

DIVERSE COMMUNITIES

Consultation to Explore Perspectives on Organ
and Tissue Donation

SECTION IV

Indigenous Peoples' Dialogue:
Winnipeg: November 4 – 5, 2005
Saskatoon: March 1-2, 2005

TABLE OF CONTENTS

INTRODUCTION.....	IV-1
CLARIFICATION OF KEY TERMS	IV-2
APPROACH	IV-3
PLANNING THE CIRCLE.....	IV-4
PARTICIPATING IN THE CIRCLE.....	IV-7
SUMMARY RESULTS OF THE CIRCLE	IV-9
DETAILED RESULTS	IV-16
EVALUATION OF THE CIRCLE	IV-49
CONCLUSION	IV-50
APPENDIX A: PROTOCOLS FOR APPROACHING ELDERS.....	IV-52
APPENDIX B: CLARIFICATION OF TERMS.....	IV-58
APPENDIX C: STEERING COMMITTEE VALUES.....	IV-60
APPENDIX D: ELDERS' AND TRADITIONAL KNOWLEDGE KEEPERS' CIRCLE INFORMATION PACKAGE	IV-61
APPENDIX E: WINNIPEG ELDERS' AND TRADITIONAL KNOWLEDGE KEEPERS' EVALUATION RESULTS	IV-72

INTRODUCTION

In Canada, there is a “persistent and growing gap” between the need for and supply of organs and tissues for transplantation.¹ This is particularly evident in ethnocultural communities because of the difficulty of finding compatible organ donors. Biological differences associated with tissue and blood typing make the waiting time for people from ethnocultural communities almost twice as long as for Caucasians.² The field of donation and transplantation is relatively young, with the first transplant being done in Canada in 1958.³ As transplants have become more routine occurrences, the need for organs consistently is greater than their availability. The decision to donate organs or tissues or to receive a transplant, in addition to being a medical decision, often involves complex and personal ideas about life, death, life after death, giving to others and sometimes political/historical considerations.

The first step toward making it easier for people to consider donation is to understand the variety of beliefs and attitudes that contribute to the decision to donate. The CCDT intends to improve donation rates through “strategies to ensure that the public not only supports donation in principle, but that Canadians take steps toward donation as a concrete individual and family consideration.”⁴ For Aboriginal Peoples, the largely western-European, biomedical approach of the health system does not always facilitate consideration of donation in ways sensitive to Aboriginal history, ceremony, traditions and beliefs. Although there is evidence that chronic diseases such as diabetes are affecting many Indigenous people, the tendency to donate or receive tissue and organs is perceived to be low for this group.

To understand the views and beliefs of Indigenous Peoples, we asked them, in a respectful way, to share their views about organ and tissue donation and transplantation. On the advice of several First Nations people about what the most respectful way would be, The CCDT Ethnocultural Steering Committee convened two Elders’ and Traditional Knowledge Keepers’ Circles; one in Winnipeg and one in Saskatoon. The aims of the Circles were to identify the range of beliefs and attitudes that may influence Indigenous Peoples when considering donation; to advise on a successful model for respectful dialogue with Indigenous Peoples; and to start or support a partnership between the Indigenous Peoples and the local donation and transplant programs.

Winnipeg and Saskatoon were chosen as sites for the dialogue because the largest proportion of Indigenous Peoples lives in those cities and the surrounding area. The highest concentration of Aboriginal population is in the north and on the prairies. Aboriginal Peoples are about 14% of the population in both Saskatchewan and Manitoba. The highest concentration of Aboriginal Peoples is in Saskatoon at 9% of its population. Winnipeg is second with a concentration of Aboriginal Peoples at 8%.⁵

The Circles were guided by six topic areas including participants’ awareness of and experience with organ donation and transplantation; views toward organ donation and transplantation; traditional values and beliefs which influence Indigenous People in regard to donation and transplantation; Support for donation decision making process and future opportunities for relationship building.

¹ CCDT RFP Reference Number D-EC-04-01, p. 2.

² Mulcahy, M. (June, 2003). “A summary of the attitudes, beliefs and values about organ donation of a variety of ethnocultural communities. p. 2.

³ Found at Health Canada website at http://www.hc-sc.gc.ca/english/organandtissue/facts_faqs/first.html on December 23, 2004.

⁴ CCDT Annual Report. (2003). P. 3.

⁵ Ibid, p. 10.

CLARIFICATION OF KEY TERMS

Western approach

The term “Western” refers to a mind-set that is a product of European culture that has been diffused into North America. Western thought is a system of knowledge, rules and values that came from Europe and the Western Hemisphere.⁶ “Eurocentrism is the notion that European civilization or the “West”, has some special quality of mind, race, culture, environment or historical advantage which gives this human community a permanent superiority over all other communities.”⁷

Indigenous Peoples

“Indigenous Peoples are the tribal peoples in independent countries whose distinctive identity, values, and history distinguishes them from other sections of the national community. Indigenous Peoples are the descendants of the original or pre-colonial inhabitants of a territory or geographical area and despite their legal status, retain some or all of their social, economic, cultural and political institutions.”⁸

Aboriginal Peoples

Aboriginal Peoples are defined as a North American Indian, Métis or Inuit.⁹ Aboriginal Peoples include people who would describe themselves as First Nations, Inuit or Métis. Within First Nations, people might describe themselves as Mohawk, Woodland Cree, Plains Cree, Swampy Cree, Ojibway, Dakota, Salteaux, Sioux, Dene or others. We were advised that the most respectful term is Indigenous Peoples rather than Aboriginal Peoples.¹⁰ The words Indigenous and Aboriginal will be used interchangeably in the report.

Culture

A distinctive way of life that characterizes a given community; it is the shared practices, beliefs, values and customs that are passed down from generation to generation.¹¹ Kirkham, Smye et al.¹² suggest that culture is neither neutral nor unitary. They took the approach of using the concept of cultural safety, which suggests “the notion of respect for one’s cultural origins, beliefs and practices but with its post-colonial attention to historical power differences...”¹³ Kirkham, Smye et al. suggest “culture as embedded in fields of power relations; as mediated by social forces such as economics, politics, and historical patterns of oppression and colonization; and as being constantly renegotiated.”¹⁴

⁶ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics, p 5.

⁷ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 5.

⁸ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 5

⁹ Statistics Canada (January 2003), “Aboriginal peoples of Canada: a demographic profile”, p. 6.

¹⁰ Personal conversation with Willie Ermine, Ethicist, First Nations University.

¹¹ Menssah, L. (1993). Transcultural, cross-cultural and multicultural health perspectives in focus. *Health and Cultures* found in Kirkham, S., Smye, V. et al. (2002) *Rethinking cultural Safety While Waiting to Do Fieldwork: Methodological Implications for Nursing Research*. Research in Nursing and Health. 25, p223.

¹² Kirkham, S., Smye, V. et al. (2002) *Rethinking cultural Safety While Waiting to Do Fieldwork: Methodological Implications for Nursing Research*. Research in Nursing and Health. 25, p223.

¹³ Kirkham, S., Smye, V. et al. (2002) *Rethinking cultural Safety While Waiting to Do Fieldwork: Methodological Implications for Nursing Research*. Research in Nursing and Health. 25, p224

¹⁴ Kirkham, S., Smye, V. et al. (2002) *Rethinking cultural Safety While Waiting to Do Fieldwork: Methodological Implications for Nursing Research*. Research in Nursing and Health. 25, p. 222.

Elder

An understanding of the term, “Elder” is useful in appreciating who attended the Circles. One author notes, “The general standard is acceptance by the community as an Elder. This is a status that denotes a great deal of wisdom and experience, and the living of an ideal ‘Aboriginal’ lifestyle.”¹⁵ Marlene Brant Castellano states that “Elders typically have been educated in the oral tradition, apart from the colonizing influence of the school system. They carry credentials that are recognizable within Aboriginal society but are invisible to those who assess expertise on the basis of formal education. They enjoy respect as sources of wisdom because their way of life expresses the deepest values of their respective cultures. In many cases, they have exceptional skills in transmitting these values to those who seek their counsel.”¹⁶

Each Elder has his or her own role to play. An Elder is consulted on a range of issues from personal to community matters such as:

- Knowledge of traditional concepts and beliefs, spirituality, ceremonies and other practices;
- Conducting traditional spiritual ceremonies;
- Providing guidance and advice;
- Prayers to bless events;
- Accurate information about Aboriginal heritage and Aboriginal communities;
- Insight on the historical role of Aboriginal peoples in Canada; their contemporary situation and aspirations.

There are respectful ways in which Elders are approached for advice, to request prayers, for participation in a meeting and in showing gratitude. Appendix A describes the protocols for approaching Elders for advice. Clarification of additional terms can be found in Appendix B.

APPROACH

Early in the planning, the consultants sought the advice of First Nations people, who suggested that the most respectful way to consult with Indigenous Peoples was through an Elders’ and Traditional Knowledge Keepers’ Circle. Research has found that there was a lack of trust of health care professionals, the health care system, government and researchers among people of Coast Salish origin living in British Columbia.¹⁷ We imagined that some lack of trust might also be found among Indigenous Peoples in Winnipeg. It was, therefore, of primary importance to conduct the dialogue with respect, using the traditions and ceremonies of Aboriginal Peoples.

We entered into the dialogue diplomatically, recognizing that the difficult history of Indigenous peoples, as a result of “colonist policies which led to a loss of traditional lands, relegation to reserve communities, residential schooling and the erosion of language and cultural traditions”¹⁸ “.....the term mistrust is emphasized because the course of Western colonialism following contact, with its trail of misconceptions, deception, domination and even violence, has left a distinct and sour imprint in the minds of many Indigenous peoples about the possibility of forging any trustful relationships with the Western World.”¹⁹ Given this history, we knew that we would have to earn the trust of the people with whom we would be dialoguing. We wanted every action that we took in planning and participating in the dialogue to reflect our values - appreciation of diversity, collaboration, integrity, excellence, capacity building and learning. (See Appendix C).

¹⁵ Waldram, J. B., (1997) *The Way of the Pipe: Aboriginal Spirituality and Symbolic Healing in Canadian Prisons*. Broadview Press, p. 109.

¹⁶ Castellano, M., (January 2004). *Ethics of Aboriginal research*. *Journal of Aboriginal Health*, p. 101.

¹⁷ Molzahn, A., McDonald, M., Loughlin, C. and Starzomski, R. (2003). *Selected perspectives on Coast Salish beliefs regarding organ donation*. P.13-14.

¹⁸ Smye, V. and Brown, A. (November 2001). ‘Cultural safety’ and the analysis of health policy affecting Aboriginal people. P. 3.

¹⁹ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples’ Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 48.

Writing down what transpired during our Circle in some way diminishes it. The writer's values, experiences and worldview necessarily seep into the written word of this report. "Until you can understand that your own culture dictates how you translate everything you see and hear, you will never be able to hear or see things in any other way."²⁰ I understand my obligation to reflect the knowledge that was shared in the Circle in a respectfully and accurately, however my accuracy will be constrained by my Western training and heritage. To the Indigenous Peoples who read this report, I ask their patience as this "newcomer" explores and tries to reflect the issues and traditional knowledge that were discussed in the Circles.

The topic of organ and tissue donation and transplantation is sensitive in that it touches on people's deeply held beliefs about illness, death, care of the dying and life after death. We offered to assist participants to obtain support outside of the Circle if needed. We saw the topic more broadly than simply as a medical treatment for a disease. We understood that the topic might touch on historical, political, socioeconomic and personal experiences involving health care. We knew that this would be complex work and would require patience and sensitivity to accomplish it well.

The purpose of the dialogue was to gather information to provide the best advice to the Deputy Ministers of Health on how respectfully to help Indigenous peoples to consider donation and transplantation. We used a more iterative approach in that we asked a few Aboriginal people how to plan and operate the Circle and then we made continuous changes as we learned more as the process unfolded. We were working with the people to find the best way to discuss the topic and learn about their views and beliefs. We went with the approach of "what we will do in our next step will depend on what we see and find as we go deeper into the process.

PLANNING THE CIRCLE

The circle is an important symbol in Aboriginal spirituality since it represents the cycle of life that has no beginning and no end. The Circle does not usually involve feedback or challenging any specific individuals. Each person is given the opportunity to speak on any topic that suits them, for as long as they want.²¹

The first step in planning the Circle was to seek Aboriginal people who were wise in the traditional ways and who were willing to work with a consultant in putting the dialogue together. The consultant spoke with four Elders over the telephone, seeking advice on how to proceed. With each contact, the consultant indicated that if she could, she would make an offering of tobacco to make the connection better. Contact was made by phone and e-mail and the Elders indicated that an offering was not necessary due to the distance. The Elders gave advice on the range of views that could be expected and made suggestions about protocol to follow in establishing the Circle. One Elder was contacted in Calgary, who provided advice on how to get started but declined participation in the project, indicating that Elders generally do not participate in circles outside of their territory.

The Spiritual and Cultural Care Coordinator for the Winnipeg Regional Health Authority (WRHA) was contacted for advice and his help was invaluable to the success of the dialogue. The WRHA Coordinator also sent the consultation organizer the protocols that should be followed when contacting Elders and asking for help.

The process of identifying participants began with an introductory e-mail from the WRHA Coordinator to several Elders asking if anybody was interested in participating. Contacts were asked to identify others who had an understanding of the topic. Participants were selected based on their interest in participating, their role as an Elder or Traditional Knowledge Keeper and sometimes on the basis of their employment (e.g. Manitoba Health and Winnipeg Regional Health Authority). During the Circle, participants invited

²⁰ Ross, Rupert, *Dancing with a Ghost: Exploring Indian Reality* Octopus Publishing Group. 1992, p. 4.

²¹ Waldram, J. B., (1997) *The Way of the Pipe: Aboriginal Spirituality and Symbolic Healing in Canadian Prisons*. Broadview Press, p. 135.

others to attend who were unknown to the organizers. In some cases, people were invited to participate for the healing of the Circle due to their personal and difficult circumstances.

In planning the Saskatoon Circle, we did not have an equivalent Coordinator within the health system. Therefore, we began with a list of individuals known to the consultant and other advisors including the Saskatchewan Organ Donation Program. The circle of invitees was expanded by using the advice of the individuals invited in the first round. In addition, the representatives of the federal and provincial governments were helpful in providing advice on who to invite from southern Saskatchewan.

Once the plan for the Circles was in place, an Aboriginal Relations Advisor was hired to assist with facilitation of the Circle and further refinement of questions. We anticipated three rounds of the Circle, discussing a different set of questions in each round. A package of information, including the purpose of the Circle, the questions and the consent forms was sent to participants one week in advance of the Circle (see Appendix D). Each Circle was held for about 10 hours each over two days. Ceremony and protocol were followed in all aspects of the Circle. Participants were smudged, as was the space used for the Circle. Gifts and other objects were smudged and prayers were offered for each participant prior to the Circle.

Small gifts were provided to each participant. Gifting might be considered to be coercion from a Western perspective but this is not the perspective of Indigenous peoples. "In the past, when an anthropologist approached a First Nation tribe to document, for example, a ceremony, it would sometimes happen that faulty information would be given. If the researcher failed to "pay" for the knowledge being offered, he risked putting himself and the giver of that knowledge in jeopardy. In Cree, "pastahow" refers to this spiritual harm or "debt" that can be visited upon the relatives of future generations of the giver or receiver if knowledge if proper payment is not made. If you take something from someone, you have to give something back: this keeps life in balance. In this way, all knowledge is spiritual knowledge."²² When we approached the Elders for their knowledge, we brought them an offering of tobacco, a small gift and an honorarium. "To the Cree and other Indigenous peoples, the words used to express stories are considered sacred and must be used with great respect."²³ When you receive stories from a person, to restore balance, you return to them a gift. One Circle member put it this way "I was also touched by the gift of receiving and how much it means to be able to receive this (holds tobacco up). We take this for granted, but it means so much to be acknowledged, to be able to receive tobacco, although a lot of people say that it causes cancer, but for me, I look at it the other way, it is someone's thoughts and prayers for your wellness."

The Circles were audio taped. The transcript was themed by two individuals independently, one who attended the Circles and one who did not. The themes are presented as answers to the questions in the results section of the report. The results were circulated (as they appear in this report) to participants to ensure accuracy.

Ethical considerations

The dialogue was not academic research and therefore we did not seek the approval of a university-based ethics committee. Instead, we circulated our questions and approach to several Western ethicists and one Aboriginal ethicist for their advice. Mr. Willie Ermine, First Nations University provided advice on ethics from the Indigenous Peoples' perspective and Dr. Rosalie Starzomski provided advice from the Western perspective.

²² Timmins, L., Research as a spiritual contract: an Aboriginal women's health project. Network, Fall/Winter 2002.

²³ Michell, H. (1999). Patitinasowin: tobacco offerings in exchange for stories and the ethic of reciprocity in First Nations research. Found on the World Wide Web at <http://www.firstnationsuniversity.ca/indian%20studies/IndigenousThought/fall99/tobacco> on September 29, 2004.

Ethical space

The concept of “ethical space” was developed by Willie Ermine, First Nations’ University, as “a space between two entities, as a space between the Indigenous and Western spheres of culture and knowledge relative to research issues. Ermine’s perspective is that the affirmation for the existence of two objectivities, each claiming their own distinct and autonomous view of the world, and each holding to a different account of what they are seeing across the cultural border, creates the urgent necessity for an understanding of what constitutes this cultural divide.”²⁴ We recognized that our consultation would include two worldviews (Western and Indigenous). We attempted to the greatest degree possible (from within our own worldview) to embrace the existence of the cultural space and to respect what we encountered across the “cultural border”. Having said that, there were likely many things that were missed and perhaps not respected because of our own substantial confinement to our Western worldview. Marlene Brant Castellano describes this idea as “jagged worldviews colliding.”²⁵

The consideration of ethics provided fertile ground for learning about the differences between the Western and Indigenous Peoples’ worldviews. We learned, for example, that the idea of gifting was only one aspect where an Aboriginal ethicist might part ways with their Western counterpart. Whereas from an Aboriginal perspective, gifting is a respectful way to ask for advice and knowledge from a Western worldview, it could be considered coercion. Another example might be that from a Western perspective, anonymity and confidentiality are paramount, whereas from an Indigenous worldview providing the opportunity to be recognized as the owner of the information was important.

A brief and high-level comparison of Western and Indigenous views of ethical considerations will illustrate the difficulty in balancing the Western worldview from which the most of the organizers had emerged with the Indigenous worldview, from which the participants came. We followed the Aboriginal approach as much as we could, as limited as we were in our understanding of the Indigenous ways by our Western training, experiences and history. Ermine, Sinclair and Jeffrey (2004) illustrate some of the differences between the Western and Indigenous Peoples approach to ethics and we have drawn heavily on their work for our information.²⁶

Consent

For consent, the Western way emphasizes individual ownership and autonomy. This emphasis leads to the value placed on individual participants signing a consent form. This emphasis on individualism is in contrast to the Indigenous peoples focus on the community and collectivity, leading to the considering of community consent being as important as individual consent. Western ethics tends to view informed consent as a one-time event to be achieved whereas others view informed consent as “an ongoing process and not merely an event or ‘hoop’ to pass through...”²⁷ (This consultation followed the Western way in that we asked each individual to sign a consent form. We informed people about any perceived risks to their involvement.)

Confidentiality

The practice of ensuring confidentiality is a Western academic stalwart, however, from an Indigenous peoples’ perspective, the requirement of confidentiality “ultimately continues to silence the Indigenous voice.”²⁸ Ermine, Sinclair and Jeffrey (2004) note that “the practice of confidentiality can have the effect of

²⁴ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples’ Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 20.

²⁵ Castellano, M., (January 2004). *Ethics of Aboriginal research*. *Journal of Aboriginal Health*. 107.

²⁶ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples’ Health Research Centre to the Interagency Advisory Panel on Research Ethics.

²⁷ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples’ Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 31.

²⁸ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples’ Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 33.

featuring the researcher's voice in instances where acknowledging the views of participants and the knowledge system as the source of that information is important."²⁹

On the advice of Willie Ermine, we offered participants the opportunity to have the identity of the contributions remain confidential or to have recognition of their contributions. "As a 'dialogue', and a level playing field, the participants may want a bigger role than just being 'subjects'. That may be a question to be put forward. It may be that the Elders/Traditional people want co-authorship or want a bigger role than just providing information and being shut out of recognition in the knowledge creation. At times, being nameless and not recognized for contributions is a direct attack on Elder integrity and also on the knowledge system."³⁰ The Western idea of protection of individuals through confidentiality does not apply across cultures and may actually have the effect of unintentionally marginalizing Indigenous peoples.

Knowledge ownership

"Consultations' have taken on a negative tone for Indigenous peoples and may be classed the same as 'research' in the minds of many. Consultation must unfold on a level playing field and be transparent. Consultation must be turned into a 'dialogue' (about intentions, understandings,) between cultures."³¹ Traditionally, researchers gathered information from individuals who had given their consent and the participants did not have any input into what was written about them or the information that was shared.

Marlene Brant Castellano states a similar idea when she says that "Just as colonial policies have denied Aboriginal peoples access to their traditional lands, so also colonial definitions of truth and value have denied Aboriginal Peoples the tools to assert and implement their knowledge."³² Castellano goes on to say that ethics are not a set of rules to guide researcher behaviour in a task, but rather ethics are related to who you are.

Access to information

Willie Ermine advised us that seeking community approval for research would be important. "It is a matter of networking with the appropriate authorities in First Nations communities. It may require Tribal Council approval or involvement. Consultation in community will involve Chief and Council approval. Community work will need the support of local Health Center/staff. This process may then put the conditions in place for Elder involvement. This political process is important if policy development that will affect First Nations is being considered."³³ Mr. Ermine's advice came too late in our process to seek community and political approval for our project, however, in the future, achieving this type of input should be addressed.

PARTICIPATING IN THE CIRCLES

It was an enriching experience to be a part of the Circles and to be in the presence of Elders and Traditional Knowledge Keepers. The generosity of Circle members in sharing their thoughts and traditions was much appreciated and respected by the organizers.

Twenty-five (25) people participated in the Winnipeg Circle. The majority was university educated and all reported that they followed traditional spirituality. Most were from Winnipeg and a few were from northern Manitoba. The age range was 30 – 65 years with most participants falling into the 50 – 65 age range. Most participants were Manitoba Cree with three Ojibway, 1 Mohawk and one Métis.

Some participants mentioned that the Winnipeg Circle was pioneering work in using a traditional way of talking with Indigenous Peoples about donation and transplant in their communities. "I think in this room we are pioneering. I have certainly never been involved in any kind of talks like this, I think because the

²⁹ Ermine, W., Sinclair, R., Jeffery, B. (July 2004). *The ethics of research involving Indigenous peoples*. Report of the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics, p. 33.

³⁰ Communication received via e-mail from Willie Ermine on October 25, 2004.

³¹ Communication received via e-mail from Willie Ermine on October 25, 2004.

³² Castellano, M., (January 2004). *Ethics of Aboriginal research*. *Journal of Aboriginal Health*. 101.

³³ Communication received via e-mail from Willie Ermine on October 25, 2004.

world has modernized our traditions, our ceremonies. I am proud to be sitting in this room talking about where we need to go with this.” Another person said “I am just going to say thank you very much to each one of you for sharing and as you can see, regardless of what race we come from, we can all help each other and make the world more understanding and good for each other.”

The Saskatoon Circle had 30 participants from the province, although most individuals were from the middle and southern regions, with few from the north. Most participants were Saskatchewan Cree. We had the honor of having three generations of one family represented with a grandmother, mother and granddaughter attending the circle. It was very interesting to witness how similar family values were expressed through three different generational perspectives.

Indigenous worldviews reflect interconnectedness and wholeness among all living beings and things. The seen and unseen worlds are two aspects of one reality, with learnings being received from both worlds.³⁴ Our Circles contained learnings from both worlds as participants described personal experiences and opinions, their understanding of traditional knowledge and the information from the Creator as received through smoking the sacred pipe and through dreams.

The Circles provided a way to interact without hierarchy in a community of understanding brought together to consider organ and tissue donation in light of personal experience and traditional teachings. Traditional knowledge “is part of the collective memory of a community, and is passed on orally through songs and stories, as well as through actions and observations.”³⁵ Best practices for receiving traditional knowledge include:

- Respect the ownership, source and origins of the knowledge and the needs and sensitivities of its holders and obtain their approval and involvement;
- Take the time needed to establish a strong, trusting relationship based on honesty, openness and sharing.
- Provide value-added knowledge back to the community in the form of useful products (such as reports) and services and share equitably with the holders any benefits arising from the use of traditional knowledge.³⁶

One participant suggested that the Circle provided a way for everyone in the group to have equal power. “In Iroquois and Mohawk teaching again there is no individual that vested with power. Power is always to be shared by a group of individuals. We do not even have a word for power in our language. The closest we have in Mohawk is [Aboriginal words] it means the strength to look after your responsibilities. No power. The strength of a group of equal individuals will look after your responsibilities.”

One person said that all issues involving Aboriginal Peoples should begin with a Circle. “It shows me that the way I do my work, I see the spirit of the Creator when these things happen, and the Creator has brought us all together in the same spirit. Today, for what we are talking about, this is excellent, it is the way it should be, the way it should have been and hopefully this is the way it will be. When we talk about that we always say, [Aboriginal words] ‘May it always be that way in our minds’.”

In the first circle in Winnipeg, the Circle facilitator explained at the evening Circle and at the beginning of the next day that people did not have to participate or to answer any of the questions. She explained that the tape recorder would be operating. The facilitator placed a table/altar at the front of the room containing sacred objects, a smudge shell and a candle. Members were invited to smudge themselves as they arrived and in some cases, smudge was offered to those whose sharing created strong emotions and tears.

³⁴ Ross, R., (1996) *Returning to the teachings, exploring Aboriginal justice*, Penguin Press, Toronto, Canada p. 276.

³⁵ Environment Canada, *Aboriginal traditional knowledge and environmental management*. Found on the World Wide Web at http://www.ec.gc.ca/scince/sandesept02/article1_e.html on December 01.04

³⁶ Environment Canada, *Aboriginal traditional knowledge and environmental management*. Found on the World Wide Web at http://www.ec.gc.ca/scince/sandesept02/article1_e.html on December 01.04

In the second Circle in Saskatoon, the Circle was held in a traditional location and a smudge was offered as part of the ceremony. Individuals were told that they were welcome to receive the smudge or not, depending on their beliefs and practices. In addition, due to a different set up of the microphones, the facilitator was able to set up an altar with a candle, smudge and sacred objects in the centre of the Circle. By using the wireless microphones rather than a collection of standing microphones, we were able to enhance sound quality and leave the centre of the Circle unencumbered by technology. The symbolism of the candle was that of the “sacred fire” which is traditionally part of a Circle.

“Circles never have a structure, they more have a life, the life that we hold in the Circle today will have six different areas of focus.”³⁷ The areas on which we focused in the Circle are described in this section. The questions were placed on flip chart paper on the walls of the room. The questions were announced at the beginning of the Circle and after that, no intervention occurred to keep participants focused on the topics. Individuals were left to decide what was appropriate in responding to the questions.

SUMMARY RESULTS OF THE WINNIPEG CIRCLE

The following is a summary of the results of the Winnipeg Circle. Detailed results including extensive quotations follow.

Topic 1: Participants' awareness of and experience with organ donation and transplantation.

Just over half of the participants spoke of personal experiences with or knowledge of organ and tissue donation and transplantation with members of their immediate family (e.g., brother, sister, father) or one of their close friends or neighbors. People indicated that their attitudes and beliefs for and against organ and tissue donation often had been formed within their families, especially with their Elders.

Dreams and prayerful reflection during the Circle played an important part in changing some people's views to speak of and be more accepting of the topic.

Organ and tissue donation and transplantation are not seen as long-term solutions to increasing disease. Participants felt that Aboriginal People should be helped to take responsibility for more healthy lifestyles and diets, and especially to educate young people about the dangers of poor nutrition. It was apparent that the determinants of health for Aboriginal Peoples needed to be considered.

Topic 2: Participants' views toward organ donation and transplantation.

Donation and transplantation were not being discussed in the community but people felt it should be. Reasons for not discussing the issue included:

- Lack of an opportunity and a process to have the discussion framed properly within a respectful context for families and community members; and
- Long-standing resentment over lack of control of their own lives.

The points in favour of saying 'yes' to donation or transplantation included the desire to:

- Prolong the life of loved ones;

³⁷ Quote from Circle facilitator, Gaye Hanson during her introductory comments to the Circle.

- Keep a part of those they lost alive by giving part of their loved one's body to help another person;
- Return to one's own or a loved one's cherished state of freedom and health; and
- Live so that one could be there to raise grandchildren and pass on one's culture.

The points leading to saying 'no' to donation or transplantation included:

- Respecting the wishes of family members, including those who do not want to burden other family members;
- Following traditional teachings and conflicting values of not prolonging one's own life; and
- Self perception of not being healthy enough to donate organs.

Topic 3: Participants' views and traditional values and beliefs which influence Indigenous People in regard to donation and transplantation.

During the Circle people shared a number of rich examples and stories which contained teachings about traditional and non-traditional beliefs about life and death.

The following values/beliefs were mentioned by participants:

- Life is a gift and it is good to respect and honour the gift of life and to thank the Creator for the gift of life.
- Medical advances are also a gift from the Creator and the will of the Creator.
- One of the most precious gifts in life is freedom.
- Giving and receiving are both part of the freedom of having life, and both giving and receiving can honour life if done with respect. Ceremony is an important component of showing respect.
- Part of respect is that decisions come from the heart and are arrived at thoughtfully and prayerfully, through asking in a ceremonial process what donation means.
- It is important to respect each person's wishes and choice. The person himself or herself is the one to make the decision about what happens to his or her body.
- Sharing is an important value.
- Respect for our bodies is good, as is recognition of the unique nature of the person who gives a body part, and respect for that person's body part itself as a part of another living being with its own history and spirit.
- Relationship is important and there is a desire to be in relationship and dialogue with the donor, to know something about that person.
- Traditional beliefs about life and death are important when considering questions of donation and transplantation. These beliefs include:
 - Creator gives each person only a certain number of days and that is all;
 - People must keep all of their body parts after death or Creator will send them searching for the lost parts and they could be searching a long time; and
 - The spirit leaves the body after death to travel to the Spirit World.
- Appreciation of and honouring diversity in life is good, as is being able to balance between traditional views and increased medical requirements for peoples' lives and meeting their needs.

- Since we come from the thoughts and actions of the past seven generations, what we do also affects the next seven generations, and we are accountable to them and need to think of long-term solutions.

Topic 4: Support for donation decision making process.

Necessities that families require to help them make the decision about contributing to donation and transplantation and that health-care workers can be more aware of were:

- There is a need to educate people about donation and transplantation, and to provide that information in their language or through interpreters so that they can understand and make informed choices.
- Families themselves have to begin to talk about donation and transplantation and people have to let their families know their wishes.
- The health care workers and the system must respect and support the choice that individuals and families make.
- Health care workers must respect the families' need to go through the decision process at their own pace, including the importance of ceremony in the process.

Topic 5: Relationship building.

Ideas concerning how to go about continuing this dialogue with Aboriginal Peoples included:

- Keep talking more about the topic in the communities;
- Dialogue is needed between Aboriginal People and health system policy makers;
- Dialogue is needed between the organ recipient and the person giving the organ;
- Create a group of individuals who will continue dealing with these issues, and
- Respect the Circle participants and provide closure for them by sending the written results of the consultation.

Topic 6: Closing

Note: The following comments were offered in response to question six. More in-depth evaluation information was gathered during telephone interviews and is documented in a separate evaluation report.

The group felt that medical schools could definitely benefit from what had been learned in the Circle. In addition, they commented on what went well and what could be improved upon.

What went well during the Circle:

- They enjoyed the discussion and felt they were taking away something that had moved them personally forward on the topic; and
- The Circle had been well organized and conducted with sensitivity to traditional values.

Things they would change included:

- Making ground rules explicit about sticking to the topic;
- Limiting each person's speaking time;
- Making the first evening session shorter; and

- Finding a venue that is a comfortable temperature where people can easily hear what others are saying.

SUMMARY RESULTS OF THE SASKATOON CIRCLE

The following is a summary of the results of the Saskatoon Circle. Detailed results including extensive quotations follow in the next section of the report.

Topic 1: Participants' awareness of and experience with organ donation and transplantation.

Many participants within the Circle had a great deal to share about people – both family (E.G. sister, cousin, uncle, aunt, brother-in-law, Elder) and friends as well as some colleagues who had undergone transplant or dialysis. One person in the group had received a kidney from her son. Those in the Circle indicated that their attitudes and beliefs related to organ and tissue donation often had been formed through their experience in relationship to family and community members.

The experience with friends and relatives requiring transplant has made some of the participants more vocal about prevention. They spoke about living a healthier lifestyle in terms of diet and exercise and how important it is to get the prevention message out to family members, specifically youth.

One member of the group spoke about how transplant improves the quality of life of the recipient as the person on dialysis is “chained to the hospital”. The burden of being away from home and not being able to live in their home community was also seen as a significant factor in reducing the quality of life for a person on dialysis.

The process of “educating one another” through sharing the experience of donation and transplantation among family and community members was seen as a powerful and effective method or changing attitudes. Individuals can change their minds about accepting dialysis or transplant when faced with a real situation within their family. As one person said “We think differently when we get into a situation like this.”

The people who live a traditional lifestyle and live in a way that expresses values and beliefs that are more consistent with the historical perspectives are often reluctant to go to the hospital or consider kidney transplant, especially the “old ones”.

Topic 2: Participants' views toward organ donation and transplantation.

Organ or tissue donation and transplantation is a topic that many Aboriginal people do not know much about or are not willing to think about until forced to by their circumstances. Some of the participants were definite in their objection to the idea of donation or transplantation while others were not sure and had mixed feelings about what they would do given if faced with the need to make a decision for themselves or a close family member or friend.

Although donation and transplantation were not being discussed in the community, people felt it should be. Reasons for not discussing the issue included:

- Concern about the differing views that people have and the worry about possible conflict;

- Feeling that they do not know enough to express an informed opinion. In some cases, a lack of medical and “mainstream” knowledge was a concern along with a lack of knowledge about traditional values and beliefs related to the subject.

The points in favour of saying 'yes' to donation or transplantation included the desire to:

- Donate in order to relieve another person’s suffering, particularly children;
- Respect the decision of the individual to donate or receive a transplant if that was their choice.

The points leading to saying 'no' to donation or transplantation included:

- Whether it is really our choice, as human beings, to extend the life of an older person or not. Traditional beliefs would say that the decision is in the hands of the Creator;
- Lack of information and little personal attention or family/community dialogue on the issue.

The points supporting indecision included:

- “I am not sure and I won’t know until I have to cross that bridge myself – at this point there is no right or wrong answer.”
- Feeling “pulled both ways” due to internal conflict over traditional teachings that our “Creator wants you whole when you go away” versus wanting to help someone else live on and having the comfort that “part of her or him remains on earth serving another human being”.
- Members of the same family can go either way on the decision and in one case, two sisters made opposite choices and the family had to respect both choices.

People raised specific questions that spoke to a need to know more about the person who either donated to them or to whom the donated organ or tissue is going. The need to understand the impact donation or transplant may have on many emotional and spiritual levels beyond the physical. One person who is Aboriginal said “I do not want to look through a white person’s eyes. I would have to shut my eyes in order to feel with my heart.” Another said “If my daughter dies, I would like to know where her parts will go.”

One participant expressed an opposing view, telling the story of a couple who did not want to meet the person who received their son’s eyes after his death. The feeling expressed was that “looking into our dead son’s eyes would be like losing him all over again.”

The range of opinions expressed indicated the need to look at the issues of confidentiality and privacy that may currently act as a barrier to individual making donations or receiving transplants to have the information they need to make meaning of the experience.

Topic 3: Participants’ views and traditional values and beliefs which influence Indigenous People in regard to donation and transplantation.

Participants expressed the view that life is sacred and there is great respect for life embedded in traditional values and views. The stories shared expressed the following values and beliefs:

- Choices about donation and transplantation are sacred, personal decisions which are typically made within the context of a family. People have been given a brain and free will to choose and it is essentially a process of using the traditional teachings and a person’s own reasoning capacity. Community information and consultation sessions help to support decision making.

- Due to the sacred nature of the decision, there is a need for guidance through prayer connecting to the spirit world and ceremony. It is important to look to elder guidance through stories in the Aboriginal languages, and through the traditional ceremonies for help in finding the answer to the sacred decision. There is a willingness to be flexible and open to what is spiritually appropriate in the present.
- Respect for the body means that we should not mess with them and a traditional Aboriginal person should not be a doctor, nurse or undertaker.
- Life is sacred and there is a great respect for life, therefore we should fight for life and for the traditions that reinforce life.
- Ceremonies are crucial to staying physically, mentally, spiritually, and emotionally balanced. There is a ceremony for everything in order to live a good life. Ceremonies take people spiritually all the way through life and are opportunities for healing. When the gift of life was taken and lost, so was the First Nations' health, which can be retrieved by living a good life with ceremonies to guide life.
- Healing comes through ceremonies.
- After death, the spirit leaves the body and journeys to the spirit world. The person goes back to the Creator spiritually whole. "When we leave the earthly world to enter the spirit world, we don't take our body. Mother earth looks after that."
- Sharing is a key value, including that animals share their bodies so that the people may live. People are willing to help one another whenever they can. There is some hesitation in accepting or donating organs because people don't know anything about the kind of person they are coming from or going to.
- Some people felt that respect for the body means not removing any organs. The traditional belief is that a person should keep all of his or her body parts or bad things will happen. One belief is that when it our time to go to the spirit world, we go. If not, we can get caught between the earthly world and the spirit world and that can cause suffering in your family members.
- Language and stories are sacred ways of understanding who the Aboriginal people are and in understanding the culture and principles of good living. Secret oral narratives told in traditional languages have spiritual knowledge, concepts and ideas embedded in them. Ceremonies also contain concepts and ideas that may provide precedence and prove relevant to the discussion of donation and transplantation.
- Many Aboriginal people are in the midst of recovering their own culture and spirituality in the wake of the residential school experience. Some are feeling the pull of "living in 2 worlds", i.e., trying both to honour the traditional teachings of the elders and to live in the modern world. Questions about donation and transplantation come from a western rather than Aboriginal perspective, and are a recent phenomenon made possible by technology and a western medical establishment which is not trusted by elders.
- Hospitals and the western medical establishment are resisted by the old people because they are wary of yet another form of colonialism, another kind of invasion of the Aboriginal peoples' space, including very private space. The western medical establishment has taken over responsibility for the health of the community. Continued debate and mutual education, and especially that the Aboriginal voices, the views of the elders, educate the western medical establishment about their issues are important for the future.

- There is some hesitation in accepting or donating organs because people do not know anything about the kind of person the organ is coming from or going to. “To get someone else’s heart, in our belief system and way of looking at things, could change a person as choices are made with the heart.” Another person spoke about a 16 year old son who was a “good person” and that the parents did not want part of him to live on in a person who was not as good.

Topic 4: Support for donation decision making process.

Participants felt that support and advice is needed for individual and families making decisions about organ donation or transplantation. Participants had the following ideas about support:

- People should be encouraged to talk about this topic early with their families and make their wishes known long before the time actually might come.
- One person thought that some parents might later feel they were let down by the system if health professionals did not offer the opportunity to have them donate a dying child’s organs at the time
- There was strong support for wide spread education sessions "so that people can think about it ahead of time." Education needs to go both ways: i.e., education by the Aboriginal community of the western medical establishment and public regarding traditional ways of approaching the topic, as well as health professionals educating Aboriginal people about the issues and their options in donation and transplantation. The educational approach must be visual, incorporate experiential learning, be culturally appropriate, and emphasize that the personal choice belongs to the individual within his or her family circle.
- Emphasis must be on individual choice within the family circle and the choices made should be respected by the medical system.
- There was quite a lot of discussion about the importance of ceremony as support to the personal decision, and making sure the family has the desired Elder support and time and space for prayerful ceremony and guidance.
- Basic information is needed to provide simple, straightforward answers on topics such as what the health system does with removed organs; what is the definition of “brain dead”, having a chronic disease does not mean that you cannot donate, matching is more critical for bone marrow than any other tissue and that organ are not accepted from people with high risk life styles, for example.

Topic 5: Relationship building.

In order to build relationships, participants in the Circle wanted to see more circles like this one, especially in the schools, and other places like community events, to reach youth. Other suggestions included:

- Working through the schools, and the Band Health Directors and Health Committees and health fairs or other community events.
- Producing and distributing different types of educational resources, including: pamphlets both for the mainstream and targeted for Aboriginal people; culturally appropriate videos, especially taking advantage of videos already available through work underway in Manitoba and Ontario; and having a special showing of movies

such as 'Return to Me' whose plot concerns the lives of people who donate and receive organs, followed by a public discussion of the topic.

Topic 6: *Closing*

Note: The following comments were offered in response to question six. More in-depth evaluation information was gathered during the telephone interviews and is documented in a separate evaluation report.

One prominent learning was the need for time and space for individuals and families to make the decision, often involving prayer and ceremony and the presence of elders for guidance. In addition, the following feedback was offered:

- Aboriginal participants appreciated the attention paid to the traditional ways of meeting: smudging, the gifting, opening prayer, the circle itself and candle symbolizing the traditional fire.
- Participants appreciated the opportunity to review the findings if they wished.
- Circle participants working in the health field learned about the traditional Aboriginal need for prayer and ceremony. They indicated they would take the learning back and incorporate it into their ongoing work, and in the development of educational and promotional material.

DETAILED RESULTS: WINNIPEG

The following is a detailed representation of the points that 25 participants made during the Elders and Knowledge Keepers' Circle held in Winnipeg, in early November, 2004, concerning their experiences and views toward organ and tissue donation and transplantation. These results are presented as summary statements under each of the six questions that guided the discussion, using peoples' words as recorded during the session as much as possible to illustrate the points (in italics).

Topic 1: *Participants' awareness of and experience with organ and tissue donation and transplantation*

People in the Circle generously shared their awareness and experiences. Just over half of the participants (8 out of 15) spoke of their personal experiences with organ and tissue donation and transplantation. These had occurred with members of their immediate family (e.g., brother, sister, father) or one of their close friends or neighbors.

My deceased brother had to undergo dialysis for a number of years, and the last few years I had the blessing to be able to spend time with him and to reminisce about his freedom..... He would not give into the idea of asking anyone for organ donation. (K.C.)

They asked us if we would allow them to take his lungs, his kidneys, his heart, and that decision had fallen to me at that time because my older brother had come home to Winnipeg. I could not make that decision. He was my dad. So the only other person there was my Grandmother, his mother. (L.B.)

One of our best friends, you may know her too, and she probably went through a heart transplant yesterday. (C.B.)

People indicated that their attitudes and beliefs for and against organ and tissue donation often had been formed within their families.

But my Grandma said [Aboriginal words]. She said when he was born he was born with all what he has in his body, let him take it back with him. So we went and told the doctor, and the decision was made to unplug the machines at ten to eleven the next day, Saturday. ...I always remember that, and when I look at my life and every year when I renew it in August, and look at my life and I look at that card and I wonder, should I sign it? Then I can still hear my Grandma's voice and I cross it, I do not sign it. That is still very strong in my belief for that. (L.B.)

My greatest teacher was my own mother. She raised us by herself after my father died when we were just children. She always worked to support us and she used to say, "If my children ever needed a kidney, I would not think twice to give them one of mine." So she passed that on to us, and I guess we are the same, my siblings and I, if anyone of us in our family needed it, we would stand in line to see which one of us could give it. We have also signed our driver's license card where after we pass on, they can take whatever to pass on to someone else who could live longer. (D.N.)

People in the Circle did not really talk about whether knowing someone who had donated or consented to donation had changed their views about it. Rather, some people told of how hearing other peoples' stories in the Circle, and their own personal prayers for guidance, had stirred dreams and deep reflection about this topic which they shared with the Circle participants as new thoughts:

I feel at peace now today. I had a dream that I was holding my kidneys and saying who am I supposed to give them to? And many things became clear to me. I hardly slept last night. I remember some of the things I have heard Elders talking about. I was focusing on the ones that said to not give our body parts away. But I also heard people say that we did not have these diseases long ago and we need to focus on where it is coming from... There are a lot of things that I have to think about, and I have to think about them differently because my dreams tell me that when you sign that donor card, that is a life gift, and it really turned my thinking around. When I was going to sleep I was praying for guidance because I was always torn between this and that. Then when I had that dream I could see myself standing and holding my kidney and blood dripping down, and I was being told that it is not up to me. (M.O.)

Last night when I spoke, I was totally against giving body parts, because that is the way that I was brought up. But I had a dream last night, too. In this dream I had an event that had happened to me a few years ago...He phoned me one day and he said I am sitting here on the road and I am staring down on a great big huge snapping turtle. He asked me what I wanted him to do with it. I knew darned well that I had dreamed it and I was supposed to have a turtle rattle for the work I do, I won't say much about it. The society that I belong to is the [Aboriginal name] and we use a big turtle rattle for healing. He said, "Here you go. This is what you need to do your work, you take every bit of me. But do it in a good way, with honour and respect." So my kids now laugh because I am always so emotional, I cry over everything. For four days I cried for that turtle. I actually had tears for that turtle because I recognized exactly what that turtle was giving up. My Elders always told me that if you need things you go to the animal world and they will give it to you. You go to the rock world, they will give to you, you go to the tree world they will give it to you. Last night, when I sat in the Circle at Thunderbird House, I was listening to people but I was thinking as a very arrogant Mohawk that we do not give our body parts away. Number of days, that is all there is to it. Then I had the dream last night about this turtle, and I realized that sometimes we give whatever we have to give, because people need it. (S.W.)

Several people also expressed the clear concern that organ and tissue donation and transplantation are not long-term solutions to increasing disease. People spoke of the need to help Aboriginal People take responsibility for more healthy lifestyles and diets, and especially to educate young people about the dangers of poor nutrition.

We have to watch our diets. This friend of mine, grew up in the country, and she decided to go back to eating what she ate when she was little. She has lost a lot of weight, I barely recognized her, she had lost 55 pounds, and it really showed on her, she is a short woman. I grew up living on moose and beaver and fish, and those sort of things, and it was very rare that we had beef when we were growing up. I remember we used to milk the cows, they were just for milking, not for eating. We had horses, the way we ate was everything from my Dad hunting ducks and rabbits and we had that sort of stuff and potatoes we grew ourselves. Corn, our vegetables, we grew ourselves. (L.B.)

Even when we are having children, how we are abusing and bringing children into the world. I guess if that does not stop in some way, we will need a lot of body parts. I know that I was in homes where people that were wanting kidneys and wanting different things, but you wondered how they really got there? They were not eating properly, they were smoking all the time, even in the home with young children there. You thought, OK if they even got an organ, how long would it actually last? (D.S.)

We did not have diabetes long ago. It has become an epidemic in the last few years, one of the things we are doing in our community is we have a healthy food policy in our school. I can see the difference, they are not so hyper, not so angry, and I believe it because of the parents that are giving a guideline of what to put in their kids' lunches. Sometimes the kids are already across the street with a bag of chips and a Coke for lunch. I have always told the kids that what they are doing is you are making sure that you will have diabetes. They think it is something that happens to old people. (M.O.)

I think there is a greater issue there of why this disease has afflicted our people that we need to concentrate on – our diet. There are people that are stopping us from accessing the important things we need to eat to regain our health. We also need short-term answers as well. For those people that are in the hospital today, saying “I need a kidney, I can’t wait for a long-term solution.” I think making a choice is what we re talking about: what is going on now, and how do we get out of this to where we can get back to a sense of balanced health and wellbeing? (S.W.)

Topic 2: Participants' views toward organ donation and transplantation.

People in the Circle spoke of how donation and transplantation were not really being discussed in the community at this point in time. Reasons included: lack of an opportunity and a process to have the discussion framed properly within a respectful context for families and community members, and a long-standing resentment over lack of control of their own lives. There was the feeling that donation and transplantation should be discussed more within the community.

Knowing my community I believe that a lot of the people in our community are not into signing those little cards. I think people like myself need to have these kinds of sessions, this kind of information, because this is something that we do not really talk about. (C.B.)

The other thing that I know from where I come from, we have three generations... My generation is the last one. To this day, we talk about how we have not been able to be in control of our lives, it has always been taken away from us. Over and over again. I have even heard that from friends and family, grandfather, that again the [unintelligible] trying to control how we should do organ transplant. There is a kind of a resentment over it. (B.C.)

Then maybe that is why in my community we never talked about this, maybe that is what is going on. Maybe there is unresolved stuff about control and making choices that has to be dealt with first when it comes to making decisions about the body. ... But it does not

involve family, family sitting like this talking. We are not even talking this way in communities. I think one is a clan process where you could engage the family and deal with all these struggles if your family decides to do this, or not to. Not doing it requires a process as well. This whole thing about a driver's license and how you sign just drives me crazy because it assumes that everybody has a driver's license. That is not the way that it is. We all have Treaty cards, or healthcare cards. I think there has to be another process. (D.S.)

During the Circle people provided context for understanding why someone might say 'yes' or 'no' to transplantation or donation for themselves or for their family members in addition to the guidance provided by dreams and prayerful reflection. The points in favour included the desire to: prolong the life of loved ones, keep a part of those they lost alive by giving part of their loved one's body to help another person, return to one's own or a loved one's cherished state of freedom and health, and the desire to live so that one could be there to raise grandchildren.

I am sure that a parent and grandparent see your children, or grandchild, and if there is an opportunity for you to donate a part of your body to extend that life, you would take that opportunity. (K.C.)

...if it came to a point where I was losing my daughter or grandchild and what if something happened to them, the best thing that could happen to me is if I allowed a body part to be given to somebody else, I would feel so good inside. It would be a part of my child or my grandchild living again. (C.B.)

He had put his name in for organ donation and one night he was called and he went up and he received a kidney. Not long after, I stopped him at one of the gas bars as I was putting some fuel in my truck, and he was there pumping gas, and I had asked him that day, because his colour had returned and he was so grateful and how much he appreciated his freedom and his health." (K.C.)

"[We] are bringing up a granddaughter right now, we are parents again, she is four years old, and I have a grandson, his name is [Aboriginal name] and he is my boy. I have talked to his dad and his mom and when he is old enough I am going to take him full time and he is going to live with us and I am going to teach him. So I am going to have to live because I have to bring up these kids, and I want to teach them. (C.B.)

Context leading to saying 'no' included: respecting the wishes of family members, including those who do not want to burden other family members, following traditional teachings, and perceiving oneself as not being healthy enough to donate organs.

He would not give in to the idea of asking anyone for organ donation....He talked about organ and donors, but he loved his family so much he did not want to put them through that... (K.C.)

I would not jeopardize my children's health by accepting a donation from them. (C.P.)

I said I would probably never be able to do it because my Grandma is standing right here telling me [Aboriginal words]. She was a feisty little woman. (L.B.)

My grandmother was totally against it. She did not really like transplants, she would say, "[Aboriginal words]." "What does that mean, granny?" "Something bad will happen". I am starting to think about it. My cousin had a transplant and my grandmother said he was not having a transplant, but he really needed one. So after she passed away, my cousin got a transplant. (C.S.)

I also went through cancer three years ago, and in terms of donating, I do not think that I would be able personally to donate any parts of my body. I went through chemo and radiation and then my body parts would not be feasible for anyone to use. (P.)

Topic 3: *Participants' views and traditional values and beliefs which influence Aboriginal People in regard to donation and transplantation.*

During the Circle people shared a number of rich examples and stories which contained teachings about traditional and non-traditional beliefs about life and death. These comments also add to what has already been revealed about how decisions to donate organs or receive a transplant are made by individuals and within families. This section will provide a summary statement about each value/belief mentioned, followed by the words spoken by the participants that illustrate that value/belief.

- Life is a gift and it is good to respect and honour the gift of life and to thank the Creator for the gift of life.

...the Elder Great Grandmother would call us as family members and begin to gather what was needed to honour life, honour the Creator, as old as the people that would travel for many miles and for a long time to dance this dance of life. (K.C.)

That is what it is about, is life. Respecting and embracing each day. Each morning I get up and I thank the Creator that I have opened my eyes and I am on the top side of the grass and just asking that He guide me... (B.S.)

- Medical advances are also a gift from the Creator and the will of the Creator.

I also believe that us in terms of this society we are blessed, all the thoughts and all the things that we do in terms of advancement, of Western Medicine, technology, it is because it is the Creator's will. We are guided, and it is important that we work together. (K.C.)

I think there have been a lot of wonderful advancements in medicine, both traditionally and in the Western world, and if those things can help prolong life, then that is what I believe in. That is why I practice traditional teachings and lifestyle. (S.L.)

- One of the most precious gifts in life is freedom.

I believe that the greatest gift that we have is freedom, and the will to live. (K.C.)

This understanding of freedom. As Mohawk People, especially, we were told we have the freedom of speech, freedom of belief, freedom of want, if we work in a community that will never be wanting, it will always be able to share. It will have that freedom of choice. (S.W.)

- Giving and receiving are both part of the freedom of having life, and both giving and receiving can honour life if done with respect. Ceremony is an important component of showing respect.

...he lost his foot, his leg, his other foot and his other leg, then his fingers, and then his kidneys. But he had the will to live. His sisters got together and they had offered to decide if one of them would be able to give a kidney to him. It was really touching. He remembered what we called it, "Giveaway". I first learned of that [Giveaway] ceremony through my soul family, where Calvin is from, many years ago when I first Sundanced and Sioux Valley, and before that down south, ... There was a young man there,

actually, a boy that just turned 11 and that was his fourth Sundance and he had pierced. His people and his family came together and he had a massive Giveaway, and he spoke about giving thanks about his family that survived the Vietnam conflict, and some of his uncles had come back with missing limbs, and because of the action that revolved in Vietnam, ... and so he had this Giveaway. Then I was really, really taken at that. I had never experienced that before. ... So I began to understand what Giveaway was... the spirit of the Giveaway. (K.C.)

I was also touched by the gift of receiving and how much it means to be able even to receive this. We take this for granted, but it means so much to be acknowledged, to be able to receive tobacco, although a lot of people say that it causes cancer, but for me I look at it the other way, it is someone's thoughts and prayers, for your wellness. I equate this experience about organ donation and transplantation with giving and receiving, and that freedom of life. (K.C.)

- Part of respect is that decisions come from the heart and are arrived at thoughtfully and prayerfully, through asking in a ceremonial way what it means.

I think to be a donor is something that you have to be able to do from your heart, to be something that you want to do. (L.B.)

It is important that we seek counsel that shares different thoughts and ideas...and asking in a traditional way, in a ceremonial way about what it means to donate your organs, and what it means to receive organs, and it is the receiving of life. (K.C.)

Smoke your pipe and go to sweat lodge, and ask Creator for whether you should do more things. Find the message in a dream. (C.P.)

Quite frankly, I think the problem is there is no respect that I see in discussing this topic, and doing it ceremoniously. Doing what you have to do and framing it in a respectful way. (D.S.)

- It is important to respect each person's wishes and choice. The person himself or herself is the one to make the decision about what happens to his or her body.

I need to respect that, when they say it is just like with traditional medicine, I know that this medicine can help you, but I cannot go out there and hold them to that, that I need to respect their decisions, and it is the same with Western medicine, if one of my people that I am working with says I want chemotherapy, I need to respect that, or I do not want a transplant, or I want to donate, that I need to be respectful of their wishes. I think it is all about is balancing and respecting what an individual chooses, because we were given a mind and we can think for ourselves what it is we need to do. (K.B.)

But I am not saying that other people have to believe what I believe, it is their choice. It is everybody's choice, and that is my choice. I have talked to my kids about that already, and they all know. (L.B.)

So I came in and I sat them all down and I said, "You know, I cannot decide for you. This is your mom. " But they could not decide either, so I said for them to go ask their mom, it is her life. (M.O.)

In this process, then, the Cancer Society here at the Centre decided that we need to put her through chemo therapy and radiation, and she said no. The doctors got quite upset with us and said that she is only six years old, she cannot make a decision like that. We told them that in the Indian way, we cannot give her body to you. She has to do that. She has to make that decision. We sat down with her and we told her everything about chemotherapy, radiation all of this stuff, quality of

life vs. quantity of life. When we were done, she made the decision, she said I want to go home and play. I choose quality. Maybe it means that medicines in this world will give me a longer life, but I choose quality. (S.W.)

- Sharing is an important value.

If we can utilize what Creator has given us, by those basic teachings, like sharing, that is good. (S.L.)

We should not bring our Elders there, we have to cherish them, they are like our libraries, they tell us stories. So I took her out of there and I stayed with her until she passed away another year and a half later. She used to tell me lots of stories about sharing. She used to say, did you ever see a baby when it is born? I said no. She said it comes out of the mother, its arms are like this. I said, "Yeah". "Why do you think his arms are like this?" I said, "I don't know." "Acceptance" she said, "the child wants to be accepted. It wants to share its love. ...The knowledge of this is that I think we should share what we have with other people, in relation to organs. (C.S.)

- Respect for our bodies is good, as is recognition of the unique nature of the person who gives a body part, and respect for the body part itself as a part of another living being with its own history and spirit. This history/spirit may be transferred into the recipient of the organ or tissue.

I have been in a lot of different settings as part of my nursing training, and hearing that people donate their bodies to science. I remember going through my nurses training and thinking that our bodies are sacred, the Creator gave us this life, and we have to look after our bodies. (B.S.)

The body is a dignified instrument. The way that they do organ transplants, from what I have seen, I really do not want to go there. There is no respect involved. (D.S.)

There was a student and I remember we had to study anatomy and physiology and study this cadaver, this dead body, and they gave this man a name, like guinea pig 60. That was really eye-opening for me because coming from up North, it seemed like a disrespect of this body, just laying there, exposing it. I thought this poor man, what was his life like? Did he have family? Was he a father, a husband? (B.S.)

In the story it talked about after having this lung transplant she began to get this enormous craving for KFC chicken nuggets, and she could not figure out what was going on with her body. She felt it so strongly she almost had tears in her eyes every time she went past a KFC. This is a place that I should stop and go in. She began to question the doctors after a while because it was getting to the point where it was affecting what she was thinking, it was affecting her emotions, and physically. She went to the doctors and started asking questions about what was going on. The doctors did not have the foggiest idea. Then one day she happened to ask him would you find out who it is that gave me these lungs? The doctor went back and found out if the young man that had died a car accident that his lungs were taken and put into her body. He was a KFC chicken nuggets fanatic. He even had them in his pocket when he was killed in the accident. I tell that story occasionally because it reminds me that when we are talking about transplant and donation, we are not just talking about a physical piece of material. (S.W.)

...you are taking somebody's body part and to me in my mind, it is coming into your being.... Even things like amputations, for instance. People amputate a leg, and what happens to that poor part? It is still part of that person, do they ever think,

“OK, just lop it off and chuck it in the garbage?” There is just such a lack of respect. (B.S.)

- Relationship is important and there is a desire to be in relationship and dialogue with the donor, to know something about that person.

Aboriginal People see it differently. Yes, you have my brother’s heart, and a heart is very sacred to our people, when you listen to our language [Aboriginal word] there is a lot of [same Aboriginal word], what it means is heart. My grandmother used to feed everyone who came over, and I would ask her about this and she would say, “I do it because that is the way we lived a long time ago. Do you ever listen to our language?” I said yes. She said, “[Aboriginal words including the word for heart] what does that mean?” I said, “hungry”. If you break it down it means that when you feed someone their heart is going to open up, and you will be able to share your stories and people will feel comfortable. She taught me quite a bit. I think I am supportive of that, but there have to be certain stages implemented in relation to cultural sensitivity, in regard to Aboriginal people. I think that is the first step – there has to be a relationship to the donor. It cannot be just “OK, my brother’s heart is over there in Toronto.” There has to be some sort of dialogue or relationship in place. (C.S.)

Apparently they said that he did not have family, and he died alone and gave his body, he agreed to have research done. But I thought, this poor man! I felt bad for him, but at the same time he is benefiting people to learn. That is how I saw it. I said a little prayer in my mind and thanked him for this opportunity and I certainly respect what he has done. (B.S.)

They said that you are going to have a blood transfusion. I was really concerned about where they were getting the blood from, is it safe? Has it been tested? We are in Germany? Like the story about the guy craving McNuggets, I am thinking I am getting this blood transfusion, I wonder who this person is? I would have liked to have thanked them for the blood and donating. (B.S.)

- Traditional beliefs about life and death form an important context when considering questions of donation and transplantation. These beliefs include: that Creator gives each person only a certain number of days and that is all; that people must keep all of their body parts or after death Creator will send them searching for the lost parts, and that the spirit leaves the body after death to travel to the Spirit World.

We were taught as well that you were given two things in life only for you to look after: you are given a number of days that you are going to live on this earth, and that natural law, we do not argue against this. You are given a number of days and however that transpires, the Creator has that number of days in his hand. This is why as young people we are taught the first thing in the morning [Aboriginal words] I give thanks to you, Creator, or this day, so that He can put on his glasses and look at the number of days with that stick that he has up there and say, “oh, it is not your time yet” and He blesses us. When that number of days are done, that is when we go back to the Creator. (S.W.)

She died very peacefully, it was just her time to go. My mom told us as far back as I can remember that when it is your time to go, it’s your time. (M.O.)

I remember in a traditional way when I talked about this to the Elder down south here and the thing he said, like Kathy just mentioned, we go and we lose body parts, I did, I really did – it was my appendix, they took it out. I remember telling him while I had my appendix removed he said, “well I guess you will be searching for that for a long time when you go to the Spirit World”. That is what he says happens, after we pass away and we go to the Creator, and we go there with body

parts missing, He will tell us to go look for it. Go search, find what you have lost. When He created us, he gave us everything we needed to survive on this earth. (L.B.)

I had a really strong traditional mother, and she always talked about [Aboriginal words] and they go where they are not supposed to go. We come into this world intact and we leave that way. (B.C.)

Knowing what the teachings are in terms of the spiritual component, I believe that when you die, after prayer and ceremony my spirit will travel back to the Spirit World. And I will go fast because I will just jump on the horse and just go. (S.L.)

I believe as well, that Mohawks say when we die that our spirit goes for ten days around the earth, then we have that peace... We looked after that girl until she passed away a year later. This is a child that shared with us her dreams. All during that time when she could still talk and speak, which was right up until the last couple of months, she told us what was going on the other side. She never once asked for anything from us. We really began to understand one of the teachings that my Elder had taught me when I was young. He said, "[Aboriginal word] You need to learn you are going to die. Do you understand what I am saying?" When I was young I was all, "yes, yes, yes". "You need to learn that you are going to die, you were born, so it means that you are going to die, accept it. Once you do this, then you really start to have fun." Once you are not afraid of that anymore, you can start to have fun. Working with my daughter during that time, I became aware of this little child that had lost her fear of death. She began to talk about, "I am still going to live, I am just going someplace else for a while. There is nothing to be afraid of. (S.W.)

- Appreciation of and honouring diversity in life is good, as is being willing to hold the tension between keeping to traditional views and changing for the good of people and meeting their needs in the current situation.

The front of my yard is well grown, I take care of the lawn, but I was asked by my uncle not to clear the back because of the medicines, so there are all kinds of stuff in the back, all kinds of brush. Bear, deer, otter, all kinds of animals come out there. More recently we saw a lynx. In all of this, I am learning that we cannot all learn the same thing. Teachings have to be different. ... Medicines have a spirit, there is young medicine, and middle age and elder medicine, and each has different potency. You cannot just go in and gather this. Some it is the stalk, some it is the flower, another the roots, it is a combination of all these medicines that come together to be able to tackle what is wrong with us, so there is a lot of hope in your words, and thank you for them. (K.C.)

The best thing I learned is that I had very rigid thinking, and last night with that dream I realize that I have to bridge that gap between my thinking and my spirit. Knowing that what the old people believed was good, but we also have to be able now, the times we have now and use what is out there. (M.O)

The other thing that brought to my mind especially when I smoke this tobacco that was offered last night, and I got up early again this morning and smoked my pipe and asked for that direction, and although the teachings talk about how we get buried, from a preventative point of view, I do not want my body going back to Mother Earth in a poisonous state. I believe that she has been abused, I believe she has been harmed enough, and she needs time to recover. By my body not going there, that will prevent and break the cycle that I see happening today in terms of that. (S.L.)

Working as a nurse for a number of years and then working in counseling, I saw a lot of people that got organ transplants and also people that were giving up their

organs. Some of what these people said was that it is not our custom to give up our organs, our body parts, but what it is, the reason why that I feel is that we are now moving into another lifestyle, because now we do not have to look after ourselves. Young people can abuse their bodies and they will get a heart later, because they are going to be giving up theirs, so what it is then someone will give me another part. (D.S.)

...I was listening to people but I was thinking as a very arrogant Mohawk that we do not give our body parts away. 'Number of days', that is all there is to it. Then I had the dream last night about this turtle, and I realized that sometimes we give whatever we have to give, because people need it. (S.W.)

- Since we come from the thoughts and actions of the past seven generations and what we do also affects the next seven generations, we are accountable to them and need to think of long-term solutions.

Do you realize that for us to sit here today, it took 1,024 people seven generations ago to put their thoughts together, and their bodies together, their minds and spirits together to create us right now. If we go back to mom and dad, grandma and grandpa, and again... by the time we get seven generations back, that is 1,024 people that if they followed that way of thinking that what you do, you do unto seven generations coming, that means that us and our families 1,024 right now need to think of long-term solutions to diabetes, to these diseases that are afflicting us. Long-term solutions. (S.W.)

Most of our people who come sick and needing these transplants and dialysis. All of us have a responsibility to teach our young ones about our habits and behaviours, this is one of the things I have done in my work. I know that families have diabetes, and when I see these kids having the pop and chips for lunch, I think we all have a responsibility to give [unintelligible] in the home to make sure that our young ones are starting to learn proper nutrition. (M.O.)

The one freedom we were always denied and told we do not have is freedom from accountability. Marie just addressed something that we are all responsible, we are all accountable. When we put this in the context of seven generations coming, we are all accountable. (S.W.)

Topic 4: Support for donation decision making process.

During the Circle, as stories were told about personal and family experiences, people spoke of things that families need to help them make the decision about donation and transplantation. They also mentioned specific things that health-care workers can be more aware of and can contribute to that support.

- There is a need to educate people about donation and transplantation, and to provide that information in their language or through interpreters so that they can understand and make informed choices.

Working with Aboriginal People at the hospital with diabetes and they come from remote communities, and a lot of them experience language barriers. They do not really know enough about the disease. It is really important that they have an interpreter with them to fully explain to them exactly what it is. Even if they have renal failure they have to move here for dialysis. I have seen a lot of them who think that dialysis is a treatment and they are actually going to get better. One man said to me that his wife has been on dialysis for two years already, shouldn't she be getting well soon, we would really like to be getting back home. There is the lack of education for them, the doctors or whoever explains to them did not tell them that it

is not a cure. The ones that were awaiting transplant, one young fellow awaiting transplant he was in his late 20s, he said. "how long is it going to take them to make a kidney anyways? I heard that they are making me one." That is how he understood that he was waiting for a transplant but he was going to get a mechanical kidney put inside him. So I had to call the doctor and make some time to explain to him that he is waiting for a transplant because after somebody else dies he will get the kidney if it matches. He was pretty shocked to learn that because he said, he never knew that doctors could do that. All he thought of was that for a pacemaker, for example, he thought that was a replacement for the heart, I guess in a way it is, so he thought it would be done with the kidney. A lot of this is what communities do not understand, like renal failure and diabetes that goes into renal failure. I think they have to understand that then to realize about the organ donation and transplantation. By the time they come to the hospital they have already been through those diseases and they are already in renal failure, they are here to have dialysis, or to relocate here to have dialysis. (D.N.)

There is an old man from my community who became ill and was taken to the hospital and I think he was away for a week or two weeks then he was back again. People went to visit him and asked how he was doing and he said, "I am very, very sick. The doctor told me I am very, very sick." "Did he say what was wrong with you?" The old man replied, "Uh-huh, sugar by Jesus." [laughter]. He did not have an interpreter, so he did not understand what he had heard. (D.N.)

- Families themselves have to begin to talk about donation and transplantation and people have to let their families know their wishes.

It is everybody's choice, and that is my choice. I have talked to my kids about that already, and they all know. (L.B.)

Depending on whether it is an accident and they need to transplant now, or if it is a planned transplant, there are two different ways to go. But it does not involve family, family sitting like this talking. We are not even talking this way in communities. I think one is a clan process where you could engage the family and deal with all these struggles if your family decides to do this, or not to. Not doing it requires a process as well. (D.S.)

I have learned a lot listening to other people, making connections with other people. I know that I will be talking to my family. (M.O.)

- The health care workers and the system must respect and support the choice that individuals and families make.

Some patients have become tired of having their dialysis and they chose to give up and go home to die. They are allowed to do that, it is their choice. It is the patient's choice, whatever they want to do. As long as they understand that they are going home and they will die. (D.N.)

The Cancer Society wanted to apprehend her, so that we had to deal with the lawyers, saying that we were not acting in her best interests. She needs to go through chemo and radiation. Fortunately we had the neurosurgeon on our side and he said that this child is dead already. She will not recover from this, it is a terminal cancer, we do not even know what to call it much less treat it. Let the family take the daughter home. (S.W.)

The doctor said that we cannot ask her because she does not know anything. So I asked why he did not bring her medication down so that she could become aware of what is going on around her. So they did that and they waited for a couple of days and then I asked my sister, "Your children are in a very hard place, and they

cannot make the decision [unintelligible] and I said what do you want to do?" She said, "I am not ready to die yet. (M.O.)

One of our strongest teachings is respect, that is something we really have to think about when a family decides not to go through this procedure. Working in Aboriginal medicines, our people when they go into the hospitals with Western medicine a lot of times they meet barriers where healthcare professionals are not open to their taking medicine. I have been doing a lot of educating of non-Aboriginal People and Aboriginal People, about finding a balance. We regard Western medicine in a very respectful way, and our Traditional medicines we need to respect them in that same manner. It should be acceptable to approach a traditional healer according to our teachings, and not according to how someone else feels that we must do in, in terms of charging for it or "tell us what you are using that made this person better". People need to understand the sacred teachings of how those medicines work, or why they work. If we do not carry on those sacred teachings, the medicine is not going to work. It is very important to me working in Traditional medicine right now, there are people that have asked, "After this transplant happens, is there medicine that I can use to help me ... (K.B.)

- Respecting the need to go through the decision process at one's own pace, including the importance of ceremony in the process.

... I felt for her because she is dealing with grieving, and her sister, and trying to deal with that and they were bugging her and bugging her about donating her organs. Maybe she would have been more receptive had she been approached in a respectful manner. (B.S.)

I will share another story with you where a surgeon was going to take some organs from a patient. The family said that they would wait, they needed a chance to have a ceremony or smudging, and they needed to pray. So while they are doing their prayer work the surgeon is walking back and forth in the hallway. "When is this hocus pocus going to end?" he said. I think they need to learn that our people need to do these things before they just go ahead and donate their relative's organs. (D.N.)

Sometimes we forget about the human side of the health that we focus on what needs to be done, what needs to be accomplished and we forget about people, real people that have fears, everything. We can assist them so much to get through this if we take the time. Unfortunately, with the health profession, I was a nurse for many years and people were so rushed when you were doing your pills, doing your meds and you go in and you ask people, you say "How are you?" and you were always hoping they would say, "Fine." because if you had someone who broke down in tears or something you just did not have the time to sit and talk to them. We need to take that time. If you are going to ask, then you need to be able to provide that support they need. We have to remember that.

"Even amputations and those things, we need to remember that that is part of that person's body, we have to respect it and consult with Elders or whoever it is to help that process to heal. Often people have that phantom pain or whatever, and believe that limb is still there, and in their minds it probably is, it is just not there physically. (B.S.)

Topic 5: *Relationship building.*

In order to build relationships, participants in the Circle wanted to see more circles like this one, especially in the schools, and other places like community events, to reach youth. Other suggestions included:

- Working through the schools, and the Band Health Directors and Health Committees and health fairs or other community events.
- Producing and distributing different types of educational resources, including: pamphlets both for the mainstream and targeted for Aboriginal people; culturally appropriate videos, especially taking advantage of videos already available through work underway in Manitoba and Ontario; and having a special showing of movies such as 'Return to Me' whose plot concerns the lives of people who donate and receive organs, followed by a public discussion of the topic.

During the Circle people shared their ideas about continuing this dialogue with Aboriginal Peoples.

The points included:

- There is a desire to be talking more about this topic in the communities.

I think awareness has to be made to the actual communities in prevention, so you won't have to go and need a transplant... I think we should go forward with this transplant, but I look at these questions there, there has to be a consultation with communities, and not just in an urban setting in relation to organ donation. (C.S.)

I think one of the things I believe this is the first session in all of Canada, am I right? [yes] I think you know what has to happen back home is that knowing my community I believe that a lot of the people in our community are not into signing those little cards. I think people like myself need to have these kinds of sessions, this kind of information, because this is something that we do not really talk about. (C.B.)

I would like to talk more about that when we can in a couple of days of how, in our own communities, the necessity of talking about this and go to those places as to why we are not talking about this. Maybe there are other unresolved issues. I think in this room we are pioneering. I have certainly never been involved in any kind of talks like this. (D.S.)

I have really enjoyed this, I find it very important to continue the discussion on this, it does not matter at which level we work at, I am sure we can take something forward. I did not really talk to anyone about this, I prayed about it, but I can at least take forward to talk to my own children and my grandson, and share what I have learned. That is important to me. (B.S.)

- Dialogue is needed between Aboriginal people and health policy makers.

...as a health professional, as I go into the work that I do working with Aboriginal health, these are new areas that I have never had a discussion about before. Now, hearing other people's perspectives, I can at least say, "this is what I have heard" As policies come forward we need to think about the cultural spirituality, that holistic way that Aboriginal People view life. (B.S.)

As leaders I believe, things are changing and moving forward politically, socially, financially, etc. Those are some of the ideas that could be shared with others. (S.L.)

There also has to be dialogue, like what my brother here talked about, they have to consult Aboriginal Elders and people in relation to health policies about Aboriginal People and to sensitize mainstream society about health, in particular in regards to

Aboriginal issues in regards to healing and Traditional methodologies, the way we healed ourselves in the past. (C.S.)

- Dialogue between the recipient and the person giving an organ is necessary.

We have to create dialogue between the recipient and the person giving the organ like a unity and relationship. That means a lot to be Aboriginal People, part of our body is given to another person, that means a lot. (C.S.)

- It is important to create a group of individuals who will continue to deal with these issues together.

I said to Gaye to bring us back together different times of the year. Let's tackle the difficult subjects, the things that are not talked about. I am more than willing to do that in this forum. (B.C.)

The one thing I am trying to get the white collar organization over there to understand is that this is how it should begin when we are working in Aboriginal health issues. In Iroquois and Mohawk teaching again there is no individual that vested with power. Power is always to be shared by a group of individuals. We do not even have a word for power in our language. The closest we have in Mohawk is [Aboriginal word] it means the strength to look after your responsibilities. No power. The strength of a group of equal individuals will look after your responsibilities. One of my goals has been to have a group formed like this that we can go to for guidance and wisdom in all areas, ...I look after seven hospitals and three long-term care facilities in this city, and I do not like the way that the non-natives think we need to have an expert, and labeling my desk as "the expert", he is the one who deals with issues. If we have a client who wants to do a ceremony on this floor, we phone him. If there are difficulties, we phone him. That is a heck of a load for one individual to carry. In my belief system, one individual is not supposed to carry that. The closer we can come to eventually formulating the group of people to deal with these issues, which is where it should have begun in the beginning. (S.W.)

- Respect to participants and closure for them to receive consultation results.

In closing, for protocol to be closed up as Aboriginal People, because we have been consulted and consulted I need to see the end result of what this looks like. If we could all get a copy of what it is going to look and where it is going to go. This would bring closure for me. Thank you.

Topic 6: *Closing.*

People in the Circle shared their closing thoughts about what they learned. The group that they felt could definitely benefit from what had been learned were the medical schools. What worked for them during the Circle were: that they enjoyed the discussion and felt they were taking away something that had moved them personally forward on the topic, and that the Circle had been well organized and conducted with sensitivity to traditional values. Things they would change included: making ground rules explicit about sticking to the topic and limiting each person's speaking time, making the first evening session shorter, and finding a venue that is a comfortable temperature where people can easily hear what others are saying.

- Other groups: Medical schools' curriculum has to be culturally sensitive.

In medical school, the curriculum has to be culturally sensitive in relation to organ donation where it is coming from an Aboriginal People's perspective. (C.S.)

This is something that surgeons should learn in university when they are going to school. (D.N.)

The doctors and nurses and the people who work in the medical field should get a lot of input about how all the cultures are working. (D.)

- What worked well: moving forward on the topic and Circle was organized well and sensitively

I could be quite honest and open and if this ever happened in my family, now, in my immediate family but also my extended family, I think I could talk about it quite openly now. It is all because of what I heard in the Circle today and what has happened in the last two days. Thank you very much, it has really helped me in my life. (C.B.)

...a major door has been opened, and that is very important regarding the issues. (K.B.)

I have learned a lot listening to other people, making connections with other people. I know that I will be talking to my family. (M.O.)

Specifically about this Circle per se, I was impressed with the quality of how things got organized in terms of some of the paperwork and the sensitivities that were shown regarding some of the Traditional [ways]... (S.L.)

I was very impressed when Bev and Gaye contacted me and said, "This is how we want to do it." I said they were starting the right way. I do not have much to add, they did all the work. But I thought they were starting in the right way. (S.W.)

- What could change: sticking to ground rules, having a shorter first session and a different first venue.

When we are doing the Circle, I think it is important that we stick to the topic that we are supposed to be talking about. Those people who are running the circle, there has to be one person who is in charge of the Circle and there have to be some ground rules in the Circle, maybe each person be given five minutes, and not some people two minutes and some people half an hour. (C.B.)

In respect to the protocol, I have to agree..., I have been involved in different forums and we have ground rules where people will say what is said here is open and transparent and respected, but also try and put some limits on it. You do not want to stop people from talking, but sometimes people can go on and on and not everyone has an equal opportunity. (B.S.)

When you have small kids, too, especially in the evening, our granddaughter that we keep has a bedtime, and we had a babysitter last night. By the time the session was over last night I was expecting maybe two hours maximum, that's it. I thought it went too long in the evening. (C.B.)

Also, I had difficulty last night, this is a beautiful place, ...I found the centre too hot for me. I was also having to strain trying to listen, and it was really getting me upset. (C.B.)

DETAILED RESULTS: SASKATOON

The following is a detailed representation of the points that participants made during the Elders and Knowledge Keepers' Circle held in Saskatoon, in March 2005, concerning their experiences and views toward organ and tissue donation and transplantation. These results are presented as summary statements under each of the six questions that guided the discussion, using peoples' words as recorded during the session as much as possible to illustrate the points (in italics).

Topic 1: Participants' awareness of and experience with organ and tissue donation and transplantation

- Participants in the Circle were open and giving in sharing their thoughts and feelings. The majority spoke of their personal experiences with organ and tissue donation and transplantation.

I guess one of my connections actually is that I have a cousin who's now passed on but he was one of the first kidney transplant recipients in Canada and was many many years ago. But kind of harkens back to when I was a child and hearing my parents talk about his experience. (1-3)

And I had a aunt who was the probably only person that I know of in my community who was a kidney transplant recipient. And she had to move from Stanley Mission to Saskatoon and because she needed dialysis twice a week she was a diabetic for lots of years. And then she was here for probably five or six years and none of her children were willing to give up a kidney for her. And then she finally did get a kidney from a unknown donor. And then I had a cousin who just passed away just before Christmas and he had complete liver failure. (1-4)

First time I ever heard about was a little girl from Thunder Child (reserve) heading out to the States to get a liver transplant. And I remember getting a phone call from my cousin. And I remember praying for that little girl. Today now that little girl is a grown women. And then the next time I heard somebody getting a heart transplant, was a elder. And he still lives in Saskatoon here and he does lots of elder work. Its like he picked up where he left off. And then my brother in law had a kidney transplant and he's still living. (1-4)

My sister had a transplant and all. We were just so happy that we could have her for many more years. And today is her birthday. Happy Birthday. (2-11)

- One participant had direct experience as a recipient and influenced the group with her story.

I am a kidney transplant recipient. My son gave me a kidney. And when I had kidney failure he wanted to give me a kidney like tomorrow. Doesn't happen that way. But I had, when my family knew about it I had all my nieces and nephews that wanted to give me a kidney. And times have changed. I know things like that don't happen along time ago. Well I really never heard about it myself until recently. When it happened to me. I was a CHR (Community Health Representative) worker. I worked for about 30 years. And I taught about...funny....you teach about health and now this thing happens to you. And then you become a better teacher (laughing). (1-7)

I was talking to one of the ladies this morning and I was telling her about the kidney my son gave me. And I wouldn't be here today if he didn't give me his kidney. But he reminds me all time if I am eating cake or something, I have to look after our kidney

(laughing). So he keeps me on track like that and he's not here today so I went to town on all the goodies. But when we went through all these ceremonies before I got the kidney and he knew all about it. Even before he learned everything about it, he was going to give me a kidney. (3-7)

- Another participant had some interesting ideas around the effects a person might experience in having an organ from someone of a different race.

I can't say I have any relatives or family experience with donation. But that the transplantation were still going through that process, our Dean from Prince Albert had a heart attack just prior to Christmas and she received a heart almost immediately. Now in my own mind, my mind tends to wonder quite a bit. She talked about having dreams in particular about Chinese people and haven't had an opportunity to ask or talk to her about it. It could be just in my own imagination but that kind of link in my mind at least I linked this idea what was the donor a Chinese person, I didn't know what to think but she did talk about having a lot of dreams about Chinese people. But in my own mind then I would think that well if it was a Chinese person she's having these Chinese dreams. What does that say about organ memory (laughing.) (1-14)

- Health care providers had experiences from other perspectives that influenced their ideas.

I started out as a dialysis nurse many, many years ago and so I had the opportunity to be working with patients who were waiting for transplant. And this was when transplant as well as dialysis was fairly new. So I've always had a very special place in my heart for patients who are waiting for dialysis as well as patients who had already received transplant. I know a number of people that have received kidneys, livers, a heart or a lung. (1-14)

- The difference in quality of life between being on dialysis and having a transplant was a frequent topic of discussion within the Circle.

An aunt of mine had a kidney transplant and where I am from, it's about 500 kilometers north of here. And when she had kidney failure she had to move down here and live in a basement for probably six years and go to St. Paul's twice a week to go for dialysis. And then when she did have the kidney transplant even though she only lived another two years after the transplant, she did have the opportunity to move back home and to be with the community that she grew up in. And I think her quality of life was a lot better in those two years than the previous six. You know being chained to the St. Paul's hospital for six years. (2-3)

- The difference in perspective when the issue becomes one for the family is also an important theme.

And I thought about if supposing my kidneys would ever fail would I accept you know somebody else's kidneys. I thought about it but I've never really talked about it. But then my son took sick, he had kidney failure and he was very, very sick. And he talked about if that if it comes to him taking dialysis he would and then if he would, if it come to a point where he would have to get transplant he would. And then as I (was) thinking it made me think differently. And we only think differently is when we get into a situation. Like we educate one another. (2-3)

- One of the reasons for wanting to know more about who donated an organ is described in this story:

I was working with an old man and he received a transplant and he asked me, he said find out I need to know what race the person comes from, who gave me this kidney. And so Bob took it to the medical staff and said well he needs to know where you know the race of the person that offered this organ. And of course there are all kinds of rules about confidentiality and fact that this information couldn't be shared. And so Bob went back and said to the old man and told him that they don't want to say, you know, they don't want to say where it comes from. Why do you need to know, tell me about why you need to know. And the old man said, well I need to know what direction to pray to when I give thanks for this. (2-11)

- A story was related about a person with a traditional lifestyle and his approach to the issue.

My experience I had a uncle who I took as a father figure in my life and he gave me a teepee to keep before he left. And at that time he was becoming very sick and he had diabetes. And they brought him into the hospital and they had do the cleaning of his kidneys and I went and sat with him hours at a time while I worked here in Saskatoon, he was in the hospital here in Saskatoon. And it amazed me as to how many First Nations out there are sitting in those hospitals for hours and hours getting their kidneys taking care. And I know I probably took a great amount of talking to him from his family to get him to go the hospital in the first place because he is a great traditionalist. That was probably the first time he had ever been in the hospital and he was in his, I don't know, mom help me out. He is like old. He hardly spoke any English and only if he absolutely had to he would talk English to his grandchildren that were very close to him. And I know that a kidney or transplant, I know I wouldn't of ask him or talked to him about it because he would of probably either pretended not to know what I was talking about or absolutely said no to it. However I really respected his way of life and he had given to many, many people a traditional way of thinking and living. So I would have respected that in his life style. (3-7)

Topic 2: Participants' views toward organ donation and transplantation.

- Donation and transplantation is not really talked about in First Nation communities and participants in the Circle often struggled with the formulation of their own views as they had not really thought about it very often until the situation and choices have to be faced.

And it doesn't seem to be until you know you're at death's door and transplant patient is the last process that we actually every think about, transplantation, speaking from myself anyway. And being a western trained nurse I never gave it much thought as to the traditional meaning of what transplant organ donation is so I'm really interested to see what the elders have to say about it. (1-4)

- The role that traditional teachings, values and beliefs play in the decision making process differs from one family to the next.

So I hear about things and then I get a teachings have been passed on to us from our elders from my grandmother, my mother but that's where it comes from. We don't have too much information before my grandmother because my grandmother was also in a residential school for years. And then my mother went to the same residential school my grandmother went to. And my father went to residential school. And that's the school I went to for 8 years (1-5)

- The struggle with the decision making and the clarity around not always being able to find the best answer was expressed.

I have mixed feelings. I often wonder if I lost a grandchild and her organs were donated to somebody else. I often wonder how I would feel looking at the person with my granddaughters or grandsons organs how I'd feel. So that's were the mixed feelings come from. Sometimes I think I would be very glad because I know the part of hers in that person. And the other part is one Jacob said, talking to some elders and said you are given this body and when you leave our Creator wants you whole when you go away. And so that gives me mixed feelings. Now what do I do with something like that. I'd like to see somebody suffering and if there's my grandchild organs are able to give him or her that organ for him to survive I think...I think in a way I think I would be very glad because I know a part of her is in there or part of him is in there. So I have mixed feelings about this and being here I'm glad I hope I can learn something. (1-17)

But I just from what I heard he was going through an awful lot of suffering so his brother gradually volunteered to give one of his kidneys. The kidney extended his life for a while and we lost him a couple of weeks ago. I think that you know how to enjoy life after but it is a hard thing. You take on somebody's part of the body to expand your own (life) and extended your own life and how many years you want to go? It's hard for me to say that, no you can't, yes you can. (1-17)

Well I told you yesterday that I received my son's kidney and when I first found out I had kidney failure he wanted to give a kidney like tomorrow. It doesn't happen that way. But when my family found out about it, I had all my nieces and nephews that came forward that all wanted to give their kidney. Now I need eyes (laughing). But I would, I've never heard anything, maybe there was, but I never heard anything about my culture being against kidney transplant. My mother died of uremia. I was healthy at the time and if I could have given her a kidney I would have, I would have gladly given her one you know. Just to have her around a little longer. (2-11)

But the father of the young girl she said, he said if this girl was to receive a heart....it had to be one special person for this heart to be at home in her body. So I thought was, that's really a nice way of putting it. However I was talking with daughter and my mom. We have discussions over every little bitty thing we can talk about. And I was thinking about what if.....I needed eyes or somebody needed eyes and I would have to go into select and I really didn't want to look through a white persons eyes. I'd have to shut, do I have shut my eyes in order to feel with my heart and just little things that were going on through my mind. (2-12)

If that was, if I was ever in a position like that, I am not too sure how I would choose. Because being selfish you want your children to live like a longer life than you have. I am not too sure what I would do. But I defiantly pray. I know I would. However if my daughter was to die and I thought about where would she go, like where would her parts go. And if often, like I started to think about. So that came into question also. And then for an older person I though well is it really our choice to make to.....have life extended. (2-12)

And I was kind of puzzled in this area where you donate your organs. I thought about it a long time. I think as far as I am concerned I guess if I came to that situation I'd have to pray for guidance. Because if I seen my children suffering and they were, they needed a transplant I think I would of changed my mind but for myself I'd like to tell my children that I like to be complete when I leave this beautiful earth and go to the other side. That's how I feel. That's me. Its kind of.....like I'd have to think about it a lot before I agree to one of my children getting a transplant. So I pulled both ways. (2-13)

I've had the opportunity to interview numerous people entrusted in donating a kidney to a relative. And I really find that quite touching, the sacrifice, the feelings of wanted to help another person in need. And I think it's certainly a real gift and a personal decision that people have to make. There is no right or wrong answers. (2-14)

- The reasons why someone might say “no” to donation or transplant were expressed.

I had a dream last night. I was wide awake, they cut me open, and they were going to put a new kidney on me. And I said no and I woke up (laughing), that's my dream. So I had these thoughts, I'll never have any operation for anybody's parts into my body after I had that dream. Because I seen all this blood and I don't think I want my kids any parts of anybody or other human being bodies. Especially if they are dead. I don't want them to donate nothing because they would be done there and some of there party parts would be running around. I don't agree with that. I am sorry but that's they way I feel. (2-16)

- The process for thinking through why a “yes” decision might be made was also part of the Circle discussion.

I lost my wife here three years ago. And I seen her suffer for a long time. And when I see young kids suffering in the hospital or I see them someplace, it always hurts me, hurts me to see the parents and the grandparents. And I often think is there something I can do for the child I would. And were talking transplant or transplantation. If for fact I could do it for a child suffering there, if I could give him something or take his pain away I would because it's in most of us native people, we don't like to see people suffer. So the one, what Velma said about you know, talking to the elders, I too have them feelings. But like I said I wouldn't want to see a child suffer if I could help him. (3-16)

And for my children and my grandchildren I say its up to you, see said that, young girl there she is a smart girl. She said that. If she could give something to somebody she would be glad to do it. I say that to my children and my grandchildren. It's up to you, do it if you think its going to help you helping that child by all means do it. But I am not saying you have to. And through prayers I think a lot of us could overcome these things we are talking about here. (3-16)

I am not saying I am against the donation recipient I think. I like so many mentioned here its up to the individual, it's a way, especially young people to maintain life you know as you want to,... If you're born with a, you know, faulty heart or faulty whatever organ, then I think you the individual needs a little bit of support in getting the kind of support that he requires to grow old like everybody else. (4-3)

Topic 3: Participants' views and traditional values and beliefs which influence Aboriginal People in regard to donation and transplantation.

Circle participants shared personal views and told stories that exemplified the traditional and non-traditional beliefs about life and death. These comments provide insight into some of the considerations that come into play when an individual or family is faced with a choice. This section will provide a summary statement about each value/belief mentioned, followed by the words spoken by the participants that illustrate that value/belief.

- Choices about donation and transplantation are sacred, personal decisions which are typically made within the context of a family. People have been given a brain and free will to choose and it is essentially a process of using the traditional teachings and a person's own reasoning capacity. Community information and consultation sessions help to support decision making.

Respect for the reality of others and how they perceive things. (1-9a)

The importance of consultation in the community, especially with elders. (1-10)

The younger elders said donation was OK provided it was an individual's choice. (3-5a)

It is everybody's choice, you have your heart and your mind to think for yourself. (3-8)

If you are going to save another person's life, spirit, that's up to you. (3-14b)

*Trying to find that middle ground. It's going to be an individual choice again.
(4-4c and 4-5)*

So it's a decision, personal decision, it needs to be done with a sacred ceremony like most of the elders are saying.... (4-8b)

*Along with the person, the families make the decision, which is respected, whatever it is.
(1-15, 2-9e and 2-10b)*

We respect all the decisions of every family. That family hope of life, the family tree, the circle of life. (3-14c)

- Due to the sacred nature of the decision, there is a need for guidance through prayer connecting to the spirit world and ceremony. It is important to look to elder guidance through stories in the Aboriginal languages, and through the traditional ceremonies for help in finding the answer to the sacred decision. There is a willingness to be flexible and open to what is spiritually appropriate in the present.

Loved ones in the spirit world come down and help us in our daily lives, so people... "do not want to break that spiritual connection with loved ones and do what is so common today as giving part of myself away." (3-5f)

Nothing is concrete, it is flexible, and if people consistently go to the ceremonies for spiritual development, they will begin to understand better what needs to be done. (2-7e)

And so he talked about the power of the sweet grass. He said its going to smudge your mind meaning the spirits from that sweet grass are going to go into your mind and make you mind capable of understanding and answering any perplexing question or problem that come in life if you do it consistently he said. Then you smudge your body because your body needs to be released of any negativity that's around you. And also to put some in your heart because your heart always has to love people that correct way, the right way. And he says that if we do that consistently like we are suppose then we will be able to answer some of the questions that come along in life. ...and yet these old people, the ones we go to or the ones we went to and the ones that we go to today still cling you know to the belief that any question that we want answered we must go to the ceremony. So that's what I do when questions like this come up or any question comes up, we go to the ceremony because that's what I learned from the old people. (2-7e)

Like nothing is concrete, nothing is,...it's flexible I guess. Because when I first started out at the sweat lodge that old man said he used 19 rocks until the spirits tell you that you can use more. That's all he said, he never gave me any other explanation. So in my early beginnings with the sweat lodge all I used was 19 rocks, just 19 all the time, all

the time, all the time because that's what he said, that old man. But then later on, because I guess of spiritually development which happens to people that consistently go to ceremonies they get spiritually development. Then they begin to understand better, you know, what needs to be done. So later on, of course, when I moved to Cree country, I began to increase the number of rocks in my sweat lodge because that's what I had to do. And nothing happened to me you know, I didn't have any guilt because I was not obeying that old man when he said 19. He said some day you will understand you may have to use more rocks. So today we use more than 19. And there's no guilt about that. (2-8e)

- Respect for the body means that we should not mess with them and a traditional Aboriginal person should not be a doctor, nurse or undertaker.

Life and death is up to a higher power who takes life and gives life. (1-11)

First Nations do not traditionally throw out their hair, but keep it in a clean place. (2-16f)

We should not be dissecting our bodies and taking stuff and giving it to somebody. (3-1)

A bone marrow transplant is disrespectful to ourselves and others. (3-6a)

When after somebody dies, really, we shouldn't fiddle around with the body. We should just let it be. Let that person go with all his parts that were given to him. (4-9)

- Life is sacred and there is a great respect for life, therefore we should fight for life and for the traditions that reinforce life.

We need ceremony to talk about this because of the sacredness of the topic, and we must ask for guidance: In our ways we had great respect of each other. I think we talk about something as a gift of life and how we can pass on that gift of life to others. We were, the people that kept and guided that life or spirit today. And we have great ways of passing on things. As I left here yesterday, I wanted a ceremony in the proper way because I felt in a way it is too sacred, the sacredness of life was being talked about. So I asked for that guidance of what we're going to talk about. When we talked about life, especially medicine and the soul of the people, the body of the people. We put our ceremony first with that pipe and ask them. (3-13c)

The personal decision is sacred and needs a sacred ceremony with family: So it's a decision, personal decision, it needs to be done with a sacred ceremony like most of the elders are saying, because if we take those animals in that ceremony, we should be thinking of yourself in the same way, you know, that we are sacred. And if they can give up their lives for us to have lives, and we chose to make this decision to give up our body parts to let somebody else take them, then that's a sacred decision, and it can only be done with that person and their family. (4-8b)

- Ceremonies are crucial to staying physically, mentally, spiritually, and emotionally balanced. There is a ceremony for everything in order to live a good life. Ceremonies take people spiritually all the way through life and are opportunities for healing. When the gift of life was taken and lost, so was the First Nations' health, which can be retrieved by living a good life with ceremonies to guide life.

We look at the positive, good lifestyle of our people, a wellness. But I know we lost a balance of life...we knew these diseases would come... (3-15a)

So there's lots we lost out lots. But like eh now, it's like the life is recycling. It's filtering through me again. I have to teach my grandchildren. I have to teach them those things. Like the after birth ceremony. When they were inside their mother's tummy, we had to honor that after birth. We have to honor their belly button. You know we have to go back to those and teach them and that way I believe if we can live such a good life that perhaps we won't get sick, we won't develop diabetes, we won't have cancer. And if we can live a good life at the same time at one hand, I am doing everything I can. It's not too late to live a good life, to go to ceremonies, to pray and to listen. We all are teachers. Every one of us are teachers. (4-7b)

- Healing comes through ceremonies.

Therefore we should be going to a ceremony, making an offering for organ giving or receiving. (2-9d)

We should be praying and giving thanks to the donor (2-10a, 2-10b, 2-11a and 2-12)

I also know that I've been told that we have been given those ceremonies as Indian people to heal ourselves, and if it's meant to be through our ceremonies, we will be healed. (3-9a)

I lost my grandson. He died of a peanut allergy. And I made a beautiful ceremony out of it. I could have been depressed, I could have been just so sad, but I looked at it as he has gone back with Great Spirit and he's not gone forever, his memories will live on. And I used to tell him, 'You know, if I should go before you, every full moon that's me over there, that's me', I used to tell him, eh. And then he said 'And if I should go, see that beautiful bright star over there? That's me', he says. So at night when the sky is clear I look. There he is over there just shining. See, that's the way I think, and it was a traditional ceremony, elders spoke. And we talked, and it was a beautiful ceremony. So we can, we can make everything beautiful. We can make everything a ceremony. (4-7a)

- After death, the spirit leaves the body and journeys to the spirit world. The person goes back to the Creator spiritually whole. "When we leave the earthly world to enter the spirit world, we don't take our body. Mother earth looks after that."

They had everything that would they have, the arms, limbs, the brightness of their faces because they were in the spirit world. When you go up there they say your body comes intact of what you have and your spirit. Cause I believe that because I made that journey. I shared that to people because we have great respect of life today. (3-14c)

When we leave the spirit world we become a spirit. We leave our body with mother earth. We don't take our body. Mother earth looks after that. (4-6a)

Like, eh, we just need our spirits. We don't really need our bodies. (4-6b)

We've been Christianized for probably over a 150 years maybe longer than that. It has the oldest church west of the Red River. So we've lost a lot of our traditional

beliefs... stuff that my mom has told me with regards to death was, even if you die when you're so old you can't walk, you can't see, most of your body parts aren't working.... When Christ returns on judgment day you will rise from the ground completely healthy with nothing wrong with you. (4-4b)

- Sharing is a key value, including that animals share their bodies so that the people may live. People are willing to help one another whenever they can. There is some hesitation in accepting or donating organs because people don't know anything about the kind of person they are coming from or going to.

I do know for myself that there have been other spirits out there, other creation, animals of creation that have given up their bodies for me. You know they have allowed me to partake in certain ceremonies for them giving up their lives... (4-8a)

If any of them ever needed something from me, it would be not a problem and that's the same for anybody. If a family was struggling or.... if I could help in any way... I would hope that someone would do the same for me. (2-13)

- Some people felt that respect for the body means not removing any organs. The traditional belief is that a person should keep all of his or her body parts or bad things will happen.

And my grandmother,... she was sick for a lot of years and I will talk about her, because they could have fixed her, she could have surgery to fix whatever was wrong with her, but she wouldn't go. She wouldn't go because she said these are my body parts, I was born into this world with the body and I am going to leave that way. And she put up with the discomforts. Its women problems and I know it must of caused her a great deal of pain, but she went with all of her body parts. (2-18)

Whatever is in you or you came into this world with it's yours not to give away. So I need some guidance about all this. I have no answers right now. (3-1)

The three tribal members said they would never donate their organs, it's against traditional law and laws to their belief system. And they've also told me the reasons why they would not donate their organs especially after they're gone to the spirit world. They tell me that after they are deceased and your organs are donated or if they are taken, they said many bad things are going to happen. They foretold that for the future. (3-4a)

And also they talked about when our time comes that's the day we are supposed to leave mother earth and go to the sacred spirit world. But they said if you interfere, that's when as you're in between the two, being on mother earth and in the spirit world and you can make your world to the spirit world, they said your relatives on mother earth suffer....And also you don't fool around with organs because they say it will fall on you, your children or your grandchildren. One lady said if you give away your heart that heart will be living and you'll be gone. By in doing that process your children, your grandchildren will be suffering from major heart problems and that's something everyone should realize. (3-4d)

- Language and stories are sacred ways of understanding who the Aboriginal people are and in understanding the culture and the meaning of a "good life". It is important to look to elder guidance through stories in the First Nations' languages, and through the traditional ceremonies for help in finding the answer to the sacred decision.

Language is a sacred way of understanding who we are as Native people. (2-5d)

Language is important in understanding the principles of good living... I used to go to AA and I used to go to the Catholic Church but once I started to understand, you know, the spirituality of our people, I began to realize that the teachings of the elders... that for me all that was necessary to live a good life was to follow their teachings. Because their teachings are based on goodness, that's what I understand. That's everything that they do, everything that they talk about is related very sacredly to a deep understanding of creation, a deep understanding of the Creator and what the Creator has given to us, and a deep understanding of human nature. (2-5b)

- Oral narratives in the language have knowledge, concepts and ideas embedded in them. One story shared was about an animal copying another animal and playing with his eyes by throwing them in the air and trying to replace them with spruce gum when his eyes did not return. The morals of the story are that "what is right for one person may not be right for another" and "don't play with the gifts that are given."

The knowledge that we seek, whether, if we are presented with a concept and we are in a dilemma about trying to understand what the concept is, my understanding is that we feed the concept to our own language. And if it comes out that the language talks about it or the culture somehow talks about it then we can talk about it. But if we feed a concept to the language or the culture and there is nothing that comes out.... (3-11)

I was reminded also that in our Dakota tradition we have a sun dance in which we do give pieces of our flesh as offerings for the common good of our people and for the survival of the group. We also give flesh offerings separately from the piercing. The piercings are either done on a rope from the tree or pulling buffalo skulls. Separately there are flesh offerings that we give for, anyone may give if they wish. These too are offerings for the common good of all. But they are personal. I guess what I was looking for was kind of precedence I guess for giving of one's self to another person.... (2-15c)

- Many Aboriginal people are in the midst of recovering their own culture and spirituality in the wake of the residential school experience. Some are feeling the pull of "living in 2 worlds", i.e., trying both to honour the traditional teachings of the elders and to live in the modern world.

...My grandfather used to say that, only one God. White people were given that God too, same one. Black people, yellow people, the same one, the same God.... And he gave the white people some good things too to use in life. And he says, especially now when we live in the modern world, we might have to take some things from other people to help us promote life you see. So that's what I understand when it comes to, you know, organ donation. All these things come into play, but it comes down to common sense, it comes down to reasoning it out, it comes to praying, doing it in a good way. Going to a ceremony, making offering for the organ that you are going to receive or for the organ that you may want to give, if its in agreement between your wife or your family, its something like that. (2-9a)

I just know that that's what I would do and I respect my kookum's (grandmother's) views so much but my heart just says something else. And...just like everybody else's cultures and traditions and views and different elders. You just have to ask yourself when the time comes and I just know. (2-13)

I have a grandmother. She was blind. And she used to always talk to us kids. And she used to tell us that the way we come in, that's the way we go when we die. She had mixed over that now today like. For instance if one of my children had a... needed an organ, I would want them to get an organ to live longer. I have mixed feelings over that what my grandmother used to say. (2-14a).

And this why today I think we must understand it is in both worlds that we live in, in our world we live in, understanding was spiritual. Because in a way, that's how we kept our minds, our body, our spirit intact. It was a gift from the Creator that we had to keep this. You talk sharing your own parts of body. You talk about sharing your own blood. Your own ancestor blood, your mother's, your father's. ... you look at way back in our ceremonies, in both ceremonies the western world and this world that we live in. It says in that big book, in that bible it says this holy man called Jesus he left his blood here for us to live. That I believe in. But I believe in too that that we gave parts of our bodies to suffer to the ceremony of a sacred tree of life called the sun dance lodge. We give our blood for so that people could live. A sacrifice is what we came through. Because I am a lodge keeper too, sun dance keeper of what my relatives, my elders have passed on to me. (3-14a)

When I talk to these people, these younger group, I got overwhelm feeling of loneliness and sadness, I don't know why that came over me. I felt so caught in between what the old, old elders said and what now younger people are saying. (3-5b)

But a lot of times us too as elders, we got to realize that we cannot bring the days of teepee, buffalo days, you know, and I was told one time... 'I wasn't born on a buffalo robe so, you know, I've got to make my own life in the main stream.... 'Those are things we come across as elders. So we have to understand that today is the present time, is now, and there are many, many changes in the way our ancestors lived, but I always say our only hope and connection to our way of life of long ago was true spirituality through prayer, through ceremony. (3-6d)

- The point was made that these questions about donation and transplantation come from a western rather than Aboriginal perspective, from a new awareness that is a recent phenomenon made possible by technology and a western medical establishment which is not trusted by elders. Hospitals and the western medical establishment are resisted by the old people because they are wary of yet another form of colonialism, another kind of invasion of the Aboriginal peoples' space, including very private space. The western medical establishment has taken over responsibility for the health of the community. Discussion of the issues, and especially that the Aboriginal voices, the views of the elders, educate the western medical establishment about their issues are important for the future.

These are western questions. These are not Cree questions. So I can see, also see from that perspective, and for I suppose all of us working in the middle. And it's often a gift to be able to see two points of view, the two worlds ...But it's also a curse because you know it pulls people into different directions to be able to see different points of view. (3-12a)

...if we go into a colonialism, that aboriginal experience, that there was an invasion of their spaces through colonialism. ...hospitals, you know, are very recent... That the western medical establishment has taken over the health of our communities or the, you know, the health of our people. ... And people nowadays don't feel any responsibility for their own health. But so this western medical establishment is sort of another form of invasion again of our peoples' spaces. So that's why the old people

would not go into hospitals, that's why they would not go in to see the doctor because they didn't trust, they'd didn't trust that that system would [not] invade them again. So the old people, even now...still resist going to hospitals or seeing doctors. And I think it's this kind of idea that you know, a very recent phenomenon such as organ donation and transplantation. (3-12b)

This debate that probably needs to happen but this is a new form of awareness that is being presented to the people and it's because of technology. You know, it's the technical aspect of the medical establishment that people are very wary of. The medical establishment has mystified itself, [so] that people do not trust what the medical establishment does. And so when people come into the community and say, you know, organ transplantation and etc, there's that mistrust that is going on in the community, and particularly with the older people. (3-12c)

So it's an education process, not only the medical establishment responsibility to inform people about technology, not mystify the medical discourses. And also on the other hand, it's very important for these discussions to continue, particularly where the old people present their views, because it's also an education process to our own world view understandings. So again it's those two worlds, you know, we need to educate ourselves about what has passionately carried our people for centuries before. Where we didn't have doctors but we, you know, life still existed without doctors. There is a different form, there's a different world view at work there. But I think it's also important that the people's voice, educate the western medical establishment about issues, so that you know there is not this overwhelming pressure on people to donate or make decisions that they don't have to make right now.(3-13b)

- There is some hesitation in accepting or donating organs because people do not know anything about the kind of person the organ is coming from or going to.

To get someone else's heart, in our belief system and our way of looking at things we talk about things, decisions that we make. And we talk about the decisions that we make, the ultimate evaluation of those decisions is what you feel in your heart. And I don't know whether if this is something, a metaphorical statement, whether the emotions come somewhere else or is a combination of all sorts of other kinds of things, I don't know... (3-16b)

In 1990 we lost our son, 16 years old, our only son, in a car accident just outside of town here. And we talk about him a lot. And I said he would have been a prime you know, recipient for donating his body parts because he was young, he must have been,... they must have been all good. He didn't drink, he didn't smoke, didn't do drugs. He was a good boy. We still lost him.... and my husband said, you know we had a good boy. What if we donated his body parts and they went to a person that was not a good person? You know we wouldn't know that. (2-16c)

Topic 4: *Support for donation decision making process.*

During this discussion, the participants were asked how health care providers could support a family in the decision making process at the consent, donation and follow-up stages of the process. The participants were also asked to identify the things that a health care provider should be particularly aware of when helping a family to make the decision.

Participants felt that support and advice is needed for individual and families making decisions about organ donation or transplantation. Participants had the following ideas about the nature of support:

- People should be encouraged to talk about this topic early with their families and make their wishes known long before the time actually might come.

I think that they, the families are in crisis when they are hospital situations and a lot of them don't have the fortitude or the even the time to sit and think for maybe five minutes or so whether they want to donate an organ or not. So I think if you do a wide spread, you know information sessions so that people can think about it in advance it may increase your changes of getting more donations. (2-3)

I think its also important that the people's voice, educate the western medical establishment about issues so that you know there is not this overwhelming pressure on people to donate or make decisions that they don't have to make right now. We don't need to create negative images in order to talk about the issue. (3-13)

- One person thought that some parents might later feel they were let down by the system if health professionals did not offer the opportunity to have them donate a dying child's organs at the time

Shortly after I started as the manager of the program I had a mom come into my office whose 17 year old son unfortunately had died in a motorcycle accident. And what she said to me was, I didn't think of donation at the time and no one helped me. She said you let me down. She said someone in the health care business should have offered me the opportunity to do, to donate if I wished but she didn't think of it in time and no offered it to her. (2-2)

- There was strong support for wide spread education sessions "so that people can think about it ahead of time." Education needs to go both ways: i.e., education by the Aboriginal community of the western medical establishment and public regarding traditional ways of approaching the topic, as well as health professionals educating Aboriginal people about the issues and their options in donation and transplantation. The educational approach must be visual, incorporate experiential learning, be culturally appropriate, and emphasize that the personal choice belongs to the individual within his or her family circle.

Like you hear all kinds of stories but you never actually hear from the people themselves and. Look I think there's got to be more education, more information for people to talk about it in their home and for First Nation people we are visual learners. You can talk to me all day long. I am not going to understand nothing. But if you show me some pictures I am going to see that and I am going to learn faster like. When I went to see this woman in dialysis when I could see that machine working, working, cleaning her blood and the waste going down. And in real life that's what our kidneys do. Our kidneys are the dialysis machine that pumps all the waste out. And then I learned that you know your recycled blood you know and then it creates urine. You know things like that you hear and you see. (2-4)

When my family, like I said, found out about it, all my nieces and nephews wanted to give me a kidney. We talked further about that and we have an elders lodge and we have elders meetings all the time. And we have lots of fun there because everybody knows each other. We grew up together so it was easier talking to me then strangers. And there were, and the kids would come, school kids would all come in and they were interested. And what I got out of that was that they would give to next of kin but wouldn't consider giving it to anybody else. And I respect that. I can't change their mind or make them believe what I believe. (3-7)

And I think today we respect of all the decisions of every family. That family hope of life, the family tree, the circle of life. That is what your grandfather, your grandmother made for you, that left here for you. (3-14)

Another thing I was thing about in way of the decision making and helping families make the decision. With the high schools and I think its really important to let people either have stated in the pamphlets targeted for First Nations people are the elders, they are elders there standing on the line of no, this is not traditionally, were aren't accustomed to. And then make some statement to that. Cause I, like all the information I've heard so far is like, yeah it's a good thing, but there was like few elders there that said no. And those are only few and far between. (4-15)

- Emphasis must be on individual choice within the family circle and the choices made should be respected by the medical system.

I was working in the intensive care unit at Royal University Hospital in Saskatoon. And saw first hand some patients who were brain dead and were being sustained artificially while the families were approached about organ donation. And I saw their struggles and trying to make a decision around that. And that was a turning point for me. I went home, I signed my organ donor card and I talked to my own husband about my wishes so that in the event that something happened to me he wouldn't be conflicted and trying to make that decision on my behalf. (1-16)

And lots has been said and it all boils downs to using a free will and talking about it with your family. Like I would know what to do. Like if my children talk about donating some parts of their body what we would do is we would have a circle, we would have ceremony. We would bring in elders not to ask what should we do but to tell them what we are going to do because we would need support. And to make beautiful and not to make it so scary because in real life were all damaged, were damaged goods. No matter how good we are we are still damaged. (2-3)

So then it becomes a family choice or I guess it's a family choice. It may be an individual choice too but usually a family choice because native people are related to families. We are all related not only biologically but spiritually as well because we come from the same philosophy of trying to live a good life, we must follow the teachings of our elders and we must not do anything that desecrates the teachings of our people. (2-9)

The most difficult thing about transplantation is that for every good outcome there is a loss. I mean at least talking about non living donors. And that is the most difficult thing that we who are involved in transplantation have to deal with. Because the losses that occur are often in the most tragic of circumstances and its often young people who've had died violently. And I guess I want you to know that those of us who are involved in transplantation, we know that the good part of transplantation does not compensate for the loss, it doesn't. I don't believe that it does. I don't even know whether it begins to compensate for the loss that family's experience. But I do know that many families and perhaps most families who can make that kind of decision, I think they do derive some kind of comfort from knowing that something good has come from this terrible loss. And I think that's what helps us continue on with all of this because these opposing forces are profound. (2-15)

another story I would like to tell is about this couple where their son donated his eyes. And as soon as he took his last breath they whisked him out of there and they took him I guess to take his eyes out. And this couple is kind of devastated you know, their, I guess...you would like to spend a few moments without the body just being

whisked and they know that their taking this body parts out. And they really felt traumatized or whatever, devastated, I don't know. Anyway about a couple years later they got this letter from some people, probably from transplant wherever, asking them if they wanted to meet the recipient of their son's eyes. That these people were so thankful that this person was able to see again. And mom and dad, the parents and all, said we couldn't imagine looking at another person with our dead sons eyes. It would like be losing him all over again. Again I guess that talks about personal choices. (2-17)

And my mom on the other hand she made us all promise her that she would not, not to put her on life support when it was time. She made us all promise that, all us kids. So the doctor asked us, do you want your mom put on life support. And we all knew, we all said no, no just let her go when its time to go because mom had told us....her dad that was her dad, her dad told her, tell them to take all these machines off me they are just holding my spirit back. They are just making me suffer..... But before that my youngest brother he addressed all of us and he said to us we can't just let mom die. You know all of us. It just set us back when he said that to us. We had to rethink but for myself I knew what he was saying but I was, I had to be firm in carrying out what my mom had asked for. (2-18)

- There was quite a lot of discussion about the importance of ceremony as support to the personal decision, and making sure the family has the desired Elder support and time and space for prayerful ceremony and guidance.

You know so that's to me that's the answers eh, is you have to go to the elders and the elders will listen to you and they will probably tell you to do a ceremony. You have to ask the creator and each of us I guess has to accept those answers. Like its not to me its not a yes or a no its something you have discuss and you have to pray, you have to go ceremony, you have to discuss it with your family to see what's the best thing. As long as it doesn't violate you know the spiritual laws that we were initially given. Because all native people were given spiritual laws to follow. (2-10)

And so would it be possible to create a system where the organs could be returned to the family for example?.....ask the family what they would like to do I guess, with the heart, kidneys or lungs when they are taken out? I'm sure they would like to...hold a ceremony...or do something... (4-12) (answer)So create an opportunity for ceremony of the organs that are taken out so that once they have been processed by pathology that there returned to the family if indeed the family wants them. (4-12)

And each area the hospital is particularly targeted at First Nations people. And there is an area for care, an area there for prayer and there's health care providers there that are First Nations that actually are suppose to be taking care of people that are going through the hospital. For instance I know if there's a death in the hospital and there is somebody dying, First Nations they're suppose to be that type of care given to the family like for support. And if an elder is need like at that minute that they be called on. I know if that was to happen to me and I was have to get some support I want to be able to call an elder right away to be able to make that contact or make that connection right away because its really important to me for traditional purposes as to am I in a quick decision making like that. I would want an elder available on hand. (4-14)

It's important too for the people that went through that. For them to be speakers and bring in the whole family. Make it culturally appropriate so we hear the children talk about it, what they went through. That's the best experience like eh, that's the way, I would like to hear the people because like you go through emotional, emotionally something happens to you. Like it's ok to talk about it, but when we have to cross

that line to get it done... like somebody mentioned, somebody donated their eyes and they had to whisk the person right away to take the eyes out eh. If that was explained it would have been lesser a trauma with the person's spirit. Because we know that's supposed to be as soon as possible eh, but if they were prepared in a ceremonial way, prayer, you know. And to even have a ceremony while the person is [alive]. Like we usually know when they are going to go, we are told. (4-15)

- Basic information is needed to provide simple, straightforward answers on topics such as what the health system does with removed organs; what is the definition of "brain dead", having a chronic disease does not mean that you cannot donate, matching is more critical for bone marrow than any other tissue and that organ are not accepted from people with high risk life styles, for example.

When someone goes through surgery and say they remove a kidney or maybe a bad heart what do you do with the organs that are not, like where do you put them, what happens to them.....(answer) In the case of kidneys it's a simple answer. The original kidneys are not removed. They do not put the new kidney anywhere close to where the original kidneys are. So you end up with three kidneys. ... As far as the hearts are concerned, hearts and lungs, those organs have to be removed to put in the new heart. And lungs. And I presume they're processed by the pathology department and studied to see what exactly was wrong with them and so on. And then they're probably cremated or whatever, I am not sure what...yeah I think they're cremated. (4-12)

I just wanted to add to what Doctor said and that is simply that if you're diabetic that does not preclude someone from being an organ donor. Someone who had cancer in the past but has been cancer free for another of years can still be an organ donor. So having other illness over your life time may or may not affected the ability to donate. (4-16)

The brain has died and the brain tells the body what to do. The brain tells the lungs to breath, tells the heart to beat. When the brain dies there is no instruction so the body dies. But what we have done in peoples whose families especially have indicated that they want to donate we can medically keep those organs just working until such time as they are retrieved. So the only the reason that that heart would be beating is because we are ventilating those lungs with a mechanical machine which just keeps the blood flowing long enough to keep those organs what we call viable. Which doesn't alive which just means functioning until they had been retrieved. So it's very, very confusing. The terminology is confusing and brain dead is a confusing type of term. (4-17)

I think the thing about donation that everyone should know is that people do worry that there will be some visible appearance that will be different, but there isn't. You know the appearance of the person is really the same as it would be normally. Because if its organs that are removed, they're removed surgically so you wouldn't even know that they were there. And eyes for example, a person eyes would be closed anyway. And a tissue or bone that would be replaced in such a way that it wouldn't be visible. So I have been to many funerals where people have been donors and you would never know that. (4-17)

And if that behaviors is considered high risk which would include drug or you know street drug use, then we would consider that not an appropriate person to take organs from because we have to very careful to always do go with an organ donation to never do harm. So we would never give an organ to someone on the chance that they might get a disease from it. So no we wouldn't accept any organs from people with high risk behaviors. Yeah. (4-19)

Topic 5: *Relationship building.*

The questions used in canvassing thoughts on relationship building included asking how the organizers should go about continuing the dialogue with Aboriginal people and how to invest in relationships. In order to build relationships, participants in the Circle wanted to see more circles like this one, especially in the schools, and other places like community events, to reach youth. Other suggestions included:

- Working through the schools, and the Band Health Directors and Health Committees and health fairs or other community events.

I think its great that we are holding this today for organ transplants and I really think that people should have more circles in developing traditions and passing on things to like, especially our youth and especially each other and letting other communities and cultures know that stuff like this comes up and that we need to think about it. Because one day in our lives you know we'll come and have to face this decision. And I know that I am prepared. (2-13)

.....just may we, just start like with the younger people I think. Schools on reserves and stuff if we could develop something in the school system in our, when they teach about health and stuff like that. That this is an option you know, cause other than that people wouldn't know. And I just like to add on about the pamphlets and stuff. I almost think it would be good if they had it targeted to aboriginal people. Cause no one wants to pick up a pamphlet just with a bunch of information. If you target it at somebody they are more likely to pick it up if you're sitting in a office and you use a logo or something more likely to pick it up, get the ball rolling, people thinking about it. Definitely the high school stuff cause other than that we just don't know about it. And we don't know what we are getting into and we don't know that there may be protocols and we don't know, you know, if nobody talks about its so. (4-13)

- Producing and distributing different types of educational resources, including: pamphlets both for the mainstream and targeted for Aboriginal people; culturally appropriate videos, especially taking advantage of videos already available through work underway in Manitoba and Ontario; and having a special showing of movies such as 'Return to Me' whose plot concerns the lives of people who donate and receive organs, followed by a public discussion of the topic.

My mom mentioned that the different tribal councils like agency chiefs, Flat Hills, they all have each health regions. And people are hired in the heath field that are First Nations that would probably be more receptive to other First Nations and the communities and the bands that they work at. Another idea was thatsometimes there's workshops in the communities or outside the communities in the health field like a health fair that information can be held as far as like a sharing circle such as this with the youth or even information to start get the ball rolling or the talk energized or you know wondering about that. (4-12)

Actually, you may know more about this than I do but I believe there are some videos that have been produced specially targeted at aboriginal people. I know there is one in Manitoba, is that right?... So those kinds of, some of those kinds of things exist. And I know there is another being produced in Ontario right now in an aboriginal community as well so those kind of resources do exist and its probably just a matter of producing enough copies and distributing them to various communities. (4-13)

Well a lot of the health centers and nursing stations in the north particularly kind of keep videos running in the waiting room most of the time. Just because people have to wait for appointments. So it can often be a really good medium for getting some of these issues. (4-13)

So people talking to the Health Committees...At the community level, absolutely. (4-13)

when I was listening to her and her, they talked about watching this movie that transplant. To me that would be an excellent resource. And maybe kind of having a dialogue after watching this movie asking the participant to stay and talk about transplants. (4-13)

They actually had a video on the heart procedure that they were going to be doing on him. So it would could if somebody would be showing the video on this organ donation or transplantation. Cause I know they do that for open heart surgery. (4-14)

Topic 6: *Closing*

Note: The following comments were offered in response to question six. More in-depth evaluation information was gathered during the telephone interviews and is documented in a separate evaluation report.

The participants asked about their learning and their assessment of how the process had worked for them.

One prominent learning was the need for time and space for individuals and families to make the decision, often involving prayer and ceremony and the presence of elders for guidance. In addition, the following feedback was offered:

- Aboriginal participants appreciated the attention paid to the traditional ways of meeting: smudging, the gifting, opening prayer, the circle itself and candle symbolizing the traditional fire.

We sit here in a circle and I like the way it started, you know, smudging our mind, body and spirit and tobacco, and then we are gifted. If we were outside there would be a fire in a middle of us, wood burning but here we are in the city, we have candles. (1-5)

And I am too very sometimes reluctant to come to these kinds of things because traditions are not practiced. But there practiced here I noticed. Because we had the prayer before meal, that's traditional. We had the smudging, that's traditional. We have the fire, that's traditional. We have the gifts that are traditional and tobacco that's traditional. In the circle that's traditional. So I guess you know the old people have always told me to pray and pray and pray so that some day all people can understand, you know the beautiful traditions that the elders have. And that they can begin to incorporate them within modern society. So I'm very, now I'm glad to be here because were this the traditional way to the best of our ability. You know the real traditional would be to sit outside in the snow but.....but it's just as good sitting in here (everyone laughing). (1-6)

And one of the things I've learned here today that I will take away that I think is going to be very important to our work is that if there is a great deal prayer and ceremony involved that I wasn't aware of and that will change the sort of how we can help people have more time perhaps when they are making decisions or how we could offer them a different place or if they need to leave the hospital for a while and do some of that work and then come back. And that's really been helpful for me to begin

to understand. Because that will be something I will take back and we will incorporate into the work that we do. Thank you. (4-4)

- Participants appreciated the opportunity to review the findings if they wished.

And you'll also have a chance, those of who you are interested to see the transcript. Well not the transcript, but some of the findings that Bev and others are going to put together of the day. Gaye obviously is going to the person that will be leading that. And so we will want to get your opinions to make sure that we captured everything in a way that you really want us to represent your thoughts. (4-20)

- Circle participants working in the health field learned about the traditional Aboriginal need for prayer and ceremony. They indicated they would take the learning back and incorporate it into their ongoing work, and in the development of educational and promotional material.

I am sure that the kind of information that has surfaced in this day and half would be very helpful information for maybe developing some promotional material either for aboriginal or for the health system people about aboriginal families and communities. To try and build in some information about creating time for ceremony or how some of things can be made available. (4-11)

EVALUATION OF THE WINNIPEG CIRCLE

The evaluation of the Winnipeg Circle was conducted by an independent evaluator. The evaluator called each of the participants of the Circle to ask the following questions:

1. Was the contact and planning prior to the Circle culturally respectful?

Not all felt they could answer this question, but the 3 who responded said yes. They had more to say about how it was actually conducted than planned, with the one embedded in the other.

2. Do you have advice for improvements to the way in which the Circle was planned?

Although people felt the Circle was the right approach, they had some comments for changes: explicit time-limit for speakers and sticking to the topic more; a different venue; an additional day for discussion, and additional protocol and tradition to be observed.

3. Was the Circle conducted in a culturally respectful way? E.g.,

- Did we follow the proper protocol?
- Use the proper language?
- Did people in the Circle feel listened to?
- Did they feel their values were respected?

Respondents all agreed that the Circle was conducted in a culturally respectful way.

4. Did the Circle cover the topics/issues that are important to you regarding donation/transplantation? Any others?

People generally felt that the main topics had been covered but again stressed that it was difficult to do this in one day, and wanted at least another day to do so.

5. Was the Circle the right approach in terms of activities/methods, timing, location, participants? Is there anything that you would advise us to change if we were doing it again?

People felt that having the Circle was helpful to the community in that it invoked the power of having members of the community come together to focus on a topic of common interest for the good of the community, and would stimulate further Circles and discussion in the communities.

6. Was the Circle useful to the community? Do you think it contributed to the community meeting its own priorities in this area? If yes, how did the Circle contribute? If no, why do you think it did not contribute?

People felt that having the Circle was helpful to the community in that it invoked the power of having members of the community come together to focus on a topic of common interest for the good of the community, and would stimulate further Circles and discussion in the communities.

7. What benefits did you receive, if any, by participating in the Circle?

People felt that respect had been shown to their culture and were pleased to be included in a forum starting to discuss a topic that mattered to the community.

8. Do you think that you will take any action in your community related to donation and transplantation because of the Circle?

Detailed results of the evaluation can be found in Appendix 6.

Three of the 7 respondents indicated that they would be willing to personally become involved in educating their communities if someone were to take a leadership role in developing the issue further in the Winnipeg and Manitoba area. Generally, however, people talked less about what they themselves would do and more about the kinds of activities that they saw were needed such as:

- *education of the Aboriginal / general public about their organs and what organ donation is all about, both in the cities and on reserves, e.g., using the AIDS education approach on reserves as a model;*
- *education for health professionals (doctors and nurses) concerning more appropriate and compassionate ways of approaching families about considering organ donation in hospital;*
- *the development within the Aboriginal community of proper ceremony to accompany the act of donation of body parts to acknowledge cultural beliefs about the afterlife;*
- *the development of the concept of organ donation as a strategy for bringing people together and combating racism;*
- *Involve local Aboriginal media, local Aboriginal advocacy groups, and people from the Circle themselves in continuing to raise awareness about the issues in donation and transplantation in the Aboriginal community.*

CONCLUSION

The objectives of the consultation were met in that information was gathered on the range of beliefs and attitudes that may influence Indigenous Peoples when considering donation. The experience of conducting the consultation provides a useful model for others to follow for respectful dialogue with Indigenous Peoples and it provides an opportunity for the local transplant and donation programs to build further a partnership with Circle members to expand on the work begun.

Future work is necessary to take what was learned in the Circle and transform it (in partnership with the Circle participants) into actionable strategies that will ultimately result in increased consideration of donation by Indigenous Peoples in ways that are respectful of their history, traditions and cosmology.

APPENDICES

APPENDIX A: PROTOCOLS FOR APPROACHING ELDERS

PROTOCOLS ON ELDERS (First Nation, Métis & Inuit) ³⁸

Elders figure prominently in their communities. Indigenous Peoples value their Elders significantly and address them with the utmost respect. There are First Nations, Métis and Inuit Elders. Each has his or her own respective role to play. Beliefs, thoughts and teachings vary between Elders, Nations and Indigenous Groups.

An Elder is consulted on a range of issues from personal journeys to community matters at large such as:

- Passing along knowledge of traditional concepts and beliefs, spirituality, ceremonies and other practices;
- Conducts traditional spiritual ceremonies; and
- Provides guidance and advice.

Services provided by Elders are unique as a result of their training and experience in matters pertaining to Indigenous culture, philosophy, practices and holistic approach to life. Elders are called upon for different reasons:

- Prayers to bless events;
- Advice and guidance;
- Accurate information about Indigenous heritage and Indigenous communities;
- Insight on the historical role of Indigenous Peoples in Canada; their contemporary situation and aspirations.

If you need to attend at an Indigenous community (you haven't attended before), need information for a specific project (S.84), entering into a joint venture (S.81), hiring Indigenous employees or establishing relationships (parole supervision in general), you will want to consult the Elder from that area for his/her perspective.

A First Nations Elder, an Inuit Elder, an Iroquois Traditionalist and a Métis Elder have been asked to share their thoughts on how they see their role in the following scenarios:

1. Calling an Elder for advice
2. Calling an Elder to request opening and closing prayers
3. Calling for full participation in a meeting or having an Elder as a member of an advisory board
4. Does the role of a male or female Elder differ?
5. What or how is the most respectful manner in which to approach an Elder, and how do you show gratitude?

³⁸ Protocols received from Sakoietta Widrick,

FIRST NATIONS ELDER

1. Calling an Elder for advice.

Whenever approaching an Elder, start by asking if the Elder will accept tobacco for you to speak with him or her. If your offer of tobacco is accepted, it means the Elder is available to listen, and then you can ask for guidance and assistance. Do not place the tobacco in the Elder's hands or hold out in front of you, rather, place it on a table between you when making your request. The Elder will take it when he accepts or if he/she cannot help, will leave it there. If you place it in their hands it may make them feel obligated and you appear aggressive.

The key....to find the Elder who is involved or familiar with the specific topic requested. Offer tobacco and acknowledge the Elder's contribution.

2. Calling to request an Elder for opening and closing prayers

Talk about what is taking place. Explain why the Elder is invited. Offer tobacco and invite the Elder. If the elder accepts the tobacco, the Elder will come.

The Opening Prayer serves to bless the meeting or the process to follow (feast, social, ceremony, etc.). The Elder speaks through the Creator to ensure that participants feel right about the process. The Closing Prayer is to thank the participants and honor the work that was done. The Elder blesses the completion of the process.

Keep in mind that when you have an Opening Prayer, you must have a Closing Prayer. The two go together.

3. Calling an Elder for full participation in a meeting or having an Elder as a member of an advisory board.

Talk about what is taking place. Explain why the Elder is invited. Describe the nature of the Elder's involvement, from contributing to the process simply by being present--the Elder's spirit provides a good feeling--to full active participation, including decision-making. Offer tobacco and request the Elder's participation. If the Elder accepts the tobacco, the Elder will participate.

The Elder's role in a meeting or on an advisory board is overall guidance. The Elder ensures a balance between both people and the issue at hand. It's also kind of like the role of the Speaker of the House in Parliament, to keep the participants on the right path, have them respect each other and start compromising.

4. Does the role of a male Elder differ from that of a female Elder?

All Elders are different--man and woman; and between First Nations too. They all have their strengths (gifts) to offer and traditional areas to work in. The key is to find an Elder who is knowledgeable and who is right for the issue in question. RESPECT ALL ELDERS!

5. What or how is the most respectful manner in which to approach an Elder, and how do you show gratitude?

Tobacco equals honor. There should only be one purpose per tobacco offering. If you can't access traditional tobacco to offer the Elder, pipe tobacco can be bought (e.g. Captain Morgan) or cigarette tobacco (e.g. Players)

Elders should receive honoraria to cover their expenses (travel, hotel, meals and time spent away from their homes and families). Financial transactions should be discrete; provide payments

separately, and whenever possible up front. When the Elder has a Helper, payments should cover costs for both of them.

Anything else can be given at your discretion (e.g., basket of fruit, cloth in traditional colors, tobacco pouches, herbal teas and products of the land).

A written acknowledgment to thank the Elder for his or her contribution is always a nice gesture. A letter can also be sent to the band office or to the person who put you in touch with the Elder IE: community member.

5.i. The Elder's Helper

Elders will often be accompanied by their Helper, everywhere they go. The Helper does the booking, takes care of the finances, and sometimes provides translation services. Elders are more comfortable speaking in their own language. The Helper can also play a role in the ceremonies. Helpers in general learn everything from the Elder and are being mentored to become Elders themselves.

It is important to include our Elders in anything we do, and we should always acknowledge our Elders. For too long, because of our ignorance, we have been shutting them out. We can't have them sit at the back of the room anymore; it's time for us to let Elder's play their full role and help us with everything they have to offer!

METIS ELDER

1. Calling an Elder for advice.

The first thing in contacting a Métis Elder is to do so through someone they already know and trust. Another important thing is to take an "offering" of tobacco. Tobacco offerings are still important to Métis Elders.

Speak slowly and plainly. Don't use big long words. Help them to feel relaxed, accepted and respected first and foremost.

2. Calling to request an Elder for Opening and Closing Prayers

Explain what you want and what the occasion is. It is a conference, graduation, birth, church service, memorial or special event? They can provide prayers usually in one or all of the following languages: English, Cree, French or Michif.

3. Calling an Elder for full participation in a meeting or having an Elder as a member of an advisory board.

Listen carefully. Good Métis Elders are good at "Indian time", and this really means getting there on time, even early. True Métis Elders don't take short cuts to becoming wise or respected. You have to earn your reputation, this sometimes takes a while. It means being honest and respectful. This advice is for those looking for a true Métis Elder. Being asked to be part of a meeting means they will sometimes do prayers, watch and listen, give advice and act in respectful ways. They will need to know what the meeting is about and what you might want them to do.

The role that a Métis Elder plays at a meeting or advisory board is "observer" and advisor. They watch for hand and facial expressions. Hands tell the story and watch to see nervousness, honesty, sincerity and to tell if they are a hard worker. They watch for eye twitching, expression on the face and the way someone sits. This tells them a lot. They watch and listen, then, when it's time, will bring up the weakness by telling someone important in the group or by saying it right there if asked,

but always with respect and kindness. They will help the meeting group by saying things nicely about what they notice and advise when it's necessary or the right time.

It's important to be honest, be yourself when you call them and in the meeting. Don't play games or be phony.....they see through that. Don't contradict a Métis Elder--you may never get another chance to work or speak with them again.

4. Does the role of a male Elder differ from that of a female Elder?

It's not important that you're a woman or a gentleman, but rather that they understand and respect the Métis culture, way of life and history. The Elder's heart and mind must be clear and honest, and they will believe in God or have some kind of good faith. Either male or female, their actions will speak for them.

5. What or how is the most respectful manner in which to approach an Elder, and how do you show gratitude?

A true Métis Elder's belief, "You can't live without finances, but if you've got enough to live on, what more do you want?"

Money for meals, travel (or you can pick them up), accommodation and a small gift of appreciation is very acceptable. I have often seen a true Métis Elder who has been given money and if it is more than required, will give it to someone in the community who needs it more, especially little children at Christmas. A true Métis Elder considers what is really needed.

It's important that they feel respected and honored for their contribution and wisdom, so please don't insult them by "trying to buy them" or "leave them feeling used or bought."

INUIT ELDER

Please Note: Protocols in dealing with Inuit Elders are changing rapidly. What may have been a customary tradition in dealing with an Inuit Elder may not necessarily be the case today. As well, the treatment of Inuit Elders in southern Canada will differ from that of those who live in northern Canada. This is only the general guideline but there are different protocols for different ceremonies.

1. Calling an Elder for advice.

Speak with kindness, love, equality and respect. Inuit Elders can play many roles depending on the situation.

2. Calling to request an Elder for Opening/Closing prayers.

Provide Inuit Elders with important information about the event and any necessary materials. Also provide Inuit Elders with transportation to and from the event (at the very least offer to ensure they arrive and depart safely)

3. Calling an Elder for full participation in a meeting or having an Elder as a member of an advisory board.

Follow the same advice as found in 1 & 2. Also provide Inuit Elders with any information beforehand so that they can understand the issues and truly participate in the meeting. Recognize that an Inuit Elder's time is very limited and precious.

Treat the Inuit Elder as you would like to be treated. Treat them as an equal, as they have great knowledge and experience. Listen to the advice the Inuit Elder may have. Remember that Inuit Elders are also learning as they go; therefore, watch how you speak so they can truly grasp the issue at hand.

4. Does the role of a male Elder differ from that of a female Elder?

The role between a male and female does differ slightly, but so does the role among Inuit Elders in general. Each Inuit Elder usually plays a certain role in his or her community. Traditionally, Inuit women Elders act as the teachers and caregivers while the Inuit men Elders act as the hunters and warriors.

5. What or how is the most respectful manner in which to approach an Elder, and how do you show gratitude?

Any recognition whatsoever for the Inuit Elder's time and effort is greatly appreciated. Inuit Elders do not usually accept tobacco offerings.

In the past, many people brought food, hides and skins to Inuit Elders to show their gratitude. For example, if it was difficult or too expensive to purchase seafood. Inuit Elders greatly appreciated seafood as an offering. They saw this gift as a special treat. Today, it is customary to provide the Inuit Elder with transportation to meetings and with meals occurring during those meetings. Most Inuit Elders do not have their own transportation and, for the ones who do, they need to be given accurate directions and payment to cover their mileage.

Inuit Elders are insulted if you consider a gift a payback for their advice. Don't try to buy off an Inuit Elder. These actions show disrespect towards them.

IROQUOIS ELDER

Iroquois People do things quite differently than other First Nations Peoples, so when requesting the services of an Iroquois Elder please keep this in mind, especially with the opening and closing of events being done by that Elder. Iroquois People use the Ohenton Karihwaterhkwen, or Thanksgiving Address to open and close the meetings. This address can take up to as long as hour, depending on the Elder. Most Elders will offer the short address to accommodate the event at hand.

It is also standard Iroquois protocol for the Elder to travel with a helper, so please keep this in mind when making requests.

1. Calling an Elder for advice.

Speak with kindness, love, equality and respect. Iroquois Elders can play many roles depending on the situation.

2. Calling to request an Elder for Opening/Closing prayers.

Provide Iroquois Elders with important information about the event and any necessary materials. Also provide Iroquois Elders with transportation to and from the event (at the very least offer to ensure they arrive and depart safely)

3. Calling an Elder for full participation in a meeting or having an Elder as a member of an advisory board.

Follow the same advice as found in 1 & 2. Also provide Iroquois Elders with any information beforehand so that they can understand the issues and truly participate in the meeting. Recognize that an Iroquois Elder's time is very limited and precious.

Treat the Iroquois Elder as you would like to be treated. Treat them as an equal, as they have great knowledge and experience. Listen to the advice the Iroquois Elder may have. Remember that Iroquois Elders are also learning as they go; therefore, watch how you speak so they can truly grasp the issue at hand.

4. Does the role of a male Elder differ from that of a female Elder?

The role between a male and female does differ slightly, but so does the role among Iroquois Elders in general. Each Iroquois Elder usually plays a certain role in his or her community. Traditionally, both Iroquois male and female Elders act as the teachers and caregivers. Both the male and female are capable of speaking on a wide variety of topics.

5. What or how is the most respectful manner in which to approach an Elder, and how do you show gratitude?

Any recognition whatsoever for the Iroquois Elder's time and effort is greatly appreciated. Iroquois Elders will generally accept tobacco offerings, as a sign of respect, but have difficulty doing so since most ceremonies done by the Iroquois Elder will be done using "Oienkwehonwe" or traditional tobacco, not the commercial kind. Please do not offer cigarettes.

Today, it is customary to provide the Iroquois Elder with transportation to and from meetings, with meals, lodging, a gift, and an honorarium to offer thanks for their participation. Most Iroquois Elders have their own transportation, except where they have to fly, and for the ones who do, they need to be given accurate directions and payment to cover their mileage.

Thanks to Melanie Setter, Dept. of Justice, for her work and assistance in forming this document.

APPENDIX B: CLARIFICATION OF TERMS

The following table³⁹ describes a variety of commonly used terms.

Ethnicity ⁴⁰	The concept of ethnicity is multidimensional and includes aspects such as race, origin or ancestry, identity, language, religion, culture, the arts, customs and beliefs and even practices such as dress and food preparation. It is dynamic and in a constant state of flux. Race is based primarily upon genetically imparted physiognomical features among which skin colour is a dominant, but not the sole, attribute.
Indigenous People	Descendants of the original inhabitants of North America, as defined in the Constitution Act of 1982, Section 35(2) "In this Act, the 'Indigenous People of Canada includes the Indian, Inuit, and Métis Peoples of Canada".
First Nations	This term is preferred by many Indigenous People and the Assembly of First Nations, refers to the various governments of the first people of Canada. First Nations is a term preferred to the terms Indians, Tribes, and Bands, and its usage has increased since it emerged in the 1970s. First Nations People were first able to vote in Canada in 1960. There are over 600 First Nations in Canada
Métis	A French word meaning "mixed blood" which usually refers to people of mixed ancestry who emerged during the days of the fur trade when Europeans and Indian people had children. The Métis are recognized as Indigenous People in the Constitution Act, 1982. The Métis history and culture draws on diverse ancestral origins such as Scottish, Irish, French, Ojibway and Cree. The Métis National Council has adopted a definition of Métis as: Métis means a person who self-identifies as Métis, is of historic Métis Nation Ancestry, is distinct from other Indigenous Peoples and is accepted by the Métis Nation. There are eight distinct Métis Settlements in Alberta in which Métis People hold land title and exercise broad self-governing powers.
Inuit	Literally, 'the people' — the name given by the Arctic People to themselves. Indigenous Peoples who reside in the eastern arctic and Arctic Ocean regions of the North West Territories, formerly known as Eskimo. Inuit do not have legal status under the Indian Act but a 1939 Supreme Court of Canada decision determined that Inuit are entitled to the same programs and services ⁴¹ .
Inuit Tapiriit Kanatami	National association representing Inuit People.
Treaties	Treaties are legal documents between government and a First Nation that confer rights and obligations on both parties. No two Treaties are identical. For example, Alberta is included in three populated treaty areas covered by Treaties 6, 7 and 8. Treaties 4 and 10 have some Alberta land but are not populated. Because of the legal, historic and sacred elements of the Treaties, First Nations consider these documents to be the essential factor in any relationship between the Government and First Nations People, leaders, governments and organizations.

³⁹ Sources: AAND The Indigenous Population of Alberta 1996 Fact Sheet; Alberta Learning First Nations, Métis and Inuit Education Policy Framework, Glossary of Key Terms; IWAC-AWPI Employer Toolkit; Lorne J. Terms, Professional Corporation. Métis National Council website www.Indigenoucanada.gc.ca

⁴⁰ Taken entirely from the World Wide Web at <http://www.statcan.ca/english/concepts/definitions/ethnicity.htm> on September 14, 2004.

⁴¹ Found at the www on October 19, 2004 at <http://www.google.ca/search?hl=en&lr=&oi=defmore&q=define:Inuit>

Status Indians
(First Nations)

Registered or entitled to be registered under the Indian Act. By virtue of the Indian Act, the Department of Indian Affairs and Northern Development is responsible for providing support and services to all Registered Indians.

Non-Status
Indians (First
Nations)

People who self-identify themselves as Indians but are not entitled to be registered under the Indian Act. This may be because they are descendants of those who married non-Indians too many generations back to be returned to status under the 1985 amendment to the Indian Act; or they elect to not register; they may be improperly refused registration contrary to law; or they lost status in some other way.

Bill C-31

Amended the Indian Act in 1985 and removed discriminatory clauses against women, restored status and membership rights in certain circumstances and increased First Nations' control over their own affairs. People who have been reinstated as Status Indians under this Act are often referred to as Bill C-31 Indians.

Band
Membership

If an individual is recognized as a Band member, his or her name appears on an approved Band List. Where a First Nation (Band) has adopted its own membership code, it may define who has a right to membership, so being a Status Indian is not synonymous with being a Band member.

APPENDIX C: STEERING COMMITTEE VALUES

Our statement of values underpinned the consultation. Communication of the values was one of the first steps toward building trust with the people with whom we were consulting. The values guided our actions in designing the dialogue and in responding to issues as they arose.

Value	Description	Expression/Indicators
Appreciation of diversity	<ul style="list-style-type: none"> Seeking to understand, not judge views. Genuine admiration for the cultural context and views expressed. Flexibility in response to diversity. 	<ul style="list-style-type: none"> Information is aimed at understanding not changing opinions. Process is focused on hearing from participants, not teaching them. Process is adjusted to respect ceremonies and traditions of the ethnocultural and Indigenous group being consulted. Diversity of opinions is welcomed. Language of dialogue reflects the dominant language of the group being consulted.
Collaboration	<ul style="list-style-type: none"> Allowing situations to develop organically. Cooperative not competitive approach. Building on existing local activities. Sharing of results with those consulted. Commitment to the future of the partnership. 	<ul style="list-style-type: none"> Consultation process and tools are developed in response to the input of the group being consulted. Not wanting to be consulted is respected. Steering committee examines motivations and values to ensure transparency. Commitment by local donation programs to time required to consult and build partnerships. Linkages with other related projects are encouraged.
Integrity	<ul style="list-style-type: none"> Trust through open communication about the purpose of the consultation, values, processes used and application of results. Respect for all involved. Respecting experience, expertise, heritage and history. 	<ul style="list-style-type: none"> People being consulted are partners in the dialogue and influence its approach and outcomes. Commitment to follow up and follow through by local agencies engaged in consultation. Clear indication of use of information to participants. Consultation will be guided by a code of ethics. Participants give permission for use of their information.
Excellence	<ul style="list-style-type: none"> The consultation will be conducted within a continuous learning approach. Process will be based on evidence available and input of local people. Rigour applied to ensure high quality information. 	<ul style="list-style-type: none"> Targeted literature searches will be done as needed. Participants will be asked for feedback on the consultation methods. Participants will be asked in advance what methods work best for them. Environmental scan will, in part, guide the consultation approach. Experts are consulted throughout for guidance.
Capacity building	<ul style="list-style-type: none"> Focus on assets within a community and on their unique ability to contribute to this topic. Identify projects underway within the community that might encompass donation and transplantation. 	<ul style="list-style-type: none"> Consultation will include an invitation to continue the work on this topic within their community. Strengths within the community will be recognized. Opportunities to marry organ donation with existing issues in a community will be considered.
Learning	<ul style="list-style-type: none"> Openness to new ways of doing consultation. Sincere desire to have the limits of our own culture identified. 	<ul style="list-style-type: none"> Asking for feedback on our approach to the consultation. Asking for our cultural errors to be identified. Willingness to hear that individuals or groups do not want to donate for cultural reasons. Willingness to identify new practices that may require changes in the medical system.

APPENDIX D: ELDERS' AND TRADITIONAL KNOWLEDGE KEEPERS' CIRCLE INFORMATION PACKAGE

Elders' and Traditional Knowledge Keepers' Circle on Organ Donation and Transplantation

November 4, 2004
7:00 – 9:00 PM
Thunderbird House
715 Main St.
Winnipeg

November 5, 2004
8: 30 AM – 4:00 PM
Place Louis Riel (Gateway Room)
190 Smith St.
Winnipeg

Purpose

The purpose of this Circle is to provide an opportunity to hear the experiences, views, traditional values and beliefs of Elders and Knowledge Keepers about organ and tissue donation and transplantation. This information will guide the Canadian Council on Donation and Transplantation (CCDT) in their advice to the Deputy Ministers of Health.

The following are values that the CCDT has agreed will guide the dialogues:

Value	Description
Appreciation of diversity	<ul style="list-style-type: none"> Seeking to understand, not judge views. Genuine admiration for the cultural context and views expressed. Flexibility in response to diversity.
Collaboration	<ul style="list-style-type: none"> Allowing situations to develop organically. Cooperative not competitive approach. Building on existing local activities. Sharing of results with those consulted. Commitment to the future of the partnership or other arrangements as they emerge.
Integrity	<ul style="list-style-type: none"> Trust through open communication about the purpose of the dialogue, values, processes used and application of results. Respect for all involved. Respecting experience, expertise, heritage and history.
Excellence	<ul style="list-style-type: none"> The dialogue will be conducted within a continuous learning approach. Process will be based on evidence available and input of local people. Rigour applied to ensure high quality information.
Capacity building	<ul style="list-style-type: none"> Focus on assets within a community and on their unique ability to contribute to this topic. Identify projects underway within the community that might encompass donation and transplantation.
Learning	<ul style="list-style-type: none"> Openness to new ways of doing dialogue. Sincere desire to have the limits of our own culture identified.

Aims of the Sharing Circle

1. Identify experiences, views, traditional values and beliefs about organ donation and transplantation.
2. Identify the best ways for engaging Aboriginal People in discussion and action around organ donation and transplantation.
3. Identify ways that Aboriginal Peoples and people from the local donation and/or transplant program might work together.

Process

Approximately 25 people will be invited to the Elders' and Traditional Knowledge Keepers' Circle. This group would include approximately 20 Elders and Knowledge Keepers plus about five other people. The five others are: Gaye Hanson (process guide); Bev Curtis (process support); Kim Young (CCDT); Rosalie Starzomski (CCDT) and Sybil Stokoloff (Manitoba Transplant).

On November 4, 2004 at 7:00 PM, we will gather at the Thunderbird House. The evening circle will be for welcome and introductions. We will meet with each person to gather information such as birth year; Nation affiliation; religious affiliation (if applicable); status/non-status; education; and rural/urban residence. We will be asking participants to sign a letter of consent for participation. We will ask your permission to make an audio tape of the session so that none of the discussion is lost. Bev Curtis will explain the project purpose, anticipated outcomes and the expected use of the information gathered in the Circle. We will welcome your questions.

The information from this meeting will be combined with information from other meetings and interviews to:

- Provide advice to the Deputy Ministers on the best ways to address issues related to donation and transplantation that are unique to Aboriginal Peoples.
- Advise other locations how best to consult with Aboriginal Peoples on the topic.
- Help health professionals understand the issues that Aboriginal People identify about donation and transplantation.
- Help develop ways that respect Aboriginal Peoples' traditions in relation to organ and tissue donation and transplantation.

On November 5, 2004, we will gather at the Place Louis Riel (Gateway room) at 8:30 AM to open the circle. We will ask the appropriate person to lead the ceremonial part of the meeting including smudge, opening and closing prayers. Gaye Hanson will support the discussion as needed.

The Circle will primarily be conducted in English. We understand, however, that there are nuances and concepts that cannot be conveyed properly in English. Members of the circle will be asked to assist with translation as needed from the Aboriginal languages into English.

The following questions are suggested to guide our discussion. Once our dialogue begins, different questions might emerge as people share their views.

1. Awareness of and experience with organ and tissue donation and transplantation

- Personal experience or knowledge of someone who has donated or consented to donation;
- Did knowing someone who had donated or consented to donation change your views about it?
- Donation while alive or after death;

2. Views toward organ donation and transplantation

- What do you hear said about organ donation and transplantation in your community?
- Help us to understand why someone might say yes or no to transplantation or donation for themselves or for their family members.

3. Views and traditional values and beliefs which influence Aboriginal People in regard to donation and transplantation

What do participants say about:

- Traditional and non-traditional beliefs about death and life after death;
- How decisions to donate organs or receive a transplant are made by individuals and within families.

4. Support to decision

- In order to support a family in the decision making process, what can be done to help them at the consent, donation and follow-up stages of the process.
- Are there things that a health care provider should be particularly aware of when helping a family to make the decision?

5. Relationship Building

- How do we go about continuing this dialogue with Aboriginal Peoples?
- How should we develop relationships with Aboriginal organizations and other individuals concerned with donation and transplantation?

6. Closing

- What did we learn today that we can take forward to other groups?
- What worked and what did not work at the evening meeting and the Circle?
- Closing comments and follow up connections.



October 26, 2004

Dear X,

Thank you for agreeing to be part of the Sharing Circle to discuss your experiences, views, values and traditional beliefs about organ and tissue donation and transplantation.

The event will begin on **Thursday, November 4, 2004 at 7:00 PM at Thunderbird House at 715 Main St., Winnipeg** with opening prayers, welcome, introductions and background to the project. Please bring slippers or moccasins or you may use the slippers provided at Thunderbird House. We will meet with you to obtain your consent and to gather other information during the refreshment break.

On **November 5, 2004** (8:30 AM - 4:00 PM), the Circle will begin at 8:30 AM in the **Gateway Room at Place Louis Riel, 190 Smith Street, Winnipeg** and will finish at 4:00 PM. We will provide an honorarium for your participation in the evening meeting and daytime Circle. We will also cover your travel and accommodation expenses.

The incidence of diabetes in Canada is quite high. Among First Nations People, the prevalence of diabetes is three to five times the national average. In some cases, diabetes can lead to kidney failure. One of the treatment options for kidney failure is transplantation. Each person in this situation must decide whether to receive a transplant, and family members might have to decide whether to donate a kidney for transplantation. The availability of transplantation as a treatment option depends on the availability of donor organs.

The purpose of this Circle is to give you and others a chance to consider organ and tissue donation and transplantation and to offer guidance to the Canadian Council on Donation and Transplantation (CCDT). Organ donation and transplantation are sensitive topics upon which many values and beliefs come to bear. We are interested in understanding your views, values and beliefs on organ and tissue donation and transplantation and other related issues which arise in the discussion.

We are enclosing an information sheet and a consent form to help you to know more about the project. If you have questions about the event, please contact Gaye Hanson at 1 867 633 6753 or Bev Curtis at 1 780 496 9067 ext. 223. We look forward to meeting you.

Warm regards,

Rosalie Starzomski, RN, PhD
Lead, CCDT Steering Committee

Elders' and Traditional Knowledge Keepers' Circle on Organ Donation and Transplantation

November 4, 2004 7:00 – 9:00 PM Thunderbird House 715 Main St. Winnipeg	November 5, 2004 8: 30 AM – 4:00 PM Place Louis Riel (Gateway Room) 190 Smith St. Winnipeg
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Purpose

The purpose of this Circle is to provide an opportunity to hear the experiences, views, traditional values and beliefs of Elders and Knowledge Keepers about organ and tissue donation and transplantation. This information will guide the Canadian Council on Donation and Transplantation (CCDT) in their advice to the Deputy Ministers of Health.

The following are values that the CCDT has agreed will guide the dialogues:

Value	Description
Appreciation of diversity	<ul style="list-style-type: none"> · Seeking to understand, not judge views. · Genuine admiration for the cultural context and views expressed. · Flexibility in response to diversity.
Collaboration	<ul style="list-style-type: none"> · Allowing situations to develop organically. · Cooperative not competitive approach. · Building on existing local activities. · Sharing of results with those consulted. · Commitment to the future of the partnership or other arrangements as they emerge.
Integrity	<ul style="list-style-type: none"> · Trust through open communication about the purpose of the dialogue, values, processes used and application of results. · Respect for all involved. · Respecting experience, expertise, heritage and history.
Excellence	<ul style="list-style-type: none"> · The dialogue will be conducted within a continuous learning approach. · Process will be based on evidence available and input of local people. · Rigour applied to ensure high quality information.
Capacity building	<ul style="list-style-type: none"> · Focus on assets within a community and on their unique ability to contribute to this topic. · Identify projects underway within the community that might encompass donation and transplantation.
Learning	<ul style="list-style-type: none"> · Openness to new ways of doing dialogue. · Sincere desire to have the limits of our own culture identified.

Aims of the Sharing Circle

1. Identify experiences, views, traditional values and beliefs about organ donation and transplantation.
2. Identify the best ways for engaging Aboriginal People in discussion and action around organ donation and transplantation.
3. Identify ways that Aboriginal Peoples and people from the local donation and/or transplant program might work together.

Process

Approximately 25 people will be invited to the Elders' and Traditional Knowledge Keepers' Circle. This group would include approximately 20 Elders and Knowledge Keepers plus about five other people. The five others are: Gaye Hanson (process guide); Bev Curtis (process support); Kim Young (CCDT); Rosalie Starzomski (CCDT) and Sybil Stokoloff (Manitoba Transplant).

On November 4, 2004 at 7:00 PM, we will gather at the Thunderbird House. The evening circle will be for welcome and introductions. We will meet with each person to gather information such as birth year; Nation affiliation; religious affiliation (if applicable); status/non-status; education; and rural/urban residence. We will be asking participants to sign a letter of consent for participation. We will ask your permission to make an audio tape of the session so that none of the discussion is lost. Bev Curtis will explain the project purpose, anticipated outcomes and the expected use of the information gathered in the Circle. We will welcome your questions.

The information from this meeting will be combined with information from other meetings and interviews to:

- Provide advice to the Deputy Ministers on the best ways to address issues related to donation and transplantation that are unique to Aboriginal Peoples.
- Advise other locations how best to consult with Aboriginal Peoples on the topic.
- Help health professionals understand the issues that Aboriginal People identify about donation and transplantation.
- Help develop ways that respect Aboriginal Peoples' traditions in relation to organ and tissue donation and transplantation.

On November 5, 2004, we will gather at the Place Louis Riel (Gateway room) at 8:30 AM to open the circle. We will ask the appropriate person to lead the ceremonial part of the meeting including smudge, opening and closing prayers. Gaye Hanson will support the discussion as needed.

The Circles will primarily be conducted in English. We understand, however, that there are nuances and concepts that cannot be conveyed properly in English. Members of the Circles will be asked to assist with translation as needed from the Aboriginal languages into English.

The following questions are suggested to guide our discussion. Once our dialogue begins, different questions might emerge as people share their views.

1. Awareness of and experience with organ and tissue donation and transplantation

- Personal experience or knowledge of someone who has donated or consented to donation;
- Did knowing someone who had donated or consented to donation change your views about it?
- Donation while alive or after death;

2. Views toward organ donation and transplantation

- What do you hear said about organ donation and transplantation in your community?
- Help us to understand why someone might say yes or no to transplantation or donation for themselves or for their family members.

3. Views and traditional values and beliefs which influence Aboriginal People in regard to donation and transplantation

What do participants say about:

- Traditional and non-traditional beliefs about death and life after death;
- How decisions to donate organs or receive a transplant are made by individuals and within families.

4. Support to decision

- In order to support a family in the decision making process, what can be done to help them at the consent, donation and follow-up stages of the process.
- Are there things that a health care provider should be particularly aware of when helping a family to make the decision?

5. Relationship Building

- How do we go about continuing this dialogue with Aboriginal Peoples?
- How should we develop relationships with Aboriginal organizations and other individuals concerned with donation and transplantation?

6. Closing

- What did we learn today that we can take forward to other groups?
- What worked and what did not work at the evening meeting and the Circle?
- Closing comments and follow up connections.

Elders' and Traditional Knowledge Keepers' Circle Information Sheet

Circle Sponsor

Canadian Council on Donation and Transplantation (CCDT); Rosalie Starzomski, Lead, Ethnocultural Steering Committee

Consultants

Beverley Curtis
Charis Management Consulting
#418 10123 – 99 St.
Edmonton, AB T5J 3H1
(780) 496 – 9067 ext. 223

P. Gaye Hanson
Hanson and Associates
42 Tamarack Dr.
Whitehorse, Yukon Y1A 4W2
Home/Office: (867) 633-6753

We want to be open and transparent. We would like you to be fully aware of what our project is and how you will be involved. Please take the time to read this material to be sure you understand. The consent form is attached and will be discussed on the evening of November 4, 2004. We welcome any questions you have.

Introduction

The incidence of diabetes in Canada is quite high. Among First Nations People, the prevalence of diabetes is three to five times the national average. In some cases, diabetes can lead to kidney failure. One of the treatment options for kidney failure is transplantation. Each person facing a disease where a transplant could help must decide whether to receive a transplant or not. Family members might also be faced with the decision to donate a kidney while living or to agree to donate the organs of a deceased loved one.

Transplantation is only available if there are donor organs. To improve organ and tissue donation in Canada, the Canadian Council for Donation and Transplantation provides advice to the government. CCDT is looking for guidance to help Aboriginal Peoples to consider organ and tissue donation and transplantation.

The Council is interested in your perspective as an Elder or Traditional Knowledge Keeper. We are holding a sharing circle to receive your guidance about aboriginal views and beliefs about organ and tissue donation and transplantation. We would like advice about how to discuss this topic with other Aboriginal Peoples.

Purpose

The aim of the Circle is to gather information to advise the Conference of Deputy Ministers (the group meets regularly and includes all of the Deputy Ministers of Health for the whole country) about what strategies will help people to consider organ and tissue donation.

The Circle will be a conversation among Elders and Traditional Knowledge Keepers about organ and tissue donation and transplantation and related issues. The Circle will be guided by Gaye Hanson, as needed. A sample of possible discussion topics is on page 3 of this consent form. It is important that you are comfortable with these topics. You are free to participate or not participate in any of the discussions.

Process

You will be participating with about 20 other men and women. In addition to the consultants, people from CCDT, Manitoba Transplant and Manitoba Health will be participating.

The discussion will take about 2 hours on the evening of November 4 and about 7 hours during the day of November 5, 2004. The Circle discussion will be audio-taped only for the purpose of typing the discussion for analysis. If you do not wish to be audio taped for any part, or all of the session, the recorder will be turned off at your request.

Possible benefits and risks

The Circle may provide you with a chance to consider a topic that may affect people in your communities and to hear others' perspectives on the topic. This discussion may assist you to clarify your thinking as you consider the impact of donation and transplantation on your community now and in the future.

There are no anticipated risks related to your involvement in the circle. It is possible that some of the topics may raise new and perhaps emotional issues for you. You need only answer questions or express your views when you wish to do so. If there are disturbing issues that arise for you in the Circle, we could support you at the time or assist you to find other suitable help.

Compensation

We will cover your travel and hotel expenses (if applicable). An honorarium for the evening and daytime sessions combined will be offered. Refreshments will be served during the evening session and lunch and refreshments will be provided during the daytime session.

Confidentiality

Your information will be kept confidential by the consultants and the CCDT people in the meeting. The information will be used to develop themes and write a report which will be provided to the CCDT, with no names of participants or other identifying information. Further, any reports or publications from this work will not name the people who took part or use any identifying information.

The audiotapes from the tape-recorded discussion will be kept in a locked drawer at the consultant's office for 2 years and then will be destroyed. There will be no identifying information of participants on the transcript. Any written material will be stored in a locked filing cabinet at the consultant's office for 7 years and then will be destroyed.

Because of the nature of the Circle, we cannot fully guarantee confidentiality of the discussion. Some participants know each other and, while we will ask members to keep the discussion in confidence, we cannot guarantee that individuals will do so.

In addition to protecting your confidentiality, there are several ways that you could be involved:

- No further involvement and no identifying information released;
- Limited involvement through providing feedback on the report on the Circle, with no identifying information included; or
- Involvement through providing feedback on the report of the Circle, evaluation of the process and providing other advice. You will be recognized in the report with your name and contribution.

Freedom to Withdraw

Your participation is completely voluntary. You may leave the Circle at any time you want and you do not have to give a reason.

Contacts

If you would like more information about the Circle, please ask Gaye Hanson at 1 867 333 2411 or Bev Curtis at 1 780 496 9067 ext. 223.

Proposed Circle Discussion Questions

The following questions are suggested to guide our discussion. Once our dialogue begins, different questions might emerge as people share their views.

1. Awareness of and experience with organ donation and transplantation

- Personal experience or knowledge of someone who has donated or consented to donation;
- Did knowing someone who had donated or consented to donation change your views about it?
- Donation while alive or after death.

2. Views toward organ donation and transplantation

- What do you hear said about organ donation and transplantation in your community?
- Help us to understand why someone might say yes or no to transplantation or donation for themselves or for their family members.

3. Views and traditional values and beliefs which influence Aboriginal People in regard to donation and transplantation

What do participants say about:

- Traditional and non-traditional beliefs about death and life after death; and
- How decisions to donate organs or receive a transplant are made by individuals and within families.

4. Support to decision process

- In order to support a family in the decision making process, what can be done to help them at the consent, donation and follow-up stages of the process.
- Are there things that a health care provider should be particularly aware of when helping a family to make the decision?

5. Relationship Building

- How do we go about continuing this dialogue with Aboriginal Peoples?
- How should we develop relationships with Aboriginal organizations and other individuals concerned with donation and transplantation?

6. Closing

- What did we learn today that we can take forward to other groups?
- What worked and what did not work at the evening meeting and the Circle?
- Follow up connections.
- Closing comments.

Consent Form

Please sign the bottom of this form to indicate that you consent to participate in the Elders' and Traditional Knowledge Keepers' Circle (sponsored by Canadian Council for Donation and Transplantation).

Participant's Understanding

I understand that I have been asked to participate in an Elders' and Traditional Knowledge Keepers' Circle.

I understand that my involvement is voluntary and that I may decline to speak or I may withdraw at any time. I have read a copy of the information sheet. Any questions I have asked have been answered, and I am content with the answers. I have been told about the benefits and risks that could occur.

I know this information may be reported, but I will not be named. I understand my confidentiality will be respected.

I agree to take part in this Circle on organ donation and transplantation and I agree to having the discussion audio-taped.

I agree to be contacted at some time after the Circle to participate in the evaluation of the process. Participation in the evaluation is voluntary and I may refuse participation when contacted.

Name of participant (please print)

Signature of participant

Date

Name of witness (please print)

Signature of witness

Date

APPENDIX E: WINNIPEG ELDERS' AND TRADITIONAL KNOWLEDGE KEEPERS' EVALUATION RESULTS

Canadian Council on Donation & Transplantation

Diverse Communities Project

Evaluation of the Aboriginal Elders and Traditional Knowledge Keepers Circle:
Questions and results from 7 respondents (4 by e-mail; 3 by interview)

January, 2005

1. Was the contact and planning prior to the Circle culturally respectful?

Not all felt they could answer this question, but the 3 who responded said yes. They had more to say about how it was actually conducted than planned, with the one embedded in the other.

2. Do you have advice for improvements to the way in which the Circle was planned? Was the Circle the right approach in terms of activities/methods, timing, location, participants? Is there anything that you would advise us to change if we were doing it again?

Although People felt the Circle was the right approach, they had some comments for changes: explicit time-limit for speakers and sticking to the topic more; a different venue; an additional day for discussion, and additional protocol and tradition to be observed.

Several people said:

- Shorten speaking time per person or add another day.
- More time to talk; add another day.

Individual comments include:

Identify the purpose and stick to it. Whoever is heading the Circle has the right to bring it back on topic (K.B.).

Hold it in a rural setting rather than downtown hotel (someplace like the Dr. Jesse Saulteaux Centre) We would have been able to focus more. Talking about human lives is so important. In a rural setting it would have contributed to the whole environment for talking. (V.M.I)

Thunderbird House was a bit too big for the group and the room at Place Louis was a bit too small. Circle format was great. (S.W.)

Bring in different kinds of people; there were too few professional Aboriginal People who have influence in the community; besides people in health care we need to involve labourers, people on welfare, people from the city, from reserves. (D.S.)

Should have offered tobacco at Thunderbird house and gone around and shaken hands with people and given new tobacco. (C.P.)

Should have had a sacred fire at Thunderbird house (C.P.)

Give nametags. (C.P.)

Should provide a bowl of cigarettes a courtesy ...use them as an offering. If people want to smoke them, that's their choice. (C.P.)

*You send a stone around – that was OK – you should have made a talking stick. (C.P.)
Encourage more community activity- ceremonies. (C.P.)*

Ask the Elders – what is your point of view on death – What is happening to our people with health in FNs? What are some of these causes? Stems back to economics. (C.P.)

3. Was the Circle conducted in a culturally respectful way? E.g.,

- Did we follow the proper protocol?
- Use the proper language?
- Did people in the Circle feel listened to?
- Did they feel their values were respected?

Respondents all agreed that the Circle was conducted in a culturally respectful way. The comments that expanded upon this general agreement included:

The organizers followed proper protocol. (S.W.)

It was in a Circle first of all; then there was the smudging, the prayers, and the acknowledging of each other, the respect for each others' views, whether they were for or not. (K.B.)

The respect that was shown, knowing that these were people who were honourable. It was like meeting of two nations that were equal. People felt very listened to. I felt like my values were respected. (V.M.)

It certainly was done in a culturally respectful, down-to-earth way, honouring the culture. My people want that. There were a lot of things that were said that weren't relevant to what was going on...talking about life, but nobody rushed them through. It was done very nicely that way. (D.S.)

I thought the Circle was very culturally respectful and the sharing was conducted in a culturally respectful way. (D.N.)

4. Did the Circle cover the topics/issues that are important to you regarding donation/transplantation? Any others?

People generally felt that the main topics had been covered but again stressed that it was difficult to do this in one day, and wanted at least another day to do so.

For an introductory meeting, it was good. (S.W.)

Yes, I feel the topics were very relevant. A lot of issues were covered there and more would have come up in another day. (V.M.)

I thought the Circle covered most of it. The Circle looked at different points of view. Maybe a full 2 day session next time as it seemed a little hurried toward the end. (D.N.)

5. Was the Circle useful to the community? Do you think it contributed to the community meeting its own priorities in this area? If yes, how did the Circle contribute? If no, why do you think it did not contribute?

People felt that having the Circle was helpful to the community in that it invoked the power of having members of the community come together to focus on a topic of common interest for the good of the community, and would stimulate further Circles and discussion in the communities.

It was helpful in recognizing the issue around donation and transplantation, even though it had come up before. The contribution was in bringing more people to the table, more health system people and more traditional knowledge keepers. (K.B.)

Yes. It was good to be able to discuss and share in a very culturally appropriate way. (S.W.)

In this busy world, all of our rushing, we forget about being human beings, and we go through days in a robotic way. In this circle, people connected in a very human way, were appreciated, not just about the subject, but connected as human beings. They say there is no new knowledge. When a group of us get together in a Circle like that, the wisdom will surface that we need. (V.M.)

From this Circle will be other Circles and so on in the communities, talking about what was shared re: donation/transplantation. Each person shared as an individual or family representation. This information will be passed on to other sharing Circles. (D.N.)

6. What benefits did you receive, if any, by participating in the Circle?

People felt that respect had been shown to their culture and were pleased to be included in a forum starting to discuss a topic that mattered to the community.

I always feel that respect has been shown for the Aboriginal way of processing information and making decisions, when the Circle format is used. (S.W.)

I was so pleased to be in that Circle, so honoured to be a part. I would look forward to getting together in a Circle again with those people. (V.M.)

This is a beginning, not something that has gone on before. (D.S.)

I certainly learned from the Circle and will be sharing the information with people in my community and workplace. Donation/transplantation is acceptable and should be regarded as an extension of life in the most respectful manner. (D.N.)

7. Do you think that you will take any action in your community related to donation and transplantation because of the Circle?

Three of the 7 respondents indicated that they would be willing to personally become involved in educating their communities if someone were to take a leadership role in developing the issue further in the Winnipeg and Manitoba area. Generally, however, people talked less about what they themselves would do and more about the kinds of activities that they saw were needed such as:

- education of the Aboriginal / general public about their organs and what organ donation is all about, both in the cities and on reserves, e.g., using the AIDS education approach on reserves as a model;
- education for health professionals (doctors and nurses) concerning more appropriate and compassionate ways of approaching families about considering organ donation in hospital;
- the development within the Aboriginal community of proper ceremony to accompany the act of donation of body parts to acknowledge cultural beliefs about the afterlife;
- the development of the concept of organ donation as a strategy for bringing people together and combating racism;

- Involve local Aboriginal media, local Aboriginal advocacy groups, and people from the Circle themselves in continuing to raise awareness about the issues in donation and transplantation in the Aboriginal community.

The comments around these points included:

There needs to be more education of the public about donation and transplantation. (K.B.)

People don't understand the terms 'give up your kidneys'....some don't know what the organs are even. How to explain that and explain to lay people by using their language. You have to put them in a frame of mind that they can concentrate...like short stories about organs. You have to teach white people too, not just First Nations. (D.S.) We have 62 reserves in Manitoba. They took AIDS education to the reserves. You have to travel. At first the people didn't want to hear about sexual things. You have to start lightly and then get more into depth. I was part of that group at the beginning. They had to get people to teach who were educated in those areas...somebody who has the wisdom with people as well as the knowledge, because you are going into an area that hasn't been touched before. This is what you can talk about. And it has to be entertaining, because on reserves there is very little entertainment. They're not going to listen if it is too technical. (D.S.)

Nurses and doctors are bound by rules that are meant to help people, but can de-humanize everything. Respect for life and respect for human beings are lost in the middle of all the rules and regulations. (V.M.)

White people lose perspective in what they are doing. They intellectualize and they lose it all. You have to talk to families in a peaceful, kind way...there is pain in not giving donations because of the way they were treated poorly. Somebody should be talking to them in a healing way because of the pain there would be in giving the organs. (D.S.)

The belief is that before your soul can go to the Great Creator you have to find all your body parts. Some people will look a long time. We have to have a ceremony when we give up a body part, because the dead person has to know where they are. In a ceremony you would know. Somebody would have to make up a ceremony. How would it work, because it has to go with the culture. Maybe go with an existing ceremony about losing a hand or mourning. Then people [who donate] will know there will be a ceremony. We could have a ceremony before an event as part of a pow-wow or another event....it would be mentioned by somebody who can talk about it at the next pow-wow. The Elders are the ones who can talk about it. (D.S.)

How to change people from not being so racist. You don't have to say things to them. This could really bring people together here. The organs have to be in sync with the body. If a white guy has the heart of an Indian, he certainly isn't going to discriminate. (D.S.)

The Aboriginal Peoples' Television Network (APTN) could do stories, because they reach a larger population. ...could be in both the languages and English. (K.B.)

I feel it could be expanded in a very broad way. This is a very dynamic Aboriginal community in Winnipeg, e.g., the Inner City Aboriginal Neighbours (ICAN) is here and has become a very strong group. It would be good to have a focus on organ donation and transplantation topics. To educate people about the issues because we haven't heard about anything. (V.M.)