

Improving Access to Living Donor Kidney Transplantation (LDKT) in Communities Marginalized by Race and Ethnicity in Canada

What is this project about?

Project background

For many patients with end-stage kidney disease, a kidney transplant from a living donor provides the best outcome in terms of longer life expectancy and better quality of life. However, access to living donor kidney transplant (LDKT) is dramatically lower among racialized groups in Canada compared to white patients. This issue is partly due to insufficient knowledge among patients and communities about the benefits of LDKT, cultural or religious concerns, and barriers to communication about health problems outside the immediate family. Potentially modifiable barriers include systemic bias and racism, and lack of trust by patients in the health care system.

There has also been an absence of thorough discussion about planning for and implementation of best practices to address inequities in Canada. While this project focuses on South Asian and African, Caribbean and Black Canadians, the project findings and tools may be able to be adapted for other at-risk groups marginalized by race or ethnicity.

Objectives

This project aims to improve equitable access to LDKT in racialized groups in British Columbia and Ontario by implementing and evaluating culturally safe tools and clinical pathways.

Overview of activities

- Identify and review existing tools and clinical pathways that support LDKT for South Asian and African, Caribbean and Black Canadians.
- Develop culturally appropriate and safe educational materials and clinical pathways to support patients from racialized groups to explore LDKT.
- Develop cultural safety training for health care professionals working in nephrology and kidney transplant.
- Conduct a pilot study to evaluate the implementation of cultural safety training, education tools and clinical pathways developed through the project with the aim of encouraging their uptake across Canada.

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Engaging South Asian and African, Caribbean and Black Canadian communities to better understand their challenges and needs in order to improve access to LDKT.
- Increasing knowledge about living donation and LDKT among South Asian and African, Caribbean and Black Canadians.
- Improving equitable access to culturally competent and safe services for South Asian and African, Caribbean and Black Canadians.
- Increasing the knowledge of stakeholders including decision-makers and health care providers about the challenges faced by at-risk communities marginalized by race and ethnicity.
- Providing the training, education materials and clinical pathways for use by across Canada.

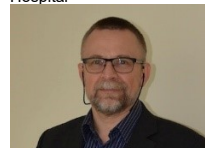
The project leads

The project is led by Providence Healthcare in collaboration with the UHN Centre for Living Organ Donation.



Dr. Jagbir Gill
Associate Professor, UBC
Division of Nephrology, St. Paul's
Hospital

"In research and in healthcare, we need to have the difficult conversations about how we have historically contributed to the mistrust from racialized communities," Lydia-Joi Marshall, Research Associate/Community Liaison



Dr. Istvan Mucsi
Associate Professor, University
of Toronto
Kidney Transplant Program, UHN

"Change takes time, but we are channeling our passion and energy into something positive. We are planting the seeds so that eventually the system can be better for everyone." Fadia Jerome-Smith, living donor kidney recipient for ACB communities

EXPECTED PROJECT COMPLETION IN 2022

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Improving Access to Living Donor Kidney Transplantation (LDKT) in Communities Marginalized by Race and Ethnicity in Canada* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Implementation of a Pan-Canadian Data Management and Performance Reporting System

What is this project about?

Project background

Despite significant improvements, compared to peer nations, Canada under-performs on a number of measures related to organ donation and transplantation (for example, rates of living and deceased donation). For better understanding of system challenges, to support evidence-informed decision-making, and drive improvements in access, efficiency, quality and outcomes across the continuum of care, a pan-Canadian data and performance reporting system has been identified as a high-priority initiative by the organ donation and transplantation community.

Objectives

In collaboration with provincial, territorial and national agencies, this project aims to modernize pan-Canadian data management and performance reporting systems for organ donation and transplantation to improve consistency and quality of data from across the country, and expand the use of data for decision-making.

Overview of activities

- Implement donation and transplantation data management systems to capture and manage data across the continuum of care.
- Create a pan-Canadian organ donation and transplantation data repository to host comparable data at the national, regional, and organ donation organization levels.
- Enable pan-Canadian reporting and access to data, and use of data for decision-making for system improvement.

**EXPECTED PROJECT
COMPLETION IN 2024**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Ensuring the deployment and integration of data management systems that will enable improvements in the supply of solid organs, and monitoring of transplant patients. Donor management systems will handle increased donor volume, minimize missed donation opportunities, reduce redundancy in data entry, and implement and improve data standardization.
- Supporting availability of local, provincial and national data to drive evidence-based decision making to improve patient access to transplant services and outcomes across Canada.

The project leads

Canada Health Infoway (Infoway) and the Canadian Institute of Health Information (CIHI) are the leads for this project.



Mark Nenadovic
Senior Director, Infoway



Greg Webster
Director, Acute and Ambulatory
Care Information Services, CIHI

“With this project Health Canada has provided organ donation and transplantation communities with tremendous and transformative opportunities that will reap benefits for generations of Canadians.”

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Implementation of a Pan-Canadian Data Management and Performance Reporting System* contributes to the Collaborative’s vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website:

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Developing a Brain-based Definition of Death and Evidence-based Criteria for its Determination after Arrest of Circulation or Neurologic Function in Canada

What is this project about?

Project background

When proceeding with deceased organ donation, a clear definition and determination of death are of critical importance. The concepts currently in practice have created the idea of two distinct forms of death – brain death and cardiac death.

However, cardiac death is indeed brain death. That is, arrest of circulation leads to absent brain blood flow, which in turn leads to the rapid loss of brain function.

There is a need to review and update Canadian clinical practice guidelines, including the definition of death, to align practices with current scientific evidence and address evolving legal and ethical considerations.

Objectives

The objective of this project is to develop a clinical practice guideline that includes a brain-based definition of death as well as evidence-based and expert-informed criteria for death determination after arrest of circulation or neurologic function.

Overview of activities

- Gather and analyze national and international evidence to determine what is applicable in a Canadian context in the areas of legislation, regulations, ethics and medical guidelines.
- Conduct stakeholder consultations, including the public, patients and their families, and a variety of health care professionals, to ensure that the values, interests and concerns of those affected are incorporated in the guideline.

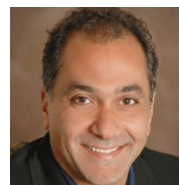
How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Improving clinical practices through an examination of medical, ethical, legal considerations related to death determination.
- Minimizing diagnostic errors.
- Enhancing trust and integrity in the deceased donation and transplantation system.

The project leads

The project is led by the Canadian Critical Care Society in partnership with the Canadian Blood Services (CBS) and the Canadian Medical Association (CMA).



Dr. Sam Shemie
Division of Critical Care,
Montréal Children's
Hospital, McGill University
Health Centre
Medical Advisor, Canadian
Blood Services



Dr. Bojan Paunovic
President, Canadian
Critical Care Society

“Organ donation after death accounts for the vast majority of transplantation in Canada. Clarity around the medico-legal definition of death and updating the clinical procedures for the determination of death in Canada are required to maintain and enhance the trust and integrity of defining and determining death for the purposes of organ donation.”

**EXPECTED PROJECT
COMPLETION IN 2022**

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Developing a Brain-based Definition of Death and Evidence-based Criteria for its Determination after Arrest of Circulation or Neurologic Function in Canada* contributes to the Collaborative’s vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Implementation of Donation Advisor - a Personalized Clinical Decision Support Tool for Improved Efficiency and Effectiveness of Deceased Organ Donation and Transplantation

What is this project about?

Project background

Patients with non-recoverable illnesses who are undergoing withdrawal of life sustaining measures can donate organs by a process called donation after circulatory determined death (DCD). However, a challenge related to this population's willingness to donate is the inability to predict accurately if a potential donor will die within an eligible time-period and manner for donation. In addition, it may be painful for families to consent to this process and can limit the availability of organs for donation.

Objectives

This project aims to implement and evaluate a clinical decision support tool, called *Donor Advisor*, in six hospitals, which will assist in identifying potential DCD donors.

Overview of activities

- Implement and evaluate the *Donor Advisor* tool with the consent of families in six hospitals.
- Assess organ suitability via biomedical waveform analysis (i.e. heart rate and blood pressure) to determine physiological patterns associated with organ ischemia.
- Evaluate the *Donor Advisor* tool in collaboration with health care clinicians.
- Assess the experience of DCD patients with respect to the implementation of the *Donor Advisor* tool.

**EXPECTED PROJECT
COMPLETION IN 2022**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Assisting health care teams in identifying potential DCD donors.
- Reducing missed opportunities and enhancing family experience of donation.
- Increasing the number of quality transplantations through a clear indication of likelihood of DCD success prior to withdrawal of life-sustaining measures.
- Providing evidence for the use of the *Donor Advisor* tool as a feasible and cost-effective way to enhance DCD in all donation centres.

The project leads

The project is led by the Children's Hospital in Eastern Ontario Research Institute Inc.(CHEO-RI).



Dr. Sonny Dhanani
Chief, Critical Care, CHEO
Associate Professor, University of
Ottawa

"We are excited to implement this novel tool in multiple centers and get the feedback from Ontario clinicians regarding its feasibility, usability and potential to materially improve donation and transplantation."



Dr. Andrew Seely
Professor, University of Ottawa
Scientist, Ottawa Hospital
Research Institute

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Implementation of Donation Advisor - a Personalized Clinical Decision Support Tool for Improved Efficiency and Effectiveness of Deceased Organ Donation and Transplantation* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website:

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Donor Identification and Referral as a Critical Patient Safety Event Leading to Preventable Harm for Transplant Candidates

What is this project about?

Project background

Over 80% of transplants arise from organ donation after death, which is predicated on frontline healthcare professionals identifying and referring potential donors to local organ donation organizations in a timely manner.

Failure to identify and refer a potential donor in a timely manner is a critical patient safety event causing preventable harm to transplant candidates (an underserved and vulnerable population) in terms of longer wait times, disability and death.

Objectives

This project aims to develop an implementation strategy to reduce missed donor identification and referral opportunities and improve accountability mechanisms in deceased donation.

Overview of activities

- Conduct an economic analysis of the resources required to implement system-wide potential donor audits.
- Conduct a root cause analysis of the missed donor identification and referral opportunities and develop strategies to eliminate (or reduce) these missed opportunities.
- Evaluate potential donor audit and feedback strategies to influence hospital and healthcare professional performance related to potential donor identification and referral.
- Integrate donor identification and referral into hospital accreditation.

**EXPECTED PROJECT
COMPLETION IN 2022**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Reducing the number of missed potential organ donors identified and referred.
- Increasing accountability mechanisms in the donation system.
- Ensuring donor identification and referral processes become common practice in hospitals.
- Embedding donor identification and referral as a standard component of end-of-life care.

The project leads

The project is led by the Research Institute of the McGill University Health Centre.



Dr. Samara Zavalkoff
Pediatric Intensive Care Unit,
Montreal Children's Hospital



Jehan Lalani
System Development Specialist,
Canadian Blood Services

"One of the Collaborative's key goals is to maximize donor identification and referral in hospitals across Canada. We know that if a potential organ donor is not identified and referred, organ donation cannot happen."

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Donor Identification and Referral as a Critical Patient Safety Event Leading to Preventable Harm for Transplant Candidates*, contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Assessing and Improving the Governance of Organ Donation and Transplantation in Canada

What is this project about?

Project background

A challenge to address in the organ donation and transplantation (ODT) system is the lack of a pan-Canadian governance model. While provincial and territorial governments have the authority to make decisions with respect to ODT system planning, funding and delivery, they operate with varying levels of collaboration, coordination and performance accountability. Identifying options for structures and processes for decision-making at a pan-Canadian level has been identified as a top priority in the ODT community.

Objectives

The project will support the achievement of a pan-Canadian consensus on a new ODT system governance structure, approach or mechanism, which includes a clear accountability framework and associated decision-making process, and respects jurisdictional authority.

Overview of activities

- Develop a comprehensive map outlining how Canada's ODT ecosystem is currently governed and identifying roles, responsibilities, strengths and challenges.
- Present a constructive set of options for consideration by key stakeholders on the future governance of ODT.

**EXPECTED PROJECT
COMPLETION IN 2021**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Providing a constructive diagnosis of governance challenges, opportunities and considerations for the creation of pan-Canadian governance.
- Supporting consensus building among key stakeholders by developing a set of guiding principles and a vision for pan-Canadian ODT governance towards achieving the goal of a higher performing ODT system.
- Ensuring meaningful improvements to the accessibility, responsiveness, quality, sustainability, and accountability of Canada's ODT system as a result of improved governance.

The project lead

The project is led by the University of Ottawa Centre for Health Law, Policy and Ethics, in collaboration with University of Ottawa/York University Global Strategy Lab.



Patrick Farfard
Full Professor, Graduate School of
Global and Public Affairs
Associate Director
Global Strategy Lab

"Improving governance is key to achieving the kind of ODT system we want. I am delighted that the Collaborative has decided to put decision making and accountability at the centre of its ongoing efforts to rethink ODT in Canada."

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Assessing and Improving the Governance of Organ Donation and Transplantation in Canada* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website:

<https://tinyurl.com/ODTCollaborative>.

Legislative Strategies to Improve Deceased Donation in Canada: A Special Focus on Evaluating the Impact of Opt-Out Legislation in Nova Scotia

What is this project about?

Project background

In April 2019, Nova Scotia became the first jurisdiction in North America to introduce legislation in which an adult will be considered as a potential candidate for organ and tissue donation unless they actively opt-out. Families will continue to be consulted to confirm a person's wishes. Other provinces currently use an opt-in model where a person must sign up to become an organ donor. While the majority of Canadians say they are willing to donate organs, a much smaller percentage have registered to do so. In countries that have adopted an opt-out model, organ donation rates are higher, however this may be only one of the factors influencing rates. Other potential factors include health care spending, infrastructure, public attitudes, and donor availability. This landmark legislation has created a unique 'natural experiment' in which to understand the implications of opt-out models, and apply this understanding to other Canadian jurisdictions.

Objectives

This project will gather evidence to inform legislative strategies aimed at improving organ donation and to evaluate the impact of opt-out legislation on organ donation in Nova Scotia.

Overview of activities

- Examine the international experience of opt-out legislation to help guide the implementation of the legislative change in Nova Scotia.
- Understand public and health care professional opinions on donation and opt-out, and the role of the media.
- Evaluate the impact of the opt-out legislative change in Nova Scotia on key donation system metrics.

**EXPECTED PROJECT
COMPLETION IN 2022**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Implementing more effective outreach strategies that could increase donation rates and acceptance of opt-out legislation through analysis of public opinion polls and engagement with leaders from specific populations, e.g. linguistic, religious and ethnic minorities, and patients with disabilities.
- Informing future policy and legislation decisions in other provinces across Canada and potentially changing the culture of organ donation to overcome the chronic shortage of organs.
- Providing health professionals with knowledge on how an opt-out system takes into consideration family decisions, wishes and experiences.

The project leads

This project involves collaboration of five partner organizations: Nova Scotia Health, Nova Scotia Department of Health and Wellness, Canadian Donation and Transplantation Research Program, Transplant Québec, and Canadian Blood Services.



Dr. Stephen Beed
Medical Director Legacy of Life and
Critical Care Organ Donation, Nova
Scotia Health Authority



Dr. Matthew Weiss
Medical Director of Organ
Donation, Transplant Québec

“Nova Scotia’s donation system is undergoing a transformative change with the passage of the Human Organ and Tissue Donation Act by moving towards an opt-out consent model. The Legislative Evaluation: Assessment of Deceased Donation Reform Program will study the implementation of this change - with the expectation that health care will improve for patients in Nova Scotia, and lessons learned can influence decision making in other parts of Canada to increase organ donations for those who need it most.”

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada and other partners, the project *Legislative Strategies to Improve Deceased Donation in Canada: A Special Focus on Evaluating the Impact of Opt-Out Legislation in Nova Scotia* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Mapping Provincial/Territorial Decision-Making Mechanisms and Implementation Procedures for Organ Sharing Policies

What is this project about?

Project background

Organs are shared across Canada to improve patient access to transplant, equity, and to maximize organ utilization (i.e. organs that can't be used in one province are sent to another). However, inter-provincial organ sharing policies and practices vary across provinces. Currently, there is no clear process for the approval and implementation of national inter-provincial organ sharing policies within each provincial and territorial jurisdiction. The lack of a pan-Canadian process to coordinate, communicate, implement, and monitor the national implementation of inter-provincial organ sharing policies has revealed the complexity of the system in which organ sharing takes place. The complex systems and rules between provinces need to be understood as a first step in removing barriers to improving the organ donation and transplantation system across Canada and ultimately increasing the utilization of organs and the efficiency of the inter-provincial organ sharing process.

Objectives

The goal of the project is to understand the current context and practices that exist in each province with the aim of developing recommendations to address long-standing barriers in the dissemination and adoption of organ sharing policies.

Overview of activities

- Review and analyze existing policies in order to create a process map for the approval and implementation of interprovincial organ sharing policies and agreements across Canadian jurisdictions.
- Develop recommendations for streamlining and improving the path to dissemination and implementation of organ sharing policies across Canadian jurisdictions.

**EXPECTED PROJECT
COMPLETION IN 2021**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Providing analysis and recommendations that will support stakeholders in reaching agreement on system improvements related to inter-provincial organ sharing policies that enhance the effectiveness of the pan-Canadian organ donation and transplantation system.
- Spreading best practices and improvements within and across organ donation organizations, regions, provinces and territories.
- Ultimately supporting increased opportunities for donation and transplantation, and the equity and quality of transplantations.

The project lead

The project is led by the Trillium Gift of Life Network.



Claire Payne
Vice President, Clinical
Transplant System

"I'm honoured to be part of this very exciting time for organ donation and transplantation in Canada. Many thanks to the Collaborative for undertaking the incredible task of bringing the ODT community together to develop an effective process to increase access to transplant for all Canadians. I look forward to the transformation that will undoubtedly result from the Collaborative and ensuring our collective goals for interprovincial organ sharing are brought to fruition."

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Mapping Provincial/Territorial Decision-Making Mechanisms and Implementation Procedures for Organ Sharing Policies* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Improving Engagement and Empowerment of Patients and Families through their Transplant Journey

What is this project about?

Project background

A transplant journey can be a long process that includes consideration of organ donation or transplantation, waiting for a donor or recipient, surgery, rehabilitation, and post-transplant maintenance. Navigating the complexities of the health care system can be challenging for patients. A better understanding of the patient experience is needed to improve services and supports, and to identify how to best involve and empower patients not only through their personal journey, but in contributing to system improvements.

Objectives

The project will focus on three overarching objectives: 1) improve health services and products for patients on a transplant journey; 2) empower patients to navigate the system across jurisdictions and advocate for their own needs; and 3) develop recommendations for patient-led and patient-focused approaches for renewed and improved ODT health policies and services in Canada.

Overview of activities

- Conduct an environmental scan and survey to better understand patient experiences with the system, and what currently exists in terms of products and services for patients.
- Engage and empower patients through the creation of a patient/advocate network and through workshops - to enable involvement in health system priority setting and improvement.
- Based on patient/advocate input, develop and disseminate a set of recommendations for short- and long-term actions to improve patient experience of the process.

**EXPECTED PROJECT
COMPLETION IN 2022**

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Promoting the involvement of patients in the development of services and supports aimed at improving their experience with the ODT system.
- Providing patients with the tools and opportunities to advocate for their needs, and to contribute to actions aimed at system improvement.
- Improving the accessibility, quality, responsiveness, accountability and sustainability of the health care system in order to meet patient needs.

The project leads

The project is led by the Kidney Foundation of Canada.



Lydia Lauder
National Director, Programs and
Public Policy



Carrie Thibodeau
Patient and Advocate Advisory
Committee (PAAC) Project Lead

"With the ever-growing waitlist and increasing complexity of our transplant population, it is vital that we develop a pan-Canadian organ donation and transplantation system that is responsive to the diverse needs of our patients," says Kristi Coldwell, transplant recipient and PAAC co-chair. "Recognizing the challenges inherent to transplantation, we endeavour, through this project, to empower patients at all stages of the transplant journey. We are grateful to Health Canada for funding this important project and embracing the power of lived experiences to improve the overall organ donation and transplant journey for patients and families."

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Improving Engagement and Empowerment of Patients and Families through their Transplant Journey* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Implementation and Evaluation of an Electronic Patient-Reported Outcome Measure Platform in Pediatric Transplantation

What is this project about?

Project background

Patient-reported outcomes are becoming increasingly recognized as a key component of quality care. Patient-reported outcomes refer to information on a patient's health condition and care experience that comes directly from the patient without interpretation of their response by a clinician or other individual. This information is typically collected via questionnaires completed by patients known as patient-reported outcome measures (PROMs). PROMs can comprise information about symptoms, functional status, satisfaction, treatment adherence, and domains of overall well-being and quality of life.

Objectives

This project aims to transform the delivery of care, and improve the health outcomes of pediatric solid-organ transplant patients in Canada by implementing patient-reported outcome measures (PROMs) as an innovative approach to clinical care in pediatric transplantation.

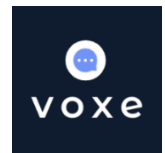
Overview of activities

- Create and design an ePROM software platform – Voxe – that will collect and report PROM data to inform clinical practice in a pediatric transplant population.
- Conduct usability testing of Voxe with patients, health care providers and administrators, and incorporate refinements.
- Provide professional education and coaching for SickKids Transplant and Regenerative Medicine Centre (TRMC) health care providers and administrators in the use of the platform and in how PROM data can be used to inform care.
- Implement and evaluate implementation of Voxe at SickKids with a future goal of spread to other pediatric transplantation centres.

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Ensuring better transplant outcomes for the pediatric population.
- Using PROM data for quality improvement processes, research and supporting a person-centered approach to care.
- Providing training to health care providers to use ePROM software platform and deliver quality services in pediatric transplantation.
- Sharing lessons learned with other transplant centres across Canada to support the spread of Voxe integration and implementation.



The project lead

The project is led by the Hospital for Sick Children (SickKids).



Dr. Samantha J. Anthony
Health Clinician Scientist
The Hospital for Sick Children
University of Toronto

“Voxe leverages eHealth technology as an innovative approach to capture the voices of children in clinical practice and to understand children’s perspectives of their illness experience.”

**EXPECTED PROJECT
COMPLETION IN 2022**

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Implementation and Evaluation of a Patient-Reported Outcome Measure Platform in Pediatric Transplantation* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.

Surgical Recovery Models in Canada: Current and Future State

What is this project about?

Project background

In organ donation and transplantation, surgical recovery teams have the responsibility for recovering organs from donors in specific care settings for the purpose of transplantation. These teams form an essential part of Canada's interprovincial donation and transplantation system. Interprovincial organ recovery arrangements support those provinces and territories with limited or no recovery capacity. Recovery service models across Canada are diverse and coordination of the process is complex. There is a need to better understand the specifics and differences of current surgical recovery models across Canada.

Objectives

This project will map out the existing organ recovery processes in each province, including successes, gaps and challenges within the existing structures, and propose opportunities and recommendations for improvements.

Overview of activities

- Conduct a survey of donation and transplant organizations across Canada to understand and document differences in organ recovery processes and interrelationships between provinces and territories.
- Conduct interviews with key medical and surgical leads across Canada to complement survey findings.
- Conduct a literature review (environmental scan) of national and international best practice models.
- Produce a report on opportunities for change and recommendations for improvements in the Canadian context.
- Execute strategies for knowledge dissemination and uptake by key stakeholders.

How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Providing organ donation and transplantation stakeholders with evidence-based information for decision making around potential improvements in regional/Canadian organ recovery processes.
- Enhancing awareness of best practices and potential improvements in organ recovery service models across organizations, provinces and territories in Canada.

The project lead

This project is led by BC Transplant, which is a program of the BC Provincial Health Services Authority.



Edward Ferre
Provincial Operations Director

“With recent successes in increasing the number of donors, organ recovery teams are experiencing significant pressure to build capacity to support the work. This project will help identify recovery models that will help build capacity and sustainability of organ recovery in Canada.”

**EXPECTED PROJECT
COMPLETION IN 2022**

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Surgical Recovery Models in Canada: Current State and Future State* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative (the Collaborative) website: <https://tinyurl.com/ODTCollaborative>.



Mapping the Canadian Research and Innovation Ecosystem in Organ Donation and Transplantation

What is this project about?

Project background

The ultimate goal of health research is to ensure that Canadians receive equitable, evidence-based, quality care and to improve their health outcomes. Within the domain of organ donation and transplantation (ODT) in Canada, research results have been applied to improve donation opportunities, wait times, and quality of life outcomes for transplant recipients. However, the lack of a unified approach to Research and Innovation (R&I) is a major barrier to establishing system priorities for ODT research.

Objectives

Develop a shared vision of the future direction for R&I with and within the ODT community to improve ODT outcomes to the benefit of patients and Canadians at large.

Overview of activities

- Create a comprehensive overview of the ODT research ecosystem in Canada through a mapping exercise that outlines an understanding of challenges, needs, roles, responsibilities, and interfaces of the key stakeholders with regards to R&I, current research priorities and their funding sources.
- Develop ecosystem-wide recommendations to support an ODT research strategic vision co-creation, which include mechanisms for sharing information and application of knowledge across the system.
- Engage Organ Donation and Transplantation Collaborative (The Collaborative) members to implement the recommendations stemming from the project.

PROJECT COMPLETION IN 2022

How will the project improve the organ donation and transplantation system in Canada?

- Provide a better understanding of R&I in ODT that helps identify gaps and opportunities for improvement.
- Foster an increased diversity of topics to be explored and an increase of quality research studies and findings that will improve the ODT ecosystem to the benefit of patients.
- Identify new synergies and alignments to continue building a stronger donation and transplantation system for Canadians thanks to a shared R&I vision and unified approach in ODT.
- Ensure that research outcomes have a clear path for integration into the ODT ecosystem to maximize impacts.

Project Support

This ODTC-driven project is supported by the [Canadian Donation and Transplantation Research Program](#) (CDTRP) under the financial authority of the University of Alberta.

"The Collaborative looks forward to the findings of this research project, and recognizes the importance and value of these findings and subsequent recommendations for the ODT community. Knowledge on the ODT research landscape will optimize the integration and impact of research and innovation in ODT systems for the benefit of Canadians."

Cindy Moriarty, Director General, Health Programs and Strategic Initiatives, Health Canada.

The Organ Donation and Transplantation Collaborative (The Collaborative) is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Mapping the Canadian Research and Innovation Ecosystem in Donation and Transplantation* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the [Organ Donation and Transplantation Collaborative](#) website.



Role of Patients in Organ Donation and Transplantation Governance Models and Decision-Making Processes

What is this project about?

Project background

While there is recognition of the need to include patients in decision-making roles in healthcare governance structures – including in organ donation and transplantation (ODT), how to best involve them in these structures is not well understood.

Indeed, there's a need to develop strategies that enable patients to have a greater say in ODT related decisions that affect them.

Objectives

The project aims to conduct an environmental scan of patient-centered governance models in Canada's healthcare sectors and make recommendations on patient involvement. The recommendations will inform the Organ Donation and Transplantation Collaborative (the Collaborative) as they move forward on the development of a pan-Canadian ODT governance model.

Overview of activities

- Examine existing models of patient involvement in organizational governance structures in Canadian healthcare sectors.
- Describe the commonalities and differences in the governance structures that include patient involvement.
- Identify existing methods of evaluating patient governance models in Canadian healthcare sectors.
- Develop recommendations or considerations for a patient governance model to inform the work of the Collaborative.

EXPECTED COMPLETION IN 2022

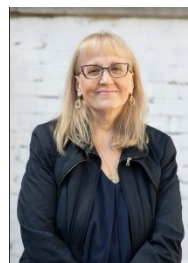
How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Promoting the involvement of patients in the ODT pan-Canadian governance model and decision-making processes.
- Increasing knowledge on inclusion of patients in governance models and its potential benefits.
- Providing guidance for the future pan-Canadian ODT model that includes a patient engagement strategy.
- Improving the accessibility, quality, responsiveness, accountability and sustainability of the ODT system thanks to a greater implication of patients in decision-making.

Project Support

The project is led by *SPOR (Strategy for Patient-Oriented Research) Evidence Alliance*, which is supported by the Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR).



Sharon Strauss, Ph.D.
Hôpital St. Michael's –
Unity Health Toronto

"This initiative will provide recommendations to inform patient engagement in organizational governance for ODT and others in a significant way."

The Organ Donation and Transplantation Collaborative is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Role of Patients in Organ Donation and Transplantation Governance Models and Decision-Making Processes* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative ([the Collaborative](#)) website.