



Speak Up – Kitchen Table Conversation Kits

Dialogue on Organ and Tissue Donation and Transplantation

www.blood.ca/speakup



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Overview

Background

Canadian Blood Services is a not-for-profit charitable organization whose mission is to manage the blood and blood products supply for Canadians. In 2008, its mandate was expanded to include organ and tissue donation and transplantation (OTDT).

Canadian Blood Services has designated funding from federal, provincial and territorial ministries of health to provide national leadership in delivering a strategic OTDT plan. In September 2008, Canadian Blood Services held a national consultation as a first step in a collaborative approach to developing a five-year strategic plan to advance OTDT in Canada. Subsequently, a Steering Committee and two Expert Committees (focused on organs and tissues, respectively) were launched in May 2009. Now, Canadian Blood Services wants to encourage those affected by or interested in OTDT, to share their ideas on how to improve the system. This is where you come in!

Throughout the fall and winter of 2009-2010, Canadian Blood Services undertook a national stakeholder and public engagement initiative to educate and engage individual Canadians and organizations in relation to the development of the strategic plan. A key component of this engagement initiative was a series of day-long public dialogues to be held across Canada in strategic locations, including: London, Vancouver, Edmonton, Halifax, Winnipeg, Regina, St. John's, Moncton and Toronto. A complementary online component allowed a larger group of Canadians to engage in the discussion. This *Kitchen Table Conversation Kit* is yet another means of further outreach to the interested public, allowing the broader community to become informed and involved in improving OTDT in Canada.

Purpose of the Engagement Initiative

- Raise public awareness about the urgency and benefits of developing a coordinated and effective pan-Canadian system for organ and tissue donation and transplantation;
- Support community champions to increase public understanding of the need for a pan-Canadian system of organ and tissue donations and transplantation;
- Identify concrete ideas in relation to the design of a national OTDT system, in particular, increasing registered donors and donation rates; and
- Generate substantial dialogue and commitment to the need for an OTDT strategy.

Planning a Kitchen Table Conversation

What is a Kitchen Table Conversation?

A Kitchen Table Conversation is a volunteer-led, informal gathering during which participants can share their experiences, perspectives and ideas on a public policy issue that is important to them – a pan-Canadian organ and tissue donation and transplantation system. Anyone can host a kitchen table conversation using the prepared materials found in this kit.

This kit provides two guides for hosting a Kitchen Table Conversation, one to last 90 minutes and a second one to last three hours. Both are based on having roughly 8 to 10 participants. You are welcome to modify the design to suit your time availability (e.g. by spending more or less time on each discussion question) and to accommodate smaller or larger groups (e.g. by breaking out into smaller groups or pairs to chat) as you see fit. The Kitchen Table Conversation can literally take place at your kitchen table, in your living room, a local coffee shop or anywhere that is convenient and comfortable.

Inviting Guests

Once you have set a convenient location, date and time (and chosen the length of conversation/which guide to use) you are ready to invite people to participate. Consider inviting a few extra people in case not everyone will be available or interested (e.g. invite 15 people if you are hoping for 12 to attend).

You may want to invite family, friends and colleagues, or you could have them pass along the invitation (forward an e-mail invitation) to others they know. Alternatively, you could open up the conversation to the general community by posting a notice in a public place. Whatever recruitment method you choose, you may want to consider trying to gather a diversity of perspectives in the room.

It would be very powerful for your guests to hear the personal story of a donor or recipient. If you do not have anyone in mind or available, you could go to www.blood.ca/speakup and print off a story from the “shared story area”.

In order for you to stay focused on guiding the group through the discussion, we recommend asking one of your guests to take notes on the key points of the conversation. This person would still be welcome to participate in the conversation, but s/he would agree to help record the conversation. If you don't have anyone in mind ahead of time, you could ask for a volunteer at the start of the conversation.

You are welcome to contact Canadian Blood Services if you would like to invite someone knowledgeable on OTDT to attend your Kitchen Table Conversation. They would be happy to oblige, if there is someone available, and they can certainly answer any questions you have about OTDT. You can reach Canadian Blood Services by visiting www.blood.ca, and click on “contact us,” or by calling toll free 1-888-2-DONATE (1-888-236-6283).

Materials Checklist

Before you host a kitchen table conversation, you will want to prepare by reading through this kit and its supporting materials. Particularly, it would be useful if you have read the fact sheets and are able to relay this information to your guests throughout the conversation. But don't worry, you needn't become an expert!

Here is a checklist to make sure you have everything you need, and have familiarized yourself with the materials ahead of time:

- Ground Rules – “Bob's Rules”
- OTDT Trivia Questions and Answers
- Organ and Tissue Challenge Statements – Fact Sheets
- Frequently Asked Questions (FAQs)
- Host Feedback Form
- Summary of the Conversation Notes

Hosting a Kitchen Table Conversation

Guide for a 90-minute Conversation

Welcome and Introductions (15 minutes)

- **Welcome** – Welcome your guests and explain a bit about the project (see Background and Purpose), and what you have invited them here to discuss.
- **Ground Rules** – Mention “Bob’s Rules” to point out that this is a friendly, informal conversation where people should feel free to express themselves and really listen to each other.
- **Introductions** – Ask each participant to introduce themselves and invite them to *share their personal, community or professional experiences with Organ and Tissue Donation and Transplantation (OTDT)*, if they feel comfortable doing so. (This can be just a brief introduction as they will have time to share more about their experiences throughout the conversation).
- **Note-Taker** – If you haven’t already arranged it, ask for a volunteer to take notes on the key points of the conversation using the *Summary of the Conversation Notes* form.

Organ Challenges (25 minutes)

- **Background** – Review the 4 challenges to Organ Donation and Transplantation in Canada (see Fact Sheets).
- **Discussion** – Considering the challenges to organ donation and transplantation in Canada:
 - Do you think the main challenges have been identified?
 - Is there an important challenge you think is missing? If so, what is it?
 - Do you have any personal or professional experiences with these challenges?
 - What do you think should be done to address these challenges? Who do you think should be involved? What should their roles be?

Tissue Challenges (25 minutes)

- **Background** – Review the 4 challenges to Tissue Donation and Transplantation in Canada (see Fact Sheets).
- **Discussion** – Considering the challenges to tissue donation and transplantation in Canada:
 - Do you think the main challenges have been identified?
 - Is there an important challenge you think is missing? If so, what is it?
 - Do you have any personal or professional experiences with these challenges?
 - What do you think should be done to address these challenges? Who do you think should be involved? What would their roles be?

Taking Action (15 minutes)

- **Share** – *Considering what needs to be done to address the challenges to OTDT, what could we do locally to improve the system?*
 - If participants are unsure of what types of actions they could take, you could provide them with some suggestions, like the ones listed below:
 - sign their donor card and talk to family/friends/family doctor about their wishes;
 - offer to speak to their service club and/or community organization about the issue;
 - host their own kitchen table conversation;
 - write an article in their local community or work newsletter;
 - spread the word
 - *What are **you** committed to do, in collaboration with others in your community, to advance the creation of an excellent OTDT system in Canada?*
 - *What would the **actions** be?*
 - *What would your **responsibility** be?*
 - ***Who** else would need to be involved?*
 - *What **resources** do you (or we collectively) possess to enable us to act, e.g. time, willingness to work together, etc.?*
 - *What additional support or materials would you need?*

Feedback and Closing (10 minutes)

- **Share** – After learning about the challenges to OTDT in Canada, and participating in this conversation:
 - *Do you feel all the important challenges were raised and if not, please tell us what is missing for you?*
 - *Do you have any new insights into the OTDT situation in Canada and its challenges?*
 - *Does anyone have any other feedback on this conversation experience that they would like to share?*
- **Collect** – Remember to get the *Summary of the Conversation Notes* from your note-taker to help you prepare a letter to your local Member of Parliament and Member of Provincial/Territorial Parliament/Legislative Assembly and to include when submitting your *Host Feedback* form, so that Canadian Blood Services benefits from your conversation.
- Make sure you have the email addresses of participants who are interested in staying/becoming more involved. Direct them to the website: www.blood.ca/speakup.

Guide for a 3-hour Conversation

Welcome (10 minutes)

- **Welcome** – Welcome your guests and explain a bit about the project (see Background and Purpose), and what you have invited them here to discuss.
- **Ground Rules** – Mention “Bob’s Rules” to point out that this is a friendly, informal conversation where people should feel free to express themselves and really listen to each other.
- **Note-Taker** – If you haven’t already arranged it, ask for a volunteer to take notes on the key points of the conversation using the *Summary of the Conversation Notes* form.

Introductions (10 minutes)

- **Ice-breaker** – Each participant briefly introduces themselves and asks an OTDT trivia question, which you will have printed out for them. Everyone can jump in to guess the answer.

Personal stories and experiences (25 minutes)

- **Share** – Invite participants to share their personal, community or professional experiences with Organ and Tissue Donation and Transplantation (OTDT), if they feel comfortable doing so.

Guiding Principles: Developing a Strategy for a Pan-Canadian OTDT System (30 minutes)

- **Brainstorm** – *What principles should guide the Organ and Tissue Donation and Transplantation system in Canada?* (Everyone try to think of a few principles that are important to them. Explain that principles are high level values, beliefs or philosophies that help guide our actions, and inform the decisions we make. E.g. planning a summer camp – guiding principles might be: safe, fun, educational, inclusive).
- **Discussion** – *What principles are important to participants?*
 - *Did participants think of similar top principles?*
 - *Do people agree or disagree?*
 - *Do any of the principles conflict – that is, contradict one another?*
 - *Are any interdependent?*

Organ Challenges (30 minutes)

- **Background** – Review the 4 challenges to Organ Donation and Transplantation in Canada (see Fact Sheets).
- **Discussion** – Considering the challenges to organ donation and transplantation in Canada:
 - Do you think the main challenges have been identified?
 - Is there an important challenge you think is missing? If so, what is it?
 - Do you have any personal, community or professional experiences with these challenges?
 - What do you think should be done to address these challenges? Who do you think should be involved? What should their roles be?

Health Break (15 minutes)

- Invite your guests to take a break to use the restroom, and refresh their drinks.

Tissue Challenges (30 minutes)

- **Background** – Review the 4 challenges to tissue donation and transplantation in Canada (see Fact Sheets).
- **Discussion** – Considering the challenges to tissue donation and transplantation in Canada:
 - Do you think the main challenges have been identified?
 - Is there an important challenge you think is missing? If so, what is it?
 - Do you have any personal, community or professional experiences with these challenges?
 - What do you think should be done to address these challenges? Who do you think should be involved? What would their roles be?

Taking Action (15 minutes)

- **Share** – *Considering what needs to be done to address the challenges to OTDT, what could we do locally to improve the system?*
 - If participants are unsure of what types of actions they could take, you could provide them with these suggestions:
 - sign their donor card and talk to family/friends/family doctor about their wishes,

- speak to their service club and/or community organization about the issue,
- host their own kitchen table conversation,
- spread the word
- *What are **you** committed to do, in collaboration with others in your community, to advance the creation of an excellent OTDT system in Canada?*
 - *What would the **actions** be?*
 - *What would your **responsibility** be?*
 - ***Who** else would need to be involved?*
- *What **resources** do you (or we collectively) possess to enable us to act, e.g. time, willingness to work together, etc.?*
 - *What additional support or materials would you need?*

Feedback and Closing (15 minutes)

- **Share** – After learning about the challenges to OTDT in Canada, and participating in this conversation:
 - *Do you feel all the important challenges were raised and if not, please tell us what is missing for you?*
 - *Do you have any new insights into OTDT situation in Canada and its challenges?*
 - *Does anyone have any other feedback on this conversation experience that they would like to share?*
- **Collect** – Remember to get the *Summary of the Conversation Notes* from your note-taker to share with the participants who may want to act on the recommendations you've developed and to include when submitting your *Host Feedback* form, so that Canadian Blood Services benefits from your conversation.
- Make sure you have the email addresses of participants who are interested in staying/becoming more involved. Direct them to the website: www.blood.ca/speakup.

Tips for Moderating a Conversation

We want you to have a good conversation that you feel gives you an opportunity for informed discussion about the challenges to the OTDT system and identify some ideas to address these challenges. The supporting materials should provide everything you need to know to lead an informed conversation.

Here are some tips to help you guide the conversation along and create a safe space for people to share their experiences and opinions.

Set the Rules

- Use “Bob’s Rules” to make sure everyone is on the same page with what type of conversation and environment you want to create.
- As the conversation moderator, you will want to model active and respectful listening. The objective is to help create an open and collaborative environment and to foster the desired behaviours and attitudes amongst participants.

Act as a Neutral Guide

- You no doubt have lots of opinions on the topic, and don’t be shy to share your experiences, but DO be conscious of letting everyone speak, especially those who have opinions different than your own. Honour and respect all voices!
- You’re not an expert, and nor are you expected to be. Using the information provided in this kit you should be able to convey to participants enough important information to have a good conversation on the challenges.
- Use the questions provided in the guide to probe participants and get them thinking and talking about what is important to them and why.
 - Try to push participants to go beyond their initial positions to understand their deeper motivations, values, and beliefs.
 - Ask that participants weigh carefully the views of others and appreciate the impact of each opinion on what others consider valuable.
 - Have participants work through the conflicting emotions that arise with the pull and tug of various issues.
- Building and sustaining the momentum of the conversation is important, so don’t feel you need to cut off a good conversation to get to the next question in the guide.

After the Kitchen Table Conversation

Reporting Back on the Conversation

Canadian Blood Services is very appreciative that you've taken the initiative to host your own Kitchen Table Conversation! You've helped engage the public and inspired people to take action to improve the system in Canada. Now we need to ensure your conversation is reported back to Canadian Blood Services.

Please feel free to contact Canadian Blood Services to talk about ways you can use the material you've generated to help make a difference in your community.

Once you've collected your designated note-takers' *Summary of the Conversation Notes*, and completed your *Host Feedback Form*, **please SEND them to Canadian Blood Services via e-mail, fax or post:**

Attn: Debbie White

Canadian Blood Services
1800 Alta Vista Drive
Ottawa, ON K1G 4J5

Phone: (613) 739-2404
Fax: (613) 739-2400
E-mail: debbie.white@blood.ca

If participants have questions left unanswered after the conversation, you can include these with your feedback to Canadian Blood Services, along with your email address, and they will respond to you.

Staying Connected and Getting Involved

Go to www.blood.ca/speakup in order to stay connected:

- Sign up to stay informed
- Submit a story or idea online
- Spread the word
- Contact Canadian Blood Services to learn about others in your community that are taking action on this issue

Supporting Materials

Ground Rules

Bob's Rules: Robert's kinder, gentler side... Henry Martyn Robert (1837-1923)

1. Respect other people, their ideas and opinions.
2. Do not interrupt others.
3. Try to say it in 25 words or less.
4. Speak only to the topic at hand.
5. No side conversations.
6. When an idea has been stated previously and you agree, only speak when you have something new to add.
7. Everyone gets a chance to share their opinion before someone else speaks again.
8. Speaking briefly and staying focused is everyone's responsibility. This will make the meeting run smoothly.
9. **These are everybody's rules and everyone is responsible for seeing that they are followed.**

SOURCE: Cece Hughley-Noel, Southeast Uplift, referenced in *The Promised and Challenge of Neighborhood Democracy – Lessons from the intersection of government and community – A Report on "Democratic Governance at the Neighborhood Level"* by Matt Leighninger, 2008

OTDT Trivia Questions and Answers

If you are hosting the 3-hour Kitchen Table Conversation, then you should have enough time to use this quick and easy Icebreaker. If you print the Conversation Kit double-sided, these trivia questions should print with their answers aligned on the back so that you can cut out and distribute the cards to participants. This way each person gets to pose a trivia question and reveal the answer if no one knows the answer.

Otherwise, you could pose the questions yourself and find the corresponding answer, e.g. Tissue (1) question with Tissue (1) answer, and so forth.

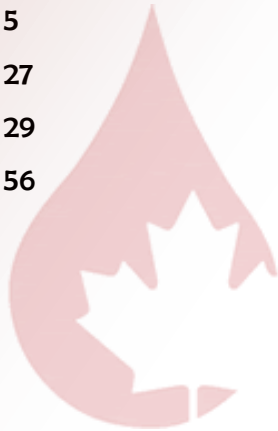
Organ and Tissue Donation and Transplantation Trivia

Tissue (1)

Question:

How many tissue banks are there in Canada?

- a) 5
- b) 27
- c) 29
- d) 56



Organ and Tissue Donation and Transplantation Trivia

Organ (1)

Question:

Where does Canada rank compared to other countries in actual organ donation?

- a) 3rd
- b) 5th
- c) 10th
- d) 11th



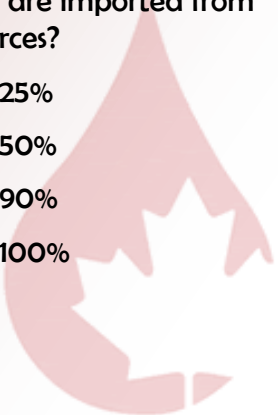
Organ and Tissue Donation and Transplantation Trivia

Tissue (2)

Question:

What percentage of tissue products, that are transplanted in Canada, are imported from foreign sources?

- a) 25%
- b) 50%
- c) 90%
- d) 100%



Organ and Tissue Donation and Transplantation Trivia

Organ (2)

Question:

Where do the majority of organs for transplantation in Canada come from?



Organ and Tissue Donation and Transplantation Trivia

Organ (1)

Answer:

Canada ranks 11th place when compared to other countries with 14.8% actual organ donation per million people. Spain has the highest rate (34.3%), followed by Belgium (28.2%) and the USA (26.6%).



Organ and Tissue Donation and Transplantation Trivia

Tissue (1)

Answer:

There are 29 tissue banks in Canada of varying sizes, inventory focuses, and geographic reaches



Organ and Tissue Donation and Transplantation Trivia

Organ (2)

Answer:

The majority of organs for transplantation in Canada come from deceased donors who die in Canadian hospitals.

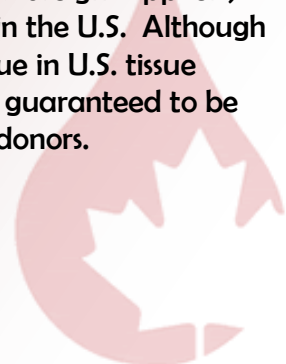


Organ and Tissue Donation and Transplantation Trivia

Tissue (2)

Answer:

It is estimated that Canada imports 90% of its allograft tissue from foreign suppliers, primarily in the U.S. Although not all tissue in U.S. tissue banks are guaranteed to be from U.S. donors.



Organ and Tissue Donation and Transplantation Trivia

Tissue (3)

Question:

What is the most commonly transplanted tissue in Canada?

- a) corneas
- b) heart valves
- c) skin
- d) bone



Organ and Tissue Donation and Transplantation Trivia

Organ (3)

Question:

How many Canadians died on an Organ waiting list in 2008?

- a) 50
- b) 140
- c) 215
- d) 325



Organ and Tissue Donation and Transplantation Trivia

Tissue (4)

Question:

How many tissue allografts (transplants) are performed in Canada every year?

- a) 20,000
- b) 50,000
- c) 75, 000
- d) 90,000

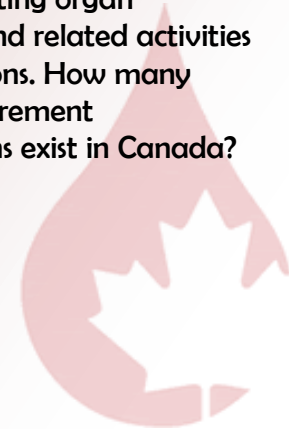


Organ and Tissue Donation and Transplantation Trivia

Organ (4)

Question:

Organ Procurement Organizations are responsible for coordinating organ donations and related activities in their regions. How many organ procurement organizations exist in Canada?



Organ and Tissue Donation and Transplantation Trivia

Organ (3)

Answer:

In 2008, 215 Canadians died while on an organ wait list. That does not count those who could have used an organ but were never referred to a wait list for whatever reason.



Organ and Tissue Donation and Transplantation Trivia

Tissue (3)

Answer:

Bone is by far the most widely transplanted tissue product in Canada, much of it through dental procedures. Cornea's are the second most common.



Organ and Tissue Donation and Transplantation Trivia

Organ (4)

Answer:

There are 10 OPOs across the country, each responsible for a specific geographic area.



Organ and Tissue Donation and Transplantation Trivia

Tissue (4)

Answer:

Approximately 90,000 tissue transplants occur in Canada each year



**Organ and Tissue Donation
and Transplantation Trivia**

Fun Fact (1)

Question:

When was the first successful
kidney transplant performed in
Canada?



**Organ and Tissue Donation
and Transplantation Trivia**

Fun Fact (2)

Question:

When are you too old to be an
organ or tissue donor?



Organ and Tissue Donation and Transplantation Trivia

Fun Fact (2)

Answer:

Everyone is a potential organ and tissue donor, regardless of their age. To date, the oldest Canadian organ donor was over 90 years of age while the oldest tissue donor was 102 years old.



Organ and Tissue Donation and Transplantation Trivia

Fun Fact (1)

Answer:

The first successful kidney transplant was performed in 1958 between identical twin sisters at the Royal Victoria hospital in Montreal.



Organ and Tissue Challenge Statements – Fact Sheets

Organ Challenge #1: Canada is currently not realizing its potential for organ donation.

A Few Facts...

- Canada's deceased donation rate is less than half that of the best performing countries.
- Canada's deceased donation rate has not improved for the past decade.
- Even if the donor has made their wishes clear, it is standard practice to ask the family for consent before proceeding with donation.
- Even though there is strong support for donation across the country, it has not necessarily translated into action. There are a variety of ways to indicate your desire to be a donor depending on where you live, and that can create confusion

Potential Actors:

- Citizens/civil society
- Legislators (federal and provincial)
- Healthcare professionals
- Transplant Programs
- Organ Procurement Organizations
- CBS
- Employers
- Medical Professional Societies
- Emergency Services
- Intensivists
- Medical Examiners
- Funeral Homes
- Pastoral Care
- Who else?

Organ Challenge #2: Depending on where you live in Canada, your wait time for an organ transplant can be very different.

A Few Facts...

- Depending on where you live, you can wait a very different length of time for the same organ. That is directly related to the donation rate in your area.
- There are varying practices across the country to refer patients to wait lists.
- There is a lack of public understanding of the organ donation and transplantation system.
- The best match for organs is often within ethnic groups therefore patients rely on their own community for transplantation.
- Highly-sensitized patients (HSP) make up about 30% of kidney transplant lists but receive less than 5% of all deceased donor kidneys.
- Aboriginal people have more than twice the rate of end-stage renal (kidney) disease compared with Caucasians, but their likelihood of receiving a transplant is significantly lower and they have a significantly higher overall wait time.
- Patients with end-stage organ failure are only placed on a waitlist after an extensive assessment and work-up, including medical examinations, lab testing, imaging (CT scans, ultrasounds) and consultation between various specialists. This can potentially take many months.
- Last year, 215 Canadians died on the organ transplant waitlist.

Potential Actors:

- Citizens/civil society
- Legislators (federal and provincial)
- Healthcare professionals
- Transplant Programs
- Organ Procurement Organizations
- CBS
- Employers
- Medical Professional Societies
- Emergency Services
- Intensivists
- Medical Examiners
- Funeral Homes
- Pastoral Care
- Who else?

Organ Challenge #3: The evaluation process for receiving an organ is not always optimal.

A Few Facts...

- The current national allocation process for urgent status patients across provinces (for heart, liver and small bowel) relies on a manual data entry and a phone or fax system of notification. The process is resource-heavy and is not in real time.
- There are concerns about organs being declined that could have been used.
- Standards to ensure common practice for organ sharing are evolving.
- National organ sharing increases transplant opportunities and can result in improved patient outcomes.
- Advancing technology, for example the software developed for the Living Donor Paired Exchange registry, has the potential to increase transplant opportunities.

Potential Actors:

- Citizens/civil society
- Legislators (federal and provincial)
- Healthcare professionals
- Transplant Programs
- Organ Procurement Organizations
- CBS
- Employers
- Medical Professional Societies
- Emergency Services
- Intensivists
- Medical Examiners
- Funeral Homes
- Pastoral Care
- Who else?

Organ Challenge #4: The current organ donation and transplantation system lacks the mechanisms to make consistent, system-wide improvements.

A Few Facts...

- The lack of comprehensive, timely, consistent, accurate, and integrated data limits the ability to fully understand how well the system is performing, and where to make improvements.
- The system has limited ability to coordinate responses to emerging issues and safety incidents such as West Nile Virus, Hepatitis C, and HIV.
- Canada is not adopting international best practices quickly enough for a variety of reasons: limited hospital capacity which provides a barrier to donation; and lack of training and awareness (few available training programs to learn about best practices).
- There exists limited inter-provincial coordination and collaboration for system improvement.
- Nationally-integrated systems are evolving, including IT systems, quality control, standards and regulation.

Potential Actors:

- Citizens/civil society
- Legislators (federal and provincial)
- Healthcare professionals
- Transplant Programs
- Organ Procurement Organizations
- CBS
- Employers
- Medical Professional Societies
- Emergency Services
- Intensivists
- Medical Examiners
- Funeral Homes
- Pastoral Care
- Who else?

Tissue Challenge #1: Tissue product quality standards are inconsistent

A Few Facts...

- Audits of tissue banks have begun, although level of compliance with Canadian regulations is still unclear.
- There is no comprehensive system in Canada to ensure traceability and surveillance of transplanted tissue from the donor to the recipient or vice versa.
- The system for reporting adverse effects is new, and has not been implemented fully

Potential Actors:

- Citizens/civil society
- Legislators (federal, provincial)
- Healthcare professionals
- Other professionals directly involved in OTDT
- CBS
- Employers
- Tissue Banks
- Eye Banks
- Bone Banks
- Who else?

Tissue Challenge #2: Canada relies heavily on importation from other countries to meet its tissue needs.

A Few Facts...

- Canada's dependency on imported (mostly US) tissue exposes Canadian patients to supply and safety risks.
 - There are a variety of factors (increase demand, volatile exchange rates, natural disasters, etc) that could impact Canadian access.
 - There have been instances of contaminated foreign tissues being imported into Canada.
 - Despite importing approx. 90% of the tissue used in Canada, the demand for some tissues (i.e. corneas) remains unmet
- Canadian tissue banks are not meeting the needs of Canadian patients, in terms of either type or volume of product resulting in tissue shortages in one area of Canada with surpluses in other regions.
- Tissue donation does not have the same time limitations for recovery as exists with organs, but those later opportunities are not always realized
- It has been estimated that there could be enough tissue donors in Canada to meet 100% of the needs of Canadian patients.
- The barriers to donation include such things as families not being aware of the opportunity and insufficient capacity in the system to recover and process tissue

Potential Actors:

- Citizens/civil society
- Legislators (federal, provincial)
- Healthcare professionals
- Other professionals directly involved in OTDT
- CBS
- Employers
- Tissue Banks
- Eye Banks
- Bone Banks
- Who else?

Tissue Challenge #3: Tissue collection, processing and distribution is not as efficient as it could be.

A Few Facts...

- The Canadian tissue system is made up of 29 independent tissue banks outside of Quebec.
- Based on volume, the hospital delivery model used by Canadian tissue banks appears inefficient. With almost the same number of tissue banks (32 as opposed to 29), US tissue banks are able to serve a population 10 times the size of Canada's.
 - The 32 US tissue banks had an average of 1,538 deceased donors per bank with an average allograft production of 49 grafts per donor.
 - Canadian tissue banks processed 244 deceased donors per bank.
- Opportunities exist to improve efficiency of tissue purchase, processing and use.

Potential Actors:

- Citizens/civil society
- Legislators (federal, and provincial)
- Healthcare professionals
- Other professionals directly involved in OTDT
- CBS
- Employers
- Tissue Banks
- Eye Banks
- Bone Banks
- Who else?

Tissue Challenge #4: The current tissue donation and transplantation system lacks the mechanisms to make consistent, system-wide improvements.

A Few Facts...

- Data collection and analysis occurs in many Canadian tissue banks and programs, generally with different standards and data definitions.
- There is no timely, consistent, integrated reporting and there is no requirement or incentive for tissue banks to share information making it difficult to make system-wide improvements.
- Lack of infrastructure makes traceability and surveillance almost impossible
- Many tissue products in Canada are used outside of a hospital setting, most often in dental offices, further making traceability a challenge
- Informed consent is not always obtained for tissue grafts.
- There are opportunities for improved consultation and collaboration among tissue users.
- There are no national wait lists or supply lists for tissues.
- The lack of common objectives results in a lack of system-wide improvements.

Potential Actors:

- Citizens/civil society
- Legislators (federal and provincial)
- Healthcare professionals
- Other professionals directly involved in OTDT
- CBS
- Employers
- Tissue Banks
- Eye Banks
- Bone Banks
- Who else?

Frequently Asked Questions (FAQs)

1. Question: What organs can be transplanted?

There are 6 organs that can be donated:

- Liver
- Kidney
- Heart
- Lungs
- Pancreas
- Intestines

2. Question: Can organs be stored?

No, organs must be transplanted within hours of being recovered.

3. Question: What organs can be donated by a living donor?

Kidney, partial liver and lung transplants can be donated by living donors.

4. Question: Who manages organ donation today?

The system is run by 10 Organ Procurement Organizations (OPOs) that are responsible for coordinating all organ donations in their region. The organization serves as the link between donors and recipients, and is responsible for the retrieval, preservation and transportation of organs for transplantation.

5. Question: What tissues can be donated?

Corneas, heart valves, bone, skin, cardiovascular tissue (including arteries and veins), and soft musculoskeletal tissues like tendons and ligaments.

6. Question: What are the most commonly transplanted tissues in Canada?

Bone is the most commonly transplanted tissue, followed by corneas.

7. Question: How many Tissue banks do we have in Canada?

There are 29 eye and tissue banks outside of Quebec.

8. Question: Is the Canadian organ and tissue system broken?

No, the system saves lives every day. We have exceptionally talented doctors and surgeons in this country, and they use this system to save lives every day. But the system could be more efficient, and improvements in efficiency can ensure even more Canadians get the transplants they need.

9. Question: If it's not broken, why are we looking at creating a new system?

Canada is lagging behind the best performing countries in terms of donation rates - our rates are less than half that of the best performing countries, and our donor rate has remained flat for a decade. We can do better.

10. Question: How is this new system recommendation being designed?

To develop this recommendation, Canadian Blood Services has launched three committees, a Steering Committee made up of prominent experts in public and healthcare policy, as well as an Organ Expert Committee and a Tissue Expert Committee. Those committees will each

meet 4-6 times a year to discuss issues, and will be leading the technical design of a new system.

11. Question: How will the public provide input into the system design?

Public input is vital to this process. Members of the public had the opportunity in late 2009 and early 2010 to sign up to attend one of the public dialogues held across the country, and they can continue to take part in a Kitchen Table conversation like this one. The outcomes of the public dialogues, and the Kitchen Table conversations are being provided directly to the design committees for consideration.

12. Question: What are the public dialogues?

From late 2009 to early 2010 CBS held a series of public dialogues across the country. They were designed to provide the public with an opportunity to learn about the state of the system today, hear from people who have been personally affected by organ and tissue donation, and to provide their thoughts and opinions on what a new system should look like, and how it should operate.

13. Question: Why has Canadian Blood Services been chosen to lead this design?

The Deputy Ministers of Health chose Canadian Blood Services for this role because of its experience running a nationally-integrated system, as well as the trust the organization has built with the Canadian people.

14. Question: Where can I go for more information?

Visit www.blood.ca/speakup to learn more and to find out how to get involved!

15. Can I read the report(s) generated out of each public dialogue, as well as the Final dialogue report?

Yes, all reports have been submitted to the committees and have been made public. They can be found at www.blood.ca/speakup

Host Feedback Form

Contact Information of Kitchen Table Host

Host's Name:	
Address:	
City/Town:	
Province:	
Postal Code:	
Email Address:	
Phone Number:	
Fax Number:	
Date of Kitchen Table Conversation:	

Participants' names and email addresses:

Participant Name	Email address (optional)
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
11.	
12.	

Host Feedback

- Did the *Kitchen Table **Conversation Kit*** (the entire package of materials) provide all the necessary information to organize your own kitchen table session?
 - Did the Conversation Kit provide all the necessary materials to have a productive conversation on the OTDT challenges?
 - If not, what kind of additional information would have been helpful?

- Please provide us with any other suggestions for improving the Conversation Kit?

- Would you recommend hosting a Kitchen Table Conversation to someone you know?

- Did you and your guests gain new insights into these challenges or the OTDT system in general?

- As a result of this conversation, were you and/or your guests motivated to learn more and become more involved?

Summary of Conversation Notes

Thank you so much for taking notes of this conversation. Canadian Blood Services is keen to learn about your conversations and ideas. You aren't expected to take notes word for word, but we would like to know the key points of the conversation, in participants' own words.

Below is a guideline to help you capture important areas of the conversation:

Guide for Notes of a 90-minute Conversation

Introduction – Briefly take note of the participants' experiences that brought them to this conversation, e.g. family member of a recipient, healthcare practitioner, etc.

Organ Challenges –

- Which of the organ challenges did participants focus on the most?
- What were their main concerns?
- What other concerns did they have that were missing from the challenges?
- What action ideas emerged to address the challenges and who did they think should take or lead these actions (e.g. citizens, governments, health etc.)?

Tissue Challenges –

- Which of the tissue challenges did participants focus on the most?
- What were their main concerns?
- What other concerns did they have that were missing from the challenges?
- What action ideas emerged to address the challenges and who did they think should take or lead these actions?

Take Action –

- What commitments were participants willing to make, individually and collectively?
- What were the most popular action ideas discussed?

Feedback –

- Was the overall feedback generally positive or negative?
- Was the conversation productive?
- Did participants gain new insights?
- Did participants have other important feedback they wanted to convey to Canadian Blood Services?

Guide for Notes of a Three Hour Conversation

Introduction – Briefly take note of the participants' experiences that brought them to this conversation, e.g. family member of a recipient, healthcare practitioner, etc.

Guiding Principles –

- What principles were most important to participants?
- Was there any disagreement or divergence of opinion?
- Did any stand out as being top priority?

Organ Challenges –

- Which of the organ challenges did participants focus on the most?
- What were their main concerns?
- What other concerns did they have that were missing from the challenges?
- What action ideas emerged to address the challenges?

Tissue Challenges –

- Which of the tissue challenges did participants focus on the most?
- What were their main concerns?
- What other concerns did they have that were missing from the challenges?
- What action ideas emerged to address the challenges and who did they think should take or lead these actions?

Take Action –

- What commitments were participants willing to make, individually and collectively?
- What were the most popular action ideas discussed?

Feedback –

- Was the overall feedback generally positive or negative?
- Was the conversation productive?
- Did participants gain new insights?
- Did participants have other important feedback they wanted to convey to Canadian Blood Services?