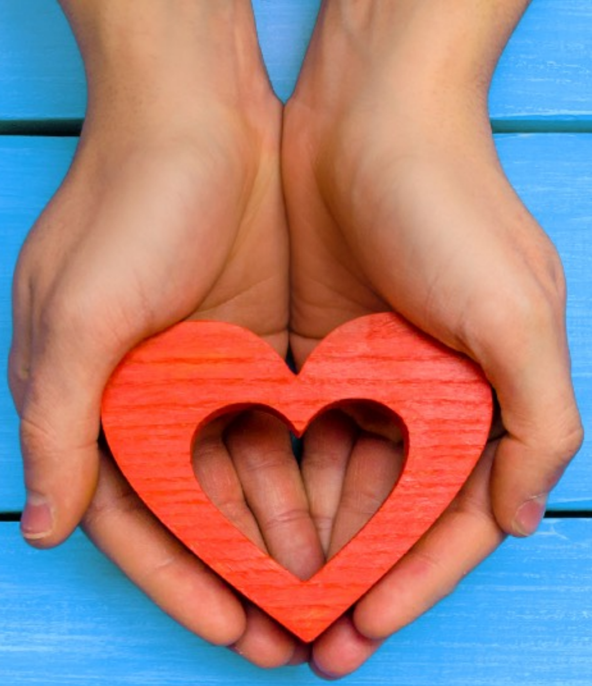

KEY POLICY ISSUES IN ORGAN DONATION & TRANSPLANTATION

17–18 JUNE 2021

CONFERENCE PROGRAM

(VERSION 31 MAY)

UNIVERSITY OF OTTAWA CENTRE FOR
Droit, politique et éthique de la santé
Health Law, Policy and Ethics

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The Canadian **DONATION** and
TRANSPLANTATION Research Program
Programme de recherche en **DON**
et **TRANSPLANTATION** du Canada

Thursday 17 June

DONATION DAY

8:45–9:00 am	**WELCOME** Jennifer Chandler Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics Mélanie Dieudé Executive Director Canadian Donation and Transplantation Research Program (CDTRP)
9:00–10:20	**1. LIVING DONATION ISSUES**
	Complex living donation arrangements: Risks and opportunities Jed Gross Bioethicist University Health Network (Toronto)
	Inequitable access to live donor kidney transplant in Canada – Possible causes and potential solutions Istvan Mucsi Nephrologist University Health Network (Toronto) Fadia Jérôme-Smith Kidney transplant recipient Rhonda George Doctoral candidate, Sociology York University
	Media representations of public solicitation for organ donors Maeghan Toews Lecturer Adelaide Law School, Australia

10:20–10:30	**BREAK**
10:30–11:50	**2. NON-THERAPEUTIC INTENSIVE CARE FOR ORGAN DONATION** Chair: Mélanie Dieudé Executive Director Canadian Donation and Transplantation Research Program (CDTRP)
	Pre-mortem interventions: How to frame the ethics of preserving donation opportunities Matthew-John Weiss Medical Director of Donation Transplant Québec
	Non-therapeutic intensive care for dead and almost dead potential organ donors: When must clinicians get consent? Thaddeus Mason Pope Professor Mitchell Hamline School of Law, U.S.A.
	Non-therapeutic intensive care in practice: What actually should you do? Dale Gardiner National Clinical Lead for Organ Donation Nottingham University Hospitals, U.K.
11:50–12:40	**LUNCH**
12:40–2:00	**3. RESEARCH ETHICS IN ODT** Chair: Mélanie Dieudé Executive Director Canadian Donation and Transplantation Research Program (CDTRP)
	Donor research – Recipient consent Maureen Meade Critical Care Consultant / Professor, Department of Medicine McMaster University
	The ethics of nontherapeutic research on imminently dying patients in the intensive care unit Charles Weijer Professor, Departments of Philosophy and Medicine Western University
	A patient's perspectives around donor research involving transplant recipients Everad Tilokee Data Analyst, Centre for Innovation Canadian Blood Services / Patient partner and transplant Recipient

2:00–2:10	**BREAK**
2:10–3:30	**4. OPT-OUT SYSTEMS OF ORGAN DONATION – RECENT SHIFTS IN POLICY** Chair: Matthew-John Weiss Medical Director of Donation Transplant Québec
	Ethics and deemed consent: Reflecting on solidarity Christy Simpson Professor and Head, Department of Bioethics Dalhousie University
	Presumed consent legislation for organ and tissue donation: Understanding the views of historically underrepresented communities in Nova Scotia Robin Urquhart Professor, Professeure, Department of Community Health and Epidemiology Dalhousie University
	The French experience with family refusal after the 2017 changes to the French presumed consent law Stanislas Kandelman Anesthesiologist Hôpital Royal Victoria (Montréal)
3:30–3:40	**BREAK**
3:40–5:00	**5. MEDICAL ASSISTANCE IN DYING AND ORGAN DONATION** Chair: Jennifer Chandler Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics
	Organ donation and MAiD in Canada: Evolution of policy and practice Andrew Healey Chief Medical Officer Trillium Gift of Life Network
	Organ donation and medical assistance in dying: Experiences of health care providers, organ donation coordinators, and key stakeholders Vanessa Gruben Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics
	Our story – Practical considerations for MAiD recipients Timmie Ann Schramm Friend of an organ donor following MAiD

Friday 18 June

TRANSPLANTATION/SYSTEMS DAY

8:45–9:00 am	**WELCOME** Jennifer Chandler Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics Mélanie Dieudé Executive Director Canadian Donation and Transplantation Research Program (CDTRP)
9:00–10:30	**6. ODT AND COVID-19**
	The COVID-19 pandemic and organ donation and transplantation: Ethical issues Marie-Chantal Fortin Nephrologist / Principal Scientist – Immunopathology Centre hospitalier de l'Université de Montréal
	Vaccine prioritization and organ transplant recipients Maxwell J. Smith Assistant Professor, Faculty of Health Sciences Western University / Member, Ontario COVID-19 Vaccine Distribution Task Force
	If you choose not to decide, you still have made a choice: Pandemic resource allocation and ODT Simon Oczkowski Intensivist / Professor, Faculty of Health Sciences McMaster University
	Running the gauntlet: A patient journey through dialysis and transplant in the era of COVID Sean Delaney Patient Partner / Associate Director, Organ Listing & Allocation Canadian Blood Services

10:30–11:00	**BREAK**
11:00–12:30	**7. TRANSPLANT LISTING AND ALLOCATION – ALCOHOL ABSTINENCE** Chair: Vanessa Gruben Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics
	Alcohol use and liver transplantation: Clinical implications Prosanto Chaudhury Interim Director, Multi-Organ Transplant Program McGill University Health Centre
	Alcohol use disorder: Treatment options and efficacy Susan Abbey Psychiatrist-in-Chief University Health Network (Toronto)
	The alcohol abstinence rule and liver transplantation: The applicability of the human rights laws under the Charter and Ontario Human Rights Code. Alyssa Tomkins Partner Caza Saikaley LLP
12:30–1:30	**LUNCH**
1:30–3:00	**8. BIG DATA AND MACHINE LEARNING IN ODT**
	Responding to the challenge of missed organ donors: Can machine learning be used for early identification of potential donors? Michaël Chassé Intensivist / Principal Scientist – Innovation Centre hospitalier de l'Université de Montréal
	The development of a clinical decision support tool integrating machine learning approaches: Can we improve shared decision-making in kidney transplantation? Heloïse Cardinal Transplant Nephrologist / Principal Scientist – Immunopathology Centre hospitalier de l'Université de Montréal
	Ethico-legal issues raised by the use of big data and machine learning in ODT Glenn Cohen Professor / Deputy Dean Harvard Law School, U.S.A.

3:00–3:15	**BREAK**
3:15–4:45	**9. REFORM OF THE CANADIAN ODT SYSTEM** Chair: Jennifer Chandler Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics
	Building trust: Mapping and restructuring pan-Canadian governance of organ donation and transplantation Patrick Fafard Professor, Public and International Affairs University of Ottawa Centre for Health Law, Policy and Ethics
	Improving ODT system performance in Canada: Health care cultural and structural factors Sam Shemie Critical Care Pediatrician Hôpital de Montréal pour enfants / McGill University Health Centre
	Governance in collaborative institutions: Process, protocol, and politics Katherine Fierlbeck Professor, Political Science Dalhouse University
	The Saskatchewan First Nations and Métis Organ Donation and Transplantation Network: Lessons learned Caroline Tait Medical Anthropologist, Department of Psychiatry University of Saskatchewan
4:45–5:00	**CLOSING REMARKS** Jennifer Chandler Professor, Faculty of Law University of Ottawa Centre for Health Law, Policy and Ethics

PANEL 1.
LIVING DONATION ISSUES

Complex living donation arrangements: Risks and opportunities

Jed Gross

Living organ donation, introduced as a way of saving patients in dire need with biological gifts from close relatives, has increasingly taken on the characteristics of organized allocation systems. Through paired exchange and chain donation, individuals may donate a kidney or part of a liver to a stranger so that a loved one will be eligible for an organ from another donor. A further innovation, known as advance donation, encourages living donation by offering “vouchers” according designated individuals priority access to a future transplant in certain circumstances. The organizations that have expanded living donor transplant options in North America are somewhat different than those that bear the primary responsibility for facilitating and overseeing deceased donor organ sharing. Both pathways to transplant, however, are now a product of complex design choices involving a balance of value-laden considerations. This talk, building on the work of my collaborator Evelyn Tenenbaum, will identify what is at stake, materially and normatively, in these design choices for patients awaiting transplant and for the rest of society.

Inequitable access to live donor kidney transplant in Canada – Possible causes and potential solutions

Istvan Mucsi
Fadia Jérôme-Smith
Rhonda George

Compared to dialysis and even deceased donor kidney transplant, living donor kidney transplant (LDKT) offers better kidney function, longer survival and better quality of life. However, compared to White patients within the Canadian context, patients with kidney failure from racialized (Indigenous, African, Caribbean and Black [ACB], South Asian and East Asian) communities are 40-70% less likely to receive a LDKT. Recent qualitative and quantitative research suggests that medical mistrust of the healthcare system exists for many in these communities due to historical and contemporary experiences of racial discrimination both outside and within the healthcare system. Unmet needs and a lack of representation among healthcare professionals are additional concerns for several of these communities. Given that culturally appropriate and safe information co-developed by communities and healthcare professionals have been helpful in the United States, our research examines how community-based peer support and providing education outside of the transplant programs in community health centres may also help address gaps to accessing LDKT for patients from racialized communities. Our presentation will focus on the specific experiences of ACB communities, briefly review results from our ongoing research, building on patient perspectives, and discuss how using a critical race analytical framework has shaped our analysis.

Media representations of public solicitation for organ donors

Maeghan Toews

With the rise of social media, public solicitation is becoming an increasingly popular way to find kidney and liver donors. There have been several high-profile cases, bringing this issue into the forefront of donation and transplantation discussions. Although this is an issue that appears to be increasing in prominence, there is little empirical research examining these requests. Given the media attention that some solicitations receive, and the need to maintain high levels of public trust in donation systems, it is important to understand how these stories are framed and portrayed to the public. In this talk, I will discuss findings from a study examining media representations of high-profile public solicitation requests, which demonstrate the types of issues that tend to be reported in relevant news coverage as well as the ways in which media discourse surrounding public solicitation can vary depending on the individual making the request.

PANEL 2.

NON-THERAPEUTIC INTENSIVE CARE FOR ORGAN DONATION

Pre-mortem interventions: How to frame the ethics of preserving donation opportunities

Matthew-John Weiss

Pre-mortem interventions (PMIs) occupy a particular place in the organ donation process. Like all medical interventions, they require consent, and that decision is informed by risks and benefits. PMIs, however, force clinicians and ethicists to consider these issues in ways that diverge from other settings. Questions arise such as who will benefit from a PMI and who will assume the risk? How, if at all, does registered consent/intent for donation influence consent for these procedures? The goal of this session will be to provide frameworks through which PMIs should be considered in order to better understand how PMIs can be integrated into an OTDT system.

Non-therapeutic intensive care for dead and almost dead potential organ donors: When must clinicians get consent?

Thaddeus Mason Pope

Potential organ donors understand that consent to donation may affect management of their body after death. But they probably do not understand or expect that consent to donation also entails significant intrusive and uncomfortable interventions before death. Even more problematic, those interventions may be inconsistent with the patient’s advance directive, wishes, or values. While the individual is still alive, she is a patient to whom clinicians owe special duties. To what extent does (or should) consent to donation waive or alter those duties? How should we balance caring for the patient herself against caring for the patient’s organs? When may clinicians deploy non-therapeutic organ-preserving interventions that risk harming a living patient? While patients can opt out of a presumption in favor of pre-mortem organ preserving interventions, that right is illusory if they do not know whether or how to exercise it.

Non-therapeutic intensive care in practice: What actually should you do?

Dale Gardiner

The previous two speakers outlined the theoretical frameworks and legal complexities of pre-mortem non-therapeutic intensive care for organ donation. How should we apply that theory in practice – in an intensive care unit, where there is a patient and their family right in front of you? By using three clinical examples this session demonstrates the frameworks in action and highlights why the acceptability of interventions may vary by jurisdiction. The clinical examples will explore: (1) a patient presenting with a devastating brain injury, (2) typical pre-mortem interventions in donation after circulatory death and (3) non-therapeutic interventions that might be taken prior to determining neurological death. These examples will inform the panel discussion.

PANEL 3.
RESEARCH ETHICS IN ODT

Donor research – Recipient consent

Maureen Meade

Clinical trials addressing interventions in deceased organ donor care are uniquely challenging and the research consent from organ recipients is a particular challenge. Pre-consenting patients on a transplant wait-list can be impracticable. Addressing research consent at the time of organ allocation risks the threat of coercion for vulnerable persons. Suitable approaches will depend upon the timing of the donor intervention, and the level of risk of the donor intervention to transplant recipients. As Canada navigates this challenge in the context of new clinical trials in deceased donor care, the landscape is changing with additional research focused on the views of organ donor families, wait-listed patients, and transplant recipients.

The ethics of nontherapeutic research on imminently dying patients in the intensive care unit

Charles Weijer

In this paper, I consider the ethical issues raised by the *Neurologic Physiology after Removal of Therapy (NeuPaRT)* study. NeuPaRT employs nontherapeutic neurological monitoring to study the temporal relationship between the cessation of brain and circulatory activity during the dying process. Findings will inform the "hands-off period" prior to organ retrieval after circulatory determination of death. But is such research ethically permissible? The vulnerabilities of the imminently dying contribute to an intuition that research with imminently dying patients is beyond the pale ethically. Yet excluding this patient population hinders the advancement of medical science to the detriment of future patients. Drawing on a foundation of internationally accepted ethical principles, I present an ethical framework for research with imminently dying patients. The framework, comprising eight ethical questions, will guide researchers and research ethics committees.

A patient's perspectives around donor research involving transplant recipients

Everad Tilokee

To date the majority of research in organ donation and transplantation (ODT) has focused on improving transplant recipient outcomes through interventions performed on the recipient. While this approach has yielded substantial advances in the field, there is a relative paucity of research developing interventions performed on the donor to improve organ quality. Naturally, interventional donor research will require the participation of recipients to determine the safety and efficacy of such interventions which raises important questions for recipients. This presentation will explore the perspectives of transplant recipients participating in interventional donor research. Incentives and barriers to participation in interventional donor research will be discussed with a particular focus on the challenges of obtaining consent from transplant recipients.

PANEL 4.

OPT-OUT SYSTEMS OF ORGAN DONATION – RECENT SHIFTS IN POLICY

Ethics and deemed consent: Reflecting on solidarity

Christy Simpson

As part of organ and tissue donation and transplantation (OTDT), considerations of solidarity have been variously invoked as part of examining and understanding the relevant ethics issues. With the new *Human Organ and Tissue Donation Act* in Nova Scotia, this provides an opportunity to critically reflect on solidarity and which aspects are primarily highlighted or drawn upon as part of a deemed consent approach. Accordingly, this presentation compares and contrasts the ways in which different aspects of solidarity operate, both within and outside of deemed consent approaches to OTDT. This includes relevant considerations highlighted by the COVID-19 pandemic, with the emphasis on "we're all in this together", and the resulting questioning and critiques of this "call" for solidarity.

Presumed consent legislation for organ and tissue donation: Understanding the views of historically underrepresented communities in Nova Scotia

Robin Urquhart

Nova Scotia is the first jurisdiction in North America to enact deemed consent legislation for organ and tissue donation. Since this legislation came into effect on January 18, 2021, all adults in Nova Scotia are considered potential organ and tissue donors unless they opt out. To inform the ongoing implementation of this legislation, we have been studying Nova Scotians' attitudes, knowledge, and views on organ and tissue donation, including deemed consent. Recognizing that certain groups may have particular concerns with deemed consent, as a part of this work, we conducted focus groups and interviews with leaders of historically underrepresented communities in Nova Scotia. This talk will present the findings of this study and discuss steps forward to implementing presumed consent legislation in culturally competent ways.

The French experience with family refusal after the 2017 changes to the French presumed consent law

Stanislas Kandelman

Depuis 1974, date de la première Loi française sur le don d'organes, tout patient est considéré comme donneur sauf s'il s'est explicitement exprimé contre le don, de son vivant. Une modification de la Loi est entrée en vigueur le 1er janvier 2017. L'objectif de cette modification était de mieux respecter le principe de « consentement présumé » et d'effectivement permettre une procédure de don en l'absence d'opposition du patient, indépendemment de l'avis des proches. L'un des buts assumés par l'instigateur de cette modification était d'augmenter le nombre de greffons disponibles. L'objectif de la présentation est de décrire précisément les modifications législatives réellement entrées en vigueur et d'analyser leur effets sur l'activité de don d'organes en particulier sur l'opposition par les proches.

PANEL 5.

MEDICAL ASSISTANCE IN DYING AND ORGAN DONATION

Organ donation and MAiD in Canada: Evolution of policy and practice

Andrew Healey

This presentation will address the trajectory of Ontario organ donation policy as it adjusted to the launch of medical assistance in dying in Canada, noting the clinical adjustments required and policy decisions that needed to be made by organ donation and transplantation organizations like Trillium Gift of Life Network. It will consider issues raised for organ donation by the recent expansion of eligibility for MAiD, and the possible further expansion to include purely psychiatric illnesses in 2023.

Organ donation and medical assistance in dying: Experiences of health care providers, organ donation coordinators, and key stakeholders

Vanessa Gruben

This presentation will offer preliminary results of a qualitative study which seeks to learn more from the experiences of health care providers and organ donation coordinators who have participated or may be called upon to participate in end-of-life care for patients who wish to undergo MAiD and are considering being organ donors. The insights of these healthcare professionals can offer important guidance about organ donation after MAID including: What legal and ethical challenges arise in the context of organ donation and patients who wish to undergo MAID? What protections or safeguards should be in place to protect the rights and interests of patients, their families and the public? What type of training and support should be in place for health care professionals? These questions have taken on a new urgency as the pool of patients eligible for MAiD has expanded with the recent Bill C-7 permitting MAID for individuals whose natural death is not reasonably foreseeable.

Our story – Practical considerations for MAiD recipients

Timmie-Ann Schramm

My friend Edna and I met by chance in 2016. Even with my background of encouraging and supporting people in self-determination, following Edna on her path was a learning for me on many levels. A passionate and principled person, Edna moved through the world on her own chosen trajectory. Edna challenged me and others in her circle of care to explore options that would be acceptable and appropriate to her. I took on the tricky and sensitive role of informing, educating and facilitating communication within her network of friends and family. By sharing our experience I hope to honour her friendship and the virtues she exemplifies.

PANEL 6.
ODT AND COVID-19

The COVID-19 pandemic and organ donation and transplantation: Ethical issues

Marie-Chantal Fortin

The COVID-19 pandemic has had a significant impact on the health system worldwide. The organ and tissue donation and transplantation (OTDT) system is no exception and has had to face ethical challenges related to the pandemic, such as risks of infection and resource allocation. In this setting, many Canadian transplant programs halted their activities during the first wave of the pandemic. This presentation will summarize the major ethical issues related to COVID-19 pandemic and OTDT such risk of COVID-19 transmission, informed consent in the context of uncertainty and organ allocation.

Vaccine prioritization and organ transplant recipients

Maxwell J. Smith

Vaccines are one of the most effective tools for protecting people against COVID-19. Yet, COVID-19 vaccines are in short supply. Consequently, priorities must be set to determine who ought to be vaccinated first and the sequencing of vaccine allocation thereafter. Many ethical principles can and have been used to guide vaccine priority setting, including prioritizing those at greatest risk of severe outcomes, those at greatest risk of exposure and infection, those at greatest risk of transmission, those who are tasked with helping others, and those who are central to the maintenance of critical infrastructure. The principle(s) adopted to guide vaccine priority setting has implications for the relative sequencing of organ transplant recipients. This presentation will discuss the ethical and empirical underpinnings of vaccine prioritization and distribution in Ontario, including how immune-suppressed transplant patients fit into the vaccine queue as well as debates regarding vaccine dose intervals for these populations.

If you choose not to decide, you still have made a choice: Pandemic resource allocation and ODT

Simon Oczkowski

The COVID-19 pandemic has placed the Canadian health care system, including hospitals, under unprecedented levels of strain. This has impacted many core functions of the hospital, especially those requiring critical care, such as organ donation and transplant. This talk will describe the challenges of resource allocation—beds, staff, equipment—between the competing needs of immediate life-saving care for patients with COVID-19, and organ donation and transplantation.

Running the gauntlet: A patient journey through dialysis and transplant in the era of COVID

Sean Delaney

COVID-19 over the past year and a half has put new and unprecedented challenges on transplant patients and professionals alike. As messaging comes at us each week from international, national, provincial, and hospital/program levels on all manner of information from masks and distancing to vaccine options and vaccine effectiveness in an immunosuppressed population, the patient challenge has been to navigate this period of rapidly evolving information and still make care decisions in collaboration with their care providers. This talk will provide a chronology and review of a patient's journey through peritoneal dialysis, hemodialysis, transplantation, and vaccination throughout the COVID era from someone who lived it.

PANEL 7.
TRANSPLANT LISTING AND ALLOCATION – ALCOHOL ABSTINENCE

Alcohol use and liver transplantation: Clinical implications

Prosanto Chaudhury

Clinical indications for liver transplantation and its and outcomes will be briefly reviewed. The principles of listing and allocation for liver transplantation will be discussed with emphasis on the ethical utilization of a scarce resource. Particular emphasis will be placed on the historic and current rules around listing for alcohol related liver disease. Current and ongoing challenges to the 6-month abstinence rule will be reviewed. The evolving landscape around transplantation for alcohol related liver disease as various jurisdictions around the country respond to these challenges will be presented in the context of a broader national initiative.

Alcohol use disorder: Treatment options and efficacy

Susan Abbey

This presentation will address the availability and efficacy of treatment for alcohol use disorder in the context of severe alcoholic hepatitis. How are patients supported prior to and after liver transplantation, and what is known about protective and risk factors for resumption of alcohol use after transplant.

The alcohol abstinence rule and liver transplantation: The applicability of the human rights laws under the Charter and Ontario Human Rights Code.

Alyssa Tomkins

This presentation will explain recent litigation in Canada regarding the alcohol abstinence rule for listing for liver transplantation – deceased or living. Arguments under both the Canadian *Charter of Rights and Freedoms* as well as provincial human rights codes have been raised by litigants across the country in relation to this rule. This presentation will consider the genesis, legal issues and outcomes in the Williams and the Selkirk litigation, as well as consider the arguments raised in the Dennis complaint to the BC Human Rights Tribunal in 2020.

PANEL 8.

BIG DATA AND MACHINE LEARNING IN ODT

TBD

Michaël Chassé

This presentation will discuss the clinical and practical challenges of identifying potential donors, and the implications this has for the organ donation system. Dr. Chassé will address his development of a prototype system using machine learning to address these challengers, and the clinical, practical and technical questions that it has raised.

The development of a clinical decision support tool integrating machine learning approaches: Can we improve shared decision-making in kidney transplantation?

Heloïse Cardinal

Renal transplantation improves longevity and quality of life and reduces health-care costs when compared to dialysis. There is a pressing need to increase the number of organ donors, as over 3,000 Canadians are currently waiting for a kidney. One of the ways to augment the number of donors is by accepting the use of organs originating from donors who have features that may limit the duration of graft function, such as older age or hypertension. The decision to accept or refuse a kidney offered by an organ donation organization (ODO) is shared by transplant physicians and transplant candidates. There are currently no reliable tools in Canada to help physicians and patients decide on the preferable strategy to accept a donor offer or refuse it and remain on waiting in anticipation to be allocated a better donor. We propose to use artificial intelligence (AI), more specifically deep-learning approaches, to develop a clinical decision support tool to help transplant physicians and candidates make an informed decision that is in the best interest of the patient when choosing to accept or refuse an organ offered by an ODO. The use of this tool could lead to increased acceptance of kidneys that have risk features for suboptimal projected long-term graft survival and increase the number of transplantations, thereby improving the health of Canadians and minimizing health-care costs. I will describe the various steps and issues associated with the development of such a tool using AI, with a specific focus on the ethical and legal aspects.

Ethico-legal issues raised by the use of big data and machine learning in ODT

Glenn Cohen

Prof. Cohen will reflect on the ethical, legal and policy questions raised by the technologies being developed by Drs. Cardinal and Chassé, as well as broader applications of AI in ODT such as optimization of transplant allocation systems.

PANEL 9.

REFORM OF THE CANADIAN ODT SYSTEM

Building trust: Mapping and restructuring pan-Canadian governance of organ donation and transplantation

Patrick Fafard

The overall effectiveness of organ donation and transplantation (ODT) in Canada is powerfully influenced by how we collectively govern the system. The current ODT governance arrangement cannot close the gap between where we are and where we want to be – an ODT system that incorporates the policy and program innovations found in countries with higher performing ODT systems that maximizes the number of organs donated and optimized utilization of donated organs. The Organ Donation and Transplantation Collaborative asked us to map the existing ODT governance structures, and make recommendations on a future system. This presentation briefly describes our map of Canada's ODT governance structures with a focus on those areas we identified as challenges, then discusses a set of governance changes that move from a system that is centred on the ODT activities of the Canadian Blood Services (CBS) to one that is much more closely tied to the existing intergovernmental machinery used elsewhere in the Canadian health care system.

Improving ODT system performance in Canada: Health care cultural and structural factors

Sam Shemie

Historically, during decades of stagnant performance and despite multiple (but ineffective) governmental initiatives, Canada’s ODT system was seen as fractured and in need of repair. The source of that ‘fracture’ was cultural and structural. The ‘cultural’ issues in the ODT system was related to the level of engagement, commitment and leadership by health care professionals in emergency medicine and intensive care who care for dying patients and potential organ donors. These health care cultural issues have largely been improved with national leadership and collaboration with the emergency and intensive care communities to develop leading practices and change the culture of deceased organ donation in hospitals. This has resulted in steady improvements in ODT system performance over the past 10 years. The current structure of the Canadian ODT system that relies on national and interprovincial collaboration based on goodwill and advisory committee structures, continues to hinder further system improvement. These structural issues, related to lack of clarity on system governance, roles, responsibilities and accountabilities in the ODT system, remain a major obstacle to further improvement.

Governance in collaborative institutions: Process, protocol, and politics

Katherine Fierlbeck

This presentation discusses the dynamics of decision-making in collaborative multilevel governance structures. When informal collaborative relationships are regularized into a more formal structure, there are both gains and losses. Communication is facilitated, procedures are codified, standards are established, and access to key decision-makers is more direct. At the same time, however, the autonomy of key players is more restricted, possible paths are narrowed, and a more hierarchical governance structure can hinder as well as facilitate. What are some of the key issues in decision-making that a reconfigured ODT may confront?

The Saskatchewan First Nations and Métis Organ Donation and Transplantation Network: Lessons learned

Caroline Tait

This presentation draws upon the work of the Saskatchewan First Nations and Métis Organ Donation and Transplantation Network. Our network places the lived experiences of First Nations and Métis patients and families at the centre of our research, policy, and advocacy work. This presentation focuses specifically on the Network's examination of equity and utility in decision making about organ transplants, specifically how decision-making processes currently risk being biased against Indigenous peoples. The presentation discusses the importance of ODT governance in Canada being reflective and responsive to the experiences and needs of Indigenous patients and families. It also highlights the overrepresentation of Indigenous people among patient groups living with end-stage organ failure and in need of a transplant. This, despite Métis, First Nations and Inuit peoples making up a small portion of the Canadian population. In Saskatchewan, it is estimated that upwards of 50% of patients waiting for a kidney transplant are First Nations or Métis. The challenge in creating culturally responsive ODT systems of care relies on ODT decision makers having comprehensive and complex understandings of equity and utility factors as they apply to the lived experience of Indigenous groups across Canada.