



Human Organ and Tissue Donation

Physician relationships with patients' Substitute
Decision Makers

Vanessa Sweet
Osama Loubani
Zaiping Liu

Tom Skinner
Cathy Connell
Allana Munro

Objectives

- Describe the HOTD Deliverables
- Review the available literature on presumed consent
- Provide an Environmental Scan
- Present HOTD Toolbox Website
- Discuss future needs

Nova Scotia

Nova Scotia to become 1st in North America with presumed consent for organ donation



January 18th, 2021


[Michael Gorman](#) · CBC News · Posted: Apr 02, 2019 1:25 PM AT | Last Updated: April 2, 2019



Under the new bill, people will be able to opt out of donating their organs, but the onus will be on them to do so once the bill is proclaimed. (Shutterstock)



What IS Presumed Consent?

 Legislative framework in which citizens place their name on a opt-out registry, otherwise consent for donating their organs will be presumed.

 But Section 15 states:


“Where a substitute decision-maker provides information that would lead a reasonable person to conclude that an individual would have made a different decision respecting donation after death than the decision recorded in the Registry or deemed under Section 11 the substitute decision-maker may consent or refuse on behalf of the individual in accordance with that information.”

Deliverables

1. Plan for engagement with existing NS authorities on human organ and tissue donation (including academic researchers (NSH) and policy makers) for the purposes of informing this ALP. The plan should consider how health system actors can inform and support other deliverables, such as the environmental scan and the focus groups (physician and substitute decision makers).
2. Toolkit for conducting consent conversations with the substitute decision makers (e.g., families) of deceased persons within the context of NS' new laws on presumed consent ("opt-out") for organ and tissue donation. Guidelines may also provide suggestions for health system coordination as it relates to determining consent and following through with processes and protocols for donation.
 - a. Literature review (international peer-reviewed) and environmental scan (other jurisdictions that have presumed consent, North American jurisdictions with guidelines for conversations with substitute decision makers for HOTD) on toolkit and recommendations for conducting conversations about HOTD with families/substitute decision makers of deceased.
 - b. Report of findings from focus groups, identifying main themes that arose in discussion.
3. Proposed opportunities for physician training and professional development on conflict resolution and family management in clinical settings, informed by consultation with social workers, counsellors, and/or other relevant experts.

Literature Review

References

- A Rithalia et al. A systematic review of presumed consent systems for deceased organ donation. (UK, 2009)
 - CMPA. Organ and tissue donation: Who has the final say?
 - H. Omer Tontus. Educate, Re-educate, Then Re-e
 - Samantha J et al. Family veto in organ donation i
 - A. Rios et al. Benefit of a hospital course about o personnel.
 - Live Jacoby et al. Providing support to families cc
 - D. Wendler et al. The consent process for cadave
 - L.A. Siminoff et al. Factors influencing families' c
 - M.J. Cherry. Consented organ harvesting from th
 - C. Tollefsen. Family consent and organ donation.
 - J.A. Parsons. Welsh 2013 deemed consent legisla
 - John Fabre. Presumed consent for organ donation: a clinically unnecessary and corrupting influence in medicine and politics
 - Etc...
- 
- cludes Should Be Established in Society
age newspaper articles.
evaluation by Spanish Hospital transplant
n: an innovative training method
transplantation
presumed consent, and familial authority

- There are two presumed consent (“opt-out”) systems characterized in the literature:

1. Hard opt-out system - meaning Families are not consulted.
2. Soft opt-out system - meaning the relatives have the right of veto over donation if the deceased’s wishes were unknown or disputed.

Literature Review



- Some of the available evidence suggests that presumed consent legislation is a/w an increase in organ donation rates. Some others show legislation alone is not enough.
- Public policy ought to ensure that altruism and the spirit of gift-giving motivates organ donation i.e. cultural attitudes are the key to improving consent rates.
- Family-oriented approaches acknowledge the foundational, social, and moral realities of family life.

Literature Review

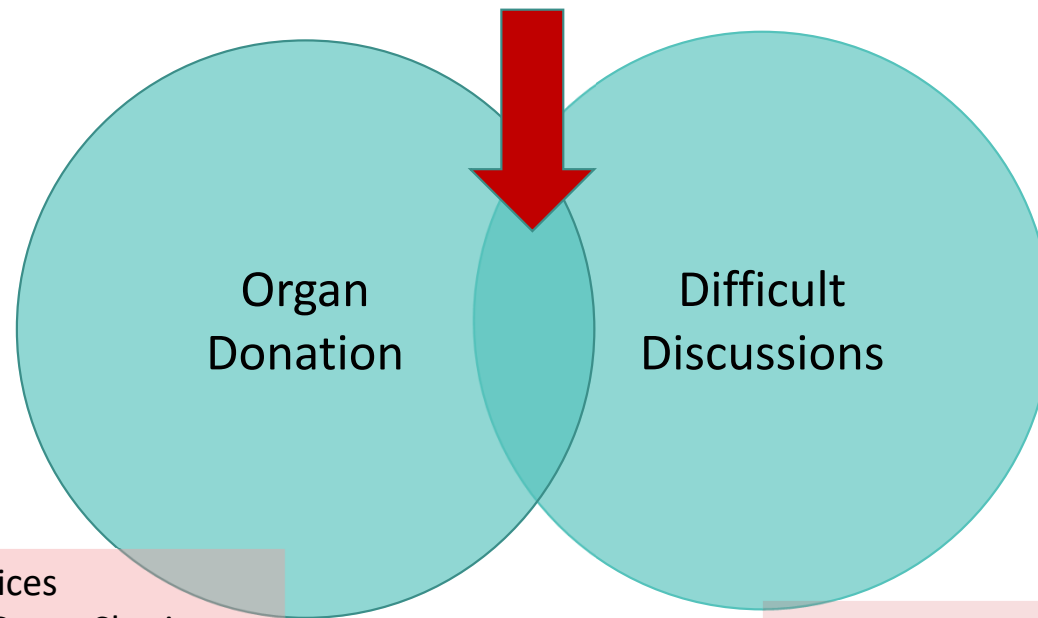


- Improving/creation of organizational transplant co-ordination infrastructure is very important
 - Increase transplant capacity and health expenditure per capita
 - Educate health care workers, fill the knowledge gap, address misunderstandings
 - Train dedicated staff to identify potential donors and build relationships with the family **ahead of time** at which decisions need to be made in the ICU.
- Build public trust:
 - Involve families, faith leaders, ethnic group leaders etc.
 - Media campaigns are hugely influential in changing public opinion gradually and successfully
 - Transparent and easy access to information
 - ? Structured “point system”: priority to those who have registered as donors or those with family members who have been organ donors...

Environmental Scan

Existing Resources:

Focus on transplant professionals

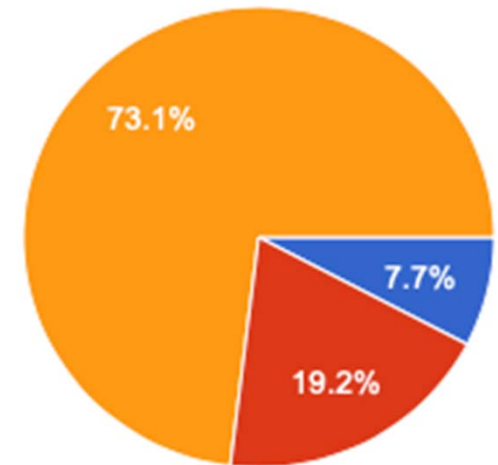


- Canadian Blood Services
- United Network for Organ Sharing
- Legacy of Life (and similar groups)

- The Conversation Project
- Advanced Care Planning Canada

Survey of Primary Care Providers

- Current organ donation practices
- Sense of knowledge gaps
- Obstacles to success
- Interest in proposed toolkit contents



- All patients
- Selected patients
- No patients

Main Themes

- Remuneration
- Amount of time required
- Knowledge of organ donation
- Not 'on their radar'
- Didn't feel it was relevant to their practice

Interest in Content


CPD

- Dalhousie CME/CPD
- Family Medicine Forum
- Dalhousie Fall Refresher
- DNS Online Modules
- Small Group Learning Sessions

Toolkit

- EMR Template
- Information Sheet
- Websites that are easy to use
- Short Info Sheet/FAQ document with access to more detailed information
- Educational Materials for patients
- Posters/Slides for clinics
- Asynchronous learning modules/Webinars/Conferences
- The ability to discuss with colleagues

 > 90 % of Canadians support organ donation

 Most patients facing donation are unable to communicate their wishes



Only 23% of Canadians
say they have registered.



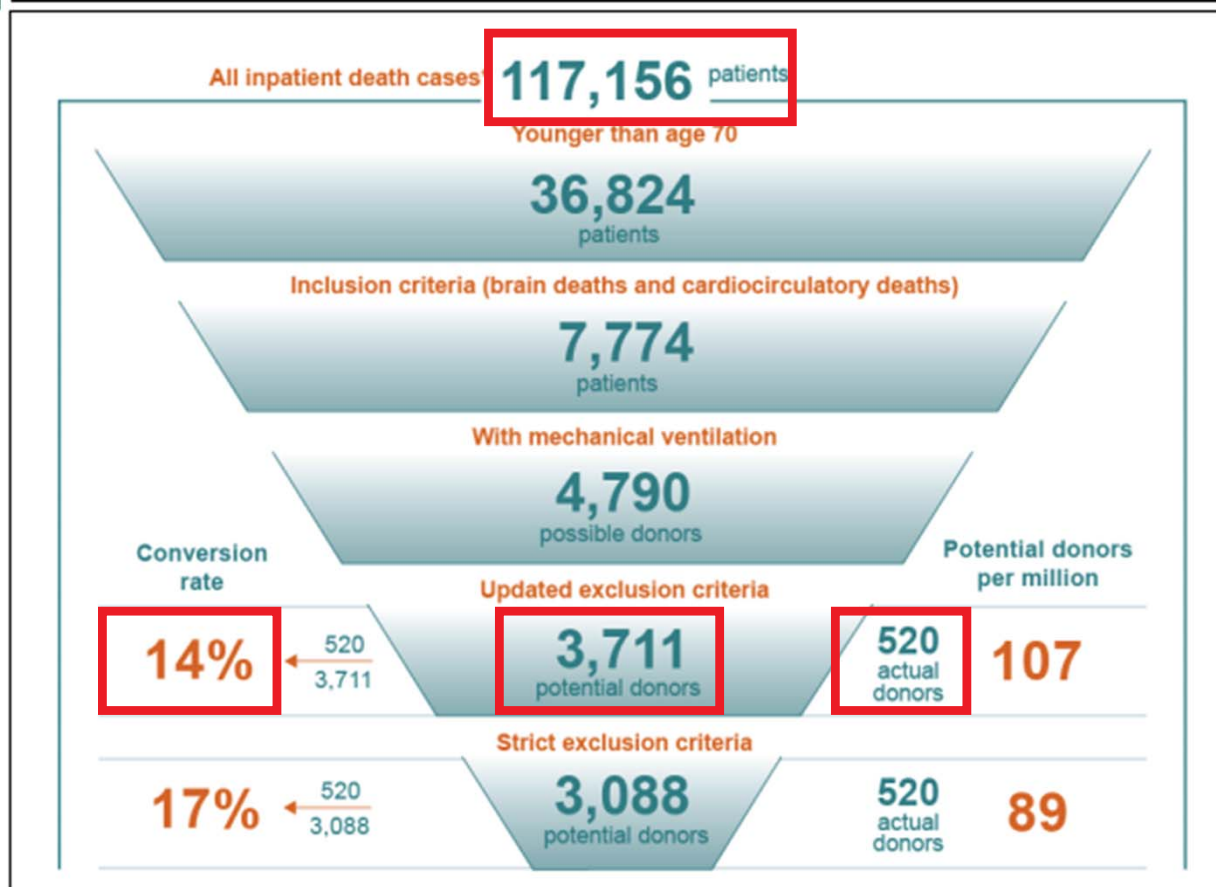
**Canadian
Blood
Services**

BLOOD
PLASMA
STEM CELLS
ORGANS
& TISSUES

Register your decision
blood.ca/organs-tissues

Poor Donor Conversion

Figure 2: Pathway to Deceased Organ Donor Potential in Canada, 2012*



Stakeholders







- Most patients have never discussed their wishes before
- SDM meeting donor team for the first time
- Extremely stressful environment
- Consent process is MUCH easier when families have discussed

What can be done?

- Role of a trusted Primary Care Practitioner is essential in promoting these conversations
- Encourage families to discuss
- The toolkit is designed to support this work and minimize the impact on a busy clinical practice



Toolkit

-  Posters
-  Waiting Room Pamphlets
-  EMR Template
-  Conversation Guide
-  Toolkit Website
-  Learning Links



Next Steps:

- When to launch the Toolkit
- Where to host the Toolkit
 - Doctor's Nova Scotia Website, Legacy for Life
- How to disseminate information about the Toolkit
 - Email, social media, presentations
- How to incentivize the tool kit and HOTD discussions
 - New fee code request (Advance Care Planning/Prolonged Counselling, Goals of Care)
 - CME
- Consideration of Group/Family Appointments
- UGME (Professional Competencies) & PGME opportunities

Dalhousie Fall Refresher

Key Message

You do NOT need to be a **content expert** to

Get Families Talking about Organ Donation!



Questions?

References

- A Rithalia et al. A systematic review of presumed consent systems for deceased organ donation. (UK, 2009)
- CMPA. Organ and tissue donation: Who has the final say?
- H. Omer Tontus. Educate, Re-educate, Then Re-educate: Organ Donation-centered Attitudes Should Be Established in Society
- Samantha J et al. Family veto in organ donation in Canada: framing within English-language newspaper articles.
- A. Rios et al. Benefit of a hospital course about organ donation and transplantation: An evaluation by Spanish Hospital transplant personnel.
- Liva Jacoby et al. Providing support to families considering the option of organ donation: an innovative training method
- D. Wendler et al. The consent process for cadaveric organ procurement
- L.A. Siminoff et al. Factors influencing families' consent for donation of solid organs for transplantation
- M.J. Cherry. Consented organ harvesting from the newly deceased: First person assent, presumed consent, and familial authority
- C. Tollefsen. Family consent and organ donation.
- J.A. Parsons. Welsh 2013 deemed consent legislation fall short of expectations
- John Fabre. Presumed consent for organ donation: a clinically unnecessary and corrupting influence in medicine and politics
- Balaban RB. A physician's guide to talking about end-of-life care. *J Gen Intern Med*. 2000;15(3):195-200. doi:10.1046/j.1525-1497.2000.07228.
- Shemie, Sam D. MD^{1,2,3}; Robertson, Adrian^{4,5}; Beitel, Janice⁶; Chandler, Jennifer LLM^{7,8}; Ferre, Ed⁹; Evans, Janet¹⁰; Haun, Mathias¹¹; Torrance, Sylvia¹² on behalf of the EOL Conversations with Families of Potential Donors participants. End-of-Life Conversations With Families of Potential Donors, Transplantation: May 2017 - Volume 101 - Issue 5S - p S17-S26 doi: 10.1097/TP.0000000000001696 End-of-Life Conversations with Families of Potential Donors: Leading Practices in Offering the Opportunity for Donation . Canadian Blood Services, 2014.
- The Conversation Project (theconversationproject.org): An initiative of the Institute for Healthcare Improvement (IHI; ihi.org). Licensed under the Creative Commons Attribution-ShareAlike 4.0 International License, <https://creativecommons.org/licenses/by-sa/4.0/> ©2021