



## DIVERSE COMMUNITIES

Consultation to Explore Perspectives on Organ  
and Tissue Donation

### **SECTION III**

Vancouver Consultation with South Asian  
Communities

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# 1. INTRODUCTION

## 1.1 Purpose of the consultation

*Fit with CCDT Diverse Communities Consultation (see Appendix A for draft description)*

This consultation report reflects input gathered 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', community members were asked to share their personal opinions or those of their religious community on organ and tissue donation and transplantation.

The Vancouver and Lower Mainland consultation is part of a national Diverse Communities Consultation of the Canadian Council on Donation and Transplantation (CCDT). A total of four consultations took place during the fall and winter of 2004/2005, including the Chinese community in Toronto, Aboriginal communities in Winnipeg and Saskatoon and this consultation in BC. Each consultation was guided by three objectives:

1. To identify beliefs and views about organ and tissue donation
2. To identify processes for engaging ethnocultural groups on the topic of donation and transplantation
3. To consider partnerships between the ethnocultural groups and the local donation and transplantation program.

The intent was to ask about personal views, values and traditional beliefs that might impact people's decisions related to organ donation and transplantation, recognizing there is diversity within cultures. The goal was not to change people's perceptions but to understand them so that people could be informed in ways that respect and support their backgrounds. Cultural and associated religious perspectives on donation and transplantation were thus approached as a topic to be better understood.

With the understanding gained from these consultations, the CCDT plans to provide advice to the Conference of Deputy Ministers to whom the Council is accountable. The ultimate hope is that every Canadian has the opportunity to consider organ donation and transplantation, and that consideration is handled in culturally sensitive and respectful manner.

Vancouver was selected as the city for holding the South Asian consultation because of the relative size of this population and because the BC Transplant Society (BCTS) had already initiated a specific strategy with these communities. While the original intent was to focus on the city of Vancouver, the consultation expanded to the Lower Mainland to reflect the geographic area where a large number of South Asians live.

### *Link with BC Transplant Society and previous research*

Starting in 2002, the BC Transplant Society began to forge links with both the South Asian and Chinese communities in Vancouver and the Lower Mainland. Working in partnership with the Provincial Language Services, BCTS co-sponsored a series of focus groups to guide the development of print material on organ and tissue donation for non-English speakers. Rather than produce direct translations, the intent was to consult and develop material that would reflect a cultural perspective. A Punjabi organ donor brochure was published in December 2004 as the inaugural piece resulting from the process.

To further develop relationships and pursue culturally appropriate awareness and educational strategies, BCTS has set aside funds to hire its first South Asian community liaison in 2005. The 'Diverse Communities Consultation' was seen as an opportunity to expand the network

and understanding of South Asian perspectives and to support the organization's evolving work with ethnocultural communities.

In addition to the work done by BCTS, Molzahn et al conducted research with South Asian communities in the Vancouver in 2003<sup>1</sup>. One of the researchers and authors, Dr. Rosalie Starzomski, is also a member of the CCDT and the Chair of the Diverse Communities Consultation Steering Committee. As an outcome of their research, interest was expressed in further exploration with women and youth as key influencers within families (*see Appendix E for findings from previous research*).

### **Consultation team**

Ann Goldblatt and Sudha Choldin were the primary consultants coordinating and facilitating the Vancouver consultation. Sunita Chera, from the Lower Mainland, joined the team to assist with facilitation of one focus group and as a recorder and observer.

## **1.2 Methods and Tools for Vancouver consultation**

**Recruitment of planning group** (*See Appendix B for planning meeting agenda and Appendix D for list of planning group participants*).

A local planning group was convened in January 2005. The intent was to begin the consultation process by asking for advice from individuals of South Asian background on how best to approach the communities to explore the sensitive topic of donation and transplantation. We wanted to consult the communities in a respectful way that honoured their history, political sensitivities, traditions and background, and avoided 'taboos' that would impede dialogue.

Through suggested leads, we made contact with 24 individuals within 15 organizations. The planning meeting attracted four individuals from the South Asian communities and one community professional from the Provincial Language Services. CCDT and BCTS provided context and experience related to the project. The community participants brought expertise as volunteers and as professionals.

As an outcome of the discussion and building on previous research, the planning group concluded that the Vancouver and area South Asian consultation would emphasize learning from youth and adult women, through focus group discussions, and from administrative leaders within the faith-based organizations, through one-on-one interviews.

Youth were seen as particularly open to considering organ and tissue donation and women were identified as key influencers of decision-making concerning health matters within families. The discussion on faith-based organizations centred on the impact of religion on views regarding organ and tissue donation, the influence of religious leaders, particularly Imams, and the potential reach into communities through places of worship. Religious leaders themselves were not likely to come to a meeting on the topic. Rather, participants suggested personal interviews with the administrative leaders as a good starting point for building a relationship and soliciting advice on appropriate approaches to the mosques and temples.

BCTS, CCDT and the other participants in the planning group made themselves available for follow-up contact to help identify leads.

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<sup>1</sup> *Selected perspectives on Indo-Canadian beliefs regarding organ donation* by Anita E. Molzahn, Michael McDonald, Chloe O'Loughlin and Rosalie Starzomski, January 21, 2003.

**Process of setting up focus groups and interviews** (see Appendix C for process for organizing planning group, focus groups and interviews and Appendix G for contacts initiated).

Given the short time frame for organizing the focus groups and the importance of building on existing relationships, we sought to identify groups of women and youth who already come together and who would be willing to focus on this topic. In particular, we followed leads to identify community-based individuals who would be willing to bring the focus groups together.

The nature of the consultation was to hear directly from community members. It was not structured as a formal research study from which statistical results could be generalized. The participants were not speaking as representatives of their entire community. Rather, the report reflects the voices of the consultation participants.

### Voices represented

The consultation involved ten data-gathering opportunities, including one planning session, three focus groups, one exploratory meeting and four interviews:

Data-gathering opportunities		
Format	Participants	Demographics
1. Planning session	4 South Asians; 3 from service agencies, 1 from religious association	4 males
2. Focus group	9 Sikh youth	5 males 4 females est. 16-30 years
Focus group	8 Muslim adult women	8 females, est. 50-64 years
Focus group	18 Hindu, Sikh and Muslim community leaders	3 males, Muslim 2 females, Sikh 8 males, Sikh 1 female, Hindu 4 males, Hindu est. 30-70 years
3. Interview	5 Hindu temple leaders	4 males 1 female est. 50-70 years
Interview	1 Sikh temple leaders	1 male
Interview	4 Sikh temple leaders	4 males
Interview	2 Sikh temple leaders	1 male 1 female
4. Exploratory meeting	4 Sikh temple volunteers	4 females
5. Informal dialogue	4 Hindu temple members	4 males
<b>Total</b>	<b>59 participants</b>	<b>38 males 21 females</b>

### Discussion notes

- The South Asian consultation in Vancouver was the last in the series of three planned consultations across the country. The intent was to build on experience through the length of the project, but that meant the planning process for this 'last' consultation was compressed into a two-month time frame, from mid-December to mid-February.
- Working as consultants from outside BC, we did not have a foundation of working relationships with leaders within the South Asian communities. Organ and tissue donation is a sensitive topic for many and was not named as a priority within the organizations we

reached. Service agencies were coping with severe funding cutbacks at the time this consultation was being launched and many had commitments to participating in the annual multicultural health fair that coincided with the timing of our consultation.

As a result of these circumstances, we connected with individuals who were able to dedicate time to organizing a focus group or interview, contributing volunteer time beyond their professional roles. Without the assistance and trusted relationships of these identified leaders, we would not have been able to make the personal contacts required, particularly within the given time frame.

- Reaching administrative leaders within the temples meant connecting with volunteers. They were generally not at their places of worship to receive calls and we hoped for someone at the temple who could offer a home telephone number for the leader. Being able to communicate in people's first language helped overcome a barrier to making this connection.

With the Muslim community, we attempted to make direct contact with an Imam who had been alerted to the purpose of our contact, but we were not successful. We did, however, learn from members of the Muslim community who consulted with their Imams.

- The communities are not homogenous and therefore, the results cannot be generalized to 'all South Asians'. For those seeking to understand South Asian perspectives, it would be helpful to develop an awareness of common cultural and religious perspectives, but individual perspectives remain a significant determining factor (see more under 2.3 and 2.5).
- The intent was to use the previous research findings (highlight in Appendix E) to lead off the questions in the various areas of interest (i.e. 'Our understanding from previous research is ... How does this fit with your opinion?'). To fully engage the participants, we chose to ask the questions without stating the previous findings, and rather use the research to help understand the input provided.

### 1.3 Profile of South Asian communities in BC

Rather than conceiving of a singular South Asian community, it is important to be aware that there are multiple South Asian communities, with people originating from six different countries within the Indian sub-continent and crossing several religions. There are commonalities but the differences are also important to understand.

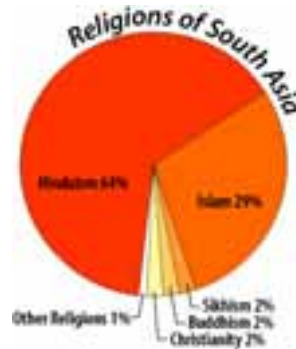
- The geographic area that is known as "South Asia" refers to the Indian sub-continent. The countries included are India, Pakistan, Nepal, Bangladesh, Bhutan and Sri Lanka. People of South Asian background dispersed to and immigrated from other parts of the world, including Africa, Asia, the Middle East and the Caribbean.
- The majority of people in India are Hindus, however, there are significant numbers from the other religions. The proportions in India are as follows: Hindus (80%), Muslims (14%), Christians (2.4%), Sikhs (2%), Buddhists (0.7%), Jains (0.5%) and Other (0.4%). In Pakistan, 98% of the population is Muslim.<sup>2</sup>

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<sup>2</sup> Santa Clara University, 2000. *South Asia*. Retrieved from [http://www.scu.edu/academic/programs/asianstudies/BAR/South\\_Asia/south\\_asia.html](http://www.scu.edu/academic/programs/asianstudies/BAR/South_Asia/south_asia.html).



- A somewhat different distribution of religions emerges when we look at the population of South Asia as a whole<sup>3</sup>:



- Sikhism, Islam and Hinduism are the three major religions of the South Asian population in Vancouver and the Lower Mainland. Other religions with smaller proportions are the Baha'i faith, Zoroastrianism, Jainism, Christianity and Buddhism.
- Size of BC's South Asian population overall and by religion:

South Asian population in British Columbia (Statistics Canada 2001) <sup>4</sup>		
	British Columbia	Vancouver (metropolitan area)
<u>Population by Visible Minority</u>		
South Asian	210,296	164,365
<u>Population by Religion</u>		
Sikh (primarily from Punjab, India)	135,310	99,000
Muslim (from all over the world)	56,220	52,590
Hindu (primarily from India)	31,500	27,410

- The largest proportion of immigration from the Indian sub-continent occurred in the 1970s. New immigration is largely among family-sponsored spouses and grandparents, and among those coming as independents under the "points" system.

<sup>3</sup> *Global Perspectives: A remote Sensing and World Issues Site. Wheeling Jesuit University/Center for Educational Technologies. 1999-2002. Retrieved from <http://www.cet.edu/earthinfo/sasia/SApeo.html>.*

<sup>4</sup> Retrieved from <http://www.statcan.ca/start.html>

### ***Religious belief systems for Islam, Hinduism and Sikhism***

Within the apparently homogenous term, “South Asian”, there are significant differences by faith, differences that translate into different worldviews about life after death and the body. The following brief explanations reflect the foundation for our understanding of the perspectives offered by the community participants.

Islam’s holy book, the Qu’ran, contains the guidelines established by *Allah* for people to follow while on earth; it is the ‘true way’ revealed by the creator. The scope of these guidelines is vast and extends beyond the western concept of religion; they address politics, law, economics, ethics and matters of personal conduct. Muslims view their present existence as preparation for their ongoing existence in the next realm.

The Muslim tradition of burial differs from other faith groups from the Indian subcontinent. Rituals related to death reflect this belief. Preparation for burial involves washing the body, often done by a member of the family, wrapping it in a clean, white cloth and, on the same day if possible, burying the body with a simple prayer. Muslims believe that, on the Day of Judgment, all will be physically resurrected and therefore cremation is forbidden.<sup>5 6</sup>

The Hindu tradition views personal or individual life as a series of lives lived through the transmigrations of the soul. A particular life is understood in the context of the transmigration of the soul and death is seen as a precursor to rebirth. Once the lessons of this life have been learned, the soul leaves the physical body. The body, an empty shell, is returned to the elements of the earth.<sup>7</sup>

Two important books guide the Sikh religion, which was a reform movement that grew out of Hinduism: The Dasam Granth and the Adi Granth (Guru Granth Sahib). The Guru Granth Sahib is the most highly regarded sacred text of Sikhism. It is considered to be the symbolic representation of its ten gurus as it preserves the wisdom of the gurus. Sikhism is monotheistic; it holds that God, or Sat Nam, is without form or substance. However, His grace can be experienced through faith and right living.

Sikhism stresses righteous life can be achieved by being a contributing member of society. It emphasizes the importance of good actions and of leading a virtuous life by practicing various virtues, among them charity as expressed through selfless service. Sikhism, like Hinduism, practices cremation, and holds similar beliefs regarding the afterlife and the body.<sup>8</sup>

These religious views of the afterlife and the body have an impact on the decision of Muslims, Hindus and Sikhs regarding organ and tissue donation.

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<sup>5</sup> *Islamic Server of MSA-USA*. Retrieved from <http://www.usc.edu/dept/MSA/>.

<sup>6</sup> *Understanding Islam and the Muslims*. Retrieved from <http://www.usc.edu/dept/MSA/introduction/understandingislam.html#Q23>

<sup>7</sup> Hajime Nakamura, *The Notion of time in India*. Retrieved from <http://www.postcolonialweb.org/india/philosophy/phil2.html>.

<sup>8</sup> *Sikhism: Its history and customs*. Retrieved from <http://members.aol.com/porchfour/beliefs/sikhism.htm>.



## 2. RESULTS

The focus groups and interviews were launched with introductory remarks to explain the purpose of the consultation and to provide a brief explanation of the terminology associated with organ and tissue donation and transplantation (see *Appendix F for introductory remarks*).

### 2.1 Participants' awareness of and experience with organ and tissue donation

In each community, there were stories about family members or friends who had received and benefited from an organ donation, usually kidney and sometimes heart transplants. Most of the stories were of living donations. The stories conveyed primarily positive impressions about the value of the donation to the recipient and the donor, or donor's family, along with some reticence about the costs and benefits.

*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. First my mom tried to donate but she was too old. Then they tested my sister who was the best match. I was the second best match, so my sister donated. The challenge is not in giving the kidney. The treatment [after] is more important than the kidney. You can go buy a kidney. People offered to buy the kidney. There is a huge market buying and selling organs ... She had to ask her husband and in-laws since this is a family decision. Her in-laws were supportive of her decision but it is still more important for women to have the permission of her family members than it would be for males. They would be concerned about her ability to contribute to the household after the donation. She has to work and do housework.*

*My first cousin needed both kidneys. He was on dialysis and they were looking for a donor. In our community, the family unit and extended family are very important. All my brothers and sisters and cousins went for extensive tests but none of them matched. One friend said, 'let me try'. 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. Otherwise he was very ill – only 38 years old with two little children. It was an eye opener for our family. The doctors dealt with our family well.*

*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.*

*My friend was in need of a liver. He had been waiting for six months. The wait list was a year to a year and a half, at least. He is thinking of going to a third world country to get an organ. We should donate. In the Muslim community, we are told that we shouldn't donate our organs. But we do believe we should donate. I think it is a good idea if you can do something for these people.*

*I know of a daughter who gave her kidney to her father. His body rejected it. It is in God's hands; we cannot guarantee the transplant [theme of God's will explored further in 2.2 and 2.3].*

*One example is a mother and sister who refused to give her kidney. Because of ignorance, they thought donating a kidney would hinder her life.*

*My dad didn't want any family members to donate since he was diabetic and in his 70s. He's already had so many problems that he didn't feel it was worth it for one of us to donate a kidney since he had lived a full life.*

*There are two incidents that made me comfortable to donate. My sister-in-law died in India. The doctors took her cornea since it was her wish that it be donated. A saint visiting Canada recited the Ramayan [Hindu epic]. When he died, his body was taken to UBC and his organs donated.*

In several discussions, people talked about a story they had heard about the parents whose child died and whose eyes were donated to another child. In that person's eyes, they were able to see their son.

The stories immediately opened discussion on participants' beliefs and values, and the religious positions. These responses are included under sections 2.2 and 2.3 below.

For many of the participants, this was a first opportunity to take part in a forum where organ and tissue donation was the focus. The responses from "youth" are noted after the quotations to provide some context for the perspectives being expressed, although responses vary within each generation.

*You don't realize how important this is until it hits home. It's more acceptable to think about the blood bank because blood is regenerated [Youth].*

*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]*

*I don't want to think about dying [Youth]*

*We [our family] don't talk about it. I have no idea what they think [Youth].*

*I never thought about it.*

*We never sit down and talk about this.*

*It's like a will. We don't do it because we don't think we're going to die.*

A number of people remarked on the level of need and on awareness of the need for organs.

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

*Drinking is a huge part of our culture. We're more likely to receive liver transplants [Youth].*

*We have nothing against it in Hinduism. 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 ...*

*I've seen a doctor on TV asking for a kidney when it was needed. I thought it could only happen in movies. As a community, we need to know.*

*The majority is not aware. There are language barriers.*

## **2.2 Participants' views toward organ and tissue donation**

On a personal level, particularly among youth, people expressed widely varying degrees of comfort with the topic of organ and tissue donation and the notion of discussing the subject with their families.

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

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

*Our generation is more matter of fact about death. With parents, it's not up for discussion [Youth].*

*I'd be freaked out if my parents wanted to talk about it [Youth].*

*This is a very important cultural issue. In our community, you have to get parents' consent to do anything. If they are ok with it, then we can go through with it [Youth].*

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

*For us, there was a problem with extended family. They were not rosy and positive. They were downright negative. Not everyone is comfortable. My dad decided he wanted to be a*

donor 20 years ago but he changed his mind. He decided he didn't feel heroic anymore.  
[Youth]

I think they would be ok with it. They don't have a problem with my sister who decided she wants to be an organ donor. We [our family] don't talk about it. I have no idea what they think. I think my mother would be uncertain and my father would say 'yes' [Youth].

We haven't thought about this topic. It's hard to say what we would do [Youth].

It is too hard a thing for me to imagine, to think about. My heart goes out to people who donate. I don't know. It's very personal. It depends on the situation.

It will take some time to think about.

### **The points in favour of saying 'yes' to donation or transplantation included:**

#### **The body is not useful to the person who is deceased [see more under 2.3 on traditional values and beliefs]**

If I'm dead, it is no good to me. I would donate any part of me. The whole thing [body] is burned within a couple of minutes [during the cremation]. They might as well salvage what they can [Youth].

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

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

It is a good thing to do donation. Our bodies become miti<sup>9</sup>. 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. In India, there is lots of fear [about doctors taking organs out without asking].

#### **Maintaining one's own quality of life (by accepting a donation)**

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]

In responding to a participant's statement, Maybe not if it was just prolonging my life for a year or so and I was going to die anyway, another person said:

But what if they find a cure? I want to live just in case [Youth]

No problem, but for a person who is 60 or 70 ... 20 or 21, yes. That person has still got a life, lots to live for [Youth].

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].

#### **Making a difference to someone else's quality of life (by donating)**

If I have one eye, one eye is good. The donor eye should go to a blind person since I still have one. But you wouldn't be able to see as well with just one eye and wouldn't be able to function in the same way. But the donation would truly be necessary [Youth]

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

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<sup>9</sup> Direct translation of "miti" is soil, earth or dirt. Connotation in relationship to the dead body would be that the body, in and of itself, without the soul, is no longer the person.

*Many people willingly donate blood. When a patient needs blood, his/her relation donates blood. It is stored in a blood bank if it does not fall in the blood group of the patient.*

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

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

#### **Beliefs about the body after a person has died [see more under 2.3 on traditional values and beliefs below]**

*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.*

#### **Uncomfortable with the idea of what is being done to the body**

*I'm skeptical. I reserve my decision. As a nurse, I've seen an autopsy and it is like a butcher shop. They use an electric saw to cut out the heart. Everybody should go and see an autopsy being done.*

*Some would not like the idea. They don't want to think about it. The psyche has to be changed. I'm all for it.*

*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.*

#### **Concerns about hastening death**

*People also believe that if someone donates their body parts, they die earlier. One, that they already have made arrangements for their death, which will be like meeting their goals, and second, someone who is in need of transplantation will be praying for donors' death, and God might hear their request.*

#### **Concerns about the health of the living donor**

*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 [Youth]*

*I would need to know the stats. I would need to know the numbers to know that my safety is assured. I need to know the risks in donating [Youth].*

*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.*

*Because of the Red Cross fiasco, I haven't donated blood for 10 years. They never admitted they made a mistake. Even though that has to do with receiving tainted blood, not donating, you still can't trust them.*

#### **Not intervening in God's plan**

*It is Allah who gives life and takes life.*

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

*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.*

*I took my mom [senior] to the emergency and they said her blood was low. I asked her if it was ok and she said 'yes'. I didn't even think about it – if it'll make me better, then yes. If it was an organ, then I don't know. If I'm sick, I would try to live my journey.*

### Not intervening in natural progression of aging

*If you're 60 or 70 years old, then enough is enough. If things are going wrong, you should just accept it [Youth]*

*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.*

*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.*

### Maintaining quality of life

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

*Here in the West, they make you suffer until you are dead. They keep you alive at all costs. If you can't breathe, they keep you on drugs and a ventilator to keep you alive.*

*In this society, people have a problem accepting mortality and therefore go to extremes to save a life. I feel sad when people younger are dying. I don't know if I'll accept an organ.*

*I saw a young girl in her 30s with cancer. Her family and doctors did ridiculous things to keep her alive, instead of being part of her journey with her.*

*I see people go on the respirator – I see people survive, but why? The brain is dead.*

### Concerns about health professionals' motives for wanting organs and tissues

Individuals shared stories they had heard and concerns they had about dishonest or dishonourable practices.

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

*Some would say ... 'You want me to die? Why should you pose such questions to me?'*

*People steal parts in India.*

*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 a match, and it is you, they can harm you so that donation is available. People might believe in it or trust it based on their experience in their home country. Education about privacy or protection of the information in Canada is also needed.*

*Some people are so poor [in India] that they give their organs to feed their families, but their lives go down. They don't have enough food for recovery.*

*There are stories in Europe of when you go to a party ... someone spikes your drink and then, the next thing you know, you wake up and you're on ice. Someone has stolen your organs. Lots of refugees in England consent to it for citizenship, to get fake passports and IDs. It would be important to know the source of the donation.*

**The points on choosing to donate the organs or tissues of a family member who has passed away centred on whether that person had expressed consent:**

*I would want to ask my parents [Youth]*

*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 [Youth]*

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

*I think my parents and grandparents would say 'yes'. I don't think they have thought about it. But I could say 'yes' because I think they would have said 'yes'. If it's my sister or brother, it's their decision. Really, we've never talked about it [Youth].*

*My parents don't like that I signed the donor card. When it comes to do the donation, they will make it hard.*

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

*There are differences by age. Young people think like people here. They were raised here. We are different from our parents.*

In the case of a child needing an organ ...

*If it was my own child, I'd say 'yes' [youth]*

*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.*

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.

### **2.3 Participants' views on traditional values and beliefs that influence people of South Asian backgrounds with regard to organ donation and transplantation**

There were two sets of religious beliefs discussed, one reflecting a clear religious position from the Hindu and Sikh communities that favours organ and tissue donation and one identifying a less clear official position from the Muslim community. The religious beliefs provide a lens for looking at the personal views expressed in 2.1.

Though the research to date identifies a 'fatwah'<sup>10</sup> in favour of organ donation for Islam, that is, a ruling representing the consensus opinion of Muslim scholars, some participants commented that the Imams they consulted prior to the focus group were not in favour of organ donation. Others explained that this fatwah is a Shi'ite position. One participant explained that the Sunni Muslim scholars are continuing to debate the question and have not yet reached a consensus.

Though Sikhism is a religion that grew out of Hinduism 500 years ago, they are two separate religions. Their perspectives are clustered together in this report because of the common beliefs regarding issues of the body, the soul, death and the afterlife.

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<sup>10</sup> The 'fatwah' on organ donation is explained in <http://www.islamicvoice.com/august.98/figh.htm#ORG> and [http://www.redhotcurry.com/pdfs/organ\\_donation\\_islam.pdf#search=fatwa%2C%20organ%20donation%2C%20Islam](http://www.redhotcurry.com/pdfs/organ_donation_islam.pdf#search=fatwa%2C%20organ%20donation%2C%20Islam). Position endorsed by the Shariah Academy of the Organization of Islamic Conference.

## Hindu and Sikh perspectives

### Beliefs about death

*The body is miti<sup>11</sup> – it is no longer of use.*

*The soul enters another body. There is transmigration of the soul. The body becomes useless. We go from ashes to ashes, dust to dust.*

*The soul is one. It's like a change in your clothes. We are temporary but the soul is forever. Nothing is yours. We come naked and we leave naked. We come into and go from the world empty-handed.*

*If life is gone, I don't think anyone would refuse.*

*In Sikhism, the body is a rental car for the soul. Disposing the body is not a major concern.*

*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.*

*It is old thinking that if you cut the body up, it changes the body. The dead body is nothing. People need more information.*

*If Sikh families were aware of organ and tissue donation, they would be fine with it.*

*We do not lock our minds. We have changed as the world changes around us. Things were done that were good at the time they were written.*

### Beliefs about giving to the community

*There are three principles of Sikhism: to share your earnings with needy people, to live honestly and meditation. This is a good cause, to save someone's life.*

*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.*

*The priest prepares us in his sermons, through the scriptures, but indirectly.*

*If it is in order to help someone, you give as much as you can. This is consistent with our religious beliefs [Youth].*

*If someone needs an organ, giving is part of the religion [Youth].*

*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.*

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<sup>11</sup> Direct translation of "miti" is soil, earth or dirt. Connotation in relationship to the dead body would be that the body, in and of itself, without the soul, is no longer the person.



## Muslim perspectives

For the Muslim participants, the Qu'ran is an essential guide for living. *Anything our prophets say, we do. It's not our job to say 'yes' or 'no'.* Because the Qu'ran does not address organ donation directly, it is left to the scholars to decide. The participants placed a heavy weight on the views of their religious leaders but several indicated the choice would ultimately remain their own:

### Beliefs about death

*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.*

*The dead body can hear what is happening around him in the house. That's why you don't cry too much or it will give the dead pain. By crying too much, you are mutilating the body.*

*When this journey is over, another journey begins.*

*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.*

### Beliefs about donating organs and tissues

*The head Iman says our body is Allah's amanat<sup>12</sup> (entrusted to us) – we shouldn't give it or take it.*

*On the last day of Judgment when we die, we will meet our Lord – we are happy to go. I will not take any organs.*

*Muslims believe what is in the Qu'ran. If it is proved in the Qu'ran that we should not donate, I will not. If I say I will not donate, then I also will not receive an organ.*

*With a dying person, the person has to be brain dead before you take the organ. You must have prior consent. In Islam, you are not allowed to do post-mortem. Breaking the bone of the deceased is the same as breaking the bone of a person who is alive.*

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

*I pray that I don't need an organ ...Don't think that I'm conservative. For organs, I don't know. I'm not yet ready.*

*Blood, we have and give it – there is no objection. We need to encourage more blood donation. We need to work on that.*

*I think we should be more open with our families. I'm very comfortable to talk to my dad and my wife.*

Some participants had researched the issue prior to one of the focus groups and shared information about the “official” position of Islam. One commented from her reading, *we didn't know we could give.* The official position includes the notions of free consent on the part of the donor and the recipient, no imminent danger to the donor, proven medical benefits and donation as the last resort.<sup>13</sup>

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<sup>12</sup> A precious valued gift to be cherished.

<sup>13</sup> Fatwah includes the following elements:

There is no imminent danger to the donor

There is complete brain death

Should have consent of person who died or of the family. Free consent, indicated through donor card or will. Alternatively, the family is in a position to make decision

Patient is informed

Living donor is in full possession of his/her faculties

Person is old enough to sign

Proven successful in the past so organ is not wasted

This is the only form of treatment possible



*It is permissible with Shariah law.*

*Necessity makes the unlawful permissible. For example, if you're hungry, and there is no other food to eat but food from a pig, you can eat. But one can never consume the blood and flesh of a human being.*

Many participants were grappling with the notion that people they know in their community accept donations but people are not committed to being donors themselves:

*If we take from people, how come we don't give? If we don't take and don't give, that's different.*

*We take organs to prolong life. We have to give. This is lacking and we need to explore this in our community. We need to find out more. We need to ask our Imam.*

### **Religious ceremonies, rituals and practices surrounding death**

There were shared views from Hindu, Sikh and Muslim participants on the need to allow the family the opportunity to carry out prayers and to show respect for the dead body.

#### **Hindu and Sikh perspectives**

*We don't expect hospitals to do the ceremonies. It's left to the family or priest.*

*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.*

#### **Muslim perspectives**

*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.*

*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 burial of the dead is very fast, very spiritual...for peace and rest for the dead and the living. The body takes its own time to decompose. People must be sensitive to this and have patience.*

*Females are buried faster than males.*

*After death, we avoid postmortem unless a crime has been committed.*

*We discourage bodies being put in the morgue. Instead, we keep a special provision in the mosque. There is no morgue. There are buried as soon as possible.*

*God's angels take the soul, so we bury as quickly as possible. As soon as the congregation moves away from the burial site, the angels come to take the soul.*

While there were no direct comments from the Muslim participants about who would assume responsibility for ceremonies, it was our understanding that the community, not the hospital, would handle this domain.

## 2.4 Support for donation decision-making process

Participants were asked to comment on who could or should approach the family to ask if they would consider organ and tissue donation for someone who has just died. For many, the idea of a doctor or community member approaching at the time of the death was inappropriate because it would be too hard to consider the possibility when they were overcome with grief. Others thought a sensitive approach could be made by the doctor or someone from the community.

In one discussion, participants emphasized the importance of the medical system being culturally responsive to families' needs in relation to illness and death before layering on a question about donation.

### Hindu and Sikh perspectives

*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.*

### Muslim perspectives

Given the nature of the discussion within the Muslim focus group, this area was not explored directly. However, in the mixed focus group with Muslim, Hindu and Sikh community leaders, there was consensus that the family should not be approached at the time of a loved one's passing.

## 2.5 Relationship-building

The groups 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.

### Dialogue within the family

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

*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].*

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

*I think we could talk about it ... most likely. They would talk about anything [Youth]*

*I don't think it would come up. There would need to be a reason, maybe something on the news. Otherwise, it wouldn't happen [Youth] – [repeat from above]*

*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]*

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

*My daughter would say about this topic, 'mom, just shut up'. My daughter would be very scared to talk about it*

*It is not a good idea to suggest donation to another family member. It is a personal decision and we cannot make people feel bad for their decision.*

*After death, people don't know [their wishes]. The best way is to tell family members.*

### **Who would be consulted in making a decision?**

This question was posed in some of the discussions.

### **Hindu and Sikh perspectives**

*My sister donated her kidney to my brother. She had to ask her husband and in-laws since this is a family decision. Her in-laws were supportive of her decision but still, it is more important for women to have permission of her family members than it would be for males. The In-laws would be concerned about her ability to contribute to the household if she is recovering from the donation or if she doesn't recover. [If I wanted to donate my kidney, as a male], I would tell my wife and that would be it – I wouldn't have to ask my in-laws for permission if I could make the donation.*

### **Muslim perspectives**

*I always go to my husband. He has the final word. He knows the Shariah law.*

*For me, my husband first, then my family, advice from the Imam and then my husband would make the decision.*

*I would think about it myself. I'm very independent. That's the way I will be on this too.*

### **Dialogue within the community - Strategies**

Within the Hindu and Sikh communities, participants were comfortable moving to the stage of raising awareness by bringing in resource people from BCTS and physicians, stories directly from or about people who have benefited from an organ or tissue transplant, and medical experts who could speak and answer questions about organ and tissue donation.

*The local society should be activated. You should have an open house to discuss this.*

*Use the media to launch this as a crusade.*

People advocated the idea of 'normalizing' the topic within the community by making information available in many venues as well as offering educational presentations. By making the information available in a variety of places where people gather, they suggested organ donation would gain the same level of visibility as solicitations for blood donation.

Within the Muslim community, there was a desire to pursue this discussion with the Imams and to study the religious position as the next step. They would invite others with knowledge in this particular area and those who could share stories. The emphasis was more on opening up

dialogue with religious leaders, creating opportunities for small group discussion, than on dissemination of material at this stage.

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

### **Messages**

In every interview and focus group, people talked about the value of hearing stories about community members who have experienced and hopefully benefited from a donation, preferably from the people who have been directly affected.

*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.*

*It is important to connect this issue with religion. That they would be contributing to the whole community, not just the South Asian community. Sewa extends to the whole community. Every human being needs something.*

*Before you start, tell people 15% are diabetic. Show people how a transplant can be of benefit. Bring in people who are affected. That will be faster than asking directly. 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.*

*It's important to show the stats. Like a lottery ticket, what are the odds of the donation causing harm to the donor? [Youth]*

*You would have to inform the community quite a bit. There would be lots of resistance. Even if most people were supportive, you would have to work hard to just comfort that one person who objects. You would have to inform them, answering their questions, like, 'do they kill you off faster if you're a potential donor?' [Youth]*

*You should not mention about organ donation in India. That is not a good idea.*

### **Formats and venues**

There were differing views on the suitability of using particular settings for addressing organ and tissue donation and transplantation.

### **Hindu and Sikh perspectives**

Among the Hindu and Sikh participants, many felt that the temples were a suitable venue for discussing this topic. In some cases, people suggested this should be part of the religious service and others saw this as a topic for discussion better suited to a separate educational program. Some expressed the view that priests could be asked to incorporate support for the topic into their sermons, directly through stories or indirectly through the teachings. Others thought this would be inappropriate and the discussion should only be pursued with temple administrators.

*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.*

*It would not be appropriate for the giannis (priests) to speak themselves on the issue – they should only speak on religious matters. But you could come to the temple and speak to the congregation.*

*Within the temples, it's important to know there is a hierarchy.*

There was some difference of opinion about using celebrations as an appropriate time for raising this issue.

*As it is very sensitive issue, talking about donating body parts, which is about saving life, sometimes includes death or someone at their last moments or sick and in need of an organ. Display of this information during the Vaisakhi Parade is not a good idea, in my opinion, based on what people around me said last year. It does not go with it as Vaisakhi is day to celebrate happiness (with a long history behind it). There is a taboo. You're not to talk about sad things, death or sickness when it is time to celebrate and enjoy and share the happiness. There are many anniversaries for sad timings.*

*This is a touchy topic to bring up at celebrations.*

One person indicated that it would be important to reach out to both fundamentalist and moderate Sikh societies.

Across a number of the interviews and focus groups, suggestions surfaced to use naturally occurring gatherings and the community media to raise awareness and educate the 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 (camp)*

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

*Use established South Asian radio and television programs*

*Media suggestions:*

*Radio Punjab <http://www.rpimedia.com/>*

*Radio Rim Jhim – in Hindi and Punjabi <http://www.rimjhim.com/>*

*Channel M <http://www.channelm.ca/>*

*The Link newspaper (weekly) <http://www.thelinkpaper.ca/about.htm>*

*Indo-Canadian Times (Punjabi weekly) <http://www.indo-canadiantimes.com/contactus.htm>*

*The main media is very expensive. We should start small with what we can do. Public service announcements were suggested as another option.*

*Use videos. People discussed the options of having videos dubbed or sub-titled, but also suggested that it is ideal to have community members featured.*

*Some discussion centred on the risk of shutting down dialogue with the negative opinions that could surface during interactive programs, prior to raising awareness and understanding in the community. One suggestion was to bring the media hosts together for an educational session (over a sponsored dinner) to increase their understanding of the issues. Some recommended using the media to communicate messages to the public rather than encouraging open line debates.*

Beyond the temples, celebrations and the community media, participants suggested more personalized approaches to opening up dialogue.

*Go to the grass-roots organizations, for example, seniors' and community centres.*

*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.*

*In doctors' offices, the doctor can explain about organ donation in the patient's own language.*

*Schools were identified by a number of people as a place to introduce the concept but there were concerns about parental consent prior to age 18. Student associations at the post-secondary level were considered an appropriate entry point.*

There were a number of suggestions about venues where brochures could be placed, including workplaces and doctors' offices, to help normalize and make the topic visible and discussable within families. The literature would help give people the language to have a dialogue. One person cautioned:

*If you put out 100 pamphlets, 50 will take them and five will read it. But if you speak to people, that's better. You need a bilingual bridge.*

To dispel myths and increase awareness, some suggested including information about organ and tissue donation in the information kit distributed by S.U.C.C.E.S.S. to newly arriving immigrants.

## **Muslim perspectives**

For the Muslim community participants, the emphasis was on creating opportunities for dialogue within a religious context.

*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.*

*Small groups are better. In large groups, some people are very shy. It's not the time to share ideas.*

*It would be good to have women and youth together. It should be a family dialogue.*

*We are thinking about having a symposium with our religious leaders and people who can talk about organ donation.*

*It is a worthy discussion. It should be advertised more – bring more people to the discussion.*

Several people commented that the mosque was not an appropriate place to bring this discussion.

## **Conduits of the message**

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.*

Some thought Hindu and Sikh priests could be asked to incorporate support for the topic into their sermons, directly or indirectly through the teachings. Others thought this would be inappropriate and the discussion should only be pursued with temple administrators.

*My mother would listen to a Gianni (priest) talking about organ donation rather than me. There are lots of functions at the temples but temples are politically contentious. The pardhan (temple leader) is not always trusted [Youth].*

*A press release from the religious leaders from the head temple of Sikhism in Punjab, India, will help.*

## Tools

*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.*

*Survey immigrants and people here for over ten years for their thoughts and questions. Use that information in question and answer flyers. 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].*

## 2.5 Closing

By virtue of being involved in the focus groups and interviews, a number of people expressed how pleased they were that this discussion was taking place and their personal intent to raise this with their respective family members and in their community.

*You were very sensitive in the way you asked the questions.*

*I'm glad this subject came up.*

*This discussion opens a window. We need time to research it.*

*I realize I need to discuss this with my family.*

*We need to dig deep and look into it*

*Thank you very much for the wonderful opportunity...Your group was pleasant and knowledgeable. The information was very valuable to me. Our group enjoyed it very much.*

At each of the focus groups and interviews with administrative leaders, people indicated they would like to have people representing BCTS return to be part of further dialogue with the community. Several requested presentations and/or organ donor registry forms and some specifically indicated an interest in becoming volunteers.

## 3. ANALYSIS

### 3.1 Reflections on the results

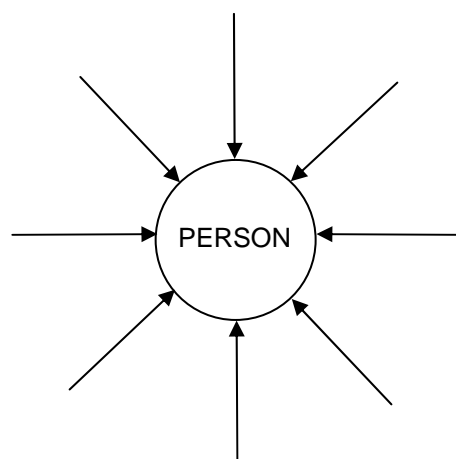
A number of key insights emerged from the findings:

#### *Contributing factors*

The dialogue among the participants raised many challenging angles, revealing that the decision to donate is influenced by multiple factors. While the decision is filtered through the lens of an individual's religion and culture, there is still a wide variation in individual viewpoints. The following diagram illustrates the notion and the table fleshes out the contributing factors.



## 8 Contributing Factors Coming In



### Factors Contributing to the Decision to Donate

*Faith and culture influence each of the following eight factors to varying degrees, depending upon the strength of the bond between the individual and his/her faith.*

Contributing Factor	Elements of Each Factor
Awareness	Need for organs and tissues, benefits from transplantation, the medical facts about who can be considered a potential donor, facts about the process within a hospital and facts about brain death.
Beliefs about illness, aging and death	What happens to the body after death, afterlife, rebirth, resurrection, intervening in God's plan, treatment, and emphasis on quality of life.
Willingness to discuss death	Comfort, fears, denial, too upsetting to consider death of loved ones, superstitions that discussion will hasten death.
Personal experience and exposure	Stories of success, medical knowledge, professional experience, mistrust based on stories of organs being stolen/taken without consent, sold, especially among poor people in India.
Ideas about giving	Giving to the family, giving to the community, perception of benefit, relationship to the person needing an organ.
Situation	In the moment decision, sensitivity of approach to ask family to consider donation.
Prior consent of the donor	Consent of the donor, honouring their wishes.
Family position on the question	Degree of openness to dialogue, generational perspectives, gender positions, in favour, doubtful or against.

#### ***Awareness in relation to donation***

Awareness was raised as a primary factor as to why people are not donating, particularly among the Hindu and Sikh communities. Awareness could be 'unpacked' to mean awareness of the need for organs and tissues, the benefits that come from transplantation, the medical facts about who can be considered a potential donor (e.g. must die in a hospital and kept on a ventilator), facts about the process within a hospital and facts about brain death.



Among the participants, there were several permutations of awareness and people's position on being donors or receiving donations. A number of factors were coming into play:

	Factors
Not aware and not donating	<ul style="list-style-type: none"> <li>Issue is not visible or discussed within the community.</li> </ul>
Aware and not donating	<ul style="list-style-type: none"> <li>Discomfort with death (i.e. superstitions that talking about death will be a bad omen)</li> <li>Negative associations with the buying and selling of organs in India</li> <li>Living donation – concern about donor's health after donating an organ or part of an organ</li> <li>Prolonging life without quality of life</li> <li>Do not believe in intervening in God's plan</li> <li>Do not believe in intervening in natural progression of aging</li> <li>Discomfort with the idea of how the body may be treated</li> <li>Too overwhelmed by grief to consider the question</li> <li>Believe religion would oppose organ and tissue donation</li> <li>Beliefs about resurrection of the whole body</li> <li>Family members are against organ and tissue donation</li> <li>Person did not express consent while living</li> </ul>
Aware and considering donating	<ul style="list-style-type: none"> <li>Uncertain about religious position</li> <li>Depends on position of religious leader</li> <li>Depends on position of husband and/or parents and/or in-laws</li> <li>Personal beliefs and religious position may not be the same</li> <li>Uncomfortable with being a willing recipient and not a willing donor</li> <li>Living donation - depends on relationship with potential recipient</li> <li>Living donation - depends on assurance that donor's health will not be jeopardized</li> <li>Depends on whether conditions are met (e.g. Fatwah conditions)</li> <li>Depends on whether traditional practices can be honoured (e.g. timeframe before cremation or burial must take place; respect for the dead body)</li> </ul>
Aware and donating	<ul style="list-style-type: none"> <li>Beliefs about the soul and the body after death create comfort with the idea of organ and tissue donation</li> <li>Beliefs about giving to the community with organ and tissue donation being one expression of this duty; serving the community is paramount</li> <li>Religious leaders are outwardly supportive</li> <li>Family members are supportive</li> <li>Bring personal experience of a relative or close friend who has received and benefited as a recipient</li> </ul>

It was evident, through many of the discussions, that providing information and raising awareness did not equate being able to make a decision and give consent. Certain steps would have to be in place for people to move from information to action, including dispelling myths and fears, stories from people who had come through the experience, a better understanding of the need and the health issues in their community that would precipitate a need for organ and tissue donations. Further exploration with the community on how to move from information to consent would be beneficial.

### ***Misperceptions across generations***

Youth participants perceived that the older generation would not want to talk about death and organ donation. Among the adult and senior participants in the discussions, many were comfortable talking about their own mortality but had not necessarily given a lot of thought to whether they would become donors themselves or how they would respond to a family member's decision to be a donor. Older participants and those with professional experience in the health system were more inclined to question whether they would want to be organ and tissue recipients.

Adult participants perceived that the younger generation would be open to discussing and supporting the idea of organ donation by virtue of being raised in the western culture. However, what we heard from young people was that they had not thought about it and were at the stage of needing to explore the related questions. Many were uncomfortable with being living donors, concerned the donation would compromise their health. They had mixed feelings about donation after death, depending primarily on who would be receiving the organs and the position of their parents. Most were in favour of accepting organs and tissues if the transplantation would contribute to their quality of life.

### *Tensions arising*

A number of tensions emerged with which participants are grappling:

Perception of religious position as for or against	Personal views for or against
Comfortable with accepting organs and tissues	Not comfortable donating organs and tissues
Know of people who have benefited from a transplantation	Not comfortable donating organs and tissues
Possibility of health benefit	Allowing the natural course of aging to unfold. Questionable quality of life following transplantation. Changing the path of God's will.
Belief that body must be whole for resurrection	Giving to save another person's life

### *Distinguishing among organ, tissue and blood donations*

A number of participants made a distinction between their comfort with tissue donation involving the eyes (corneas) or blood donation, and their discomfort with organ donation. One can surmise that the eye and blood donation are viewed as less intrusive or less desecrating to the body.

### *Normalizing the topic of organ and donation*

Participants spoke to the importance of disseminating the material through the places people naturally go, e.g. workplaces, temples, doctors' offices. Placing the materials throughout the community communicates a message that this topic is discussable within families and within the community. Further, it provides people with the language to have the dialogue since it may be new territory. Some suggested that it ought to be as visible as solicitations for blood donation.

### *A topic to be studied*

Mirroring the fact that Muslim leaders are not necessarily aware of or in agreement on how they interpret the 'official' position, or in agreement that the official position applies to all Muslims, participants were in flux on their personal positions through the discussions. Many of the Muslims came to the discussions having studied or inquired about the religious perspective and were keen to pursue opportunities to discuss, learn and consider various aspects of the topic.

### **The significance of cultural, religious and historical context for developing strategies**

Given experiences that have created distrust of medical systems, particularly in India, establishing trust and dispelling myths with the communities will be an important feature of raising awareness and increasing comfort. 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.

The use of story or example from religious or mythological scripture may be helpful with some South Asian audiences. Many participants referred to examples from the Ramayan or Mahabharat to illustrate acceptance of organ donation within Hinduism. Muslim participants spoke of the writings or sayings of scholars who have studied on the issue of organ donation from an Islamic perspective to justify acceptance within the Muslim community. The concept of

sacrifice and service (*sewa*) to the community (the community as a whole) would be useful for the Sikh community.

Since South Asian culture is sociocentric, one's relationships with others and one's position within the family are critical for determining how the individual makes decisions.

Given the reality of people who go to the mosques and temples and those who do not, it will be important to use multiple strategies in multiple settings to remain inclusive.

### **3.2 Reflections on the process of undertaking a consultation**

#### ***Relationship-based practice***

Working as consultants from outside BC, we did not have a foundation of working relationships with leaders within the South Asian communities. As a result, we connected with individuals who were able to dedicate time to organizing a focus group or interview, contributing volunteer time beyond their professional roles. Without the assistance and trusted relationships of these identified leaders, we would not have been able to make the kinds of personal contacts required, particularly within the given time frame. Hence, relationships are important at every stage, to find the right contacts to plan the overall strategy, and people who are well connected to organize the focus groups engage community members in the group discussions.

#### ***Supporting the need to move slowly***

The Diverse Communities Consultation, with its premise of listening rather than trying to change people's opinions, was in a position of relative 'neutrality' in asking people to articulate and explain the factors influencing their beliefs. When the work continues through the organ donor organizations that are mandated to promote organ donation, it will be more challenging to assume a neutral position. Yet, it was evident that people needed 'space' and a sense of safety to explore their beliefs without worrying about judgment.

#### ***Ingredients for effective group process***

Food, covered by the project, was part of every group discussion. Two of the focus groups took place in a restaurant. For the youth, the particular place was chosen as one that would attract them to come in the middle of mid-term exams. Among the adults, we can surmise that the restaurant was chosen as both a way of acknowledging people's contribution and as a neutral ground for an interfaith event. The third focus group took place in a community centre with a catered lunch of Middle Eastern cuisine.

The restaurants could not provide enough privacy for a dialogue on a sensitive topic. The long tables and the background sounds of music and conversation, common to restaurants, were not conducive to an exchange. The community centre, on the other hand, offered the privacy and quiet required, and the catered meal offered the message of appreciation.

Groups under ten allowed more people to take part in the discussion than in the larger group.

We welcomed having the option of offering honouraria to participants as an additional token of appreciation. However, we took our cue from the organizer as to whether it would be appropriate to offer in each of the focus groups.

#### ***Maintaining momentum***

Many people assumed that we were with BC Transplant Society. They were eager for follow-up activity to maintain momentum. A number of people made specific requests or offers to assist as volunteers. Those contacts and requests were forwarded to BCTS at the conclusion of the consultations. People also made suggestions for further small group discussions, including a cross-generational group.

## 4. RECOMMENDATIONS

### *Maximize relationship-based practice*

Build upon existing relationships wherever possible by engaging people who are able and willing to make connections within their own community.

### *Support people's need to move slowly*

Honour community needs to move slowly through the stages of information and awareness to a decision to donate. Research the most effective ways of enabling the process to take place. Tap into personal stories, among community members, about receiving organs to learn how it has changed people's lives and how families arrived at the decision to donate. Respect the cultural, religious and historical context of the South Asian communities.

### *Honour essential elements of group process*

Build in elements of group process that respect people's contributions of time and that create an environment of safety.

### *Create opportunities for cross-faith consultation*

Create opportunities for people of diverse faiths to come together to explore the similarities and differences in their views and to share insights about moving from awareness to action.

### *Create opportunities for intergenerational consultation*

Create opportunities for mixed-age focus groups to address the misperceptions between generations and to help people find the language to have this kind of discussion within their own families.

### *Maintain momentum*

Take advantage of the momentum generated through the consultation to follow up on expressed interest for education and to support ongoing interests in further dialogue.

## 5. CONCLUSION

The findings of the Vancouver consultation for the Diverse Communities Consultation Project are consistent with the previous inquiries with the South Asian communities in the Vancouver area. The Hindu and Sikh participants were clear in their interpretation that there are no objections to organ and tissue donation from a religious perspective. Muslim participants expressed more ambiguity and a desire to take time to explore the matter with their religious leaders. However, at an individual level, many people were grappling with their level of comfort. Culture and religion provide a lens, but, drawing on the findings in this consultation, individual variations were contingent on a wide range of contributing factors.

In fulfilling the ultimate goal that every Canadian has the opportunity to consider organ and tissue donation, strategists will benefit from an ongoing process of listening and responding to the unique and collective perspectives of the South Asian communities.

## **APPENDICES**

- A. CONSULTATION ON ORGAN AND TISSUE DONATION AND TRANSPLANTATION, VANCOUVER, DRAFT DESCRIPTION, JANUARY 10, 2005**
- B. PLANNING MEETING AGENDA**
- C. PROCESS FOR ORGANIZING PLANNING GROUP, FOCUS GROUPS AND INTERVIEWS**
- D. FINDINGS FROM PREVIOUS RESEARCH (VANCOUVER AND LOWER MAINLAND)**
- E. FOCUS GROUP AND INTERVIEW INTRODUCTION**
- F. INTRODUCTORY LETTER AND CONSENT FORM**

## APPENDIX A: CONSULTATION ON ORGAN AND TISSUE DONATION AND TRANSPLANTATION , VANCOUVER DRAFT DESCRIPTION, JANUARY 10, 2005

CCDT Diverse Communities Consultation  
Consultation on Organ and Tissue Donation and Transplantation with  
South Asian Communities, Vancouver

January 10, 2005

### Introduction

The Canadian Council for Donation and Transplantation (CCDT) has contracted Beverley Curtis of Charis Management Consulting (for more information on Beverley and Charis please visit the Charis website at [www.charismc.com](http://www.charismc.com)) to organize a series of consultations with three cultural communities across Canada.

Bev Curtis contracted Ann Goldblatt ([ajg@compusmart.ab.ca](mailto:ajg@compusmart.ab.ca)) to organize and conduct the consultation with the South Asian communities in Vancouver. The intent is to ask about people's personal views, values and traditional beliefs that might impact their decisions related to organ donation and transplantation. Cultural understandings of donation and transplantation will be approached as a topic to be better understood, recognizing there is diversity within cultures. **The goal of this consultation is not to change people's perceptions** but rather to understand them so that people can become informed in ways that respect and support their backgrounds.

We want to begin by asking individuals from the South Asian communities how best to approach people to ask questions about the sensitive topic of donation and transplantation. The purpose of our proposed meeting is to plan for consulting with South Asian people in the Vancouver area about organ donation and transplantation. We want to consult people in a respectful way, which honours their history, traditions and background. We also want to build on existing relationships and develop new ones among the British Columbia Transplant Society and organizations involved with South Asian people.

### Background

In Canada, there is a persistent and growing gap between the need for and supply of organs and tissues for transplantation. This can be a particular problem in some ethnocultural communities because of the difficulty of finding organ donors. The mandate of the (CCDT) is to provide advice to the Conference of Deputy Ministers of Health (the group meets regularly and includes all of the Deputy Ministers' of Health from each province and territory) in support of their efforts to coordinate activities relating to organ donation and transplantation in Canada.

With this consultation, the CCDT hopes to gain an understanding of the cultural background, views, values and traditional beliefs that might come to bear on a South Asian person's decision to donate organs or to receive a transplant. Through this understanding, the Council will be able to provide advice to the Conference of Deputy Ministers that is guided by South Asian community perspectives. Ultimately, more Canadians may consider donation and transplantation within an environment that respects and responds to their cultural background and needs.

The information gathered in the consultation will be used to:

- Provide advice to the Deputy Ministers on useful policies and strategies to address issues related to donation and transplantation that are unique to South Asian people.

- Advise other locations how best to consult with South Asian communities on donation and transplantation.
- Facilitate understanding among health professionals about the issues that people of South Asian background identify relative to donation and transplantation.
- Facilitate donation and transplantation in ways that accommodate spiritual and cultural traditions of people of South Asian background.

## Overall Project Aims

1. Identify stated beliefs and views about organ and tissue donation in selected diverse communities.
2. Identify processes that work for engaging ethnocultural groups on the topic of donation and transplantation.
3. Consider partnerships between the ethnocultural group and the local donation and/or transplant program.

## Planning meeting draft agenda

The first steps will involve:

- Discussing and agreeing on the values upon which the consultation will go forward;
- Agreeing on the local objectives for the consultation;
- Discussing consultation questions;
- Discussing background materials;
- Reviewing consultation strategies and tools and determining the best fit;
- Discussing the management of language issues;
- Establishing boundaries (e.g. topics that are absolutely taboo for discussion or topics that must not be discussed in a mixed gender situation); and
- Selecting strategies, participants and timeframes for the consultation.

## Scope

The scope of the consultation involves the following areas:

- I. Participants' awareness of and experience with organ and tissue donation (living and deceased) and transplantation
  - Personal experience or knowledge of someone who has donated or consented to donation or received a transplant;
  - Personal experience about whether knowing someone who has had a transplant or donated for a transplant changed the individual's views about donation and transplantation; and
  - Donation while alive or after death.
- II. Participants' views toward organ and tissue donation and transplantation
  - Range of attitudes about donation and transplantation held by people of South Asian background.
  - Understanding what people say about organ donation and transplantation in your community.
  - Understanding why someone might say no to transplantation or donation for themselves or for their family members.
- III. Participants' traditional values and beliefs which could influence people of South Asian background in regard to donation and transplantation
  - Traditional and non-traditional beliefs about death and life after death;

- Traditional and non-traditional beliefs about missing body parts while alive and after death;
  - How decisions to donate organs and tissue or receive a transplant are made by individuals and within families.
  - Cultural rituals and ceremonies that should occur during the donation and transplantation experience, including delivering bad news.
- IV. Support to decision process
- In order to support a family in the decision making process, what can be done to help a South Asian family at the delivery of bad news, consent to donation, donation and follow-up?
  - What can a health care provider be particularly aware of when helping a South Asian family to make the decision to donate or receive a transplant?
- V. Relationship Building
- How do we go about continuing this dialogue with South Asian Canadians?
  - How should we develop relationships with South Asian organizations and other individuals concerned with donation and transplantation?

## Conclusion

Thank you for your interest in helping us with this consultation. Please call Ann Goldblatt at 780-439-8813 or 780-953-8642 (cell) with any questions or concerns. Bev Curtis can be reached at 780 496-9067, Extension 223.



## APPENDIX B: PLANNING MEETING AGENDA

### CCDT Diverse Communities Consultation Consultation on Organ and Tissue Donation and Transplantation with South Asian Communities, Vancouver

Planning Meeting Agenda  
**Friday, January 14, 2005, 10 a.m. to 1 p.m.**  
BC Transplant Society, 3rd Floor, West Tower,  
555 West 12th Ave, 604-877-2240

1. Welcome and introductions
  - Participants in today's meeting
  - The role of the Canadian Council on Donation and Transplantation (CCDT)
  - CCDT Diverse Communities Consultation
2. Profile of the donation and transplantation experience in Vancouver
  - BC Transplant Society
3. Dialogue on issues and consultation strategy
  - Discuss community issues and experience related to organ donation and transplantation
  - Advise on the strategy to consult South Asian communities in Vancouver
    - Confirm local objectives and values to guide the consultation.
    - Explore options and tools for the consultation to determine the best fit.
    - Discuss consultation questions and background materials.
    - Establish boundaries (e.g. topics that are absolutely taboo for discuss, topics that are not appropriate for a mixed group of men and women).
    - Select strategies, participants and timeframes for the consultation.

*Lunch will be brought in at noon  
and we will continue our conversation until 1 p.m.*

We would like to bring this group together for one "debriefing" discussion after the consultation.  
Date to be confirmed with the group.<sup>14</sup>

*If you would like to invite someone else from the community you think should be included on January 14, please let Ann Goldblatt know at [ajg@compusmart.ab.ca](mailto:ajg@compusmart.ab.ca) or 780-953-8642 (cell) by Wednesday, January 12, so that we can be sure to order enough food.*

***We look forward to meeting with you and thank you for your time!***

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<sup>14</sup> A different set of participants became involved in the implementation of the plan and hence, a debriefing discussion with the original group was not pursued. A follow-up letter was sent to provide closure.

## APPENDIX C: PROCESS FOR ORGANIZING PLANNING GROUP, FOCUS GROUPS AND INTERVIEWS

Using a combination of leads suggested by BCTS and CCDT, lists of community organizations, internet searches and the snowball technique of asking those people reached for further suggestions, we made contact with 24 individuals within 15 organizations, plus an additional two people, to recruit a small group to take part in a planning session.

Following the planning discussion, the following table describes the process for organizing each of the data gathering opportunities:

Opportunity	Process for organizing
1. Focus groups	Contact made with individual leaders in the Sikh, Muslim and Sikh communities. These individuals were willing to make the necessary set of phone calls to invite and encourage people in their network to participate.
2. Interviews	Planning group member suggested particular Hindu and Sikh temples that would be receptive to the invitation to participate. Direct contact led to the interview with the Hindu temple leaders. The interviews with the Sikh temple leaders came through personal contacts by one community member willing to contact administrative leaders. Initial attempts to make direct contact were not successful.
3. Exploratory meeting	An immigrant-serving agency worker, who is also a volunteer in a Sikh temple, organized the exploratory meeting. Prior to deciding whether to have a focus group, the temple's organizing committee for a family support program wanted an opportunity to meet and learn more about the project. Follow-up was planned with BCTS.
4. Informal dialogue at the Hindu temple	As a direct outcome of an interview and focus group participation, a temple leader invited the project team to his Hindu temple for the service and to make a brief presentation about organ and tissue donation. Along with the temple leader, a project team member spoke to approximately 100 people. Informal dialogue followed with people requesting donor registry forms and suggesting further strategies.

## APPENDIX D: PLANNING GROUP PARTICIPANTS

1. Mr. Ravinder Dhir  
Settlement worker  
Immigrant Services Society  
Vancouver
2. Mr. Charan Gill  
Progressive Intercultural Community Services Society  
Vancouver
3. Mr. Gurpreet Nagra  
Settlement worker  
S.U.C.C.E.S.S. United Chinese Community Services Enrichment Society  
Vancouver
4. Mr. Abdullah Nasib Ali  
BC Muslim Association  
Vancouver
5. Ms. Angela Sasso  
Coordinator, Special Projects  
Provincial Language Services, Provincial Health Services Authority
6. Dr. Rosalie Starzomski  
Chair, CCDT Ethnocultural Steering Committee
7. Ms. Sally Greenwood  
Communications Director  
British Columbia Transplant Society
8. Ms. Lisa Despins  
British Columbia Transplant Society
9. Ms. Ann Goldblatt, Goldblatt Consulting  
Chair, Planning Committee
10. Ms. Beverley Curtis  
Charis Management Consulting  
Project Manager, CCDT Diverse Communities Consultation

## APPENDIX E: FINDINGS FROM PREVIOUS RESEARCH

Prepared January 26, 2005

The following are highlights of the learning from Molzhan et al's study<sup>15</sup> and the BC Transplant Society's brochure project<sup>16</sup>, organized under the five topic areas for the current consultation. Highlights can be used as starting points for the Vancouver consultation.

### Participants' awareness of and experience with organ and tissue donation (living and deceased) and transplantation

- Many know family members, friends and acquaintances awaiting transplants or who have received organ transplants.
- There is a lack of knowledge about organ donation, e.g. registry system in BC, whose organs are considered useful. Perceived lack of knowledge in the broader South Asian community.

### Participants' views toward organ and tissue donation and transplantation

- Not opposed to the idea of organ donation.
- Extended family is important; there is a duty to help one another.
- Viewpoints depend on educational background.
- Caste not considered relevant if a person needs a transplant.
- In India, physicians are of high socio-economic status and are held in high esteem; disrespectful to question them or their judgments.
- Greater willingness to donate to a younger person. More willing to consider living than cadaveric donations.
- Young people and older adults would be willing to donate.
- A philanthropic act – 'a great thing to do'; doing good for others; "you are to be useful forever". No stigma to giving or receiving an organ. Good to give your life to save someone else's life.
- Some said it depended on their relationship with the person needing the organ.
- Fears: surgery, receiving adequate care if the health professionals want your organs, disfigurement, giving something up you might need in later life and the donated organ would not work for the recipient.
- Conscious of people who are poor selling organs in India because they need money.
- Noted: Attitudes about donating to people outside the community not explored.

### Participants' traditional values and beliefs that could influence people of South Asian background in regard to donation and transplantation

- The religion does not say that organ donation is morally right or wrong.
- Particularly clear for Hindu, Sikh and Christian faiths; an individual decision.
- Less clear in the Islamic faith. If nothing is said in the Qur'an or by Mohammed, no central body can provide advice.
- For young adults, religious, cultural and spiritual beliefs about organ donation would not be major factors.
- Members of the community do not like dealing with very serious issues like these ones unless it's brought upon them.
- God decides how long we should live; very western to think we can overcome nature. Might be different if faced with the situation of a life-threatening illness themselves.
- There are religious and cultural practices around the time of death that need to be considered. Burial is common among Christians, Muslims and Parsi. Muslims bury the body the same day as the death. Cremation is the norm in Sikh culture. Treating the body with honour and respect is important.

<sup>15</sup> *Selected perspectives on Indo-Canadian beliefs regarding organ donation* by Anita E. Molzahn, Michael McDonald, Chloe O'Loughlin and Rosalie Starzomski, January 21, 2003.

<sup>16</sup> Provincial Language Services and Provincial Health Services Authority, *Proposal outline for the development of BCTS Chinese and Punjabi Brochures*, February 15, 2004.

### Support to decision process

- Young people said they would make their own decisions but parents and elders would be influential. The decision for adults needs to be supported by one's spouse. This is not a community decision, but the "collectivist" beliefs require extensive consultation with extended family members.
- Varied opinions on who should be making the request. Most said the physician should be the one. Some said "social worker" because this person has no other interest. One said the request should come from a religious leader. Depends on relationships.
- Give family time to consider the options after they are explained.
- Challenge – discussing decision to register with one's own family. Families not aware persons were registered.
- Challenge – culturally competent counseling to affirm consent for eligible donor organ recovery.

### Relationship-building

- Strategies suggested for increasing awareness included community functions, events and gatherings via the temples (not in the religious part of the temple)
- Listen to people outside the community
- Media publicity – radio, newspaper
- Schools
- Oral rather than written communication recommended. Literacy level is low.
- Suggestion: Target people susceptible to various diseases that lead to organ failure as potential spokespeople.
- Key informants for BCTS/PLS study favoured translated material as a first step.
- Messages should emphasize benefits to quality of life rather than examples of people close to death who were saved; breakthroughs; high quality of donation program; voluntary nature; how to tell family members about decision to register.
- Do not describe brain death; do not describe removal of organs from the body; do not explain organ donation does not interfere with funeral arrangements.

### Learning about the process of conducting the focus groups

- Sensitive topic; people need to feel the questions are worded in a way that will not bring negative consequences to them

## APPENDIX F: FOCUS GROUP AND INTERVIEW INTRODUCTION

### Introductory remarks

Organ and tissue donation and transplantation is a sensitive topic for many of us. We have asked you to be part of this dialogue to better understand your traditions, beliefs and values about organ and tissue donation and transplantation. The purpose in this consultation is not to change your views but to listen and understand. We also want to understand how to sensitively increase awareness about the topic within South Asian families so that people can make informed choices.

This consultation has a very wide scope. We are consulting with people from three cultural communities in three cities, people of Chinese background in Toronto, Aboriginal peoples in Winnipeg and people of South Asian background in Vancouver.

The results of these consultations will be put together in a report for the Canadian Council on Donation and Transplantation. The BC Transplant Society is interested in what we learn to build on work they are already doing with the South Asian communities.

### What do we mean by organ and tissue donation?

1. A **living organ donation** takes place when someone donates an organ or part of an organ to another person.

This would usually be a kidney or portion of a liver. For kidneys, each of us has two and a person can live well with only one kidney. For the liver, a person can donate a portion of their liver and the remaining portion of liver regenerates to perform at a greater capacity.

2. 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.
3. **Tissue donation** takes place when someone has died. Tissues that can be donated include corneas, heart valves, bones and skin.

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Someone can receive an organ or tissue transplant in any of these three ways. These are all called 'transplantation'

## APPENDIX G: CONTACTS INITIATED

### Community organizations and associations

- Abbotsford Community Services
- Affiliation of Multicultural Societies and Service Agencies (AMSSA) of BC
- Bangladesh Cultural Association of BC
- Immigrant Services Society
- Indo-Canadian Information and Crisis Centre
- Lower Mainland Bengali Cultural Society of BC
- MOSAIC, multilingual non-profit organization
- Pacific Immigrant Resources Society
- Progressive Intercultural Community Services Society
- Punjabi Women's Association
- South Asian Women's Centre
- S.U.C.C.E.S.S. United Chinese Community Services Enrichment Society Contact names
- Simon Fraser University
- University of British Columbia
- Vancouver and Lower Mainland Multicultural Family Support Centre
- Vancouver Multicultural Society
- VIRSA – Sikh Alliance against Youth Violence
- Akali Singh Society
- BC Muslim Association
- BC Muslim Women's Council
- Gurdwara Ravidas Sabha Community Centre
- Guru Nanak Sikh Temple
- Ismaili Council for British Columbia
- Aga Khan Health Board for British Columbia
- Vedic Hindu Society (temple)
- Vishva Hindu Parishad Society (temple)

Additional temples suggested by Ravinder Dhir as contacts:

- Canadian Ramgarhia Society
- Five Rivers Community Services Society
- Nanak Sar Gursikh Temple
- Gurdwara Sahib Dasmesh Darbar
- Khalsa Diwan Society, New Westminster
- Khalsa Diwan Society, Vancouver
- BC Provincial Renal Agency
- India Mahila Association
- Kidney Foundation of Canada – BC Branch
- Provincial Language Services, Provincial Health Services Authority
- Vancouver Coastal Health Authority - Cross-cultural Care and Diversity
- Indian Consulate
- Ministry of Community, Aboriginal and Women's Services
- Volunteer, BCTS
- Former multicultural community liaison for the school board; retired
- Formerly with Burnaby School District
- Consultant, member of team for Vancouver consultation
- Senior contact for administrative leaders within Sikh temples

### Organ and Tissue Donation and Transplantation contacts in BC

- BC Transplant Society (BCTS)
- Canadian Council on Donation and Transplantation (CCDT)



## APPENDIX H: INTRODUCTORY LETTER AND CONSENT FORM

February 6, 2005

Thank you for agreeing to take part in a discussion on organ and tissue donation and transplantation.

Organ and tissue donation and transplantation are sensitive topics. People have values and beliefs that influence their views. We are interested in understanding your views, values and beliefs on organ and tissue donation and transplantation and related issues.

Your views will help guide the Canadian Council on Donation and Transplantation (CCDT). A copy of the final consultation report will be sent to you.

All information you provide will remain completely confidential. Your name will not be used. Participation is voluntary and you do not have to answer any questions that you do not want to answer. Your participation will in no way affect your current or future health care services.

Before beginning, we would ask you to complete the attached consent form.

If you have any questions, please direct them to Ann Goldblatt at 780-953-8642 ([ajg@compusmart.ab.ca](mailto:ajg@compusmart.ab.ca)) or Bev Curtis at 780-717 5792 ([bcurtis@charismc](mailto:bcurtis@charismc))

We greatly appreciate your participation.

Kind regards,

Rosalie Starzomski, RN, PhD, Lead, CCDT Steering Committee





## CONSENT FORM

Title of Consultation: Diverse Communities Consultation, Consultation on Organ Donation and Transplantation with South Asian Communities, Vancouver

### Understanding of the Participant

I understand that I have been asked to take part in a discussion on organ donation and transplantation. I understand that my involvement is entirely voluntary. I may choose to withdraw at any time. I have had the chance to ask questions about this project and I am satisfied with the answers.

I understand that all written material and data will be stored at the Charis Management Consulting office for 7 years and then will be destroyed. If this information is used for future reports, there will be no information that identifies me by name. I will not be asked for further permission.

### Tasks

**If you agree to take part, you will participate in a focus group of about ten persons. The discussion will take about two hours. The focus group will be audio-taped only for the purpose of typing the discussion to help write the report.**

### Possible Benefits and Risks

There is no direct benefit to you for participating in the focus group. The information will help us to understand people's views on organ and tissue donation and transplantation. There is little or no known risk to you.

I have read this signed consent form. I know there will be a report about this consultation, but I will not be named.

I agree to take part in this consultation by taking part in this discussion.

\_\_\_\_\_  
Name of participant  
(please print)

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of witness  
(please print)

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
Date