age.
Years Living with Diabetes

We asked participants how many years they lived knowing they had diabetes. Almost half were very recently diagnosed, within the last 5 years. When comparing this with the age of the participants it is plausible that the younger individuals were most recently diagnosed thus leading to a greater sample of people more recently diagnosed. This finding is important in making recommendations for programmes and services for the Aboriginal community in Toronto.

This research involved almost 50% of people who were diagnosed within the past five years. Those earlier on in their diagnosis require more specific education and assistance in order to learn how to manage diabetes; therefore programmes need to be able to meet the potential increased capacity of individuals needing more one-on-one education.

Income

Past research has identified insufficient income as a challenge to eating healthy for people who do not have diabetes and people with diabetes alike (Shah, 2005). Rather than ask the actual annual income of participants which can be misinterpreted when factors such as household size, dependents, and other financial constraints are not considered, we asked if participants felt their income was enough to meet their needs. 86 (62.3%) stated no, 24 (17.4%) said yes and 28 (20%) did not answer or were not asked. Participants involved in the brain-storming sharing circles of the Concept Mapping were not asked. These findings are not surprising. Based on the 2006 Canada Census we know that 1 in four Aboriginal people in Toronto reported living below the low-income cut-off. While not identical to the question asked in this study, the low-income cut-off is the threshold below which a family will likely devote a large share of its income on the necessities of food, shelter and clothing.

A recommendation of this study is that programmes and services take into account the financial constraints of Aboriginal people living with diabetes and provide transit, childcare and monetary incentive that can help with purchasing better quality foods.
Concept Mapping

As described in the previous section, the Concept Mapping method used in this project involved three participatory phases of data collection: sharing circles (brainstorming), sorting, and rating. The Concept Systems computer software pulls all of this information together and represents it visually in a cluster map. All 79 statements that originated in the sharing circles are individually numbered in the first map below, which also shows how participants’ sorting of the statements clustered into thematic groups (Cluster Map 1). An aggregate of the way participants rated these statements according to their level of agreement with the statements is represented in a second map (Cluster Map 2) and discussed further below. Participants were also asked to rate the 79 statements in terms of their level of control over the issue described in each statement, however, we found this latter question did not fit well with most of the statements and the data was inconclusive. In this section, we therefore focus on the results of the Concept Mapping method with reference only to the rating of agreement. Together the maps provide a collective visual display of the research participants’ understanding of living with diabetes. The initial map interpretation made by the research team refined the cluster labels to best reflect the content of statements assembled in each cluster. The insights and reactions to the maps shared with participants, the Governing Circle, AHT Traditional Healers, Diabetes Education Team, and Dr. Shah are also reported here.

Looking at the Cluster Map Through a Wholistic Lens

Cluster Map 1 (see next page) visually represents how participants’ sorting of the 79 statements cluster together under particular themes. In this project, it was decided that seven clusters best represented the participants’ sorting activity, based on the collective discussions of the research team, and sharing with participants and other stakeholders we engaged in the project.

These seven themes are:

- Culture and Ceremony
- Community Wellness
- Emotional Stressors
- Wholistic Fear
- Diabetes Management Challenges
- Challenges to Healthy Eating
- Frustrations with Western Medicine

The placement or sizes of the clusters themselves do not represent a hierarchy. Rather the size of the cluster represents the closeness of fit of the statements within a cluster, and the distance between clusters demonstrates the relationships of the themes to each other. So, for example, the cluster called Culture and Ceremony is smaller because the statements it contains are closest in meaning to each other according to the way participants sorted them. The location of the Culture and Ceremony cluster means that it is closer in relationship to, for example Community Wellness, than it is to Wholistic Fear. The Culture and Ceremony cluster is very important, but that is not why it is located at the top of the map. The importance of Culture and Ceremony is better understood through the interpretations made with Cluster Map 2 and with the quantitative analysis further below.
Cluster Map 1

- Frustrations with Western Medicine
- Community Wellness
- Emotional Stressors
- Wholistic Fear
- Challenges to Healthy Eating
- Diabetes Management Challenges
- Culture and Ceremony
In many cases where others have used this method, one cluster may end up in the middle of the map. This would indicate that one central theme is linked in a pivotal way to each of the surrounding clusters (Risisky et al. 2008; Ridings et al. 2008). This was not the case in this research. Instead, the seven clusters in our map formed a circle. There is some variation of distance between the clusters but the formation of the map tends to highlight the relational ties and the continuous interconnection of all of the themes.

Typically, researchers using concept mapping focus on the relationships of clusters that are closest to each other because “they have greater meaning than those situated farther apart” (Risisky et al. 2008, 79). While we do provide a focused analysis of the cluster map here, we also found it important to draw on and incorporate Indigenous knowledge frameworks for our discussion of our results from this method. For example, it may be more appropriate to describe the map in terms of the cardinal directions frequently used in Aboriginal interpretations of positioning as opposed to referring to the top, bottom, left and right of the map. This may be more precise as well because it accounts for the all the space between the cardinal directions with greater nuance. For example, the clusters with the themes of Community Wellness, Emotional Stressors, and Wholistic Fear are closely linked together on the east side of the map, while the Challenges of Healthy Eating and Frustrations with Western Medicine are positioned on the west side of the map with a bit more distance between them. Culture and Ceremony in the north and Diabetes Management Challenges in the south may be interpreted as sites of linkage between the western and eastern themes. This interpretation will be detailed below.

Consultation with members of the project’s Governing Circle added further insights into this wholistic interpretation of the cluster map and of Aboriginal people’s experiences with diabetes. Both Pauline Shirt and Marie Gaudet were struck by the fact that the number seven best represented the way the key themes clustered into groups. A core set of teachings in the Anisnaabe way are those of the Seven Grandfathers (Wisdom, Love, Honesty, Respect, Bravery, Humility and Truth). Pauline and Marie suggested that these cluster themes could be adapted to tools for diabetes education and prevention in correlation with these teachings.

Pauline also visualized the cluster map as a tree, with each cluster resembling clumps of leaves (statements) at the end of main branches, again emphasizing the interconnection and relationships between them. She also saw movement in the clusters, like “leaves swirling in the wind.” This prompted Pauline to share a teaching about Mother Earth dancing her last dance in the fall, when all the leaves are coming off the tree and swirling around to go back into the earth and nurture her to come back in the spring. Likewise, the cluster map is a collective representation of the voices of the people expressing where they are right now with their diabetes, but there is movement toward regeneration. “It looks like the dance of wellness.” Pauline concluded.

Each numbered point on the map corresponds to each of the 79 statements. These are detailed by cluster below. As noted in the description of the method, the distance between the numbered statement points are significant. Points that are close together were sorted together more frequently by the participants and are more likely similar in meaning than those that are very distant from each other on the map. For example, the Culture and Ceremony cluster is smaller than any of the others because of the close proximity in meaning that participants found in sorting these statements together. The Frustrations with Western Medicine cluster has almost the same number of statements but appears larger because its statements were less closely related to each other even though participants generally sorted them within this theme. Again, Marie Gaudet’s reflection on the way points fell within clusters on the map is insightful. She described them as resembling “sound-waves” that spoke the voices of the people; if the map could be set to music it would highlight both the diversity and the harmonies of these voices.
It is important to understand the overall visual display that the cluster map represents as our Elders, Traditional teachers and healers have interpreted. This interpretation has practical value for the recommendations made at the end of this report by providing clear examples of how the challenges to diabetes management may be addressed through a wholistic vision.

**Culture and Ceremony in Relation to Frustrations with Western Medicine and Community Wellness**

Positioned in relation to Frustrations with Western Medicine in one direction and Community Wellness in the other, the Culture and Ceremony cluster includes statements that highlight the ways in which Aboriginal culture provides learning frameworks that are self-affirming and supportive. These include for example, “Traditional ceremonies, such as smudging and the sweat lodge, helps me feel calmer and manage my diabetes” and “I have received help from seeing Elders and Traditional counsellors about my diabetes” (see Table 1 below). Culture and Ceremony thus contributes these strengths to the Community Wellness cluster in which numerous statements emphasized the value of intergenerational and interpersonal learning, such as “I need to find a way to express my feelings in a way that is healthy” and “I want to pass on good habits to future generations by being a good role model” (see Table 2 below).

The relationship revealed in the closeness of these two clusters asserts the need for the establishment and further development of programmes for Aboriginal persons living with diabetes in the city that bring together culture and ceremony with opportunities for learning from each other as community and family members. This was asserted by numerous participants who attended the circle on December 9 to review the cluster map themes. They underscored the ways that the methods used in this project, which brought them together in sharing circles within Aboriginal cultural settings and approaches, were life-changing for them in terms of improving the management of their diabetes. They found empowerment, encouragement, hope, support, equality and inclusiveness, a lightening of their burdens of fear and frustration, and gained practical knowledge. All of this was made possible by learning from one another as Aboriginal persons living with diabetes. Participants noted that they had seen measurable changes in themselves as a result. These changes included losing weight, changing dietary habits, and even an improvement in test results for kidney disease. Several recommendations rest upon these findings. Programmes for Aboriginal persons living with diabetes in the city that bring together culture and ceremony with opportunities for learning from each other as community and family members should be a very high priority. In particular, sharing circles for Aboriginal persons living with diabetes in which they can simply hear each other’s stories and support each other are needed. Further research which measures improvement of diabetes management as a result of participation in such sharing circles would also be useful.

Culture and Ceremony also equip individuals to face Frustrations with Western Medicine, which in that cluster included statements that revealed the ways Aboriginal persons with diabetes encounter difficulties expressing concerns or being heard in relationships with biomedical doctors (see Table 7 below). For example, statements in this cluster included, “I feel doctors and others judge and blame me for getting diabetes.” Again, participants at the December 9 circle discussed issues with the way diabetes educational information is generally communicated by Western practitioners with little follow up, in ways that do not take into account the difficulties of applying the information to everyday life, or in relation to non-physical aspects such as emotional well-being. The wholistic understandings found in Aboriginal Culture and Ceremony, for example in the statement “Our cultural teachings like the
Medicine Wheel (balancing physical, mental, emotional and spiritual wellbeing) can help us frame the experience of western medicine in ways that may improve the experiences of Aboriginal persons with diabetes within the mainstream health care system. To paraphrase one participant’s reflection, “We are all faces of diabetes and as a nation we have to be self-directed to get back to wellness,” suggests that Aboriginal self-determination (at the personal and community levels) is fundamental to improvement of the relationship between Aboriginal and non-Aboriginal approaches to diabetes care and management.

**Recommendations from this analysis include creating and supporting new culture-based programming that is initiated, self-determined, and led by the Aboriginal community to help coordinate and support Aboriginal people with diabetes in their interaction with the mainstream health care system.**

It was also in the Culture and Ceremony cluster that the statement, “We need more positive collaboration among Aboriginal peoples and mainstream knowledge about diabetes” was located at the center of the cluster. This suggests that this idea may be pivotal in relation to the range of other statements within this cluster, and as a bridge to reducing the impacts of Frustrations with Western Medicine. AHT Traditional Healer and Governing Circle member Dolores Esquimaux picked up on this result in the cluster map stating that healing will best result from elaborating on how the western and traditional ways of healing can actually go hand in hand.

**Diabetes Management Challenges in Relation to Emotional Stressors, Wholistic Fear and Challenges to Healthy Eating**

Diabetes Management Challenges in its southern location, between Challenges to Healthy Eating on the west, and Emotional Stressors and Wholistic Fear on the east, may be most usefully understood by examining the relationships between the positioning of specific statements within these clusters in more detail (Tables 3, 4, 5 and 6 below). Statements 45 and 46 along the north-eastern edge of the Diabetes Management Challenges cluster describe how living in the city and increased sedentary lifestyle have negatively impacted diabetes management. Statement 9 at the north-western tip of the Challenges to Healthy Eating cluster signals the desire to manage diabetes naturally without medication. A solution suggested by their proximity might entail programming that more directly addresses the availability and activity that surrounds accessing medicinal foods within the urban context. As Traditional Healer, Jake Ago Neh felt, our people need to get back to eating the old way as best they can. We need to eat more fruits and vegetables and wild meat if we can get some. It is not always easy to do this while living in a city. Nonetheless, increased knowledge of the nutritional and philosophical aspects of traditional foods can be applied in any context.

On the western edge, statements 62 (in the Diabetes Management Challenges cluster) and 63 (in the Emotional Stressors cluster) may well have ended up within the same cluster as both refer to difficulties in managing diabetes. However, it is important to see that participants sorted these separately, emphasizing with statement 63 the emotional toll of controlling diabetes. Here the cluster map accentuates the importance of understanding emotional stressors as challenges to diabetes management.

Finally, in concept mapping, “regions of meaning” can also be interpreted as a means of developing relevant strategies for action based on the research (Kane & Trochim, 2007). As Ridings et al. described in their use of concept mapping to build a Latino health programme, “Regions of meaning emerge inductively as participants recognize logical cluster groups and are identified by examining gaps in the
map (white spaces). These regions enhance the overall interpretability of the concept map.” (Ridings et al., 2008, p. 42). Marie Gaudet noted that the underlying method of Concept Mapping is “foreign/western” in its conceptualization but it can be re-shaped or moulded into a representation that reflects “the culture.” One final overall observation of the cluster map may be made with the medicine wheel in mind. In the teachings of the medicine wheel, emphasis is on balance and harmony, equal distribution of elements knowledge or experience within each of its four parts, and the interconnectedness and interdependence of these parts. The cluster map as a whole expresses imbalance in the overall experience with diabetes where much of life is occupied with physical challenges, emotional stress, and fears in the overall southern region of the map. It also suggests specific points where adjustments need to be made to bring this experience into balance through culture and ceremony and community wellness, located together in the north-eastern quadrant of the map. In this framework, these two broader groupings of the clusters may be viewed as regions of meaning in this map.

A Closer Look at Each Cluster and the Agreement Rating

Distinctions between the clusters are as important as the relationships between them. In this section, the features of each cluster are summarized. As noted earlier, clusters are formed based on the frequency with which participants sorted statements in similar ways. The closeness of the statements to each other within each cluster measures this frequency. The farther points are from each other within the cluster, the less frequently they were sorted together and vice-versa. The closer points are to each other within the cluster the more similar they are in meaning to each other (Concept Systems 2002). Hence, more tightly clustered themes, such as Culture and Ceremony indicate that the participants in the sorting exercise put these statements together most often. The fact that the Diabetes Management Challenges is a large cluster reflects the diversity of the participants’ views and experiences with the ideas expressed in these statements. The information in this analysis is thus very important for practitioners and policy makers to consider, as it may be quite different from their views and expectations of persons living with diabetes.

In this section, we also discuss the way each cluster was rated by participants, as shown in the second cluster map below (Cluster Map 2). This map is the same as Cluster Map 1 above with the exception that each cluster shows the levels to which participants agreed with the statements collectively gathered within the cluster. This is indicated by the thickness of each cluster which corresponds to the rating question, “How strongly do you agree with the statement?” which participants were asked to rate on a scale of 1-5 as described in the methods section of this report. The numbers of the statements have been removed in this map to make it clearer to see. Taken together with the refined analysis using the quantitative software, discussed below, this rating information provides additional insights on how the findings of this research may be prioritized in the application of recommended actions.
This cluster as a whole was the most highly rated by participants, indicated by the five-layer thickness of the cluster in the map, and an overall average rating of 3.8/5. Nine of the seventy-nine statements were sorted in this cluster very closely together, indicating similarity in the participants’ understanding of where the ideas these statements fall together (Table 1). The statement 47, “We need more positive collaboration among Aboriginal peoples and mainstream knowledge about diabetes” falls near the centre of the cluster suggesting its relationship to almost all the surrounding statements. The statements within the cluster may also be further categorized into two additional groupings (see Cluster Map 1). In the first one are statements that speak to the learning and helpfulness aspects of ceremony and culture (49, 50, 48, 51). Statement 53 may also fall within this group even though it is a bit more distant from the others indicating that fewer people found similarity of these with the others. This difference is negligible given the overall tightness of this cluster. A second grouping (47, 52, and 35) reflect on how the past and relations between Aboriginal and non-Aboriginal people may play a role in understanding diabetes. Statement 56, only slightly more distant relates along with statement 47 to a need for greater dialogue and openness of discussion of diabetes.
Table 1: Culture and Ceremony Statements by Number

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>56</td>
<td>Our people need to talk more about how to care for ourselves and be responsible for our own health and healing.</td>
</tr>
<tr>
<td>47</td>
<td>We need more positive collaboration among Aboriginal peoples and mainstream knowledge about diabetes.</td>
</tr>
<tr>
<td>49</td>
<td>The support and companionship of sharing circles for groups of people living with diabetes are helpful.</td>
</tr>
<tr>
<td>53</td>
<td>Our cultural teachings like the Medicine Wheel (balancing physical, mental, emotional and spiritual wellbeing) can help us.</td>
</tr>
<tr>
<td>50</td>
<td>Learning about Aboriginal culture helps me and our communities to overcome diabetes.</td>
</tr>
<tr>
<td>48</td>
<td>Traditional ceremonies, such as smudging and the sweat lodge, helps me feel calmer and manage my diabetes.</td>
</tr>
<tr>
<td>52</td>
<td>Diabetes is a spiritual wound of our people that has not been dealt with.</td>
</tr>
<tr>
<td>35</td>
<td>I think the difficulties that our ancestors faced, such as residential schools, play a part in diabetes.</td>
</tr>
<tr>
<td>51</td>
<td>I have received help from seeing Elders and traditional counsellors about my diabetes.</td>
</tr>
</tbody>
</table>

At 4.4/5, the most highly rated statement within the context of this cluster was number 56, “Our people need to talk more about how to care for ourselves and be responsible for our own health and healing.” This further emphasizes what we reported above about the importance participants accorded to the value of having opportunities to share their frustrations, experiences, insights, and learn from other persons with diabetes. It is significant that this highly rated statement was sorted within this grouping of cultural and ceremonial ideas, that it focused on both collective and personal responsibility for health and healing, and situates diabetes within the broader value of openness about health needs. This provides some very specific ideas about how to frame the most appropriate approach to take action on this finding.

*Recommendation: Programming aimed at Aboriginal persons with diabetes should be framed within cultural approaches that speak to both collective and personal responsibility for health and healing, and which situate diabetes in relation to broader health concerns.*

In reviewing the cluster map, members of the Anishnawbe Health Diabetes Education Team commented that they have the greatest success when culture is a prominent aspect of their work, noting that there is a higher level of comfort among their participants who also come in greater numbers. Although this cluster was highly rated overall, there are important areas of variation in the ways participants rated individual statements. A deeper understanding of the rating of statements within this cluster is helped by the quantitative analysis detailed below.

- **Community Wellness**

Community Wellness was the next highest rated cluster in terms of overall average agreement with the statements within this cluster (3.75/5 average overall). It included ten of the seventy-nine statements (Table 2), although they were more dispersed than those within the Culture and Ceremony cluster (see Cluster Map 1). It is therefore difficult to speak of the similarity in meaning among sub-regions of statements within this cluster.
Table 2: Community Wellness Statements by Number

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>65</td>
<td>The first step to living healthy is accepting that I have diabetes.</td>
</tr>
<tr>
<td>37</td>
<td>I want to pass on good habits to future generations by being a good role model.</td>
</tr>
<tr>
<td>44</td>
<td>I am worried about the prevalence of diabetes in our communities.</td>
</tr>
<tr>
<td>43</td>
<td>I have found diabetes educational workshops helpful.</td>
</tr>
<tr>
<td>74</td>
<td>Prayer has helped me to be calmer.</td>
</tr>
<tr>
<td>69</td>
<td>I need to find a way to express my feelings in a way that is healthy.</td>
</tr>
<tr>
<td>68</td>
<td>Diabetes has helped me revaluate my lifestyle and change my life for the better.</td>
</tr>
<tr>
<td>72</td>
<td>I find volunteering and getting out in the community helps me manage my diabetes.</td>
</tr>
<tr>
<td>41</td>
<td>I learn from the younger generations about how to take care of myself and live in a good way.</td>
</tr>
<tr>
<td>36</td>
<td>I don’t want my family members, friends or co-workers to know I have diabetes.</td>
</tr>
</tbody>
</table>

Statements 37, 43, and 41 form a small but significant grouping, which focuses on the value of diabetes education, passing on good habits to future generations, and learning from younger people. That these statements were sorted in close proximity to each other in the theme of community wellness suggests an emphasis on the integration of family and intergenerational learning in Aboriginal community wellness.

Recommendation: Diabetes education programming should try to integrate family and intergenerational learning opportunities, as well as open spaces for youth to be heard with regards to diabetes within the Aboriginal community.

The location of statement 68, “Diabetes has helped me revaluate my lifestyle and change my life for the better,” at the center of the cluster suggests that this perspective may be central to understanding the role of diabetes in community wellness. Throughout this research project and in review of the results, Governing Circle member Pauline Shirt reminded us of the importance of recognizing and understanding the spirit of diabetes. As she explained, disease can be a teaching tool and not a death sentence; every experience teaches us something. Disease represents humans being out of balance with the way to live with creation. For example, in the past it was the job of Elders to make sure everyone ate and that the distribution of food was balanced; that we followed the calendar of nature to gather our foods and to take care of the earth including feeding the spirits to keep all in balance. This flow and the roles of Elders has been disrupted, but there are still people who follow these ways, who are respectful of living this way of life, and it is possible to approach life from this perspective no matter where one lives now, as Jake Ago Neh also stated. As described at the beginning of this report with regards to the name of this project Kina go Gmushkiimnaan, the knowledge and all we need to take care of diabetes is there for the people to use and to take care of this disease.

Recommendation: Diabetes programming aimed at helping people to manage diabetes through lifestyle change should balance the diverse needs, knowledge, social circumstances, and relationships individuals have to living with diabetes with the appropriate supports and structures which community can provide.

The remaining statements that form the edges of this cluster, numbers 65, 44, 74, 69, 72 and 36 speak to the diverse dimensions of diabetes in community wellness. These statements integrate personal factors such as prayer, acceptance, expression of feelings, and privacy surrounding diabetes status, with collective concerns that include the high prevalence of diabetes in Aboriginal communities and the value of community service. The highest rated statement was number 65 (average: 4.36/5), “The first step to living healthy is accepting that I have diabetes.” Acceptance requires personal and community effort in
unison. More detail gleaned from the quantitative analysis regarding these statements, which revolve around acceptance and denial, and further recommendations are discussed below.

- **Challenges to Healthy Eating**

As shown by the thickness of the cluster, Challenges to Healthy Eating is another group of statements rated in high agreement by the participants (3.74/5 average overall). Interestingly, six of the eight statements in this cluster (numbers 22, 18, 23, 26, 21, and 19) form a tighter group along its south-eastern edge, with two outliers (numbers 1 and 9) pulling the cluster toward the north and west of the map (see Cluster Map 1). The six statements closer to each other might be described as social and physical challenges to healthy eating. They include issues such as the time commitment and complexity perceived as necessary to cook at home and eat healthy or to stay on a diet. Reasons participants agreed these were challenges included busy or uncooperative family life, the marketing pressures stores place on shoppers to impulse buy, deceptive labelling of products, as well as issues with transportation and physical disabilities (see Table 3).

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>I feel better if I eat healthy foods</td>
</tr>
<tr>
<td>1</td>
<td>It is expensive to live a healthy lifestyle and manage diabetes.</td>
</tr>
<tr>
<td>9</td>
<td>I would like to be able to manage my diabetes naturally without medication.</td>
</tr>
<tr>
<td>23</td>
<td>Healthy cooking and eating is difficult and requires extra time.</td>
</tr>
<tr>
<td>21</td>
<td>It is hard to avoid processed foods and things like salt, flour, sugar, milk, lard.</td>
</tr>
<tr>
<td>19</td>
<td>It is difficult to maintain a diet for more than a couple of weeks.</td>
</tr>
<tr>
<td>18</td>
<td>It is difficult to maintain a diabetes diet when my family doesn't want to eat what I have to eat.</td>
</tr>
<tr>
<td>26</td>
<td>I have trouble reading all the labels on food packages.</td>
</tr>
</tbody>
</table>

Participants who came to review the concept map clusters on December 9 talked about the gap between the information provided by dieticians or doctors and the challenges of being able to apply this information. The information can be overwhelming, and while there may be tools available to translate complex food labels information into a balanced day of meals appropriate to manage diabetes, these were often not provided. Dr. Shah also commented on problems with conveying biomedical knowledge about diabetes to patients and that is helpful for physicians to use visual aids and take the time to explain what is going on in the body. As he said, people can rattle off data about diabetes but connections are rarely made.

Several participants shared that their visits with their doctors were infrequent and detached. There is little to no follow up on the information provided in doctors’ visits, which are also often too short for the full discussion the patient would like to have about the range of complex issues going on with diabetes, physically but also emotionally, mentally, and spiritually, all of which impact healthy eating. At the same meeting, other participants shared positive results of their successful adaptations to healthy eating through participation in community programmes such as AHT’s cooking classes and other diabetes education programmes. These included losing considerable weight, learning appropriate portion sizes, and switching from drinking pop to water and tea. Importantly, these successes were framed in relation to Aboriginal family and cultural motivators. Jake Ago Neh emphasized that we need to set examples for our children and grandchildren if we want the next generation to be healthy. One male participant shared how he remained focused on healthy eating by thinking about how important it is to him to be there for his children, and to see them grow into adults and the children they will have. Another
participant related in this discussion that it was only in the wholistic approach of the diabetes education and cooking classes at AHT that she had heard a discussion about connections to emotional health.

Statement number 22, “I feel better if I eat healthy foods,” ranked the highest in agreement on average (4.33/5) within this cluster. This may seem to be an obvious statement but its placement within a cluster largely focused on challenges speaks to the fact that Aboriginal people with diabetes often know what they need to do to manage diabetes but face these specific barriers to meeting these needs. Finally, the two more distant statements within this cluster, number 9, “I would like to be able to manage my diabetes naturally without medication,” and number 1, “It is expensive to live a healthy lifestyle and manage diabetes” are complex and may be understood on numerous levels. Further analyses of these statements using quantitative analysis are discussed with detailed reference to engagement with our Governing Circle and participants’ input below.

- **Wholistic Fear**

The next highest rated cluster was Wholistic Fear with an average agreement rate of 3.46 on the scale of 5. This cluster contains thirteen statements, many of which contain the word fear (see Table 4).

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>I am concerned about the effect of diabetes on my eyesight.</td>
</tr>
<tr>
<td>17</td>
<td>I fear losing body parts.</td>
</tr>
<tr>
<td>39</td>
<td>I am aware of my body and how it feels.</td>
</tr>
<tr>
<td>7</td>
<td>I fear having to go on dialysis.</td>
</tr>
<tr>
<td>66</td>
<td>I fear dying of complications from diabetes.</td>
</tr>
<tr>
<td>15</td>
<td>I fear having a heart attack.</td>
</tr>
<tr>
<td>30</td>
<td>I get frustrated because I can't lose the weight.</td>
</tr>
<tr>
<td>16</td>
<td>Recurring infections upset me.</td>
</tr>
<tr>
<td>59</td>
<td>Diabetes is like an addiction.</td>
</tr>
<tr>
<td>11</td>
<td>I feel my body deteriorating.</td>
</tr>
<tr>
<td>13</td>
<td>I tend to ignore pain or dissociate myself from it.</td>
</tr>
<tr>
<td>33</td>
<td>I don't feel physically able to exercise.</td>
</tr>
<tr>
<td>58</td>
<td>I feel possessed by food.</td>
</tr>
</tbody>
</table>

The team felt it was important to contextualize the fears represented in this cluster as wholistic in order to connect the emotion fear with the physical, mental, and spiritual dimensions of the trepidation collectively expressed within this cluster. As shown by the way several statements (66, 59, 17, 13, 11, 15, and 7) cluster along the eastern edge of this group (see Cluster Map 1) their common meaning does not necessarily revolve strictly around fears related to the physical impacts of diabetes on the body. Fears of dying, loss, and deterioration stem from the impact of diabetes on the body, but prevention of complications may best be addressed through a wholistic approach that considers the emotional, spiritual, and mental aspects of the fears associated with physical impacts of the disease. Participants discussed the idea that diabetes operates like an addiction; that it is difficult to maintain the will-power to resist high-sugar foods, smoking or alcohol. Similarly to other types of addiction, some participants stated that people with diabetes are aware that these forms of consumption were likely to compound and quicken the speed with which they may suffer from complications from diabetes. The fellowship of groups like Alcoholic Anonymous (AA) go a long way to soothe the fears and loneliness of addiction to which some participants’ likened diabetes. Therefore, the value they would find in the type of support groups and networks called for elsewhere in this report were spoken of along these lines for some.
Four statements (16, 14, 33, and 39) are not as closely related to each other or other statements within the cluster, although they each speak to the emotional or other impacts of physical impairment or self-awareness of the body. Statement number 14, for example, “I am concerned about the effect of diabetes on my eyesight,” was rated the highest at 4.24/5 of all the statements in this cluster. This may be because of the host of fears that come with the loss of eyesight such as loss of independence or the ability to work. These four statements highlight different wholistic consequences of the impact of diabetes on the body that may be manifest in fears of the unknown.

**Recommendation:** Prevention of diabetes should be addressed within a wholistic approach that takes into account the emotional, spiritual, and mental aspects, including the fears associated with physical impacts of the disease.

Statements number 58 and 30 are in proximity to each other within this cluster. With food and weight loss as their topics, it is important to consider why these statements were most frequently sorted by participants within this cluster that revolves around fears. Together they are also close to the adjacent cluster, Emotional Stressors, suggesting a link between stress, (over)eating, and frustrations with the inability to lose weight. This was clarified by participants who reviewed the results of the research, and who spoke of how diabetes can be such an abstract thing that it may be easier to deny longer term effects for short term desires like eating a candy bar. As noted above, with regards to frustrations with the complexity of understanding misleading food labels one might believe they are consuming the right foods only to find out this is not the case. For example, one participant shared how she was enticed to purchase food labelled “no added sugar” under the assumption it would be an acceptable diabetic diet food. Fortunately, she asked the cashier at the store to help her understand the label details and discovered that the naturally occurring sugars in the product were very high so she did not buy it. Experiences like this can heighten fears about not really knowing what is actually in food and what it does to the body, which in turn impedes the management of diabetes.

**Recommendation:** More needs to be done to provide tools to help diminish fears and frustrations associated with food choices and weight loss. These tools must be tested and utilized in applied and/or programmatically organized situations so that people can make the best use of them, and information can be shared in a bi-directional way with practitioners. This way, persons with diabetes and the health professionals who help them can learn together about what is and is not working and adjust strategies in collaboration.

**Diabetes Management Challenges**

This cluster contains the highest number of statements (see Table 5), although its thickness indicates it was of average importance to the participants in this study who rated their agreement with the statements in this group (3.29/5). The points are also quite dispersed and distributed throughout this cluster (see Cluster Map 1). Nonetheless, a small grouping of statements (20, 25, 28, and 10) gather at the south-western side of the cluster. These statements were most frequently sorted together but they varied considerably in terms of the rate at which participants agreed with them. Statement number 20, “I need to be more conscious of what I eat, when I eat, and what it does to my body,” was rated highest at 4.21/5, while statement 10 having to do with keeping track of taking medications was rated at 2.62/5, indicating that this statement perhaps applied to fewer participants. Statements 25, “Staying away from junk food to better manage my diabetes is difficult,” and 28, “I have difficulty eating smaller portions of food” are more consistent with statement 20. These are close to, but did not fall within, the neighbouring cluster Challenges to Healthy Eating. This is most likely because they more directly address
connections between food and diabetes management and reflect that participants’ have relatively good knowledge of these connections.

Table 5: Diabetes Management Statements by Number

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>I need to be more conscious of what I eat, when I eat, and what it does to my body.</td>
</tr>
<tr>
<td>34</td>
<td>I find walking and exercise help me manage my diabetes.</td>
</tr>
<tr>
<td>8</td>
<td>I am concerned about the negative side effects of diabetes medication.</td>
</tr>
<tr>
<td>31</td>
<td>A routine or plan helps me to exercise, eat better, and feel less stressed.</td>
</tr>
<tr>
<td>62</td>
<td>It is difficult to change the habits I have acquired throughout my life.</td>
</tr>
<tr>
<td>25</td>
<td>Staying away from junk food to better manage my diabetes is difficult.</td>
</tr>
<tr>
<td>46</td>
<td>Societal changes like the increased influence of television and computer have negatively influenced my activity levels and eating habits.</td>
</tr>
<tr>
<td>40</td>
<td>It is difficult to slow down and do what I need to do to manage my diabetes.</td>
</tr>
<tr>
<td>6</td>
<td>Dealing with needles and taking injections is a challenge.</td>
</tr>
<tr>
<td>28</td>
<td>I have difficulty eating smaller portions of food.</td>
</tr>
<tr>
<td>45</td>
<td>Living in the city negatively impacts my eating and activity habits.</td>
</tr>
<tr>
<td>27</td>
<td>I have late night snack or meals and then feel very tired the next morning.</td>
</tr>
<tr>
<td>29</td>
<td>I find myself needing to eat all the time to maintain my sugar levels.</td>
</tr>
<tr>
<td>24</td>
<td>I find I always feel hungry.</td>
</tr>
<tr>
<td>32</td>
<td>I do strenuous exercise which causes my blood sugar to drop.</td>
</tr>
<tr>
<td>10</td>
<td>I find it difficult to keep track of all the pills I have to take or take my medication properly.</td>
</tr>
<tr>
<td>12</td>
<td>I don’t check my blood sugar because it hurts my fingers.</td>
</tr>
</tbody>
</table>

Statements 6, 29, 32, and 34 are not as closely positioned to other statements as others. Number 6, “Dealing with needles and taking injections is a challenge,” like number 10 above, may simply have not applied to a greater number of participants in this study. Statements 29, 32 and 34 are located near the center of the cluster and speak to understanding among the participants of the connection between exercise, food and blood sugar levels. Statements 31, 45 and 46 in the north-western corner of the cluster center on activity levels. Again, their situation within this cluster indicates that participants are aware that exercise or inactivity impact diabetes management. Some of these statements are discussed in greater detail in connection with the quantitative analysis below. Number 31, for example, “a routine or plan helps me to exercise, eat better, and feel less stressed,” was highly rated with an average 4.21/5 and receives further attention in that discussion. Statements 62 and 40 located together in the north-eastern section of the cluster raise the difficulties of changing lifelong habits and doing “what I need to do to manage my diabetes.”

Recommendation: Recognize and acknowledge the comprehensive knowledge that Aboriginal people with diabetes have of their condition and what is needed to manage diabetes in terms of the broader emotional issues and other challenges that impede them from carrying out what they know they need to do.

Although statements numbers 8 and 12 were sorted most frequently together, they were rated differently by participants. Statement number 12, “I don’t check my blood sugar because it hurts my fingers” was rated low on the agreement scale by participants (2.49/5) although it is difficult to know if this is because they check their blood sugar regularly without problems, or if they don’t check their blood sugar for reasons other than the one in the statement. Statement number 8, on the other hand, “I am concerned about the negative side effects of diabetes medication,” was rated near the top of the scale at 3.76/5 on average. The quantitative analysis also shows that this statement was largely agreed with by the participants with almost 60% very much or completely agreeing, suggesting the
recommendation that health practitioners should do more to explain diabetes medications and their side effects more fully and in light of the concerns of their patients.

Finally statements 27 and 24, near the center of the cluster also suggest an area where health care providers and diabetes educators might focus more information in a practical way on the best ways to understand how different foods impact diabetes management, as outlined under the Wholistic Fears cluster above. Information about how hunger and fatigue paired with practical observations made by persons with diabetes as part of a programme that tracks change over time may lead to improved diabetes management.

- **Emotional Stressors**

This cluster includes 14 of the 79 statements (see Table 6) and was rated as a whole at a slightly lower average level of agreement by participants (3.25/5) and appears less thick than the other clusters discussed so far. In terms of significant regions of relationships within the cluster, there are two clear groupings (see Cluster Map 1). One, on the western side of the cluster includes statements 67, 63, 71, 64, 70, and 76, which highlight where participants saw their greatest struggles and barriers. These statements speak to the isolation and loneliness of having diabetes, the futility one can feel in struggling to control diabetes and conform to social expectations of others who do not have diabetes, and of the obstacles that may only be removed by individuals themselves.

Table 6: Emotional Stressors Statements by Number

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>67</td>
<td>Maintaining hope and a positive outlook is important in managing my diabetes.</td>
</tr>
<tr>
<td>79</td>
<td>I think diabetes can lead to depression.</td>
</tr>
<tr>
<td>38</td>
<td>I fear leaving my family or loved ones behind.</td>
</tr>
<tr>
<td>63</td>
<td>I wish I could find ways to control my diabetes instead of my diabetes controlling me.</td>
</tr>
<tr>
<td>71</td>
<td>It is important not to be alone or isolated as I manage my diabetes.</td>
</tr>
<tr>
<td>75</td>
<td>The additional stresses of everyday life make it harder for me to control my diabetes.</td>
</tr>
<tr>
<td>57</td>
<td>I use food to comfort myself or suppress feelings.</td>
</tr>
<tr>
<td>61</td>
<td>I am my worst enemy because I sabotage myself.</td>
</tr>
<tr>
<td>64</td>
<td>I am not being serious about managing my diabetes.</td>
</tr>
<tr>
<td>73</td>
<td>I worry that my depression may make me give up on managing my diabetes.</td>
</tr>
<tr>
<td>70</td>
<td>I struggle to keep up or compete with others who do not have to manage diabetic symptoms.</td>
</tr>
<tr>
<td>60</td>
<td>I was or am in denial about having diabetes.</td>
</tr>
<tr>
<td>78</td>
<td>I feel hopeless in being able to control my diabetes.</td>
</tr>
<tr>
<td>76</td>
<td>Alcohol and/or drugs are a major obstacle to managing my diabetes.</td>
</tr>
</tbody>
</table>

On the eastern side of the cluster, self-sabotage, denial, hopelessness, suppressing feelings, depression, worrying about leaving loved ones behind and everyday stressors are themes that impede management of diabetes. On the whole, the rating of these statements indicate that an important number of participants did not relate to these experiences, or at the very least they see within themselves the courage and capacity to overcome these emotional stressors. This is revealed by the fact that statement 67, “Maintaining hope and a positive outlook is important in managing my diabetes,” rated most highly among the statements on average (4.13/5). Further discussion of this is found in the quantitative analysis section below.

Recommendations: It is important to recognize the courage and capacity of Aboriginal community members with diabetes and find ways to encourage hope and a positive outlook. A peer support system may be a way to bring individuals together with mutual benefit, and on a smaller more private level than
the sharing circles also recommended in this report. Stress reduction should be an integral part of the health care of persons living with diabetes. Culture-based approaches that are wholistic in nature should foreground efforts to address stress reduction.

- **Frustrations with Western Medicine**

Participants agreed the least overall with the statements that fell within the cluster, Frustrations with Western Medicine. Only one level of thickness can be perceived on the map for this cluster rated at 2.86/5. The cluster includes 8 of the 79 statements, which are generally dispersed within the cluster (see Table 7 and Cluster Map 1). Statements 2, 3, 4 and 5 can be examined together as these generally denote negative relations with Western medical practitioners or the mainstream health care system. While still separated by some distance, statements 42, 77, 54, and 55 voice broader interpersonal frustrations. Statements 54 and 77 deal directly with western medicine, in one instance decidedly favouring traditional medicines to western forms, and in the other noting that personal frustrations interfere with the potential of western medicine to help.

**Table 7: Frustrations with Western Medicine Statements by Number**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>42</td>
<td>I wish someone had taught me how to cook and eat properly before I got diabetes.</td>
</tr>
<tr>
<td>55</td>
<td>When I was growing up I wasn't able to talk about my feelings and I think that had an impact on stress and getting diabetes..</td>
</tr>
<tr>
<td>2</td>
<td>The health care system is unable to provide adequate care for persons with diabetes.</td>
</tr>
<tr>
<td>5</td>
<td>Doctors seem more concerned with collecting patient statistics and giving out medication than they do with helping.</td>
</tr>
<tr>
<td>54</td>
<td>Traditional medicines have helped me more than medicines from the medical doctor.</td>
</tr>
<tr>
<td>4</td>
<td>I feel doctors and others judge and blame me for getting diabetes.</td>
</tr>
<tr>
<td>3</td>
<td>I am angry my doctor did not catch my diabetes earlier.</td>
</tr>
<tr>
<td>77</td>
<td>My own anger and bitterness prevent my doctor from helping me.</td>
</tr>
</tbody>
</table>

Statements 42 and 55 suggest that past outside forces, perhaps influences of broader mainstream society prevent the individual from acquiring skills - cooking, eating properly, expressing feelings - needed to manage diabetes, or which may have helped prevent diabetes in the first place. Some context from the brainstorming sessions from which these statements arose may help clarify. In some instances, for example, participants shared that being raised in foster care, residential school, or adoption into non-Aboriginal families were the environmental factors that contributed to not acquiring these skills. The quantitative analysis below examines the rating of some of the individual statements within this cluster with greater attention as they raise interesting questions. Recommendations based on statements in this cluster are included there.

**Concept Mapping Summary**

Overall, the results of Concept Mapping used in this research provide insights from and for Aboriginal persons living with diabetes, as well as for service providers and policy-makers. Interpretation of the maps in relation to Indigenous knowledge frameworks enhanced the value of the information this method provided. This also allowed for the inter-relatedness aspect that is central to Concept Mapping to be clarified in relation to the wholistic principles emphasized throughout this report and in relation to the other methods used. The cluster maps show that Culture and Ceremony were not only highly rated by participants but that participants share some common understanding of their meaning. Culture and Ceremony are the location of frameworks that are self-affirming, supportive, intergenerational, and
interpersonal, and are central to community wellness, where the integration of family learning was described. In particular, culture and ceremony as described in this section signal the importance participants accorded throughout this research to the value of having culturally-safe opportunities to share frustrations, experiences, insights, and learn from others with diabetes. Community wellness was the location of an important statement which talked about the ways diabetes may provide an opportunity for individuals, but also the community, to re-evaluate life and change for the better, by understanding from the Aboriginal perspective how disease can be a teacher. Acceptance of diabetes as both personal and community effort was also a highlight of this cluster. Finally, Culture and Ceremony equip individuals with tools to enable them to use western medicine to its most productive potential, by situating it in a wholistic manner to one’s overall well-being, and emphasizing self-determination, balance, and responsibility.

Diabetes Management Challenges identified by the participants in this study represented a great deal of diversity. This cluster also demonstrated that participants already have a wide range of substantial knowledge about what they need to do to manage their diabetes, which further emphasizes the need to pay attention to the connections participants made between the challenges they identified and emotional stressors such as isolation, loneliness, and futility, as well as wholistic fears, and barriers to healthy eating. It was in discussions of healthy eating, for example, that participants elaborated on the detached relationship they have with their medical doctors, as well as with dieticians and diabetes educators in general, because there is little to no follow-up in terms of concrete actions with the information they receive during this contact. Successes observed by participants through programmes such as AHT’s cooking classes were noted through discussions of the results of the Concept Mapping, and emphasized again how these successes were framed by Aboriginal cultural and family motivators. Many of the fears identified by participants were verbalized around physical complications from diabetes, but the concept map again emphasizes that these may be best addressed through attention to the emotional, spiritual and mental aspects of the fears associated with the physical. Fears around food choices, for example, were cause for considerable anxiety among some participants. Participants identified a wide variety of stressors through this method; however, it also enabled us to see that Aboriginal persons with diabetes see within themselves the capacity to cope as individuals partnered with the service providers who are there to help them, and with other community members. There is imbalance in the overall experience with diabetes; however, this method also provides specific points where readjustment can bring the lives of Aboriginal persons with diabetes back into alignment.
Quantitative Analysis with the Statistical Package for the Social Sciences (SPSS)

Further quantitative analysis was conducted with a computer programme called SPSS. It is recognized that this research did not obtain a random sample of Aboriginal people living in Toronto who have diabetes; therefore any quantitative analysis needs to be interpreted in this light. Typically, the Canada Census list would be used to obtain a truly random sample, based on the assumption that everyone completes the census. Most research conducted in Toronto with the Aboriginal community is not based on such a random sample. Even using the Canada Census to obtain a random sample is limiting because of the inaccurate representation of Aboriginal people who complete the census. Recognizing this limitation the statistical analysis did not include any comparisons between groups, such as differences in responses between males, females and two-spirited. Rather, simple descriptive statistics were obtained to more closely observe the responses to the 79 statements. We focused on the responses to whether or not participants agreed with the statement. Reported below are statements that stood out for the research team as being significant to share and those that did not duplicate the findings reported for Concept Mapping. Full report of these demographic statistics is not included in the appendix because of the size of the document. The full report can be obtained by contacting Anishnawbe Health Toronto.

Ceremony and Culture

The importance of culture and ceremony was identified through many of the statements made by the participants. As noted in the Concept Mapping, for the most part participants strongly agreed that culture and ceremony was important in living with and managing diabetes. All these relationships were positively skewed, meaning there was a gradual incline along the continuum with more people scoring completely as a rating. For instance, participants strongly agreed with the following statements related to the importance of culture in living with and managing diabetes:

- Traditional ceremonies, such as smudging and the sweat lodge helps me feel calmer and manage my diabetes (statement #48)
- Learning about Aboriginal culture can help our communities overcome diabetes (statement #50)
- Our cultural teachings like the Medicine Wheel (balancing physical, mental, emotional and spiritual wellbeing) can help us live well and manage our diabetes (statement #53)
However, when asked if participants have received help from seeing Elders and Traditional counsellors about their diabetes (statement #51) the relationship of agreeing with the statement shifted. The relationship was no longer positively skewed but was tri-modal with peaks (not at all, somewhat, and completely) and valleys (not applicable, slightly and very much). While 38.2% either completely or very much agreed with the statement, 26% somewhat agreed and approximately 23.6% did not agree at all with this statement and 2.4% felt the statement was not applicable to them. The response to the statement whether Traditional medicines have helped more than medicines from the medical doctor (statement #54) had a similar response.

Governing Circle member Brian Marion shed some light on how this discrepancy might be interpreted. Brian had diabetes and stated that for the longest time he was in denial about his diabetes until he became an amputee, several years before his passing to the spirit world at the time of the writing of this report. He struggled with significant pain and recurring infections. Brian was a traditional man and participated in ceremony. He credited his endurance and persistence in living to his engagement in ceremony and prayer when he said, “I am still alive” in a feedback session with a member of the research team. While his pain was relieved for a short time, he stated it does “re-enter”, but he acknowledged that ceremony and prayer was helpful.

The degree to which someone assesses ceremony or prayer to be helpful may vary. For instance, Brian’s interpretation was that the ceremony was helpful for a short time but someone else may feel that even a short lived reduction in pain is not helpful and subsequently would have rated statement 51 more negatively. Another importance in interpreting this statement is that some participants may not have
had much or any experience seeking help from Elders or Traditional Healers for their diabetes. Some participants, particularly those who were part of the sharing circles in the Region of Peel and Ajax expressed the lack of culturally related and culturally safe services in their area.

Recommendation: To develop a strong outreach service that includes cultural activities, Traditional Healers and Elders.

Colonial Influence

Historical trauma and intergenerational grief are often cited as contributing to the ill-health of Aboriginal people, arguing that unresolved grief from the extensive “losses of lives, land, and culture from European contact and colonization resulting in a long legacy of chronic trauma contributes to the current social pathology of high rates of suicide, homicide, domestic violence, child abuse, alcoholism and other social problems” (Brave Heart, 1998, p. 56). While little attention has been given to the role of historical trauma in relation to diabetes, a community-based study conducted by the Native Canadian Centre of Toronto found that ruptures in access to and knowledge of traditional nutrition, physical abuse associated with food, starvation, and the regimentation of dining experienced by residential school survivors had a significant impact on their eating patterns, physical activity, and overall health status. These findings were incorporated into a very well-received wholistic diabetes education programme which focused on re-learning positive relationships with food through activities that included Traditional teachings, communal food preparation, and validating residential school survivors’ stories (Howard-Bobiwash 2008, 2004).

Participants were very astute in distinguishing between the importance of culture as noted above with statements 48, 50, 53 being agreed upon by many and the relationship of colonial influence on the current health status of Aboriginal peoples not being as agreeably. Participants were asked if they thought the difficulties that our ancestors faced, such as residential schools, played a part in diabetes (statement #35) and if they felt diabetes was a spiritual wound of our people that has not been dealt with (statement #52). These two statements, which may be interpreted as dealing with historical trauma, received mixed responses from the participants in this study.

This mixed response could be explained in a variety of ways that is consistent with the diversity of the participants. Some participants may not have experienced nor had family that have been directly impacted by residential schools and subsequently did not link it to diabetes. While completing the rating sheet several participants expressed that they did not agree with the statements because they reflected
living in the past and thinking negatively about life. It may also be that people do not like to hear and deal with horrific past events. However, it is important to have a healthy engagement with the past, coupled with an optimistic view of the future which will always remain informed by our history, whether we know it or not. These are important findings that highlight the need to recognize the diversity of views and experiences of Aboriginal people with diabetes, and to be mindful that some see the negativity of the past as a hindrance to the positive outlook they feel is important to diabetes management.

Recommendation: Service providers developing culturally safe and competent practice should recognize the diversity of views and experiences people have with the past but that it is important to have a healthy engagement with the past coupled with an optimistic view of the future.

Traditional and Western Ways Coming Together

The need for more positive collaboration among Aboriginal peoples and mainstream knowledge about diabetes (statement #47) was one of the most positively agreed with statements with 80.5% very much or completely agreeing. In addition, many of the statements related to the Western health care system, while more negatively rated than statements related to culture and community (as noted in the Concept Mapping), were not rated as highly disagreeing as expected. It is clear that some people have good relationships with Western medicine practitioners and some do not.

For instance, when asked to rate whether participants agreed with the statement, I feel doctors and others judge and blame me for getting diabetes (statement #4), 45.5% completely disagreed with this statement and only 13.8 completely agreed. In addition, 46.3% were not at all angry that their doctor did not catch their diabetes earlier (statement #3). As demonstrated in the two graphs below the relationships are negatively skewed with most rating as ‘not at all’.
However, when asked whether participants felt the health care system was unable to adequately provide for persons with diabetes (statement #2) almost 70% somewhat, very much or completely agreed with this statement. However, this relationship is not positively skewed, rather it is curvilinear with most scoring somewhat.

In addition, participants were asked if they agree that doctors seem more concerned with collecting patient statistics and giving out medication than they do with helping (statement #5), again the response was mixed. Twenty percent did not agree with this statement at all and 20% completely agreed with the statement.
While participants may not be angry or feel judged by the health care system, the majority of participants felt the health care system did not meet their needs, either somewhat, very much or completely. One of the research team members felt that participants might not be blaming their doctors because they feel more individually responsible for their physical state. Even though they are dealing with denial, they “own” said denial. However, they are not in control of what is offered to them in terms of mainstream health care services. After reviewing the results, Governing Circle member, Traditional Healer and counsellor Dolores Esquimaux remarked that we have come such a long way in terms of healing demonstrated by the acceptance of our community of Western and Traditional ways of healing going hand in hand with the traditional way of healing looking wholistically at the mind, body, spirit and emotion. She elaborated that it is very important that we teach the younger generation early so they will learn how to take care of their bodies.

Recommendation: Traditional Healer Pete Keshane expressed the need for Western medicine to work in conjunction with traditional medicine and that it was fine if people did not want to participate in traditional ways. He noted that what is most important is the individual’s health.

Manage Naturally without Medication

Approximately 66% of participants completely or very much agreed that they would like to be able to manage their diabetes naturally without medication (statement #9).
While it may be realistic for those who do not have as severe progression of diabetes or for those who have borderline diabetes, Governing Circle member Brian Marion, stated it was impossible for him to manage his diabetes naturally without medication.

Recommendation: From the perspective of service providers it may be important to recognize that managing diabetes naturally is important. Appropriately planning of the natural management of diabetes without causing harm would be a critical component in the education about diabetes.

Healthy Eating and Physical Activity

As noted in the Concept Mapping, many of the statements made about living with diabetes involved challenges to healthy eating. The most notable positively agreed upon statement was, it is expensive to live a healthy lifestyle and manage diabetes (statement #1). Seventy percent of participants completely or very much agreed with this statement. While this may have been interpreted as purchasing healthy food, it could also be interpreted as being unable to exercise because the statement did not specifically mention food or nutrition.

Governing Circle member Brian Marion agreed with this statement stating it is a hard disease to maintain especially when you cannot afford the good foods. He added that eating healthy was compounded by the fact that his stove was not accessible to him because of his wheelchair.

Recommendations: More food preparation programmes are needed to help people learn how to cook healthy on a budget and for those that use food banks. Although there is a lot of information available about healthy eating, the challenge is to translate knowledge into action. In addition, there are many problems related to outreach, capacity and funding of such programmes.

Many individuals expressed that traditional food at events, such as powwows need to be transformed back into traditional healthy meals. Dr. Shah added that the change of behaviour towards healthy eating also needs to be facilitated in Aboriginal cultural gatherings. Mindful eating should be included in our cultural gatherings.

Some participants indicated they found it hard to maintain their diet for more than a couple of weeks (statement #19). Almost 50% very much or completely agreed with this statement.
**Recommendation:** Flowing from this finding in conjunction with other statements related to healthy eating is that Aboriginal people with diabetes should have frequent access to dieticians and/or weight loss specialists whereby regular check-ins can continually monitor progress and keep people on track.

While just over 60% of participants expressed that they very much or completely agree that walking and exercise help manage diabetes (statement #34), almost 35% very much or completely agreed that they felt physically incapable of exercising (statement #33). Further, 50% of participants somewhat, very much or completely agreed that when they do strenuous exercise their blood sugar drops (statement #32).
Finally, a whopping 77% somewhat, very much or completely agreed that having a routine or plan helps with exercise, eating healthy and feeling less stressed (statement #31).

**Recommendation:** Taking all the above factors related to eating healthy and trying to be physical active and the emphasis that having a routine or plan helps, a strong recommendation of this report is to support wholistic programmes for Aboriginal people that provide on-going support, guidance, and education.

This recommendation also comes from the consultations with the Traditional Healers. For instance, Pete Keshane noted that there are few Aboriginal specific or culturally related physical activity programmes in Toronto. He mentioned that in some communities there are jogging tracks and people regularly walk or jog the track to maintain health. There is little to support Aboriginal specific physical activity and weight loss in the greater Toronto area. Pete went on to further note that such a programme could be wholistic, incorporating culture, traditional healing and medicine, healthy eating, and emotional support. He emphasized that diabetes is the illness but there is something much more deep; things such as identity and loss of culture. Therefore programmes need to stop focusing on the disease itself and take a more wholistic approach. Pete noted that when done in a group setting such a programme could create peer support. With regular check-ins (weekly or monthly) issues can be further explored in more depth about what and why people are eating the way they are. Blood sugar could be monitored along with eating habits, physical activity and stressors that may cause people to lose focus.

**Recommendation:** Walking and exercise help manage diabetes; however there are many obstacles to being physically active. More needs to be done to develop and maintain physical activity programs that are wholistic in approach and adapted to the varying degrees of ability of persons with diabetes. One-on-one instruction and support would be beneficial to allow individuals to cater their physical activity within their own limitations.

**Denial, Acceptance, and Self-Responsibility**

Denial, acceptance, and self-responsibility were themes that emerged from the sharing circles. When asked if participants were, or are, in denial about having diabetes (statement 60) 46% stated not at all or slightly and 34% completely or very much agreed they were or are in denial. In contrast, almost 80% completely or very much agreed that the first step to living healthy is accepting that I have diabetes (statement 65). So while people may understand the importance of acceptance, it appears to be more easily said than done.

**Recommendation:** Service providers should focus on developing programmes aimed at acceptance and denial, recognizing that they are two different constructs that people may understand in very different ways.
Another noteworthy mention with respect to denial is the composition of the participants. As mentioned earlier, the sample of participants was based on voluntary involvement in the project. It is possible that the people who volunteered for this research were not as much in denial as others. The sample included more females than males or two-spirited individuals.

Recommendation: Practitioners and future research may explore questions about denial and other possible reasons males and two-spirited people are not accessing services as frequently as women.

Self-responsibility and sabotaging oneself were two other opposing notions. Participants were asked if they agreed that our people need to talk more about how to care for ourselves and be responsible for our own health and healing (statement 56). Over 81% completely or very much agreed with this statement. However, when asked if “I am my own worst enemy because I sabotage myself” (statement 61), the response was mixed. Twenty-four percent said somewhat, almost 35% very much or completely agreed, and 23.6% slightly agreed or did not agree at all.
Recommendation: People with diabetes and service providers may find it helpful to explore how to build skills related to taking self-responsibility and avoiding sabotage. As recommended by Pete Keshane, a group programme that regularly checks progress and exploring reasons for losing focus may be a way to address self-responsibility and self-sabotage.

Governing Circle member Brian Marion stated he was in denial for a long-time about his diabetes and he saw a lot of people with diabetes but they have not had the complications he had, like amputation. Brian wished that people could learn from him to take self-responsibility, so they do not end up being an amputee like him. That was one of the reasons for his interest in this research project. Peer group programmes may allow for this sharing of knowledge by people who live with the challenges of diabetes.

The service providers who were involved in the consultation process of this research had much to share on the issue of denial and self-responsibility. Teresa Salzmann, Lead of the Diabetes Education Team at Anishnawbe Health Toronto stated that she always reminds people that she is there for them and that it is important to develop trust. When people can trust her and the team they will come and share and that is an important step in accepting diabetes. Teresa quoted the Executive Director of Anishnawbe Health Toronto, Joe Hester, stating that practitioners need to be “consistent and persistent” in order to develop trust with clients.

Dr. Shah agrees that some people do not accept that they have the disease, even after 26 years. But he does not fault them because it is a silent disease. Health is not always our first priority when we consider housing, income and employment issues. Unless people own or accept they have the disease nothing will happen. Acceptance does not mean individuals will change their behaviour. Dr. Shah notes that behaviour change has to come from individual health behaviours rather than a professional insisting on change. The denial aspect to diabetes is that some people will be diagnosed and have a hard time accepting the disease. They will disappear and only reappear in the office when something bad happens.

Finally, another theme related to denial was focusing on the future generations. Through role modelling and even as Brian stated above, learning what not to do is critical to a healthier future generation. To pass and share the knowledge that they know, so others can possibly avoid getting diabetes, but they in turn will be putting themselves out there as supports, in order to help others get through it, and get on a healthy track to manage in a healthy way.
Positive Outlook and Depression

While individuals recognized the importance of a positive outlook, depression seems to have a grip on people who have diabetes. When asked if maintaining hope and positive outlook was important in managing diabetes (statement #67) 72% very much or completely agreed this was important. When asked if participants worried that depression may make them give up on managing diabetes (statement 73), 26% were not at all concerned; however almost 25% were somewhat concerned and almost 36% were very much or completely concerned about depression causing them to give up on managing diabetes.

![Chart 1: Degree of agreement with statement 67](chart1.png)

![Chart 2: Degree of agreement with statement 73](chart2.png)

Recommendation: Emotional stressors including depression need to be incorporated into diabetes education and treatment programmes.

It may be useful to explore what characteristics predispose someone to being depressed because of their diabetes, such as whether they have been successful in avoiding some of the complications of diabetes. Finally, as mentioned by Pete Keshane, programmes for people with diabetes need to take a multi-disciplinary approach. Emotional and spiritual health is just as critical to dealing with the physical aspects of diabetes, like maintaining blood sugar levels. People with diabetes and practitioners must be aware of depression and other emotional issues that may be barriers to successful management of diabetes.

Sharing Circles and Wholistic Programmes

Many of the recommendations thus far point toward wholistic, peer led programmes. When participants were directly asked if the support and companionship of sharing circles for groups of people living with diabetes are helpful (statement #49), almost 75% very much or completely agreed. In our final sharing circle on December 9th the participants shared that the group workshops where instructions are given such as information about blood sugar and proper nutrition were not that helpful because it was not directly applicable to them. They shared that one-on-one instruction on these issues was better in order to cater to the individual differences. However, the sharing circles similar to those used in this research that involved peer sharing, learning and no judgement are beneficial.
As emphasized by Governing Circle member Brian Marion, he hoped that he might entice people to take care of their diabetes when they heard his story. He also stated that when he shared, it was an escape for him from his own processing by seeing how others process the disease. There is a need for people to have the space and freedom to talk amongst others who can relate to what they are going through, creating peer supports, having positive collaboration in a sharing circle where there is no judgment. The research team found that through the course of the project, participants simply wanted to talk. There seemed to be an overwhelming need for people to share their stories. This was sometimes challenging because we were conducting research, not service delivery. However, as required by our ethical guidelines, there was always an Elder on hand, and we referred individuals to the proper resources for help when needed.

Governing Circle member Marie Gaudet shared that circles can be very empowering; they can help people to reverse denial. People are at all different stages and terms with their diabetes, and so if a person could have a venue to talk about how they were in denial it might also support another person in the circle who may not be there yet to think differently about their own situation.
Quantitative Analysis Summary

Exploring the responses to the statements provided valuable insight that lead to important recommendations for a framework for diabetes service planning, but more importantly it provides information for persons with diabetes that may help in processing and managing diabetes.

The quantitative analysis echoes the findings of the Concept Mapping as well as the consultations with the Governing Circle, Traditional Healers and diabetes practitioners. Wholistic programme development that includes, not only the physical challenges to diabetes but focuses on delivery of physical activity, emotional and spiritual supports is critical. Ensuring that culturally relevant programmes are accessible to those not in the downtown core could include visiting Elders and Traditional Healers. In addition, programmes need to be consistent and persistent so that trust can be developed. Finally, programmes need to provide on-going support and guidance.

It is important to recognize the diversity within the Aboriginal population and that trying to involve youth, males, Métis, and two-spirited people requires specific focus. In addition, difference of opinion when it comes to colonialism and its impacts today on individuals and communities should be recognized while at the same time ensuring people have the knowledge of how historic trauma and intergenerational grief impact our people today.
Anishnaabe Symbol-Based Reflection

The symbols produced by the participants told stories about living with and managing diabetes. Some symbols were put together by gathering objects that represented life with diabetes, and as such, were a cross between Anishnaabe Symbol-Based Reflection and Photovoice.

The activities ranged from poetry, to a sacred blanket, medicine wheels made with computer media, canvas paintings and drawings. The symbols depicted the diversity of ways diabetes makes sense to each person, but collectively there are themes, patterns and teachings in each of the images. The stories that accompanied the symbols reflected struggle and in the same breath, self-responsibility, confidence and hope. The stories spoke of feeling alone and needing help while acknowledging the caretakers. As noted by Pauline Shirt, these pictures and the artwork are the participants’ spirits talking. Each symbol shows where each person is on his or her journey. Healer Pete Keshane noted that the symbols represented identity and the spirit of diabetes. He elaborated that the symbols showed the relationship between the spirit of diabetes and the spirit of the individual. Participants’ symbols demonstrated each person was at a different point in their journey. These are their visions and feelings – only that person can know what the spirit is saying to them. This spirit is talking to them, and these pictures really show where they are at in their consciousness. The images tell the story of the spirit. Elder Shirt also noted that there were several images of trees tied this to the cluster map presented earlier. The clusters, like the leaves on trees, are interconnected and represent relationships.

The symbols will be presented without analysis or summary. The participants’ stories have not been altered and appear as were written. This chapter is meant to give voice to the participants and reflect their stories. At the participants’ request some of their real names were used while others remain anonymous.

A Poem - By Nancy Paulwoods

Starts out bad enough
It can escalate into a nightmare
Constant hunger
Constant thirst
It gets worse
Sometimes visited by anger
Try to be more aware
Enough, enough is enough...
Diagnosed with diabetes
What is that?
Never heard of it before...

Have to find out on my own
Nobody would tell me what it is...
Sugar diabetes is what it was called before
Actually, it’s quite a sin
Taking pills then insulin
Talking, walking and exercise
Can help stay healthy and wise
Thing about eating is what I hate
Eating, exercise and losing weight
Food -good food- bad food
Can be the culprit
Catching the sugars in your body
Everything turns to sugar – Sweetness!
I was type 1 right from the beginning in 1987. I was very sick and ended up in the hospital for 3 weeks. The first week I was in and out of consciousness not knowing what was going on. When I became aware of what was going on, I was told that I was diabetic. The nurses were giving me insulin shots daily, first once a day then twice a day. This didn’t fully sink in until I had to give myself my own shots. It was one of the hardest things that I had to do. I couldn’t do it or I didn’t want to do it but by the third week I had to do it. In the beginning I thought that this was just temporary, that one day I wouldn’t have to this, that I would be cured. I quickly learned that I couldn’t eat or drink what I wanted anymore. I couldn’t have the cakes, pies, all the desserts that I loved. I had to cut down on the bread that was a favourite of mine. Alcohol was a no, beer being my drink of choice. Smoking pot was also a vice that I had to quit because it made me eat whatever was on hand. Feeling severely depressed from being diagnosed as a diabetic and from the other things happening in my life, I tried to commit suicide. Being diabetic was the last straw. I was extremely angry and felt there was no hope. I consumed alcohol and a bottle of pills. I couldn’t talk or remember things for about a week. I thought I was to stay this way for the rest of my life. Recovery was long and hard.

I have coped with being diabetic by embracing my culture. I never knew my culture before. One day I went to AHC [Anishnawbe Health Clinic] and met a counsellor that changed my life. She encouraged me in every way so that my self-esteem could grow and I could feel better about myself. Seeing healers, participating in all the ceremonies, going to teachings and living the Traditional way of life has helped me immensely. Eating and exercising will help in managing a healthier and better way of life. I have had eye problems and have gotten laser procedures on both eyes, once in one eye and three times in the other. This was to clean up blood vessels that have burst. HE described it as a sidewalk where the grass grows between cracks and you cut the grass to clean it up. The last time it was done it hurt a lot and I felt physically sick.

I still have to test my blood sugar daily. I still have to give myself insulin shots twice daily, sometimes three times depending if I’m sick or not. It never ends. I still don’t know if I have fully accepted being diabetic even after all this time. I’m still angry but there is so much help and support that eases the burden. I am not alone. I’m still hoping for a cure!!!
**Butterfly and Spiders**  
By Yvonne Caissie-Boyd  

Even though we all are a part of life, each one of us has their own path in life to follow. With diabetes, other medical conditions can arise. Butterflies came from cocoons and spiders built webs but each are unique & beautiful to see.

**Thunderbird (canvas painting)**  
By Michelle Kahnapace  

This picture represents my temple, my Spirit, what I think my bodies Aura looks like; it is a picture of a Thunderbird. I know it’s a Mythical Symbol but, I think this would be somewhat the way they would look, if Thunderbirds existed. This picture reminds me that I can have control, have power, and the Strength to maintain a healthy lifestyle. My challenges with Diabetes started 2 years ago. I take 500mg of Metformin to maintain my blood sugar. I have been managing to adjust to the Medication well but, I notice the changes. Sometimes I feel dizzy, get headaches and the fact that it takes longer to heal from anything.  

I know that diabetes is common among Aboriginals and it is in my Family History but, I feel that it doesn’t have to conquer us.  

This picture is to remind me and anyone who appreciates it that, I will not give up on my health. This is also, my first ever canvas painting. I thank everyone for listening and I hope to see all of you again, in the best of health.  

Thank you.
Three Drawings of Diabetes

By Helen Parker

Our bodies are like trees when affected by illness.

Confusion – unable to control diabetes

Wolf howling at Grandmother moon for help with diabetes
The Cliff (drawing)
By Robin

This shows how I felt when I first found out about diabetes. I thought it was an end of everything. I had just had my son, my husband was still in prison and I was alone.

My World of Fantasy (painting)
By Michelle Labrecque

Diabetes although a reality, I prefer to escape to my world of fantasy that allows me to accept all the things I cannot. In this world I have complete control and diabetes is nonexistent. There are no glucometers, no syringes, no limits and I am whole without any complications. But there are really are no escapes for now only HOPE!
Three Pictures

By Dorothy

Relaxation – Remembering what it is like back home, the water, the nature.

Joy and Happiness – Remembering what it was like before

Confusion – With understanding diabetes
Acrylic Painting
By: Ginny Boissoneau

Lightning separates- good healthy ways of the past- natural diet- wild game deer, mouse, rabbit, partridge, beaver cattails, roots-berries= No diabetes
Dark - white refined products -cookies, soda, white bread, muffins
Aboriginal people are not used to this diet- higher rates of Diabetes-now more than ever
Lightning also represents-shock to my system when I was diagnosed
Aboriginal – tribal sun – 4 colors
Thunderbird – ruler of the skies
Storms = mood swings
Skull & bones – poison diet for Aboriginal people

Shape Shifter (canvas painting)
By Donii

I am a visual artist and a graphic designer. I have had a lot of problems with things going wrong in my life. In my early ’30s I developed vertigo and anxiety and panic attacks. At that time I worked in mining exploration and had to always be in helicopters. I couldn’t get in them anymore, and my income went from $12,500 a month to zero. I have had many other medical problems over the years and most recently been told I am a borderline diabetic, and so I think, “Oh, here we go! This is something else!” In this painting, this is a shape shifter moving along this line which represents that borderline, along the edge (like the edge of the water). I also drew a moccasin but it needs to be decorated. I didn’t get a chance to finish it. These circles are like the microbes that affect or are carried by the blood.
My Diabetes Symbol Story: I chose the Medicine Wheel (computer media)
By Clifford

I chose the Medicine wheel upon a background of amorphous colours and shapes, to represent my Autistic World, where my brainwave patterns were that of someone in the deepest state of sleep, a dream world existence. The Medicine Wheel represents my emergence out of this state when I was diagnosed at age 55 and started a treatment program which included medication to bring me out of the dream state.

I vividly remember 11:00 am Saturday September 29th, 2007 within seconds of taking my first medication I realized I had been violently assaulted by an intense cacophony of sensory stimulation all my life which made me vulnerable to diabetes by a lifetime of overconsumption of the most damaging food in an effort to sooth the pain and suffering inflicted by my own senses. I am now living with the realization of the horrendous damage gone unnoticed due to the inability to differentiate the symptoms of diabetes from my sensory overload. I had been told many times by Doctors that this was happening but was incapable of understanding the meaning of the message. Hence I was blamed by the Doctors who felt I was wilfully ignoring them. My Mother and Chief Bull taught me the Traditional Teachings through my early Childhood which I internalized to the extent I could given my Neurological disabilities with the enthusiasm, sense of wonder and innocence of the Eternal Autistic Child. It is this symbol that I now focus on to bring meaningful healthy change to my life in order that I may move forward into a restored life that I will love to live.

Diabetes Is...
By: Tim Sim

Diabetes
Is
An endless cycle of
Blood sugar testing
Eating with forethought
Telling oneself NO! to past life pleasures
Exercising regularly (even with numbness)
Surviving to repeat it tomorrow
Acceptance

Acceptance is the answer to all my problems today.

When I am disturbed it is because I find some person, place, thing or situation – some fact of my life – unacceptable to me, and, I can find no serenity until I accept that person, place, thing, or situation as being exactly the way it is supposed to be at the moment.

Nothing, absolutely nothing happens in the creator’s world by mistake. Until I could accept life completely on life’s terms I cannot be happy.

I need to concentrate not so much on what needs to be changed in the world, as on what needs to be changed in me, and in my attitudes.
Eagle Feathers
By Wawaskones Murrell

I have chosen to use my eagle feather to show the way that I feel about my views on having diabetes....I feel like a little eagle feather all ruffled when I am not taking care of myself I know that my life is special and sacred as an eagle feather.

I have chosen to take care of myself and when others decide to change their lives as well that little eagle feather will form back to its natural form without the ruffles. Lives will come together when we start to take care of ourselves in all aspects of our life, like the eagle feather.

You Do The Math
By Sherry Meawasige

People + Sugar = Diabetes

Our people are represented with diversity therefore there are people of many colours. Our family consumes a lot of Pepsi. I looked into our recycling bin one week and it was full of Pepsi cans. Representing my diabetes I have my glucometer which I have to use daily to monitor my blood sugar.
Photovoice

Participants of the Photovoice method showed creativity in gathering photos of nature – waterfalls and trees, pictures of family, pain and challenges. Once again, the pictures with the stories will be presented without analysis to give voice to the participants.

Life Can Be Like a Raging River

By Ernie Sandy

When I think of my diabetes I picture a raging river that once symbolized my life. I was diagnosed with diabetes ten years ago. Like a leaf gently floating down the river, there were times when the leaf (representing my life) encountered a few raging rivers. At least that was how my life was in my younger years. I have since slowed down to a meandering stream. With respect to the management of my diabetes, I have learned to navigate around the ‘rapids of life’. Said in another way, I am in control of my diabetes through exercise and a balanced diet.

G’chi miigwetch

Crossing the Generations

By Troy

My Mom has diabetes, I have diabetes but we want to stop my son and the next generations from getting diabetes.

(permission was granted to use this photo)
Governed by the Clock
By Eve
I’ve submitted a photo of my clock which has fallen off the wall a few times therefore it is missing a few pieces. I feel like I watch the clock, all the time. This clock reminds me to be vigilant at all times and reminds me when it is time to eat and take my meds. The broken and missing pieces remind me that sometimes I forget I am diabetic and I will leave the house for a long walk, without taking anything sweet should I have an incident with my blood sugar levels dipping to low. The part that is missing on the clock also represents the strength I lose in my legs when my blood sugar is low and it feels like I am walking in slow motion when I am trying to hurry home. I feel like I am in a race against the clock.

My Leg
By Mary
I have type one diabetes. Due to high sugar my photo shows some symptoms which is my itching, my feet are swollen with no circulation and one of my toes was highly infected.

Because of poor vision due to diabetes as well I was unable to see the infection on my toe, I also couldn’t feel anything.

If it wasn’t for my foot Doctor Theresa, I would not have known and most important, she saved my leg.

The above are some reason we need to be more careful with our body.

Urban Sunset
Anonymous
The sunset symbolizes the beginning of dark time ahead ... when I first found out about being diabetic. After time had passed I realized that the sunset wasn’t the coming of a darkness but the ending of not knowing what to expect and the beginning of living a better lifestyle.
Fenced Tree
By Amber Caissie

These trees behind the fence shows how I feel, like an outcast. I don’t want my daughter to get it. The leaves on the ground represent what I have went through with having diabetes. The leaves still in the tree represent me rebuilding my life, working on improving my health in a positive way so I’m here for my daughter as she grows. There are two paths also in my picture; this represents what path I will make.

Yellow Tree
By Beverley Caissie

I picture this yellow tree symbolizing me having diabetes, different from the trees behind it. Having diabetes with all the leaves on the ground represents what we have been through, and me trying to rebuild my life. There are two paths here at the front, asking “Which path will you take?”

A Tree with May Branches and Roots
By Donna Morshed

A tree with branches going in many directions
And different ways
Its life
My life
Hard for me to choose
My decisions and the way to follow
Which branch to choose
It’s scary and makes me mad.
I have many roots with my family and two of us have to make good choices.
Reflections on the ASBR and Photovoice Sharing Circle

As noted in the methods section of this report, ASBR is a method that provides immediate reciprocity to the participants of the research. We adapted the Photovoice method to include a final sharing circle with all of participants. Photovoice does not require such a process. In sharing of symbols and photos there is healing and voice given to participants. This was evident in the sharing circle held November 1, 2011.

Staff of programmes at AHT, the Governing Circle and the Toronto Central Local Health Integration Network were invited and attended the sharing circle. The following are thoughts of some of the people who observed the Anishnaabe Symbol-Based Reflection and Photovoice sharing circle:

*Teresa Salzmann and the Diabetes Team at Anishnawbe Health* Toronto - On behalf of the Diabetes Team, I would first like to thank your team for inviting us to the sharing circle. The Anishnaabe Symbol-Based Reflection and Photovoice sharing circle reinforced to all of us the human aspect of the disease we call Diabetes. Participants portrayed through symbols and pictures how they are coping with diabetes, there are the physical challenges and there are also the emotional challenges. This sharing circle made it very clear that the path to wellness includes not only the physical but also the emotional aspects of health.

Vern Harper said he was blown away by the sharing circle. He called this a healing circle that brought people together who have had their differences. He saw them put those differences aside, some people had not talked to each other for years, and some would not want to be in the same room together. He saw them reconcile and walk out of the building as friends. Vern said that these participants are warriors because they had such strength in coming forward with their stories. It was a very beautiful evening and Vern really felt the healing energy of the night. Vern also noted that this event made people proud of their culture.

Brian Marion, a man who had lived with diabetes for a long time, felt this was an eye opening experience, and like Vern, he felt the healing powers of this event. Brian emphasized there needs to be a continuance of these sorts of things and sharing circles because it fosters awareness within the individual as well as in the community.

Jane Harrison stated that it was a very emotional event. She saw strong inter-generational relationships with people caring for the next 7 generations. There was some sadness too about people they have lost.

Ernie Sandy exclaimed there was sincerity in the presentations. We were honoured by their tears. Everything seemed to flow. People were genuinely open. I learned a lot from what the participants said. Their words represent the voices of the nation.

Nancy Sagmeister noted that there was a feeling of family and that this is just the start of the work that needs to be done.

It is vital that research with the Aboriginal peoples immediately gives back to community and leaves the community in a better way. The ASBR and Photovoice methods and the way they were delivered allowed for this to happen while at the same time producing results that allow the individual’s voice to shine through.
If research methods are delivered in a way that is not congruent with community needs, any method can do harm. For instance, there was discussion about trying to capture the sharing circle on videotape so it could be shared more widely. However, an observant research team member who had close contact with the participants throughout the entire project expressed that videotaping would be very intrusive and counterproductive to leaving the community in a better way. We decided not to videotape participants sharing. However, the community forum allowed the participants of the ASBR and Photovoice a choice and opportunity to present their symbols and stories. Allowing participants of research to present findings gives true authority to participants, not the researchers. Of course, in respecting participants comfort levels, there must be choice and no pressure to present if this is something that would not be ideal for the participant.

In summary, the ASBR and Photovoice bring to life the findings of the Concept Mapping and the statistical analysis of the statements. For example, the symbols and stories of the sacred blanket, thunderbird paintings and shape shifter echoed the importance of culture and community in managing diabetes. The feather, ruffled and in its nature form, the trees, and the clock represent the challenge of maintaining a physical, mental, emotional and spiritual balance. The symbols and stories bring to life the spirit of the individual and the spirit of diabetes.
Conclusion and Recommendations

The participants are the ones who breathed life into this work. This report is a living document because it captures the life stories of people living with diabetes. The purpose of the document is to share it as widely as possible with people who are living with diabetes, Western and Traditional practitioners working with Aboriginal people who have diabetes, policy makers and funders of diabetes related programmes, and researchers. It is a living document because in this sharing we anticipate people will read something that strikes them and make a change, whether it is a person living with diabetes who sees him or herself in the stories of denial to funders and policy makers who can create change in programme delivery criteria.

Commonalities and Diversity

The three methods used in this research to explore how the needs of Aboriginal people living with diabetes were interconnected. Some of the common themes across the methods are represented in the symbol of the tree. Trees were used in Anishnaabe Symbol-Based Reflection and Photovoice to describe both the positive and negative aspects of managing diabetes. In a blanket made by one participant, coping with ceremony, culture, healthy eating and checking blood sugar regularly were displayed. Challenges were portrayed in other participants’ drawings and photographs of trees as disease infected branches. Governing Circle member Pauline Shirt relayed how the cluster map resembled a tree and tied this to the tree symbols and pictures. The clusters resemble branches and each statement a leaf, with all the clusters interconnected and related. Together, Concept Mapping, Anishnaabe Symbol-Based Reflection and Photovoice capture the voices of the people and where they are right now with their diabetes; how their spirits are interacting with the spirit of diabetes in a continual state of motion.

The symbols, photos and Concept Mapping statements also demonstrated the diversity of the ways diabetes makes sense to Aboriginal people living with diabetes. This diversity could be seen in relation to age, with older participants offering reflective insights on their past struggles, learning over time to live well with diabetes, and hope for future generations. Younger participants expressed fears as well as positive outlooks in their understanding of the responsibility they carry moving toward eradication of diabetes. Participants dealing with emotional difficulties such as depression and anxiety found comfort in finding out about resources in the community and from others who have lived through similar experiences. Others newly diagnosed gained awareness from the knowledge shared in the circles by those who have lived with the disease for many years.

**Recommendation:** Policies, particularly related to funding of programmes should provide for increased flexibility to enable programs to respond to the diverse physical, mental, emotional and spiritual needs of Aboriginal people living with diabetes. In addition, policy makers must broaden criteria for diabetes programmes for urban Aboriginal peoples in Toronto, particularly related to services for younger age groups, females of child-bearing age and/or with gestational diabetes, and outreach services that are inclusive of cultural ways of coping.
Research is Medicine

This research began with the community with a focus on exploring how the needs of Aboriginal people living with diabetes can better manage diabetes. Governing Circle member James Carpenter reiterated at our final meeting the significance of Aboriginal community involvement in the work done to ensure that this project was led by the community. In keeping with the principle of reciprocity and research being of mutual benefit to the community, the process engaged to explore the research question was critical. As stated by Aboriginal scholar Shawn Wilson, “research is ceremony” (Wilson, 2008) when conducted in a good way. In this project participants shared with us that all aspect of the project; the sharing circles, the Anishnaabe Symbol-Based Reflection and Photovoice were healing. In one of the closing sharing circles a participant stated that since starting his involvement in this research he lost 30 pounds and has been to the doctor, dietician, foot and eye doctors, and dentist. Another stated that throughout these sharing circles a great deal was learned from each other. Participants spoke of this research project as though it was a service delivery programme. In a sense, this was an intent built into the design of the research. Sharing circles instead of focus groups (Howard, 1999, 2004; Lavallée, 2009) open the door to allowing research to be medicine, healing or ceremony. The main reason this research had such a profound impact on the participants was because of the caring research team. The team was consistent and persistent with participants, gaining their trust and respect. In commenting on the pleasure of being involved in the project, Dolores Esquimaux noted that the project helped to teach community about awareness and that they are not alone with diabetes. She felt it was clear from the Anishnaabe Symbol-Based Reflection and Photovoice participation that people were listening and practicing their culture and she was very glad to see this.

For some of the participants, particularly the younger ones and those more recently diagnosed or with prediabetes, we hope the process of sharing throughout this research has served secondary and tertiary preventative roles. For instance, one insulin-dependent participant who has had diabetes for 33 years felt that if she could share some of the pitfalls she has experienced with younger people she could prevent them from travelling the difficult road she has experienced. Some of the younger participants stated that participating in this project had them reflect more on how they might choose a different path, as stated in the Photovoice stories by Amber and Beverley Caissie. Other younger participants in the sharing circles, who themselves have young children, remarked on how the project motivated them to manage their diabetes in order to be there to see their children as adults with children themselves, and to be a positive role model for future generations.

Research as medicine and research as healing involves our Traditional people and Elders. Governing Circle member Vern Harper shared that he resisted getting involved in research over the past few years. However, Vern’s family has been impacted by diabetes and he feels a strong tie to this type of work. In addition, he was reminded about his responsibilities as an Elder and was assured that as an Elder he would have input into the project and not just used as a “rubber stamp”. He sees this as Elder abuse and says, “Use me but don’t abuse me!” Vern shared that it is important to make use of the Elders because of their life experience. When you have a young person and an Elder you have a winning combination because the Elder has the life experience and the younger person can carry through with the work to be done.

As Ernie Sandy concluded in the final sharing circle with participants on December 9, 2011, this project has been successful because the strength of the people comes from sharing. At the last meeting of the Governing Circle, Marie Gaudet shared that she was really honoured to be a part of the process and that hearing that all our medicines, Kina go Gmushkimmaan, are here. She has gone through her own struggles with diabetes and was happy to share her knowledge, but the process empowered her as well.
Research as medicine and research as healing generates knowledge for community. Dr. Shah shared that the problem with some academics is that they publish for their own audiences and move on to the next project. Unless knowledge is translated and becomes available and useful to the public and to practitioners in the field, then it cannot lead to the concrete steps that need to be well planned and executed. Lynn Lavallée stated, “When you do research with the Aboriginal community, you are a ‘lifer’. It is a life-long commitment.” Each project is a life-long commitment. Researchers need to remain committed to sharing the knowledge so that effective policy and programmatic change can happen. They go one step further to ensure policy and programmatic changes happen. This can be done by researchers working together with community. Related to this notion of change is the key recommendation of this project. At the closing sharing circle on December 9, 2011 the participants were in agreement that this research cannot end here. The sharing and peer support needs to continue. Governing Circle Brian Marion echoed this stating, “Keep it up!” And in that vein we have developed a framework for diabetes service planning for the Aboriginal community in the Greater Toronto Area. At the last meeting of the Governing Circle, Vern appealed to us to listen now and act on what we know. Pauline Shirt summed it up saying that now the researchers have gone to work but this is only the beginning, this research shows that there is a lot of work to be done.

**Framework for Service Planning and Evaluation**

**Wholistic Programming**

Diabetes service planning needs to be wholistic incorporating physical, emotional, spiritual and mental (mind) well being. The health care system tends to compartmentalize treatment focusing mostly on the physical (blood sugar, weight, medication) and sending patients elsewhere for emotional mental health concerns. These are usually not part of the routine appointments patients have with their doctors and only come up when they may be at a crisis level. We clearly found in this research that emotional challenges are barriers to diabetes management and must be part of a wholistic approach.

With respect to the education about the physical aspects of diabetes, most of the focus on the physical is on things such as blood sugar, foot problems, and medication. Physical activity is not as widely discussed or emphasized by practitioners. There needs to be one-on-one instruction, as well as group sharing, and learning by doing, such as AHT’s diabetes cooking workshops which integrate topics such as proper nutrition with label-reading into enjoyable, social and meaningful activities. The same can be done for exercise programmes which include physical activity plans. Something similar to a weight watchers weekly check-in and support group sharing would be critical to retain focus and deal with challenges like how to manage blood sugar levels when exercising. While not specifically focused on diabetes, Wabano Centre for Aboriginal Health in Ottawa has such a programme called the Medicine Wheel Makeover that focuses on physical, mental, emotional and spiritual goal setting and includes traditional and cultural activities, peer supports, and one-on-one instruction for physical activity. The latter is particularly helpful when individuals do not feel physically able to exercise and need to modify activity.

A visit to the doctor, dietician or endocrinologist is packed full of information and is overwhelming, so a continuous, follow-up wholistic programme will ensure that people remain focused. As one participant stated, “The medical system is so cold and our way of healing and wellness is sharing and caring.” A wholistic supportive programme would involve sharing and caring.
Wholistic programming would allow for balancing physical, mental, emotional and spiritual well being. As illustrated in the Photovoice project of one of the participants who displayed a picture of one ruffled feather alongside a photo of one that was smooth, disease, like the ruffled feather, represents being out of balance. Diabetes programming, like the smoothed feather, should focus on restoring balance.

A wholistic supportive programme will incorporate a spiritual, cultural and community focus. There was tremendous support for Traditional ways being implemented in the management of diabetes. The use of Traditional Healers and Elders and the use of Traditional teachings are important to incorporate in a wholistic programme.

**Mobile Wholistic Outreach**

Wholistic supportive programmes would include outreach to areas outside the downtown core and to individuals who have difficulty leaving their homes. Elders and Traditional Healers alongside dieticians, chiropodists, and nurses can be part of this mobile team. Participants from Peel Region, Scarborough, and Oshawa came to AHT’s downtown location to participate several times in aspects of this research because it was important to them. They passionately requested that wholistic programming be made available outside the downtown core. There are agencies providing services to Aboriginal people but these are few and small. Among them, Peel Aboriginal Network and the Oshawa Community Health Centre expressed wanting to partner with downtown Aboriginal agencies.

**Targeted Outreach**

Addressing the needs of individuals who are socially isolated and dealing with depression and anxiety is a critical component in managing diabetes. Special emphasis on strategies for outreach to hard to reach or underserved communities should be a part of future service planning. The Métis, Inuit, men and two-spirited should be part of targeted outreach. In addition, programme support for individuals who regularly eat at food kitchens and who need information about healthy choices is critical in programme delivery.

**Women and Gestational Diabetes**

In our interactions with participants it was noted that there is a gap in programming for women with gestational diabetes. Special programmes for expectant mothers and/or women of child rearing age must be part of a wholistic service planning to help Aboriginal people manage diabetes in the Greater Toronto Area.

**Children and Youth**

As noted in past research and in this study, Aboriginal people are diagnosed with diabetes at a younger age. Sharing circles bringing together those who are newly diagnosed with those who have lived longer with the disease can allow for learning across the generations. However, programmes might also target younger age groups. For instance, youth and children may be reached through collaboration with schools. Governing Circle member Marie Gaudet lives with diabetes and works closely with youth. She
emphasized the need for more work on diabetes by youth for youth and children. Such programming might bring together youth and children with diabetes with those who do not have diabetes to serve as a strong primary prevention programme. Youth and child programmes might use technology and interactive tools geared toward health and wellness in a creative way to reach more individuals.

Evaluation

Planning for diabetes services for Aboriginal people should also incorporate meaningful evaluation to ensure programmes are successful (Howard & Dutton, under review). The process set out to conduct this research can be used as a model for evaluation so that the evaluation does not become just a means of gathering statistics. Evaluation, just as research, must hold the principle of reciprocity. The process involved in Concept Mapping is useful for evaluation because it brings service users together to share their ideas on how a programme is (or is not) working, but it goes a couple of steps further in also involving service users in the additional processes of targeting relationships between ideas which may enhance successes and address flaws in programming, and in the development of concrete action items for change and improvement. However, the software and training to conduct this analysis with Concept Mapping may be prohibiting. Sharing circles, Anishnaabe Symbol-Based Reflection and Photovoice can be incorporated into programme delivery and used as a form of programme evaluation. In fact, AHT service providers who observed the Anishnaabe Symbol-Based Reflection sharing circle will be incorporating this method as a service delivery tool.

Diabetes programmes are doing important work to limit complications from diabetes on the physical level as they may include eye, foot, and dental care, however, diabetes is expressed as a symptom of other systemic issues, such as poverty. Evaluation should seek to explore the impact of a diabetes programme on spiritual, emotional, and social well-being as well as the physical measures now typically the focus of most programmes such as blood sugar levels, weight, and body mass index.

Limitations

This study did not involve a random sample of the Aboriginal community in the Greater Toronto Area; therefore the results cannot infer that the findings are representative of the entire Aboriginal population with diabetes in the Greater Toronto Area. The Aboriginal population in Toronto is culturally, linguistically, and economically diverse. There is no Aboriginal enclave or neighbourhood in Toronto and the community is therefore most visibly defined by a relatively large network of Aboriginal social service organizations (Sanderson & Howard-Bobiwash, 1997; Howard, 2011). Even if there was an Aboriginal neighbourhood, in order to achieve a random sample the total Aboriginal population in the Greater Toronto Area would have to be known, and from there the people living with diabetes would have to be extracted and then randomly sampled. Recruitment of participants relied primarily on collaboration with Aboriginal and non-Aboriginal organizations and events, as well as through word of mouth. While our recruitment strategy involved contact with over 200 organizations and individuals, challenges were encountered in reaching out to Métis, Inuit, men and two-spirited persons.

The Concept Mapping method posed some challenges to participants. In particular, the sorting and rating phases of Concept Mapping were difficult for some of our elder participants as well as for those with low comprehension and literacy skills, or for those whose first language is not English. These limitations were identified early in the research process and some efforts were made to mediate them. As much as possible, the full team was present at sorting and rating sessions to assist participants on a
one-on-one basis with completing these tasks. Ernie Sandy, who is fluent in Anishnaabemowin translated the statements to help a few participants.

Another issue identified with the rating part of the Concept Mapping approach had to do with the applicability of our rating question regarding the degree to which a person may have control over each idea expressed in the statements they were asked to rate. This question was applicable to a smaller number of the statements than the question regarding whether participants agreed with the statement, and once we were able to examine the results more closely we found that the data did not produce meaningful information.

**Recommendations**

Many recommendations emerged from this research project. They have been discussed throughout this report and are summarized here. An overarching suggestion weaved throughout all recommendations is that diabetes programming aimed at helping people manage diabetes through lifestyle change should balance the diverse needs, knowledge, social circumstances, and relationships individuals have to living with diabetes with the appropriate supports and structures.

We implore those who may use this report to keep in mind the words Brian Marion felt were so very important to leave us with, “Keep it up! Do your best!”

**Targeted Outreach**

- Service providers should establish special programs and outreach strategies that address the needs of males and two-spirit people. These might include understanding how prevention, early diagnosis, regular clinical contact for diabetes management, and participation in social programming would best serve men and two-spirit people. Practitioners and future research may explore questions about denial and other possible reasons males and two-spirited people are not accessing services as frequently as women.

- Aboriginal researchers and agencies should develop stronger partnerships with the Métis Nation so the Métis be included in the planning of future research and programmes for Aboriginal peoples. Targeted outreach to the Inuit community is recommended.

- More needs to be done to reach out to people with intermediate to severe complications, including limb amputation, who feel isolated, depressed, or may need assistance with transportation or personal home support care. Given the younger age onset of diabetes and complications in the Aboriginal community, this service should not be limited by age. In addition, it should be recognized that trust needs to be developed to allow practitioners to enter one’s home.

**Policy**

- Policies, particularly related to funding of programmes should provide for increased flexibility to enable programs to respond to the diverse physical, mental, emotional and spiritual needs of
Aboriginal people living with diabetes. In addition, policy makers must broaden criteria for diabetes programmes for urban Aboriginal peoples in Toronto, particularly related to services for younger age groups, females of child-bearing age and/or with gestational diabetes, and outreach services that are inclusive of cultural ways of coping.

**Western Practitioners**

- There is strong need for western medicine practitioners to work in conjunction with those who practice traditional medicine and be more aware of the value of traditional medicine and the importance of personal choice.

- It is important to create and support culture-based programming that is initiated, self-determined, and led by the Aboriginal community to help coordinate and support Aboriginal people with diabetes in their interaction with the mainstream health care system.

- Health practitioners should do more to explain diabetes medications and their side effects more fully and in light of the concerns of their patients.

**Sharing Circles with Peers**

- Programs for Aboriginal persons living with diabetes in the city which bring together culture and ceremony with opportunities for learning from each other as community and family members should be a very high priority. Sharing circles should be considered in Region of Peel (Mississauga, Caledon, Brampton), Oshawa, Scarborough and north of the downtown core.

- Sharing circles that are participant-led for Aboriginal persons living with diabetes in which they can simply hear each other’s stories and support each other are needed. Such peer group programmes may allow for this sharing of knowledge by people who live with the challenges of diabetes.

- Further research which explores improvement of diabetes management as a result of participation in such sharing circles would be useful.

**Programmatic Recommendations**

- This research involved almost 50% of people who were diagnosed within the past five years. Those earlier on in their diagnosis require more specific education and assistance in order to learn how to manage diabetes; therefore programmes need to be able to meet the potential increased capacity of individuals needing more one-on-one education.

- Programmes and services must take into account the financial constraints of Aboriginal people living with diabetes and provide transit, childcare and monetary incentive that can help with purchasing better quality foods.
Prevention of physical complications of diabetes should be addressed within a wholistic approach that takes into account the emotional, spiritual, and mental aspects, including the fears associated with physical impacts of the disease.

Service providers should recognize the diversity of views and experiences people have with the past, such as experiences with and perceptions of residential school. This diversity includes people not wanting to focus on the ‘negative’ and others who feel the need to acknowledge past injustices that still impact Aboriginal people today.

More should be done to provide flexibility in programs to allow Aboriginal people with diabetes frequent access to dieticians and/or weight loss specialists whereby regular check-ins can continually monitor progress and keep people on track.

Walking and exercise help manage diabetes; however there are many obstacles to being physically active. More needs to be done to develop and maintain physical activity programs that are wholistic in approach and adapted to the varying degrees of ability of persons with diabetes. One-on-one instruction and support would be beneficial to allow individuals to cater their physical activity within their own limitations.

Outreach services are needed in areas of Peel (Mississauga, Brampton, Caledon), Oshawa, Scarborough and just north of the downtown core.

Developing a strong outreach service that includes cultural activities, Traditional Healers and Elders is critical in programme development.

Service providers need to be aware that managing diabetes naturally is important to people living with diabetes. Appropriate planning of the natural management of diabetes without causing harm would be a critical component in the education about diabetes.

Diabetes education programming should try to integrate family and intergenerational learning opportunities, as well as open spaces for youth to be heard.

Nutrition

Food at events, such as powwows needs to be transformed back into traditional healthy meals. Increased knowledge of the nutritional and philosophical aspects of traditional foods is needed.

Although there is a lot of information available about healthy eating, the challenge is to translate knowledge into action. Nutrition programmes need to be very specific and adjusted to the individual’s lifestyle; for instance, how to eat healthy when using food banks or how to eat appropriate based on one’s activity level.

More needs to be done to provide tools to help diminish fears and frustrations associated with food choices and weight loss. These tools must be tested and utilized in applied and/or programmatically organized situations so that people can make the best use of them, and information can be shared in a bi-directional way with practitioners. This way, persons with
diabetes and the health professionals who help them can learn together about what is and is not working and adjust strategies in collaboration.

- Participants noted that they often feel hunger and after eating late at night they felt very fatigued the next morning. Information about how hunger and fatigue paired with practical observations made by persons with diabetes as part of a program which tracks change over time may lead to improved diabetes management.

**Education and Prevention**

- The seven cluster themes from the Concept Mapping in this report could be adapted to tools for diabetes education and prevention in correlation with traditional teachings, such as the Seven Grandfathers in the Anisnaabe tradition.

- Primary prevention programmes aimed at youth and children might use technology and interactive tools geared toward health and wellness in a creative way to reach more individuals.

- Accessibly appropriate diabetes education materials should be developed with consideration for people with low to no literacy, visual impairment, and/or cognitive challenges.

**Emotional Supports**

- A recommendation for service providers is to focus on developing programmes aimed at acceptance and denial, recognizing that they are two different constructs that people may understand in very different ways.

- Emotional stressors including depression need to be incorporated into diabetes education and treatment programmes. It is important to recognize the courage and capacity of Aboriginal community members with diabetes and find ways to encourage hope and a positive outlook. A peer support system may be a way to bring individuals together with mutual benefit, through small, informal sharing circles.

- Stress reduction should be an integral part of the health care of persons living with diabetes. Culture-based approaches which are wholistic in nature should foreground efforts to address stress reduction.

- Many of the participants in this study demonstrated that they have comprehensive knowledge of what they need to do to manage their diabetes. This should be recognized and acknowledged with more focus on how this knowledge can be best put to use in relation to the broader emotional issues, and other challenges that impede them from carrying out what they know they need to do.

- Programming aimed at Aboriginal persons with diabetes should be framed within cultural approaches that speak to both collective and personal responsibility for health and healing. People with diabetes and service providers may find it helpful to explore how to build skills related to taking self-responsibility and avoiding sabotage. A group programme that regularly
checks progress and exploring reasons for losing focus may be a way to address self-responsibility and self-sabotage.
Closing

In keeping with *Kina go Gmushkiimnaan*; we gathered all of our medicines in order to carry out this research in a good way with the community. Many recommendations have emerged from this project, through the voices of Aboriginal people living with diabetes.

Our job is not done as researchers. We remain committed to the participants to ensure the recommendations of this project come to fruition. A community forum was held that shared the knowledge gained through the project. Participants were given the opportunity to share their involvement in the Anishnaabe Symbol-Based Reflection and Photovoice. The participants are the experts in this project and their voices are critical.

In closing, the co-investigators would like to honour the research team that worked so closely with the participants and were the reason this research was successful. Most importantly, the research team is the reason this project will leave a lasting memory with participants. Capacity building was the guiding principle in working as a team and we want to honour the research team by giving them the last word.

Following are the reflections by the team that highlight what the project meant to them.
Reflections from the Research Team

Reflections by Krystine Abel

As a peer researcher whose family has been impacted by diabetes, I had a personal responsibility to the project. I wanted to learn as much as I could and provide my mother with the experience of meeting and sharing with other individuals her struggles and successes with diabetes. I really saw how some participants were in need of support and that by visiting with my mom, sharing and supporting each other emotionally I was doing something positive all along for both of us. For my mother, I think it gave her perspective on how far she has come in managing and taking control of her diabetes, and I think that gave her assurance that diabetes doesn’t have to be a fatal disease.

Our team worked beautifully together during the past 9 months. We combined all our strengths to turn the project into a labour of love. Our entire team was dedicated to providing a safe and supportive atmosphere for our participants. Many of us were connected in different ways, some friends, some family. The very foundation of our project was held up by our commitment to conduct community based research, by and for the community. I believe this project was for all of us to benefit from.

I also want to acknowledge Ernie Sandy, who share his Traditional knowledge with the team and became a friend to all of us. I also want to thank Nancy Sagmeister for all her hard work and strength in coordinating our events. I have been blessed with such incredible knowledge from both Lynn Lavallée and Heather Howard-Bobiwash. They gave us the opportunity to learn methodologies in both Indigenous and non-Indigenous research. Lynn and Heather both remained true to their vision of the project and worked in tandem to give us creative freedom and unwavering confidence we would get the job done. On more than one occasion I remember Lynn saying these are the tools you will take forward, as all of us, Jessica, Carolyn, and Melissa, are the next generation of Aboriginal women working to make our community healthy. Going forward I know the journey is not over for me that the success of this project is something I can look back on to give me the motivation to continue doing good work in diabetes and other issues close to my heart.

And finally, I want to thank all the people who participated in the project and shared deeply. Your words, your paintings, pictures and presence are what ultimately made this process a pleasure and a success. After hearing all the challenges that many of our people are experiencing, I hope that this report will be useful to the whole community of educators, healers, and people living with diabetes. In everything we learned from each other, the overarching theme was that we are a strong community and can work through our differences and work together to make us healthier and stronger. Chi-Meegwetch!!
Reflections by Carolyn Akiwenzie

As I think about all of the knowledge I have acquired over the course of this project, I am immediately left feeling overwhelmed. Coming into this project opened my eyes to many things, our elders; our advocates on First Nation issues, First Nation youth, and most importantly it put faces to a disease that I’ve come to known as diabetes.

As I look at diabetes, and think of all the people I know personally and have met throughout the course of this project. I now have a better understanding of the struggles that many individuals feel they have to face alone. The various phases in this project gave me insight on some of the struggles that accompany the illness which was difficult to fathom, but I couldn’t have been more humbled to hear their stories of fear, denial, frustrations, and above all else they retained hope.

At many moments throughout this project, I’ve been moved to tears. I have sat down with numbers of people whom created statements, completed the sorting and rating phase of the 79 statements that we collected, and lastly created an art piece/photo of what diabetes means and looks like to them. I recall sitting with an elderly woman at the Native Child Pow Wow, having to read all the statements so she could rate them in her importance. At times I could see her level of discomfort with some of the statements which must have hit close to home. After the completion of getting through the statements, she stood up and gave me a hug with tears in her eyes. Saying that "this was so very important, and that I’m glad you guys are doing this". Many ideas were shared from the people on what they would like to see happen and what they think might be useful. The ideas were relatively easy, and I’m sure could be developed no problem, but then there is the issue of trying to convince government/funders to see the importance of what the people need for their survival. I’ve also seen the various stages people were at with their diabetes, some were recently diagnosed, to those who have had it for years, some displaying the negative aspects such as bad eye sight, infections, medications and amputation. In many cases their livelihood has been interrupted.

These stories from our people were like cries for help along with a message that has been longing to be shared, and no longer locked up, as we have been so silenced throughout our history. As Vern Harper so wonderfully put it, they are our warriors in this disease. I see them fight, get knocked down, but they still get up. For those warriors who may let this battle overcome them, they still give their message through their stories of the fight, and giving us strength to continue the battle.

I would also like to acknowledge a brave man that sat on our governance circle, who breathed a new kind of life into this project, someone who had the bravery to show us in his physical body on what diabetes can do, but he shared stories of hope for others, Brian Marion Chi-Miigwetch for your wisdom, your words will inspire others who will encounter this battle.

This project would not be able to have been done without the team that we were composed of. I felt empowered to share my thoughts, to be a team composed of all non-diabetics, with the exception of Ernie but how it affected us greatly in one way or another with people we love or lost to diabetes. I would also like to mention a heart filled Chi-Miigwetch to the Kina Go Gmushkiimnon team. Over the past 9 months, I have had the honour of working alongside Nancy Sagmeister, Melissa Ricciuti, Krystine Abel, Jessica Keeshig-Martin, Ernie Sandy and Dr.’s Heather Howard-Bobiwash & Lynn Lavallée, your dedication to the community and the knowledge you’ve all shared have inspired me so. So once again I say Chi-Miigwetch!!
Reflections by Jessica Keeshig-Martin

I see diabetes so differently now. Having worked on two important research projects dealing with the issues Aboriginal people face on a daily basis in the G.T.A., I see that it is so much more than something that can be treated separately. The major practice in the mainstream health system is to treat diabetes as a physical affliction and away from the emotional, the mental and the spiritual aspects of the being. This is where the teachings and philosophies within Aboriginal culture come in to provide a basis for healing in a wholistic way. Wholism is also being recognized in some mainstream health practices, however within the Aboriginal community this perspective is closely tied to identity and so it is very important that Aboriginal people be able to practice wholism in a nurturing space and around people that understand Traditional cultural practices. This is why culture in the health and well-being of Aboriginal people living with diabetes came up as a significant need through this project *Kina go gmushkiimnon* (please see page v for an explanation of the importance of this name). When I think about the life force of this project three important characteristics come to mind: awareness, healing, and trust.

This project began with the acknowledgement of the issue at hand and the need to have the voices heard of Aboriginal people living with diabetes within the Toronto area. Out of the sharing circles many people spoke about being in denial and then by listening to one another’s stories it became apparent that this was a very powerful method in helping people become more aware and accepting of having this disease. Within the final weeks of working on this project a member of the Governing Circle, Brian Marion, had passed away. I was deeply affected by his thoughts on the project when I had spoken to him a week before his passing in his home filled with his magnificent artwork. That will be a day I will never forget. Brian spoke candidly about his denial and that his work as part of the Governing Circle was his way of ensuring that others do not follow in his footsteps of denial and neglect of his body. It was said by a Traditional Healer at AHT that people that have diabetes often spend a lot of energy within their minds and need to be more aware of what is happening to their bodies. The mind and the body are connected, if one is neglected the other is greatly impacted, and both must be healed coincidently through spiritual guidance. Brian expressed his gratitude to me in having someone there to listen to his story and although he is gone into the spirit world now, we still carry his message.

Without foreseeing all the consequences of the research process itself, the project ended up being a very healing experience for all those involved. The intention was, as it usually is, to create a final report that helps the community heal through its recommendations however the healing in this project was a characteristic throughout. In any research done in a good way there is a certain amount of healing happening and through the research activities involving the 138 participants, through Governance Council work and meetings, and through team meetings, team interactions and the work we did at AHT healing was continuous. I began to see it happening everywhere and I began to really feel my own transformation.

Finally I would like to reflect on the trust aspect of this project. Without trust awareness and healing would cease to have happened. I was so grateful to be able to speak with Urban Elder Vern Harper. He came into the project critical of how he was going to be utilized because of past experiences where an Elder would be used as what he called a “rubber stamp”. Vern saw that trust was gained in participants and seeing this helped earn his trust in this project. I am so honoured to have worked with so many amazing people Heather, Lynn, Ernie, Nancy, my sister research assistants, Vern, Brian, Pauline, Marie, Delores, James, Jane and all those that participated in the research activities. Like so many people that I have listened to over the last while, I too hope for continuance within the healing process toward *minobimaadiziwin*. 
Reflections by Melissa Ricciuti

Each team member brought a variety of knowledge with them to the Urban Aboriginal Diabetes Research Project. This knowledge ranged between academic, spiritual, emotional, cultural, and lived experiences. As an Aboriginal woman pursuing my degree in social work, I was looking forward to working on this project because I was curious about discovering possible connections between trauma and diabetes, as well as whether Aboriginal cultures and traditions impacted positively upon treatment and the overall health of Aboriginal individuals living with diabetes in the GTA. Academically, I was very interested in developing my knowledge in regards to Indigenous and Western research methodologies.

Along with the other team members, I believe that I too brought a range of knowledge to this project. Having engaged in various events and ceremonies within my Aboriginal community, as well as having worked with the Toronto Aboriginal community as a facilitator for a Post-Secondary Aboriginal Summer Experience Program, I was familiar with the process of ‘facilitating’ a sharing circle. I also brought some knowledge concerning tobacco, as a sacred medicine, as well as how to make a tobacco tie – an important component of the project’s informed consent process. I had never before been involved in the process of ‘naming’ a project, so it was all new to me when the team asked Pauline Shirt (a member of the project’s Governing Circle) if she would provide the project with a name. Personally, I found that the project receiving it’s name, ‘Kina Go Gmushkiimnon’, or ‘All Our Medicines’, to be significant as it helped to provide the project with another piece of its identity. In doing so, it strengthened my connection to the project. Also, the subsequent feasting of the name (at each Governing Circle meeting) further emphasized this identity and my connection.

As mentioned previously, I was very interested in learning more about both Indigenous research methodologies as well as Western research methodologies. Upon reflection I feel very blessed to have had the opportunity to learn so much about both methodologies via Anishnaabe Symbol-Based Reflection, Photovoice, and Concept Systems. I had no idea what an impact creative expression (via Anishnaabe Symbol-Based Reflection and Photovoice) would have on the participant’s ability to express their feelings. It is very clear that Anishnaabe Symbol-Based Reflection and Photovoice are tools that are tremendously useful in regards to helping participants access and express, their feelings - in this case it was their feelings about living with diabetes. This may have something to do with the accessibility of art as a universal form of communication. Alternatively, Concept Systems - a Western research method, proved difficult when using it with clients for the purpose of ‘rating’ and ‘sorting’. It required the participants to have quite a high level of literacy, therefore many of the participants we were working with struggled when asked to read and comprehend the statements. Unfortunately, this obstacle may have resulted in skewed data results – impacting negatively upon the aims of the project. I have learned that Concept Systems may not be the most appropriate method to use when working with individuals who do not have strong literacy skills.

The objectives that I had hoped to better understand at the outset of the project - the connections between trauma and diabetes, whether Aboriginal cultures and traditions impacted positively upon treatment and overall health of Aboriginal individuals living with diabetes in the GTA – were not definitively answered by the data collected during this research project. According to the statements collected from the sharing circles and the relationships identified by the concept maps/clusters, there seems to be a positive correlation between an engagement with Aboriginal cultures and traditions and diabetes management. Participants did indicate that ceremony, sharing circles, prayer, and other traditions, assisted them with their diabetes management. Additionally, as the focus of this project was on diabetes management, there was not much opportunity to explore whether or not a relationship exists between trauma and the onset of diabetes.
Reflections by Nancy Sagmeister

Although no-one in my family has had diabetes, I was up close to the deadly impact of the disease as a young child and to the problem of addiction to the wrong kind of food. One of the tenants in my parent’s house was a woman in her sixties who had diabetes and needed to take a daily injection of insulin. When she first moved in I noticed right away how unhealthy she looked, and also how she packed her cupboards with ‘sugar substitute’ sweet foods. My mother, who was self-taught about healthy eating, explained to me what diabetes was and that this was why she had to give herself a needle every day and couldn’t eat anything with sugar. Our tenant was a lovely woman and she became a family friend. After supper was visiting time when my mum and I would head upstairs and I would hang around listening as they read each others’ tea leaves and discussed what the leaves were saying about the future.

One day our tenant moved out because she couldn’t walk up the one flight of stairs anymore and she needed to be closer to the grocery store. She was having trouble with her feet. She and my mum remained friends though, and not long afterwards, we found out she was in the hospital. She had a foot wound that wouldn’t heal and it had become infected. She died before leaving the hospital. This was my first experience as a child of losing an adult who I was close to, and I still remember the last time I saw her in the hospital bed with her foot bandaged up.

As I sat listening to the people in our sharing circles talk about their own experiences and struggles living with diabetes, as I saw them present and explain the photos and artwork they created, and how these represented their feelings, hopes and fears about the future, I was mostly struck by the weight of this condition on people’s lives. Regret, sadness, fear, denial, frustration were mixed with words of hope about their future and wishes that their children won’t have to deal with diabetes in their lives.

What I learned from this experience of working on this project for the last 6 months was the enormity of the impact of diabetes on the spiritual and emotional well-being of people. It’s been many years since I watched our tenant/friend who lived on the second floor of our house hide sweets and candies away in her cupboard, knowing full well that that she shouldn’t be eating them and that her health would suffer. Diabetics may have information about what they should do to keep themselves healthy – what to eat, how much to eat, when to eat – and understand that eating healthy and exercise will help to reduce the effects of diabetes on their bodies – but knowing what to do and actually doing what is needed to stay healthy for as long as possible is where the challenge lies. For more than a few of the people who participated in this research, the opportunity to stand in front of a group and talk about living with diabetes and how it’s affected them and their families, was an emotional release that brought tears to their eyes. For some this was the first time they had ever been able to just talk about their feelings and the challenges they face on a daily basis to try to follow-through with what they need to do.

The medicine wheel teachings are about bringing balance to our lives and recognizing that if one area of our selves is off-balance, then our whole being is affected. What I learned from this experience is that the road to the healthiest life possible for people with diabetes has to make room for opportunities to receive spiritual and emotional support as they move forward. The physical self is clearly affected by diabetes. The mind knows what is needed to stay healthy. Let’s release the strength of good spirit and good emotion to complete this circle and bring people to a better place.
Reflections by Ernie Sandy

As the Indigenous Research Integrity Advisor with the Urban Aboriginal Diabetes Research Project, I would have to say the experience in working at the front line with other diabetics was rewarding in terms of expanding my knowledge about the frustrations and challenges in managing diabetes.

Since being diagnosed about ten years ago, I made it my goal to learn as much about diabetes as I could. Some of the knowledge I brought to this position was that the onset of diabetes occurs when your body is not able to use the insulin made by the pancreas properly. In some cases, not enough insulin is produced; the results may mirror each other in the symptoms. Insulin is vital to your body. Insulin is what turns sugar from the food you eat into energy. There are a number of the symptoms of diabetes such as constant thirst and urination, and in the case of low sugar, an acute sense of fatigue.

Diabetes is unique as a disease because it requires constant medical attention. Even though life with diabetes can be overwhelming at times, it need not interfere with one’s daily routine. Management of the prescribed medications, regular exercise and proper diet are the best way to keep it under control. Keeping my blood sugar as close to normal as possible is my primary goal in the management of this disease. The blood sugar level being too low or hypoglycaemia is just as dangerous as having a high blood sugar count or hyperglycaemia. I know that if I fail to properly treat my diabetes, it can lead to some fairly serious problems. Over time, high blood sugar can damage blood vessels, kidneys, and other vital organs. Long term consequences can sometimes be severe, such as a stroke or heart attack, along with loss of limbs or eyesight.

There are three types of diabetes with very distinct characteristics, for example, type 1 is when the body doesn’t make insulin; type 2 happens when the body has a problem in making insulin; lastly, gestational diabetes occurs when a woman can’t use insulin while pregnant. I am sad to note that my people are more likely to get Type 2 diabetes than other Canadians. Because of the sedentary lifestyle, lack of exercise, and improper diet, members of the younger generation are developing Type 2 diabetes at an alarming rate. While growing up in the 1960s and 1970s, I don’t recall ever hearing about diabetes. In other words, it is not a health issue. We lived a Traditional lifestyle with lots of physical activity and Traditional foods such as fresh fish and wild game. It is only recently that this has become an epidemic.

I came to this position knowing that living a healthier lifestyle can give my people a better chance of not developing diabetes. Even though it is too late for me, I maintain an active lifestyle, eat in moderation, take my medication, and check my sugar levels regularly to help manage my diabetes.

What did I learn during the last six months in working directly with Aboriginal peoples with diabetes? In listening to the many people who participated in the sharing circles, I came away with a whole new perspective on the disease. There are dozens of learning moments that helped to broaden my knowledge of diabetes. For the sake of brevity and to remain within the parameters of this short reflection, I will mention only a few examples of increased awareness with respect to challenges and frustration expressed by the diabetics who share their stories with us.

There is no question that diabetes can be challenging and frustrating. This was validated by the nearly four dozen diabetics who shared their misery. The disease can take over one’s life if it is allowed. However, establishing a routine helps to minimize discontent. Part of a diabetic’s life may involve taking certain medications at a certain time; poking their fingers two if not more times a day; not being able to eat the food they want, or perhaps, not being able to afford the proper food. As a diabetic, I realized that I was not alone in meeting the challenges of diabetes.
References


Howard, H. and Dutton, J. (under review). The production of knowledge in diabetes program evaluation indicators in Aboriginal populations. *Social Science and Medicine*.


Martin, A. (2011) Aboriginal men more likely to avoid diabetes clinics, says researcher. *Regina Leaderpost*, June 28. Retrieved from [http://www.leaderpost.com/health/Aboriginal+more+likely+avoid+diabetes+clinics+says+researcher/5014110/story.html#ixzz1gYVlJAqL](http://www.leaderpost.com/health/Aboriginal+more+likely+avoid+diabetes+clinics+says+researcher/5014110/story.html#ixzz1gYVlJAqL)


Appendices

Appendix A – Excerpts of Research Agreement

Appendix B – Demographic Sheet, 79 Statements and Rating Sheet
Appendix A – Excerpts of the Research Agreement

PRINCIPLES:
• Maintain mutual respect and accountability between the parties;
• Recognize the complementary and distinct expertise, responsibilities, mandates and accountability structures of each party;
• Ensure the highest standards of research ethics;
• Respect the individual and collective privacy rights of Aboriginal peoples;
• Recognize the value and potential of research that is scientifically and culturally validated;
• Recognize the value of capacity building at all levels;
• Maintain Aboriginal control and ownership of Aboriginal data,
• Uphold further principles described in the Statement of Governing Principles specific to the Assessment and detailed in Appendix B

Incorporating Aboriginal Research Values:
The research will incorporate Aboriginal values to research ensuring that the project builds capacity within the Aboriginal community, directly involves the Aboriginal community and provides outcomes that will be immediately helpful to the community, including recommendations for program and policy development. See attached Statement of Principles.

Capacity Building:
The capacity building components of the project include the co-mentorship among the project research scientists, the hiring and training of Aboriginal research staff, and training of the researchers and staff with the concept mapping method.

A Statement of Governing Principles -- Toronto Aboriginal Diabetes Project
• Aboriginal health research should be governed and managed by Aboriginal people and Aboriginal organizations.
• Aboriginal health research needs to respect the cultures, languages, knowledge, values, and right to self-determination of Aboriginal peoples.
• Aboriginal organizations should be given the first opportunity to receive and manage Aboriginal health research funding.
• Aboriginal organizations need to set the Aboriginal health research agenda, including research topics and priorities.
• Aboriginal organizations should be able to choose the researchers that they would like to work with.
• Aboriginal organizational representatives should be invited to actively participate in the complete research process, from design to implementation to dissemination.
• Aboriginal health research should prioritize Aboriginal community understandings of health and wellness.
• Aboriginal health research needs to be respectful of the diversity of Aboriginal experiences and cultures and be conducted in a manner that provides cultural security to research participants.
• Individual and collective rights to privacy and confidentiality need to be respected.
• Informed and voluntary consent needs to be obtained from all research participants.
• Translation of Aboriginal health research data and findings into improved community programs and services needs to be a priority.
• The lead Aboriginal organizations have the right of final review and approval of any project documents.
• Collective rights to the governance and management of Aboriginal health data need to be respected.
• Aboriginal organizations and communities should benefit from Aboriginal health research.
• Individual and collective harms that may result from research need to be carefully considered and minimized.
• These principles, once agreed upon, will be operationalized in a research contract that clearly sets out roles and responsibilities of the governing Aboriginal organizations, partner organizations and project researchers.
Anishnawbe Health Toronto

**URBAN ABORIGINAL DIABETES RESEARCH PROJECT**

**DEMOGRAPHIC INFORMATION**

This information will not be attached to your name or any other details that may identify you.

**Sex:** □ Male □ Female □ Other

**What is your age:** ______

**Aboriginal identification:** □ First Nations status, □ First Nations non-status, □ Métis registered, □ Métis unregistered, □ Indigenous, multiple identities/nations

**How many years have you lived in an urban area?** ______

**Do you feel your income is enough to meet your needs?**

□ Yes, □ no, □ maybe/not sure

**How long have you known you had diabetes or have been pre-diabetic?**
If less than one year, answer “1” (one): ______
Instructions:

We asked people who live with diabetes what issue, feeling or though occurred to them about living with diabetes. Below are 79 responses that we would like you to rate based on whether you agree or can relate to the issue and whether or not you feel you have control over the issue. Please indicate how you would rate each statement to the left according to the two questions to the right. Place a checkmark ✓ in the numbered circle that best describes how you feel about the statement, according to the following scale:

1= not at all        2=slightly        3 =somewhat        4=very much       5=completely
or n/a = not applicable (only for statements #6 and 18)

Please check only one circle for each question.

A specific issue, feeling or thought that occurs to me when I think about living with diabetes is…"

<table>
<thead>
<tr>
<th>#</th>
<th>Statement</th>
<th>How strongly do you agree with this statement?</th>
<th>To what degree do you feel you have control over this?</th>
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<td>1=not at all 2=slightly 3=somewhat 4=very much 5=completely</td>
<td>1=not at all 2=slightly 3=somewhat 4=very much 5=completely</td>
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<tr>
<td>1</td>
<td>It is expensive to live a healthy lifestyle and manage diabetes.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<td>2</td>
<td>The health care system is unable to provide adequate care for persons with diabetes.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>3</td>
<td>I am angry my doctor did not catch my diabetes earlier.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>4</td>
<td>I feel doctors and others judge and blame me for getting diabetes.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>5</td>
<td>Doctors seem more concerned with collecting patient statistics and giving out medication than they do with helping.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>6</td>
<td>Dealing with needles and taking injections is a challenge.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5 On/a</td>
</tr>
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<td>7</td>
<td>I fear having to go on dialysis.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<td>8</td>
<td>I am concerned about the negative side effects of diabetes medication.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>9</td>
<td>I would like to be able to manage my diabetes naturally without medication.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>10</td>
<td>I find it difficult to keep track of all the pills I have to take or take my medication properly.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>11</td>
<td>I fear my body deteriorating.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>12</td>
<td>I don’t check my blood sugar because it hurts my fingers.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>13</td>
<td>I tend to ignore pain or dissociate myself from it.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>14</td>
<td>I am concerned about the effect of diabetes on my eyesight.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>15</td>
<td>I fear having a heart attack.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>16</td>
<td>Recurring infections upset me.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>17</td>
<td>I fear losing body parts.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<td>18</td>
<td>It is difficult to maintain a diabetic diet when my family doesn’t want to eat what I have to eat.</td>
<td>O1 O2 O3 O4 O5 On/a</td>
<td>O1 O2 O3 O4 O5 On/a</td>
</tr>
<tr>
<td>19</td>
<td>It is difficult to maintain a diet for more than a couple of weeks.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>20</td>
<td>I need to be more conscious of what I eat, when I eat, and what it does to my body.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>21</td>
<td>It is hard to avoid processed foods and things like salt, flour, sugar, milk, lard.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>22</td>
<td>I feel better if I eat healthy foods</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>23</td>
<td>Healthy cooking and eating is difficult and requires extra time.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>24</td>
<td>I find I always feel hungry.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<td>25</td>
<td>Staying away from junk food is difficult.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>26</td>
<td>I have trouble reading all the labels on food packages.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>27</td>
<td>I have late night snacks or meals and then feel very tired the next morning.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>28</td>
<td>I have difficulty eating smaller portions of food.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>29</td>
<td>I find myself needing to eat all the time to maintain sugar levels.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>30</td>
<td>I get frustrated because I can't lose weight.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>31</td>
<td>A routine or plan helps me to exercise, eat better, and feel less stressed.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>32</td>
<td>I do strenuous exercise which causes my blood sugar to drop.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>33</td>
<td>I don't feel physically able to exercise.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>34</td>
<td>I find walking and exercise help me manage my diabetes.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>35</td>
<td>I think the difficulties that our ancestors faced, such as residential schools, play a part in diabetes.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>36</td>
<td>I don't want my family members, friends or co-workers to know I have diabetes.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>37</td>
<td>I want to pass on good habits to future generations by being a good role model.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>38</td>
<td>I fear leaving my family or loved ones behind.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>39</td>
<td>I am aware of my body and how it feels.</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
</tr>
<tr>
<td>40</td>
<td>It is difficult to slow down and do what I need to do to manage my diabetes</td>
<td>O1 O2 O3 O4 O5</td>
<td>O1 O2 O3 O4 O5</td>
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<tr>
<td>41</td>
<td>I learn from the younger generations about how to take care of myself and live in a good way.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>42</td>
<td>I wish someone had taught me how to cook and eat properly before I got diabetes.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>43</td>
<td>I have found diabetes educational workshops helpful.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>44</td>
<td>I am worried about the prevalence of diabetes in our communities.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>45</td>
<td>Living in the city negatively impacts my eating and activity habit</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>46</td>
<td>Societal changes like the increased influence of television and computers have negatively influenced my activity levels and eating habits.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>47</td>
<td>We need more positive collaboration among Aboriginal peoples and mainstream knowledge about diabetes.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>48</td>
<td>Traditional ceremonies, such as smudging and the sweat lodge helps me feel calmer and manage my diabetes.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>49</td>
<td>The support and companionship of sharing circles for groups of people living with diabetes are helpful.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>50</td>
<td>Learning about Aboriginal culture can help our communities overcome diabetes.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>51</td>
<td>I have received help from seeing Elders and traditional counsellors about my diabetes.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
</tr>
<tr>
<td>52</td>
<td>Diabetes is a spiritual wound of our people that has not been dealt with.</td>
<td>1  2  3  4  5</td>
<td>1  2  3  4  5</td>
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</tr>
<tr>
<td>53</td>
<td>Our cultural teachings like the Medicine Wheel (balancing physical, mental, emotional and spiritual wellbeing) can help us live well and manage our diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>54</td>
<td>Traditional medicines have helped me more than medicines from the medical doctor.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>55</td>
<td>When I was growing up I wasn't able to talk about my feelings and I think that had an impact on stress and getting diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>56</td>
<td>Our people need to talk more about how to care for ourselves and be responsible for our own health and healing.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>57</td>
<td>I use food to comfort myself or suppress feelings.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>58</td>
<td>I feel possessed by food.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>59</td>
<td>Diabetes is like an addiction.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<td>60</td>
<td>I was or am in denial about having diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>61</td>
<td>I am my worst enemy because I sabotage myself.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>62</td>
<td>It is difficult to change the habits I have acquired throughout my life.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>63</td>
<td>I wish I could find ways to control my diabetes instead of my diabetes controlling me.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>64</td>
<td>I am not being serious about managing my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>65</td>
<td>The first step to living healthy is accepting that I have diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>66</td>
<td>I fear dying of complications from diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>67</td>
<td>Maintaining hope and a positive outlook is important in managing my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<td>#</td>
<td>Statement</td>
<td>How strongly do you agree with this statement? 1=not at all 2=slightly 3=somewhat 4=very much 5=completely</td>
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</tr>
<tr>
<td>68</td>
<td>Diabetes has helped me re-evaluate my lifestyle and change my life for the better.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>69</td>
<td>I need to find a way to express my feelings in a way that is healthy.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>70</td>
<td>I struggle to keep up or compete with others who do not have to manage diabetic symptoms.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>71</td>
<td>It is important to not be alone or isolated as I manage my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>72</td>
<td>I find volunteering and getting out in the community helps me manage my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>73</td>
<td>I worry that my depression may make me give up on managing my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>74</td>
<td>Prayer has helped me to be calmer.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>75</td>
<td>The additional stresses of everyday life make it harder for me to control my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>76</td>
<td>Alcohol and/or drugs are a major obstacle to managing my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>77</td>
<td>My own anger and bitterness prevent my doctor from helping me.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>78</td>
<td>I feel hopeless in being able to control my diabetes.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>79</td>
<td>I think diabetes can lead to depression.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

**CHI MIIGWETCH!!!!!!**