CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION



CCDT CONSEIL CANADIEN POUR LE DON ET LA TRANSPLANTATION

DIVERSE COMMUNITIES

Consultation to Explore Peoples' Views on Organ and Tissue Donation

Discussions with South Asian Canadians

Vancouver and the Lower Mainland: February 2005

SUMMARY REPORT TO PARTICIPANTS

Who is this report for?

This report is for the people who participated in the Diverse Communities Consultation. It is also for their families, their neighbours, and members of their communities. The Canadian Council for Donation and Transplantation and the other organizations that participated in the consultation are grateful to all the individuals who so generously opened their hearts and minds to share their beliefs, values, and opinions. This report honours CCDT's commitment to share the results of the consultation with its participants.

About the Canadian Council for Donation and Transplantation

In 2001, the Canadian Council for Donation and Transplantation was established to advise the Federal, Provincial, and Territorial Conference of Deputy Ministers of Health about the shortage of organs and tissues for transplantation. The CCDT helps coordinate federal, provincial, and territorial activities to develop standards, policies, and best practices for organ and tissue donation and transplantation.

Why were the consultations held?

In 2005, 4025 Canadians were on waiting lists for organ transplants. Over half of these people—2758—needed kidney transplants. Successful transplants depend on finding a suitable match. A suitable match usually means that the donor and recipient must have similar biological traits—like matching blood types. That is why suitable matches are usually found among family members and among people from the same racial or ethnocultural background.

Sometimes people stay on waiting lists for up to a year or longer. Of course, the longer they wait, the more likely it is that their health will get worse. Some ethnocultural groups have a higher risk of getting illnesses that need a transplant as part of the treatment. For example, South Asians have a greater chance of getting kidney disease than people from other ethnocultural groups. Unfortunately, the waiting times for some ethnic minorities can be twice as long as the waiting time for Caucasians. Of course, the difference in waiting times has to do with a shortage of suitable matches. It is this situation that prompted the CCDT to organize the Diverse Communities Consultation.

What do we mean by organ and tissue donation?

A **living donation** takes place when someone donates an organ or part of an organ to another person. This would usually be a kidney or a portion of a liver. Everyone has two kidneys and someone can live well with only one. A person can donate a portion of their liver and the remaining portion of liver will regrow to a normal size.

A **deceased organ donation** takes place when someone dies suddenly and loved ones agree to donate organs of the person who has died. The heart, liver, kidneys, pancreas, lungs, small bowel, or stomach are organs that can be donated.

Tissue donation takes place when someone has died. Tissues that can be donated include corneas, heart valves, bones, and skin.

Someone can receive an organ or tissue from another person in any of these ways. These are all called "transplantation."

Why were these communities chosen?

Canada's population is already very diverse. We represent many races, ethnic groups, cultures, and religions. But by 2017 it is likely that 23% of Canadians will identify themselves as "racially visible" and 4% will call themselves Aboriginal. The largest racially visible communities will be Chinese, South Asian, and black. In cities such as Toronto and Vancouver, certain ethnocultural communities will form the majority of the population.

These are some of the reasons why the CCDT chose to consult members of the South Asian communities of Vancouver and the Lower Mainland, members of Toronto's Chinese community, and Aboriginal peoples in Winnipeg and Saskatoon.

Other participants

In each community, a local donation and transplantation organization contributed to and participated in the consultation. These organizations were: **The British Columbia Transplant Society**, **Manitoba Gift of Life**, **Saskatchewan Transplant**, and the **Trillium Gift of Life Network** (Ontario).

What were the goals of the consultation?

The general goal of the consultation was to learn more about the beliefs and views of people from these communities and how those influence what they think about organ and tissue donation and transplantation. The goal was not to change people's views, but to try and understand them. In the end, the CCDT hopes that every Canadian will have the chance to consider donation and transplantation in a culturally sensitive and respectful way.

The consultation had three specific goals.

- To find an appropriate and respectful way to discuss donation and transplantation with each community.
- To learn about participants' beliefs and views about organ and tissue donation.
- To help create partnerships between these communities and their local donation and transplantation programs.

From the first planning stages, the consultation was guided by six values.

Appreciation of Diversity. To understand, not judge. To listen, not teach. To truly admire the cultural views being shared.

Collaboration. To build on existing local activities. To share results with participants.

Integrity. To be completely open about the purpose of the consultation, its guiding values, the processes used, and the use of the results.

Excellence. To plan the consultation using available evidence and the advice of local people. To learn from each session and apply what was learned to the next one.

Capacity Building. To focus on each community's unique ability to contribute. To recognize and work from each community's assets and strengths.

Learning. To be open to new ways of doing things. To be willing to hear that individuals or groups have cultural reasons for not wanting to donate.

How was the consultation carried out?

Donation and transplantation are sensitive subjects. They are more than simply medical treatments for a disease. They touch people's deeply held beliefs about illness, death, care of the dying, and the body after death. Decisions about donation and transplantation must be made in the context of people's religious, cultural, political, and personal experiences involving health and health care.

The CCDT wanted to make sure that everything about the consultation was done ethically. The participants were all volunteers. Participants were asked to sign a consent form that outlined the purpose, context, and scope of the consultation. All consultation materials were reviewed to make sure that they were culturally sensitive and in agreement with the consultation values and principles.

Five principles were recognized in carrying out the consultations.

Heterogeneity of Populations. This means that there are differences to be acknowledged, even within an ethnocultural or Aboriginal community. There may be differences in languages, religions, traditions, and countries of origin. There are also differences between urban and rural residents, between individuals who live on- and off-reserve, between young and old, and between newcomers to Canada and long-time residents.

Individuality of Participants. Each participant must be recognized as an individual, not just as a member of a group.

Role of Local Community Representatives. Local community representatives must be invited to participate as partners, to help choose topics, to recruit participants, and to help make arrangements.

Flexibility. At all stages of the consultation, it was important to be willing to adapt to the community's needs and to be willing to make changes.

Relationships and Trust. It takes time to build relationships and trust. Because the consultation organizers were not members of the participants' communities, it was important to work with existing community organizations. It was also important to use interviewers and facilitators from the community.

How was the South Asian community involved?

A cultural advisor and a Planning Group made up of South Asian community representatives were consulted. They advised about how to discuss donation and transplantation in a way that honours South Asian history, political sensitivities, and traditions, while recognizing the diversity of this ethnocultural group. The Planning Group suggested that the South Asian consultations should include youth and adult women in focus groups. They also suggested interviewing administrative leaders from religious organizations.

The South Asian consultation took place in Vancouver in February 2005. Participants were from either Muslim, Sikh, or Hindu communities. Altogether, 59 people (38 men and 21 women) shared their opinions through focus groups, individual interviews, a dialogue session, or meetings.

At each focus group, a brief description of Islam, Hinduism, and Sikhism was given to help the organizers understand the views of participants. To make sure that people were comfortable and could relate easily, the facilitators and interviewers spoke the same language as the participants.

What did South Asian participants say?

... from *Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation*

"All consultation participants shared their ideas and feelings openly and generously. This Summary Report cannot begin to encompass the rich details they provided about their personal experience with organ and tissue donation and about the impact of the beliefs embedded in their cultures and faith traditions."

In all consultations, five topics were discussed.

- 1. The participants' awareness of and experience with organ and tissue donation and transplantation
- 2. The participants' views on organ and tissue donation
- 3. The traditional values and beliefs that influence donation and transplantation
- 4. Suggestions about support for making a decision about donation
- 5. Relationship building within families and communities

1. What is your personal awareness of and experience with organ and tissue donation and transplantation?

There were stories about family members or friends who had received and benefited from an organ donation, usually kidney and sometimes heart transplants. Most people had positive impressions about the value of organ and tissue donation.

My sister donated her kidney almost 10 years ago. It was an easy decision. My brother needed it. It was a life or death situation.

My cousin got a kidney from somebody who is not a blood relation—this person made this gift. It is two years since then and my cousin is well and up and going.

I know a 50-year old man with heart failure. He was waiting for a heart transplant. He received a heart from a 27-year old white male. He is now able to function so well—he goes hunting.

The stories opened a discussion about participants' beliefs and the religious positions. For many of the participants, this was the first chance to take part in a discussion where organ and tissue donation was the focus.

I don't think it would come up [in my family]. There would need to be a reason, maybe something on the news. Otherwise, it wouldn't happen [Youth] It's like a will. We don't do it because we don't think we're going to die. We never sit down and talk about this. We [our family] don't talk about it. I have no idea what they think.

A number of people commented on the need for organs. They said that there was a general lack of awareness about organ donation.

There are a lot of people waiting for kidney and heart transplants from our community.

We do not practice as much. One of the main reasons is awareness. If people knew how badly the organs are needed, how much people could benefit ...

The majority is not aware. There are language barriers.

2. What are your views toward organ and tissue donation?

General Views

Participants—especially youth—were not all comfortable talking about organ and tissue donation. They had concerns talking about it with family and bringing up death and dying.

For the younger generation, death is far away [Youth]

For us, there was a problem with extended family. They were not rosy and positive. They were downright negative. Not everyone is comfortable...[Youth].

If I wanted to do a donation, I would first try to educate my parents about it [Youth].

It's a scary thought to think about. You don't want to think about your own mortality [Youth].

Views in Favour of Donation

Participants raised some points in favour of donation. These included the belief that organs should be put to good use by helping others who need them. One could make a difference in somebody else's quality of life by donating, particularly after one dies.

If I'm dead, it is no good to me. I would donate any part of me [Youth].

You're more likely to donate when you're dead. You would be giving another person the opportunity to live [Youth].

It is a good thing to do donation. Our bodies become 'miti'.

Before, I didn't agree with organ donation, but when I went to get my license renewed, the lady asked my daughter to ask me about being an organ donor. I said no. Then my daughter explained to me about it – that it is a good thing. So now I agree with organ donation.

Some participants said that they would accept a donation to maintain or to improve their own quality of life or chance of getting better.

Yes, there is no question I would accept anything to get better. [Youth] If I were asked now, I would say 'yes.' If it meant I could do things I enjoy, 'yes.' [Youth]

Participants also made a distinction between donating 'major organs' versus donating blood or eyes.

Eye transplant or blood transfusion – I accept that. That's a quality of life matter. For major organs, no.

Some participants were sensitive to the opportunity lost if an organ is accepted. In other words, some raised doubts about accepting an organ if one is elderly because the organ might be better used for someone younger.

Yes, there is no question I would accept anything to get better [Youth].

Maybe not if it was just prolonging my life for a year or so and I was going to die anyway.

If I were 80, I would say to give it to somebody else. If I were still going to live a long life, then I would say 'yes' [Youth].

Views Against Donating

Various points were raised by participants against donation. These included beliefs about the body after a person has died and beliefs about the removal of organs.

As a Muslim, we are supposed to go back to God as we came.

There was discomfort about what is being done to the body during organ removal. Individuals shared stories they had heard and concerns they had about dishonest practices by health professionals to get an organ.

I'm sceptical. I reserve my decision. As a nurse, I've seen an autopsy and it is like a butcher shop...

Older people don't know what is going to happen to the body. Once information is provided, they will understand. It's a matter of educating the people.

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

Many people believe that if you are donor, you risk your life.

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...

Concerns were also raised about the health of the donor and whether the person would have a good quality of life after donating. Some participants believed that donating an organ may cause one to die earlier than if one chose not to donate.

People also believe that if someone donates their body parts, they die earlier. One, that they already have made arrangements for their death,... and second, someone who is in need of transplantation will be praying for donors' death.

If I'm dead, take what you want. But living ... it's probably selfish but I might need the parts later on; it's hard to let go.

I wouldn't go through the process for a living donation. I'm concerned I won't be able to do the same things or function in the same way.

There were also participants who believed that organ donation got in the way of the natural course of aging. Some viewed donation as interfering with a Divine plan.

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

In old age, you are going to go. When my time comes, I'm prepared to go. I will leave it to Allah's will. I won't take a heart or something else.

Some participants said they would be willing to donate their own organs to others in need, especially to a child within the family. Some also said they would not accept donated organs themselves.

If it was my own child, I'd say 'yes'.

I don't have any children. My nieces are young. If anything happens to them, I would give my life. For me, though, it's different. It's about accepting your mortality, your lifespan.

Participants said that choosing to donate organs or tissues of a family member who had passed away depended upon whether the family member had expressed consent while alive. But for some, their concern was about doing what the deceased family member would have wanted is carried out, whether it was written down or not.

If they wanted to say 'yes', they would have said so. I don't want to be responsible. I don't want to make that decision for them [Youth].

It's not my business. It's their decision, their call. I can't make a decision for them.

It depends on how well you know the person. If you live with them all your life, you know what they would want.

Most people said that they would give or accept organ donations outside their community. One person said it would be important for an organ to come from a true believer.

3. What are your views about traditional values and beliefs, and how do they influence your thoughts in regard to donation and transplantation?

The religious beliefs discussed reflect views from Hindu, Sikh and Muslim communities. They help us understand the personal views expressed above. Though Sikhism is distinct from Hinduism, their perspectives are presented together in this summary paper because of the common beliefs that came from participants about issues of the body, the soul, death and the life after death.

Hindu, Sikh and Muslim participants believed that there is a need to allow the family to carry out prayers and to show respect for the dead body.

There is purification of the body. The body is cleansed and bathed. The body should be cremated as quickly as possible, so the organs should be taken as soon as possible.

If you are a Muslim and if you die, you have to be buried as soon as possible, within 24 hours. They bury before the next sunset and often immediately. They wash the body, do the rites and prayer and then bury as soon as they can. In Islam, they do not encourage even doing an autopsy.

Hindu and Sikh Views

Participants believed that the Hindu and Sikh communities favour organ and tissue donation.

Participants said there was a strong Sikh and Hindu belief encouraging sharing, giving and donating to the community, helping others and saving other's lives.

There is nothing explicit in the Guru Granth Sahib [holy book] about how the body can be changed after death ... The Sikh religion or holy book Guru Granth Sahib does not say anything about donating body parts, but does say about sharing, giving, donating, helping others and saving other's lives.

If you can save someone's life, if someone can live, yes.

If a person dies, if a life can be saved, I'm 100% in favour. The majority of East Indians would feel this way.

It is a noble thing – body parts are useless to the person who has died – to give new life to a person and for their family. You give those people a new lease on life.

This is a humanitarian cause.

The religion would say this is a good humanitarian thing to do. And, it's logical.

Muslim Views

It is less clear what the 'official' position is for the Muslim community. A fatwah or ruling by Muslim scholars in favour of organ donation was identified. But some participants said that this fatwah is a Shi'ite position and that Sunni Imams are still debating this issue.

Muslim participants said that they did not believe that the Quran addresses the issue of organ donation directly. Most participants said the question of donation is a personal choice. One participant expressed the view that it is important *'to go back to God as we came'*. The belief was that the physical body is a gift (*Allah's amanat*) and it cannot be dismembered even after death.

I'm a visitor, a passerby—when my time comes, I will go. I didn't go for open-heart surgery; it was not for me.

We are prepared [for death]. We are here for a specific time.

Some participants had researched organ donation before one of the focus groups. They shared information about the 'official' position of Islam. One commented from her reading, '*we didn't know we could give.*' The official ruling or fatwah includes the ideas of free consent on the part of the donor and the recipient, no upcoming danger to the donor, proven medical benefits and donation as a last resort.

It is Allah who gives life and takes life. God is keeping that person alive, not you. There is no personal pride.

Like other participants, Muslim participants suggested that more open communication about organ donation is needed among family members and within the general community. Many participants knew people in their community who would accept donations, but these same people are not committed to being donors themselves.

4. What kind of support do you think is required to help you make decisions regarding donation?

Participants were asked about who could or should ask the family of someone who had just died about organ and tissue donation. For many participants, it was not a good idea for a physician or community member to approach the family at the time of death. It would be too hard to consider donation after losing a loved one. Others thought that the physician or someone from the community could explore the issue, if it was done sensitively.

It should be the doctor. This is a very sensitive time when everyone is grieving... When someone is dying, the family is in grief. They won't be able to listen...

5. How is it best to build relationships in this area?

Participants talked about family and community discussions on donation and transplantation.

Discussion in the Family

Participants, particularly the youth, said that there were challenges in discussing donation and transplantation within the family—especially between generations.

It's hard for parents to think about their kids dying [Youth]

Youth bring a new perspective. It's appropriate to raise awareness through young people [Youth]

With older people, it's a lot harder. The topic of dying or death is hard. It's so bad to talk about dying since they don't want it to happen [Youth]

The following question was asked in some of the discussions: *Who would be consulted in making a decision?* Hindu, Sikh and Muslim participants said that it would be important for a woman to get permission from her husband and in-laws before donating an organ. One Muslim woman participant expressed complete independence in making the decision to donate.

Discussion in the Community

Various suggestions were made by participants to hold dialogue within the community and to raise the level of awareness on organ donation.

Hindu and Sikh Views

Within the Hindu and Sikh communities, participants were comfortable about raising awareness in the community by bringing in people or experts who could speak about and answer questions on organ and tissue donation. Sharing stories on individuals who have benefited from organ or tissue transplants was encouraged.

The local society should be activated. You should have an open house to discuss this. Use the media to launch this as a crusade.

Participants suggested making information available on the subject of donation and transplantation. By having the information in many places where people gather, people will be more comfortable thinking and talking about it.

Muslim Views

Within the Muslim community, participants wanted to discuss the issue with the Imams and to study the religious position as the next immediate step. At this point, making information available about donation was not necessary. People wanted to be clear on the position of Islam.

This discussion has opened windows. Give us time to research. I'm not ready to give or take.

6. Messages

Participants said that it is useful to hear and share stories from community members who had had an experience with successful organ donation. Participants also believed that it is important to talk about organ donation as something that saves lives.

....Show people how a transplant can be of benefit. Bring in people who are affected...It's more convincing it's emotional. You have the feeling. The first two times you come, don't ask for donations. Link these things with practical stories. People will follow you faster.

Use real life stories, especially stories about children. Use people from the community to share these stories [Youth]

It's important to start with your kids in school and go all the way through college and post-secondary. We have to approach the issue as a civic or moral responsibility.

Use a humanitarian approach. Organ donation is a way of saving lives at no cost to the person.

7. Where and How to Share Messages on Donation

A number of suggestions were made by participants about where and how to share messages on donation.

Hindu and Sikh Views

Hindu and Sikh participants believed that temples were a good place to discuss the topic. In some cases, participants suggested that the issue be included as part of religious services, such as a sermon. Others thought the issue should be raised with administrators. People believed that gatherings and community media were good ways to raise awareness and educate communities.

Hold an open forum, a round table for young people. You could hear from people who have gone through it, where it made a difference.

Link with blood donation drives.

Use the radio—a lot of people listen. Live debates are very effective [Youth].

Use established South Asian radio and television programs.

It would be better for community members to go house to house, using a more personal approach to reach people from the community. It's not a matter of convincing people.

Muslim Views

For Muslim participants, the emphasis was on creating opportunities for discussion within religious and family environments. But, several participants said that the mosque was not a good place to discuss or raise the issue of organ donation and transplantation.

First we have to educate ourselves. We need to have a dialogue with the Imams. We need to have dialogue and discussion.

We are not scholars. We have to go and study. We need sisters like you to come with information and open the dialogue.

Ways to Get the Message Out

Many participants identified physicians, particularly family physicians, as credible and respected sources for encouraging people to participate in organ and tissue donation.

Doctors are so well respected in our community.

Religious leaders were identified as another source to open the discussion. However, some participants believed that the discussion should only be pursued with administrators. Flyers and pamphlets were also identified as a good way to get the message out. Participants suggested that they be in languages other than English, such as Punjabi.

Literature and pamphlets with questions and answers are good. But not everyone is able to read them. It is good to have them in languages besides English.

...Just the flyer is not enough. Something should be there to deal with their beliefs, opinions or immediate questions, such as 'can they still perform all the traditions or activities of purification if they are donors?' Something should be on Punjabi version of the flyer [on this].

What did we learn?

The consultation with South Asian communities in Vancouver and the Lower Mainland was a tremendous experience. It provided CCDT and BCTS representatives with the opportunity to gather rich information on South Asian views toward organ donation and transplantation.

For many participants, this was the first time they talked about these issues in the community or with family. As in many communities, we learned that discussions of death and dying are not easy. But we developed a deeper understanding of how faith and culture influence people's views.

We found that there are many different cultural factors that affect decisions to donate. Views on organ donation are affected by *many* factors and appear to differ for each participant.

We also learned that participants strongly favoured learning more about organ donation through the stories of people in the community who have experienced donation.

On-going and open discussions with the South Asian community shows promise for establishing trusting relationships. We can share and learn about donation and transplantation in ways that are culturally sensitive.

Where can I get more information?

The complete report on the Diverse Communities Consultation and all background reports are available on the Canadian Council for Donation and Transplantation website. Reprints of the report can also be obtained by contacting the CCDT. If you want to know more about organ and tissue donation and transplantation, you can contact these organizations or visit their websites.

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Manitoba Gift of Life

(204) 787-1897 http://www.gov.mb.ca/health/donor.html

Saskatchewan Transplant

Regina 306-766-3477 Saskatoon 306-655-5054 http://www.health.gov.sk.ca/ph br ae organdonor.html

Trillium Gift of Life Network

522 University Avenue, Suite 900 Toronto, ON M5G 1W7 **General Inquiries**: 416-363-4001 (in Toronto) or 1-800-263-2833 http://www.giftoflife.on.ca

Canadian Association of Transplantation

Transplant Programs <u>http://www.transplant.ca/cancon_transprogram.htm</u> Donor Programs <u>http://www.transplant.ca/cancon_donorprog.htm</u>

Canadian Diabetes Association

www.diabetes.ca

Canadian Liver Foundation

www.liver.ca

Heart and Stroke Foundation of Canada

www.heartandstroke.ca

Kidney Foundation of Canada

www.kidney.ca or La Fondation canadienne du rein www.rein.ca

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