

DIVERSE COMMUNITIES

Consultation to Explore Perspectives on Organ
and Tissue Donation

SECTION II

Toronto Consultations:
CHINESE-CANADIAN COMMUNITY

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EXECUTIVE SUMMARY

As part of its national Diverse Communities Initiative, the Canadian Council for Donation and Transplantation conducted a consultation process in Toronto with the Chinese-Canadian community to better understand the variety of perspectives people have on organ and tissue donation and transplantation. In particular, the study looked at: awareness of deceased and living donations, views and concerns, traditional values and beliefs, support for the donation process and relationship building. The approach taken with the consultations gave a primary importance to relationship-building through the process. The intent was to maximize the opportunities for a lasting impact by forming and/or reinforcing relationships between Chinese-Canadian groups and associations and the local donor agency, in this case Trillium Gift of Life Network¹ (TGLN). Respect for the traditions and beliefs of the people being consulted were another important principle. The goal was 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.

Based on the advice of a planning committee, made up largely of representatives of the Chinese-Canadian community, the methods used were surveys and focus groups. Two surveys were developed – one for the general public, which was completed by 110 respondents, and one for Chinese family physicians serving primarily patients from the Chinese community, which was completed by 22 respondents. Three focus groups were held, with a total of 44 participants.

Beliefs and Views

There were several beliefs discussed that could serve as a barrier to organ and tissue donation and transplantation. The tradition that the body should be buried whole seemed to be most important of these. This was related to two concepts: filial piety and the importance of wholeness and harmony. A concern that the body needed to be whole to be reincarnated whole was also mentioned. Consistently, people commented that tradition of being buried whole was losing ground in the Chinese community – that it was primarily a belief of the older generation. A second important belief was that the one's destiny was pre-ordained and that one should not attempt to prolong one's life.

On the positive side, people commented that giving was an important concept and practice in the Chinese community and that an extension could be made to the idea of an organ or tissue donation being a gift. There was a connection made between wastefulness and not donating organs once one was deceased.

There was also strong respect for the medical tradition and a high trust in doctors as evidenced by the survey results. This was nuanced somewhat in the surveys by a fear that a patient may not get every possible treatment if he or she is a potential organ donor.

There did not seem to be any beliefs about the receipt of an organ. Indeed, except for considerations of age and the resulting health of the donor (if it was a living donation), people were very open to the idea of receiving a transplant. Indeed in the survey results, it was clear that people were not concerned that the organ might come from someone not of Chinese origin as long as there was a compatible match medically.

The survey results further indicate that there may not be a strong connection between one's faith and the decision to donate. Sixty-seven percent (67%) of respondents indicated that their decision to donate would not be influenced by any particular faith. Seventy-eight percent (78%) responded that they would not talk to their religious or spiritual leader about organ and tissue donation and transplantation.

¹ Trillium Gift of Life Network is Ontario's central organ & tissue donation agency.

Family

The importance of family came up in a number of ways in the focus group discussions. In particular, people suggested two forms of incentives that might encourage donations that build on the sense of family in Chinese culture. The first of these was the idea that donating brings a family honor. This apparently relates to a Chinese tradition that the actions of an individual can bring honor to the family who becomes recognized in the community for the individual's achievement.

The second idea was whether one could gain a "credit" for their family by donating. Thus at a future point, if a family member required a transplant, they could move up the waiting list because a family member had previously donated to some-one else.

Interestingly, the decision about whether to donate or not was seen to be primarily an individual's decision that should be respected by the family. Indeed, in the focus group, there was a sense of incredulity that a family could "over-rule" a donors' wish to donate. That being said, there was a clear message about the importance of talking to one's family about one's wishes, even if the topic was uncomfortable.

Public Education and Awareness

For many participants, the key to increasing donations was about public education and awareness-building. Most felt that people would sign a donor card if they had more information and were asked clearly to donate. People spoke about the importance of positive stories. Several people mentioned that there have been extensive public campaigns in Hong Kong that they felt were effective and perhaps could provide a model. It would be important to respond to people's information needs in three areas:

- Statistical information: e.g. What is the need? How long are the waiting lists?
- Medical information: e.g. What's the operation like? How long does it take to recuperate if it's a living donation? Is there an upper age limit on donations?
- Donor process: e.g.: How does one get a card? Can I have an open casket if I donate? What conditions can one put on their donation, e.g. that an organ not go to medical research?

Assuaging fears would also be important. For example, concerns were raised about whether the body would be respected; about whether organs could go to prisoners or to those who have abused their own organs, e.g. a kidney to an alcoholic. Twenty-eight percent (28%) of respondents indicated that would not currently be willing to sign a donor card because, for them, organ and tissue donation and transplantation is an uncomfortable topic. It would be important to have a better understanding of the components of this discomfort in terms of developing messages that help to make it an accessible subject.

Recommendations

There are a number of recommendations that emerge from this consultation in terms of ongoing work on organ and tissue donation and transplantation with the Chinese community. Key ones are:

1. **Continue to work with and through community groups and associations.** These groups are essential for trust, outreach and advice on appropriate cultural practices.
2. **Do further research into the possible generational difference** in the belief that the body should be buried whole. Having a better understanding of this difference could impact on the design and targeting of public education for different age groups.
3. **Build on the importance of family** by exploring incentives such as recognizing a "family of honor" or allowing a credit that can be used for a needy family member in the future. For the latter incentive, it would be important to have further discussions that would look at the potential trade-offs between such a credit and the values underlying the current system such as equity and fairness.

4. **Do more public education and awareness-building.** The value of giving would be one important cultural tradition to build from. Another message, given the importance of family but also the view that it is an individual's decision whether to donate or not, might be "Talk to your family. Ensure they know that you want to donate".
5. **Build on the connections made with Chinese family physicians.** There is a lack of knowledge about organ and tissue donation and transplantation and an interest to learn more. There also seems to be a willingness to participate in education work and to discuss organ and tissue donation and transplantation with patients.

1. CONTEXT

The Toronto consultations were part of a larger initiative of the Canadian Council for Donation and Transplantation (CCDT), called the Diverse Communities Project. The project was exploratory in nature and sought to better understand the perspectives people within three different ethno-cultural groups in Canada have on organ and tissue donation and transplantation. In particular, the study looked at: awareness of deceased and living donations, views and concerns, traditional values and beliefs, support for the donation process and relationship building. At the conclusion of the consultation process, in the Spring of 2005, CCDT will submit their report to the Deputy Ministers of Health.

The Toronto consultation focused on the Chinese-Canadian community. Toronto was chosen as the place for consultations with the Chinese Community because of the extremely diverse nature of the city and the large Chinese population. This diversity in itself presents many challenges in terms of organ and tissue donation. There is a real need to understand the variety of perspectives on organ and tissue donation and transplantation and identify both opportunities and barriers to increasing donation rates. The Chinese community is considered a priority for the consultations because there are a large number of people waiting for transplants, while the rate of donation is low. The typical waiting time for a kidney transplant within the Chinese community in Toronto is eight years. The overall objectives for the Toronto consultations were:

1. Identify stated beliefs and views about organ and tissue donation in the Chinese-Canadian community.
2. Identify processes that work for engaging Chinese-Canadians on the topic of donation and transplantation.
3. Consider partnerships between local Chinese cultural groups and the local donation and/or transplant program.

2. APPROACH

The approach taken to the consultations gave a primary importance to relationship-building through the process. The intent was to maximize the opportunities for a lasting impact by forming and/or reinforcing relationships between Chinese-Canadian groups and associations and the local donor agency, in this case Trillium Gift of Life² (TGLN). Strengthening the collaborative relationship between CCDT and TGLN was also important. TGLN had already identified working with Chinese-Canadian community as a priority in their own community work. This was an important consideration in choosing Toronto as the location for this consultation.

It was also crucial that the approach respected the traditions and culture of the people being consulted, including incorporating rituals as appropriate. The overarching message to guide the consultation was: *We are seeking to understand not change your views. The CCDT is interested in increasing the numbers of people who consider organ and tissue donation and we think more people will consider donation if the messages about it are given in a culturally appropriate way. We respect the culture and history of the people with whom we are consulting and we will make every effort to accommodate cultural traditions and rituals.*

The goal was 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.

In following these consultation principles, the first step was to organize a planning committee with representatives of the Toronto Chinese-Canadian community who could offer advice on the process and help to make connections with appropriate organizations. TGLN used its existing contacts to bring this meeting together. The list of planning group members is included in Appendix A. At this meeting, participants proposed three consultation strategies:

- Focus groups targeting the general Chinese-Canadian population
- A survey targeting the general Chinese-Canadian population
- A survey designed specifically for family physicians serving predominantly Chinese-Canadian patients.

A number of groups were identified who could help implement these strategies. Most of these were groups affiliated with the planning group members, e.g. Chinese Renal Association, and therefore it was relatively easy to make the necessary contacts to begin the process. For other groups, notably the Yee Hong Centre for Geriatric Care, a contact needed to be established. In this case, TGLN was able to do this. Thus the process and the groups worked with were a direct product of those people who had been at the planning committee. This is important to underscore. The process was not meant to be research-rigorous in terms of sampling or statistical significance. However all the public tools, i.e. letters of invitation, consent forms and surveys were reviewed by research ethicists? An Ontario-based consultant was contracted to assist with the Toronto consultations. This person worked with TGLN and the other identified groups to implement the strategies. The planning committee members continued to provide valuable advice through-out the process, including reviewing research tools such as the surveys and their translations, and providing advice on appropriate practices, e.g. gifts. They also were essential to recruiting participants, both for the surveys and for the focus groups.

In total, three focus groups were held – two through the auspices of the Yee Hong Centre and one through the Chinese Cultural Centre of Greater Toronto. There were 110 useable responses to the survey for the general population. The physician survey was distributed at a dinner on organ and tissue donation and transplantation hosted by TGLN and CCDT as part of the consultation process. Twenty-two physicians completed the survey. Further details on the methodologies as well as the tools used are included in the appropriate sections of this report.

² Trillium Gift of Life Network is Ontario's central organ & tissue donation agency.

3. FOCUS GROUP REPORT

3.1 Context

Three focus groups were held as part of the consultation with members of the Toronto Chinese-Canadian community. These focus groups were with members of the general population of the Chinese-Canadian community. Two of the sessions were organized by the Yee Hong Centre for Geriatric Care and the third by the Chinese Cultural Centre of Greater Toronto (CCCGT). The 18 participants in Focus Group 1 were seniors between the ages of 70 and 92, who attended a congregate dining room program at a local Chinese Community Church. Three were men and the remaining 15 were women.

There were 12 participants in Focus Group 2 – six men and six women. Most were volunteers or program participants at the Chinese Cultural Centre of Greater Toronto. One person had recently arrived in Canada from China. The majority of the others had been in Canada for more than 20 years. There was a broad age range – from mid-20s to 70s.

There were 8 women and 6 men in the third Focus Group for a total of 14 people. Most were volunteers, program participants and/or tenants at the Yee Hong Centre. Again there was a broad age range – from 20s to 80s. Most had been in Canada for a considerable period of time.

The primary language spoken at the focus groups was Cantonese. This and the examples provided by participants indicate that the majority of participants were not Canadian-born and came from Hong Kong. Relatively few came from China.

3.2 Methodology and Tools

The Yee Hong Centre and CCCGT were approached and agreed to host focus groups, made up of their program participants and volunteers. The hosting role included recruiting participants and arranging for a meeting space. A letter of invitation and consent form was prepared and, after review by the ethicists, translated into simplified and traditional Chinese. The intent was that both these documents would be sent to participants before the session. However in reality, most people were invited verbally. Thus for many participants, they saw the consent form for the first time at the actual session. This was largely a result of the very tight time frames for the preparation of the focus groups. The consultation ran up against the Chinese New Year and therefore the process was more rushed than would have been desired. This led to some last-minute confirmations of focus group locations and times.

A focus group script was prepared which covered the four broad topics provided below. It is included in Appendix B, along with the invitation and consent form. The script was designed to be flexible, allowing the facilitator to focus in on topics that were of particular interest for each group.

The focus groups were professionally facilitated. A translator provided non-simultaneous translation in English, Cantonese and Mandarin. Simultaneous translation was not used as the recommendation from the hosting groups was that the headphones and the perceived formality would be off-putting for participants. However the sessions were audio-taped and microphones were used for this purpose. A resource person from TGLN was present at each session to answer questions about organ and tissue donation and transplantation in Ontario. Other support, as required, was provided by staff of the centers involved. For example, at the first focus group, where participants were members of a seniors program, the staff and volunteers who support this group were present and assisted individual members as necessary.

Refreshments were provided, with consideration given to cultural preferences. For example, the refreshments provided for the first group were Chinese sweets and tea. Participants were given gifts in thanks for their participation. This was done at the suggestion of the hosting groups. The gifts included calendars and t-shirts from TGLN.

A CCDT observer took notes at two of the focus group sessions. The tapes of the three focus groups were transcribed, using the English translation. A thematic analysis was done to distil the key ideas. This was done independently by two analysts and then compared. A draft of the analysis was sent to a staff person of the Yee Hong Centre who had been present at two of the sessions to ensure that views and perspectives had not been misinterpreted.

3.3 Results

The broad topics for discussion in the focus group were:

- A. Awareness of and experience with organ and tissue donation and transplantation
- B. Views toward organ donation and transplantation
- C. Views and traditional values and beliefs which influence your perspective on donation and transplantation
- D. Support to decision (including family concerns and relationships)
- E. Relationship-building (including public education and outreach)
- F. Closing (including an evaluation of the session)

The questions used to elicit discussion on each topic are provided in the focus group script (Appendix B).

Through-out the report, quotes are used to provide direct reference to the ideas expressed by participants. However, as translation was required in most instances, these quotes are not usually in the words spoken by the person. Rather they are the translated version of what was said. Quotes that are in the words of the participants (because they spoke English at that point) are noted in italics.

A. *Awareness of and Experience with Organ and Tissue Donation and Transplantation*

Relatively few participants knew of some-one personally who had received a transplant or given a donation. Two groups mentioned a pastor³ who had received a kidney transplant from a member of his congregation and now, made good use of his position as a pastor, to speak publicly and positively about organ donation and transplantation.

He witnesses in many different places I believe, and I received a publication where he spoke about it (organ donation and transplantation). I read it and that is how I got to know about it.

I have a friend who lives in Hong Kong who had a very bad liver. He has had his new liver for 3-4 years now and he has been taking anti-rejection drugs and he's very healthy.

Two examples were provided of people waiting for a transplant – in both cases for a kidney. A number of participants knew of people who had signed a donor card and/or had signed a donor card themselves.

³ As a result of the focus groups, CCDT has contacted this individual and he will be a speaker at an upcoming faith forum on organ and tissue donation and transplantation.

The majority of participants said they knew relatively little about donations and indeed there were many questions about donation and the donor card through-out the sessions. It was crucial to have a resource person in the room who could speak to the reality in Ontario.

I'm in a nursing program. I've been in the program for three years. But today is the first time I've heard about the 3 kinds of donations. I'm happy to hear about it.

I've worked as a volunteer for a senior centre since 1992 and this is the first time I've heard about organ donation and transplantation. Even kidney transplant, I have not heard about before.

The types of questions people had can be grouped into two categories. The first category was general questions about donations and transplantation. The other category was about the system of organ donation and transplantation, including the donor card and how it works.

Examples of questions related to donations and transplantation

- If the person is old, are the organs still usable?
- If the blood type is not the same between the donor and the recipient can the transplant still work?
- Can organs be donated to some-one who has Hepatitis B?
- In a living donation, is the health of the donor affected?
- In a living donation, how long does it take the donor to recuperate? How much work might they miss?
- If I had cancer, could I still make a donation?
- Can I direct my donation to my family?

Examples of questions related to the system of organ donation and transplantation and the donor card

- Are the hospitals connected to the information systems about who has signed a donor card? Is there a registry?
- What happens if I die outside Toronto or outside the province? How can my family be consulted?
- Why does my family have to approve of the donation if I have signed a donor card?
- Who in the family has to approve? Is it consensus?
- What happens if the family does not approve donating my organs, even though I've signed my card?
- If the person doesn't have a signed donor card, can the doctor still ask the family about donating organs?
- What do the codes mean on the Ontario Health Card where it notes willingness to be a donor?
- Does the doctor have a copy of the signed donor card?
- Could there be a metal bracelet to indicate one's willingness to donate, like there is for medic alerts?
- What if I don't want my body to be used for some purposes? For example, research?

B. Views towards organ donation and transplantation

In general, participants felt that most people had probably not reflected much on organ donation and transplantation. They noted that there was a lack of information and education. Some traditional beliefs (most notably, the belief that one should be buried whole) work against donations and therefore, in a busy world, people may choose not to fully consider the option (see Section C.)

What I hear mostly is that people are scared of it as there is still the old concept of being buried whole.

Most comments I hear are negative. People worry that you lose something, when something is cut off.

Alternatively there were some views expressed that would favor organ and tissue donation. For the most part, these seemed to be the evolving views, whereas the more traditional beliefs were spoken about as being “out-dated”.

I've been dealing with science and engineering my whole life. So for me, after death, the body returns to nature. Its part of a natural cycle.... it's better to donate as the body will just disintegrate.

More people are now being cremated. So after death, the organs are useless unless donated.

A strong recurring theme was the significance of donating in the Chinese culture. People spoke about the importance of donating money and time and that this is very valued. They made the link that organ and tissue donation could be seen as another form of donating – of contributing to others.

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

Giving is more than gifts and flowers.

In two of the three focus groups, people were asked whether they would consider receiving a donation if they were in need. Their answers to this question revealed two other views. The first view was related to the age of the recipient. Most felt that if they were over age 70 that they would not accept a donation – that it was better that the organ go to some-one younger.

If I was old – say 80 and my son or daughter wants to donate an organ to me I would not accept it.

I am 80 and I have had enough for this life.

If I am under 70 I would accept, but over 70 I would not.

While we are younger, we can all say at age 70 or 80, I would not accept a kidney transplant, but maybe at that time life is very painful and troublesome and I want to continue living. At that moment maybe I would accept. It's easy to say when I am healthy that I would not accept, but when the situation arrives, a person may decide differently.

My uncle is about 80 and he had an organ transplant, but he is not happy because even after the transplant he could not go out – he had to stay at home. He spent a lot of money on the operation and having nurses to take care of him and now he is regretting the operation. At age 80, living a few years longer is not of use to him.

I've already lived a full life. Death is a must so whether I live a longer or shorter life doesn't matter to me.

My mother is over 90 years old, living in China and she is not happy. She wants to die but she cannot as her health prevents her from dying. Perhaps being old, living a long life is not happy.

The second view was a strong concern for the health of the donor (if it were a living donation). The health of the donor was an important concern for most participants and it was clear that people were not willing to jeopardize the health of others in order to receive a donation. Educating people about the risks to and safety of the donor was suggested as important.

I would not accept, because, even if it doesn't affect their health immediately, it could affect the health of the donor later on in life. Who knows?

If it would not affect the health of the donor, then I would accept.

One participant shared a story of a brother who had made a living donation to his sister. Becoming a living donor meant that he had to take time off work, which caused some tensions in the workplace. This flagged a concern about the impact of making a living donation on one's work life. Participants mentioned the importance of educating the employers about living donation.

When my colleague donated his kidney to his sister, he had to take sick leave and the boss was not happy...Most of his co-workers accepted it as it was for his sister – but some people had to do his work too and they complain.... Some people may not make a donation because they feel their boss may not like it.... There needs to be education with employers.

Finally there was a view that the donation may end up being useless or going to people to whom the donor may not wish to donate.

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

But what if no-one can use the organ – then it becomes like garbage.

C. *Views and traditional values and beliefs which influence your perspective on donation and transplantation*

The traditional belief that was mentioned most often as a barrier to donation was the tradition of burying the body whole. This view is related to the concept of filial piety which has a deep-rooted influence on all classes of Chinese (Kwok-Keung Fung, 1998⁴). In explaining the concept of filial piety, Fung notes that “Taken to the extreme, children are expected to be in absolute obedience to their parents...The reverence for parents is carried into adulthood. Adult children are expected to serve their parents and inform them of their major decisions.” (pg. 24-25) “Filial piety is not directed only to one's own parents. It is extended to the ancestors as well as other senior members of the extended family” (page 27). The notion of being buried whole was also related to another traditional concept - that of harmony and balance.

⁴ Kwok-Keung Fung, *Understanding Chinese Cultures: A Handbook for Health Care and Rehabilitation Professionals*, Yee Hong Centre for Geriatric Care, 1998.

One participant referred to a Buddhist belief that could reinforce the view that it is important to be buried whole. This related to the idea of reincarnation and a fear that if one is not buried whole, they may not come back whole.

For the majority of people, the belief that the body should be buried whole was always associated with the older generation, even if the participants were in their 80s. Thus it seems to be a changing concept. People also remarked that it would be an essential concept to address in any education campaign.

Traditional thinking is that a corpse should be buried whole.

It is a traditional rule – a reasonable rule and I follow the rule.

It's a notion we heard from our parents, our grandparents.

It is a traditional Chinese viewpoint that all parts of the body are given by the parents and we are not supposed to hurt any part of it. This is part of Filial Piety – a very old concept. Your parents have given you a complete body; you should be buried whole and complete.

(Even) the skin and hair are given by the parent - damaging them would be disrespectful.

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

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

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

The second most expressed belief that emerged in the focus groups was the belief in predetermined destiny. Fung (1998) notes that: "Birth, illness, aging and death are foreordained and are to be accepted as such. Life has to be allowed to run its full course naturally. Artificially changing life's course is an act against nature." (pg. 66)

One participant used a Chinese proverb to explain the idea:

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

D. Support to Decision (including family concerns and relationships)

In two of the focus groups, participants were asked their advice on how a family could be respectfully approached to donate a deceased family member's organs. People commented that the request could come from a respected person such as a doctor and/or spiritual leader. The request should also be in the language most comfortable for the family.

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

If the family is Cantonese-speaking, you have a person of authority who is Cantonese asking the questions. If the person can explain things in Cantonese it will be much easier.

There were a number of suggestions about the way a request could be made - what types of messages to stress. Many of these were about the privilege of donating - of helping another.

Would you help some-one else extend their life?

Giving can be more than money and flowers.

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

Donating an organ helps that person live on in another person.

Participants expressed the idea that in donating one's family could become honorable. This is based on a traditional concept that an individual's actions can bring honor to the family. Some suggested that the family could get a certificate or some sort of recognition when one of their family members' donates. Many liked the approach of Trillium Gift of Life which gives out medals to the families of donors.

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

Having a certificate would help to educate the offspring that it is a good idea to donate organs after death.

I am against the idea of recognition either monetarily, which is the worst kind of reward, or even a certificate – because the donor gave voluntarily and there is no need to publicize or advertise about the dead person.

People suggested that it would be important to give practical and technical information, such as success rates.

Organ transplant is a technical solution... so family members should be made aware of the success rate of donating an organ. If they have this information it would be easier for them to make a decision.

There was significant concern that a family could over-ride a donor's wishes at the death bed. Several felt that it was an individual's decision and most felt that decision should be respected. Ultimately people suggested that it would be important to talk it over with one's family so they are aware of the prospective donor's wishes.

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

Since the family has over-riding power, whether a donor signs a card or not, it's better that the donor, before signing the card, talk with the family members and get consensus and agreement before signing. Then there would be no problem and no argument after death.

If I put my wish to donate in my will, can the family still contradict this?

Another incentive to donating that was raised by two of the three focus groups was the idea that the family of the person donating could receive a “credit”, in the instance that a family member needs a donation in the future.

What if I donate organs, would my relatives or my family members' offspring have a priority in the future? Could there be a credit for the family in case in the future some-one in the family needs an organ transplant - they can move up the list in priority?

The family members may not need a donation at the time of the deceased, but one day a son or daughter may need one. It would be peace of mind (*to know they would be more likely to get one*).

It should be noted that this idea had considerable resonance for a number of the participants – perhaps because it relates to the importance and obligation of family which seems to be a strong precept in Chinese culture.

E. Relationship-building (including public education and outreach)

The major theme raised by participants was the importance of doing education/promotional campaigns in the Chinese community. People felt that lack of information was a key reason people did not donate.

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

Several participants suggested that an education campaign was essential to increase donations. Several gave examples of work already done in Hong Kong.

In Hong Kong many people have signed donor cards because it was widely publicized and promoted by the British Hong Kong government. Movie stars were involved in the campaigns, for the younger generation; most of them signed the donor space on their driver's license. It's a well-known campaign in Hong Kong and most people were receptive because of the education.

There was a poster used in Hong Kong that I found useful. It asked: “Do you want your life to be extended?”

In Hong Kong there were advertisements on TV promoting organ transplantation.

It would be important to stress the opportunity to help others.

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

In terms of groups that could play a role in helping educate people about donations, two groups were mentioned. These were religious groups and doctors.

F. Closing

In two of the focus groups, people were asked to share their views on the sessions. Participants in one group noted that it had not been very clear what they were coming to participate in. (A show of hands indicated that only a minority knew what the topic was.) They had been invited verbally and at least one participant had been confused about the starting time. They suggested that a written invitation would have helped.

It would be very clear in a written note instead of just passing it on verbally. That would help especially when you have a big group.

The same group also expressed some confusion about the consent form that was handed out as they sat down. They suggested that, as people didn't necessarily know what they were coming to, it would have been good to have had a brief introduction and then be given the form.

In both groups, people expressed thanks for the opportunity to learn more about organ and tissue donation.

It was very useful.

I got much more information.

Even I could understand it (followed by laughter).

Thank you very much for today.

3.4 Conclusion

The points in favor of saying “yes” to donation or transplantation included:

- Giving to others is an important action in the Chinese community.
- There is a respect and trust in medical authorities.
- Growing trend towards cremation, in which the body is not being buried whole:
More people are now being cremated. So after death, the organs are useless unless donated.
- The impact of a scientific way of viewing the world:
I've been dealing with science and engineering my whole life. So for me, after death, the body returns to nature. Its part of a natural cycle.... it's better to donate as the body will just disintegrate. It's a waste of cells otherwise.
- Donating could bring honour to the whole family.

The points leading to say “no” to donation and transplantation included:

- A lack of information;
- The body needs to be buried whole:
 - in respect for one's parents and ancestors;
 - to be in harmony and balance; and

- to ensure one is reincarnated whole.
- One's life span is preordained and should not be tampered with.
- Age – the feeling that a donation is wasted if one is too old and may not want to continue life.
- Concern for the immediate and long-term health of a living donor.
- Potential impact on one's work life.
- Worry that the donation may go to a criminal or bad person.

While the belief that the body needs to be buried whole was the most common one associated with donation and transplantation, participants also noted that they felt this concept was becoming out-dated and that, with education, it would not be a major barrier to donation. Since this belief was largely attributed to the older generation, participants felt that it was not a big factor for younger people.

Participants were concerned that an individual's wish to donate could be over-ridden by the family at the time of death. This reinforced the importance of a potential donor speaking with his or her family members about the decision to donate.

Finally people emphasized the need for more education about organ and tissue donation and transplantation. Several referred to work done in Hong Kong that may offer some models and approaches that could be used in Canada.

4. GENERAL SURVEY REPORT

4.1 Context

A survey was developed to collect quantitative (and some qualitative) information on the views and perspectives of people in the Toronto Chinese community on organ and tissue donation and transplantation. The survey was available in three versions: English, simplified Chinese and traditional Chinese characters. The majority of surveys were completed in English and/or traditional Chinese – which tends to be used by those with roots in Hong Kong. (Simplified Chinese is used on mainland China).

A consent form was also developed to accompany the survey. The English versions of both the survey and consent form are included in Appendix C.

4.2 Methodology and Tools

The survey was designed to address similar themes as the focus groups, but to obtain more quantitative data. The key themes were:

- A. Awareness of and experience with organ and tissue donation and transplantation
- B. Views toward organ donation and transplantation
- C. Views and traditional values and beliefs which influence your perspective on donation and transplantation
- D. Family/community issues
- E. Support to decision

The survey was piloted with members of the planning committee and several changes were made based on their advice. The survey (and the consent form) was then translated into both

simplified and traditional Chinese. A member of the planning committee reviewed both documents to ensure an accurate and comprehensible translation.

The survey was distributed through community groups and contacts. The survey was meant to be exploratory in nature and not statistically rigorous. As well as word-of mouth, the survey was distributed in the following ways:

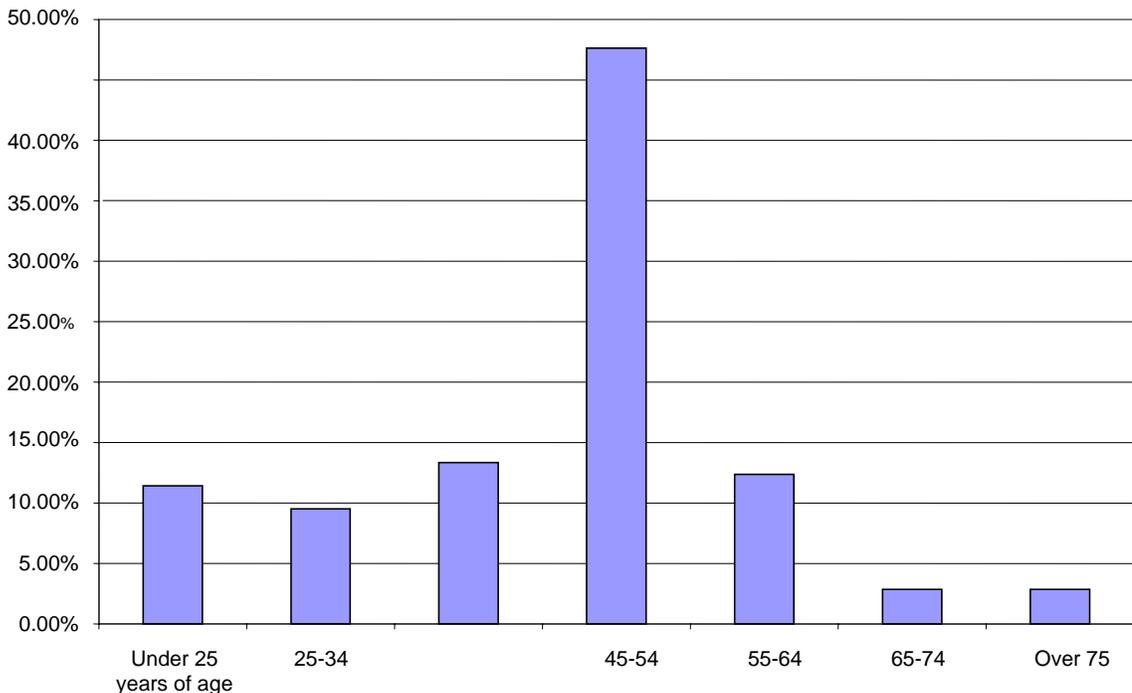
- Scarborough Hospital Chinese Outreach Committee meeting
- Participants in two recreation programs at the Chinese Cultural Centre of Greater Toronto
- Staff, patients and family members at the Scarborough Hospital Hemodialysis Unit
- Members of the Chinese Renal Association
- Youth group meeting at a Chinese Baptist Church

In total, 110 usable surveys were collected and are the basis of the analysis below. The consent forms were also collected and kept separately to safe-guard the anonymity of the respondents.

4.3 Demographics

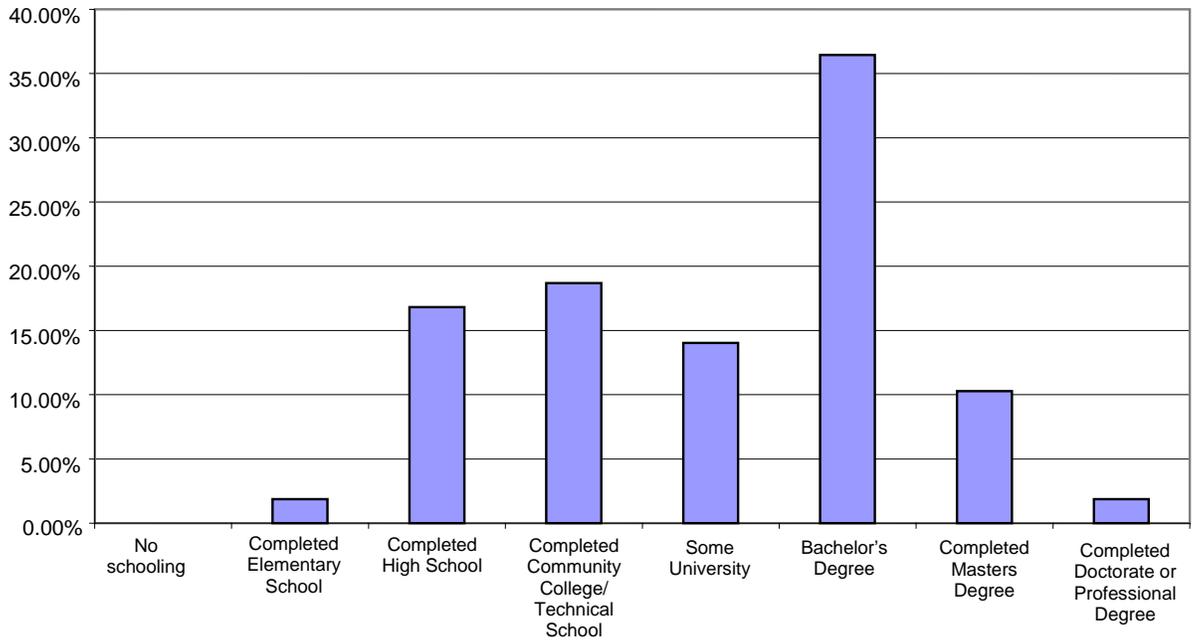
Respondents were 51% female and 49% male. The age range, as the chart below shows, showed a good spread, with 48% being within the ages of 45 -54 years of age.

WHAT IS YOUR AGE?



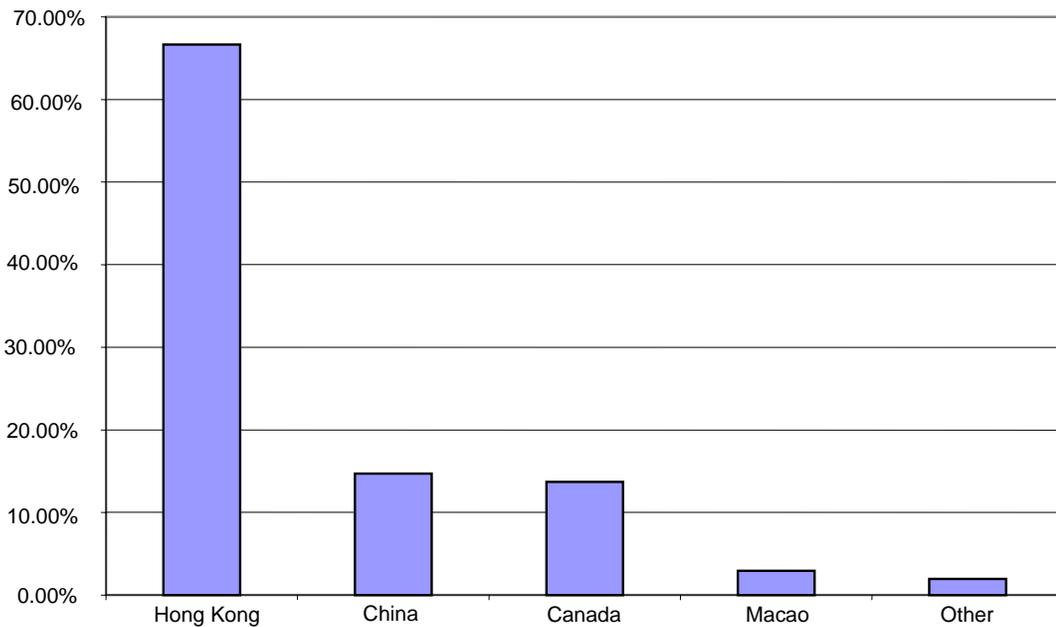
Respondents were well-educated, with 81% having education past high school completion. The following chart provides a detailed breakdown.

WHAT IS THE HIGHEST LEVEL OF EDUCATION YOU HAVE COMPLETED?



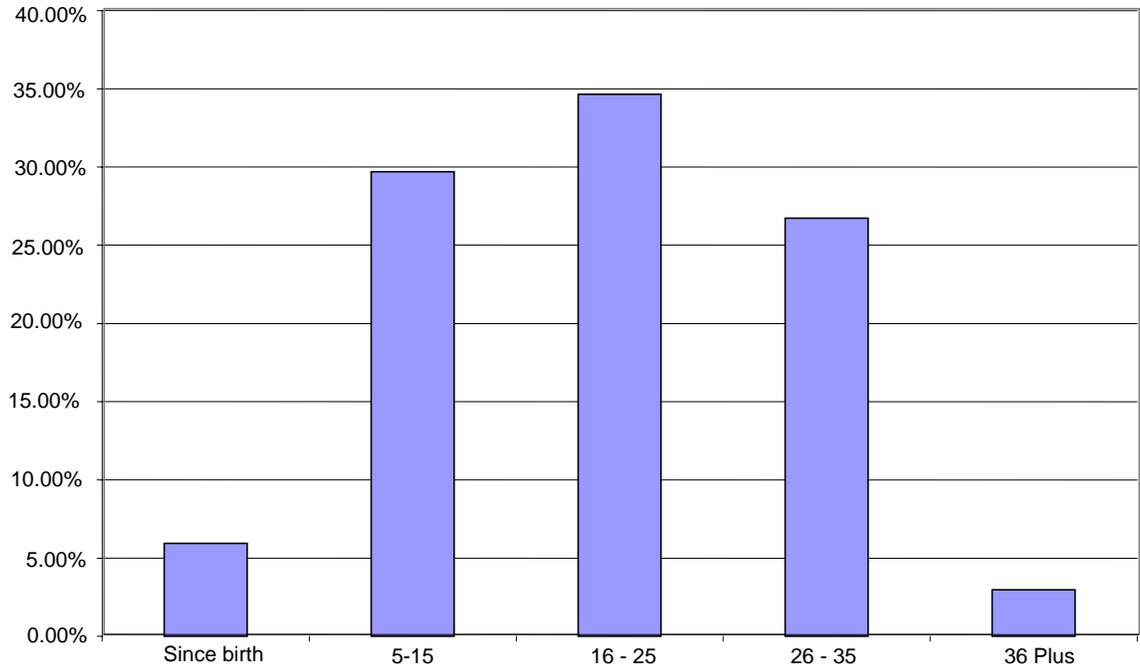
Sixty-seven percent of respondents came from Hong Kong, with nearly 14% indicating that they were born in Canada as the chart below illustrates.

IN WHAT COUNTRY WERE YOU BORN?



The following chart shows the breakdown in terms of the number of years respondents have been living in Canada.

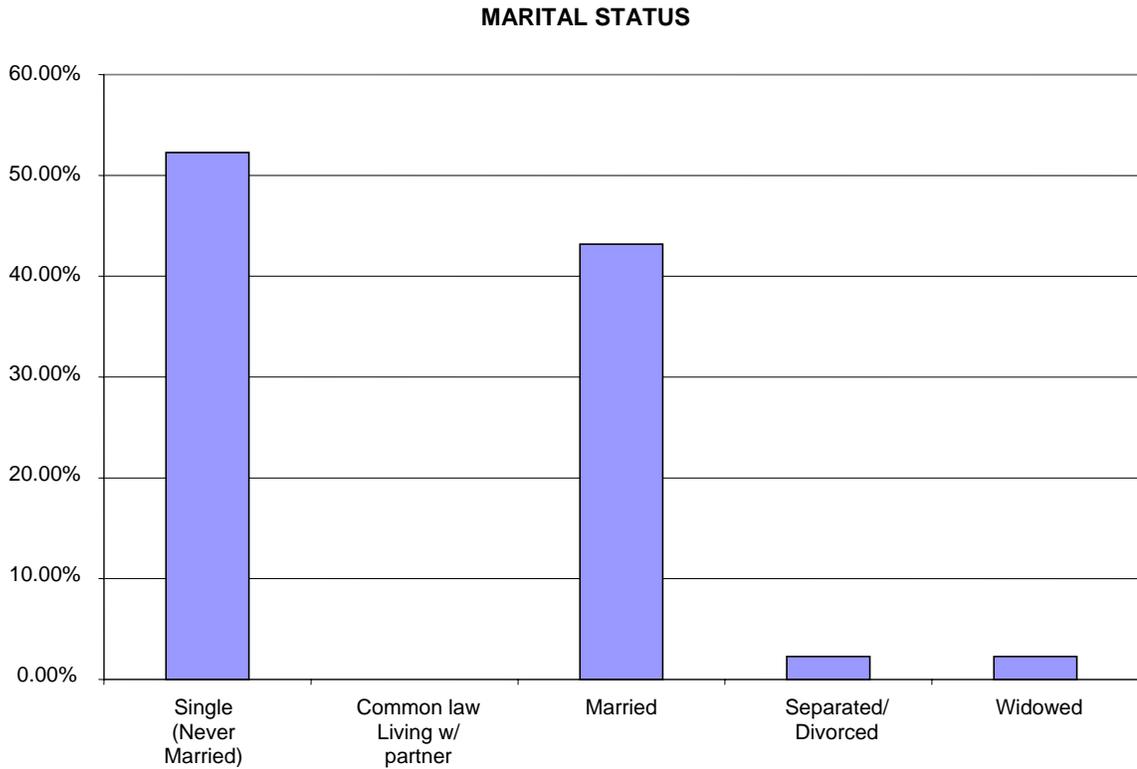
HOW LONG HAVE YOU BEEN LIVING IN CANADA?



Ninety-eight percent indicate that they are Chinese. The remaining two percent indicated that they belonged to other groups such as Asian.

In terms of the mother tongues, for 55% it was Cantonese, with 29% indicating Chinese. Twelve percent indicated English and a remaining 4% noted other languages such as Mandarin.

As the chart below illustrates, 52% of respondents are single and 43% are married.



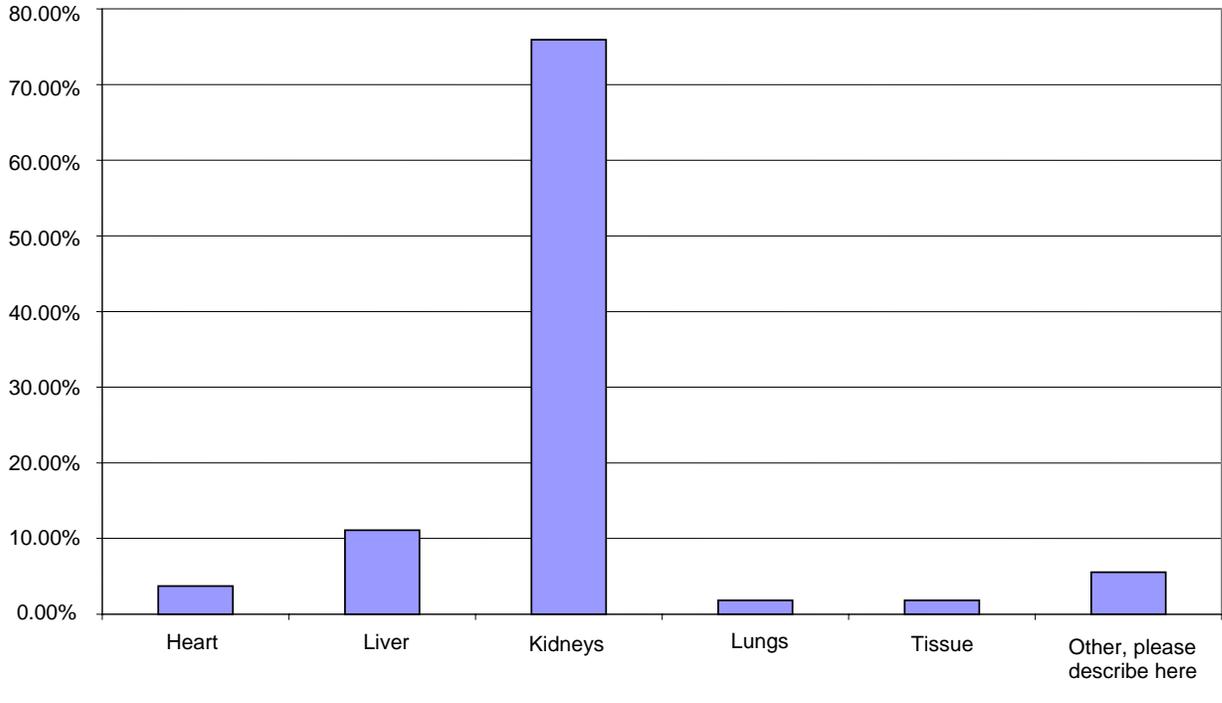
4.4 Results

In reporting on the results, examples of comments are included as they were written on the surveys to provide direct reference to the ideas expressed by respondents.

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

Forty-one percent of respondents indicated that they knew someone who had received a transplant in Canada. Of these, for nearly 76% it was a kidney transplant. The chart below presents the full breakdown.

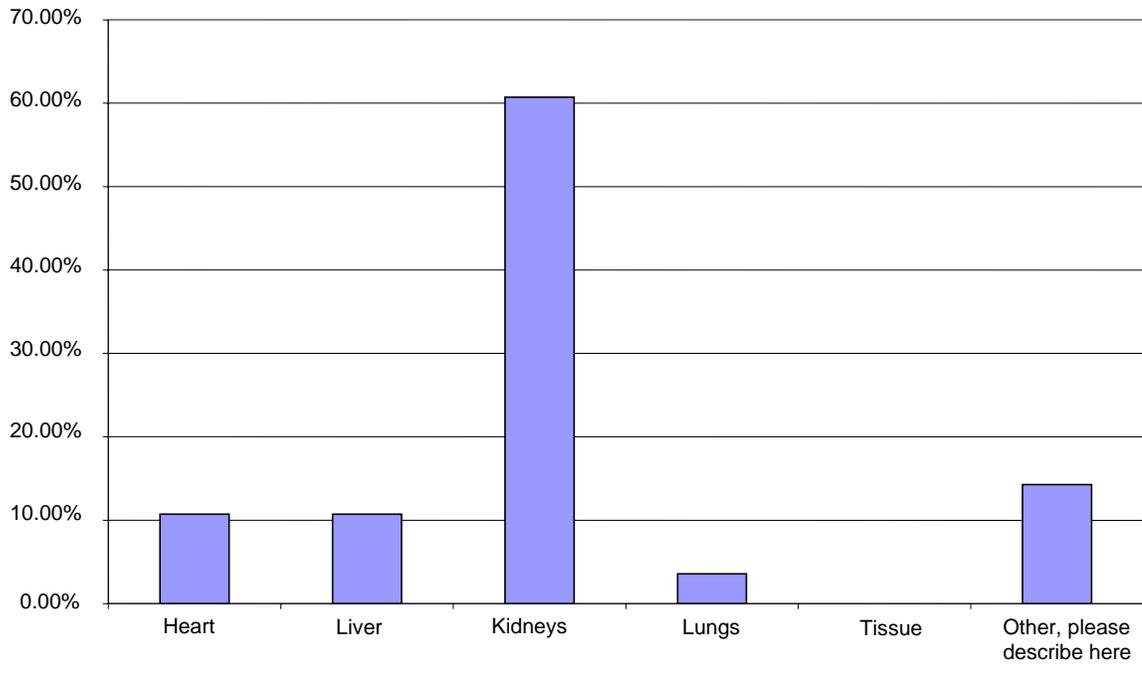
DO YOU KNOW ANYONE WHO HAS RECEIVED A TRANSPLANT IN CANADA? IF YES, WHAT TYPE WAS IT?



It should be noted that the survey data is probably skewed towards people who would have more familiarity with kidney transplants than the general Chinese population might. While this is conjecture on the part of the consultant, it is a reasonable assumption given that the survey was distributed at a haemodialysis clinic and through the Chinese Renal Association.

Only 16 % of respondents knew some-one waiting for an organ or tissue transplant. As the following chart indicates, 61% were waiting for a kidney. The only body parts mentioned under the “other” category were the pancreas and the cornea.

IF YES, WHAT KIND OF TRANSPLANT IS THE PERSON WAITING FOR?

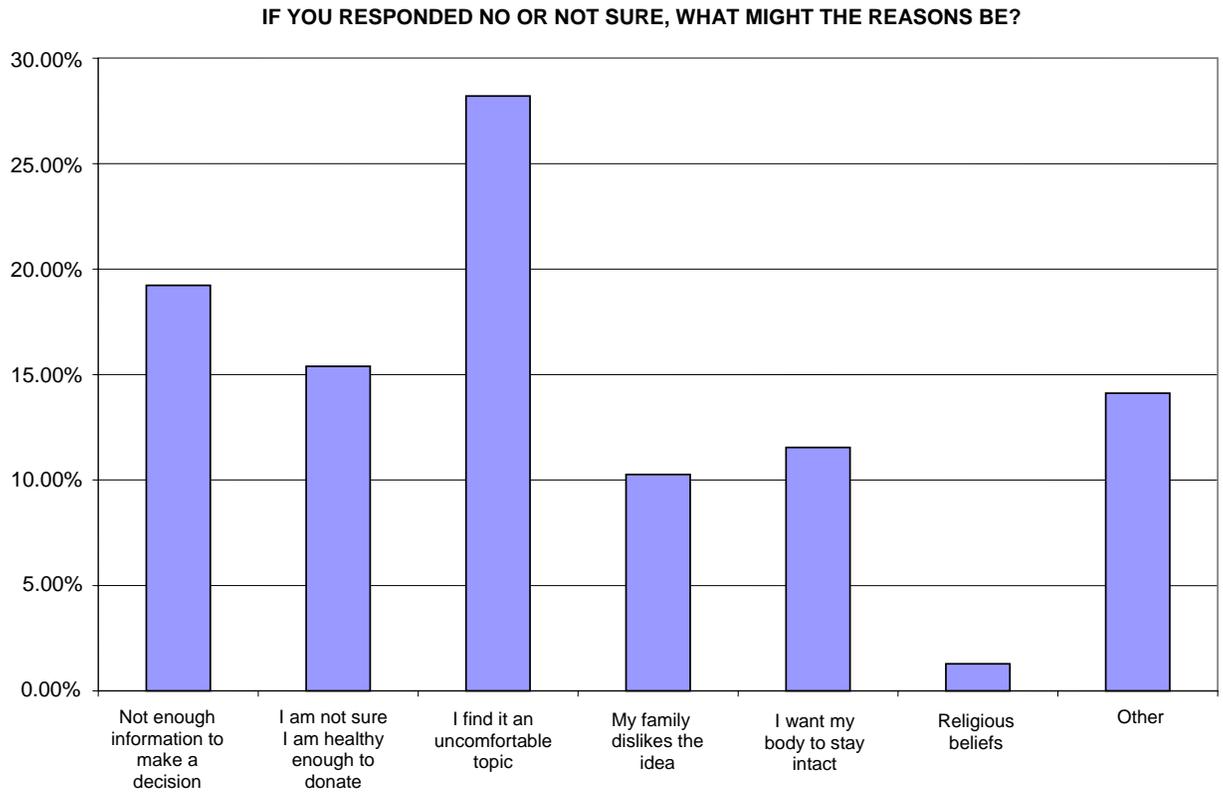


Twenty-eight percent of respondents knew some-one who had donated an organ or tissue.

In terms of the donor card, 78.5% indicated that they knew one could express their intent to donate by completing a donor card. Of these, 35% had signed a donor card.

B. Views toward organ donation and transplantation

For those who had not completed a donor card, 31.5% said they would be willing to do so. 14% were not willing and the majority, nearly 55% were unsure. The chart below provides a breakdown of the reasons people noted if they were not willing or were not sure of whether they would sign a donor card. Interestingly, the highest percentage (28%) was for the reason that it was an uncomfortable topic.



Comments received under the “other” category included:

- Lack of confidence about being given proper treatment
- I am a Hepatitis B patient
- I was told by my physician that I have weak kidneys
- I have never discussed the topic with my family
- I don't have a driver's license so I have not been asked or confronted with the situation
- Psychologically unprepared

Three mentioned that they had just not given it serious thought.

Eighty percent of respondents indicated that they would be willing to accept an organ transplant if they had a chronic disease that led to kidney, liver or heart failure. For those who would accept, people noted that the transplant would extend their life and improve the quality of their life.

Sample comments were:

I would like to accept the treatment because it can save my life and (I could) lead a normal and health lifestyle.

I want to continue to live.

It would help me stay alive longer and allow me to enjoy what life can offer.

Family was another important theme:

I don't want to leave my family behind.

If it can save my life, why not? My family and those who love me will probably be more than glad to see me alive and walking. It is never too much of a concern for me.

I am thinking of my future wife and children.

Three people nuanced their response noting that age would be a consideration:

Depends on my age, before 60 yes, after 60 no!

For those who said they would not receive a transplant, there were two themes. The first was a concern or fear for oneself or the prospective donor:

I am afraid of an organ transplant operation.

I do not want some-one to get sick because of me.

Depends on the kind of treatment.

The second theme was a fatalism or sense of predetermined destiny, which included feeling that one was too old for the transplant:

Leave the chance to others as I have enjoyed a good enough life already.

No I won't consider because of age.

I have decided to prepare for the worst.

Finally, there were three respondents who indicated that they had not given the issue sufficient reflection to respond.

I have never thought about accepting a transplant because I don't have any of the medical problems.

This is a matter that requires consideration so until the occasion or need arises, I don't think about it ahead of time. Such matters trigger a lot of emotional reactions.

Meanwhile I'd rather spend my emotion/attention to keeping myself healthy so I won't need an organ donation.

The majority of responses to the open-ended question: “What are your current views about organ and tissue donation and transplantation?” were positive. There were several comments made showing respect for those who have made a donation.

I think that organ transplantation is one of the greatest progresses in life-saving medical science. I am expecting that it will save many more human lives.

I really prize organ and tissue donation and transplantation

It is acceptable.

Anything that can save a life is good.

I think it is a great idea to donate everything when I have no use for it anymore.

I honestly believe that all organ donors are angels.

Those organ donors are great people.

I think donors are very compassionate, generous and courageous.

Several people indicated an overall positive response, but then had a concern or two – a “yes, but” type of response.

It is a good means to overcome organ failure, but I worry about not being given proper treatment.

Safety is my major concern.

I am willing to donate my body but it would be very hard if I had to make a decisions to donate the body parts of my loved ones (husband or children).

I am not sure if I would be willing to donate if I were still alive as I would fear that my own quality of life would be compromised.

Good, but I want to know if I can have an open casket if I donate certain parts.

Necessary, but hopefully we will be able to grow organs soon or have better artificial replacements.

I find it strange, but necessary.

For those who viewed organ and tissue donation and transplantation negatively, some of the concerns were medical-related. For at least one, it was a more fundamental belief.

I worry about the success rate of organ transplantation.

How long can the recipient survive after the transplantation?

I don't encourage healthy people to donate organs because the donor and the recipient have the same human right.

I'm afraid of the process – how does it work?

Long waiting lists, complication of rejections and side effects of medicines

Organ and tissue donation and transplantation disrupt law of nature. There is no dignity if the person is already dead and yet cut open and has organs removed.

A common theme that emerged in the response to this question was that of public education. It was specifically mentioned by at least eight respondents.

I think more awareness is necessary, especially towards youth

Requires more public education and real life examples.

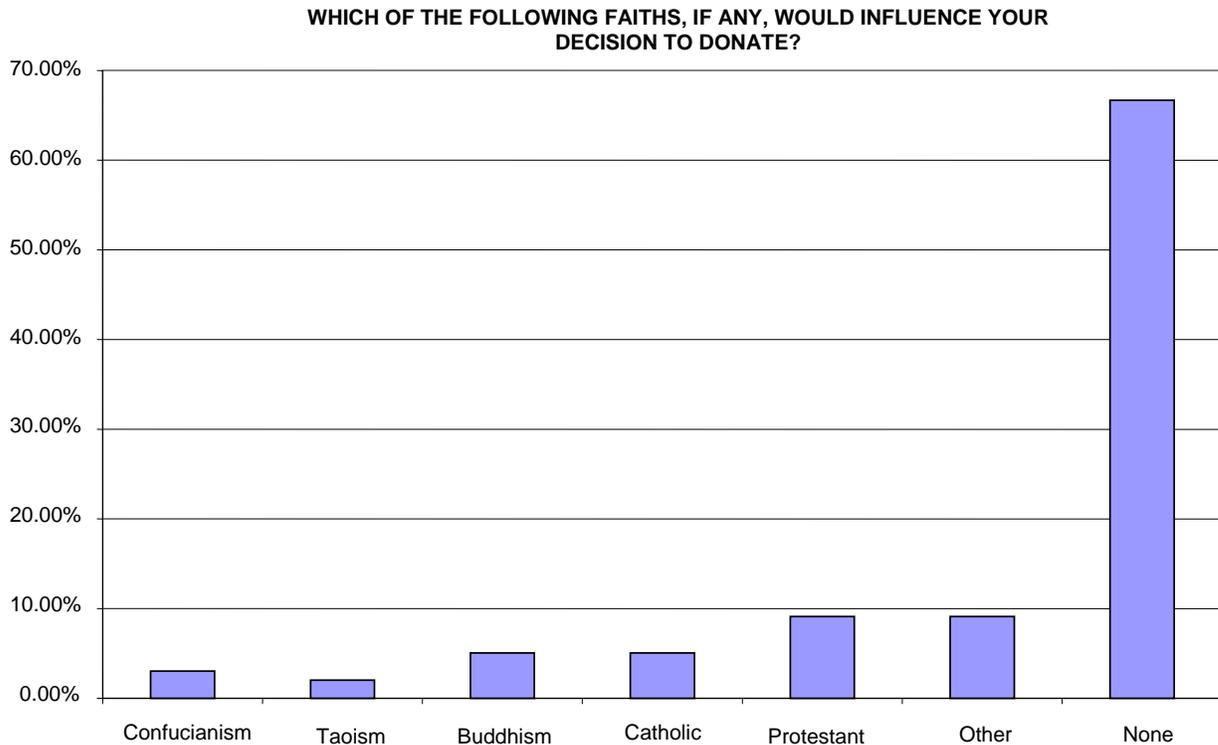
There needs to be more promotion to encourage people to give.

The Ontario government needs to do more work on promoting and publicizing organ donation.

C. Views and traditional values and beliefs which influence your perspective on donation and transplantation

Sixty-seven percent of respondents indicated that their decision to donate would not be influenced by any particular faith. The chart below gives the full breakdown. It is important to underline that this question does not indicate the respondents' faith, but whether or not their faith would influence their decision. The most common "Other" was Christian.

As a further reinforcement of the lack of influence of faith on their decision to donate, 78% responded that they would not talk to their religious or spiritual leader about organ and tissue donation and transplantation.



Five key themes emerged from the responses to the open-ended question: “What are the most important beliefs/concerns (religious or non-religious) that influence your perspective on organ donation and transplantation?”

The first and most common theme (mentioned by 11 people) related to beliefs that were motivating and positive in terms of organ donation:

It’s a gift of humanity.

With regards to Christianity, I suppose understanding that our bodies and life is a gift; plus the underlying principles of love and therefore helping other generously.

To give is better than to receive; everything is in God’s hands.

To help some-one without sacrificing the other.

Love and helping those around us.

I believe that the donation of organs is an act of kindness and shouldn’t be in conflict with my Buddhist faith.

A second theme encompassed the view that the body was of no use after death and that therefore donation was acceptable. This was mentioned by three people.

The body is useless after a person is dead.

The third theme, mentioned by six people, was the importance of being buried whole. For some this was based on tradition, while for others it was the fear of being dismembered.

The belief in a bodily (not just a spiritual) resurrection!

In our culture and tradition, people believe that the body should remain intact on death.

I see the importance of having my body intact.

I could not imagine myself being dismembered and treated as some kind of material without respect. Sorry, I have such an impression because I have witnessed such a situation before.

Have seen corneas being removed – very disgusting.

My belief that I would feel the pain and would hate the person cutting me apart.

The fourth theme related to health concerns.

I am frightened by the thought of an organ transplant and the difficulty of undergoing such an operation.

I concerns me is that I smoke and drink. Will that make my organs unhealthy to donate?

Whether I would be healthy enough to donate.

The final theme related to family and was specifically mentioned by two people.

It is probably the decision of my family. Having a Chinese family background, I can imagine that it would take some time to get approval for my decision to donate.

My parents’ concerns

A few people expressed an unwillingness to respond to the question either because of a lack of information or because of a seeming discomfort with the idea.

I am afraid of making any comments on this topic.

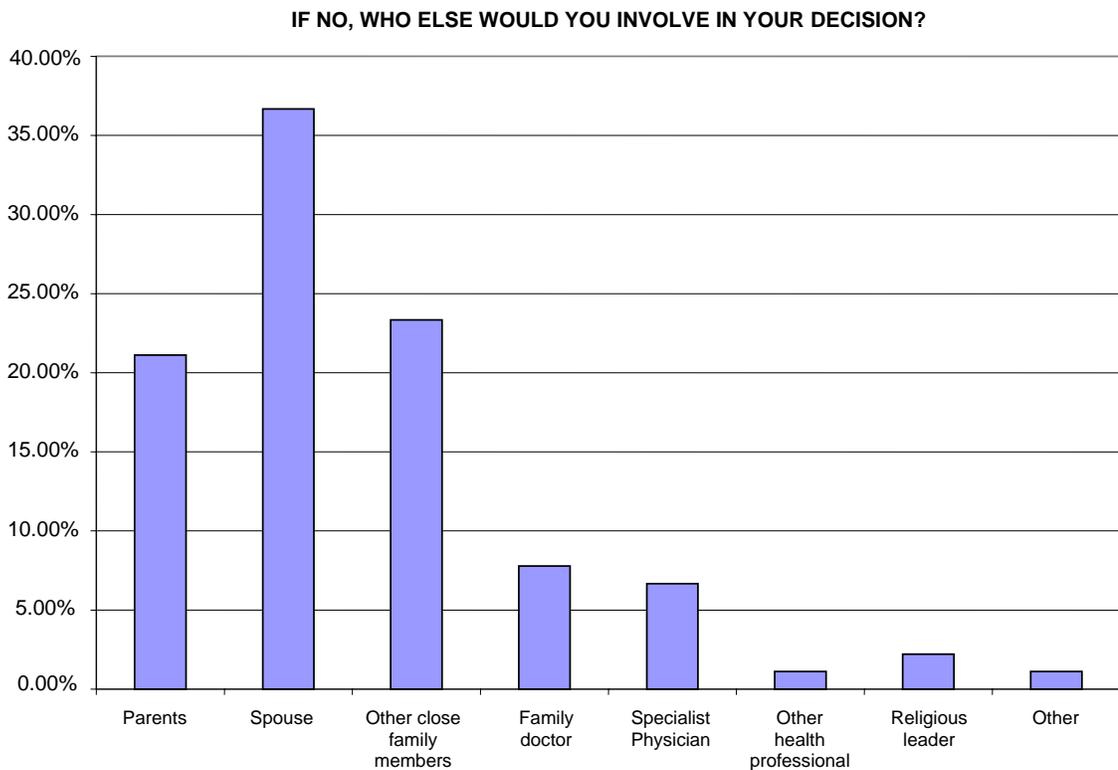
I don't want to give a hasty answer to this question.

Who sets the priority? For whom? To whom? Is there any quality or fairness? For richer or poorer, let's say?

Finally a few people reiterated that they have no religious beliefs that would influence their decision.

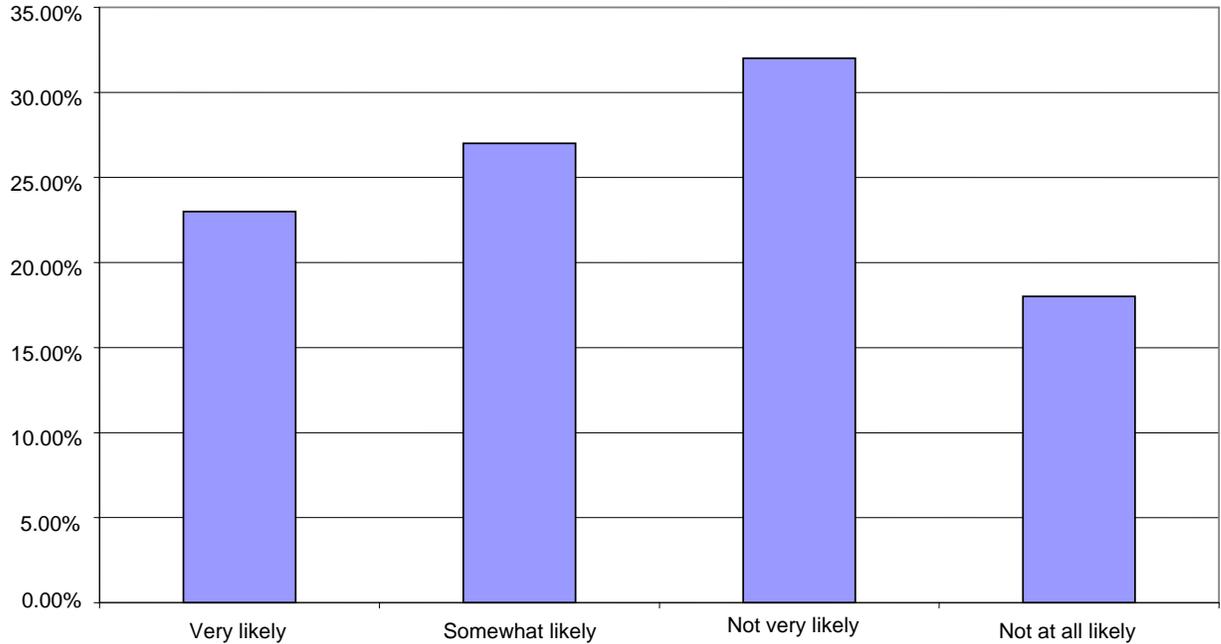
D. Family/community issues

Sixty-six percent of respondents indicated that they thought the decision to donate was a personal one to be made by the individual alone. Of the 34% who thought it should involve others, 81% felt that family (spouse, parents, and other close family members) should be involved. The chart below presents the breakdown.

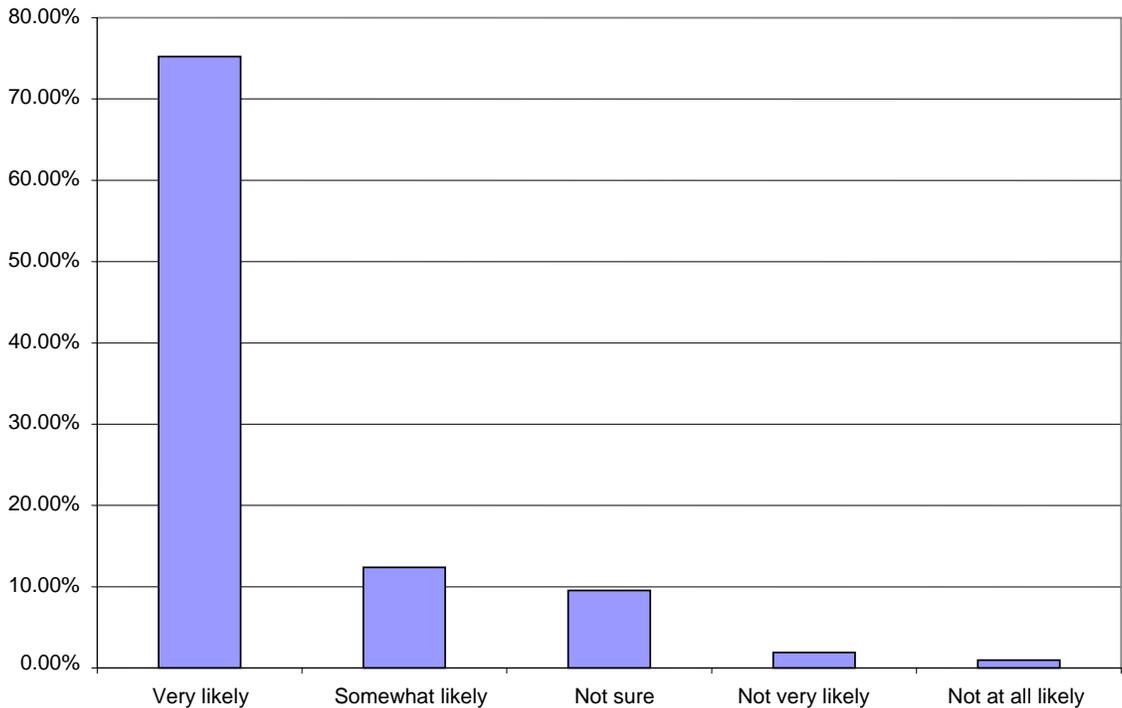


The next series of questions related to how willing family would be to donate a deceased one's organ under different situations. The following charts present the detailed results.

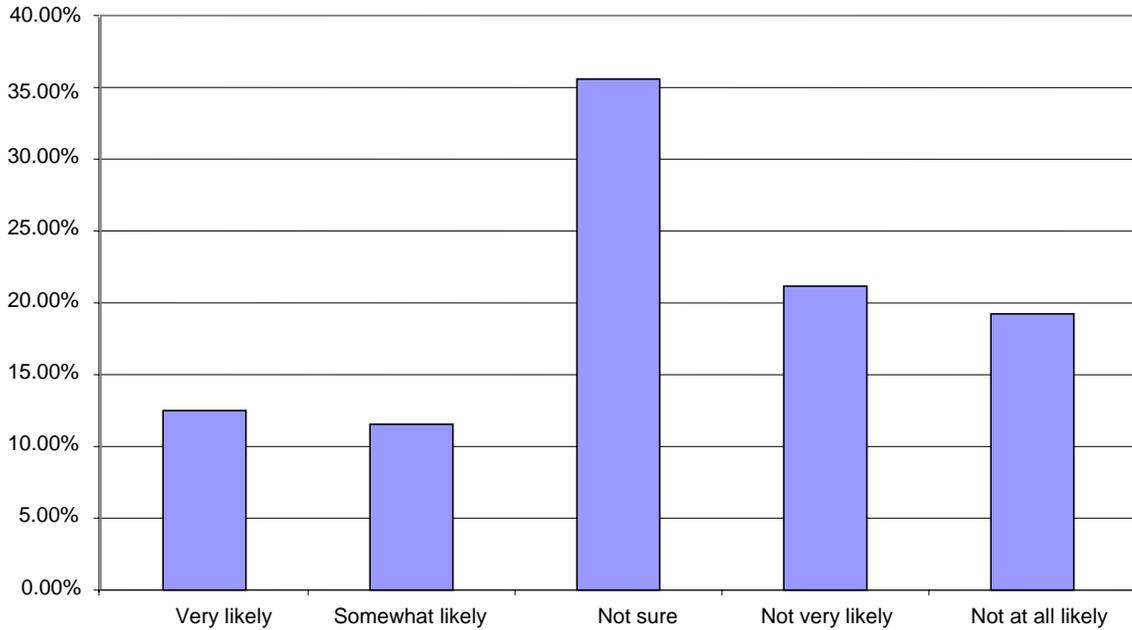
THAT YOU WANT TO DONATE AN ORGAN OR TISSUES UPON YOUR DEATH, HOW LIKELY WOULD YOUR FAMILY BE TO DONATE YOUR ORGANS OR TISSUE FOR PURPOSES OF TRANSPLANTATION?



IF A FAMILY MEMBER HAD REQUESTED THAT THEIR ORGANS OR TISSUES BE DONATED UPON THEIR DEATH, HOW LIKELY WOULD YOU BE TO DONATE THEIR ORGANS OR TISSUE?



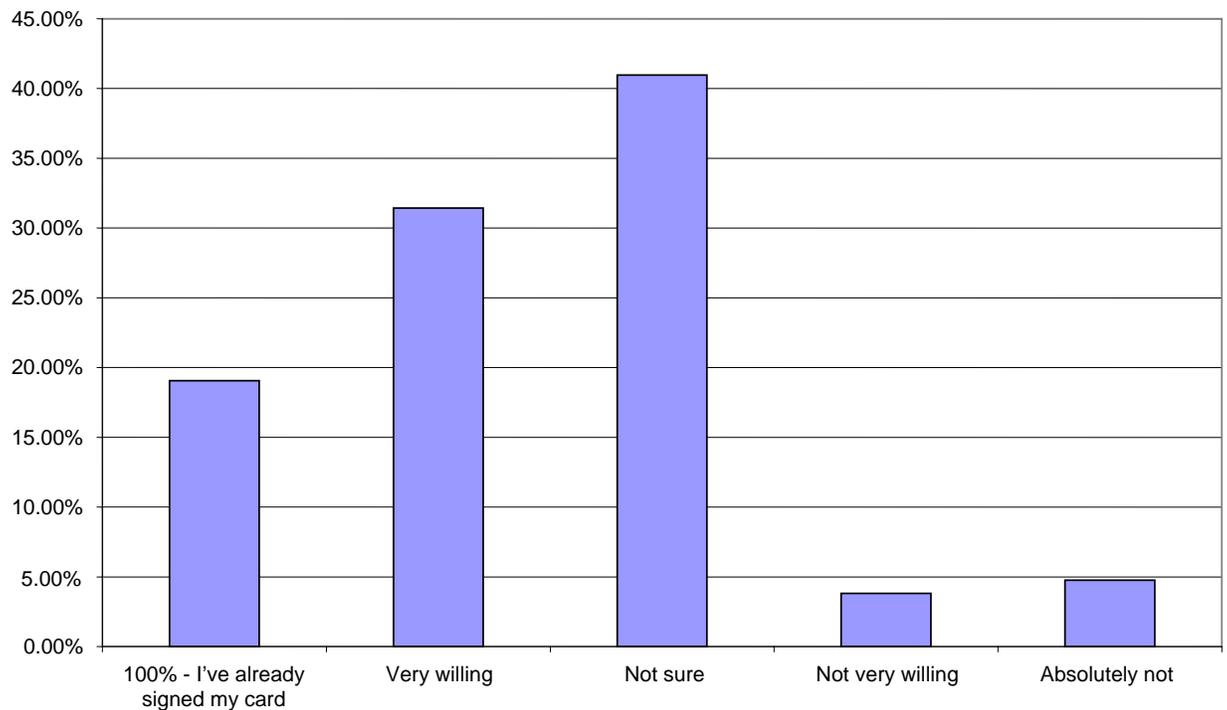
DONATION WITH YOU, HOW LIKELY WOULD YOU BE TO DONATE THEIR ORGANS OR TISSUE UPON THEIR DEATH?



It is interesting that 75% respondents were very confident that their family would respect a family member's decision to donate, with a further 12 % saying it would be somewhat likely. This is a strong affirmation of the respect for an individual's decision, which came up strongly in the focus groups as well.

Half of respondents indicated that they either had or were very willing to sign a donor card. The chart below gives this breakdown. Twenty-four percent said they would place some restrictions on their donation.

HOW WILLING WOULD YOU BE TO MAKE AN ORGAN OR TISSUE DONATION UPON YOUR DEATH?



Two people mentioned particular body parts they did not want donated and for one of these it was concerns about the health of the organs. Seven people stated that their condition was that the body not be used for experimentation or medical research.

Only for transplant, not for medical study

Not for experimental purposes

Donation for research if it helps with furthering knowledge about a disease. No donation for teaching internal anatomy.

Five people placed restrictions on the possible recipients.

The condition is not to donate any organs to bad people (e.g. prisoners)

I don't want my organ given to criminals, terrorists, etc.

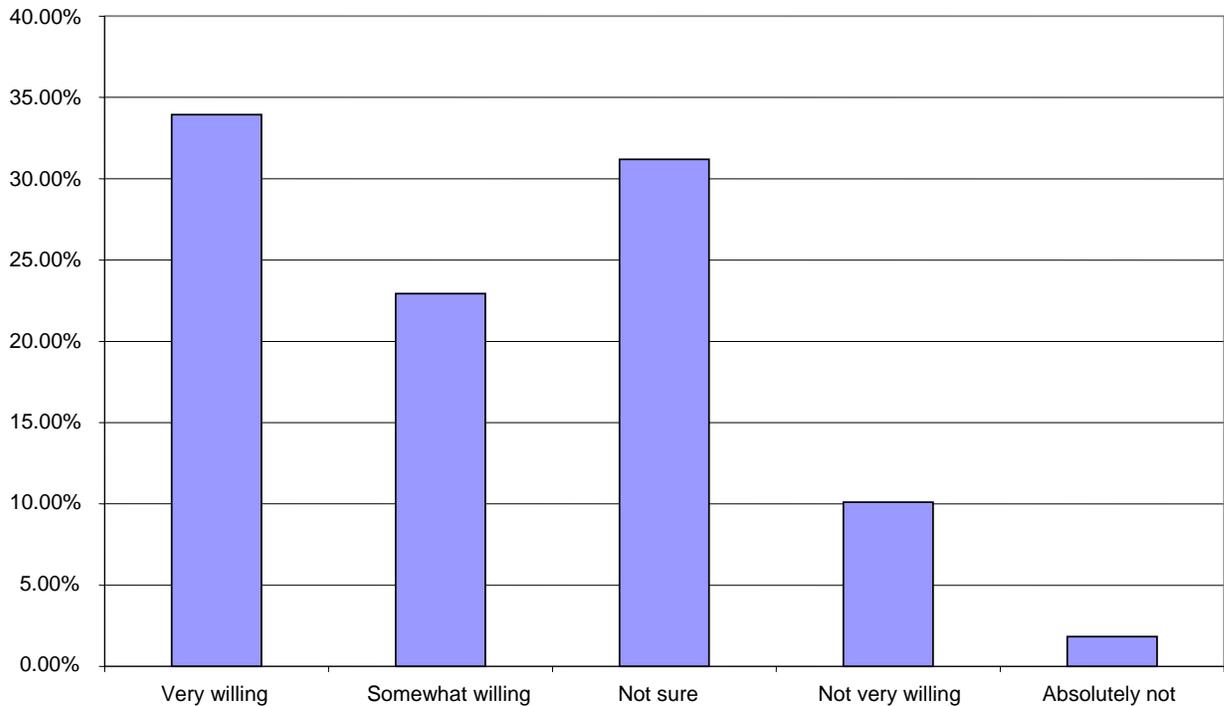
If it is a lung, that the person doesn't smoke. If it's a kidney, that the person doesn't drink.

I would like my organs to be donated to kids first.

Two people mentioned the importance of respecting and keeping the rest of the body intact.

Fifty-seven percent of respondents indicated that they would be very or somewhat willing to make a living donation. The chart below presents this breakdown.

HOW WILLING WOULD YOU BE TO MAKE A LIVING DONATION (E.G. DONATE A KIDNEY OR PORTION OF A LIVER TO A FAMILY MEMBER OR RELATIVE?)



A resounding 88.5% indicated that it would be OK for a family member to accept a donation from someone who is not of Chinese descent. People’s comments for the most part reflected the view that it was the compatibility of the donated organ and not the ethnicity of the donor that mattered.

As long as the organ is compatible with the recipient.

Racism is an unacceptable prejudice.

Race doesn’t matter as long as it matches.

Origin of the organ in irrelevant.

Life is more important than ethnicity.

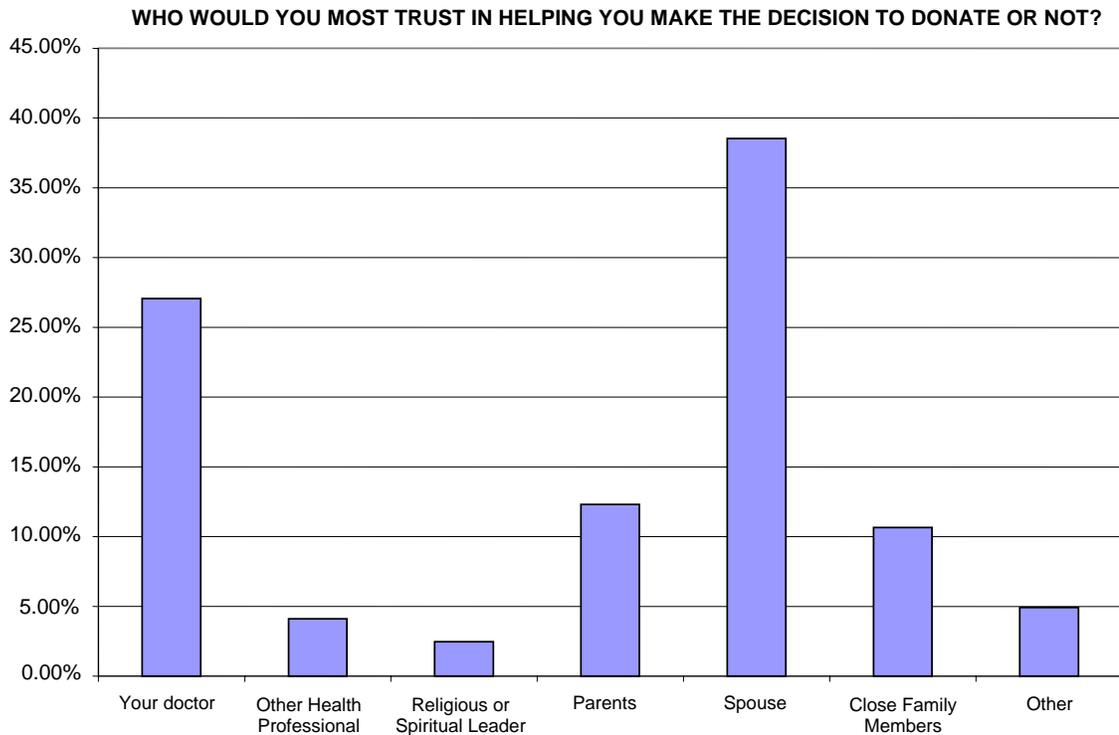
For the 11.5% who said it was not OK, their comments included:

I am very conservative about this matter.

Only if there isn’t any other choice.

E. Support to decision

Thirty-eight percent of respondents indicated that they most trusted their spouse in helping them make the decision to donate. For twenty-seven percent it was their doctor. The full breakdown is given in the chart below.



Fifty-eight percent believed that they had enough information to make a decision about being a donor. Of the remaining 42%, the type of information they required tended to group into three areas. The first was information about the medical procedure involved, including the operation itself and the impact on one's health.

How does the operation happen to me and how does it impact my health after the operation?

How long does it take? How painful it is? How do they repair the body?

Risk, side effects and length of life after transplant.

The second area of information was about the donor process.

Is there an age limit on organ donation or transplantation?

My own health status.

How do I know if my organs are healthy enough for other people? Or will some-one check that?

How the match is made? Any obligation to get in touch between the two parties? Will the background of the donor be revealed?

Basic information

Psychological information

Can organs be sold legally?

The need – tell me why it's needed, what other options are available, the number of people in need.

The final area of information relates to the state of the body after the organ(s) have been removed.

I would like to know how they will treat the rest of my body. I still want my remains to look good and be in one piece, even if they take things out of me.

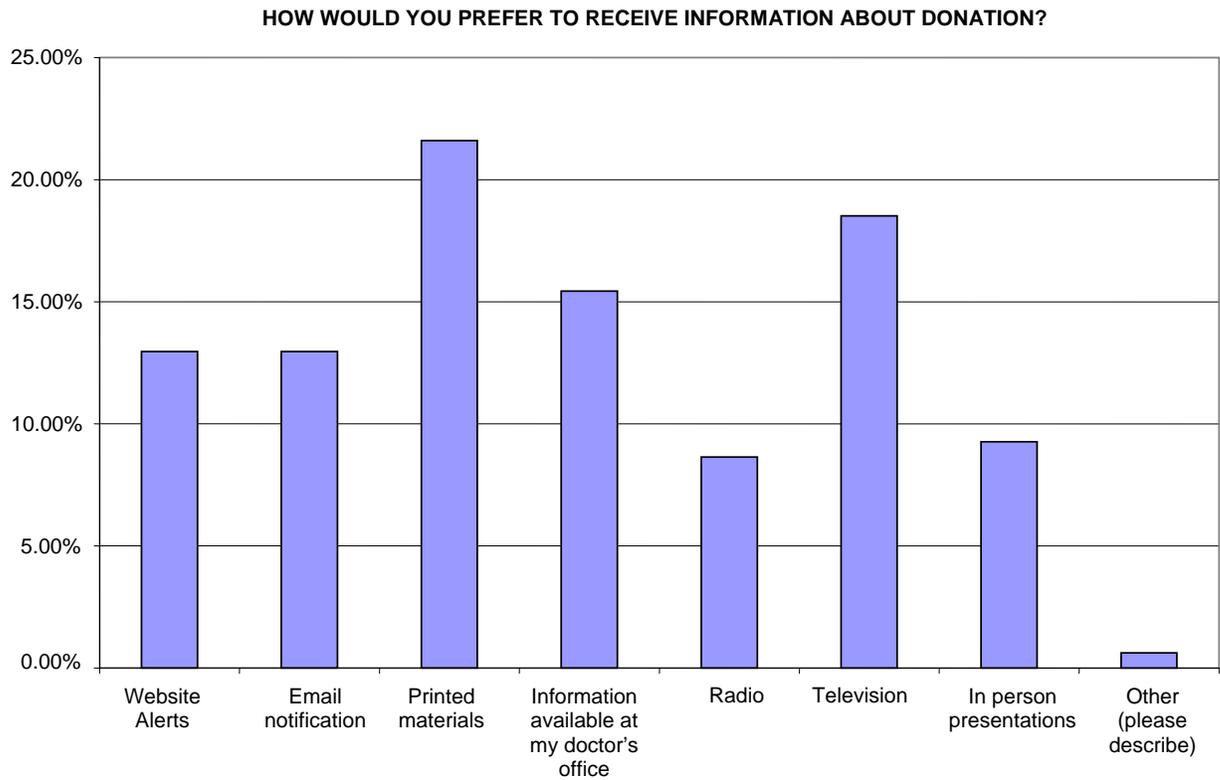
Which organs can I donate and still have an open casket.

One person commented that he or she would need to know:

What my faith says about this topic.

Finally people were asked how they would prefer to receive information about donation. Twenty-one percent said printed materials, with television running a close second at 18.5%.

The chart below gives the complete breakdown.



4.5 Conclusion

In general the views expressed about organ and tissue donation and transplantation were quite positive, with a higher level of awareness than was present in the focus groups if one uses knowledge of donors or recipients as an indicator. This may be partly due to the survey distribution at points such as a haemodialysis clinic which touches upon a patient group for whom transplants are a more immediate reality than for the general population.

For a strong majority of respondents, faith and family did not seem to play a predominant role in taking a decision to donate or not. There was a strong sense that it was the individual's decision to make, but once that was given, then spouses and doctors were trusted sources to help make a decision. Likewise, three-quarters of respondents felt that family would respect a family member's decision to donate if one was deceased.

The views and beliefs expressed about organ and tissue donation and transplantation echoed for the most part those of the focus group. There is perhaps one exception to this, which is a concern about the medical practice that surrounds donations. Fears about pain, about whether every effort would be made to keep a potential donor alive, about respect for the body in terms of its treatment by medical practitioner, were revealed in the survey. However it should also be noted that these were fears expressed by only a small proportion of the respondents.

5. PHYSICIAN SURVEY REPORT

5.1 Context

The planning committee recommended that a survey be developed for family physicians serving the Chinese community in Toronto. This was a unique contribution to the Diverse Communities Project as it was the only time when family physicians were specifically-targeted. In large part, the support for this research component came from a doctor who was Chairperson of the Journal Club of Chinatown Physicians.

5.2 Methodology and Tools

A survey was developed that focused on the following three themes:

1. Advisory role with patients
2. Toronto Chinese-Canadian community
3. Future opportunities

The survey asked questions of physicians in their professional capacity. They were not asked for their personal beliefs about organ and tissue donation and transplantation. A consent form was also prepared. The survey and consent form are provided in Appendix D.

The survey was piloted with a member of the planning committee and subsequently revised. It was made available in English, based on the advice of the planning committee member.

The survey was distributed at a dinner meeting of the Journal Club of Chinatown Physicians, to which members of the Uptown Doctors Association had been invited. The meeting was co-sponsored by the Canadian Council for Donation and Transplantation and Trillium Gift of Life Network. This was an important opportunity for both these organizations to make contact with family physicians.

Upon arrival and registration, physicians were given the survey form to complete. There were then two presentations on organ and tissue donation and transplantation, followed by a question and answer period. Most physicians had completed the survey before the presentations but surveys did continue to come in through-out the evening.

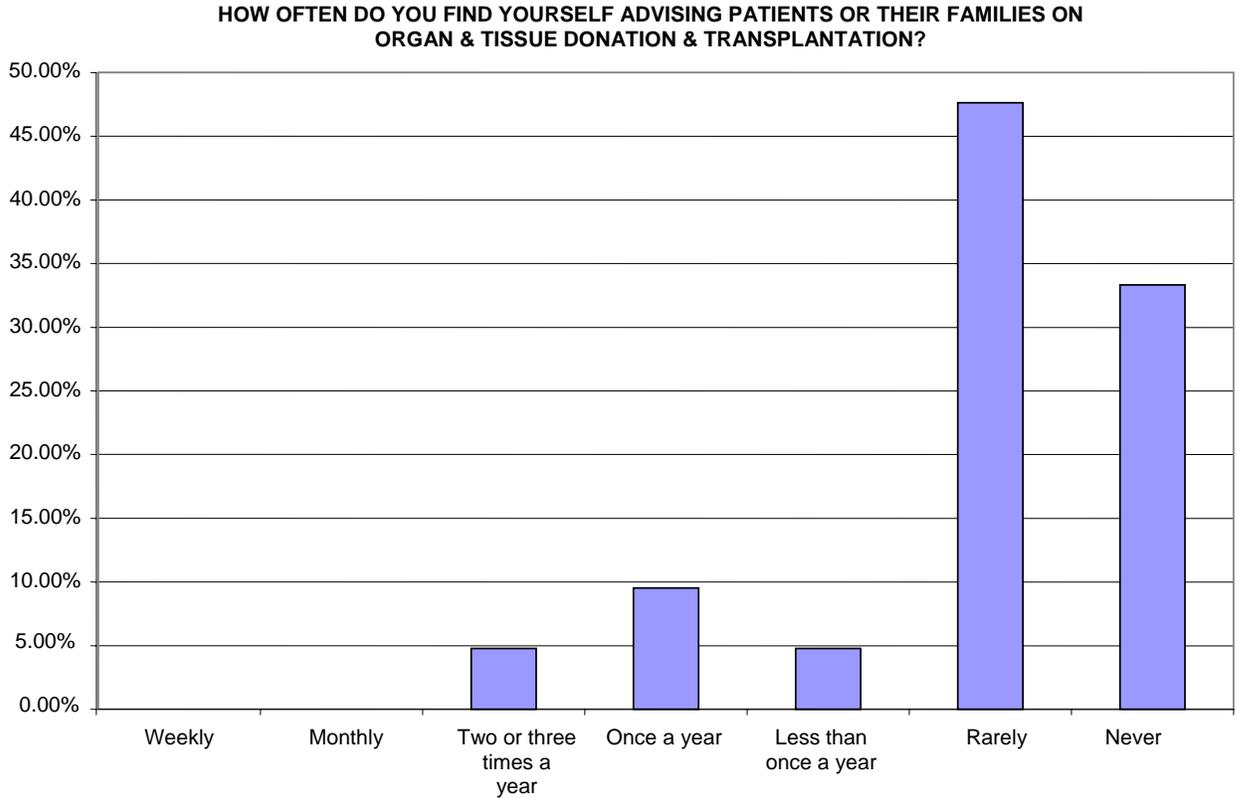
5.3 Results

Twenty-two physicians completed the survey. These were all Chinese family doctors, whose patients, for the most part, were from the Chinese community in Toronto. For many, it was one of their first times to get specific information about organ donation and transplantation and to have the opportunity to meet with people knowledgeable and active in this field.

In reporting on the results, comments are included as they were written on the surveys to provide direct reference to the ideas expressed by respondents.

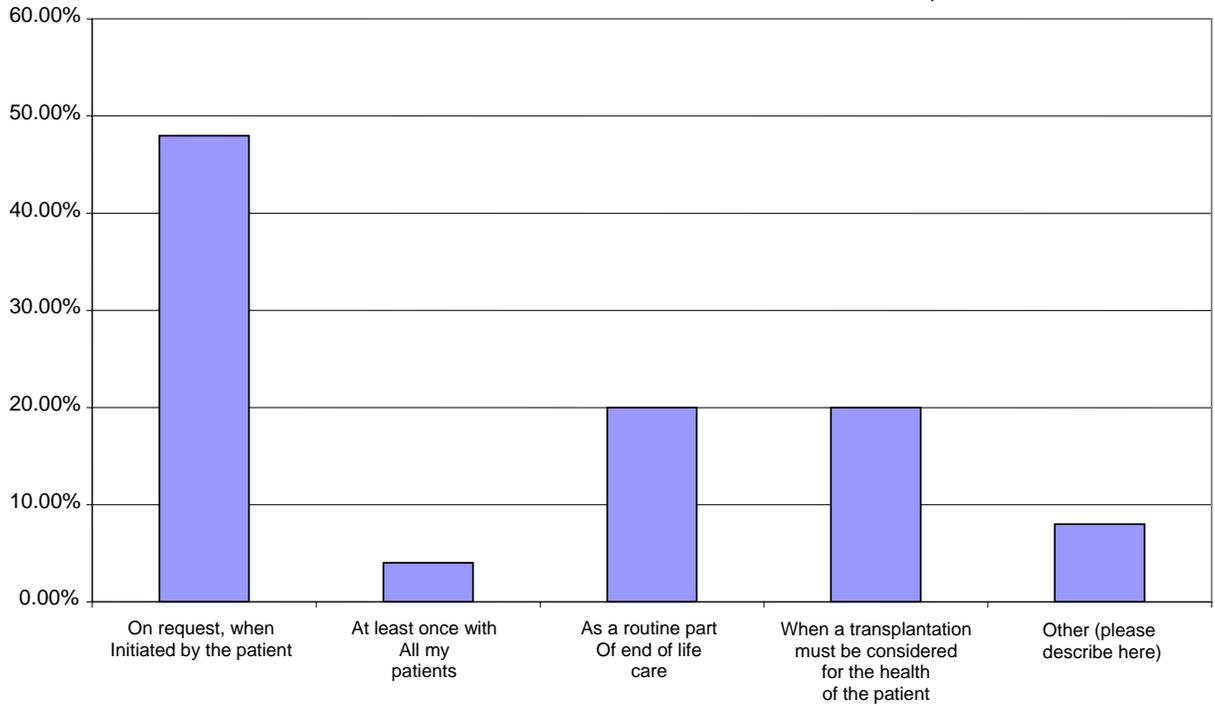
A. Advisory Role with Patients

Ninety one percent of respondents said that it was important for physicians to discuss organ and tissue donation and transplantation with their patients. However as the chart below illustrates, the opportunity to do this were rare or did not happen at all.



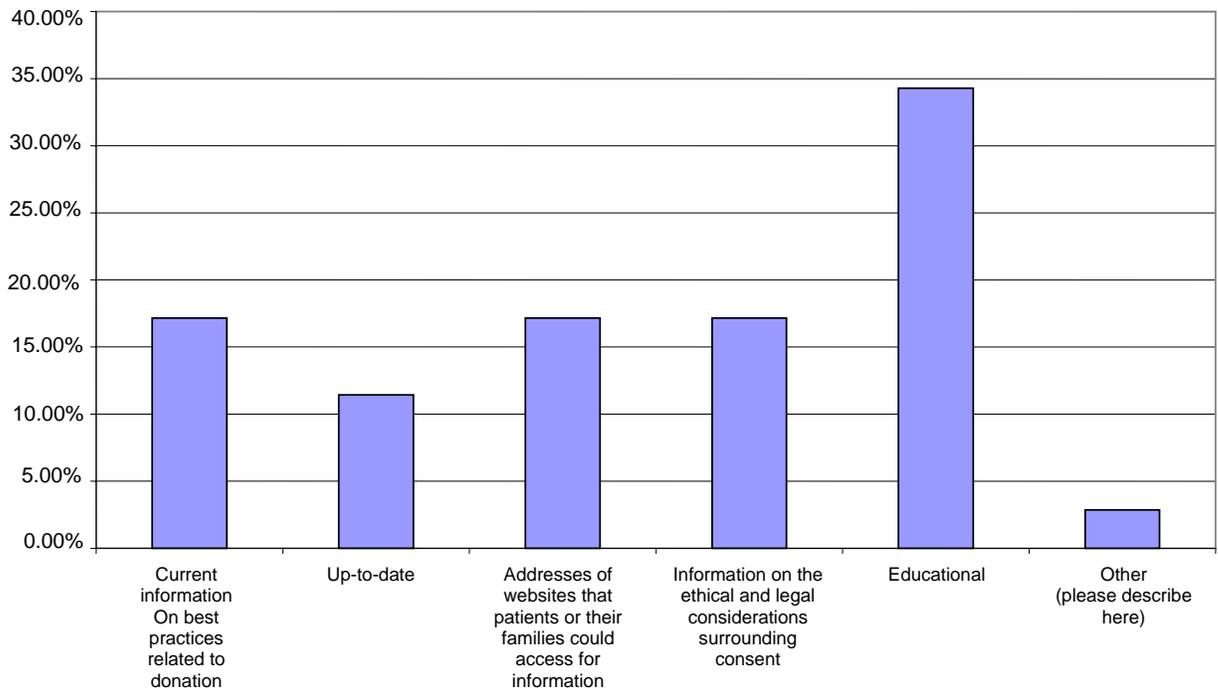
When asked to identify when it was important to discuss organ and tissue donation and transplantation with patients, 48% indicated on request by the patient, as the chart below illustrates. One doctor commented that it would be useful to talk about organ and tissue donation and transplantation with all first year drivers.

DO YOU THINK IT IS IMPORTANT FOR PHYSICIANS TO DISCUSS ORGAN & TISSUE & TRANSPLANTATION WITH THEIR PATIENTS? IF YES, WHEN?

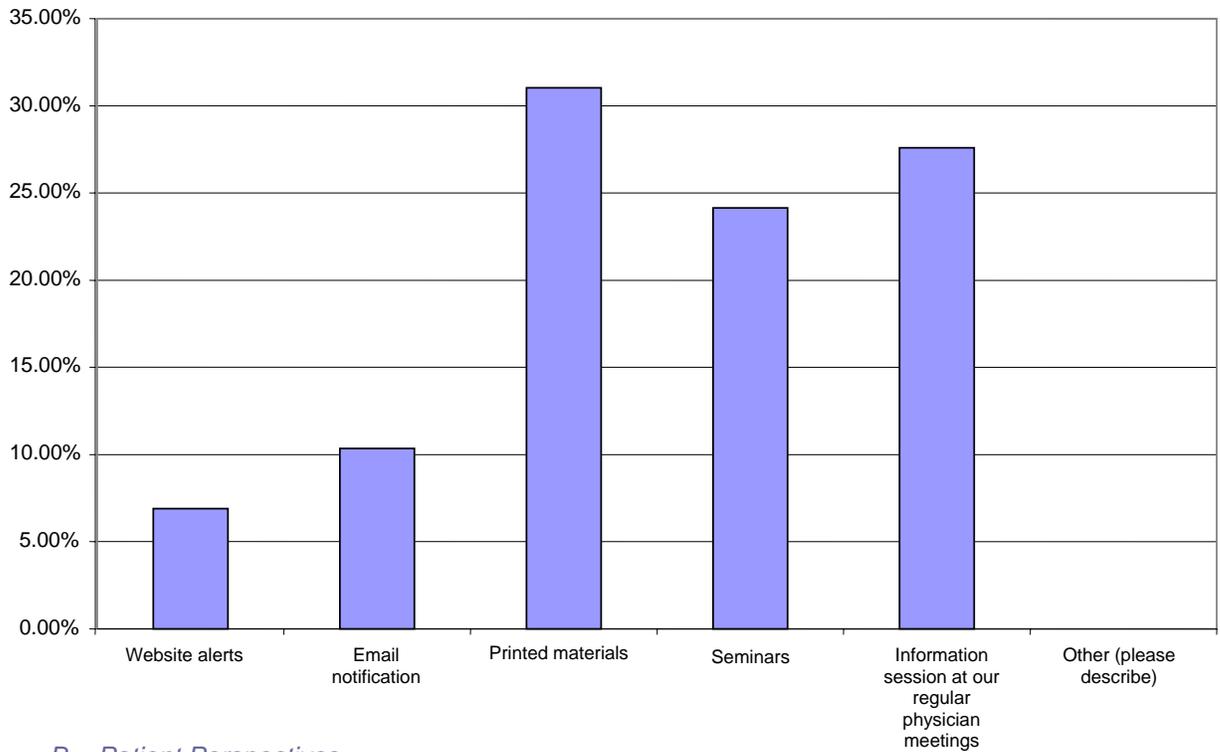


The following charts provide an indication of the information family physicians would find useful to help them advise their patients and/ or families. Comments included that educational material for patients should be available in Chinese. One suggested that patient information provided on a pad that allowed the physician to tear off a page of information to give to the patient would be useful. Another respondent suggested the production of a professionally-made video for physicians.

WHAT TYPES OF SUPPORT OR INFORMATION WOULD HELP YOU TO ADVISE PATIENTS AND/OR THEIR FAMILIES ABOUT ORGAN AND TISSUE DONATION & TRANSPLANTATION?



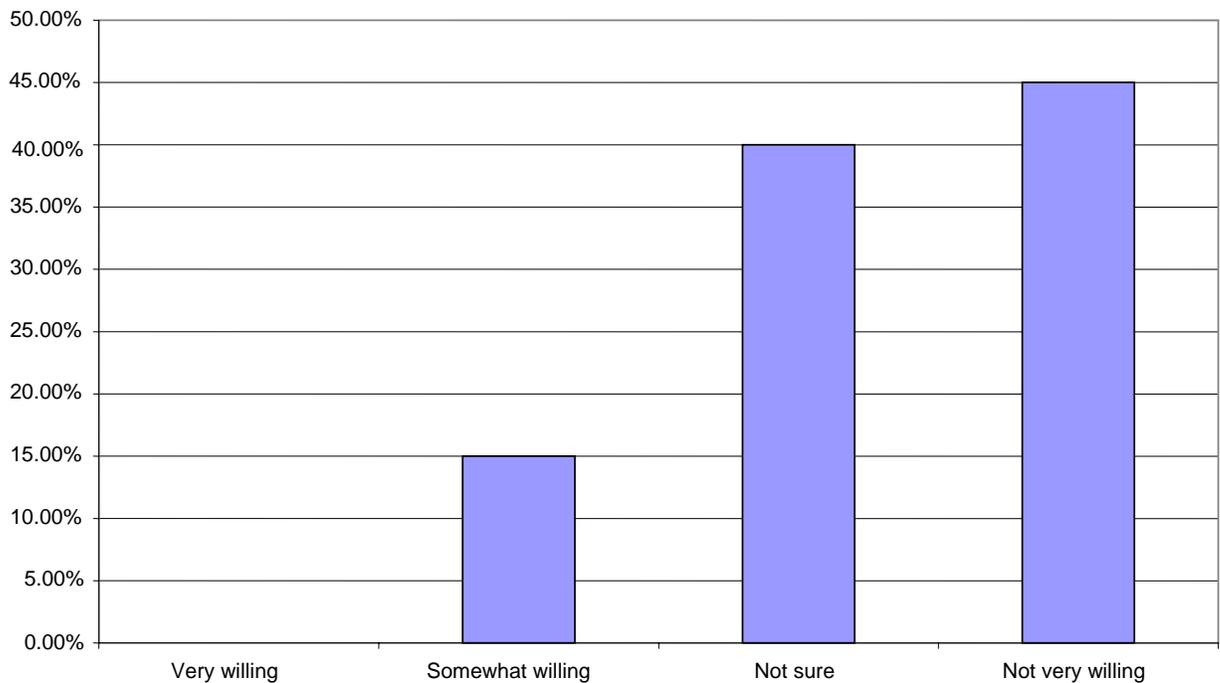
HOW DO YOU PREFER TO RECEIVE INFORMATION?



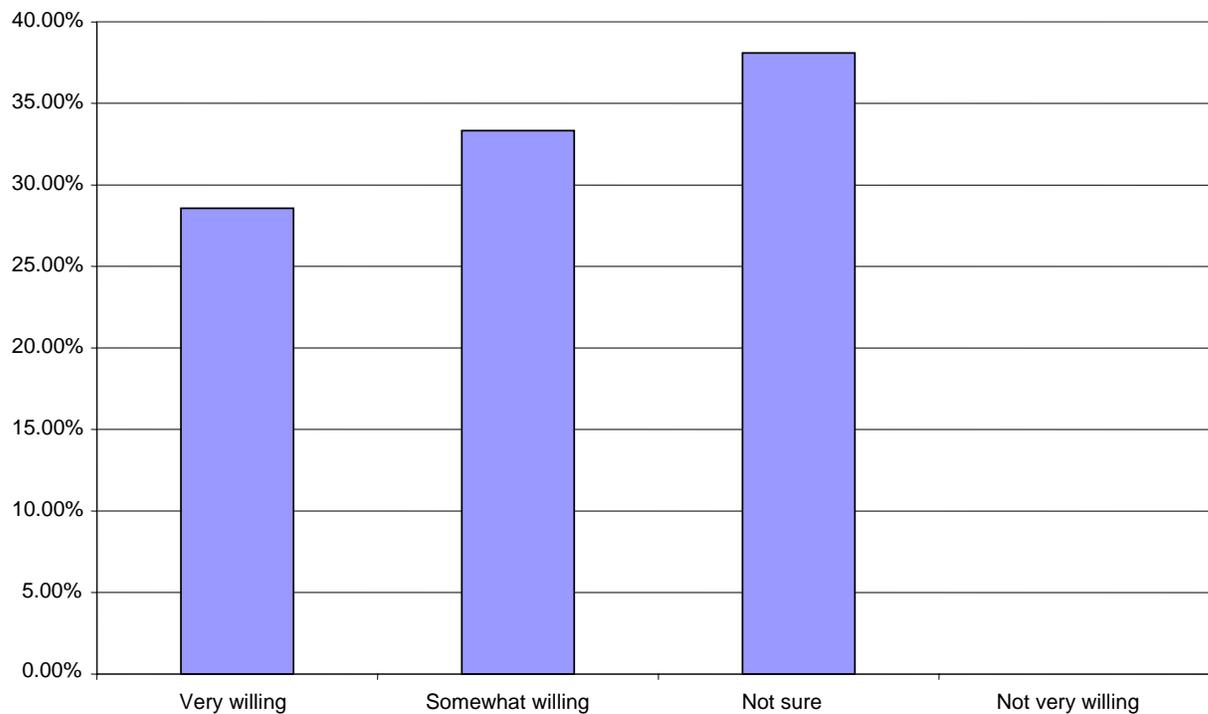
B. Patient Perspectives

As the charts below indicate, 45% of respondents felt that their patients would not be very willing to sign a donor card. However 62% indicate that their patients would be very or somewhat willing to accept and organ and/or tissue donation. In the response to both these questions, there are a high number of physicians saying they are not sure what their patients’ reaction would be. This reinforces that finding that family physicians rarely discuss organ and tissue donation and transplantation with their patients.

CANADIAN COMMUNITY ARE TO EXPRESS THE INTENT TO DONATE BY SIGNING A DONOR CARD?



IN GENERAL, HOW WILLING WOULD YOUR PATIENTS BE TO ACCEPT AN ORGAN OR TISSUE DONATION?



Of the 22 respondents, nine mentioned the tradition of the body being buried whole as one influence on patients' perspectives on organ and tissue donation and transplantation. Other comments, mentioned once each, were:

They are afraid of having another person's organs in their own body, even though it may save their life.

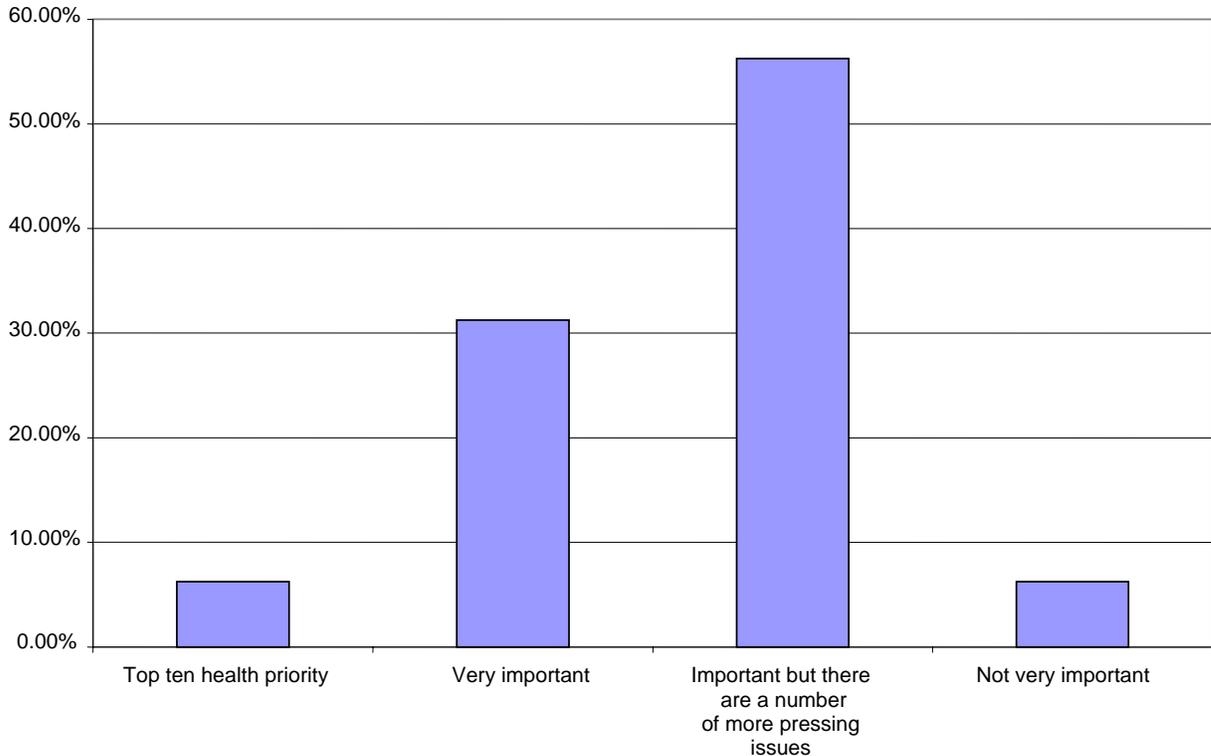
Chinese are accustomed to doing without. If there is no available donor, it is meant to be.

There is a fear that doctors may not give them the best care if they are a potential donor, letting them die instead so their organs could go to another.

The majority of respondents (56%) commented that the issue of organ and tissue donation and transplantation was important but that there are a number of more pressing issues. The response breakdown to this question is shown below. One commented that:

With population size and growth, the need will increase.

HOW IMPORTANT IS THE ISSUE OF ORGAN DONATION & TRANSPLANTATION FOR THE CHINESE-CANADIAN COMMUNITY IN TORONTO?



C. Future Opportunities

Eighty-one percent (81%) of the respondents felt there was a role for family physicians in making it possible for people within the Toronto Chinese-Canadian community to have more informed opportunities to consider donations.

Five commented that one of the roles of family physicians would be to talk to their patients:

Medicine is based on scientific knowledge. As a doctor, one knows donation/transplants are part of current medical treatments available to patients. Thus a family doctor can explain it to their patients in a rational way.

Tell the patients that there are many Chinese on the waiting list.

Show them how urgently the organs are needed.

More open dialogue that dispels “myths’ about organ removal and donation.

Tell the patients old organs are useful too. Make it a routine in patient registration to discuss donation.

Other comments included:

Open the concept to the young members of the Chinese community (born in Canada).

The Journal Club publishes a “Health Digest”. An article about organ donation might help.

The patients who are elderly may think about donation but most have multiple illnesses: therefore would need an exclusion list of patients who are not suitable donors.

There were a number of suggestions as to other actions that could be taken to increase the level of donations. Public education through the media e.g. newspaper, TV, talk radio shows, was mentioned by seven respondents. Two suggested public forums, one suggesting that high school students be targeted. Other comments included:

More communication with doctors as a reminder.

Government passing a law to make donation the norm, unless family objects or the patient has a written objection.

Government education for the public, e.g. ads, brochures

Quote people who have been saved by donation; presentation by a recipient is always impressive

Promise patient that you will dispose of the body for free.

Ask the public to speak to their GP about organ donation

Education materials in the waiting room.

Make it a concern for the family members. Have the donor card available in Chinese.

When asked if there were important research questions that need to be addressed in the area of organ and tissue donation and transplantation, 37% responded yes and 37% responded no. Examples of possible research given were:

What is the outcome of the recipients' quality of life and their feedback?

Practical results

Research telling patients that side effects of transplantation are now less and less

Results of different organ transplants.

Finally 48 % of respondents indicated that there are other associations of Chinese-Canadian physicians to get in touch with. Names provided were: Chinese Canadian Medical Society (CCMS), Federation of Chinese-Canadian Physicians (FCCP), Agincourt Chinese Family Physicians, Scarborough and Mississauga.

5.4 Conclusion

From this small sample of family physicians, it would appear that organ and tissue donation and transplantation is rarely, if ever discussed with patients. However there is a willingness to do so, if more supports and information could be made available both for patients and for physicians. Education, both for the public and with the physicians, would be important.

In terms of beliefs that might influence organ donation, the one mentioned most currently is the same one that arose most frequently in the focus groups and the general survey – that the body should be buried whole. A new concern mentioned was distrust in doctors – which they might not provide the best possible care if a donor recipient was waiting. This was a minor refrain in the general survey but did not come up in the focus groups.

One of the objectives of the survey and dinner was to make contact with family physicians and begin a process of relationship-building with them as contributors to patient education. It is therefore interesting to note that three of the physicians have already contacted Trillium Gift of Life to offer to volunteer in some capacity. Another half a dozen have called to request further information.

6. PROCESS LEARNINGS AND RECOMMENDATIONS

One of the aims of the consultation was to provide input on processes that work for engaging the Chinese-Canadian community. This section captures some of the key learnings from this process and offers some process recommendations for future work.

Working with community groups and associations.

A key part of the strategy was to build relationships with the Chinese-Canadian community that could continue into the future. The establishment of the planning committee was essential to this process, as was the extensive collaboration with Trillium Gift of Life. These contacts provided the entry point into the Chinese-Canadian community and brought with them a certain level of trust. This was very important - especially for the focus groups. The invitation was made by people the participants knew in the language of choice, the sessions were held in familiar environments and, in the case of the Yee Hong session with the seniors, staff was present to support participants. Similarly the fact that the dinner for physicians was hosted by the Journal Club of Chinatown Physicians gave the event an immediate profile and comfort level – physicians knew the type of event they were coming to as it was set-up in the model of their regular meetings. The surveys too benefited from the connection with community associations, either as a point of distribution or as a reputable reference point.

The potential weakness in relying on community contacts for outreach is that there is a narrowing of the potential pool of participants to those who are already known to and/or engaged in the group or association.

By and large, the approach of working with community groups went well. However, a number of improvements could have been made and lead to the following recommendations (noted in bold):

- **Ensure an adequate time frame.** Working with community groups is time-consuming and their priorities are not always the sponsors⁵. They must fit the work into already very full workloads, and often in situations where staff is already over-loaded. Volunteers may be assisting.
- **Formalize expectations and roles.** Different community groups have different levels of resources and ability. The clearer the sponsoring organization can be about its requirements the better. Even in collaboration, it is useful to have a clear differentiation of tasks and in some cases, a contract is useful. For example, in this process, the expectations about participant recruitment for the focus groups were not clear. For the sponsor, there was an expectation that the community groups would provide a list of participants and volunteers to call for each focus group. But for the community group, this didn't make sense, as there was a trust relationship between themselves and the prospective participants. They would have needed to call the prospective participants anyway to let them know some-one else would be calling, so there was no time saved. However, if time had permitted, the letter of invitation could have possibly gone out from the sponsor once participants had been confirmed.
- **Recognize that “control” is being distributed.** Community groups have their own ways of working and engaging with their constituency. Not only are time frames different, but also the way people work may be different. The sponsor needs to be flexible. There are strong benefits to be gained, not least of which is the language capacity.
- **Ensure good follow-up.** While this project is not yet complete in terms of follow up, it is important that this be planned for in advance. Certainly distribution of the results in one form or another would be a minimum expectation. There were good and valuable linkages made for future work. For example, important connections were made with at least one Chinese physicians association and these are already bearing fruit in terms of volunteers for TGLN. The

⁵ Sponsors or sponsoring organizations, in this case, refers to CCDT and/or the consultants it contracted.

connection with the Yee Hong Centre, with its constituency and health focus, could be a very strategic ally in any education program about organ and tissue donation and transplantation.

Language

There were three verbal languages used in the consultation: Cantonese, Mandarin and English, and three written languages: English and simplified and traditional Chinese. This was challenging for the sponsor's implementation team (e.g. consultants, facilitator) who were all English-speaking. A good trilingual translator was essential both for written and verbal translation, which was necessary for the focus groups and for some of the points of distribution of the survey. For the everyday work of implementing the consultation:

- **Have the appropriate language capacity on the team.** One member of the implementation team, at least, should be fluent in the appropriate language(s). While the consultation did work without this, the onus was on those from the community groups or planning committee to work in English in the organization of the consultation. In addition, because of the limited time for each focus group, the translator at times needed to paraphrase people's comments and some of the nuances might have been lost to the facilitator and researchers present. A team member who was fluent in Cantonese could have recorded these nuances.

Respect of Chinese culture

One of the guiding principles for the process was to respect the traditions and culture of the Chinese community. In large measure, because of the good advice from the planning committee and the community groups, this was done. One strong example was the dinner for the Chinese physicians, where the importance of food to Chinese culture was well-respected and appreciated. However, with more forethought, improvements could have been made, e.g. not planning the consultation so close to the Chinese New Year.

- **Consider cultural customs and food.** For the Chinese culture, food is important. Gifts were also an important and appreciated component.

Consultation methodologies

The consultation methodologies of surveys and focus groups were recommended by the planning committee. It is not clear that these were chosen because of cultural considerations. It is possible that they are simply familiar consultation practices that most people know about. The methodologies were adequate, although a survey, which is primarily a quantitative tool, does have limitations in terms of getting a fuller understanding of beliefs and views. For that, the more participatory focus groups were required. Although there was a concern that people may be reticent in terms of expressing views or disagreement, this was not evident in the focus groups. Most people expressed themselves freely and openly. However a written participant evaluation was not done, where people who might have felt inhibited could have commented on this. This form could also have captured demographic information from participants.

There was some confusion about the consent forms that accompanied both the surveys and the focus groups. For those completing surveys, there was a concern that this could affect the anonymity of their response, especially if they were faxing back the survey. In the focus groups, some people felt that the consent form was consent to donate. Perhaps this would have been less confusing if the invitation letter and consent form had gone out in advance.

- **Have a written evaluation form.** While verbal evaluations were done at the focus groups (and these were positive), a written form would have allowed for more personal feedback.
- **Use consent forms judiciously.** As this consultation was exploratory in nature and was not intended to be research-rigorous, the consent forms may not have been necessary. They were somewhat off-putting for some participants.

7. OVERALL CONCLUSIONS AND RECOMMENDATIONS

Beliefs and Views

There were several beliefs discussed that could serve as a barrier to organ and tissue donation and transplantation. The tradition that the body should be buried whole seemed to be most important of these. This was related to two concepts: filial piety and the importance of wholeness and harmony. A concern that the body needed to be whole to be reincarnated whole was also mentioned. Consistently, people commented that tradition of being buried whole was losing ground in the Chinese community – that it was primarily a belief of the older generation.

A second important belief was that the one's destiny was pre-ordained and that one should not attempt to prolong one's life.

On the positive side, people commented that giving was an important concept and practice in the Chinese community and that an extension could be made to the idea of an organ or tissue donation being a gift. There was a connection made between wastefulness and not donating organs once one was deceased.

There was also strong respect for the medical tradition and a high trust in doctors as evidenced by the survey results. This was nuanced somewhat in the surveys by a fear that a patient may not get every possible treatment if he or she is a potential organ donor.

There did not seem to be any beliefs about the receipt of an organ. Indeed, except for considerations of age and the resulting health of the donor (if it was a living donation), people were very open to the idea of receiving a transplant. Indeed in the survey results, it was clear that people were not concerned that the organ might come from someone not of Chinese origin as long as there was a compatible match medically.

The survey results further indicate that there may not be a strong connection between one's faith and the decision to donate. Sixty-seven percent (67%) of respondents indicated that their decision to donate would not be influenced by any particular faith. Seventy-eight percent (78%) responded that they would not talk to their religious or spiritual leader about organ and tissue donation and transplantation.

Family

The importance of family came up in a number of ways in the focus group discussions. In particular, people suggested two forms of incentives that might encourage donations that build on the sense of family in Chinese culture. The first of these was the idea that donating brings a family honor. This apparently relates to a Chinese tradition that the actions of an individual can bring honor to the family who becomes recognized in the community for the individual's achievement.

The second idea was whether one could gain a "credit" for their family by donating. Thus at a future point, if a family member required a transplant, they could move up the waiting list because a family member had previously donated to someone else.

Interestingly, the decision about whether to donate or not was seen to be primarily an individual's decision that should be respected by the family. Indeed, in the focus group, there was a sense of incredulity that a family could "over-rule" a donor's wish to donate. That being said, there was a clear message about the importance of talking to one's family about one's wishes, even if the topic was uncomfortable.

Public Education and Awareness

For many participants, the key to increasing donations was about public education and awareness-building. Most felt that people would sign a donor card if they had more information and were asked clearly to donate. People spoke about the importance of positive stories. Several people mentioned that there have been public campaigns in Hong Kong that they felt were effective and perhaps could provide a model. It would be important to respond to people's information needs in three areas:

- Statistical information: e.g. What is the need? How long are the waiting lists?
- Medical information: e.g. What's the operation like? How long does it take to recuperate if it's a living donation? Is there an upper age limit on donations?
- Donor process: e.g.: How does one get a card? Can I have an open casket if I donate? What conditions can one put on their donation, e.g. that an organ not go to medical research?

Assuaging fears would also be important. For example, concerns were raised about whether the body would be respected; about whether organs could go to prisoners or to those who have abused their own organs, e.g. a kidney to an alcoholic. Twenty-eight percent (28%) of respondents indicated that would not currently be willing to sign a donor card because, for them, organ and tissue donation and transplantation is an uncomfortable topic. It would be important to have a better understanding of the components of this discomfort in terms of developing messages that help to make it an accessible subject.

Recommendations

There are a number of recommendations that emerge from this consultation in terms of ongoing work on organ and tissue donation and transplantation with the Chinese community. Key ones are:

1. **Continue to work with and through community groups and associations.** These groups are essential for trust, outreach and advice on appropriate cultural practices.
2. **Do further research into the possible generational difference** in the belief that the body should be buried whole. Having a better understanding of this difference could impact on the design and targeting of public education for different age groups.
3. **Build on the importance of family** by exploring incentives such as recognizing a "family of honor" or allowing a credit that can be used for a needy family member in the future. For the latter incentive, it would be important to have further discussions that would look at the potential trade-offs between such a credit and the values underlying the current system such as equity and fairness.
4. **Do more public education and awareness-building.** The value of giving would be one important cultural tradition to build from. Another message, given the importance of family but also the view that it is an individual's decision whether to donate or not, might be "Talk to your family. Ensure they know that you want to donate".
5. **Build on the connections made with Chinese family physicians.** There is a lack of knowledge about organ and tissue donation and transplantation and an interest to learn more. There also seems to be a willingness to participate in education work and to discuss organ and tissue donation and transplantation with patients.

APPENDICES

APPENDIX A: PLANNING GROUP MEMBERS

The list indicates the community association each person is active in that was relevant to this consultation.

Beatrice Ip	Board Member, Trillium Gift of Life Network
John Ip	Scarborough Hospital Chinese Outreach Committee
Dr. Rosalind Ling	Journal Club of Chinatown Physicians
Ms. Billie Potonjak	Canadian Liver Foundation
Justin Poy	Board Member, Trillium Gift of Life Network
Mr. Benson Sy	Chinese Renal Association
Mr. Joseph Wan	Chinese Cultural Centre of Greater Toronto
Sam Watt	Hemodialysis Clinic, Scarborough Hospital
Angela Diano;	Community Relations Advisor, Trillium Gift of Life Network

APPENDIX B: FOCUS GROUP TOOLS

FOCUS GROUP DISCUSSION CANADIAN COUNCIL FOR ORGAN DONATION AND TRANSPLANTATION Feb. 2 - 4, 2005; Three sessions

Format: 1hr 30min - 2 hr sessions with 12 to 15 people from the Chinese–Canadian Community in Toronto

Process:

**Welcome and introduction to the session
and the ground rules for participation - 15 minutes**

- Introduce myself and thank all participants for attending and the Yee Hong Centre (or the Chinese Cultural Center of Greater Toronto – Feb. 3) for hosting the session;
- Explain translation and how it will work. Introduce Ambrose;
- Explain purpose of consultation; (Ambrose reads from letter)

This focus group is part of a larger consultation to better understand the views, beliefs and concerns that people from the Toronto Chinese-Canadian community may have about organ donation and transplantation. The purpose of the consultation is to offer guidance to the Canadian Council on Donation and Transplantation (CCDT) a not-for-profit organization mandated by the federal government to explore organ and tissue donation rates in Canada. The Council has been working closely with Trillium Gift of Life Network – an agency of the Ontario government.

There are a number of chronic diseases that can sometimes lead to a need to receive a donated organ (e.g. heart transplant, liver or kidney) or tissue. Diabetes is one such ailment. In some cases, diabetes can lead to kidney failure. One of the treatment options for kidney failure is transplantation - to receive a donated kidney. The typical waiting time in the Toronto area for a kidney transplant within the Chinese-Canadian community is eight years. The availability of transplantation as a treatment option depends on the availability of donor organs.

Organ donation and transplantation are sensitive topics upon which many values and beliefs come to bear. We are interested in understanding your views, values and beliefs on organ and tissue donation and transplantation and other related issues.

- Explain my role in the discussion as unbiased facilitator and note that the session is being audio-taped. Explain that data will be used only to transcribe the session. Confirm anonymity of comments.
- Explain use of mikes. Let's test them out – do a round of introduction, including guests.
- Introduce the consent form and verify if everyone has signed it. If not, hand out copies and review it with people so they can sign. (This will take some time.)
- Explain that the discussion is a means of soliciting a variety of viewpoints and letting participants respond to each - the discussion is not a planning session or an attempt to reach consensus;
- Emphasize that there are no "right" or "wrong" answers and that everyone should freely express their ideas and opinions;
- However feel free to not respond to a particular question if you don't wish to. You have the right to pass.

- Explain that you will have to keep the group moving to get through the entire agenda and that you will not, therefore, be able to solicit each participant's viewpoints on all of the issues to be discussed. You may also have to interrupt people once in a while in order to keep within to the time constraints.
- Note that there will be a short break after about an hour, and that the session will end at noon (12:30 on Feb. 4). (Feb. 3 –stretch break – finish about 11:30)
- Check if there are any concerns; Ready to go?

**Exploring Perspectives - 90 minutes (including 10 minute break)
(Feb. 3 – 60 minutes)**

- Work through the questions as time permits, following the flow of discussion, elaborating areas where there seems to an interest and energy. (Test group out to see if they respond better to more personal questions or to more conceptual ones.)
- At an appropriate point, early in the discussion, present the following information:

There are three different donation scenarios: (Ambrose reads)

1. A living organ donation takes place when someone donates an organ or part of an organ to another person and goes on to lead a healthy life. Most typically it is a kidney or liver that is donated in a living transplant, as each of us has two of these organs.
2. A deceased organ donation takes place when someone suffers sudden death and loved ones opt to maintain vital organs by ventilator to keep them safe for transplant. Donated organs could be the heart, liver, kidneys, pancreas, lungs, small bowel or stomach.
3. Tissue donation takes place when someone has died but there is no need to maintain blood flow to the tissue through artificial ventilation. Tissues that can be donated include corneas, heart valves, bones and skin.

Some-one can receive an organ or tissue transplant through any of these three donation scenarios. This is called transplantation.

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

1. Has anyone known anyone who received an organ transplant? If yes, can you tell us briefly the story?
2. Do you know anyone who is waiting for an organ transplant? Again get a story if possible.

B. Views toward organ donation and transplantation

3. What do you hear said about organ donation and transplantation in your community?
4. Why might some-one say yes or no to transplantation or donations for themselves or for family member?
5. If a family member (e.g. son, daughter, mother, brother) indicated that they wanted to be an organ donor, how would you respond? (May need to clarify if speaking of living donation or upon death) Why?
6. If you had a bad kidney and a close family member offered to give you one of his or hers, how would you respond? Why?

C. Views and traditional values and beliefs which influence your perspective on donation and transplantation

7. What religious and/or cultural beliefs influence your perspective on organ donation and transplantation?
8. How do your view and beliefs about organ donation and transplantation compare to others in the community? Other age groups? Are there other beliefs in the community?
9. If it has not arisen in the discussion, note that the concept of filial piety comes up in the literature. Can you explain to me how this concept relates to organ donation and transplantation?
10. Are there other concerns you may have? e.g. distrust in medical system, my organs are too old to be useful, etc.

D. Support to Decision

11. Clarify that a family /close kin must approve a donation from a family member who is deceased – often done with a donor card. If you knew one of your close family members had signed a donor card, how would you respond? Why?
12. What information would you need to know?
13. What would be a respectful way to ask a family if they would consider a donation of the organs of their deceased loved-one? Who should make the request?

Conclusion - 15 minutes

E. Relationship Building

- How do we go about continuing this dialogue with people of Chinese descent/background?
- What role if any do you see for your community groups? Doctors? Religious leaders?

F. Closing

1. How important is this issue to you? Do you think that others would want to discuss it?
2. Any surprises? New reflections?
3. How did you find the process? Is there anything we could do to improve it?
4. Any other final comments or questions?

Thank you for participating in this discussion. As a token of our appreciation, there are t-shirts and calendars.



Canadian Council for Donation and Transplantation

January 17, 2005

Thank you for agreeing to participate in the focus group to discuss your views and perspectives about organ and tissue donation and transplantation.

The focus group will take place on Feb. 4 at the Yee Hong Centre for Geriatric Care. It will last for 2 hours. Refreshments will be served. Interpretation will be provided so that participants can express themselves in Mandarin, Cantonese or English.

There are a number of chronic diseases that can sometimes lead to a need to receive a donated organ (e.g. heart transplant, liver or kidney) or tissue. Diabetes is one such ailment. In some cases, diabetes can lead to kidney failure. One of the treatment options for kidney failure is transplantation - to receive a donated kidney. The typical waiting time in the Toronto area for a kidney transplant within the Chinese-Canadian community is eight years. The availability of transplantation as a treatment option depends on the availability of donor organs.

This focus group is part of a larger consultation to better understand the views, beliefs and concerns that people from the Toronto Chinese-Canadian community may have about organ donation and transplantation. The purpose of the consultation is to offer guidance to the Canadian Council on Donation and Transplantation (CCDT) a not-for-profit organization mandated by the federal government to explore organ and tissue donation rates in Canada. Organ donation and transplantation are sensitive topics upon which many values and beliefs come to bear. We are interested in understanding your views, values and beliefs on organ and tissue donation and transplantation and other related issues.

We are enclosing an information sheet and consent form to help you learn more about the project. If you have any questions about the focus group, or the consultation, please contact Jacquie Dale who can be reached at jdale@owi.ca or by telephone at (613) 562-4073. Jacquie will also be facilitating the focus groups and would be happy to respond to your questions at that time, as well.

Best regards,

A handwritten signature in black ink, appearing to read 'Rosalie Starzomski', is written in a cursive style.

Rosalie Starzomski RN, PhD, Lead, CCDT Steering Committee



Information Sheet and Consent Form

Title of Consultation: Focus Group on Organ and Tissue Donation and Transplantation

This Consent Form, a copy of which you have, is part of your agreement to take part in this consultation. It will tell you what the process is about, and how you will be involved. Please take the time to read it carefully. Be sure you understand this and any other information we will give you. Please ask us any questions you may have.

Purpose

The purpose of this consultation is to better understand the views, beliefs and concerns that people from the Toronto Chinese-Canadian community may have about organ and tissue donation and transplantation. The information from this focus group, as well as information from surveys, will provide information to assist the Canadian Council for Donation and Transplantation.

A focus group is a conversation with a group of participants about a particular topic. The conversation is directed by a moderator so that the discussion can focus on the topic of interest. It is important that you are comfortable with the discussion topics. You are free to not participate in any discussions with which you are uncomfortable. A sample of possible discussion topics is on page 3 of this information sheet. You will not be asked to discuss your own personal history or circumstances although you may believe that this is something you would like to draw upon in order to help others understand your point of view.

Tasks

If you agree to take part, you will participate in a focus group of about 12 -15 individuals. The discussion will take about 2 hours. The focus group will be audio-taped only for the purpose of transcribing the discussion for analysis of the content.

Possible Benefits

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.

Confidentiality

If you agree to take part in this focus group, all information given by you will be kept confidential. The information from this focus group will only be reviewed by the staff doing the consultation. Any reports or publications from this consultation will not name the people who took part in the consultation or use any other identifying information. A copy of the consultation report will be sent to you.

The audiotapes from the tape-recorded discussion will be kept in a locked drawer at the Charis Management Consulting office for 2 years and then will be destroyed.

All written material and data will be stored at the Charis Management Consulting office for 7 years and then will be destroyed. It may be used for future reports, without any personal identifying information and without further consent from you.

Because of the nature of the focus group, we cannot guarantee confidentiality of the discussion outside the focus group. However, the facilitator will remind group members about their responsibilities to each other.

**Freedom to withdraw**

Your participation in this consultation is completely voluntary and will not affect your health care services in any way. You may leave the meeting at any time you want and you do not have to give a reason.

Contacts

If you would like more information about this consultation, you can contact Jacquie Dale at jdale@owi.ca or by telephone at (613)562-4073.

Please bring this information sheet and the consent form to the focus group. Thank you.



Possible Discussion Topics

1. Understanding what concerns and beliefs might influence people's decisions about organ and tissue donation and transplantation.
2. Understanding how decisions about organ and tissue donation and transplantation are made by individuals and within families.
3. Ideas on how to further discussions on organ and tissue donation and transplantation within the Toronto Chinese-Canadian community.
4. Ideas on how community organizations and local organ and tissue donation and transplantation programs can work together. (For focus groups with staff on community organizations.)



CONSENT FORM

Title of Consultation: Focus Group on Organ and Tissue Donation and Transplantation

Understanding of the Participant

I understand that I have been asked to participate in a focus group. I understand that my involvement is entirely voluntary and that I may decline participation or withdraw at any time without affecting my current or future health care services. I have received and read a copy of the information sheet. Any questions I have asked have been answered, and I am content with the answers. I have been told about the benefits and risks that could occur.

I have read this information sheet and this signed consent form. I know this consultation may be reported on, but I will not be named. I understand my confidentiality will be respected.

I agree to take part in this consultation by being a participant in a focus group and having it audio-taped.

You will be provided with a copy of this consent form for your records.

Name of participant (please print) Signature of participant Date

Name of investigator (please print) Signature of investigator Date

APPENDIX C: GENERAL SURVEY TOOLS

Sponsored by the Canadian Council on Donation and Transplantation (CCDT) – a not-for-profit organization mandated by the federal government to improve organ and tissue donation rates in Canada.

There are a number of chronic diseases that can sometimes lead to a need to receive a donated organ (e.g. heart transplant, liver or kidney) or tissue. Diabetes is one such ailment. In some cases, diabetes can lead to kidney failure. One of the treatment options for kidney failure is transplantation - to receive a donated kidney. The typical waiting time in the Toronto area for a kidney transplant within the Chinese-Canadian community is eight years. The availability of transplantation as a treatment option depends on the availability of donor organs.

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

All information you provide will remain completely confidential. Participation is voluntary and you do not have to respond to any question that you do not wish to answer. The survey will take about 20 minutes to complete. We appreciate your participation.

An Introduction to Organ and Tissue Donation

There are three different donation scenarios:

1. A living organ donation takes place when someone donates an organ or part of an organ to another person and goes on to lead a healthy life. Most typically it is a kidney or portion of a liver that is donated in a living transplant. 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 live well with a reduced liver capacity.
2. A deceased organ donation takes place when someone dies suddenly and loved ones agree to donate organs of the deceased. Donated organs could be the heart, liver, kidneys, pancreas, lungs, small bowel or stomach.
3. Tissue donation takes place when someone has died. Tissues that can be donated include corneas, heart valves, bones and skin.

Someone can receive an organ or tissue transplant through any of these three donation scenarios. This is called transplantation.

The survey begins on the next page.

For each question, please put an X in the appropriate box. Some questions are open-ended and we would appreciate it if you can write your response in the space provided.

1. Do you know anyone who has received a transplant in Canada?

- Yes
- No

If yes, what type of transplant was it?

- Heart
- Liver
- Kidneys
- Lungs
- Tissue
- Other, please describe here: _____

2. Do you know of anyone waiting for an organ or tissue transplantation?

- Yes
- No

If yes, what kind of transplant is the person waiting for?

- Heart
- Liver
- Kidneys
- Lungs
- Tissue
- Other, please describe here: _____

3. Do you know anyone who has donated an organ or tissue?

- Yes
- No

4. Did you know that people can express their intent to donate organs or tissue by completing a donor card? (This card may have been sent with your drivers licence or you may have received it from some place like your doctor's office or an OHIP office.)

- Yes
- No

5. If yes, have you indicated your intent for organ or tissue donation by completing a signed donor card?

- Yes
- No

6. If you have not completed a donor card, would you be willing to do so?

- Yes
- No
- Not sure

If you responded no or not sure, what might the reasons be?

- Not enough information to make a decision
- I am not sure I am healthy enough to donate
- I find it an uncomfortable topic
- My family dislikes the idea
- I want my body to remain intact
- Religious beliefs
- Other (Please describe in the space below:)

7. If you had a chronic disease that led to kidney, liver or heart failure, would you be willing to accept organ transplantation as a means of treatment or cure?

- Yes
- No

Why or why not?

8. What are your current views about organ and tissue donation and transplantation?

9. Which of the following faiths, if any, would influence your decision to donate?

- Confucianism
- Taoism
- Buddhism
- Catholic
- Protestant
- Other, please describe here: _____
- None

10. Would you talk to your religious or spiritual leader/advisor about organ and tissue donation or transplantation?

- Yes
- No

11. What are the most important beliefs/concerns (religious or non-religious) that influence your perspective on organ and tissue donation and transplantation?

12. Do you think the decision to donate or not should be made by the individual alone?

- Yes
- No

If no, who else would you involve in your decision?

- Parents
- Spouse
- Other close family members
- Family doctor
- Specialist physician
- Other health professional, e.g. nurse
- Religious leader
- Other, please describe here: _____

13. If you had not yet completed an organ donor card and/or told your family that you want to donate an organ or tissue upon your death, how likely would your family be to donate your organs or tissue for purposes of transplantation?

- Very likely
- Somewhat likely
- Not very likely
- Not at all likely

14. If a family member had requested that their organs or tissue be donated upon their death, how likely you would be to donate their organs or tissue?

- Very likely
- Somewhat likely
- Not sure
- Not very likely
- Not at all likely

15. If a family member had not discussed their views about organ or tissue donation with you, how likely you would be to donate their organs or tissue upon their death?

- Very likely
- Somewhat likely
- Not sure
- Not very likely
- Not at all likely

16. How willing would you be to make an organ or tissue donation upon your death?

- 100% - I've already signed my card
- Very willing
- Not sure
- Not very willing
- Absolutely not

17. Would you place any conditions on your donation?

- Yes
- No

If yes, what conditions would these be?

18. How willing would you be to make a living donation (e.g. donate a kidney or portion of a liver to a family member or relative)?

- Very willing
- Somewhat willing
- Not sure
- Not very willing
- Absolutely not

19. If a close family member required an organ or tissue donation, would it be OK to accept a donation from someone who is not of Chinese descent?

- Yes
- No

Why or why not?

20. Who would you **most** trust in helping you make the decision to donate or not? (Please put an X in only one box.)

- Your doctor
- Other health professional – e.g. nurse
- Your religious or spiritual leader
- Parents
- Spouse
- Other close family members
- Other, please describe here: _____

21. Do you believe that you have enough information to make a decision about being a donor?

- Yes
- No

If no, what type of information would you need?

22. How would you prefer to receive information about donation?

- Website alerts
- Email notification
- Printed materials
- Information available at my doctor's office
- Radio
- Television
- In person presentations
- Other (please describe here:)

Demographic Information

Your gender:

- Male
- Female

Your age:

- Under 25 years of age
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- Over 75

What is the highest level of education you have completed?

- No schooling
- Completed elementary school
- Completed high school
- Completed community college or technical school
- Some University
- Completed Bachelor's Degree
- Completed Master Degree
- Completed Doctorate or Professional Degree (Law, Medicine, Dentistry)

In what country were you born? _____

How long have you been living in Canada? _____

To what ethnic or cultural group do you belong? _____

What language is your mother tongue? _____

At present, are you?

- Single (never married)
- Common law/living with a partner
- Married
- Separated/Divorced
- Widowed

Thank you very much for completing this survey. Please return your completed survey to the person who gave it to you.



January 17, 2005

Thank you for agreeing to complete the attached survey on organ donation and transplantation. The purpose of this survey is to understand your views on organ and tissue donation and transplantation and to offer guidance to the Canadian Council on Donation and Transplantation (CCDT). Organ donation and transplantation are sensitive topics upon which many values and beliefs come to bear. We are interested in understanding your views, values and beliefs on organ and tissue donation and transplantation and other related issues. A copy of the final consultation report will be sent to you.

All information you provide will remain completely confidential. Participation is voluntary and you do not have to respond to any question that you do not wish to answer. Your participation in this survey will in no way affect your current or future health care services.

The survey will take about 20 minutes to complete. Before beginning the survey, however, we would ask you to complete the attached consent form. In order to safeguard the anonymity of your survey responses, please return the consent form separately from the completed survey. You may wish to have a copy for your records.

If you have any questions, please direct them to the person who is administering the survey, or, if you are completing this survey electronically, contact Jacquie Dale who can be reached at jdale@owi.ca or by telephone at (613)562-4073.

We appreciate your participation.

Best regards,

A handwritten signature in black ink that reads 'Rosalie Starzomski'.

Rosalie Starzomski RN, PhD, Lead, CCDT Steering Committee



CONSENT FORM

Title of Consultation: Survey on Organ and Tissue Donation and Transplantation

Understanding of the Participant

I understand that I have been asked to complete the survey on organ donation and transplantation. I understand that my involvement is entirely voluntary and that I may decline participation or withdraw at any time without affecting my current or future health care services. Any questions I have asked have been answered, and I am content 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. It may be used for future reports, without any personal identifying information and without further consent from me.

I have read this signed consent form. I know this consultation may be reported on, but I will not be named. I understand my confidentiality will be respected.

I agree to take part in this consultation by completing this survey.

Name of participant (please print)

Signature of participant

Date

Name of witness (please print)

Signature of witness

Date

APPENDIX D: PHYSICIAN SURVEY TOOLS

Sponsored by the Canadian Council on Donation and Transplantation (CCDT) – a not-for-profit organization mandated by the federal government to improve organ and tissue donation rates in Canada.

There are a number of chronic diseases that can result in the end-stage need to receive a donated organ or tissue. The availability of transplantation as a treatment option depends on the availability of donor organs and the need for organs far surpasses the current availability.

This survey is part of a larger initiative to understand better the perspectives, values and beliefs of people in the Toronto Chinese-Canadian community with respect to organ donation and transplantation. The initiative will provide guidance to the Canadian Council for Donation and Transplantation as it works to improve the opportunities people have to consider donations.

All information you provide will remain completely confidential. Participation is voluntary and you do not have to answer any questions that you do not want to. The survey will take about 20 minutes to complete. We appreciate your participation.

For each question, please put an X in the appropriate box. Some questions are open-ended and require that you write a response. As you respond to the following questions, please reflect only on your patients within the Chinese-Canadian community.

Section A: Advisory Role with Patients

1. Do you think it is important for physicians to discuss organ and tissue donation and transplantation with their patients?

- Yes
 No

If yes, when?

- On request, when initiated by the patient
 At least once with all my patients
 As a routine part of end-of-life care
 When a transplantation must be considered for the health of the patient
 Other (please describe here:)

2. How often do you find yourself advising patients or their families on organ and tissue donation and transplantation?

- Weekly
- Monthly
- Two or three times a year
- Once a year
- Less than once a year
- Rarely
- Never

3. What types of support or information would help you to advise patients and/or their families about organ and tissue donation and transplantation?

- Current information on best medical practices related to donation and transplantation
- Up-to-date information on waiting lists
- Addresses of websites that patients or their families could access for more information
- Information on the ethical and legal considerations surrounding consent
- Educational materials for patients
- Other (please describe here:)

4. How do you prefer to receive information?

- Website alerts
- Email notification
- Printed materials
- Workshops or seminars
- Information sessions at our regular physician meetings
- Other (please describe here:)

Section B: Patient Perceptions

5. In general, how willing do you think your patients from the Chinese-Canadian community are to express the intent to donate by signing a donor card?

- Very willing
- Somewhat willing
- Not sure
- Not very willing

6. In general, how willing would your patients be to accept an organ or tissue donation?

- Very willing
- Somewhat willing
- Not sure
- Not very willing

7. What, in your opinion, are beliefs or concerns (religious or non-religious) that influence your patients' perspectives on organ and tissue donation and transplantation?

8. How important is the issue of organ donation and transplantation for the Chinese-Canadian community in Toronto?

- Top ten health priority
- Very important
- Important but there are a number of more pressing issues
- Not very important

Can you please expand on your answer on the lines below?

Section C: Future Opportunities

9. Is there a role for family physicians in making it possible for people within the Toronto Chinese-Canadian community to have more informed opportunities to consider donations?

- Yes
- No

If yes, could you expand on what you think the role should be? If no, please explain why you do not see a role for family physicians.

10. What else could be done to increase the level of donations?

11. Are there important research questions that you think need to be addressed in the area of organ and tissue donation and transplantation?

- Yes
- No

If yes, what are some of these questions?

12. Are there other associations of Chinese-Canadian physicians with which we could be in touch – locally, provincially or nationally?

Yes

No

If yes, please note the names of these associations in the space below.

Thank you very much for completing this survey.



January 17, 2005

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Rosalie Starzomski RN, PhD, Lead, CCDT Steering Committee



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Date

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Signature of witness

Date