



The Canadian **Donation and Transplantation** Research Program

Programme de recherche en
don et transplantation du Canada

JUNE 19, 2023

Patient, Family & Donor **RESEARCH FORUM**

4TH EDITION | JUNE 8-9, 2023 | #PFDForum

POST-EVENT REPORT

TABLE OF CONTENTS

02

Overview

04

The program

06

Program highlights

16

Support

17

Attendees

17

Post-Event

OVERVIEW

The Canadian Donation and Transplantation Research Program (CDTRP), in cooperation with the Organ Donation and Transplantation Collaborative and the Canadian Society of Transplantation (CST), virtually hosted the 4th edition of the Patient, Family, and Donor (PFD) Research Forum on June 8 – 9, 2023.

CDTRP's PFD Research Forum brings investigators, trainees, PFD partners, and stakeholders to advance patient-oriented research and engagement in donation and transplantation. This year's Forum focused on capacity building in patient engagement for CDTRP members and the public through presentations and priority-setting workshops.



Learning outcomes



Build skills and resources to enhance the donation and transplantation research community's capacity for patient engagement during project development and research execution.



Develop and share practical approaches to enhance equity, diversity, and inclusion in patient engagement and research training within the Canadian donation and transplantation network.



Understand emerging best practices for integrating PFDs in knowledge mobilization and sharing the knowledge developed with the broader research community.

Planning Committee

The 2023 Planning Committee consisted of three CDTRP PFD partners, two CDTRP Trainees, and representatives of the Organ Donation and Transplantation Collaborative and the Canadian Society of Transplantation.

- **Leonard Hodder**, Co-Chair, living kidney and liver donor
- **Dr. Ruth Sapir-Pichhadze**, Co-Chair, nephrologist, CST representative
- **Jennifer Kingdon**, Caregiver to a heart transplant recipient
- **Lindsay Thompson**, Bone marrow transplant recipient
- **Chloe Wong-Mersereau**, CDTRP Trainee (Theme 1)
- **Amy Thachil**, CDTRP Trainee (Theme 4)
- **Sarah Douglas**, Organ Donation and Transplantation Collaborative Secretariat
- **Hannah Murray**, National Institute for Health and Care Research (UK) Representative

Together, committee members utilized their experience and expertise in donation and transplantation to develop the Forum's program between March to June 2023.

The CDTRP Management team supported the Planning Committee throughout the process: Dr. Patricia Gongal, CDTRP Executive Director; Manuel Escoto, Patient, Family, and Donor Partnership & Education Platform Manager; and Stéphanie Larivière, Communications and Events Manager.



Leonard Hodder
Patient Partner



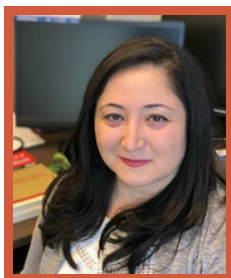
Jennifer Kingdon
Family Partner



Lindsay Thompson
Patient Partner



Sarah Douglas
Health Canada Representative



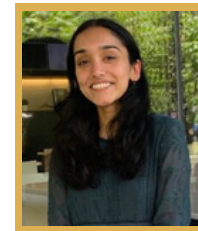
Dr. Ruth Sapir-Pichhadze
Canadian Society of
Transplantation Representative



Hannah Murray
National Institute for Health & Care
Research (UK) Representative



Chloe Wong-Mersereau
CDTRP Trainee



Amy Thachil
CDTRP Trainee

THE PROGRAM

Integrating patient engagement (PE) within a patient-oriented research (POR) lens is vital to improving outcomes and enhancing patients' overall experience in donation and transplantation. The PFD Research Forum is a platform for researchers and PFDs to share their experiences of collaborating with one another in co-design to better inform research, interventions and support patient outcomes.

The program aimed to share knowledge and build capacity in PE and POR by tackling issues that matter most to PFD partners. It also informed the research community of emerging and best practices.

To accomplish this, the Forum was divided into four blocks over the two-day event, thematically aligned with research processes within donation and transplantation fields, each moderated by a planning committee member.



Block 1

Integrating Patient, Family, and Donor Partners in Research Development and Funding



Block 2

Integrating Patient, Family, and Donor Partners in Research Execution



Block 3

Integrating Patient, Family, and Donor Partners in Knowledge Mobilization



Block 4

CDTRP Patient, Family, and Donor Priority Setting Workshops

The Committee invited **20 speakers** to present **11 topics** covering these blocks. The speakers included researchers or professionals with expertise in patient engagement and patient-orientated research. The program also had PFD partners from across Canada and the UK with a variety of experiences in research. Per CDTRP's Terms of Reference, PFD partners are compensated for their time preparing and presenting at the Forum.



“Many of us know the value of having patients, family, and donors involved in research projects from the ground floor. Ensuring that researchers are informed, showing examples of the ways that patients, families and donors have become involved, and the impact they have had on research outcomes drives home the value we can offer. It’s also important to continue to make sure that as new trainees and researchers come along, they think about equity, diversity, and inclusion in their undertakings.”



Leonard Hodder
Co-Chair



Dr. Ruth Sapir-Pichhadze
Co-Chair

“As a Clinician Scientist, I strive to conduct research that promotes the well-being of transplant candidates and recipients. The PFD Research Forum is an opportunity to advance collaborations between researchers and patient, family, donor partners, and present research in donation and transplantation to key stakeholders.”

PROGRAM HIGHLIGHTS

The following section of the PFD Research Forum wrap-up report provides an overview of each presentation, key learnings, and recommendations.

Block 1 - Integrating Patients, Families, and Donors During Research Question and Funding Development

Topic: Undertaking research with First Nations, Metis, and Inuit peoples: what researchers need to know about research governance and Indigenous patient engagement | Dr. Caroline Tait

Overview

The PFD Forum began with a presentation by **Dr. Caroline Tait**, a medical anthropologist with research interests in Indigenous health and social justice, who co-established the Saskatchewan First Nation and Métis Organ Donation and Transplantation Network made up of Knowledge Keepers, persons with lived experience, researchers, physicians, and students. Dr. Tait's presentation guides researchers on ethical research practices and respectful engagement with First Nations, Metis, and Inuit (FNMI) peoples in Canada, focusing on data sovereignty.

Historically, Indigenous data and research has been withheld from the community. Researchers will go into the community, collect data, and members will never hear back from them. "We've been researched to death" is how First Nations, Metis, and Inuit (FNMI) view research. FNMI communities have been the objects of study and left out of the decision-making and prioritization process. Dr. Tait says building relationships, trust, reciprocity, and relevance is essential to ethical and meaningful research.

Key Learnings and Recommendations:

- If you involve PFD partners, you must connect and build relationships with the broader community, including leadership.
 - If your project is researching the unique experience of Indigenous groups and you are collecting unique Indigenous data, researchers are responsible for engaging with FNMI leadership
 - If your project includes Indigenous PFD partners but does not collect unique data specific to FNMI communities, you do not need to engage with FNMI leadership.

- Integrating Indigenous PFD partners and understanding the experience of FNMI communities is essential. It is best to ask PFDs directly and not only work with leaders because community members' and leaders' living circumstances and priorities may differ.
- Understanding FNMI lived experiences through a lens of colonial history is important.
- Do not use "Indigenous" as a term in research - each group is distinct. At a minimum, use the term FNMI; the best practice is to specify by each group.
- Organ and tissue donation and transplantation (OTDT) is a secondary issue for FNMI leadership, whose priorities may focus on food insecurity, access to clean water, housing, etc. It can be challenging for researchers to involve leadership in OTDT research. Tips for researchers include:
 - In designing a POR project, involve appropriate Indigenous health leaders as soon as possible in the design phase.
 - Encourage Indigenous patients/family partners to be involved in partnership building with FNMI community partners.
 - Update Indigenous leaders/partners on every aspect of the project.
 - Share research outcomes with Indigenous partners and include them in knowledge translation activities.

Topic: Patient and Public Partners in Research Prioritization: Experiences of the Blood and Transplant Research Unit in Organ Donation and Transplantation | Hannah Murray & John Fuller

Overview

The United Kingdom's Blood and Transplant Research Unit (BTRU) does research to improve the supply of blood, blood products, stem cells, tissues, and organs for transplantation. The overarching aim of the BTRU is to increase the number of organs available, improve long-term outcomes, and enhance the quality of life after transplant.

Patient and Public Involvement and Engagement (PPIE) are essential to the BTRU to ensure that the research questions explored matter to patients.

BTRU PPIE Manager **Hannah Murray** and PPIE Partner **John Fuller** joined the Forum to provide an overview of their experience. PPIE is at the heart of all BTRU activities and is guided by their 5-year strategy. The focus is on co-design between researchers and the public. The strategy follows the UK Standards for Public Involvement, a framework for good public involvement in research, and is adaptable to different situations.

Key Learnings and Recommendations:

- PFD partners within the BTRU support prioritizing research questions, steering research priorities, and meeting with researchers as early as possible to ensure their work is relevant and impactful.

- BTRU recommends measuring and assessing the impact of PFD involvement, which requires reflection among PFDs and researchers to understand and learn from what works and does not.
- BTRU recommends checking in with PFDs and researchers – how are they feeling? How can they be supported? OTDT conversations are emotionally charged – is there a way to make conversations easier?
- Building relationships is important and can include building ‘Talking Spaces.’ Talking Spaces can consist of discussing OTDT in community spaces, using activities/sports as an icebreaker, not having a set agenda to start the conversation, and getting feedback from your partners.
- Patient partnership engagement requires flexibility, clear roles, support and training, strong communication, and diversity so everyone can contribute.

Topic: Navigating Research NET | Manuel Escoto

Overview

Integrating PFD partners early in the research cycle is critical to the meaningful integration of PFDs in developing the research question and funding required. CDTRP’s Patient, Family, and Donor Partnerships Manager, **Manuel Escoto**, presented at the Forum with three goals in mind.

- Supporting PFDs to attain the required components to join a CIHR grant application
- Supporting researchers in understanding the necessary details to list PFDs in CIHR grant applications
- Providing a step-by-step guide on how to complete all required CIHR components

[You can access the step-by-step guide here.](#)

Key Learnings and Recommendations:

- Effective patient engagement occurs throughout the entire research process. PFD partners can and should be involved in all research stages, starting with priority setting and planning.
- PFDs can and should help guide the conversation to ensure the project represents a patient priority.
- PFDs should be engaged early, on an ongoing basis, and at all stages.
- PFDs may find it challenging to engage and be involved when invited to join at the later stages of a project, especially once decisions have been made and the research team is ready for their knowledge exchange and translation work. Joining at later stages of the process can lead to a tokenistic approach to patient engagement.

Topic: Best practices in involving patient partners in grant applications | Dr. Marie-Chantal Fortin & Paul Cormier

Overview

Led by CDTRP Theme 1 co-lead **Dr. Marie-Chantal Fortin**, and CDTRP PFD partner **Paul Cormier**, the presentation highlighted the importance of PFDs in research, how to identify and recruit patient partners, strategies for collaborating with patient partners, and best practices for ensuring that patient partners' perspectives and needs are adequately incorporated into the grant application.

Key Learnings and Recommendations:

- Partnering with PFDs improves the relevance of research, better facilitates participant recruitment, and knowledge transfer, provides unanticipated research topics, and acknowledges patients' expertise.
- PFDs can impact the research cycle and support by identifying and prioritizing questions; research design; development of grant applications; research execution; data collection; data analysis; dissemination; implementation; monitoring, and evaluation.
- Specific roles for PFDs can include one or more of the following:
 - Ensure that the research proposed and the methods are acceptable for patients and ethical.
 - Inform where patients could be involved in the research.
 - Help define what to measure.
 - Advise and help with writing the lay summary.
 - Patients become co-applicants.
 - Help to develop and select data collection instruments.
- Winning conditions for PFD engagement include:
 - Spending time and resources
 - Involving patients as early as possible
 - Developing a meaningful relationship between researchers and patients
 - Training for researchers and patients
 - Mutual respect
 - Clear expectations

Block 2 - Integrating Patient, Family, and Donor Engagement in Research Execution

Topic: Best practices when communicating research opportunities and integrating patient, family, and donor partners to a project | Dr. Sofia Ahmed

Overview

Starting Block 2 was **Dr. Sofia Ahmed**, nephrologist, and Alberta SPOR Support Unit Capacity Lead. Dr. Ahmed's presentation focused on how researchers and PFD partners can work together to close knowledge gaps in research, the importance of using first-person and inclusive language, and the value for everyone involved in research to understand their positionality.

Positionality refers to our unique situation – how social position and power differences shape identities and access in society (and research). Positionality, for example, influences the questions we study, how we recruit, who we recruit, the study design, and how knowledge is disseminated.

Key Learnings and Recommendations:

- Understanding that we live with conditions we don't have them, and this is why learning from the lived experience is so important to understand how language impacts communities.
- When engaging PFDs with diverse lived experiences (i.e., when collecting gender identity, cultural identity, etc.), it is crucial to have "another option not listed above" to give participants the option if they do not identify with a pre-determined option.
- The worst option we can provide is to have an "other" option – people do not want to be labeled as "other." A strong practice is to have an open text option where participants can write their responses or a "prefer not to answer" choice.
- Safety first is essential: Cultural safety needs to be embedded in a research protocol – researchers need to consider the impact of their ask from research participants. For example, if you require urine samples, what does this mean for participants who are not cis-gendered?
- Training on cultural safety is critical to implementing a safety-first approach.
- We must value other people's time - researchers are recognized and paid for their research. Community partners/PFDs should be valued in ways they want to be compensated.

Topic: Inclusive Method for Developing Patient-Oriented Research Tools | Selina Allu

Overview

Can-Solve CKD Network Knowledge Broker and Implementation Specialist **Selina Allu** shared the Can-Solve experience of developing POR tools with patients. Can-SOLVE is a pan-Canadian research network involving patients, researchers, healthcare professionals, policymakers, academic health centres, health charities, and other organizations. Selina explained that as the network grew, they recognized knowledge gaps, including a need for more resources for patient engagement, skills development in storytelling, information on kidney research, how to engage with Indigenous communities, and knowledge translation.

These knowledge gaps led to the creation of the Training & Mentorship Committee, which included patient partners, staff, subject matter experts, and an Indigenous Knowledge Keeper, and the development of The Learning Tree.

[Access The Learning Tree training modules here.](#)

Key Learnings and Recommendations:

Can-SOLVE's process was rooted in their core values of Respect, Relevance, Reciprocity, Responsibility, and Reflection. Below are the five main learnings that emerged from this process, which provide practical tips when engaging different stakeholders and developing POR tools.

- Foster a culture of inclusiveness and mutual respect.
- Leverage in-person meetings and content experts.
 - Although virtual work does lead to collaboration, there is value in in-person meetings allowing for time to brainstorm, bond, and learn from each other.
- Invest in paid staff to coordinate activities and be responsible for project management, which is too demanding for volunteers/patient partners.
- Be flexible - developing tools is an iterative process that requires time to create, reflect, test, launch, and evaluate.
- Be mindful of patient needs and preferences and consider the timing and duration of meetings, required supports, and changing health status.

[Can-SOLVE's detailed process and learnings can be accessed here.](#)

Topic: Integrating Patient, Family, and Donor Partners in Clinical Trials | Dr. Dawn Richard & Terry Hawrysh

Overview

Closing day one was **Dr. Dawn Richards**, Director of Patient and Public Engagement at Clinical Trials Ontario (CTO), and **Terry Hawrysh**, PFD partner with the College of Lived Experience within CTO. The presentation delved into incorporating patients, family members, and donors in the clinical trial process. Practical tools were provided to help clinical trial teams that wish to engage people with lived experience on their teams.

The CTO's mission is to strengthen, promote, and capitalize on Ontario's strengths in conducting clinical trials. One strategic priority in accomplishing this is by engaging with patients and the public to increase awareness, foster collaborations, and improve how clinical trials are conducted. The College of Lived Experience includes patient partners who reflect the diversity of patients interested in clinical trials in Ontario and are responsible for providing input to the CTO community.

Key Learnings and Recommendations:

- CTO's approach to patient and public engagement includes:
 - Having resources, including a budget & honorarium, to support engagement.
 - Being flexible around meeting times and approaches.
 - Communicating the context and timelines for projects in an accessible way.
 - Closing the loop and let partners know project results, outcomes, and next steps.
 - Engaging a large group so there isn't pressure to participate (or continue participating) among partners.
- Sharing Terry's experience in clinical trials, Terry explained his role in trials from the start to dissemination. Relationships are essential to engagement, and Terry recommends that researchers spend time onboarding, communicating, respecting, listening, and using a collaborative approach with partners.
- CTO has created decision aids for engaging as a patient partner or with patient partners in clinical trials. These tools are self-guided, interactive, and provide basic training. [They can be accessed here.](#)

Block 3 - Patients, Families, and Donors in Knowledge Mobilization

Topic: Engaging Patient, Family, and Donor Partners in Arts-Based Research | Fraser Allan Best & Dr. Suze Berkhout

Overview

Day two began with a focus on integrating PFD Partners in knowledge mobilization. We were pleased to invite **Fraser Allen Best**, Toronto-based photographer, filmmaker, and liver transplant recipient, to discuss the use of documentaries and film to explore the experiences of transplant patients. Joining Fraser was **Dr. Suze Berkhout**, an early career clinician-investigator and practicing psychiatrist whose research program focuses on ethnographic, narrative, and arts-based methods to explore social and cultural issues impacting access and navigation through healthcare systems.

The presentation aimed to showcase the benefits of inclusive research methods involving patients, families, and donors as active partners and how arts-based research methods can engage these partners meaningfully.

As noted by Fraser in the presentation, “Documentaries provided a great way to examine topics in a way that is much more detailed and jagged edges that get removed in the literature of transplant [...] including transplant manuals [...] which are geared in more common experience. The goal of the film is to focus on the [experiences] that get lost in manuals”. Fraser’s documentary, *The Donor*, focused on the relationship between Fraser and his donor.

[ACCESS THE CLIP HERE.](#)

Key Learnings and Recommendations:

- Different experiences can be shared in various methods.
- Storytelling captures the complex and often various decision-making processes within donation and transplantation.
- Films and other methods capture the emotional journey from the patient, family, and donor experience across the donation and transplant process.

Topic: Developing a modernized organ donation and transplantation data and reporting system: A lens on patient, family, donor engagement | Rachel McGihon & Ryanna Bowling

Overview

Ending our formal presentations was **Rachel McGihon**, a program specialist at the Canadian Institute for Health Information (CIHI), and **Ryanna Bowling**, a program lead CIHI responsible for stakeholder engagement for the ODT Data and Performance Reporting. The presentation focused on how CIHI is engaging PFD partners to modernize the donation and transplant data.

Key Learnings and Recommendations:

- The project stems from the federal government's recognition that there was an opportunity to support innovation in Canada's OTDT systems.
- Creating a world-leading data-driven system informed by high-quality and timely information benefits PFD partners by allowing stakeholders to measure performances, increase transparency, stimulate research, decrease wait times, improve transplant and living donor outcomes, and measure progress towards a timely and equitable system.
- PFDs were engaged throughout the project, including representation within working groups, the Patient and Advocate Advisory Committee, participation in webinars & conferences, social media, and podcasts.
- Through their multi-year engagement, the CIHI team provides these learning lessons:
 - Ensure diversity in patient voice (e.g., patient background, characteristics, geography, role).
 - Target at least 2 PFD representatives per advisory group or session to create a safe place.
 - Provide opportunities for patients to speak and share their opinions in an interactive setting.
 - Partner with PFDs in planning and delivery of engagement activities.
 - Provide PFDs with recognition for intensive time and work.
 - Plan for virtual sessions to increase accessibility and participation rates.

[Learn more about the project and outputs here.](#)

Block 4 - Patient, Family and Donor Research Priority Setting

Using Machine Learning to Enhance Equity and Access in Organ Donation and Transplantation Health Systems: Patient Perspectives Workshop

Overview

The first of two CDTRP National Priority Setting Workshop, Using Machine Learning to Enhance Equity and Access in Organ Donation and Transplantation Health Systems: Patient Perspectives, was led by **Drs Mamatha Bhat, Suze Berkhout**, PFD partners **Shilpa Raju, Sandra Holdsworth**, and trainee **Cherry Xu**.

The session began with an overview of artificial intelligence (AI) as it is currently used in organ donation and transplantation, including a summary of sex and gender equity issues as they relate to organ allocation, shared decision-making, and machine learning.

Participants were then split into two breakout rooms to provide their perspectives. **Breakout room #1** asked participants to consider the implications of developing and testing machine learning algorithms to help understand and manage transplant-related risks and improve outcomes and equity across the temporal span of transplantation. PFD partners were asked:

- What do you think are some benefits of using AI in treatment plans?
- What do you think are some concerns?

Breakout room #2 focused on the ethical and social issues of machine learning and artificial intelligence in organ donation allocation. PFD partners were asked:

- What does equity mean to you?
- Where do you imagine equity-related issues coming up?

Following an engaged discussion, both groups reported back to the larger groups.

A National Approach to Prioritizing Emerging Issues in COVID-19 in Transplantation Workshop

Overview

The PFD Forum closed with the final CDTRP National Priority Setting Workshop, A National Approach to Prioritizing Emerging Issues in COVID-19 in Transplantation, led by **Drs Patricia Gongal, Margherita Cameranesi,** and PFD partners **Sherrie Logan and Rienk de Vries.** The goal was to develop consensus on the most pressing knowledge gaps related to therapeutics, mental health and well-being, and the economics of COVID-19 in transplant patients and families and plan the studies to address them.

After an overview of the national project, participants joined two breakout rooms (one for transplant recipients and another for caregivers) and asked to brainstorm and prioritize the questions researchers should ask about COVID-19. The categories include questions related to COVID-19 treatment, mental health and wellness, financial burden, and an open category. After reviewing the ideas presented by both groups, the group came together to discuss and prioritize the ideas.

SUPPORT

The CDTRP counted on the support of **19 organizations** to help promote the Forum to their networks via social media, their organization's website, and newsletters.



Each supporter received an English and French **Communications Kit** containing an overview of the event, prepared articles for their newsletters, post-ready social media posts, and graphics.

We also wish to thank **AstraZeneca** for their financial support.



The Twitter event hashtag (#PFDForum) **reached 95,000** individuals. Twitter posts with #PFDForum received **229 interactions**, including 67 mentions and 174 likes.

#PFDForum

ATTENDEES

The Forum was attended by **106 participants** from **52 cities across Canada and globally**. Participants self-identified as researchers, health professionals, transplant patients or recipients, living donors, family/caregivers, or partner organization supporters.

POST-EVENT

The CDTRP prepared a **post-event survey** and shared it with the participants throughout the event in the Zoom chat and on social media platforms, and also sent it to all participants by email the week following the Forum.

The recordings are posted and will remain available on the [CDTRP's website](#) and [YouTube channel](#).

CHECK OUT THE RECORDINGS!

Stay tuned for updates regarding CDTRP's 5th Annual Patient, Family, and Donor Research Forum scheduled for June 2024!

STAY UPDATED

Participants who want to be updated for the 2024 Forum or other patient, family and donor opportunities are encouraged to subscribe to [CDTRP's weekly newsletter here](#).

GET INVOLVED

Participants interested in joining CDTRP's Patient, Family, and Donor Partnership Platform are encouraged to complete our online application below.

[JOIN THE PFD PLATFORM!](#)

THANK YOU for helping make the CDTRP's 4th Annual Patient, Family, and Donor Research Forum a success!

If you have ideas for new sessions, email us at info@cdtrp.ca.



The Canadian **Donation and Transplantation** Research Program

Programme de recherche en **don et transplantation** du Canada