

PiPER | Pride in Patient Engagement in Research

RESEARCH DAY 2025

SUMMARY



On October 8th, 2025, the Pride in Patient Engagement in Research (PiPER) initiative hosted its 3rd Annual Research Day at the beautiful Guild Inn Estate in Scarborough. The in-person event offered an inspiring space for learning, connection, and celebration of innovative and meaningful research. The program centered on the theme ***“Do the Right Thing, Share it With Others, Build a Better Tomorrow.”***

PiPER envisions a future where UHN is an international exemplar for the participation of people with lived experience (PLEX; includes patients, family members, caregivers, and community organizations) in our research. PiPER works towards this vision by building organizational structures, processes, and technologies that promote and embed the engagement of PLEX in research at UHN.



www.uhnpiper.ca



PiPER Research Day encouraged attendees to collaborate across disciplines to reduce duplication, abandon ineffective practices, create an opportunity to learn from one another and build a better tomorrow.

The day featured a thought-provoking keynote speaker, a panel discussion on long-COVID, and a dynamic trainee panel offering quick engagement insights. Attendees also participated in six concurrent sessions showcasing poster and oral presentations, alongside workshops, storytelling sessions, an art exhibit, and an interactive panel—all designed to foster dialogue and spark new ideas for building a better future.

Bradly Wouters, Executive Vice President of Science and Research at UHN opened the event by highlighting PiPER's remarkable achievements. PiPER has reached several key milestones, including:

1,522 Toolkit Downloads

25 Roadshows

>30,000 Annual Website Visits

26 Communities of Practice

10 Internal Grants awarded from 2022–2024

21 Internal Grants awarded in 2025

PiPER's impact has also been recognized through four major grants and awards, such as the **CIHR IMHA Patient Engagement Prize** and the **UHN Mission Excellence Award**, underscoring the growing value of PLEX engagement in research across UHN.



Cathy Craven, PiPER Executive Lead also introduced PiPER's latest initiative, 'UHN Research Explained', a public-facing website that offers easy-to-read summaries of our research. This is a platform where anyone from around the world can access and appreciate ongoing and completed research at UHN.



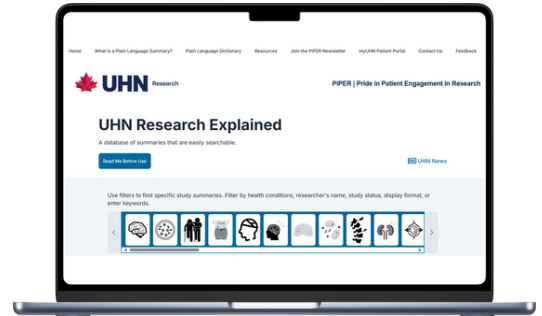
Welcome to UHN Research Explained!

We've built a new online space dedicated to sharing UHN Research with the public in a way that is easy to understand!

The website is a searchable space where scientists are sharing plain language summaries of their ongoing and completed work. You can filter by health condition, researcher's name, study status, written or infographic format, or enter keywords.



www.uhnresearchexplained.ca



RESEARCH DAY OVERVIEW

Themes & Areas of Focus

This year's themes reflect the ethical responsibility to engage PLEX in research and to see PLEX as equal partners in the research process (***Do the Right Thing***), the value of sharing insights through knowledge translation (***Share it with Others***), and the need for innovation to improve future research practices and outcomes (***Build a Better Tomorrow***).

There were **12 sessions** and over **40 speakers**, sharing principles, practices, and processes related to:

Do the Right Thing

How to engage

Diverse engagement

Education and training

Strategies for effective communication

Technology/digital engagement

Share it with Others

From theory to action: Examples of PLEX engagement

Creative ways to share research

Build a Better Tomorrow

Dissemination

Impact and outcomes

Public awareness

Collaborate for success

With **175 attendees** from across various research fields, the day was a resounding success!



Perspectives of Attendees

- Academic Researcher: **19%**
- Clinician: **2%**
- Community Member: **20%**
- Community Researcher: **5%**
- Healthcare Leader: **4%**
- Research Support Staff: **35%**
- Student/Trainee: **15%**

47% of attendees self-identified as a person with lived experience.

KEYNOTE SPEAKER: MAHADEO SUKHAI



- » World's first congenitally blind geneticist
- » Chair of the Employment Technical Committee for Accessibility Standards Canada
- » Chief Operating Officer of IDEA-STEM
- » External Co-Chair of the Canadian Institutes of Health Research Expert Advisory Committee on Accessibility and Systemic Ableism



"Anti-Ableism in Patient Engagement and Research: A Personal and Professional Journey"

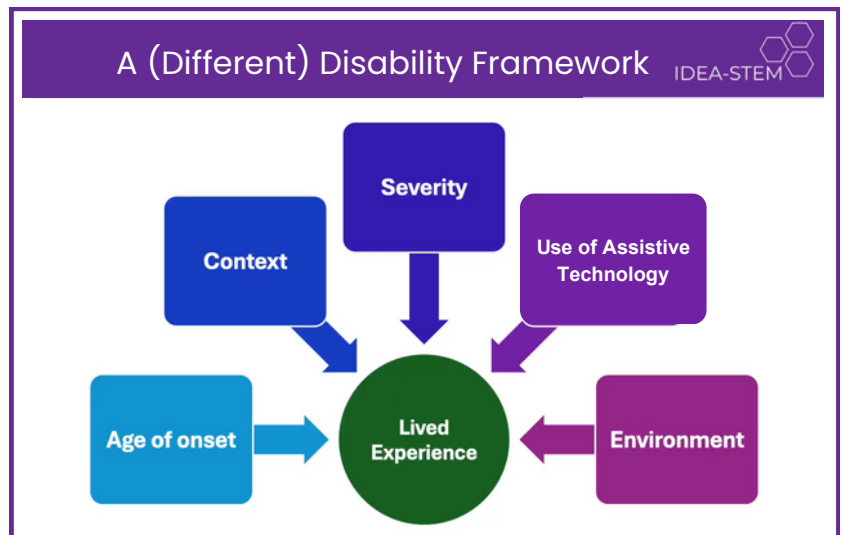
During his keynote, Mahadeo Sukhai examined traditional models of engagement in healthcare and contrasted them with the realities of PLEX, specifically those living with disabilities. He highlighted the gap between how these models are intended to function and how they are actually experienced.

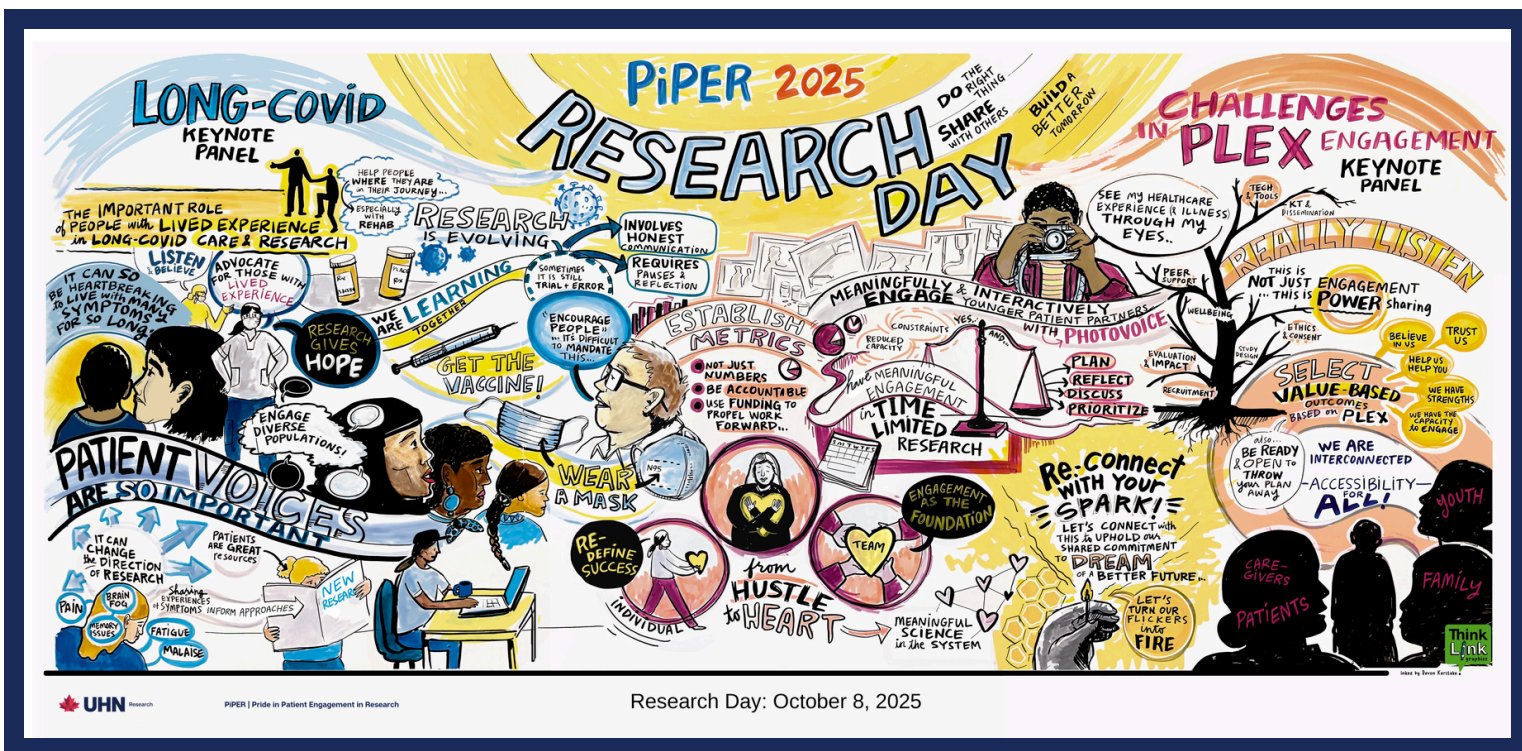
A central theme of his talk was the Iceberg Model, which demonstrates how barriers faced by people with disabilities are often misinterpreted as personal challenges rather than recognized as systemic issues. While every disability journey is unique—reflected in the experiences of more than 8 million adults with disabilities in Canada—the presence of structural barriers is a shared reality.

Mahadeo also invited the audience to reflect on how disability is defined and understood: *Is it a health outcome, an identity, both, or neither?* He noted the persistent tension between person-centered approaches and lingering quasi-eugenic thinking to shape research and healthcare environments.

He further emphasized that three-quarters of Canadians equate equal treatment with fairness, even though uniform approaches rarely meet diverse needs. Achieving true equity, he argued, requires practices that recognize and meaningfully accommodate different experiences.

Overall, Mahadeo's talk championed the heart of PLEX engagement in research—building truly inclusive models, dismantling outdated beliefs, and transforming how we perceive and value disability.





List of Organizations

People from 31 different organizations were present:

- ACCESS
- Alberta SPOR Support Unit
- Asthma Canada
- BioCanRx
- Brain Injury Canada
- CAN-BIND
- CanChild
- Canadian Cancer Survivor Network
- Centre for Addiction and Mental Health
- Chronic Pain Centre of Excellence for Canadian Veterans
- Chronic Pain Network
- Holland Bloorview Kids Rehabilitation Hospital
- Institute for Clinical and Evaluative Sciences
- IDEA-STEM
- Lumenus Community Services
- McMaster University
- Ontario AIDS Network
- Ontario Brain Institute
- Ottawa Hospital Research Institute
- POND Network
- SciVoc Consulting Inc.
- Spinal Cord Injury Ontario
- Sunnybrook Research Institute
- The Hospital for Sick Children
- The Neurodiversity Collaborative
- UDAAN Inc.
- University Health Network
- University of Calgary
- University of Toronto
- Waypoint Centre for Mental Health Care
- Women's College Hospital

PRESENTATIONS

The event featured a diverse array of presentations, bringing together PLEX, researchers, trainees, and healthcare leaders.

32 Posters

4 Creative Works

1 Workshop

10 Oral Presentations

2 Storysharing Sessions

1 Keynote Panel

1 Young Investigator Panel

2 Interactive Panels



Long-COVID panelists (from left) Angela Cheung, Susie Goulding, Rebecca Lewkowicz, and Ali Rendely



Posters and an Art Exhibit showcased innovative projects, emphasizing PLEX engagement in areas such as chronic illness management, mental health, and community-based care, enabling researchers and PLEX to connect and collaborate on future initiatives. The art pieces featured different media such as video and print.



Workshops and Oral Presentations throughout the day, moderated by PLEX, explored how to integrate the voices of PLEX into research, from early planning stages to final evaluation and dissemination. Several topics were covered including using plain language, family engagement, empowering caregiver partners, and creating inclusive and accessible research spaces.



Storysharing Sessions and Panels, also moderated by PLEX, highlighted the real-world impact of engagement on research quality and outcomes. Speakers shared how PLEX-centred research can improve treatments and foster more compassionate, effective research environments. The Long-COVID keynote panel highlighted a number of health, policy, and lived experience perspectives to inform health system and service improvements.

EVALUATION HIGHLIGHTS

WHAT WORKED WELL

Event Program

Program was well-balanced, and appreciated the dedicated time for breaks and networking

Accessibility

Clear signage throughout the venue, a ramp to the main stage, and quiet rooms were aspects that made the event accessible

PLEX Engagement

Attendees appreciated that PLEX were involved in leadership roles throughout the event, including keynote speakers and moderators

AREAS TO IMPROVE

Interactivity

Attendees noted that they would like to see greater interactivity with the audience across all presentation types

Actionable Takeaways

A greater focus on take-home actions to advance PLEX engagement in research would improve the impact of the sessions throughout the day

Focus on Equity

Sessions should focus more on best practices for engaging equity-deserving groups, including Indigenous populations

“ I was excited to network and connect with peers and so I appreciated the multiple time points set aside in the agenda to connect. ”

“ I appreciated that there was an outdoor area available to have lunch without a mask and that quiet rooms were available for those who need them. ”



OVERALL EXPERIENCE

80%

Agreed or strongly agreed that the event was a safe and inclusive space to participate in conversations and learn about PLEX engagement in research

88%

Met their personal goals for attending Research Day

96%

Rated the conference as a positive experience



Overall Session Ranking

Oral presentations and PLEX storysharing were widely regarded as the most insightful and enjoyable components of the conference.

Overall Session Accessibility

“

I was permitted to bring a mobility guide with me to navigate the conference site as a person who is visually impaired. Also, all of my food restrictions were accommodated in detail. Lastly, when I first arrived at the conference, a PiPER staff personally escorted me into the conference and got me fully set up. I could not ask for more.

”

We would like to acknowledge our sponsors and funders who made this event possible.

Funders



PLEX Sponsors

Our generous sponsors below supported a total of **10 PLEX** to attend PiPER Research Day:



PiPER supported **24 PLEX** to attend Research Day through the CIHR-IMHA Inclusive Research Excellence Prize – Patient Engagement (RE5-195224).

 Anna Gordon	 Ann Heesters	 Anita Kaiser	 Sylvia Langlois	 Amanda Silva	 Tracy McQuire	 Farrah Schwartz	 Gordon Myers	 Jackie Bender	 Joan Conrad	 Janet Rodriguez	 Karen Martens	
 Louise Brisbois	<div> <div> Institute of Musculoskeletal Health and Arthritis Prize Canadian Institutes of Health Research Instituts de recherche en santé du Canada </div> <div> PIPER Pride in Patient Engagement in Research </div> </div>										 Amanda Weston	
 Michael Voth	 Kerri Scane	 Philip Wong	 Laura Williams	 Miranda So	 Rob O'Reilly	 Samantha Engbers	 Noha Dewan	 Peter Athanopoulos	 Rebecca Charew	 Srinivas Ravi Kumar	 Anita Morava	 Julie Vu

PiPER Team

From left: Curtis Black,
Anisa Morava, Julie Vo,
Erin Smith, Cathy
Craven, Dawn
Richards, Mat Wiest,
Lindsie Blencowe



We would also like to acknowledge the following individuals for their crucial support in making Research Day a success!

PiPER Research Day Planning Committee:

Anu Shukla-Jones
Carolyn Genautis
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Nikki Weeks

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Pia Kontos
Rudayna Bahubeshi
Samantha Thompson
Tracy McQuire

Concurrent Session Moderators and Facilitators:

Anita Kaiser
Anna Gordon

Dawn Richards
Joan Conrad

Tom Walden
Suban Kangatharan



Volunteers:

Amanda Weston
Andrea Brown
Anita Kaiser

Anna Gordon
Joan Conrad
Maryam Omidvar
Masae Miyatani

Mohammad Alavinia
Suban Kangatharan
Tom Walden

Photography credits: Tim Fraser, Kite Studio

Beyond Research Day, PiPER continues collaborating with TeamUHN to develop new policies, processes, resources, and research methods that support the implementation of transformative research experiences, driving collective impact toward a healthier world.

We can't wait to see what we can achieve together in the future to re-imagine PLEX engagement in research!

Contact the Team

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