

DIVERSE COMMUNITIES

Consultation to Explore Peoples' Views on Organ and Tissue Donation

Discussions with Indigenous Peoples

Winnipeg: November 4 and 5, 2004

Saskatoon: March 1 and 2, 2005

SUMMARY REPORT TO PARTICIPANTS



Who is this report for?

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

About the Canadian Council for Donation and Transplantation

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

Why were the consultations held?

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

Sometimes people stay on waiting lists for up to a year or longer. Of course, the longer they wait, the more likely it is that their health will get worse. Long waiting times are more likely for some groups, such as Aboriginal peoples. These waiting times can be twice as long as the waiting time for Caucasians. Of course, the difference in waiting times has to do with a shortage of suitable matches. It is this situation that prompted the CCDT to organize the Diverse Communities Consultation.

What do we mean by organ and tissue donation?

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

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

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

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

Why were these communities chosen?

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

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

Other participants

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

What were the goals of the consultation?

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

The consultation had three specific goals.

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

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

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

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

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

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

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

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

How was the consultation carried out?

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

The CCDT wanted to make sure that everything about the consultation was done ethically. For the consultations with Aboriginal people, several Western ethicists and one Aboriginal ethicist reviewed the questions and approach. They considered these elements: consent, confidentiality, knowledge ownership, and access to information.

Consent

The Western idea of consent focuses on individual ownership and independence. Indigenous peoples emphasize the community, placing equal emphasis on community and individual consent. Also, researchers using Western ethics usually only seek consent once for the whole process. For Indigenous peoples, informed consent is usually an ongoing process. This consultation followed the Western approach, with each individual signing a consent form that outlined the purpose, context, and scope of the consultation. However, the idea of consent as an ongoing process was followed, because participants made decisions to stay in or leave the Circles as discussions unfolded.

Western approach

“Western approach” refers to a way of thinking that is the product of European culture.

Confidentiality

The Western research practice of protecting individuals by allowing them to remain anonymous does not apply to all cultures. It can, without meaning to, have the effect of silencing some people. To try to ensure that the participants’ voices were clearly heard, they were offered the opportunity to have their statements remain anonymous, or to be identified by their names in reports about the consultations.

Knowledge ownership

To be effective, consultation must take place in an open partnership of equals. In the past, Western researchers gathered information from individuals who had no say in what was written or even an opportunity to read what was written about them. By sharing this report, the CCDT is giving participants the opportunity to read what we write about them.

Access to information

Getting approval from the community to conduct research is very important. Approval by the Tribal Council or by the Chief and Council is often required for Elders to be involved. In the future, the CCDT will seek that approval before conducting research with Aboriginal peoples.

In carrying out all of the consultations, five principles were followed.

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

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

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

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

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

How were Aboriginal Peoples involved?

We sought the advice of First Nations people early in the planning. The advisors suggested that the most respectful way to consult with indigenous peoples was through an Elders' and Traditional Knowledge Keepers' Circle. It was very important to CCDT that we conduct the dialogue with respect, using the traditions and ceremonies of Aboriginal peoples.

The consultations with Aboriginal people took place in Winnipeg and Saskatoon in November 2004 and March 2005. Winnipeg and Saskatoon were chosen as sites for the Circles because the largest proportion of Indigenous Peoples lives in those cities and the surrounding area.

Twenty-five people participated in the Winnipeg Circle, with most from Winnipeg and a few from northern Manitoba. Everyone said that they followed traditional spirituality. Participants were mainly Manitoba Cree, along with three Ojibway, one Mohawk and one Métis. In Saskatoon, most of the 30 participants came from the middle and southern regions of Saskatchewan and a few, from the north. Most of these participants were Saskatchewan Cree.

How were the Circles run?

The Circle is an important symbol in Aboriginal spirituality because it represents the cycle of life that has no beginning and no end. The Circle does not usually involve feedback or challenges to participants. Participants are given the opportunity to speak on any topic that suits them, for as long as they want.

We followed ceremony and protocol in conducting the Circles, which lasted for about 10 hours over two days. The space used for the Circle and the participants were smudged. Gifts and other objects were smudged, and prayers were offered for each participant before the Circle. Elders were given an offering of tobacco, a small gift, and an honorarium. Participants said that they appreciated the gestures, noting that tobacco symbolizes "someone's thoughts and prayers for your wellness."

At the beginning of each Circle, the facilitator explained the process, noting that people did not have to participate or to answer any of the questions. An altar table, bearing sacred objects, a smudge shell and a candle, was placed close to the Circle. Participants were invited to smudge themselves as they arrived, and in some cases, smudge was offered to those who became emotional in telling their stories.

The people who planned and conducted the consultations said that it was an enriching experience to be part of the Circles and to be in the presence of Elders and Traditional Knowledge Keepers, with everyone generously sharing their thoughts and traditions. Some participants felt that using the Circle to talk with Indigenous peoples about donation and transplantation was groundbreaking:

I think in this room we are pioneering. I have certainly never been involved in any kind of talks like this, I think because the world has modernized our traditions, our ceremonies. I am proud to be sitting in this room talking about where we need to go with this.

One participant suggested that the Circle provided a way for everyone in the group to have equal power:

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

What did Aboriginal participants say?

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

“Writing down what transpired during our Circle in some way diminishes it. ... I understand my obligation to reflect the knowledge that was shared in the Circle respectfully and accurately; however, my accuracy will be constrained by my Western training and heritage. To the Indigenous people who read this report, I ask their patience as this ‘newcomer’ explores and tries to reflect the issues and traditional knowledge that were discussed in the Circles.”

In all consultations, five topics were discussed.

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

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

Many participants had personal experience with or knowledge of organ and tissue donation and transplantation. This was usually with family (for example, brother, sister, father, cousin, aunt) or with friends and colleagues. One person had received a transplant.

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

I had an aunt who was probably the only person that I know of in my community who was a kidney transplant recipient. And she had to move . . . to Saskatoon because she needed dialysis twice a week. . . . And then she was here for probably five or six years and none of her children were willing to give up a kidney for her. And then she finally did get a kidney from an unknown donor.

I am a kidney transplant recipient. My son gave me a kidney. And when I had kidney failure he wanted to give me a kidney like tomorrow. Doesn't happen that way. But I had, when my family knew about it, I had all my nieces and nephews that wanted to give me a kidney.

Participants said that their attitudes and beliefs about organ and tissue donation often were formed within their families and communities, especially with their Elders. They noted that people living a traditional lifestyle (often older people), with traditional values and beliefs, were often reluctant to go to the hospital or to consider a transplant.

Dreams and prayerful reflection during the Circle played an important part in changing some participants' views so they could speak of, and be more accepting of, the topic. One participant said,

I feel at peace now today. I had a dream that I was holding my kidneys and saying who am I supposed to give them to? And many things became clear to me."

The experience of having friends and relatives who need or needed an organ transplant made some participants more vocal about prevention. They did not see organ and tissue donation and transplantation as long-term solutions to the health care problems among their people. Instead, they spoke about living a healthier lifestyle, in terms of diet and exercise, and about how important it was to get the prevention message out to family members, especially youth.

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

One Circle member spoke about how transplantation improves the quality of life of the recipient, as a person on dialysis is "chained to the hospital." The burden of being away from home significantly reduces the quality of life for the person on dialysis.

Participants viewed the process of "educating one another" through sharing the experience of donation and transplantation among family and community members as a powerful and effective way to change attitudes. They believed that people could change their minds about accepting dialysis or transplant if someone in their family needed it. As one person explained, "We think differently when we get into a situation like this."

2. How do you feel about organ donation and transplantation?

Participants noted that many Aboriginal people did not know much about organ or tissue donation and transplantation. For some, it was a topic that they were not willing to think about until they had to. Some participants definitely objected to the idea of donation or transplantation. Others were not sure and had mixed feelings about what they would do if faced with the need to decide for themselves or for a family member or friend.

Many Circle participants believed donation and transplantation should be discussed in the community. They noted that there were few opportunities or processes for a respectful discussion

with families and community members. This situation was sometimes made worse by some peoples' resentment over the lack of control of their own lives.

Maybe there is unresolved stuff about control and making choices that has to be dealt with first when it comes to making decisions about the body. . . . We are not even talking this way in communities.

Some participants were concerned about discussing an issue that they did not know very much about, not only in terms of medical information, but also in terms of traditional values and beliefs that relate to organ donation and transplantation. Some also worried about possible conflicts between differing points of view.

Those who said “yes” to donation or transplantation could see benefits for both the donor and the recipient. Donor families could benefit both by knowing that they helped relieve another person's (particularly a child's) suffering and by keeping alive some aspect of a loved one through another person's life.

And when I see young kids suffering in the hospital . . . it always hurts me, hurts me to see the parents and the grandparents. . . . If . . . I could do it [transplantation] for a child suffering there, if I could give him something or take his pain away, I would because it's in most of us native people, we don't like to see people suffer.

Participants could see the value of prolonging the life of a loved one and helping that person return to a cherished state of freedom and health. They also valued the recipient's opportunity to be able to raise grandchildren and pass on their culture. Other participants supported the decision not to be involved in donation or transplantation of organs.

On a personal level, some participants thought that they were not healthy enough to donate organs. Others believed they lack the information, personal awareness, and dialogue with family and community required to make that decision.

Participants understood that not making a decision was also an option, noting that it is a very personal issue, shaped by family, tradition and culture. Some felt “pulled both ways” by the conflict between traditional teachings that say, “The Creator wants you whole when you go away,” and wanting to help someone else live on. They could see the comfort of knowing that “part of her or him remains on earth serving another human being.” One participant said:

I am not sure and I won't know until I have to cross that bridge myself—at this point there is no right or wrong answer.

Participants wanted to learn more about the person who would donate to them, or to whom the donated organ or tissue would go. They expressed the need to understand the impact donation or transplantation might have on many emotional and spiritual levels. One participant said, “If my daughter dies, I would like to know where her parts will go.”

Another participant expressed the opposite view, telling the story of a couple who did not want to meet the person who received their son's eyes after his death. They feared that "looking into [their] dead son's eyes would be like losing him all over again." One woman expressed a similar thought from the recipient's point of view:

I do not want to look through a white person's eyes. I would have to shut my eyes in order to feel with my heart.

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

Those who held traditional Aboriginal values and views expressed great respect for life, embracing it as sacred. During the Circle, participants shared a number of rich examples and stories focused on teachings of traditional and non-traditional beliefs about life and death. The values they expressed included:

The value of life.

Participants declared that they saw life as a gift from the Creator that should be respected and honoured. They viewed life as sacred, believing people should fight for life and for the traditions that reinforce life.

Each morning I get up and I thank the Creator that I have opened my eyes and I am on the top side of the grass and just asking that He guide me.

The freedom of life.

Freedom was viewed by participants as one of the most precious gifts in life. They believed that giving and receiving were part of the freedom of having life and that both giving and receiving could honour life if done with respect.

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

Respect for our bodies.

Participants voiced respect for their physical bodies. Some thought that the unique nature of the person who gave a body part should be recognized. Others noted that the body part itself should be recognized as a part of another living being with its own history and spirit.

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

Respect for the body also means that people should not interfere with it. This is in keeping with the belief that a traditional Aboriginal person should not be a doctor, nurse or undertaker:

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

Respect for decisions.

Participants stressed that it was important to respect each person's wishes and choice, whatever they may be, and to respect the fact that their decision was final:

We respect all the decisions of every family. That family hope of life, the family tree, the circle of life.

Participants noted that choices about donation and transplantation were sacred, personal decisions that were typically made within a family. They expressed a strong belief that people had the capacity and will to choose, and should be supported in their decisions by traditional teachings, information and community consultation sessions. They also said that decisions made must be respected because they came from the heart and were arrived at thoughtfully and prayerfully, often through a ceremonial process.

The importance of ceremony.

Circle participants noted that ceremony plays an important role in traditional Aboriginal beliefs, starting with the belief that healing comes through ceremonies. Because of the sacred nature of a decision about organ donation or transplantation, participants believed that there was a need for guidance from the spirit world, through prayer and ceremony:

We need ceremony to talk about this because of the sacredness of the topic, and we must ask for guidance. In our ways we had great respect of each other. I think we talk about something as a gift of life and how we can pass on that gift of life to others.

Participants saw ceremonies as crucial to staying balanced—physically, mentally, spiritually and emotionally. They noted that ceremonies take people spiritually all the way through life and provide opportunities for healing.

They considered guidance from Elders as valuable to finding the answer to sacred decisions. This guidance is given through stories told in Aboriginal languages and through traditional ceremonies. Participants noted that secret stories told in orally in traditional languages contained spiritual knowledge, concepts and ideas.

Language is the sacred way of understanding who we are as Native people.

The importance of sharing.

Sharing is important and participants want to help one another.

Sharing is a key value, including that animals share their bodies so that the people may live. People are willing to help one another whenever they can.

Relationships between donors and recipients are important.

Many participants expressed the desire to know something about the donor. Participants weren't sure if they would accept or donate organs if they didn't know anything about the kind of person who would be donating or receiving.

To get someone else's heart, in our belief system and way of looking at things, could change a person, as choices are made with the heart.

There is some hesitation in accepting or donating organs because people don't know anything about the kind of person they are coming from or going to.

The parents of a 16-year-old “good person” expressed the worry that he might live on in a person who was not as good. Similar concerns came from the recipient’s point of view:

. . . the father of the young girl . . . said if this girl was to receive a heart. . . it had to be one special person for this heart to be at home in her body.

Traditional beliefs about life and death are important.

Those who held traditional beliefs thought that the Creator gave each person only a certain number of days to live and that one should not tamper with this. Also, they believed that people must keep all of their body parts after death or the Creator would send them on a search for the lost parts. If the body was not whole, they feared that people would get caught between the earthly world and the spirit world, causing suffering to family members. In keeping with this view, some participants believed that respect for the body meant not removing any organs:

I had a really strong traditional mother, and she always talked about [Aboriginal words]. . . We come into this world intact and we leave that way.

On the other hand, some believed that after death, the spirit left the body and journeyed to the spirit world, returning to the Creator spiritually whole:

When we leave the earthly world to enter the spirit world, we don't take our body. Mother earth looks after that.

Thinking of their ancestors and descendants, some participants believed that they came from the thoughts and actions of the past seven generations, and what they did would affect the next seven generations: “We are accountable to them and need to think of long-term solutions.”

Balance between traditional views and modern medicine.

Participants in the Circles said they appreciated and honoured diversity in life, and related that to the balance required between traditional views and medical needs. They said that medical advances were among the gifts from the Creator.

. . . it's often a gift to be able to see two points of view, the two worlds. . . But it's also a curse because you know it pulls people into different directions to be able to see different points of view.

Some participants remarked that older people resisted hospitals and the Western medical establishment because they were seen as another form of colonialism, another kind of invasion of the Aboriginal peoples’ private space. This affects the entire community:

Western medical establishment has taken over the health of our communities. . . the health of our people. . . And people nowadays don't feel any responsibility for their own health.

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

Participants believed that individuals and families needed support and advice for making decisions about donation or transplantation. They strongly supported two-way education sessions to help people consider donation as an option. Participants thought that the Western medical establishment and public would benefit from being educated by the Aboriginal community about traditional ways of approaching the topic. They thought that Aboriginal people had much to learn about the issues and their options in donation and transplantation.

They stressed that education must be visual, build on people's experiences, be culturally appropriate, and be provided in Aboriginal languages or through interpreters to encourage informed choices. Participants noted that various educational resources were required, including pamphlets targeted to Aboriginal people, culturally sensitive videos, and special showings of movies such as *Return to Me*, whose plot concerns the lives of people who donate and receive organs, followed by a public discussion of the topic.

Participants believed that people should be encouraged to discuss donation with their families. They needed to make their wishes known long before the time actually might come to act upon them. They said the emphasis needed to be on individual choice within the family circle and that the choices made should be respected by the health care system.

One of our strongest teachings is respect, that is something we really have to think about when a family decides not to go through this procedure.

On the other hand, participants thought that parents should be given the opportunity to donate a dying child's organs because they could later believe that they were let down by the system if health professionals had not made the offer. To help support such decisions, participants wanted to see simple, straightforward information on topics such as what the health system does with removed organs and the definition of "brain dead." They also felt that some things needed to be clarified, such as the fact that having a chronic disease does not mean that a person cannot be a donor, and that organs and tissues are not accepted from people with high-risk lifestyles.

The Aboriginal people consulted stressed that health care workers must respect the need of families to go through the decision-making process at their own pace. They must also recognize the importance of ceremony, Elder support, and time and space for prayerful ceremony and guidance.

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

To build relationships, participants wanted to see more discussions, using Circles in the community and involving schools, Band Health Directors and Health Committees, and health fairs or other community events. Participants believed that dialogue was needed between Aboriginal people and health system policy makers, and between organ recipients and donors. One health professional who participated in the Circle commented:

. . . as I go into the work that I do working with Aboriginal health, these are new areas that I have never had a discussion about before. Now, hearing other people's perspectives, I can at least say,

“This is what I have heard.” As policies come forward we need to think about the cultural spirituality, that holistic way that Aboriginal people view life.

To continue the dialogue, participants suggested that a group be formed to deal with these issues among Aboriginal people. They also wanted to show respect and provide closure to Circle participants by providing them with the written results of the consultation.

What did we learn?

The consultation Circles on organ donation and transplantation gave the CCDT an excellent opportunity to understand an Aboriginal point of view on this sensitive subject. It is CCDT’s belief that by sharing their views on traditional values and beliefs, and how they influence decisions about donation, participants have begun a process that will lessen the gap between the need for and the supply of organs and tissues for transplantation among Aboriginal people.

Circle participants stressed respect—for individuals, Elders, relationships, and the decision-making process. Throughout the discussions, they also emphasized the central role of ceremony and of addressing Aboriginal peoples in a culturally appropriate way. These concepts should form the core of future recommendations on working with Aboriginal communities on organ and tissue donation and transplantation.

Where can I get more information?

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

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Canadian Association of Transplantation

Transplant Programs

http://www.transplant.ca/cancon_transprogram.htm

Donor Programs

http://www.transplant.ca/cancon_donorprog.htm

Canadian Diabetes Association

www.diabetes.ca

Canadian Liver Foundation

www.liver.ca

Heart and Stroke Foundation of Canada

www.heartandstroke.ca

Kidney Foundation of Canada

www.kidney.ca

or

La Fondation canadienne du rein

www.rein.ca

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The views expressed herein do not necessarily represent the views of the CCDT and/or the federal, provincial or territorial governments of Canada.

Production of this advice/report has been made possible through a financial contribution from Health Canada.