



The Canadian **Donation and Transplantation** Research Program

Programme de recherche en
don et transplantation du Canada

Patient, Family & Donor **RESEARCH FORUM**

JUNE 8-10, 2026

POST-EVENT REPORT

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Support

The CDTRP is hosted by The University of Alberta and acknowledges that we are located on the territory of Nêhiyaw (Cree), Niitsitapi (Blackfoot), Métis, Nakoda (Stoney), Dene, Haudenosaunee (Iroquois) and Anishinaabe (Ojibway/Saulteaux), lands that are now known as part of Treaties 6, 7 and 8 and homeland of the Métis.

The CDTRP respects the sovereignty, lands, histories, languages, knowledge systems and cultures of all First Nations, Métis, and Inuit.

OVERVIEW

The Canadian Donation and Transplantation Research Program (CDTRP) hosted the 7th edition of the Patient, Family and Donor Research Forum from June 8-10, 2026. Each year, the PFD Research Forum program is designed to strengthen patient and community engagement capacity across donation and transplant research, policy, and knowledge mobilization.

This year's PFD Research Forum, ***Pathways for Partnership: Strengthening Patient and Community Engagement with Indigenous Communities***, reflects CDTRP's commitment to building partnerships with First Nations, Métis, and Inuit (FNMI) patients, communities, leadership, and researchers to better understand their priorities for research, policy, and knowledge mobilization.

Over three days, the 2026 Forum brought together Indigenous and non-Indigenous speakers, including persons with lived experience, clinicians, researchers, and community leaders.

Learning outcomes



Strengthen capacity among researchers, trainees, PFD partners, and health professionals to engage in ethical, community-driven research partnerships with Indigenous Peoples.



Support learning on cultural safety, partnership, and appropriate engagement strategies with Indigenous Peoples.



Enhance understanding of effective patient and community engagement strategies tailored to underrepresented people.



Highlight community-driven and Indigenous-led programs and research projects that foster ethical collaboration and partnership.

EXECUTIVE SUMMARY

Throughout the three days, speakers described how racism, geography, fragmented services, financial pressures, and past harms shape access to donation and transplantation care and research.

Several messages recurred. Relationships should begin before a study or service is designed and continue after results are produced and shared with patients and communities. In research and healthcare delivery, FNMI peoples and communities have distinct rights, priorities, and approaches to knowledge and data governance that must be acknowledged and respected. Measures of success should reflect what communities value, including wellness, trust, and the benefits that return to them.

The lessons from this year's Forum are intended to support those across the donation and transplantation ecosystem in learning how to work more effectively and respectfully with Indigenous patients, communities, and partners, so that Indigenous Peoples can meaningfully shape the research, policy, and knowledge mobilization activities that affect them. The session summaries that follow below document the speaker key learnings and recommendations. Recordings are available on CDTRP's YouTube channel.

[CLICK TO VIEW THE RECORDINGS!](#)

In 2024, CDTRP established the Indigenous Platform to strengthen meaningful, respectful, and sustained partnerships with FNMI patients, families, donors, communities, and partners. The Platform supports the co-development of research priorities and knowledge mobilization activities with Indigenous patients and leadership. Through partnerships, CDTRP aims to ensure that Indigenous perspectives, priorities, experiences, and ways of knowing shape and guide the work and research undertaken across CDTRP's Indigenous Platform and Network.



Scan to visit the Platform's website

This year's Forum reflects that commitment by creating opportunities for CDTRP members to learn from Indigenous patients, community members, and leaders about how to build stronger relationships, support Indigenous leadership in research, and work in ways that contribute to more culturally safe, relevant, and community-informed organ donation and transplantation research.

Across the three-day Forum, several themes emerged. These include:

- Relationships and accountability must shape the full research process.
 - Engagement begins with listening to community priorities, clarifying who makes decisions, recognizing the time and expertise of partners, and agreeing on how findings and benefits will return.
 - An invitation to participate is only one part of partnership. Governance structures, resources, feedback, and accountability are also required.
- Donation and transplant health pathways, along with research engagement opportunities, must respond to geography and lived realities.
- Cultural safety requires changes in practice and systems.
 - Healthcare providers and researchers should avoid assumptions about Indigenous beliefs or patients' ability to navigate western systems.
 - Understand individual and family preferences, make space for cultural needs, and examine policies that may reproduce unintentional harm or inequities.
 - Training in cultural safety can support this work only when it is accompanied by changes in governance and accountability structures.
- Indigenous leadership and distinctions-based approaches are essential.
 - FNMI peoples should not be treated as a single group.
 - Research teams need to learn the relevant local context and work with local leadership rather than applying a research team's own research framework.
- Success should be defined with communities.
 - Does research produce benefits in a meaningful way? These measures should be developed with partners rather than imposed after a project is underway.

The learnings from this year's Forum will help inform the ongoing direction of CDTRP's Indigenous Platform, including how it develops priorities, partnerships, and future activities. These insights will also support the Platform in advancing the commitments and areas of work identified in CDTRP's Strategic Plan, helping ensure that this work continues to be shaped by Indigenous patients, families, communities, and partners.

[CLICK TO REVIEW](#)
[THE 2026-2030](#)
[STRATEGIC PLAN](#)



Scan to visit CDTRP's Strategic Plan

PROGRAM DEVELOPMENT

ADVISORY GROUP



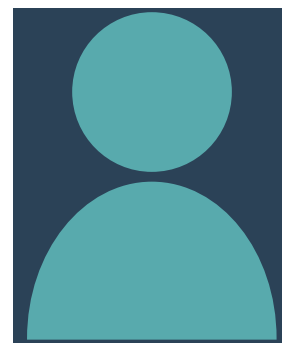
Craig Settee



Carmen Carriere



Ramona Big Head



Roberta Yellow Horn

PLATFORM LEADERSHIP



Lindsay Thompson



Sandra Holdsworth



Dr. Shaifali Sandal

The 2026 PFD Research Forum program was co-developed by a planning committee that included PFD partners and CDTRP staff support.

Planning was led by CDTRP's Indigenous Advisory Group: Carmen Carriere, Craig Settee, Ramona Big Head, and Roberta Yellow Horn. They were supported by PFD Platform leaders Lindsay Thompson, Sandra Holdsworth, and Dr. Shaifali Sandal.

Manuel Escoto, Director of Patient, Family, and Donor Partnerships & Knowledge Mobilization, supported the committee on behalf of the CDTRP Management Team.

THE PROGRAM

FNMI patients and communities are underrepresented in donation and transplantation research, and their distinct priorities are poorly understood. The Forum was a timely and necessary initiative that centred FNMI representation and perspectives to help guide interdisciplinary research that reflects Indigenous priorities, strengthens patient and community engagement, improves access to care, supports knowledge translation, and builds research capacity.

By centring Indigenous voices and lived experiences, the program sought to deepen understanding of community priorities in donation and transplantation, support shared learning, and explore approaches to meaningful patient and community engagement. These discussions aimed to inform research, policy, and knowledge mobilization that reflect Indigenous priorities and support more equitable access to care.

To support these aims, the Forum was organized over three days, each exploring a different dimension of patient and community engagement:



Day 1

Centred lived experience and featured the release of digital stories produced by Dr. Caroline Tait.



Day 2

Explored how researchers and research systems incorporate Indigenous patient and community engagement into research projects.



Day 3

Examined how organizations approach patient and community engagement in their work.

28 speakers presented or shared their lived experiences over the three days.

Per CDTRP's Terms of Reference, the Advisory Group, the PFD Platform co-leads, and persons with lived experience who presented at the Forum were compensated for their time preparing for, and presenting at the Forum.

THE SPEAKERS



Day 1

Centred lived experience and featured the release of digital stories produced by Dr. Caroline Tait.



Dr. Caroline
Tait



Verna
St. Denis



Dr. Mike
Moser



Earl
McKay



Kim
Roblin



Dr. Sean
Spence



Ramona
Big Head



Wanda
Neufeldt



Kira
Morrisette

Special thank you to Darlene Arcand, Knowledge Keeper

THE SPEAKERS



Day 2

Explored how researchers and research systems incorporate Indigenous patient and community engagement into research projects.



Kidney Check Team: (not in order) Elder Harley CrowShoe from the Piikani Nation, Lena Jorgensen, Dr. Aminu Bello (not pictured), Aaron Russell, Leta Philp, and Nicki Kirlin.



Dr. Anurag Singh



Jia Lin



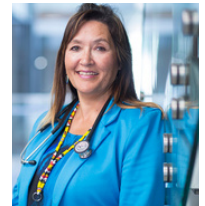
Carmen Carriere



Dr. Danièle Behn Smith



Kate Jongbloed



Dr. Veronica McKinney

THE SPEAKERS



Day 3

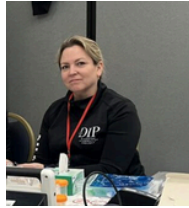
Examined how organizations approach patient and community engagement in their work.



Dr. Karennahawi
McComber



Joseph
Emmanuel
Amuah



Tannyce Cook



Cathy
Woods



Crystal
Hardy



Dr. Robert
Henry



Carrie
Thibodeau



Tamara Beardy

Special thank you to Darlene Arcand, Knowledge Keeper

PROGRAM HIGHLIGHTS

The following summaries reflect the key messages, learnings, and recommendations shared by presenters during their respective sessions.

Day 1: Centring Lived Experience

Conversations between a Donor Physician and a Donor Family: Approaching First Nations families to discuss organ donation

Speakers: Ramona Big Head and Dr. Sean Spence

Moderator: Craig Settee

Overview

This session highlighted the lived experiences and reflections of Indigenous families and healthcare professionals engaged in organ donation conversations following catastrophic loss. Ramona Big Head, an Indigenous mother and educator, recounted her family's journey through a series of profound losses to fentanyl overdose, culminating in the passing and organ donation decision for her daughter, Shawnee Brave Rock.

Dr. Sean Spence, an intensivist in Lethbridge, Alberta, offered his perspective as a physician working closely with Indigenous families in end-of-life care and organ donation. Their exchange underscored the unique cultural, emotional, and systemic considerations faced by Indigenous families, while also framing universal elements of compassion, respect, and humanity required in all such conversations.

Through storytelling, they explored the challenges, emotions, and cultural sensitivities involved in discussing organ donation during times of profound loss, highlighting the importance of respect, clear communication, and relationship-building between healthcare providers and Indigenous communities, including lessons in compassionate care and cultural sensitivity for both healthcare providers and families navigating organ donation.

Key Learnings:

- Healthcare providers must approach every donation conversation with empathy and recognize the unique trauma and cultural context of each family.
- Healthcare providers must be aware of the overrepresentation of Indigenous families among those affected by overdose, and the historical experiences of marginalization,

- racism and inequity in the healthcare system. Healthcare providers must understand the potential for mistrust, and strive to build authentic relationships rooted in respect and active listening.
- Recognize that there is no single "Indigenous perspective" on organ donation. Beliefs and practices vary widely within and between communities.
 - Take time to learn about the family's preferences, traditions, and worldviews.
 - Incorporate practices such as elder involvement and ceremonial prayers where appropriate.
 - Avoid assumptions about beliefs or practices, and as each circumstances dictates, ask families which traditions they wish to observe and support those practices.
- Storytelling can be healing and sharing personal stories can foster understanding, validate experiences, and help keep the memories and teachings of loved ones alive.

The Questions We Avoid: Trust, Transplantation, and First Nations Patient and Community Engagement.

Speakers: Roberta Yellow Horn

Moderator: Craig Settee

Overview

This session focused on the challenges and opportunities related to trust, transplantation, and First Nations patient and community engagement in the context of organ donation and transplantation. Through personal lived experiences shared by Roberta Yellow Horn, a First Nations kidney recipient, the discussion highlighted personal journeys through transplant, systemic barriers faced by Indigenous patients, cultural considerations, and best practices for researchers and healthcare providers seeking to engage with Indigenous communities in a respectful and effective manner.

The conversation highlighted persistent issues such as racism, misunderstanding of medical requirements, lack of communication, and skepticism stemming from historical mistreatment within healthcare. It also emphasized the resilience of Indigenous patients and the value of relationship-building and culturally informed, community-led engagement.

Key Learnings:

- Foster relationship and trust building by establishing ongoing, positive relationships with Indigenous patients and communities before seeking partnership or research collaboration. Take time to understand the community and expect that genuine trust may require multiple interactions.
- Prioritize open communication and ask questions, even those that may seem uncomfortable or taboo, to reduce misunderstandings and foster clarity.

- Understand the impact of past and current racism, mistrust, and negative healthcare experiences on Indigenous individuals' perspectives. Engage in cultural safety training to build foundational understanding before engagement.
- Center community voices in research and avoid extractive approaches where research is conducted “on” communities without returning value or results. Share results and ensure the benefits are felt by the communities involved, not just the researchers or institutions.
- Use storytelling, resources, and peer experiences to normalize conversations about donation and transplantation and dispel taboos.
- Engage leadership sensitively and strategically. Tailor messages to emphasize how donation and transplant research or policy align with the community priorities.
 - Recognize and offset barriers arising from poverty, rurality, and systemic inequities, including improving local access to dialysis and transplantation services.
- During transplant itself, create space for discussions about ceremonies, traditional healing, and spiritual needs as part of holistic health and transplantation journeys. Allow patients to discuss and utilize traditional medicines alongside biomedical treatments, and ensure medical teams are aware of these preferences for safety.

Day 2:

Kidney Check in Rural and Remote Indigenous Communities

Speakers: Elder Harley CrowShoe from the Piikani Nation, Lena Jorgensen, Dr. Aminu Bello, Aaron Russell, Leta Philp, and Nicki Kirlin.

Moderator: Chloe Wong-Mersereau

Overview

This session presented Kidney Check, a community-based point-of-care screening program for diabetes, hypertension, chronic kidney disease, and obesity delivered in First Nations communities across Alberta. The presentation team discussed the co-creation of Creating Harmony in Care, the framework that guided the development and delivery of Kidney Check, as well as the program’s implementation across Alberta since 2017.

Kidney Check was developed in response to the disproportionate burden of diabetes, kidney disease, and related complications experienced by First Nations peoples. Data presented from 2020 indicated that almost 15% of First Nations people in Alberta were living with diabetes, compared with approximately 7% of non-First Nations Albertans. Rates of lower-limb amputation and kidney dialysis were also approximately three times higher among First Nations populations.

To address these inequities, Creating Harmony in Care was co-designed with Indigenous healthcare providers, community wellness champions, and Elders. The framework emphasizes

healthcare providers, community wellness champions, and Elders. The framework emphasizes trust, cultural safety, community knowledge, and collaboration between traditional and Western approaches to health. Creating Harmony in Care guided the development of Kidney Check in Alberta. The program brings screening, kidney health education, personalized support, and referrals directly into First Nations communities, reducing the need for individuals to travel to urban healthcare centres.

Creating Harmony in Care includes four interconnected bundles:

- Person: Respecting individual health needs and preferences.
- Community: Building on local knowledge, strengths, and resources.
- Care: Combining evidence-based and traditional approaches to health.
- System: Addressing barriers such as transportation, food security, geography, and healthcare access.

Key Learning:

- Community-based health programs should be co-designed with Indigenous communities.
- Programs should be adapted to local priorities, resources, and cultural practices.
- Programs should strengthen the skills and capacity of local healthcare providers while continuing to offer mobile support to communities with limited staff or infrastructure.

Hybrid Transplant Care as a Strategy for Equitable Access and System Resilience in Northern Indigenous Contexts

Speaker: Dr. Anurag Singh

Moderator: Chloe Wong-Mersereau

Overview

This session explored how hybrid transplant care could improve access to kidney transplantation for people living in rural, remote, and Indigenous communities in northern British Columbia (BC). Dr. Singh, a nephrologist with Northern Health and an Assistant Professor in the University of British Columbia Faculty of Medicine based at the Northern Medical Program in Prince George, BC, explained that patients living farther from transplant centres are less likely to receive a transplant and often face significant barriers during the assessment process, including long-distance travel, limited access to specialists, delayed testing, and unfamiliar urban healthcare environments.

The proposed hybrid transplant care model is evolving as a systems redesign solution to address structural gaps across the kidney care pathway for rural, remote, and Indigenous communities and bridge the transplant gap. The hybrid transplant care model builds on community-based kidney care by combining in-person outreach with virtual follow-up. It aims to bring transplant services closer to patients, strengthen relationships between local and transplant teams, and reduce the need for repeated travel to urban centres.

Hybrid transplant care brings transplant assessment and follow-up closer to home, reducing the need to travel outside the community. It improves communication between local and urban healthcare teams and supports earlier completion of transplant testing and assessments. By providing more continuous, relationship-based care, it helps patients feel supported throughout the transplant process.

Key Learning:

- Distance remains a major driver of inequity in access to kidney transplantation.
- Indigenous patients experience additional barriers associated with a structural gap:
 - Access barriers: large distance from transplant team, long travel time, limited transplant and specialty outreach.
 - System barriers: limited access to specialties, 40% of patients do not have a primary care provider, delay in transplant referral.
 - Relational barriers: historical mistrust, lack of community engagement to develop culturally sensitive safe practices.
- Hybrid transplant care can face challenges, including unreliable internet access in some rural and remote communities and discomfort among some patients when discussing difficult or personal topics virtually. Building trust may require several in-person visits before virtual care is effective, and there is no single approach to providing culturally safe care in a virtual setting. Sustaining hybrid care also requires long-term funding and ongoing health-system support.
- Co-design hybrid transplant services with Indigenous communities, patients, Elders, and local healthcare providers.
- Use virtual care to maintain relationships, not replace in-person contact.
- Integrate transplant care into the broader kidney care pathway rather than treating it as a separate service.
- Strengthen communication between regional teams and urban transplant centres.
- Evaluate success using patient experience, community priorities, health outcomes, access, cost, and program sustainability.

Understanding Indigenous Patients, Families and Communities Experiences of Pediatric Organ Transplant

Speakers: Jia Lin and Carmen Carriere

Moderator: Sarjana Alam

Overview

This presentation explored the experiences of Indigenous children and families navigating pediatric solid organ transplantation in Canada. Drawing from a multi-site, patient-oriented, participatory research project, the speakers explored how Indigenous patients and families encounter unique barriers and opportunities across the transplant journey. The research team, comprising Indigenous and non-Indigenous partners, used storytelling and narrative inquiry to meaningfully engage participants, centre Indigenous knowledge, and advance health equity.

Drawing on interviews with 26 participants, the presenters shared preliminary findings highlighting how culture, identity, racism, geographic barriers, and financial pressures shape transplant experiences. Families described transplantation as a life-saving turning point within an ongoing journey that often involved separation from community, navigating unfamiliar healthcare systems, and advocating for equitable care. Their stories also identified opportunities to strengthen culturally grounded, relationship-based support.

Key Learnings and Recommendations

- Meaningful Indigenous engagement requires sustained relationships, shared decision-making, and a willingness to unlearn and relearn research practices.
- Researchers need to invest time and resources for relationship building, shared learning, and patient and family participation from the outset, while maintaining relationships beyond the end of a funded project.
- Engagement must also recognize the distinct identities, knowledge, and priorities of FNMI peoples, including differences within and across urban, rural, and remote communities.
- Storytelling offers an important approach to understanding transplant experiences, revealing gaps in care, and identifying priorities for change.
 - Stories functioned as both research data and a source of healing and validation.
 - Researchers have a responsibility to preserve the meaning and authenticity of these stories, involve patient and family partners in interpreting findings, and return knowledge in forms that communities value.
- Improving transplant care requires addressing structural barriers alongside strengthening cultural safety. Priorities included improving access to primary and community-based care, reducing delays and dismissal of families' concerns, simplifying access to financial and travel supports, and helping families maintain connections with community, culture, and land.
 - The presence of Indigenous staff, access to ceremony, and efforts to make hospital spaces more inclusive were identified as powerful facilitators of trust and improved care experiences.

Unlearning and Undoing Systemic White Supremacy and Indigenous Specific Racism

Speakers: Dr. Danièle Behn Smith and Dr. Kate Jongbloed

Moderator: Sarjana Alam

Overview

This presentation explored how researchers, healthcare professionals, and organizations can identify and address systemic white supremacy, settler colonialism, and Indigenous-specific racism within their everyday work. Drawing on their experience in British Columbia's Office of the Provincial Health Officer and the Unlearning and Undoing (U&U) Lab, the presenters described an approach grounded in naming racism, examining how it operates within one's sphere of influence, and taking sustained action. They emphasized that learning must lead to changes in organizational policies, practices, and accountability.

The presentation unpacks persistent systems of oppression, including white supremacy, settler colonialism, and Indigenous specific racism to demonstrate how systems and policies maintain structural harm. The presenters emphasized that Indigenous identity is a source of strength and resilience. Reporting on health inequities should clearly identify the effects of racism, settler colonialism, and structural barriers, avoiding language that presents Indigenous identity itself as a risk factor.

Key Learnings:

- Meaningful reconciliation requires organizations to take responsibility for changing their own systems. This work should be resourced across the organization, with clear responsibilities for leadership and staff, rather than assigned solely to an Indigenous health lead or a small advisory team.
- Researchers and healthcare professionals can begin by examining the policies, research processes, and routine decisions they influence, identifying how these may reproduce inequities, and making concrete changes.
- Data should also be communicated with recognition that the numbers represent people, families, and communities experiencing loss and harm.
- A rights-based approach must recognize the distinct rights, laws, jurisdictions, and priorities of First Nations, Métis, and Inuit peoples.
 - Organizations should avoid treating Indigenous peoples as a single homogeneous group or include Indigenous rights within general equity, diversity, and inclusion initiatives.
- The colonial knot review offers a practical starting point for reviewing research proposals, policies, and reports.
 - It involves examining whether Indigenous rights are absent, whether communities are described through stereotypes or deficit-based language, and whether an initial acknowledgement of rights carries through to the document's recommendations and implementation. This reflection should occur before requesting Indigenous review, helping ensure that Indigenous partners are not left to identify and correct every problem.
- Education and cultural safety training must be linked to sustained changes in practice and evaluated for their impact.
 - Organizations should assess whether learning changes staff behaviour, care experiences, and accountability.
 - This requires consistent effort, openness to correction, and a willingness to work through discomfort as part of an ongoing commitment to reconciliation.
 - Individuals and organizations must regularly examine and challenge their own participation in systems of oppression, rather than externalizing or minimizing their roles.
 - Effective anti-racism requires ongoing self-reflection and the willingness to recognize (and unlearn) one's own biases and inherited advantages.
- Engaging in this work will produce discomfort. This is a necessary indicator of growth, rather than wrongdoing, as it signals the disruption of old paradigms and the formation of new, equitable pathways.

Exploring Geographic Barriers to Health Care in Northern Communities

Speakers: Dr. Veronica McKinney

Moderator: Sarjana Alam

Overview

This session discussed systemic, geographic, cultural, and logistical obstacles impacting health outcomes and access to essential medical services. Drawing on her experience leading Northern Medical Services at the University of Saskatchewan, Dr. McKinney discussed how geography, transportation, fragmented services, food insecurity, language barriers, racism, and jurisdictional complexity intersect to shape patients' experiences. These challenges affect the entire transplant pathway, from early diagnosis and referral to assessment, wait-listing, and ongoing post-transplant care.

Dr. McKinney outlined the need for health professionals to understand missed appointments, delayed care, and difficulties following treatment plans in the context of systemic inaccessibility. Repeated travel, limited access to nutritious food, inadequate accommodations, and experiences of discrimination can make accessing care exhausting or unsafe.

The presentation also highlighted the strengths of northern Indigenous communities, including kinship networks, cultural knowledge, relationships with the land, and community-led solutions. Improving equitable access requires health systems to adapt to these communities through Indigenous leadership, stronger relationships, flexible care pathways, and services delivered closer to home.

Key Learnings:

- Recognize systemic barriers rather than assigning blame to patients. Labels such as “non-compliant” or “no-show” can obscure the transportation, financial, family, and safety challenges that prevent people from accessing care.
 - Transportation challenges are compounded by harsh weather, limited flights, and high costs, which affect access to both basic and specialized care (including transplant services).
 - Multiple assessments and follow-up appointments can require repeated absences from home, family, and community. Expand appropriate local testing, mobile services, telehealth, and remote specialist support.
 - Racism and previous harmful experiences can lead people to delay or avoid care. Providers should ask patients whether they feel safe, respond to their concerns, and support continuity through respectful, relationship-based and trauma-informed care.
- Housing, transportation, food insecurity, and access to follow-up services can influence assessments of a person's ability to manage transplantation. Programs should examine how these factors affect referral and eligibility decisions.
 - Health systems need to adapt to community realities rather than expecting patients to adjust to these processes.

- Patients, families, Elders, and community members should help shape services and solutions.
- Invest in Indigenous-led programs and training opportunities that enable community members to deliver care locally.
- Engage Elders and community members in developing culturally relevant information, allow time for questions, and build trust. Engage Elders and community leaders in health discussions, especially around sensitive issues like organ donation.

Day 3:

Respecting First Nations, Inuit and Métis Data Sovereignty at CIHI

Speaker: Joseph Emmanuel Amuah

Moderator: Kendra-Lee Dupuis

Overview

This session featured Joseph Amuah, Manager of Indigenous Health at the Canadian Institute for Health Information (CIHI), who presented on CIHI's approach to respecting First Nations, Inuit, and Métis data sovereignty. CIHI is an independent not-for-profit organization established to collect, analyze, and distribute health information about Canada's health systems and population.

The presentation highlighted CIHI's partnership-based analytics work with First Nations and Métis organizations. Key partnerships include: 1) a 10+ year collaboration with Sioux Lookout First Nations Health Authority, including recent work on maternal and newborn health analytics; 2) a formal Memorandum of Collaboration with the First Nations of Quebec and Labrador Health and Social Services Commission; and 3) work with the Children's Hospital of Eastern Ontario Research Institute on a national Indigenous data governance framework.

Mr. Amuah also introduced a First Nations Reference Guide to accessing data that was released June 2026. The guide outlines six steps for communities to access their health data from CIHI. Finally, he provided an update on CanODT (Canadian Organ Donation and Transplantation), CIHI's newest data holding, which began receiving data in 2025 and includes distinctions-based data.

Key Learnings:

- Respecting data sovereignty requires formal policies that mandate community authorization before data sharing. CIHI's identifiable data policy ensures community leadership is informed and agrees to data releases about their communities.
- Research priorities must be aligned with community priorities rather than predetermined by researchers. CIHI has developed new measures based specifically on what communities identify as important.
- Historical harms from data extraction have created justified mistrust that must be addressed through transparent relationship-building. Researchers must demonstrate how data will benefit communities and involve them as partners in the research process.

- Distinctions-based Indigenous identifiers are essential for meaningful research. CanODT's inclusion of First Nations, Inuit, and Métis identifiers represents important progress.
- Data sovereignty is best respected when data is repatriated to communities. The Reference Guide emphasizes communities leading decisions about accessing and using their health information.

Indigenous Engagement in Action: Lessons from IPERC and the Kidney Check Project

Speakers: Cathy Woods and Tannyce Cook

Moderator: Kendra-Lee Dupuis

Overview

This session featured Cathy Woods, Patient Partner and Co-Chair of the Indigenous People's Engagement and Research Council (IPERC) for the Can-SOLVE CKD network, and Tannyce Cook, Director of the Diabetes Integration Project at the First Nations Health and Social Secretariat of Manitoba. The speakers presented on IPERC's role in guiding network activities for patient-oriented research involving FNMI peoples. IPERC was established to ensure Indigenous voices are heard in research, addressing the historical lack of Indigenous involvement. The council developed Indigenous Measures of Success using a two-eyed seeing approach that combines Western science with Indigenous ways of knowing. A guiding principle emerged that shifted the focus from statistics to wellness: helping communities get well rather than simply documenting how sick they are.

The Kidney Check Project provides point-of-care screening with results available within one hour, identifying risk of needing dialysis in the next five years. The project screened over 700 people in 10 First Nations communities in Manitoba. The team also organized a kidney walk in 2024 with 25 First Nations communities participating to increase awareness of kidney disease.

Key Learnings:

- Indigenous-led research requires shifting from a deficit-based approach to a wellness-oriented one. Communities want to be helped to get well, not to hear statistics about how sick they are. This principle guides all project activities.
- The Six Rs framework (Respect, Relevance, Reciprocity, Relationships, Reflection, Reconciliation) provides guidance for community engagement. Research must be relevant to community concerns, provide mutual benefit, and reflect genuine partnership.
- Building relationships before entering communities is essential. A careful process includes sending letters to Chief and Council, meeting with leadership, discussing whether and when to proceed, identifying community contacts, and ensuring patient partners are present during activities.
- Cultural safety training for researchers and providers is critical. IPERC developed a Learning Pathway including land acknowledgements, blanket exercises, San'yas training, and cultural competency bundles.

- Community engagement takes time and cannot be rushed. Communities may face trauma and competing priorities, requiring flexibility and additional training for staff on working with youth and recognizing trauma.
- The high burden of kidney disease in Indigenous communities requires ongoing advocacy.

Indigenous Kidney Health Project

Speaker: Crystal Hardy

Moderator: Sarjana Alam

Overview

This session featured Crystal Hardy, an Anishinaabe doctoral candidate in Health Sciences at Lakehead University and Coordinator of the Indigenous Kidney Health Project (IKHP) at the Ajmera Transplant Centre, University Health Network. Crystal is from Rocky Bay First Nation and has lived experience with chronic kidney disease.

Crystal illustrated systemic inequity through a representative case: a First Nations man from a remote community forced to permanently relocate for dialysis, losing his housing and connection to community, then traveling alone to Toronto for transplantation and managing complex post-operative care in a hotel room without supports. This scenario represents the norm, not an exception.

Epidemiological data shows First Nations peoples experience kidney disease at two to three times the rate of non-Indigenous populations. Access to transplantation is markedly inequitable, with Northern Ontario patients referred at roughly one-third the rate of those in Toronto. Indigenous patients travel on average four times further for care.

The IKHP comprises three coordinated research projects.

- Project One mapped the landscape of kidney care through qualitative interviews with healthcare providers, patient partners, stakeholders, and First Nations leadership.
- Project Two is a mixed-methods dissertation investigation pairing qualitative interviews with a retrospective cohort study.
- Project Three is a five-year study co-developing and validating the Adult Health and Well-being Measure, which captures holistic dimensions of wellness, and evaluating whether standard measures function equivalently for First Nations adults

Key Learnings:

- Relocation and isolation are major barriers to care. Treatment often requires permanent relocation with loss of housing, community, and connection to land and culture. Patients are frequently left to navigate complex care alone in unfamiliar urban centres.

- Culturally relevant measurement tools are essential. Standard measures may not function equivalently for First Nations adults, potentially biasing clinical decisions and resource allocations. The Adult Health and Well-being Measure responds by integrating spiritual, social, emotional, physical, and relational dimensions of wellness.
- Barriers to transplant access are multi-layered, including geography and relocation, fragmented navigation, cultural mismatch, colonial and structural factors, and living donor barriers such as smaller donor networks and financial strains.
- Research must translate into actionable change through Indigenous navigators, culturally grounded education tools, disaggregated data tracking, community-based knowledge mobilization, and ensuring change is led by and accountable to First Nations communities.
- Emotional safety requires patients being listened to, heard, and seen within the system. Support must be provided through the lens of patient experiences, with care providers and community members working together to understand and respond to patient needs.

Network Environments for Indigenous Health Research

Speaker: Dr. Robert Henry

Moderator: Sarjana Alam

Overview

Dr. Robert Henry is a Métis from Prince Albert, Saskatchewan, an Associate Professor in the Department of Indigenous Studies at the University of Saskatchewan, and a Tier II Canada Research Chair in Indigenous Justice and Well-Being. Dr. Henry's presentation focused on the establishment of the Network Environments for Indigenous Health Research (NEIHR) as a decentralized "network of networks," comprising nine (and transitioning to ten) independent provincial and territorial hubs alongside a National Coordinating Centre (NCC).

The presentation provided insight into the NEIHR's role in improving Indigenous health research involving FNMI peoples through strengthening Indigenous health research capacity through training, mentoring, educating communities and supporting Indigenous health research leadership. Dr. Henry's presentation also discussed the collection and management of distinction-based data, emphasizing the importance of recognizing differences in local communities' health experiences. He described what community-driven and accountable health research looks like in practice, highlighting the value of building ethical relationships with local Indigenous communities before planning a research project or clinical trial. Finally, Dr. Henry discussed approaches and efforts to create pathways for leadership among Indigenous students and community members in Indigenous health research.

Key Learnings:

- Local Indigenous communities are diverse and have vastly different health experiences. Therefore, a distinction-based approach in using and managing data is strictly necessary. For example, using the broad term "Indigenous" while relying primarily on First Nations data misrepresents the distinct health experiences of Métis and Inuit populations.

- Researchers are required to acknowledge the differences between Indigenous communities and understand the culture and history in depth before building a research program or clinical trial.
 - For example: The First Nations Principles of OCAP® (Ownership, Control, Access, and Possession) are First Nations-specific and do not recognize or apply to evolving Métis or Inuit data sovereignty models.
 - Another example is the highly localized cultural concepts, which are frequently misappropriated as universal frameworks. Applying frameworks like "Two-Eyed Seeing" (Etuaptmumk in Mi'kmaq) or the "Medicine Wheel" (Plains Cree/Anishinaabek) outside of their originating territories misses the necessary geographic precision and risks cultural misrepresentation.
- When building a research project, researchers need to allow local communities to have control and focus on building ethical relationships and partnerships at the same time.
 - Researchers must shift their foundational inquiries from "What is our scientific question?" to "What is the outcome a specific community wants to see?"
- Building partnerships with Indigenous local communities requires time and relational accountability that is achieved through:
 - Respect, regardless of different views, by allowing open space to address issues through meeting community-led priorities.
 - Reciprocity, through recognizing cultural protocol that allows for knowledge exchange. For instance, tobacco is First Nations-specific and not traditionally practiced by Métis or Inuit groups. This can be achieved through visiting the local communities, interacting and learning about their different cultures and history.
- The NEIHR is supporting Indigenous students by creating a new cohort that provides the necessary training, resources, and a supportive 'network of networks' environment. This initiative empowers them to conduct health research for Canadian Indigenous communities and prepares them to become future research leaders.

Developing a Chronic Kidney Disease Framework: Patient and Community Engagement with Indigenous Partners

Speakers: Carrie Thibodeau and Tamara Beardy

Moderator: Sarjana Alam

Overview

This session featured Mrs. Carrie Thibodeau, the National Director of Programs and Public Policy at the Kidney Foundation of Canada, and Mrs. Tamara Beardy, an Indigenous health advocate and living kidney donor from the Tascawaya Cree Nation. In this session, Mrs. Thibodeau discussed the practical development and mission of the National Strategic Framework for Chronic Kidney Disease (CKD). The discussion focused on the main objectives of the National Strategic Framework, highlighting structural efforts to embed Indigenous patient voices into governance and oversight committees. Mrs. Beardy grounded these policy concepts by sharing her family's reflective trajectory through the organ transplantation and donation system.

Her story emphasizes the importance of constant screening for CKD within Indigenous communities for better kidney health outcomes. The speakers also discussed issues regarding the clinical biases experienced by Indigenous individuals, the psychosocial impacts of mandatory medical relocation for dialysis, and insights on how to improve health care advice for CKD patients were discussed by both speakers.

Key Learnings

- Equity-focused approach in CKD health is required because FNMI people:
 - Are at higher rates of risk factors for developing chronic diseases that can lead to CKD.
 - Are disproportionately affected by CKD as they are three times more likely to develop kidney disease.
 - Encounter barriers to accessing dialysis and transplantation specialist care.
 - Experience other challenges such as systemic inequities, food insecurity, geographic isolation and cultural barriers that affect their quality of life.
- The national framework for CKD serves as a roadmap for coordinated actions across Canada, including federal, provincial and territorial governance. The framework:
 - Focuses on prioritizing prevention, earlier detection and timely intervention to improve outcomes and equitable access to care for all Canadians.
 - Advances kidney health research for better kidney health care.
- The national strategic framework was able to successfully engage Indigenous partners by:
 - Including both Indigenous patients and allied health professionals, participating in their patient, caregiver and donor advisory committee.
 - Conducting national surveys for people affected by kidney diseases, including caregivers and donors.
 - Outreach efforts to northern and remote communities.
 - Co-leading with Indigenous partners in national consultations and advocacy activities with policymakers.
- The speakers recommended:
 - The need for Indigenous leadership and community-driven solutions.
 - An understanding of the impact of systemic racism, historical harm, cultural safety aspects and the need to build trust within the health care system.
 - Considering real-life community challenges, such as geography, food insecurity and transportation, when providing health guidance.
 - Ensuring Indigenous involvement is always intentional, inclusive and based on distinction-based approaches and needs.

THANK YOU, MODERATORS



Chloe Wong-Mersereau (she/her) is a recent graduate in social work at McGill University where she has worked with Dr. Shaifali Sandal on numerous qualitative research studies on living kidney donation and transplantation. She has a background in cultural medical anthropology at the University of Toronto where she worked with Dr. Suze Berkhout on a multimodal solid organ transplant study. Her research interests include psychosocial and health inequities in transplantation and creative storytelling methodologies.



Kendra-Lee Dupuis RN, MA (Nursing), BScN (she/her) is a PhD student at Brock University in the Faculty of Applied Health Science, working under the supervision of Dr. Silva e Silva. Kendra-Lee is passionate about end-of-life care in emergency settings and hopes to make a meaningful impact for care providers and patients within this context.



Sarjana Alam is a master's student at the University of Alberta conducting basic science research in transplantation. During her undergraduate studies, she completed a research project under the supervision of Dr. Esme Dijke focused on defining optimal cryopreservation conditions for regulatory T cells (Tregs) used in tolerogenic cell therapy. Her research aims to develop an improved cryopreservation protocol that supports the long-term storage of Treg cells, with the potential to reduce costs and support the broader clinical implementation of tolerogenic Treg cell therapies in transplantation.

THANK YOU, SESSION SUMMARY AUTHORS



Ysabel Fine is a masters candidate in the Latner Thoracic Labs under the supervision of Dr. Mingyao Liu. Her research expertise centres on lung transplantation, transcriptomics, and single-cell RNA sequencing. Her work focuses on identifying predictive biomarkers from donor samples to improve organ assessment, risk stratification, and long-term transplant outcomes. Ysabel is interested in collaborative projects that integrate immunology, bioinformatics, and patient-centred transplant care.



Irene Chen is an MD student at the University of Calgary. Previous to her current role, she was an MSc student at UBC in the Women and Children's Health Sciences program under the supervision of Dr. Tom Blydt-Hansen. Her research explores social media use among young people with transplants, specifically in relation to seeking and sharing information about mental health.



Asra Almubarak, PhD, is a Director in Training at the Histocompatibility and Immunogenetics and clinical fellow in the Transplant Lab North-University of Alberta Hospital. Asra is a graduate of the University of Alberta with a PhD in Medical Genetics.

SUPPORT

The 2026 PFD Research Forum was supported by the Canadian Institutes of Health Research (CIHR).



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ATTENDEES

The Forum was attended by **138 participant**. Participants self-identified as researchers, educators, health professionals, transplant patients or recipients, living donors, family/caregivers, or partner organization supporters.

RECORDINGS

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

CHECK OUT THE RECORDINGS!

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Participants who want to be updated for the 2027 Forum or other CDTRP opportunities are encouraged to subscribe to [CDTRP's weekly newsletter here](#).

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THANK YOU for helping make the CDTRP's 2026 Patient, Family, and Donor Research Forum a success!

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



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