The Canadian **Donation and Transplantation** Research Program

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

Patient, Family & Donor RESEARCH FORUM

5TH EDITION | JUNE 13-14, 2024

POST-EVENT REPORT

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OVERVIEW

The Canadian Donation and Transplantation Research Program (CDTRP) hosted the 5th edition of the Patient, Family and Donor Research Forum on June 13 & 14, 2024.

The Forum serves as a space for building capacity in patient engagement, bringing together researchers, patients, families, donor (PFD) partners, and trainees. Through a combination of presentations, workshops, and priority-setting discussions, it fosters collaboration and shared learning.

The 2024 Forum focused on strengthening patient engagement in clinical trials and equity, diversity, and inclusion (EDI).

Learning outcomes

- Advance multi-disciplinary collaborations in donation and transplantation research, with a focus on innovative clinical trials.
- Support investigators, trainees, and PFD partners in understanding and embedding equity, diversity and inclusion principles in their patient engagement strategy and research methods.
- Enhance understanding of cultural safety and employ effective patient engagement strategies tailored to underrepresented communities.

PLANNING COMMITTEE

CO-CHAIRS

Leonard Hodder

Dr. Ruth Sapir-Pichhadze

Planning of the 2024 PFD Research Forum was led by Leonard Hodder, CDTRP PFD Partner, and Dr. Ruth Sapir-Pichhadze, CDTRP Researcher and Co-Chair of the Canadian Society of Transplantation Education Committee.

The CDTRP Management team supported the Planning Committee throughout the process: Dr. Patricia Gongal, CDTRP Executive Director; and Manuel Escoto, Director of Patient, Family, and Donor Partnership & Knowledge Mobilization.

CDTRP and co-chairs began planning when they submitted a CIHR Planning & Dissemination Grant in August 2023, which developed the framework for the 2024 Forum.

The Co-chairs and the CDTRP met on four occasions to plan the event, and initiate speaker outreach. Their goal was to create a practical program and draw insights from experts in patient engagement. To achieve this, speakers from outside the field of donation and transplantation were invited to contribute their expertise.

THE PROGRAM

Integrating patient engagement (PE) through a patient-oriented research (POR) approach is essential for improving outcomes and enriching patients' experiences in donation and transplantation. The PFD Research Forum serves as a venue for researchers and PFDs to share their collaborative experiences in co-design, which helps guide research and enhance patient outcomes.

The program aimed to share knowledge on enhancing patient engagement in clinical trials, advancing understanding on equity, diversity, and inclusion principles in health research, and how to apply these aspects in fields of donation and transplantation.

To accomplish this, the Forum was divided into two blocks over the two-day event. Each was moderated by a planning committee member, trainee, or PFD partner.

Block 1 Implementing Patient, Family, and Donor Research Partnerships to Shape Clinical Trials

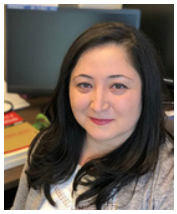
Block 2 Advancing Equity, Diversity and Inclusion in Donation and Transplantation

The Committee invited **22 speakers** to present **11 topics** covering these blocks. The speakers included researchers or professionals with expertise in patient engagement and patient-orientated research. Speakers also included patient partners from across Canada with a variety of experiences in patient-oriented research.

Per CDTRP's Terms of Reference, PFD partners are compensated for their time preparing and presenting at the Forum.

THE SPEAKERS

Block 1 Implementing Patient, Family, and Donor Research Partnerships to Shape Clinical Trials


Dr. Ruth Sapir-Pichhadze


Len Hodder


Stuart Nicholls


Linda Hunter


Maureen Smith


Charles Weijer


Laurie Blackstock


Susan McKenzie


Kathleen Brown-Blake

Block 2 Advancing Equity, Diversity and Inclusion in Donation and Transplantation


Dr. Caroline Tait


Dr. Jacqui Getfield


Osazogie Osadolor


Hayden John

THE SPEAKERS

Dr. Dimitry Rozenburg

Sandra Holdsworth

Jia Lin

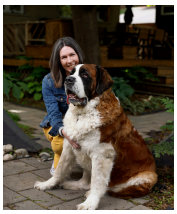
Carmen Carriere

Manuel Escoto

Sarah Douglas

Nadine Hare

Shilpa Raju



Heather Badenoch

Events like the PFD Forum provide a vehicle to engage and support all stakeholders - researchers, medical staff, patients, donors, caregivers, and others, in the research process. It's critical that research in transplantation, among other disciplines, includes the patient/family/donor voice, especially from underrepresented groups. It's just too easy to conduct research in a bubble, without including those for whom the outcome of that research most greatly impacts in the design and execution of the research. I expect that researchers participating in the forum will benefit from the knowledge and experiences of the presenters who have either already included PFD partners in their research, or who can offer practical solutions to doing so.

Leonard Hodder
Co-Chair

Dr. Ruth Sapir-Pichhadze
Co-Chair

The PFD forum is a valuable opportunity to bridge the perspectives, wants and needs of patients, families and donors with those of researchers, clinicians, trainees, and policy makers. By unifying the voices of pertinent partners, we can ensure that scientific inquiries and clinical initiatives are more likely to result in improved patient outcomes and experiences.

PROGRAM HIGHLIGHTS

Below is a detailed overview of each presentation, key learnings, and recommendations across the 2-day PFD research forum.

Block 1: Integrating Patient, Family, and Donor Partners in Research

Topic: High Value Research: The Role of Patient Engagement in Clinical Research | Dr. Ruth Sapir-Pichhadze, Len Hodder

Overview

The PFD forum began with a discussion and presentation led by Leonard Hodder, a non-directed living liver and kidney donor who is an active PFD partner, and Dr. Ruth Sapir-Pichhadze, a clinician-scientist at McGill University Health Centre in Montreal and representative from Canadian Society of Transplantation. Both co-chairs shared perspectives and meaningful insight on the importance of engaging patients and patient partners in the research process given there is an increased interest in patient-oriented research and growing recognition of its importance. Dr. Sapir-Pichhadze and Mr. Hodder started off with questioning: if we reflect on how to have patients and patient partners active in research involvement, what would that involve?

Key Learnings and Recommendations:

- Having a patient partnership role has high value in adding patient voices to the research process, whereby patients can share both lived experiences and non-health experience expertise to assist in the initiation, execution, knowledge dissemination and translation.
- Patient partner involvement is not necessarily ingrained in current practices, as patients are more typically involved as participants in the studies.
- Granting agencies are increasingly encouraging engaging patient partnerships.
- Mr. Hodder advises that patient partners can bring forward skills (i.e. through employment, education, hobbies, volunteering) beyond lived experiences to the research process.
    - Hard skills (e.g. analyzing results) such as knowledge of software platforms (e.g. Excel, SPSS) to help with processing data and development of devices (e.g. app development).
    - Soft skills (e.g. engaging with patients, healthcare partners, managers community. programs) whereby patient partners have a broader perspective and experiences with their interactions and can add to the richness of patient involvement in research studies (e.g. conducting interviews with patients, collecting feedback).

- A research study by Getchell et al. (2022) was highlighted about inclusive methods for developing patient-oriented research tools.
- PFD partners can offer to improve the research process by:
  - Commenting and providing feedback on research questions and the study rationale.
  - Informing considerations on patient recruitment methods.
  - Providing feedback on materials and instruments developed and used for patients in data collection.

Topic: Clinical Trial Landscape in Canada: Barriers and Motivators Impacting Patient Engagement in Clinical Trials | Stuart Nicholls, Linda Hunter

Overview

This session was led by **Dr. Stuart Nicholls** and **Linda Hunter**. Dr. Nicholls is the Strategy for Patient-Oriented Research (SPOR) program facilitator in the Office for Patient Engagement and Research Activities at Ottawa Methods Center. Linda is a national coordinator for Stream 4 Community Partners and Patients with Canadian Consortium of Clinical Trials Platform (CAN-TRAIN) and an active research engagement ambassador with CIHR.

There has been a transition over the past 40 years in Canada from patient-led advocacy to partnered approaches via partnerships between patient organization and institutions and industry funders to increase patient engagement. Dr. Nicholls and Linda focused on multiple perspectives of patient engagement in clinical trials, such as describing what active and meaningful patient engagement and collaboration in clinical trials is, moving from patient-led advocacy to partnered or institution-led engagement, current challenges, barriers and benefits, what trainings/resources are available for PFDs and motivations for engaging patients in clinical trials.

Key Learnings and Recommendations:

Canadian infrastructure has grown to support patient engagement in clinical trials (e.g. ACT, CAN TAP talent, IMPaCT, Health Data Research Network Canada, Child-Bright Network, CPN, Diabetes Action Canada, Can-Solve CKD Network, ACCESS Open Minds, IMAGINE, SPOR Evidence Alliance, CANTRAIN).

Patients are involved in clinical care, grant reviews, advocacy, conferences, knowledge implementation and translation, education, and research.

Motivations and patients' perspectives for engagement include:

- Intrinsic, moral, value-related rationales (i.e. if I am to be affected by something, I should have a voice in it).
- Value on patients' insights, experiences and perspectives.
- Larger societal changes, such as empowering the roles and rights of citizens.
- External motivators (e.g. funders, publishers requiring patient engagement).
- Improving the quality, acceptance, and relevance of research.
- Emphasize importance of transparency, communication and collaboration.

To determine evidence of impact, it is critical to understand what type of motivation we have in the rationale for patient engagement and what we want to achieve:

- Societal change and empowerment – does the intervention improve health outcomes or systems?
- Moral democratization of research – do patients sense they were listened to?
- Improvement in quality relevance/acceptance of research.

Ongoing challenges and barriers of patient engagement include:

- Relatively low levels of patient engagement reported in trial reports.
- Under-reporting of patient engagement.
- Engagement is emphasized on trial conduct aspects, not on research questions, findings or implementations.
- We ought to shift from "why?" to "how?" - despite creation of research tools for patient engagement (e.g. core outcome sets), lack of uptake and implementation in clinical trials.

CANTRAIN has implemented unique training programs and courses that adapt core competency framework for clinical research professionals for patient, public, and community partners' needs in understanding clinical trials.

Stream 4 was created to bridge gap in education between researchers and patient/patient partners across Canada. It is pertinent to have the following:

- Building trust and relationships with patients, listening to and understanding patients' stories.
- Understanding patient values and preferences.
- Understanding what patients require out of the value-proposition of working with research teams.
- Prioritize patient engagement and consultation with a consistent feedback loop.
- Ensure courses and modules developed reflect audiences' needs.

Further work remains in education of patient engagement in clinical trials:

- Information on patient participation in clinical trials versus patient partnerships in clinical trials - patients should feel supported in both aspects.
- How patients can effectively advocate – what is advocacy, what tools/skills are required.
- Creating patient research fellowship to certify and authenticate patients' competency, knowledge, and expertise to be involved in clinical trials.

Power differentials will exist between patients, patient partners, researchers, and clinicians. Patients often do not hold power – power dynamics must be appreciated and understood to prevent exploitation and marginalization.

Patient vulnerability takes many forms (e.g. power dynamics, finance, limited training/support, ethics, tokenism, emotional vulnerability) and to support these challenges, the following aspects should be considered:

- Ongoing support and training.
- Trauma-informed training and practice.
- Commitment when partnering with patient and patient partners.
- Transparency and open communication.
- Commitment to EDIA research practices.
- Equitable compensation and recognition.

Ways of supporting patient partners are multifaceted and include:

- Creating safe spaces to build trust and ability to open up, offering support and options through breaks/meeting times, understanding pain/fatigue.
- Providing executive support.
- Ensuring feedback and closing the loop by having one point of contact
- Learning to "listen to understand."
- Including patient co-presenter when speaking about research in conferences.
- Including diverse patient partners with your research; engaging them with each other and the research team.

Topic: A Roadmap to Youth Engagement in Clinical Trials: Lessons for Donation and Transplantation Research | Maureen Smith

Overview

On behalf of INFORM RARE, Maureen Smith, a co-principal investigator, presented knowledge and tools for youth engagement in clinical trials. INFORM RARE is a multi-disciplinary research network that is co-designed by patients and families, with a focus on registries and registry-based clinical trials for 3 rare pediatric diseases (MPS, PKU, SMA). INFORM RARE convened a national youth advisory group in April 2021 to engage youth in providing advice on key points during INFORM RARE research projects which has now increased to higher engagement levels. Engagement with youth is multifaceted and requires building and maintaining trust in their engagement, adopting a continuous learning approach, ensuring that they are listened to, and communicating long-term impacts. Herein, Maureen discusses the lessons from INFORM RARE on the benefits, common concerns and challenges, gaps, and the value in engaging youth in clinical trials and research.

Key Learnings and Recommendations:

Special considerations are required when engaging with youth in clinical trials:

- Consent and parental involvement.
- Respecting privacy, choice and ways to be acknowledged in public.
- Respecting vulnerability.
- Inclusivity.
- Youth-centered (e.g. listening to youth, taking feedback on engagement regularly).

There are multiple methods of engagement, that require active feedback and revisions:

- Compensation, accountability (“What we heard/what we did”), meeting formats led and informed by youth preferences/recommendations, providing options for continual. feedback/engagement, preparation of slides/materials appropriate to age group, virtual meetings and providing direct contact with researchers.
- Highlighting what youth have done to remind them of their engagement and valuable contributions and perspectives.
- Conducting engagement evaluations to actively improve engagement.

Benefits of engaging youth engagement in clinical trials:

- Enhance ethical standards.
- Wider and more effective dissemination and/or translation of research.
- Better data collection given rapport and trust development.
- More recruitment of research participants.
- Increases relevance of the research agenda.
- Increased insightful data analysis.

Gaps still exist in youth-partnered research such as:

- Research studies do not report backgrounds of youth involved in studies (difficult to discern inclusivity).
- Youth are more frequently involved in research design and data collection, less in dissemination and translation of findings, agenda-setting.
- Youth have some level of control in decision-making but less than adults.
- Excludes disadvantaged youth populations whereas most research includes privileged populations.

INFORM RARE's work with youth has had a broad impact on clinical trials through various ways:

- Feedback on PKU feasibility study.
- Assessed questionnaires, promotional materials, videos and websites for PKU and MPS Patient Registries.
- Looked at activity logs and created trial video in developing a SMA video game.
- Involvement in trial design, consent form, and having youth co-investigator in MPS Humira trial.
- Had voting attendees in MPS core outcome set consensus meeting.
- Infographic and video development on clinical trials for rare diseases.

Maureen ends with a digital story from Ofélie, an INFORM RARE youth advisor, on her journey and inspiration for her involvement. (Link: Youtube.com/watch?v=qBMmIXX8OWs).

Topic: Advancing Donation Research Clinical Trials: Current Landscape and Role of PFD Partners | Charles Weijer, Laurie Blackstock

Overview

This session featured Dr. Charles Weijer, a bioethicist and internationally recognized expert in research ethics from University of Western Ontario, and Laurie Blackstock, a Theme 1 co-lead of PFD partners at CDTRP, as well as an intercultural facilitator and learning designer in Ottawa with first-hand knowledge of deceased organ and tissue donation processes. In this session, Dr Weijer and Laurie discussed their respective experiences in collaborating on normothermic regional perfusion (NRP) research. NRP entails perfusing organs to provide oxygen repletion circulatory determination of death (DCD) donors. NRP is not present in Canada but widely used in Europe and in some US centers.

Dr. Weijer and Laurie worked on pilot work on applications of NRP in Ontario, and are looking to expand nationally. Laurie, a PFD partner, brought experience as a donor family, educator, facilitator and was involved in study design, funding applications, devising interview guides and participating in interviews. Questions such as what role donor family partners offer in research studies and a reflection of what strategies were effective, and which could be improved upon were discussed in depth.

Key Learnings and Recommendations:

While normothermic regional perfusion is widely used around Europe and in some centers in the US, NRP presents ethical dilemmas:

- Dead donor rule, donor safety, informed consent, and the impact of NRP on stakeholder trust in donation system.
- Core outcome sets (i.e., outcomes deduced by experts as critical for researchers to measure and report) allow knowledge synthesis, better efficiency, improved outcomes for practice, however core outcomes for donor families are lacking.

What roles can PFD partners offer in studies?

- Asking the right questions.
- Plan effective recruitment strategies.
- Develop educational and consent materials.
- Promote study results uptake.
- Design relevant studies and choose outcome measures.

Laurie detailed a breakdown of what worked as she participated in the study:

- One-on-one meetings between PFD and core team members are meaningful.
- Familiarize the PFD to the nature of study, closely understand the PFD's perspective and experience, provide flexibility, deduce level of involvement, answer questions.
- Building a supportive team and treating PFDs as experts shows value and respect for PFD's involvement.
- A participatory approach and having team charter gives sense of co-ownership and genuine care of everyone on the research team.
- Attention to logistics and maintaining respect for everyone's time were appreciated.

Check out the team's recently published study on "Sowing 'seeds of trust': How trust in normothermic regional perfusion is built in a continuum of care".

Topic: Engaging Patients in Research and Policy | Susan McKenzie, Kathleen Brown-Blake

Overview

Wrapping up Day 1 of the PFD Forum was Susan and Kathleen on their experience in creating national kidney donor and patient network committed to advancing education, outreach, and research for patients and patient partners. Susan, an active patient partner, co-founded the Transplant Ambassador Program (TAP), a volunteer-driven peer support program which helps kidney patients and living donors on navigating their transplant journey. Susan also founded the Kidney Patient and Donor Alliance Canada, a non-profit that drives patient-led advocacy. Kathleen is a communications and knowledge translation specialist for London Health Sciences Center where she translates research into communication for public use and implementation. She supports Kidney Dialysis and Transplantation program, KDT and pragmatic trials teams at Schulich School of Medicine and Dentistry. Both Susan and Kathleen present their respective organizations' objectives, initiatives, and ways of engaging patients and patient partners.

Key Learnings and Recommendations:

- Patients and living donors are unique in their credibility, authenticity to advocate for an accountable healthcare system.
- Create a speaker's bureau of patients and living donors who are skilled at speaking to discuss key issues with important stakeholders (policy makers, government, researchers/clinicians, media).

- Promote a two-way exchange of patient and researcher ideas.
    - Promote and connect transformational kidney research opportunities.
- Create an accessible kidney patient and donor database to increase engagement across patients, living donors, and family across Canada.
- Identify, mentor, and support pools of skilled patient research partners (i.e. assist in manuscripts, publications of interest to patients).
- The Alliance is a Knowledge Translation and Implementation Plan that has transformed the way patient-partner research is conducted and has served as a framework for other research groups.
    - The Transplant 1st Patient Partner coalition advocated for mobilizing research findings to increasing LKD transplants, held advocacy campaigns, and had outreach to media/policy makers led by patient partners.

Block 2: Advancing Equity, Diversity and Inclusion in Donation and Transplantation.

Topic: Creating Ethical Research Partnerships with Indigenous Patients and Communities | Dr. Caroline Tait

Overview

Opening Day 2 of the PFD forum was Dr. Caroline Tait, a medical anthropologist who co-established the Saskatchewan First Nation and Métis Organ Donation and Transplantation Network and is the lead of the Indigenous Health platform of CDTRP. Dr. Tait discussed how researchers can build and act on ethical research practices and partnerships with indigenous populations in Canada.

Indigenous peoples have been conducting lived experience and participatory action research for multiple decades in a culturally safe way across all research domains that maintains cultural values. However, historically, Indigenous youth and peoples have been vulnerable in many, different ways when being involved in research. “Nothing about us without us” is a powerful statement Dr. Tait shared when discussing Indigenous sovereignty and inclusion of Indigenous leaders in research practices regarding Indigenous health.

In June 2024, a resolution was passed by BC First Nations Chiefs that prioritizes organ and tissue donation and transplantation as a health issue for First Nations people in BC.

Key Learnings and Recommendations:

Despite progress, there is still a lack of protection and vulnerability for Indigenous peoples in research where they are uncomfortable but afraid to speak up - there is a strong need to have protection at university, hospital, and government-level for Indigenous peoples.

Despite the benefit that groups of Indigenous populations can have when participating in donation and transplantation research, they are vulnerable through multiple ways:

- Not understanding what it means to live with inter-generational trauma.
- What triggers are associated with trauma and how to understand and navigate invasive questions/procedures.
- How to navigate power dynamics in a research setting.

How can Indigenous peoples get involved with research? How can we approach them?

- Have First Nations, Métis, and Indigenous (FNMI) groups create research ideas or ensure that researchers consult with FNMI groups.
- Connect with rights holders such as Indigenous health leaders, persons with lived experience, Elders, and knowledge keepers.
- Adhere to FNMI values and principles, and maintain the nature of partnerships grounded in the ethical principles adopted by Indigenous groups.
- Do not use Indigenous as a term - you must distinguish cohorts of First Nations, Métis, and Indigenous separately.

Intergenerational trauma and the impacts of colonization are not easily solvable. It is a marathon to tackle and must be kept in mind by researchers and stakeholders when entering in research with indigenous groups. How can we build collaborative partnerships in research?

- Recognize that every person coming into the partnership, between FNMI community, researchers, and stakeholders, has needs and expectations.
- Adherence to research and data principles is paramount given the existence of power imbalances.
- Some FNMI groups are specifically disadvantaged and vulnerable (e.g. housing insecurity, financial insecurity) therefore health leaders must be involved.
- We must build trust and build relationships with the community.

There is pragmatic consideration in where sovereignty lies when engaging Indigenous populations with research; it lies with the Indigenous patient and their caregiver/guardian, with FNMI communities at the community-level.

The Prince Albert Study was mentioned and discussed as an example of how Indigenous groups can be exploited due their vulnerability. Researchers might also encounter anger, lack of distrust, and challenge in future studies given the lack of protection and exploitation in previous studies. It shows that the involvement of Indigenous leaders is critical going forward.

Topic: CARM: Significant Milestones in Building Partnerships with ACB Communities Across Ontario and Online | Dr. Jacqui Getfield

Overview

Caribbean African Regenerative Medicine (CARM) project was introduced by Dr. Getfield, project manager of CARM, and founder of Mothers United in Mediating Mutual Alliances (MUMA). Dr. Getfield discussed significant milestones in building partnerships with the African-Caribbean Black (ACB) communities. There are barriers caused by systemic racism, discriminatory practices and prejudices, that has led to a lack of trust between healthcare professionals and ACB patients. This affects ACB patients' and their families' ability to trust, understand and gather relevant information, and decision to get involved in research.

Key Learnings and Recommendations:

Healthcare professionals and communities must do their part to develop and build trust with ACB communities, recognize issues and impact ACB patients' ability to perform in ways that healthcare professionals prefer (e.g. religious, cultural beliefs).

Certain diseases are more prevalent in ACB communities, such as sickle cell anemia and chronic diseases. Additionally, the risk of kidney disease is 2-4 times higher in ACB communities.

Lack of adequate resources combined with the systemic barriers that have impacted the health of ACB communities has led to a large gap in donation and transplantation research that relates to ACB communities. How does CARM bridge the gap?

- Delivers information in both individual and group meetings, in-person and virtually (100+ conversations initiated by CARM).
- Meets and engages with healthcare professionals, undergraduate and graduate level students, community organizations, and host community conferences (2+ hosted thus far).
- Utilize a decolonial approach to gathering information – data from communities (e.g. thoughts, perspectives, experience of ACB members) are as important as medical/clinical information shared by healthcare professionals and subject experts.
- Make meaning and make sense of our lives in relation with each other (i.e. social interaction is paramount).

Topic: Partnering with ACB Communities: Successes and Challenges | Osazogie Osadolor, Hayden John

Overview

Osa and Hayden share their journey in coordinating 2 events in partnering with ACB communities in Ottawa and Hamilton. Osa is a third-year biomedical sciences student at University of Guelph with a minor in Black Canadian Studies. Hayden is a first year medical student at Queen's University and a CARM Project Team Member. Historically, research lacks minority representation, especially Black communities, due to systemic barriers and mistrust. Community engagement is an effective solution in helping bridge the gap. Events hosted by CARM focused on building trust and confronting the anti-black racism that exists in health and regenerative medicine. Osa and Hayden recapped their experiences from the events that allowed invaluable connections.

Key Learnings and Recommendations:

- Many ACB community members can be apprehensive about donation given the lack of trust in the health care system and healthcare professionals.
- There is a lack of ACB representation in research.
    - It is important to ensure that people who look like them are engaged at different levels of the projects.
    - Involvement through community engagement and grassroots organization can build trust and engagement of minority populations with clinical trials.
- There is a need for continuity of CARM to increase collaboration with ACB communities, health organizations, and health researchers to inform discussions of relevant health topics (e.g. fibroids, endometriosis, diabetes) and initiatives focused towards ACB youth.
- Health literacy represented through a lack of relevant information and resources to learn about health conditions.
    - Action items include: recognizing gaps in communication and improve them across the healthcare field (e.g. improve communication protocols, improve cultural competency).
- There is anti-black racism in healthcare: "...the physiology and biology is divorced from the realities of the black body or what we sociologists deem Blackness..."
    - Action items include: acknowledging historical inequities, comprehensive education on diversity, engagement, diverse representation in medical schools, recognizing and addressing bias.
- Different cultures have different methods of education, health literacy, and getting access to healthcare – understanding these factors will be important for improving practices.
- It is impossible to divorce the socioeconomic and biological backgrounds of marginalized populations – it is integral to take an intersectionality lens to these issues.

Topic: Bridging Research and Patient Engagement: Insights from CDTRP-supported Projects | Dr. Dimitry Rozenberg, Sandra Holdsworth, Carmen Carriere, Jia Lin

Overview

As CDTRP has evolved and grown, it has paved the way for involving PFD partners extensively with researchers and current research projects. This panel featured Dr. Dimitry Rozenburg, a clinician-scientist focusing on physical function and skeletal muscle dysfunction before and after lung transplantation; Sandra Holdsworth, a patient partner co-lead on Theme 5: Restore long-term health, who has been actively involved with her lived experiences in CDTRP-supported research; Jia Lin, a research project coordinator working with Dr. Samantha Anthony at the Hospital for Sick Children and manages multiple clinical trials including a current multi-phase cross-Canada study exploring the experiences of Indigenous children and families who have received solid organ transplants; and Carmen Carriere, who has educational training in history, teaching, and Indigenous women and community leadership. She is passionate about culturally-sensitive and accessible healthcare through her lived experiences as a patient partner.

This panel discussion addressed how and why PFD partners got involved, how researchers incorporate PFD partners in research, the logistic and systemic barriers encountered in integrating PFD partners, what role CDTRP has played in facilitating this partnership, and what advice panelists can offer from their experiences as next steps for improvement.

Key Learnings and Recommendations:

Dr. Rozenberg spoke on how these experiences have been rewarding and it is important to discuss with PFD partners the lessons learned and the future steps current research points towards. He discussed a need for researchers to:

- Involve PFD partners early in grant writing process, study planning, handout material development and health literacy assessment, patient recruitment strategies.
- Receive training on how best to engage PFD partners.

Jia spoke from her experience in FNMI research studies where she shared that it is paramount to recognize the history of unethical research conducted ON Indigenous populations rather than WITH Indigenous populations and to also recognize the western colonial structure of research – these are key in involving patients throughout the research process.

Carmen noted how it is challenging for researchers to conduct research outside of the norm with Indigenous populations. She identified a need for relationship building and developing of trust. To accomplish this, time and space must be given to build relationships, given the historical racism and violence Indigenous populations have experienced.

Involving patients in research has multifold advantages:

- Influences on research direction.
- Keep researchers in check and check their assumptions.
- Lived experiences influence the direction of priorities research.

All panelists discussed building and establishing relationships with PFD partners as a central theme. Recommendations for establishing relationships includes:

- Researchers should understand what training/support PFD partners need.
- PFD partners are beyond their health experiences, organ story, and conditions – they have skills and knowledge beyond these factors.
- The time commitment should be gauged and communicated clearly, given that studies can extend over several years.
- Flexibility for PFD partners' engagement, given they have their own lives, responsibilities, and caregiving roles.
- Reimbursements for PFD partners offering their expertise and time.

It can be challenging to increase diversity with PFD partners. Some reasons include:

- It can be challenging to identify patient partners without an entity like CDTRP that can facilitate the PFD partnership.
- Research institutions and clinical settings have not set up the environment for more diverse populations to get involved.
- Logistics can be challenging - consider time commitment and time zones, equipment and tools to access meetings.

Topic: Project Heart: A Collaborative Exploration of the Future of Engagement | Sarah Douglas, Nadine Hare, Manuel Escoto

Overview

3 panelists explored how to meaningfully engage people with lived experiences in healthcare policies and programs. Sarah Douglas is a policy analyst at Health Canada, co-leading Project Heart. Nadine Hare is design mentor who helps teams embed design and participatory research at OCAD and University of Toronto. Manuel Escoto is CDTRP Director of Patient, Family and Donor Partnerships and Knowledge Mobilization, as well as a 17-year kidney transplant recipient.

Project Heart is a collaborative endeavor to co-envision meaningful impact. Funded by the Solutions Fund, this network is comprised of those with lived experiences, researchers, designers, and policy analysts and their diverse experiences in the healthcare system.

Key Learnings and Recommendations:

“About 65-75% of the work is building relationships and 25% of the work is actually doing the work that you are setting out to do” (attributed to Mary Beaucage). We are in a moment of cultural change – people are demanding more transparency and expect to meaningfully shape decisions that impact them. Therefore, Project Heart aims at understanding engagement from people with lived experiences being engaged and how government employees can approach engagement in a meaningful way.

There remains tension between what PFDs say is an ideal engagement (e.g. trust, partnership, collaboration, strong relationships) versus what some engagement entailed (e.g. tokenism, inconsequential, being invited to check a box, stuck in a method, unsure of what is “right”). In these instances, patient partners are not respected, engaged, and not utilized to their full potential; this can lead to trauma.

One of the key learnings of Project Heart was that strong relationships are at the root of meaningful engagements and we need the following: (a) mindset shift: change how we think about engagements and (b) preferred approaches: change how we conduct engagement.

Preferred approaches for meaningful engagements include:

- Relating as collaborators.
- Fostering inclusive spaces.
- Value whole people and their perspectives.
- Demonstrate deep listening and showing impact, showing people with lived experience are heard.

Participants want to be more than a source of data – they want to be a team. This can be achieved by co-design. Co-designing is a process where participants become part of the design team – they can be involved in knowledge/concept development, idea generation thereby everyone is allowed to bring ideas and take actions.

Project Heart hosted 3 co-design workshops where people with lived experiences and policy analysts went through the co-designing process. This method of co-designing requires a commitment to learning and adapting, feel impact to both people with lived experience and policy analysts, and allow building of trust and strong relationships.

You may access the full report and recommendations here: Cdtrp.ca/en/project-heart

Topic: Exploring CDTRP Members Priorities in Equity, Diversity, and Inclusion | Shilpa Raju, Heather Badenoch, Manuel Escoto

Overview

This last session of the PFD forum ended on a high note of discussing how CDTRP focuses on fostering an organization where all people pursuing a collaborative experience feel a sense of belonging. This requires an intersection between diversity, inclusion, and equity in order to collectively create a space that engages everyone's potential where innovation can thrive, and beliefs/values/views can be integrated. The session concluded with an invitation for participants to join breakout rooms and collaborate on brainstorming ideas. Discussions focused on what CDTRP is doing well, areas for improvement, what members would like to see from CDTRP, and successful practices from other organizations that could be applied to CDTRP.

Key Learnings and Recommendations:

Equity involves recognizing that that power imbalances are there, real or perceived, and redistributing power. CDTRP prides itself on collaborative, non-hierarchical decision-making, implements co-design and co-leadership, and incorporates approaches where research is representative of all member priorities.

Diversity entails reflecting on who is missing and why, who is represented, and how can all partners be involved at all stages. CDTRP has recognized, implemented, and continues to improve on the representation at the executive, management, membership, community engagement, partnership development levels.

Inclusion is empowering all members to contribute meaningfully by sharing their thoughts, ideas, and perspectives. CDTRP recognizes and reflects on who is invited to participate in ensuring accurate representation of partners, recognition for time and contributions, and provision of training/support for members.

Summaries of breakout room discussions:

What works well?

- There are many opportunities to support different perspectives and participation.
- Co-design value with participants as a source of data in a process-focused manner.
- Outreach efforts, including connecting with non-CDTRP patient partners and community-based organizations.
- Patients are involved everywhere in CDTRP, and there is a continued desire to be involved in all areas.
- PFDs are leaders within CDTRP.

What can be improved upon?

- Promoting PFD compensation and having multiple modes of compensation.
- Research teams should have visible diversity in terms of the researchers on the team and the PFDs involved.
- Increase diversity and representation for research from patients.
- Gender representation, pediatric caregiver representation, LGBTQ+ member representation.

What can CDTRP do moving forward?

- Go beyond big groups to categorize people (e.g. Indigenous health, LGBTQ+ health) and specify cohorts.
- Ensure caregivers are appropriately involved in research and leadership.

- Trauma-informed research – how can research trigger trauma and how to work past that?

How can gaps be addressed?

- More accessibility for those who work in the daytime (i.e. those more impacted with the health barriers should be accommodated for).
- Offer more, different modalities for getting involved in research (i.e. surveys versus focus groups, option for anonymity).
- Include more family and community perspective in transplant journey.
- Identifying social background and incorporating more EDI practices to ensure feedback and perspective from patients is not coming from a place of privilege and excluding those who experience barriers.
- How can CDTRP address trauma-informed partnerships?

SUPPORT

The CDTRP counted on the support of **10 organizations** to help promote the Forum to their networks via social media, their organization's website, and newsletters.

Each supporter received an English **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 **CIHR** for their financial support.

ATTENDEES

The Forum was attended by **187 participants** from **52 cities across Canada and globally**. Participants self-identified as researchers, educators, 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 YouTube channel.

CHECK OUT THE RECORDINGS!

Stay tuned for updates regarding CDTRP's 6th Annual Patient, Family, and Donor Research Forum scheduled for June 2025!

This report was written by Aisha Adil (CDTRP Trainee, Theme 3, University of Toronto).
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Formatting and Design by Marie-Claire Kapesa.

STAY UPDATED

Participants who want to be updated for the 2025 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 5th 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