

## DIVERSE COMMUNITIES

Consultation to Explore Perspectives on Organ  
and Tissue Donation

### **SECTION I**

March 30, 2005

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# 1. BACKGROUND

The Canadian Council for Donation and Transplantation (CCDT) was created as an advisory body to the Federal, Provincial and Territorial Conference of Deputy Ministers of Health in response to concerns about a persistent and growing gap between the demand and supply of organs and tissues for transplantation in Canada. Canada is reported to have the one of the lowest donation rates among developed countries.<sup>1</sup> The development of an ongoing social marketing strategy that is sensitive to all societal groups was identified as a key requirement for improving donation rates.<sup>2</sup> The CCDT believes that information to assist Canadians to make informed choices about donation is best delivered in an ethnoculturally respectful and appropriate way. The CCDT Ethnocultural Steering Committee (see Appendix A) asked members of three groups; Chinese Canadians, South Asian Canadians and Indigenous Peoples to discuss their beliefs and attitudes about organ and tissue donation, with a view to understanding better the factors leading to donation decisions by people from diverse communities.

In May 2004, the CCDT hired a consultant to undertake the development of a Diverse Communities Consultation to identify and discuss issues affecting organ and tissue donation and the development of key considerations and related recommendations.<sup>3</sup> The purpose of the consultation was to identify and understand the unique perspectives on organ and tissue donation of people from three diverse backgrounds.

The objectives for the consultation were to:

- Develop methods for government, donor programs and stakeholders to work together for the support of communities in:
  - Understanding and learning about donation and transplantation;
  - Determining changes that would assist communities in receiving information in a culturally appropriate way; and
  - Assessing what can be done to augment the existing systems to ensure that communities are supported from within.
- Establish a set of principles (key considerations) or a model for use in each Federal/Provincial/Territorial (FPT) jurisdiction in Canada as they develop specific strategies for communicating information relative to organ and tissue donation.
- Consider current values and beliefs about organ and tissue donation in selected diverse communities.
- Assist people in considering organ and tissue donation and signifying their intent by providing them with information that is appropriate for their community.

The consultation served the CCDT's priority of improving 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."<sup>4</sup> It is anticipated that understanding the unique perspectives of people from diverse ethnocultural and Aboriginal backgrounds will lead to more effective and respectful communications about organ and tissue donation and transplantation with these groups. It is also expected that the consultation will have generated discussion about organ and tissue donation within communities that will be ongoing beyond the consultation.

The word "consultation" was for this purpose defined as a tool for answering key policy questions. The results of the consultation combined with the results of the limited environmental scan and literature search (see Appendix B) provided the basis for the recommendations in this report which answer the overall policy question of how to improve the system of organ and tissue donation and transplantation so that it includes specific and unique diverse populations.

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<sup>1</sup> CCDT RFP D-EC-04-01 "Diverse Communities Consultation to Explore Perspectives on Organ and Tissue Donation", May 20, 2004.

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> CCDT Annual Report. (2003). P. 3.

## 2. REPORT ORGANIZATION

**Section I** of this report (pgs. I-1 to I-55) describes the overall consultation methods, scope, values, results and recommendations.

*Appendices to Section I include:*

- Appendix A: Steering Committee membership
- Appendix B: Diverse Communities Environmental Scan
- Appendix C: Diverse Communities Consultation Plan

**Section II** (pgs. II-1 to II-68) contains the Toronto report on the consultation with people of Chinese heritage.

*Appendices to Section II include:*

- Appendix A: Planning Group members
- Appendix B: Focus Group Tools
- Appendix C: General Survey Tools
- Appendix D: Physician Survey Tools

**Section III** (pgs. III-1 to III-39) contains the Vancouver report of the consultation with people of South Asian heritage in Vancouver, British Columbia.

*Appendices to Section III include:*

- Appendix A: Consultation on organ and tissue donation and transplantation. Vancouver draft description
- Appendix B: Planning meeting agenda
- Appendix C: Process for organizing planning group, focus groups and interviews
- Appendix D: Planning group participants
- Appendix E: Findings from previous research
- Appendix F: Focus group and interview introduction
- Appendix G: Contacts initiated
- Appendix H: Introductory letter and consent form

**Section IV** (pgs. IV-1 to IV-53) contains the Winnipeg report on the consultation with Indigenous Peoples. The report on the Saskatoon, Saskatchewan consultation will be added to the next draft of this report.

*Appendices to Section IV include:*

- Appendix A: Protocols for Approaching Elders
- Appendix B: Clarification of Terms
- Appendix C: Steering committee values
- Appendix D: Elders' and Traditional Knowledge Keepers' Circle Information Package
- Appendix E: Winnipeg Elders' and Traditional Knowledge Keepers' Evaluation Results

## 3. METHODS

### 3.1 Purpose

The consultation purpose was to identify and discuss issues affecting organ and tissue donation and develop of key considerations and related recommendations, based on the findings.

### 3.2 Process

The consultation was conducted in two phases with learning from each phase contributing to the next. The first phase involved an environmental scan. The scan consisted of focused Internet searching; review of existing documents provided by the CCDT Steering Committee; and telephone interviews with key stakeholders to further explore consultation strategies. The second phase involved conducting the consultation using the findings of the environmental scan and the advice of the members of the diverse communities with whom we were consulting.

#### Environmental scan

An environmental scan was conducted to identify community consultation strategies that have been used in other locations with the following ethnocultural communities: Aboriginal, Chinese, and Indo-Canadian.

Several themes emerged with respect to working with diverse communities. The following table describes each of the themes of heterogeneity of populations, individuality, role of local community representatives, flexibility, and relationships and trust. For details of scan methods and results see Appendix B.

<i>Heterogeneity of Populations</i>	Considerable variations exist within each community. For example, there are many different Aboriginal tribes with different customs and beliefs. Similarly, different languages are used throughout the Indo-Canadian community depending on country of origin (e.g., Pakistan, India), and there are differences within the Chinese community depending on a variety of contextual factors (e.g., time since arriving in Canada). In addition, urban versus rural differences, as well as intergenerational differences exist within communities, similar to the overall Canadian population. Any consultation approach selected must respect diversity within communities.
<i>Individuality</i>	In addition, the individuality of all potential participants must be respected. Belonging to a given ethnocultural group, for example, does not necessarily mean that the individual will have the same beliefs as all other members of the group.
<i>Role of Local Community Representatives</i>	Local community representatives should be invited to participate as partners in the community consultation strategy. Community representatives can help to gauge the relevance of the topic, find an entry point for the consultation, recruit participants, and provide space for focus groups, meetings, or forums.
<i>Flexibility</i>	The importance of maintained flexibility throughout all aspects of the consultation was emphasized, including planning the consultation strategy and approach, selecting methods, and working with community partners. For example, communities may not follow the same timelines as a given consultation project. In addition, participation rates may be higher if times are flexible and convenient.

<i>Relationships and Trust</i>	The importance of relationship and trust emerged as key considerations for planning community consultations with diverse communities, particularly if the researchers were not from the same ethnocultural community. Using interviewers and facilitators from within a given ethnocultural community was considered important for establishing trust with participants, as well as for assisting with data analysis and interpretation. Relationships and trust take time to build. These relationships may in some cases already be established with existing community based organizations.
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## Conducting the consultations

Phase 2 involved the consultation with a people from a variety of backgrounds, including:

- Aboriginal: 65 individuals involved in Elders' and Traditional Knowledge Keepers' Circles in each of Saskatoon and Winnipeg;
- Chinese: 110 individuals completed surveys; 22 of which were completed by Chinese family physicians and 88 by Chinese people being served in Chinese cultural Centres and the Chinese Renal Association; 44 Chinese participants in focus groups in Toronto; and
- South Asian: 59 people from South Asian background participated in either focus groups or individual interviews in Vancouver and the Lower Mainland.

A consultation plan was developed and approved by the Steering Committee in September 2004. The plan was altered as we learned from each consultation and as we received advice during the planning phases of each consultation. (See Appendix C)

This consultation occurred in three ways (focus groups, written surveys, and interviews) on four sites (Toronto, Winnipeg, Saskatoon, Vancouver). Indigenous Peoples' were consulted through the process of an Elders' and Traditional Knowledge Keepers' Circle, using ceremony and protocol in planning and implementing the events. One Circle was held in Winnipeg, Manitoba and the other Circle was held in Saskatoon, Saskatchewan. People of South Asian heritage were consulted largely through focus groups in their places of worship (Hindu and Sikh temples) and community locations. Chinese Canadians were consulted in Toronto through two focus groups, one held at a Chinese Seniors' Centre and one at a Chinese Cultural Centre. Unique to the consultation in Toronto, Ontario was a survey of Chinese family physicians and a survey of people of Chinese descent who were contacted through Chinese cultural programs and the Chinese Renal Association. Unique to the consultation in Vancouver, British Columbia and the Lower Mainland were several one-to-one interviews of local administrative leaders from Hindu and Sikh temples.

For each consultation, we engaged cultural advisors. For the Winnipeg and Saskatoon events, we engaged an Aboriginal consultant, experienced in Circle protocol and ceremony, who led both Circles. For the South Asian consultation, we engaged a cultural advisor of South Asian background, who could speak English, Hindi and Punjabi. The cultural advisor for the South Asian consultation initiated contacts with community leaders to set up activities and led the focus groups. For the Chinese consultation, we relied on the planning committee (who were of Chinese heritage) to provide advice. Cultural advisors assisted the consultants in understanding protocol and interpreting the responses and actions of consultation participants.

The consultation with Chinese Canadians in Toronto, Ontario began with a planning committee meeting of representatives of the Chinese community and Trillium Gift of Life Network in November 2004. Based on the advice of a planning committee, the methods used were surveys and focus groups. Two surveys were developed – one for the general public, which was completed by 110 respondents, and one for Chinese family physicians serving primarily patients from the Chinese

community, which was completed by 22 respondents. Three focus groups were held, with a total of 44 participants. The activities occurred during January and February 2005. Participants were contacted by community members who had attended the planning session. The consultant sent each confirmed participant a package which included a letter from Dr. Rosalie Starzomski and included a description of the event or a survey and a consent form. The surveys were available in English and Cantonese and a trilingual translator was available in all focus groups. Details of the Chinese consultation can be found in Section II.

The consultation with people from a South Asian background occurred in Vancouver, British Columbia. A planning meeting was held in January 2005 with representatives of British Columbia Transplant Society, CCDT and members of the South Asian community in Vancouver and Lower Mainland. The planning committee advised that we should connect with women and youth and with administrators within the Hindu and Sikh temples. This consultation gathered input from 59 people within the South Asian communities of Vancouver and the Lower Mainland during the month of February 2005. Through ten 'data-gathering opportunities', including focus groups and personal interviews, community members were asked to share their opinions or those of their religious community on organ and tissue donation and transplantation. Contacts with participants were made through "cold-calling" by the consultants to various community agencies and through members of the planning committee. Each participant was sent a letter of invitation from Dr. Rosalie Starzomski and a package of information that included the questions, a description of the project and a consent form. Details of the Vancouver consultation can be found in Section III.

The consultation with Indigenous Peoples occurred in Winnipeg, Manitoba on November 4 & 5, 2005 and consisted of an Elders' and Traditional Knowledge Keepers' Circle attended by 25 people. The second Elders' and Traditional Knowledge Keepers' Circle was held in Saskatoon, Saskatchewan and was attended by approximately 30 people. Participants' names were gathered through contact with Mr. Sakoietta Widrick, Winnipeg Regional Health Authority Regional Aboriginal Spiritual/ Cultural Care Coordinator. An essential feature of success was in following the protocol for approaching participants as suggested by Mr. Widrick.

Circle participants received an introductory e-mail to describe the purpose of the consultation and to ask their advice about the questions and process to undertake. Each time a contact was made, the consultant indicated that she would like to offer tobacco but it was difficult to do via long distance communication. The consultant indicated that she wished to follow proper protocol in addressing the Elders and sought their advice about it. E-mail contact was followed by a letter from Dr. Rosalie Starzomski, Chair, Ethnocultural Steering Committee formally inviting the individuals to the Circle. The invitation included an outline of the purpose of the event, the questions to be asked and a consent form. Details of the approach used to plan and conduct the Circles and the results can be found in Section IV.

Consultation materials for each consultation were sent to three ethicists who were serving on the CCDT Ethnocultural Steering Committee. The same individual from the committee provided advice for all three consultations. In addition, ethics advice was provided for the Indigenous Peoples' consultations by Mr. Willie Ermine, First Nations University.

Manitoba Transplant, Saskatchewan Transplant, the British Columbia Transplantation Society and the Trillium Gift of Life Network were active partners in planning and conducting the consultation in their locations. One of the key elements of the consultation was the importance of building upon existing or establishing new relationships between the group being consulted and the local donation and transplantation organization. We believed that connections made in the consultation would result in ongoing activities with the donation agency to promote donation within the ethnocultural and Indigenous Peoples' communities.



## Scope

The consultation activities were intended to provide information on the range of views and beliefs on organ and tissue donation in people from two ethnocultural communities and Indigenous Peoples. The results represent the views of these specific participants and cannot be generalized toward the entire population of that heritage.

The topic that was addressed was views related to organ and tissue donation and transplantation. We did not address issues such as stem cell research or xenotransplantation.

Each consultation asked questions of participants that addressed the following overall aims:

- Identify stated beliefs and views about organ and tissue donation in selected diverse communities.
- Identify processes that work for engaging people from a variety of diverse backgrounds on the topic of organ and tissue donation and transplantation.
- Consider partnerships between the group being consulted and the local donation and/or transplant program.

The questions for each consultation were worded a little differently depending on the group but generally fell into six areas of inquiry:

### *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;

### *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.

### *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.

### *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?

### *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?

## 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.

## Values

The Steering Committee agreed that the following values would guide the consultation. In every aspect of the consultation, the consultants made every effort to reflect the following values.

Value	Description	Expression/Indicators
Appreciation of diversity	<p>Seeking to understand, not judge views.</p> <p>Genuine admiration for the cultural context and views expressed.</p> <p>Flexibility in response to diversity.</p>	<p>Information is not aimed at changing opinions.</p> <p>Process is focused on hearing, not teaching them.</p> <p>Process is adjusted to respect ceremonies and traditions of the ethnocultural and Aboriginal groups.</p> <p>Diversity of opinions is welcomed.</p> <p>Language of consultation reflects the dominant language of the group being consulted.</p>
Collaboration	<p>Allowing situations to develop organically. Follow the paths that open up.</p> <p>Cooperative not competitive approach.</p> <p>Building on existing local activities.</p> <p>Sharing of results with those consulted.</p> <p>Commitment to the future of the partnership.</p>	<p>Consultation process and tools are developed in response to the input of the group being consulted.</p> <p>Not wanting to be consulted is respected.</p> <p>Steering committee examines motivations and values to ensure transparency.</p> <p>Commitment by local donation programs to time required to consult and build partnerships.</p> <p>Linkages with other related projects are encouraged.</p>
Integrity	<p>Trust through open communication about the purpose of the consultation, values, processes used and application of results.</p> <p>Respect for all involved.</p> <p>Respecting experience, expertise, heritage and history.</p>	<p>People being consulted are partners in the consultation and influence its approach and outcomes.</p> <p>Commitment to follow up and follow through by local agencies engaged in consultation.</p> <p>Clear indication of use of information to participants.</p> <p>Consultation will be guided by a code of ethics.</p> <p>Participants give permission for use of their information.</p>
Excellence	<p>The consultation will be conducted within a continuous learning approach.</p> <p>Process will be based on evidence available and input of local people.</p> <p>Rigour applied to ensure high quality information.</p>	<p>Targeted literature searches will be done as needed.</p> <p>Participants will be asked for feedback on the consultation methods.</p> <p>Participants will be asked in advance what methods work best for them.</p> <p>Environmental scan will, in part, guide consultation approach.</p> <p>Experts are consulted throughout for guidance.</p>

Value	Description	Expression/Indicators
Capacity building	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.	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 (e.g. diabetes strategy; end of life care).
Learning	Openness to new ways of doing consultation.  Sincere desire to have the limits of our own culture identified.	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.

The purpose of the consultation was to gather practical information to provide the best advice to the Conference of Deputy Ministers of Health. At the outset, we concluded that we were not conducting traditional research and therefore we would not submit our plan to an academic ethics review board. We would, however, make every effort to ensure that the information we collected was of high quality. The following are illustrations of the rigour we utilized to ensure that the consultation was conducted properly to give results that could be trusted.

We submitted each consultation plan to three ethics specialists who were members of the Ethnocultural Steering Committee. One ethicist responded to all three calls for advice and in the case of the Aboriginal consultation, we received the advice of an Aboriginal ethicist from First Nations University, Mr. Willie Ermine.

The questions for each consultation were field tested with several respondents before they were finalized. For Vancouver and Toronto, the planning committee members tested the questions and for the Aboriginal consultation, the Aboriginal cultural advisor and the Aboriginal Spiritual Coordinator (Winnipeg Regional Health Authority) reviewed the questions for the Elders' Circles.

For the Elders' Circles in Saskatoon and Winnipeg and for the focus groups in Toronto, we audio taped the sessions to ensure accuracy. The transcripts were read and coded by two consultants (independent of each other) who then discussed the meaning that each had ascribed to the statements and coding was agreed upon. The codes were then used to allocate participant statements to the relevant area of inquiry. One consultant (PHD-trained with many years of experience with qualitative data analysis) themed the results and conducted the analysis.

The consultation activities within the South Asian communities did not lend themselves to audio taping, however, three individuals took notes during the sessions. Two consultants then reviewed and coded the notes independently and then discussed their findings and agreed upon the coding. One consultant themed and analyzed the results.

While we did not seek a representative sample of people within the Aboriginal and ethnocultural communities, we did ensure that we were careful to document the demographics of participants and to make every attempt to ensure that a variety of people were consulted.

An important part of the method was the engagement of the local donation agency in planning and conducting the consultation. The purpose of this engagement was to seed the possibility of

ongoing work with the ethnocultural or Aboriginal community and the local agency as we suspected that real change in attitudes and decisions to donate would occur over time and with more trust and information shared. The contracted consultants relied heavily on the local agencies for contacts in the ethnocultural or Aboriginal groups. Trillium Gift of Life Network had already begun many relationships with the Chinese community and these relationships were invaluable to the success of the consultation. Dialoguing with the South Asian community in Vancouver was relatively new to BCTS and therefore the consultants spent considerable time establishing relationships and inroads into the South Asian community. Manitoba Transplant had had experience with public awareness activities with Aboriginal Peoples and referred the consultants to contacts from this previous work. Saskatchewan Transplant had recently hired an individual to manage Aboriginal relations and this individual was helpful in organizing the Elders' Circle.

## Field Notes

It was important to us that people be heard in their own voice. We made extensive use of quotes as they appeared in transcripts. We did not come into the process with preconceived notions of what we would find or even how we would access the information. In many situations, to embody the value of respect, we participated in customs and protocols which were not familiar to us.

We observed the importance of gifting and sharing of food to building relationship and trust. Gifting was an especially important requirement in the Indigenous Peoples' consultation as it conveyed a respect and trust at the outset of the consultation rather than as a thank you at the conclusion (common in the Western way). This created a trusting and benevolent tenor to the meeting and yet had we not received protocol advice, we likely would not have done it. Food was another important aspect of community building in the consultation. For the South Asian community, the consultants were fed at every temple meeting. The consultants also shared a dinner of traditional Indian food with an 18 member focus group. In the Toronto consultation, snacks were provided to focus group participants and a traditional New Year's dinner was shared with the Chinese Family Physicians group.

A necessity for this type of work is an enthusiastic willingness to abandon the comforts of one's known and dominant culture and to risk being in the vulnerable place of "not knowing" within another's culture. The openness of the human spirit was profound as we entered into others' cultures and into sensitive parts of others' lives to consider profound topics like death, life after death and beliefs about the afterlife or spirit world. We are grateful for the generous participation of all of the people who spoke with us and who opened their hearts and minds to us.

## 4. OVERALL RESULTS

The decision to donate or receive an organ or tissue was, across all three groups, a deeply personal decision that needed to be considered carefully and discussed with family and community members such as a priest or Elders. All groups (except for participants from the Sikh and Hindu faiths) said that the traditional beliefs of their heritage would not support donation but that they believed that these concepts were changing in the younger generation. Some people mentioned that when these traditional beliefs were formulated before the advent of donation and that those beliefs may have to be reconsidered in light of medical advancements. Consistently, groups said that they had not considered organ donation before and that the topic should be discussed more in their families and communities. Within each of the areas of inquiry, several similar themes emerged across groups as well as several themes that were unique to a specific group.

The following themes occurred frequently across all three groups: South Asian, Chinese and Indigenous Peoples:

### 4.1 Common beliefs, views and attitudes related to organ and tissue donation and transplantation

#### *One must go into the afterlife whole*

The traditional belief among Indigenous participants, Chinese participants and South Asian participants (of Muslim faith) was that one must go into the afterlife whole, possessing all of one's body parts. South Asian people from the Sikh and Hindu traditions do not share this belief, but rather consider the body useless to the soul at death. Except for those individuals from the Muslim tradition, all others said that this view is changing with younger generations.

In the Aboriginal traditional way of life, it is believed that if one does not go to the afterlife whole, the person will have to wander in the SpiritWorld searching for their lost parts.

*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.)*

A Chinese traditional belief is that one must go into the afterlife whole and that one is gifted with a whole body from one's parents and it is a filial duty to return in death whole of body.

*I think the Chinese believe in harmony; it's a very strong feeling of being in harmony... the sky, the earth... so wholeness is very important – destiny, happiness, good hopes – anything that is whole is very important. At the end of the year the whole family gets together for supper at a round table. This is very fundamental – wholeness and harmony and I think that ... completeness of body is part of it.*

*In my father's generation, some people believe in the Buddhist concept of reincarnation of life. So they may have an unfounded belief about whether a person, if an organ has been removed from his body, can be reincarnated whole in the next circle.*

South Asian participants of Muslim faith told us that it was important to bury the body whole.

*As a Muslim, we are supposed to go back to God as we came. We are not allowed to be cremated. We cannot do the donation since you are not allowed to dismember the body. After death, they cleanse the body and wrap it in a white cloth.*

*Giving to another human being and one's community is valuable and organ donation is part of giving*

All three groups mentioned in different ways the importance of giving to another human being and giving to the community.

For the Winnipeg Elders' Circle the spirit of Giveaway was mentioned as an important aspect of their tradition. For instance, a family wishing to commemorate the death of a loved one, often hosts a giveaway during a pow-wow. This tradition embodies the value of sharing with others. Gifts such as blankets, beadwork and crafts are given to friends and visitors followed by appropriate songs and dances.<sup>5</sup>

*...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.)*

*...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.)*

Participants from a Chinese background spoke of their tradition of giving money and time to community issues and that this type of giving reflects honour on a Chinese family. Some participants thought that donating an organ would also be an act of giving in keeping with the honourable family tradition of giving to others.

*You give your time as a volunteer or you give out money because you have an excess that you can share with others. But now you can do something more, which is that a donation can be an organ, can be your living tissue.*

*Giving is more than gifts and flowers.*

*Since the family is grieving about their dying relative, maybe one could alleviate the grieving of somebody else waiting for an organ to sustain or prolong life. Would you consider having other families not grieve about a family member dying?*

Participants expressed the idea that in donating one's family could become honorable. This is based on a traditional concept that an individual's actions can bring honor to the family.

Participants from a South Asian background also mentioned the value of giving and supporting others.

*We believe in giving. You give everything for the sake of the community. You're not to charge a penny. If someone can benefit, it's not difficult. If it can benefit, we are there.*

*It's good to give – then, if we need it, it will be there for us.*

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<sup>5</sup> Found on the World Wide Web on March 20, 2005 at [http://www.remp.ca/ccaps/spirit\\_e.htm](http://www.remp.ca/ccaps/spirit_e.htm)

### *Showing respect is many faceted and important in the donation process*

The value of respect was emphasized across the three groups. The concept of respect covered many aspects including respect for those who say no to donation; respect for traditions, protocols and ceremonies related to donating a body part; respect for the deceased, respect for the body part itself and in the case of Aboriginal Peoples, respect for traditional medicine.

For Aboriginal participants, respect for protocol, ceremonies and Elders was stressed. The importance of asking for donations in a respectful way according to the traditions was highlighted. The importance of respect for peoples' decisions even when it is a decision to not donate and respect for the deceased was emphasized as well.

*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.)*

*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. (K.B.)*

*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.)*

Participants from a Chinese background also spoke of respect with regard to their parents and to their body as a gift from their parents.

*I could not imagine myself being dismembered and treated as some kind of material without respect. Sorry, I have such an impression because I have witnessed such a situation before. (Even) the skin and hair are given by the parent - damaging them would be disrespectful.*

*In China there is a very popular way of doing things like this. If you do something good, they say this honourable family. The whole family is happy about it.*

*My parent's generation is more resistant to the idea of donation because they think the body is given by the parents and they should respect previous generations. They accept the old Confucius way of protecting ones' body...whereas for me and my children, we know more about organ donations from the news and can inform my parents of the benefits of organ donation.*

For South Asian participants, respect centred on respect for the deceased and respect for the religious views in relation to donation.

*Our funeral services are so fast. The body is washed, shrouded and buried. The dead person enjoys a certain amount of respect. Cutting a dead person's bone is akin to cutting the bone of someone who is alive. They are very gentle with the dead person. There is time frame for burial – which is good for both the family and the body – so that the family can get peace.*

*The divergent views within the Muslim faith, across the Suni, Shia and Ismaili sects, emphasize the need to respect the community's desire to engage the Imams in the discussion.*



*There is a close connection between faith and traditional teachings and people's decision to donate.*

South Asian and Aboriginal participants most often mentioned the connection between their faith and traditional way of life teachings and donation. The impact of faith was mentioned less often in the Chinese community but it was considered a factor by some. The impact of the belief in destiny or fate was mentioned across three groups, including the idea of not interfering in God's plan for the number of days of life assigned by God to each person.

Aboriginal participants said:

*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.)*

Chinese participants most often mentioned the Confucian teachings about the requirement of wholeness of the body.

*Traditional thinking is that a corpse should be buried whole. It is a traditional rule – a reasonable rule and I follow the rule. It's a notion we heard from our parents, our grandparents.*

*One's riches are destined, by God or the Sky and one's life is also destined or guided by the sky, or heaven or God. (She went on to explain:) Whether one is rich or poor or dies early or dies old, one cannot control. It's all to do with luck, or God, or heaven.*

*They accept the old Confucius way of protecting ones' body...whereas for me and my children, we know more about organ donations from the news and can inform my parents of the benefits of organ donation.*

South Asian participants frequently spoke of the importance of faith beliefs and the decision to donate.

*My mom, she says 'yes', except for her eyes because she wants to be able to see God after she dies [Youth].*

*As a Muslim, we are supposed to go back to God as we came. We are not allowed to be cremated. We cannot do the donation since you are not allowed to dismember the body. After death, they cleanse the body and wrap it in a white cloth.*

*It is Allah who gives life and takes life. Whatever time Allah has given to me, I accept that. As for taking, I don't want to take anything. As for accepting organs from family members? We have time frame from Allah. I don't know. I need to think about it.*

*Allah created the disease and the cure. Do not treat yourself with prohibited things. There is no cure for old age. There is a cure for everything. It's all in your attitude. When the time is there, you go. Leave it to Allah's will.*

*To change the course of what God has planned for me – I don't think I could accept an organ.*

*The importance of relationship in donating and receiving was emphasized*

Aboriginal participants spoke most often about the importance of relationship between the donor and recipient.

*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.)*



*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.)*

Chinese participants mentioned the concern about giving to a good person and knowing that the recipient was leading a good life.

*Can one have access to information about the receiver? The reason I ask is because I think everybody here would like their donated body parts to go to a good person, some-one who had made a contribution to society. They don't want to donate to a prisoner or somebody who is very bad.*

South Asian participants

On the question of to or from whom people would give or accept organ donations, most people, across the focus groups and interviews, indicated that whether the person was from their own community would not be a consideration. One person said it would be important for an organ to come from a true believer.

## 4.2 Differences in beliefs, views and attitudes among groups

Although all groups mentioned the importance of ceremony, Aboriginal participants mentioned the importance of ceremony most often especially in relation to making the decision to donate and the procurement of organs.

*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.)*

South Asian participants were the only group to mention distrust in the medical system as a factor. This factor seemed to relate to the situation in India where doctors perform the surgery unethically to steal organs from poor people.

*My father is concerned the doctors may not try to save his life. It's fear, paranoia [Youth].*

*In India, there is lots of fear, especially when young people go to hospital. After an accident, they take people to the hospital and the doctors take your organs out – the family will be waiting outside to see what is happening, waiting for news, and the doctors are taking out their organs. Especially the young people. No one asks; there is no consent. Here, they ask. In India, no one asks. They are not consulting. They should have a seminar. Lots of people don't want to donate.*

*In India, they are used to corruption and fraud in hospitals. No one wants to even donate blood since they might use a dirty needle.*

*Many people believe that if you are donor, you risk your life. They believe when someone needs transplantation they will search the records. If they find match, and it is you, they can harm you so that donation is available.*

## 4.3 Common suggestions to support to decision making for donation

All groups agreed that the decision to donate should be made with family before the crisis of an illness or death. Some South Asian participants said the family should not be approached at all at the bedside. Chinese and South Asian (Hindu and Sikh) participants thought that a physician should approach a family about deceased donation in the hospital.

*It should be the doctor. This is a very sensitive time when everyone is grieving. All the community is grieving and it not good for community leaders to approach the family about this matter.*

*When someone is dying, the family is in grief. They won't be able to listen. It's such a bad time. That's natural. I don't think they should be approached.*

*After the person has died, the medical authority could ask. There are many forms to fill out and this could be one of them. The doctor is impartial. If the person had said 'yes', and the family said no, they could be approached by a friend.*

Chinese participants also frequently mentioned the role of the doctor in asking for donation.

*The best way to do it is for the prospective donor to discuss it with his or her family members before signing the donor card and then it would be much easier for the doctor to ask the family if the donor dies. They would be aware of his wishes – it would influence them.*

*Most Chinese believe in doctors and if they have been going to see the same doctor for awhile then there is a bond. You believe in that person's skill. If I take the medication the doctor's prescribed, I will be healed – that kind of belief. So if it's an old person who is chronically ill and been seeing the same doctor for while, there is respect and support.*

Aboriginal participants stressed the importance of making sure people understand their illness and the implications.

*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. 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. (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, "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." He did not have an interpreter, so he did not understand what he had heard. (D.N.)*

## Relationship Building

We asked people how CCDT or other organizations should proceed with future dialogues on organ and tissue donation and transplantation. All groups all discussed the potential for dialogue within families and within communities, reflecting both on the level of comfort and the most effective strategies for pursuing the dialogue.

Aboriginal participants mentioned the importance of family, community and Elder involvement in guiding decision making.

*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 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.)*

*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.)*

For Chinese participants, they would like to see more information to guide them in decision making.

*There should be statistical information too: How many people are on the waiting list? In Ontario? In your community? Direct information.*

*I think the major problem is that people lack information – where you can donate organs, where to get information, what institutions to contact. I think there is an education barrier between people that want to donate and people that accept donations.*

For some South Asian participants, education has to come from within families.

*The way I see it, your job as kids is to educate your parents. For example, with racism, they say, 'don't play or spend time with a white person'. Our job is to educate our parents about every topic [Youth].*

*Without consent, no, the family can't donate. We should talk about these things at home. It's a good thing to talk about.*

South Asian participants most often mentioned the importance of reaching people through the temples and the temple leadership.

*When you speak to people in the temple versus in their homes or elsewhere, their mindset is totally different. Their internal feelings are different – they are more calm, at peace and open to listen to new ideas. The Gianni (priest) as well as the general secretary or [president], we can discuss this issue. We discuss many issues in the temples.*

## **5. RECOMMENDATIONS**

TO BE ADDED FOLLOWING THE STEERING COMMITTEE DISCUSSION.

## **6. CONCLUSION**

TO BE ADDED FOLLOWING STEERING COMMITTEE DISCUSSION

## **APPENDICES**

## **APPENDIX A: STEERING COMMITTEE MEMBERSHIP**

### Ethnocultural Steering Committee Members

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## **APPENDIX B: ENVIRONMENTAL SCAN**

# DIVERSE COMMUNITIES

## Consultation to Explore Perspectives on Organ and Tissue Donation

September 13, 2004

### PURPOSE

The purpose of this environmental scan is to inform the development of a community consultation strategy that includes selected ethnocultural groups in Canada regarding their unique perspectives on organ and tissue donation. The community consultation will be conducted by Charis Management Consulting on behalf of the Canadian Council for Donation and Transplantation (CCDT).

The focus of the scan is on identifying consultation strategies that have been used in other locations with the following ethnocultural groups: Chinese, Indo-Canadian, and Aboriginal peoples.

### METHODS

The scan consisted of the following data collection methods:

- focused internet searching for examples of community consultation strategies used with ethnocultural groups in Canada and internationally;
- review of existing documents recommended and/or provided by the CCDT Steering Committee; and
- telephone interviews with key stakeholders to further explore consultation strategies (e.g., those considered most successful and culturally relevant).

For each ethnocultural community, information was based on a review of online resources and documents as well as telephone interviews with one or more of the following:

- representatives from community agencies;
- cultural organizations; and
- consultants or researchers with specific expertise working with a given community.

In addition, overall strategies for consulting with diverse communities as well as principles for working within a community development approach were identified.

Medline and Cinahl were searched using key words "ethnicity" and "organ donation". The identified examples of community consultation strategies that have been used with specific communities are not intended as definitive approaches but rather as a menu of possible strategies for consideration. Considerable variations exist *within* each community. Any consultation approach selected must respect the individuality of all potential participants, and should be selected in collaboration with local community representatives.

## SUMMARY

### Overall Approaches to Working with Diverse Communities

An environmental scan was conducted to identify community consultation strategies that have been used in other locations with the following ethnocultural communities: Aboriginal, Chinese, and Indo-Canadian.

Several themes emerged with respect to working with diverse communities. These included heterogeneity of populations, individuality, role of local community representatives, flexibility, and relationships and trust.

<i>Heterogeneity of Populations</i>	Considerable variations exist within each community. For example, there are many different Aboriginal tribes with different customs and beliefs. Similarly, different languages are used throughout the Indo-Canadian community depending on country of origin (e.g., Pakistan, India), and there are differences within the Chinese community depending on a variety of contextual factors (e.g., time since arriving in Canada). In addition, urban versus rural differences, as well as intergenerational differences exist within communities, similar to the overall Canadian population. Any consultation approach selected must respect diversity within communities.
<i>Individuality</i>	In addition, the individuality of all potential participants must be respected. Belonging to a given ethnocultural group, for example, does not necessarily mean that the individual will have the same beliefs as all other members of the group.
<i>Role of Local Community Representatives</i>	Local community representatives should be invited to participate as partners in the community consultation strategy. Community representatives can help to gauge the relevance of the topic, find an entry point for the consultation, recruit participants, and provide space for focus groups, meetings, or forums.
<i>Flexibility</i>	The importance of maintained flexibility throughout all aspects of the consultation was emphasized, including planning the consultation strategy and approach, selecting methods, and working with community partners. For example, communities may not follow the same timelines as a given consultation project. In addition, participation rates may be higher if times are flexible and convenient.
<i>Relationships and Trust</i>	The importance of relationship and trust emerged as key considerations for planning community consultations with diverse communities, particularly if the researchers were not from the same ethnocultural community. Using interviewers and facilitators from within a given ethnocultural community was considered important for establishing trust with participants, as well as for assisting with data analysis and interpretation. Relationships and trust take time to build. These relationships may in some cases already be established with existing community based organizations.

## Data Collection Methods

No one particular data collection method emerged as the best approach for any given ethnocultural community. Multiple methods were often utilized. For example, some consultation strategies included a variety of data collection methods, including individual interviews, focus groups and surveys. The final compilation of methods was often determined in collaboration with a Steering Committee and community representatives.

A variety of both quantitative and qualitative data collection methods were used to collect information from diverse communities. These included the following:

- Surveys
- Focus Groups
- In-depth Interviews
- Participant Observation
- Informal Discussions
- Meetings
- Requests for Consultation Workbook responses
- National Symposium
- Teleconferences
- Telephone discussions
- Visits to Ethnocultural Organizations

The decision to use qualitative versus quantitative data collection methods did not emerge as a critical decision, as many consultation strategies used both types of data collection methods. In general, it was observed that qualitative methods such as focus groups and interviews were used to gather more in-depth and sensitive information from diverse populations. Surveys were used to gather information from larger numbers of participants (e.g., perceptions of 300 immigrant serving agencies).

## Aboriginal Communities

Several considerations regarding consulting with Aboriginal communities emerged through the environmental scan. The role of Aboriginal elders should be considered during the planning of the consultation strategy. Elders may play a role in determining relevance and fit, recruiting participants, and gaining access to the community. Furthermore, it should be noted that not all “older” Aboriginal individuals are considered “elders”, and there are different levels of titling specializations. When working with Aboriginal communities, healers, cultural advisors, and elders should be appropriately titled and addressed, not all referred to as elders.

For more information about working with Aboriginal elders based on extensive research conducted in Winnipeg, Manitoba refer to *Working with Aboriginal Elders: An Introductory Handbook for Institution-Based and Health Care Professionals Based on the Teachings of Winnipeg-Area Aboriginal Elders and Cultural Teachers* (Ellerby, 2001).

It was stressed that respect for Aboriginal culture must be demonstrated. Ellerby (2001), for example, reported that bringing a gift of tobacco would be considered respectful and culturally appropriate.

There is lack of trust for researchers in many Aboriginal communities. It will be important to establish trust, and ensure that the research gives something back to the community. This might include a presentation, information, or resources that can be left behind regarding diabetes or other health concern expressed by the community.

In-depth interviews and focus groups were described as some of the methods used during consultations with Aboriginal communities. One research team reported the successful use of focus groups to discuss healthy sexuality with a group of Aboriginal youth. Another research team reported difficulty using focus groups as a method for discussing organ and tissue donation with one Aboriginal community in Vancouver. It was suggested that the topic of organ and tissue donation, and the close connection with death and dying, might

be too sensitive to discuss in a group setting. Individual in-depth interviews were recommended, with higher participation rates in this study.

## Chinese

Considerations for consulting with Chinese Canadian communities included the importance of building on existing relationships, using researchers/interviewers who could speak the same language, and considering cultural differences that may exist depending on country of origin and time since arrival in Canada.

*Note: Calls made to national level Chinese cultural associations during the timeframe for the scan were not returned. It is suggested that relationships at the municipal and community level should be the focus for the consultation strategy. One organization in Vancouver, for example, (acronym SUCCESS) may be a willing partner for working with the Chinese communities in that geographical area. [Note: SUCCESS was not directly contacted for the scan, but may be contacted to explore possible partnership arrangements for the current consultation.]*

## Indo-Canadian

Similarly, considerations for consulting with Indo-Canadian communities included the importance of building on existing relationships, using researchers/interviewers who could speak the same language, and considering cultural and other contextual differences with the community.

*Note: Calls made to national level Indo-Canadian cultural associations were not returned during the timeframe for the scan. A brief telephone interview was conducted with a representative from a local Indo-Canadian organization in Edmonton. The representative expressed willingness to include information from the Canadian Council for Donation and Transplantation in subsequent public events similar to a recent presentation regarding health disease in the Indo-Canadian community. This discussion further highlighted the importance of working at the community level with local representatives to discuss issues of shared interest and mutual benefit.*

## Data Collection Table

The environmental scan for the *Diverse Communities Consultation to Explore Perspectives on Organ and Tissue Donation* project includes:

- 1) Examples of consultation strategies that have been used in other locations with Chinese, Indo-Canadian, and Aboriginal peoples;
- 2) Identification of recent academic literature regarding the attitudes, beliefs, and values about organ donation of a variety of ethnocultural communities (updating reference list from June 2003 literature review); and
- 3) Examination of existing data regarding donation, transplantation, ethnicity, waiting times and disease trends.

Consultation Strategies: Aboriginal Groups					
Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Aboriginal Diabetes Initiative (Health Canada).	2004	First Nations, Métis, Inuit and Aboriginal peoples in Canada.	<p>A National Steering Committee engaged in consultations with First Nations and Métis communities, off-reserve and urban Aboriginal peoples, Aboriginal health care professionals, First Nations and Inuit Health Branch Regional personnel and national level non-Governmental organizations.</p> <p>Different methods of gathering information were used for different groups, including:</p> <p>Meetings were held with Chiefs and Aboriginal Nurses Association.</p> <p>Questionnaires (posted on website), focus groups and key informant interviews were held.</p> <p>3-day Inuit Diabetes workshop.</p> <p>National level focus group.</p> <p>Environmental scan conducted.</p> <p>Resource catalogue developed.</p>	Multiple strategies used.	Not stated.
A summary of the attitudes, beliefs, and values about organ donation of a variety of ethnocultural communities (Mulcahy, M.).	2003	<p>Aboriginal people (American and Canadian).</p> <p>Asian Americans (Chinese, Japanese, Asian Indian).</p> <p>Hispanic and African Americans.</p>	<p>Surveys (Native Americans, African Americans).</p> <p>Focus groups and interviews (Asian communities).</p> <p>Interviews (Aboriginal Canadians).</p>	The advantages of these strategies to collect information regarding organ and tissue donation were not stated.	<p>Considerable differences exist within and among ethnocultural communities. One strategy was not necessarily considered the best strategy for collecting information from any specific cultural community.</p> <p>The author recommended increased use of qualitative methods for future studies.</p>
Public Consultation to Inform the Integrated Pan-Canadian Healthy Living Strategy: Report on the Ottawa,	2003	Aboriginal communities (Canadian).	<p>Pre-consultation meetings.</p> <p>Strategic roundtables (participants included a range of national, provincial, regional and local organizations and individuals from a variety of sectors and provinces and territories).</p>	Multiple strategies used.	Not stated.

## Consultation Strategies: Aboriginal Groups

Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Aboriginal Roundtable (prepared by the Alder Group).			<p>Submission of a consultation workbook.</p> <p>Feedback from the roundtables and workbook were compiled with recommendations to set the stage for a national symposium on healthy living.</p> <p>A distinct Aboriginal voice was perceived as essential in the process, as well as Aboriginal-specific solutions.</p>		
Selected perspectives on Coast Salish beliefs regarding organ donation (Molzahn, A.E., McDonald, M., O'Loughlin, C., Starzomski, R).	2003	Coast Salish community (Aboriginal; Canadian).	<p>Individual interviews were held with 14 Coast Salish people, and one focus group was conducted.</p> <p>Researcher was Aboriginal.</p>	Qualitative, exploratory research.	<p>The researchers reported difficulty recruiting participants for the focus groups.</p> <p>There appeared to be a reluctance to talk about organ donation, despite a positive pre-existing relationship between the researcher and many of the potential participants.</p> <p>The team did not proceed with focus groups because of this reluctance, and questions by investigators about the cultural appropriateness of focus groups.</p>
Child and Youth Mental Health Consultation Process and Summary of Results (Government of British Columbia, Ministry of Children and Family Development).	2003	Aboriginal communities and ethno-cultural organizations.	<p>Meetings were held with representatives from key program areas to establish a plan for a mental health plan consultation process.</p> <p>Initial consultation was achieved through the distribution of a planning document, questionnaires, focus groups, teleconferences, and individual interviews.</p> <p>Consultation with Aboriginal groups included meetings with the Regional Aboriginal Services Managers Forum, and Directors of First Nations Family Service Agencies, as well as with consumers and service providers. Feedback was also received through discussions with an Aboriginal family service agency.</p> <p>Consultation regarding multicultural issues occurred through a meeting with the [a provincial] Ethnocultural Advisory Committee, and a focus group with members of [a municipal] Ethno-cultural Advisory Committee.</p>	Multiple strategies.	Not stated.
National Native American AIDS Prevention Center Needs Assessment: Focus Groups Series on Young Native Adults and Sexual	2003	Native Americans.	<p>Focus groups were conducted with groups of Native American youth regarding sexual health.</p> <p>Focus groups were conducted in five communities nationwide. The initial goal was to hold focus groups in three urban and two rural/reservation communities. The final locations were</p>	<p>Flexibility.</p> <p>Involving the host communities.</p>	Not stated.

## Consultation Strategies: Aboriginal Groups

Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Health (Satter, D.E., Zubiato, A., Gatchell, M.).			<p>selected based on convenience, feasibility, and pre-existing relationships with one of the research partners.</p> <p>Host organizations conducted participant recruitment through lists, nominations, and flyers. Times and location of the focus group was selected by host community to maximize participation.</p> <p>Reminder calls were made one day before the focus group. Refreshments and resources were provided, as well as an honorarium of \$35.00 per participant.</p>		
Working with Aboriginal elders: An introductory handbook for institution-based and health care professionals based on the teachings of Winnipeg-area Aboriginal elders and cultural teachers (Ellerby, J.H.).	2001	Aboriginal communities (Canadian; Manitoba).	<p>Interviews were conducted with Aboriginal cultural advisors (also referred to as teachers). The cultural advisors were chosen by a group of Elders who recommended those suggested for interviews.</p> <p>The original elder committee assisted in approaching the interview candidates.</p> <p>Private interview times and locations were determined based on the convenience of Elders and cultural advisors.</p>	Participatory consultation approach.	<p>The authors caution that the manual is merely one contribution towards better cross-cultural understanding and relationship (e.g., “to truly understand the life ways and teachings of traditional Aboriginal Elders is a commitment that takes a lifetime”).</p> <p>The teachings in the manual reflect the views of individual Elders and cultural teachers. Aboriginal communities are diverse in culture and practice, each maintaining distinct cultural beliefs, practices, and language.</p> <p>Within a community there are wide individual beliefs and practice. There are no accurate cultural or psychosocial generalizations that can be made about all Aboriginal people or communities. Variation has to be expected and respected.</p>
Bioethics for clinicians: 18 Aboriginal cultures (Ellerby, J.H., et al.).	2000	Aboriginal communities (Canadian).	<p><u>Note:</u> This article was prepared for clinicians working with Aboriginal patients. It was based on research conducted with Aboriginal elders; however, the process for consulting with elders was not described.</p> <p>The authors recommended the following strategies for clinicians working with Aboriginal patients:</p> <ul style="list-style-type: none"> <li>▪ use of interpreters;</li> <li>▪ involvement of the family;</li> <li>▪ practicing conscious communication (e.g., body</li> </ul>	Not applicable (i.e., this article did not describe the advantages and disadvantages of specific strategies for consulting with Aboriginal communities).	The authors caution that “Aboriginal cultures and communities are diverse, and therefore it is difficult to develop generalizations about values or decision-making processes”.



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			<p>language) and non-interference;</p> <ul style="list-style-type: none"> <li>allowing for Aboriginal medicine; and</li> <li>demonstrating respect for the individual.</li> </ul>		
Aboriginal & Northern Affairs: Community Consultation for Self-Reliance (Manitoba Health).	2000	Aboriginal community in Manitoba.	Encouraged participation of community councils through correspondence, telephone conversations, and meetings to provide recommendations and to have input regarding changes and modifications.	Multiple strategies.	Not stated.
Improving health services through consumer participation: A resource guide for organizations (Department of Public Health, Flinders University, and the South Australian Community Health Research Unit).	2000	Aboriginal communities (Australia).	<p><u>Note</u>: this publication is a resource guide for increasing consumer participation in health. There is a short section regarding culturally appropriate approaches. The authors provided the following general recommendations:</p> <p>Consumer participation strategies should engage people from cultures that experience barriers to accessing the health service.</p> <p>Listen to consumers from different cultural backgrounds.</p> <p>Use interpreters.</p> <p>Set up culturally specific advisory or support groups.</p>	Not stated (the document offers broad based suggestions consistent with a community-development approach).	The guide includes the following advice and caution regarding time commitment: <i>"To get the local Apex Club on your committee may take a letter. To get someone from the Aboriginal Community Association will take a lot of time, meetings, building relationships and establishing trust and understanding and, if your aim is reducing health inequalities in your community, then it's going to be worth it."</i>
End-of-life decision making among Aboriginal Canadians: Interpretation, mediation, and discord in the communication of "Bad News" (Kaufert, J.M., Putsch, R.W., and Lavallée, M).	1999	Aboriginal communities (Canadian).	<p>The authors provided two case studies (based on previous research) regarding end-of-life decision making among Aboriginal Canadians. Data collection strategies included direct clinical observation, audiotape and videotape of interactions, and follow-up participant interviews.</p> <p>Each case involved intervention by professional interpreters providing translation in Cree, Ojibway, and Island Lake languages.</p>	Interpreters were considered important for helping to articulate values and ask questions.	Consent negotiation and mechanisms for encouraging care providers and patients to clarify values may be of limited value in emergency and palliative care settings. Interpreters may be pressured to provide simplified or de-contextualized explanations, blurring differences between the values of each participant.
Culture and ethical decision-making in the treatment of end-stage renal disease: The experiences of Aboriginal communities (Kaufert, J. et al.).	1998	Aboriginal communities (Canadian).	<p>In-depth interviews were conducted with clients, family members and caregivers. These interviews were used to develop case studies of clinical decision-making. In addition, interviews were conducted with clinicians, program managers, and policy makers to document various decision-making frameworks.</p> <p>Participant observation was conducted to document decision-</p>	The involvement of Aboriginal health interpreters was considered important. The authors noted that, "both professional	Not stated.

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			making involving clinicians, Aboriginal renal patients and their families. Aboriginal health interpreters were involved as primary research team members.	interpreters and voluntary translators from the client's family and community function as intermediaries and have a significant impact on communication between client and caregiver."	

**Consultation Strategies: Chinese Canadian Groups**

Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Selected perspectives on beliefs regarding organ donation in the Chinese-Canadian community (Molzahn, A.E., McDonald, M., O'Loughlin, C., Starzomski, R.).	2003	Chinese-Canadian.	Similar strategies to Indo-Canadian groups (described below). The research team included a Chinese-Canadian researcher. The study was conducted after the Chinese Renal Association had a public information campaign to communicate issues regarding organ donation.	Similar advantages of focus groups as stated below for the Indo-Canadian groups.  The authors also stated that the Chinese Renal Association's public information campaign may have sensitized some participants to the area of organ donation.	Similar to Indo-Canadian groups below.

### Consultation Strategies: Indo-Canadian Groups

Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Selected perspectives on Indo-Canadian beliefs regarding organ donation (Molzahn, A. E., McDonald, M., O'Loughlin, C., Starzomski, R.).	2003	Indo-Canadians.	<p>Exploratory descriptive qualitative approach including individual semi-structured interviews and group interviews (focus groups) with 40 South Asian people.</p> <p>Purposive and snowball sampling.</p> <p>Inclusion criteria included the ability to express values and beliefs about organ donation, understanding of ethno-cultural and religious factors related to organ donation, ability to speak English, and willingness to participate.</p> <p>Individual interviews were conducted at times and locations that were mutually convenient for the participants and researchers.</p> <p>The investigators employed an Indo-Canadian researcher for the interviews. Focus groups were single gender groups.</p> <p>One interview and one focus group were in another language because participants were more comfortable in their native language than in English.</p>	<p>Focus groups were considered useful for group interaction, producing data and insights that would be less accessible using other methods.</p> <p>Focus groups provide an opportunity to learn more about attitudes and understand participants' experiences.</p>	<p>The authors caution that because a purposive sample was used, views of individuals interviewed may not necessarily be representative of other sections of the Asian population.</p>

### Consultation Strategies: Mixed Groups

Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Diversity Calgary. Best Practices Research.	2004	Diverse groups (Calgary).	<p>A wide variety of consultation methods were summarized in an appendix labeled best practices, including, for example, focus groups, letters, e-mails, briefs, and telephone interviews.</p> <p>Other recommended practices included: advertising the consultation internally as well as externally; offer flexibility in location and time; providing an open public process; providing understandable language and format; offering flexibility in communications and consultation; and including stakeholder input during the planning phase.</p>	Not stated.	Not stated.
Culturally Appropriate Best Practice Models for Healthy Aging (Eapen, S. Canadian Ethnocultural Council).	2003	Various ethnic groups in Canada.	<p>A questionnaire was distributed and individual interviews were conducted with seniors from 18 different ethnic communities to determine their perceptions of health aging. . asking about common illnesses, and treatment.</p> <p>In addition, 200 agencies were surveyed to learn about the approach of agencies serving ethnic seniors (50 responses were received).</p>	Not stated.	<p>Only those groups who were identified by the community liaison in each of the provinces were included in the study.</p> <p>The study was conducted over two years and constant changes required numerous updates to information.</p>

**Consultation Strategies: Mixed Groups**

Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
<p>Ethno-cultural external consultation: Regional diversity steering committee project, Calgary Health Region (Kneeshaw, R., Arnold, S.).</p>	<p>2002</p>	<p>Hispanic. South-Asian. Vietnamese. Chinese. Iraqi.</p>	<p>Focus groups and interviews were conducted with members of the selected communities.</p> <p>Participant recruitment was conducted with the assistance of host agencies and individuals, and an honorarium was provided for each host organization. Recruitment strategies included letters, working through others, personal networking, telephone calls, and radio advertising.</p> <p>Focus groups and interview participants were asked to share personal experiences and views on a range of topics (e.g. service awareness, priority issues, future services, and participation).</p> <p>Focus groups took place in the gathering places of the various cultural communities. Interviews were conducted in the homes of participants.</p> <p>A focus group was also held with members of immigrant serving agencies.</p>	<p>Personal networking, telephone calls, and radio advertising, were more successful recruitment strategies than passive strategies such as letters of invitation.</p> <p>Giving each community the opportunity to make decisions about who to invite, when and where to conduct focus group and meal sharing was considered empowering. The authors reported that "relationships were also strengthened because the [organization] made sure that community concerns and issues were validated, allowing them to work at the pace suitable for their community and accommodating and respecting their customs and traditions".</p>	<p>The authors cautioned that <b>focus group data is limited</b> by small sample sizes. Also, participants self-select by agreeing to attend and group interaction can influence individual perception and opinion. The authors noted similar limitations for interview data; however, they also noted the added benefit of the rapport established during the in-person interview process.</p> <p>Passive recruitment strategies were less successful than active recruitment strategies.</p>

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Source	Year	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages/Cautions
Ethnocultural Groups and the Justice System in Canada: A Review of the Issues (Currie, A., Kiefl, G.).	1994	Various cultural groups in Canada.	<p>Interviews with ethnocultural organization representatives.</p> <p>Visits to organizations.</p> <p>Informal discussions.</p> <p>Formal consultations.</p> <p>A survey of 300 ethnic community organizations, advocacy groups and multicultural service organizations representing Canada's multicultural groups to identify problems considered priorities by ethnic group representatives.</p> <p>In addition, a small sample of specialists in ethnic affairs (e.g., academics and lawyers) were interviewed for information to assist interpretation of results.</p>	Multiple strategies used.	<p>The authors caution that the views of ethnic organization representatives may be partial, and that the results of the study may serve as a basis for further research to define the nature of problems identified.</p> <p>Language was reported as an accessibility issue. Using plain language in information materials is important when producing written materials for populations with educational or linguistic limitations (in this case referring to legal material).</p>

## Key Informants

Representatives from the Chinese Canadian National Council, Canadian Indonesian Society, National Association of Indo-Canadians and the Canadian Ethnocultural Council were contacted, but there has been no response to date.

Key Informant	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages	Evaluation	Overall Advice
Sally Greenwood (British Columbia Transplant Society).	Chinese communities in Vancouver.	Brochures are currently being developed by the Provincial Language Services Group regarding organ donor registration material, based on extensive consultation including focus groups with Chinese communities in Vancouver (including physicians and volunteers).  Consultations were developed based on extensive work with the planning committee including members of Chinese community, BCTS, and others.	Community involvement.  Materials being developed to be culturally appropriate versus simple translation of English materials.	Donor families in the Chinese community do not want to let anyone know they've had a transplant. To encourage the patient to feel less self-conscious about a transplant and be able to talk about it publicly is a challenge.	Not discussed.	Build on what's already been done. Ensure that something tangible emerges from the process that the agency can use in its work.  It may be important not to mention "death" in some Chinese communities.
Yvonne Chui Multicultural Health Brokers (Edmonton)	Primarily regarding previous consultations with Chinese Canadians, although various groups considered. Detailed notes are available for this interview. A brief summary is included here.	Has used in-depth interviews with key informants and focus groups with community members.  Donation is a sensitive topic (illness and death) - needs to be relevant to the people.  Will need to find an entry point to the community to discuss the topic. Important that the people invited to share their experiences are invited by people they trust.  A community leader should be at least a co-facilitator if you do focus groups. For interviews, it also requires a skilled and respected community worker.	Working with existing community representatives, and respecting the work that has already been done, helps to build trust and relationships.	May be some confidentiality concerns among participants asked to share personal information in a focus group setting.  Requires skilled and sensitive researchers who can communicate in the same language.	Post-research reflection revealed importance of providing support to the interviewers – this also may represent another level of data analysis.  Great deal of time and effort required.	Regardless of the topic, there should be explicit relevance to the people involved. Consider inviting people directly impacted by organ and tissue donation, or with a propensity for diseases that might require organ donation.
Sue Wilson and Angela Diano Trillium Gift of Life.	Currently working with Chinese communities (although have worked with Sikh and Muslim	In the Chinese community: awareness activities at health fairs (including upcoming Nov/04 health fair – possible opportunity for consultations); working with the Greater Toronto Chinese Cultural	They have discovered that providing literature alone is not enough but promotional items such as	Not stated.	Observation that promotional items help improve awareness strategies.	Not stated.

Key Informant	Ethnocultural Group(s) Consulted	Strategies Used	Advantages	Disadvantages	Evaluation	Overall Advice
	<p>communities, and would like to work more with Black and Aboriginal communities).</p>	<p>Centre (which is interested in organ donation); and working closely with the Chinese Outreach Program at Mt. Sinai and Scarborough hospitals.</p> <p>The Chinese Canadian Council has worked in the past with the Heart and Stroke Foundation to publish culturally appropriate Chinese material (versus simple translations).</p> <p>The Chinese cultural centre of Toronto produced a health passport in Chinese. People will record health information which they can carry to medical and other health related appointments as a communication tool.</p>	<p>fridge magnets or key chains seem to be more effective awareness activities.</p>			
<p>Maanaw Seva Association.</p>	<p>Indo-Canadian.</p>	<p>Large-scale forum (500 people) on heart disease. Information booklet.</p>	<p>Not stated.</p>	<p>Not stated.</p>		<p>Contact this organization to include organ donation messages.</p>

## Selected Literature Results

Attitudes, Beliefs and Values About Organ Donation Abstracts are reproduced from selected databases.				
Author	Title	Source	Year	ABSTRACT
<a href="#">Daniels DE.</a> <a href="#">Smith K.</a> <a href="#">Parks-Thomas T.</a> <a href="#">Gibbs D.</a> <a href="#">Robinson J.</a>	Organ and tissue donation: are minorities willing to donate?	Annals of Transplantation. 3(2):22-4, 1998.	1998	<p>The Report of the Task Force on Organ Transplantation (DHHS,1986) recommended that "educational efforts aimed at increasing organ donation among minority populations be developed and implemented, so that the donor population will more closely reflect the ethnicity of potential transplant recipients, in order to gain the advantage of improved donor and recipient immunologic matching (DHHS,1986). Donor rates for minorities has increased as follows: 16% in 1988 to 23% in 1995 among cadaveric donors and 24% in 1988 to 28% in 1995 among living donors. The improvement in donor rates among minorities may positively affect the transplantation success rate experienced by organ recipients of the same race.</p> <p>Strategies must be implemented that will increase the effectiveness and frequency of communication between minority patients and the medical community. An increase in the effectiveness of communication between potential minority donor families and the health care community will contribute to the process of Consciousness Raising as discussed by Prochaska. The result of increased awareness of the organ donation and transplantation process may have a favorable impact on organ donation.</p> <p>The media has, through public service announcements, paid advertising and entertainment programming, attempted to promote discussion of organ donation in the community and within families. Johnson et al. discussed Mexican-American and Anglo-American Attitudes Toward Organ Donation. The primary impediment contributing to the disparity of consent rates between Mexican-American and Anglo-American population occurs with regard to the donation of organs of relatives. Johnson stated that this impediment to organ donation can be effectively addressed by promoting family discussion. Communication within families will inform surviving next of kin of the desire of the deceased to be an organ donor and hence improve the likelihood of the donor family consenting to organ donation (Johnson et al., 1988). The promotion of communication within families must continue to be a goal of the transplant community regardless of race/ethnicity. Despite the efforts of the government, the transplant community, the media and the corporate sector to address the critical shortage of donors in the United States, the reality is that no community has the supply of donor organs suitable to meet the need.</p>
<a href="#">Feldman EA.</a>	Culture, conflict, and cost. Perspectives on brain death in Japan.	International Journal of Technology Assessment in Health Care. 10(3):447-63, 1994 Summer.	1994	<p>Japanese surgeons have performed only one heart transplant in the quarter century since the procedure was developed. Possessing the requisite training and technology, transplant surgeons have been stymied by several factors that elude professional and political solution. Most critically, the lack of a brain death standard limits the availability of transplantable organs. Mistrust of the medical profession, traditional outlooks on death, and the primary placed on consensual decision making have fueled debate about brain death and transplantation. Volatile and value laden, these issues have overwhelmed the discussion of health care resources, equal access to high-</p>



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				technology medical procedures, and insurance coverage for transplantation.
<a href="#">Kim JR.</a> <a href="#">Elliott D.</a> <a href="#">Hyde C.</a>	The influence of sociocultural factors on organ donation and transplantation in Korea: findings from key informant interviews.	Journal of Transcultural Nursing. 15(2):147-54, 2004 Apr. (31 ref)	2004	Although brain death was formally recognized in Korea in 2000 for the purpose of organ donation, traditional Confucian-based thought still prevails. The aim of this study was to explore sociocultural perspectives that influence health professionals' attitudes and perceptions regarding organ donation. Semi structured interviews were conducted with nine key informants from three major hospitals providing transplant services in South Korea. Several themes were identified as barriers to organ donation: Confucianism, misunderstandings and myths, organs as spare for selling, lack of clarity in the definition of death in the new legislation, and limited medical insurance coverage. It remains difficult for brain death to be accepted as true death, and there is currently a poor rate of organ procurement. Findings of the study will help identify socioculturally appropriate strategies to promote acceptance and accessibility of organ transplantation among South Koreans.
<a href="#">Lock M.</a>	Cultural aspects of organ donation and transplantation.	Transplantation Proceedings. 31(1-2):1345-6, 1999 Feb-Mar.	1999	Abstract not available Department of Social Studies of Medicine, McGill University, Montreal, Quebec, Canada.
<a href="#">Mavroforou A.</a> <a href="#">Giannoukas A.</a> <a href="#">Michalodimitrakis E.</a>	Organ and tissue transplantation in Greece: the law and an insight into the social context.	Medicine & Law. 23(1):111-25, 2004.	2004	Advances in biological sciences and medicine have revolutionized current practice and opened new horizons. Tissue and organ transplantation is a miracle and an action of love and sacrifice for the sake of fellow human beings. Organ transplantation has been commonplace over the last decade but Greece still remains the lowest numerically among European countries in this field because of the lack of organ donation although it is highest in traffic accidents. Despite this, the legal framework regulating transplantation was enacted late in comparison to other European countries, and was not the only obstacle to the development of organ donation. Several other factors such as philosophy, culture, traditional and religious attitudes, lack of public information and lack of the relevant social fabric, have all contributed to the current sad situation. This article aims to present a critical view on the evolution of the legal framework in the field of tissue and organ transplantation in Greece. Issues that still deter organ donation are discussed along with an insight into the current situation in the Greek social context in order to make a constructive contribution to future perspectives.
<a href="#">McCunn M.</a> <a href="#">Mauritz W.</a> <a href="#">Dutton RP.</a> <a href="#">Alexander C.</a> <a href="#">Handley C.</a> <a href="#">Scalea TM.</a>	Impact of culture and policy on organ donation: a comparison between two urban trauma centers in developed nations.	Journal of Trauma-Injury Infection & Critical Care. 54(5):995-9, 2003 May.	2003	The similarities and differences in organ donation policies, consent rates, and number of organs transplanted from patients declared "brain dead" after traumatic injury in different countries has not been previously reported.  An international trauma survey questionnaire was developed. Analysis of two responding centers with regard to organ donation practices between urban, free-standing adult trauma hospitals is presented: the R Adams Cowley Shock Trauma Center (STC) in Baltimore, Maryland, and the Lorenz Bohler Hospital (LBH) in Vienna, Austria.  Hospital admissions resulting from traumatic brain injury (TBI) account for a significantly greater number of admissions at the STC than at the LBH (761 vs. 276), and the STC has a higher number of patients admitted with severe

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				<p>TBI (Glasgow Coma Scale score &lt; 8). Of 39 medically suitable brain-dead patients at the STC, 18 went to organ donation. At the LBH, 16 patients were declared brain-dead, 7 were considered to be medically suitable, and all 7 went to donation. A "presumed consent" organ donation policy in Austria resulted in 100% of medically suitable patients going to donation at the LBH. With a volunteer donation policy at the STC, 46% of patients went to donation.</p> <p>Of those families who refused donation at the STC, 9 of 16 eligible African Americans (56%), 10 of 21 eligible Caucasians (48%), 1 Hispanic, and 1 Native American Indian family declined donation. CONCLUSION: "Presumed" organ donation in Austria led to 4 organs transplanted per trauma brain-death at the LBH, as compared with 3.8 organs per brain-death at the STC. The greater number of patients with severe TBI at the STC accounts for a similar organ donation rate compared with the LBH, despite the fact that the consent at the STC is voluntary and at the LBH is "presumed."</p> <p>A higher organ donation rate in the United States would result in a greater number of organ transplants from patients who die after traumatic injury and a resultant increase in potential lives saved. There does not appear to be a significant difference in ethnicity between families who accept and those who refuse organ donation after traumatic brain death declaration at the STC.</p>
<p><a href="#">Molzahn AE.</a> <a href="#">Starzomski R.</a> <a href="#">McCormick J.</a></p>	<p>The supply of organs for transplantation: issues and challenges. [Review] [73 refs]</p>	<p>Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association. 30(1):17-26; quiz 27-8, 2003 Feb.</p>	<p>2003</p>	<p>The success of organ transplantation has been well documented, with improvements in quality of life and cost-effectiveness being notable outcomes of the therapy. In this paper, we focus on the major issues and challenges related to the shortage of solid organs available for transplantation. The reasons for the organ shortage are complex and multifaceted.</p> <p>Fewer motor vehicle accident deaths, public perceptions about organ donation, attitudes of health professionals, knowledge of health professionals regarding organ donation, donor identification processes, family consent rates, and ethnocultural considerations are all issues that are important to consider in addressing the shortage.</p>
<p><a href="#">Prieto LR.</a> <a href="#">Miller DS.</a> <a href="#">Gayowski T.</a> <a href="#">Marino IR.</a></p>	<p>Multicultural issues in organ transplantation: the influence of patients' cultural perspectives on compliance with treatment.</p>	<p>Clinical Transplantation. 11(6):529-35, 1997 Dec.</p>	<p>1997</p>	<p>The potential influence of racially or ethnically diverse cultural perspectives on patient compliance with post-transplant treatments is discussed. Domains of competency regarding culturally sensitive clinical practice are outlined to assist providers in better understanding the perspectives that may influence the views and behavior of culturally diverse patients.</p>
<p><a href="#">Rubens AJ.</a></p>	<p>Racial and ethnic differences in students' attitudes and behavior toward organ donation. Source</p>	<p>Journal of the National Medical Association. 88(7):417-21, 1996 Jul.</p>	<p>1996</p>	<p>Donor authorizations tend to be especially low among African Americans and other minority and ethnic groups. This study assessed and compared the beliefs, attitudes, and rates of participation regarding organ donation among a sample of racially and ethnically mixed university students.</p> <p>A 64-item survey questionnaire regarding organ/tissue donation issues was administered to 683 undergraduate students from different racial and ethnic backgrounds at a state-assisted university in the Midwest. The findings from the study indicated that African-American students differ significantly from white students in their attitudes and beliefs toward organ donation, while</p>

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Author	Title	Source	Year	ABSTRACT
				<p>Asian-American, Hispanic, and international students were similar to white students in their attitudes and beliefs regarding organ donation. However, a greater percentage of African-American students have granted permission for organ donation compared to African Americans in the general population.</p>
<p><a href="#">Smith-Brew S.</a> <a href="#">Yanai L.</a></p>	<p>The organ donation process through a review of the literature. Part 2. [Review] [53 refs]</p>	<p>Accident &amp; Emergency Nursing. 4(2):97-102, 1996 Apr.</p>	<p>1996</p>	<p>Several studies have attempted to investigate the role of culture and race in organ donation and transplantation. These studies go beyond ones conducted out of mere interest. The researchers have found that there are indeed human leukocyte antigens that are specific to individual races and that affect transplantation outcomes (Milford et al 1987). Similarly, Weller et al (1987) have shown that graft and patient survivals were improved when donors and recipients are of the same race. (53 Refs)</p>
<p><a href="#">Spigner C.</a> <a href="#">Weaver M.</a> <a href="#">Cardenas V.</a> <a href="#">Allen MD.</a></p>	<p>Organ donation and transplantation: ethnic differences in knowledge and opinions among urban high school students.</p>	<p>Ethnicity &amp; Health. 7(2):87-101, 2002 May.</p>	<p>2002</p>	<p>Purpose: To assess knowledge and opinions about the process of human organ donation and transplantation among American teenagers.</p> <p>A culturally sensitive 35-item self-administered survey assessing knowledge, opinions, and family discussion about organ donation and transplantation was conducted with 247 students in 13 separate classrooms encompassing three urban high schools in the same city.</p> <p>More than 50% of the students did not know the correct answers to 13 of the 16 questions on factual knowledge. The sources of information about organ donation and transplantation among students were primarily television and school. African-Americans and Asian-Americans were significantly less likely to want to become organ donors when compared to non-African-Americans and non-Asian-Americans, respectively. Asian-Americans were significantly less likely to have discussed the matter with family members.</p> <p>Accurate, up-to-date, culturally sensitive youth-oriented health education that emphasizes family discussions about organ donation would be beneficial.</p>
<p><a href="#">West R.</a> <a href="#">Burr G.</a></p>	<p>Why families deny consent to organ donation.</p>	<p>Australian Critical Care. 15(1):27-32, 2002 Feb. (18 ref)</p>	<p>2002</p>	<p>Advances in medical practice and technology and the success of organ transplantation over the past 2 decades have resulted in an increased demand for organ donors. However, the health care community and organ procurement organizations (OPO) are faced with a worldwide shortage of donor organs. The non-consent of families is the most common reason that organs of medically suitable potential donors are not recovered.</p> <p>A review of published research post 1990 was conducted to primarily determine the major factors that influence a family's decision to deny consent to donation. The literature review indicates that the significant factors associated with denial of consent include: the misunderstanding of brain death; cultural beliefs; the specific timing of the request; the setting in which the request is made; the approach of the individual making the request; and characteristics of the deceased.</p> <p>Organ donation and transplantation rates could be increased by the joint involvement of medical, nursing and OPO personnel to enhance the quality of hospital care and to ensure that requests for donation are handled in a way that meets the family's informational and emotional needs.</p>

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Author	Title	Source	Year	ABSTRACT
<a href="#">Xiao H.</a> <a href="#">Campbell ES.</a> <a href="#">Song KS.</a>	A trend analysis of organ transplantation among ethnic groups. [erratum appears in J Natl Med Assoc 2002 Jul;94(7):659-60.].	Journal of the National Medical Association. 94(1):15-20, 2002 Jan.	2002	<p>This research provides public policy implications regarding organ resource allocation and increases public awareness of the current status of transplant use in various ethnic populations.</p> <p>Healthcare Cost and Utilization Project (HCUP), National Inpatient Sample (NIS) data were used to obtain a yearly estimate of the number of organ transplants by organ and by ethnic origin for 1988-1997. ICD-9-CM codes identified lung, heart, liver, and kidney organ-transplantation procedures. Each record in the sample was weighted by its respective discharge weight in order to extrapolate a national estimate. To assess whether there are significant differences among ethnic groups in organ transplantation rates over time, regression models were estimated for heart, liver, and kidney transplants. Transplantation rates were modeled as a function of time, ethnic origin, and interaction variables.</p> <p>Examination of time trend graphs and regression analyses indicates that transplantation rates have not varied substantially across ethnic groups between 1988 and 1997. Rates for all groups, with the exception of Asians, exhibited similar time trends with little systematic variation.</p> <p>Further research is needed to determine whether variations exist due to organ availability versus prevalence of the disease.</p>
<a href="#">Zavala EY.</a> <a href="#">Gabriel A.</a>	Public attitudes and beliefs toward organ donation and transplantation: focus on American ethnicity	Journal of Transplant Coordination. 4(1):31-7, 1994 Apr. (12 ref)	1994	<p>The Association of Organ Procurement Organizations commissioned a study in November 1990 to gather current data to elucidate the factors which may affect the public's attitude toward organ donation and transplantation. The public attitude survey conducted telephone interviews with a random sample of 503 respondents, aged 18 and older. An oversampling of black (79) and Hispanic (74) respondents was part of the study.</p> <p>The results show that the total, black, and Hispanic populations are favorable about being an organ donor. In addition, there was a consistent positive reaction by the total, black, and Hispanic populations to considering organ transplantation for themselves. Sixty-one percent of blacks and 54% of Hispanics became more positive about organ donation and transplantation following the survey interview. The impact of the survey as an influencing factor and educational tool showed significant impact in the minority populations.</p> <p>If public education efforts are to affect donation rates, they must directly target the segments of the population not currently supportive of organ donation. A successful campaign should direct itself toward helping the individual successfully carry out his/her intention rather than simply attempting to influence the intention.</p>

## Disease Trend Data

Key Informant or Source	Availability of Data by Ethnocultural Group(s)	Donation Trends (# of donors, etc.)	Waiting List Trends	Transplantation (#of recipients, differential access to transplantation, etc.)	Treatment / Disease / Health Trends
Kim Badovinac Consultant, Canadian Organ Replacement Register (CORR).	CORR collects data on donor ethnicity; however, donor ethnicity has not been completely reported by Organ Procurement Organizations (OPOs).  There is also a lack of a meaningful denominator to compare groups. As a result, existing data on ethnicity have not been released.	Not reported by ethnicity.	Waiting list data within CORR is aggregate data (e.g., counts provided by OPOs on a quarterly basis).  Ethnicity/race is not collected.	Work on differential access to transplantation in the U.S. and Australia shows that sex, ethnicity, and SES are important variables.  Schaebel et. al. (2000) found a sex disparity in transplant rates among Canadian kidney transplant programs, which increased with increasing age and with specific racial groups. This study was based on an examination of CORR data for the years 1981 to 1996.  Retrospective analysis of liver transplants performed in British Columbia showed a difference in referral rates for liver transplantation among aboriginal and non-aboriginal patients based on underlying cause of the liver failure (Yoshida et al., 2000). Compared to non-aboriginal patients, aboriginal patients were more likely to be referred for liver transplantation when they had a diagnosis of primary biliary cirrhosis and less likely when they had a diagnosis of Hepatitis C or alcoholic cirrhosis.	Hospitalization databases do not capture ethnicity/race of inpatients.  Information regarding ethnicity/race is collected within CORR for recipients of treatment for end-stage organ failure. The challenge, again, is finding meaningful denominators to reflect the rates.  We have found that Aboriginal patients tend to have higher mortality than Caucasian patients, while Asian patients tend to have lower mortality than Caucasians.
Nephrologist.	Findings will be available on the CMAJ website at 5:00 PM, September 13, 2004. Findings cannot be discussed before that time.	Not available.	Not available.	Rates of transplantation by race for the prairie provinces are available through CORR.	It is possible to calculate incidence of end-stage-renal disease by race. Certain comparisons are possible in the prairie provinces such as access to transplantation by race (which is defined based on the provider's best estimate of race).
Sybil Stokoloff Manitoba Transplant.	No data. In general, Manitoba has the highest rate of diabetes in Canada and a large Aboriginal base.	The organization has not attempted to maintain this data – there is no budget to do so.	Not available.	Between 1996 – 2002, out of 200 transplants, 119 were from deceased donation. Only 5% of deceased donation is Aboriginal. Deceased donation is a problem because often the deceased is flown to Winnipeg (while not yet declared dead) and there is no family around for discussion and decision-making.	Given the high incidence of diabetes, there is a high need for transplants among Aboriginal people.

Key Informant or Source	Availability of Data by Ethnocultural Group(s)	Donation Trends (# of donors, etc.)	Waiting List Trends	Transplantation (#of recipients, differential access to transplantation, etc.)	Treatment / Disease / Health Trends
Sue Wilson and Angela Diano Trillium Gift of Life (Ontario).	Three documents are being sent to Charis including information on organ donation issues in the Muslim, Chinese, and Sikh Indian communities. It is anticipated that these documents will include relevant data. Further comments regarding availability of data were not provided during the interview.	Not available.	Not available.	Not available.	Not available.
Sally Greenwood British Columbia Transplant Society.	Regarding the question of ethnicity and donation trends, the BCTS does not perceive a greater need for genetic matches thus making this data less critical to track. For example, with anti-rejection drugs, the need for a genetic match between donors is less important than previously. Organ donation does not require the same genetic match as bone marrow.	Not further discussed.	Not available.	Not available.	Not available.
Excessive burden of end-stage renal disease among Canadian Indians: A national survey (Young, T. K. et al., Am J Public Health, 1989).	Aboriginal communities (Canadian).	Not stated.	Not stated.	Not stated.	Based on a review of demographic and clinical data from 75 treatment centres in nine Canadian provinces, the researchers concluded that Aboriginal people in Canada are at a much higher risk for ESRD than the Canadian population in general (at least 2.5 times the national incidence rate). [Note: this study was published in 1989.]
The Rising Tide of End Stage Renal Disease in Toronto (Toronto District Health Council, 2003). <a href="http://www.tdhc.org/pdf/">http://www.tdhc.org/pdf/</a>	The authors cited a previous study of incidence rates for specific ethnoracial groups in Canada	Not stated.	Not stated.	Not stated.	Caucasians had a significantly lower incidence rate of ESRD compared with Aboriginal Canadians, Blacks and Orientals. Aboriginal Canadians had the highest rate of ESRD overall.

Key Informant or Source	Availability of Data by Ethnocultural Group(s)	Donation Trends (# of donors, etc.)	Waiting List Trends	Transplantation (#of recipients, differential access to transplantation, etc.)	Treatment / Disease / Health Trends
<p><a href="#">REPORT/Dialysis%20Final%20Report%20March%202003.pdf</a></p> <p>Yeates, K.E., Zhu, N., Badovinac, K., Fenton, S.S.A. (2001) "Trends in Incidence Rates of Canadians Initiating Renal Replacement Therapy: Does Racial Disparity Exist?"</p> <p>Journal of the American Society of Nephrology.</p>	<p>(Yeates et al, 2001) and a subsequent study of Toronto-specific ESRD rates which showed significant differences between Native Canadians, Blacks and Orientals versus Caucasians.</p> <p>Caucasians had a significantly lower incidence rate compared with other racial groups. Aboriginal Canadians had the highest rate overall. The authors further noted that these three ethnoracial groups at highest risk of developing ESRD comprise nearly a third of the population in Toronto.</p>				
<p>Aspinall, Peter and Jacobson, B. (July 2004) "A Focused Review of the Evidence and Selected Examples of Good Practice." Centre for Health services Studies, University of Kent.</p>	<p>This report was commissioned by the UK Department of Health to produce an evidence based review that addressed ethnic differences in health and health care, including access to care and outcomes, with an emphasis on equity issues.</p> <p>The report focuses on current UK health priorities including coronary heart disease and diabetes.</p> <p>Ethnic disparities in the wider determinants of health were not studied.</p>				<p>Studies show that coronary heart disease is moderately higher in South Asian groups than in the population as a whole. There is evidence that the poorest groups of Pakistani and Bangladeshi origin have the highest rates.</p> <p>Many studies have reported a much higher prevalence of diagnosed non-insulin dependent diabetes among South Asians and Caribbeans.</p> <p>Mortality directly associated with diabetes amongst South Asian migrants is about three and half times that of the general population. Diabetic neuropathy and end stage renal failure are significantly more common in South Asian diabetics than in white diabetics.</p>



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#### Community Agencies / Cultural Organizations

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2. Multicultural Health Brokers. <http://www.capitalhealth.ca/Health+Services/Hospitals/Northeast+Community+Health+Centre/Programs+and+Services/Multicultural+Health+Brokers.htm>. Edmonton, Alberta. 780-423-1973
3. Canadian Indonesian Society. No website available. Vancouver, B.C. Phone number listed in directory of Vancouver Community Network site [www.vcn.bc.ca](http://www.vcn.bc.ca) 604-875-8445.
4. National Association of Indo-Canadians. No website available. Phone number listed in directory of cultural associations <http://www.cassa.on.ca/CommDirectory/coomCentres.html>. 905) 677 4442
5. Canadian Ethnocultural Council. Ottawa, Ontario. 613-230-3867 <http://www.ethnocultural.ca>

#### Transplant Specific

1. Manitoba Transplant Program. Sybil Stokoloff at 204-787-1897
2. Trillium Gift of Life Network. Darwin Kealy. 416-363-4001 (Main #) [Indo-Canadian experience?] [www.organdonationontario.org](http://www.organdonationontario.org)
3. British Columbia Transplant Society. Sally Greenwood or Bill Barrable. [Chinese communities experience?] 604-877-2240 [http://www.transplant.bc.ca/who\\_we\\_are\\_main.htm](http://www.transplant.bc.ca/who_we_are_main.htm)
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# Consultation Strategies Interview Guide

## Sample Interview Script

Hello. My name is Laurie McCaffrey and I'm calling on behalf of the Canadian Council for Donation and Transplantation (CCDT) and Charis Management Consulting in Edmonton. The Council is in the process of planning a community consultation regarding organ and tissue donation with diverse communities across Canada. As part of the planning process, we are conducting an environmental scan to identify consultation strategies that have been used in diverse communities in other fields. The consultation will be conducted across Canada with Chinese, Indo-Canadian, and Aboriginal communities.

Your name was [recommended by XX or found in the literature or document search] as someone who could provide some input regarding the [XXX specific community, if applicable]. If you agree to participate, I will take hand-written notes during our conversation and would like to include your comments in the final report that will be submitted to the CCDT. The interview should take no longer than 20 minutes of your time.

[If available and willing,] I have a few specific questions:

1. Can you please briefly describe the overall consultation process?
2. What strategies did you use to engage communities? Collect information? Share findings?
3. What were the advantages of these strategies?
4. Disadvantages?
5. Can you comment on the importance of communicating in the same language(s)? How have you handled the variety of dialects?
6. Was an evaluation of the process conducted?
7. Do you have any additional advice for the CCDT in planning the consultation approach?

Thank you very much.

If you have any further questions regarding the consultation project please contact Kimberly Young or Beverly Curtis.

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# Disease Trends Interview Guide

## Sample Interview Script

Hello. My name is Laurie McCaffrey and I'm calling on behalf of the Canadian Council for Donation and Transplantation (CCDT) and Charis Management Consulting in Edmonton. The Council is in the process of planning a community consultation regarding organ and tissue donation with diverse communities across Canada. As part of the planning process, we are conducting an environmental scan to identify disease trends within Chinese, Indo-Canadian, and Aboriginal communities.

Your name was [recommended by XX or found in the literature or document search] as someone who could provide some input regarding the [XXX specific community, if applicable].

If you agree to participate, I will take hand-written notes during our conversation and would like to include your comments in the final report that will be submitted to the CCDT. The interview should take no longer than 20 minutes of your time.

[If available and willing,] I have a few specific questions:

1. Do you have data available by ethnocultural group with respect to organ and tissue donation? We are interested in the following elements:
  - donation trends
  - waiting list trends
  - transplantation trends / differential access
  - disease trends
2. What are the barriers to maintaining complete data?
3. Do you have other suggestions for who we might contact?
4. Do you have any additional advice for the CCDT in planning the consultation approach?

Thank you very much.

If you have any further questions regarding the consultation project please contact Kimberly Young or Beverly Curtis.

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## **APPENDIX C: DIVERSE COMMUNITIES CONSULTATION PLAN**

# CCDT Diverse Communities Consultation Approach

Working document  
September 20, 2004

## Policy Context

The Canadian Council for Donation and Transplantation (CCDT) is interested in consulting with three ethnocultural communities to identify and understand their unique perspectives on organ and tissue donation. The consultation will explore cultural beliefs and issues related to donation and transplantation. Ultimately, this understanding may lead to more Canadians considering donation within an ethno-culturally sensitive environment.

This project serves CCDT's priority of improving 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." It is anticipated that understanding the unique perspectives of people from diverse ethnocultural and Aboriginal backgrounds will lead to better communication about organ donation and transplantation.

The consultation will result in advice to the conference of Deputy Ministers on public policy to support the delivery of culturally appropriate donation and transplantation awareness messages and services. The project will develop a model for engagement with ethnocultural and Aboriginal communities on organ donation and transplantation that could be adopted or adapted by organizations across Canada, if they choose to do so. This advice will be grounded in the evidence from the literature and others' experiences as well as the feedback from the members of the cultural and Aboriginal communities.

The consultation will document the "lay of the land" in relation to engaging ethnocultural and Aboriginal groups in discussions about organ donation and transplantation and assess local readiness for partnerships.

## Definition of Consultation

For the purposes of this project, the consultation will be defined as a tool for answering key policy questions. The consultation will be a dialogue with a variety of people from Indo-Canadian, Chinese-Canadian and Aboriginal heritage to understand their views about donation and transplantation. This understanding will inform the Council's advice to the Conference of Deputy Ministers regarding effective strategies and policies to undertake in communicating about donation and transplantation to members of diverse communities. This consultation will enable people from diverse cultural and Aboriginal backgrounds to contribute to the advice to the Deputy Ministers.

## Aims and Values

From the CCDT's perspective, the overall aim of the consultation is to gather information to advise the Conference of Deputy Ministers about what strategies will support people from diverse cultural and Aboriginal backgrounds to make the decision to donate (or not) and to act on that intention. The consultation will help the CCDT to understand the factors (cultural and spiritual) that influence decisions and actions related to donation. The consultation could lay the groundwork for a partnership between the ethnocultural or Aboriginal group and the local donation and transplantation program, if both desire it.

Until we meet with people from the participant groups, we are unable to say what their aims and values might be for the consultation. This is something we would ask at our first planning meeting with the local group. The consultation will emphasize a mutual interests approach to ensure that the groups and people being consulted gain something from their participation.

## Aims

- Identify stated beliefs and views about organ and tissue donation in selected diverse communities.
- Understanding and learning about the perspective of the group being consulted regarding donation and transplantation;
- Determining strategies that would assist communities in receiving information in culturally appropriate ways;
- Assessing what can be done to augment existing systems to ensure that communities are supported from within their community; and
- Identifying barriers to donation and what, if anything, could be done to address them.
  
- Identify processes that work for engaging ethnocultural and Aboriginal groups on the topic of donation and transplantation.
- Using a continuous improvement model to make changes to the process as we gain feedback from the groups; and
- Assessing what worked and did not work from the participants' perspectives.
  
- Consider partnerships between the ethnocultural group and the local donation and/or transplant program.
- Build on existing connections and work through the local contacts in the donation agency as much as possible;
- Establish new connections between the local donation programs and the ethnocultural group where none exists; and
- Be a source of information on donation and transplantation in the communities, if asked by participants.

## Values

We wish to be explicit about the values that will guide the consultation. The values will be discussed with the local planning groups to determine areas of convergence and divergence and to make adjustments accordingly. This values discussion will be the entrée into the discussion of organ donation and transplantation.

Value	Description	Expression/Indicators
Appreciation of diversity	<p>Seeking to understand, not judge views.</p> <p>Genuine admiration for the cultural context and views expressed.</p> <p>Flexibility in response to diversity.</p>	<p>Information is not aimed at changing opinions.</p> <p>Process is focused on hearing from participants, not teaching them.</p> <p>Process is adjusted to respect ceremonies and traditions of the ethnocultural and Aboriginal group being consulted.</p> <p>Diversity of opinions is welcomed.</p> <p>Language of consultation reflects the dominant language of the group being consulted.</p>
Collaboration	<p>Allowing situations to develop organically. Follow the paths that open up.</p> <p>Cooperative not competitive approach.</p> <p>Building on existing local activities.</p> <p>Sharing of results with those consulted.</p> <p>Commitment to the future of the partnership.</p>	<p>Consultation process and tools are developed in response to the input of the group being consulted.</p> <p>Not wanting to be consulted is respected.</p> <p>Steering committee examines motivations and values to ensure transparency.</p> <p>Commitment by local donation programs to time required to consult and build partnerships.</p> <p>Linkages with other related projects are encouraged.</p>

Value	Description	Expression/Indicators
Integrity	<p>Trust through open communication about the purpose of the consultation, values, processes used and application of results.</p> <p>Respect for all involved.</p> <p>Respecting experience, expertise, heritage and history.</p>	<p>People being consulted are partners in the consultation and influence its approach and outcomes.</p> <p>Commitment to follow up and follow through by local agencies engaged in consultation.</p> <p>Clear indication of use of information to participants.</p> <p>Consultation will be guided by a code of ethics.</p> <p>Participants give permission for use of their information.</p>
Excellence	<p>The consultation will be conducted within a continuous learning approach.</p> <p>Process will be based on evidence available and input of local people.</p> <p>Rigour applied to ensure high quality information.</p>	<p>Targeted literature searches will be done as needed.</p> <p>Participants will be asked for feedback on the consultation methods.</p> <p>Participants will be asked in advance what methods work best for them.</p> <p>Environmental scan will, in part, guide consultation approach.</p> <p>Experts are consulted throughout for guidance.</p>
Capacity building	<p>Focus on assets within a community and on their unique ability to contribute to this topic.</p> <p>Identify projects underway within the community that might encompass donation and transplantation.</p>	<p>Consultation will include an invitation to continue the work on this topic within their community.</p> <p>Strengths within the community will be recognized.</p> <p>Opportunities to marry organ donation with existing issues in a community will be considered (e.g. diabetes strategy; end of life care).</p>
Learning	<p>Openness to new ways of doing consultation.</p> <p>Sincere desire to have the limits of our own culture identified.</p>	<p>Asking for feedback on our approach to the consultation.</p> <p>Asking for our cultural errors to be identified.</p> <p>Willingness to hear that individuals or groups do not want to donate for cultural reasons.</p> <p>Willingness to identify new practices that may require changes in the medical system.</p>

## Scope

The scope of the consultation involves policy questions within three topic areas which correspond to the project objectives including:

- Awareness, beliefs and attitudes towards donation and transplantation
- We want to know:
  - What are the attitudes about donation and transplantation held by people from ethnocultural and aboriginal backgrounds?
  - Has the person registered their intent to donate?
  - What are the beliefs about death and afterlife, body integrity, role of ancestors in the spirit world and older living adults? Do these beliefs influence organ donation decisions (for themselves or a loved one) and if so, how?
  - Does culture matter in donation decisions and if so how?
  - What are the barriers and issues from a cultural perspective with regard to donation?
  - Are there cultural rituals and ceremonies that could be adapted for application during the donation and transplantation experience so that people can be true to their beliefs and support donation and transplantation? How do we best approach people with the bad news that surrounds donation?
- How does attention to cultural issues make for better practice in donation requests? What are the best ways to approach ethnocultural and Aboriginal peoples to involve them in discussing and taking action in donation and transplantation?

### Process of engagement.

We want to know:

- What processes worked well?
- What should change if another consultation were held?
- Was the consultation conducted according to stated values?

### Potential for partnership

We want to know:

- Is there interest in working with the local donation agency to address issues raised in the consultation?
- Could organ donation become a priority in the community?
- Could organ donation become part of a bigger health strategy in the community?

We will maintain a list of possible future research needs, if they are identified. This learning could possibly contribute to identifying a research agenda for ethnocultural and Aboriginal issues related to donation and transplantation.

## Areas of Interest

The following are the topics within which we will gather information. The questions that we will ask of participants will be constructed in consultation with members of the ethnocultural or Aboriginal groups involved in planning the consultation locally. We will gather information about aspects of donation from approach and consent to retrieval, transplant and follow up.

### Demographics

We want to ask the minimum requirements in this section. Possible characteristics:

- Age;
- Years in Canada or born in Canada;
- Traditional; neo-traditional; assimilated Canadian;
- Ethnic origin; First Nations affiliation; Inuit; Metis;
- Religious affiliation; traditional spirituality;
- Status/non-status;
- Education;
- On/off reserve;
- Rural/urban; and
- Gender.

### Awareness of and experience with donation and transplantation

- Deceased donation;
- Live donation;
- Personal experience or knowledge of someone who has donated or consented to donation;
- Interest in receiving donation awareness information (what is donation, who is involved, what will happen);
- Source of information leading to awareness; and
- Indication of intention to donate.



### Beliefs which may influence attitude toward donation and transplantation

- What is the belief about:
- Death and life after death;
- Missing body parts in life and in life after death;
- The importance of ancestors in the spirit world and older living adults in decision making; and
- Other beliefs that are relevant to this topic.
- What impact does this belief have on the decision to donate?

### Attitude toward organ donation

- How do they view organ donation and transplantation – is it considered a good thing? If yes, why is it a good thing and if not, what beliefs contribute to that opinion?
- Should donation and transplantation occur?
- Does the attitude hold for themselves only? For children and other loved ones? For the public?
- What is their rationale for this attitude? (underlying barriers)

### Barriers/Issues

- What are the issues unique to this ethnocultural and Aboriginal group related to donation and transplantation (by stages in the donation process – awareness, consent, donation, follow up).
- What have others said about issues related to donation?
- Should these barriers be addressed? If yes, what could be done?

### Consultation process

- Prior to the consultation: what mechanisms and approaches are helpful in consulting with people from your cultural background?
- During the consultation: what mechanisms and strategies were effective and which were not? Why?
- Did we act on the values we expressed to guide the consultation?

### Partnership

- Is this a topic you or your group would want to pursue within your community?
- What is their desired role in future activities locally related to donation and transplantation?
- How would you propose to do this?
- How can we help?

## Project Approach

### Initiation

Contacts have been made with the transplant and/or donation program in Winnipeg, Vancouver, Toronto and Saskatoon to:

- determine the interest of the donation and/or transplant program in participating in the project and initiating relationships with the ethnocultural or Aboriginal groups in the community; and
- Identify existing relationships and partnerships upon which to build.

Contacts have been made with Aboriginal people in Winnipeg. Several elders have indicated an interest in assisting with the consultation.

## Planning

Once the Steering Committee agrees to the consultation approach, a one-day planning session in Winnipeg will be held to scope out the consultation with Aboriginal people, including the identification of data sources. The local planning committee will hopefully include the health authority, people from the ethnocultural or Aboriginal communities and the consulting team. The outcomes of the planning day will be agreement on:

- Guiding values;
- Understanding of terms;
- Consultation questions;
- Consultation tools (e.g. interviews, focus groups, community events, Council of Elders, kitchen table discussions, deliberative dialogue, contemplative dialogue)
- Information sources – identification of people and organizations with whom we will consult.
- Identification of linkages (e.g. Pallium or other local projects)

## Implementation

The consulting team will gather the information, do the analysis and inform the Steering Committee and local planning committee.

## Evaluation

A one-day post-consultation meeting with the local planning group is expected. The outcomes of this meeting will be to:

- Share the consultation results;
- Conduct an evaluation of the consultation processes used; and
- Determine next steps (if any) for an ongoing partnership locally.

As part of the evaluation, during the data collection phase, we will ask questions about how the processes worked for the participants and what they would change in the future.

## Ethics Requirements

The requirements for the ethics discussion regarding the consultation will be documented following the Steering Committee meeting on September 20, 2004. We want to ensure that an ethical approach to the consultation is taken, however, it may not be necessary or desirable to go through a formal university research ethics board review.

## Site selection

Manitoba Transplant, Saskatchewan Transplant, the British Columbia Transplantation Society and Trillium Gift of Life were approached and have indicated a preliminary interest in further discussions with regard to participating in a consultation in their locations. It may be necessary to choose sites for the consultation depending on the local situation in relationship with project resources.

Possible criteria for site selection could include:

- Strength of existing relationships between local groups and the donation/transplantation programs;
- Resources that the local donation and transplantation group has to contribute to the consultation. This means in-kind resources and interest/capability in pursuing ongoing partnerships with the groups being consulted in their location;
- Willingness of the ethnocultural group to become involved;
- Availability of existing activities and projects onto which this consultation could piggyback; and
- Other criteria as identified by the Steering Committee.