

PARTNERING FOR BETTER RESEARCH: PIPER TOOLKIT 2.0 & PLEX NETWORK FORUM



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UHN Foundation

Ethos of the Day: Accessibility is Equity.

Acknowledgements: We thank the Canadian Institutes of Health Research (CIHR) and UHN Foundation for their generous support of the PiPER Toolkit refinement (Version 2.0).

Event Aim

To bring together people with lived experience, scientists, research staff, and community organizations to learn about the PiPER Toolkit 2.0 and to learn about the purpose and vision of the PLEX Network.

Event Summary

The event opened with an introduction of key concepts surrounding engaging people with lived experience (PLEX) in research, UHN's refreshed strategic directions, and key PiPER activities.

The PiPER Toolkit 2.0 was unveiled and working group members from the first and second versions participated in a ribbon cutting. New elements of the Toolkit were presented and physical copies were circulated.

We later featured the PLEX Network Working Group who led open discussion and commentary regarding three Network goals. The event closed with a networking hour and opportunity to strengthen collaborations within TeamUHN!



Anisa Morava
Community of Practice



Matheus Wiest
Manager



Cathy Craven
Executive Lead



Erin Smith
PiPER Grants



Mohammad Alavinia
Data and Evaluation



Dawn Richards
Consultant



Lindsay Blencowe
Digital Manager



Farnoosh Farahani
Ending Relationships

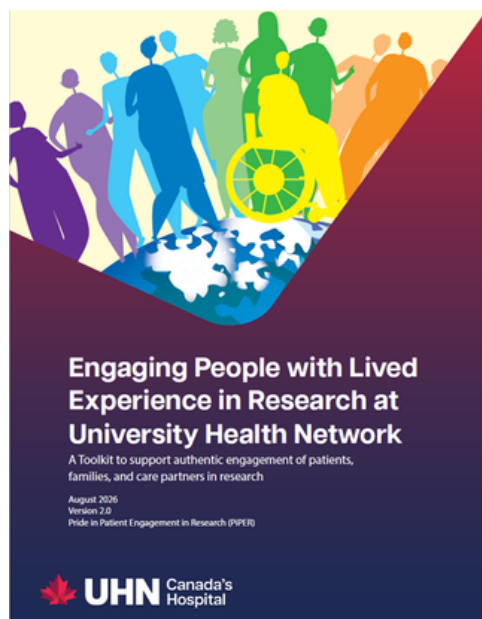


There were a total of:

120+ ATTENDEES

50+ ORGANIZATIONS REPRESENTED

PIPER TOOLKIT 2.0



What's New?

- Expanded spectrum of engagement to highlight that PLEX are driving research innovation
- Improved layout and accessibility for those with vision, hearing and mobility impairments
- Updated training resources for scientists, research staff, and PLEX partners
- A new budget planning and financial compensation section
- A new checklist for end of project considerations and planning next steps

	Inform	Consult	Involve	Collaborate	Empower	Innovate
Goal of person with lived experience	To ask questions and learn more	To give feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with scientists in all aspects of research	To make decisions and lead research activities	To create, design, and lead the development of new ideas, methods, and devices
Goal of scientist	To give information, listen, and answer questions	To seek input and feedback	To include people with lived experience as standing members of an advisory group	To partner with people with lived experience as equal team members	To follow the lead of people with lived experience and support their decisions	To support the generation of new ideas, methods, and devices

Expanded Spectrum of Engagement

Download the PDF & Word Version of the PiPER Toolkit 2.0 here!





Anna Gordon



Anna Heesters



Sylvia Langlois



Amanda Silva



Tracy McGuire



Farrah Schwartz



Gordon Myers



Jackie Bender



Joan Conrad



Janet Rodriguez



Karen Marten



Louise Brisbois



Michael Voth

The PiPER Toolkit was awarded the CIHR Inclusive Research Excellence Prize - Patient Engagement.

If you want to go fast, go alone.
If you want to go far, go together.



Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



PIPER | Pride in Patient Engagement in Research



Amanda Weston



Catherine Creven



Kierulff Scane



Philip Wong



Lauren Williams



Miranda So



Rob O'Reilly



Sumantha Engbers



Neha Dewan



Peter Athanassopoulos



Rebecca Charrow



Sowmya Bavi Kumar



Anisa Morena



Julie Vo

Special thanks to Anita and Camille for their critical review and constructive feedback!





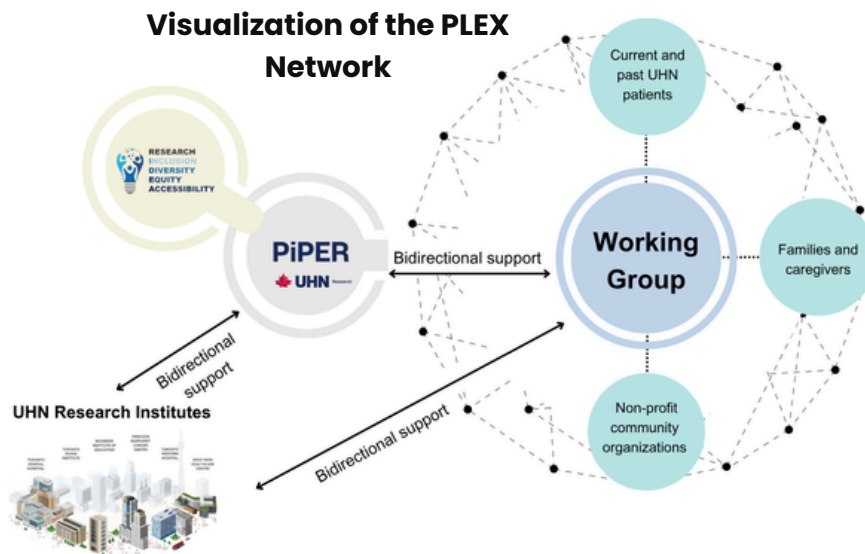
Kudos to Genevieve Groulx & Farrah Schwartz for their fabulous design work!

PLEX NETWORK FORUM

Mission: PLEX co-creating a community and resources to support patient engagement in research at UHN.

Goals:

- Start to build a PLEX community
- Collaborate to support authentic PLEX engagement
- Develop educational and other opportunities to support PLEX engagement



PLEX Working Group Members

Zahra Brown
Oksana Hlyva
Mame Awa Lajante
Paresh Jamnadas
Stuart Matan Lithwick

*Not in photo: Kathy Aston, Rachel Peiris, Miriam Bergeret

Priority 1: Connecting with Communities Excluded from Research	Priority 2: “Humanizing” Research Teams	Priority 3: Peer Support
What communities are not often engaged? • Equity-deserving groups • Socially marginalized groups • People facing accessibility barriers	Key considerations: • Cultural safety & humility • Trauma-informed engagement • Inclusion across life circumstances (e.g., ageism, caregiving, work demands) • Level the playing field (e.g., orientation sessions, plain language summaries) • Learn about Indigenous ways of knowing	What could these sessions look like? • Interactive peer-learning sessions • Informal networking (e.g., coffee chats, buddy systems) • Engaging community events outside of research settings
What challenges have you faced? • Building trust takes time • Participation barriers • Research system barriers		Suggestions for Peer Support: • Make sessions interactive • Provide captioning and ASL interpretation • Virtual coffee chats, Reddit, and Facebook communities

NEXT STEPS & OPPORTUNITIES

EVENT EVALUATION



93%

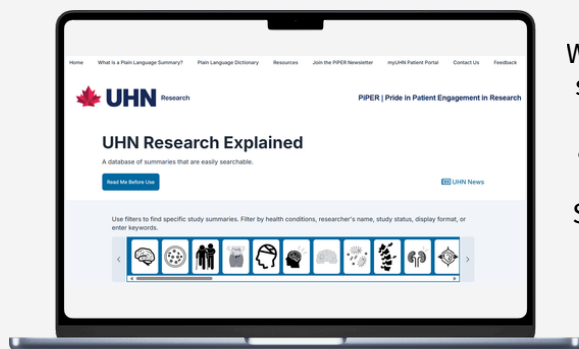
respondents met their goals for attending the event



95%

respondents felt the event was a safe and inclusive space to participate in conversations and learn from each other

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Gabriela Melo Ghisi – UHN Research Scientist pictured reviewing the Research Knowledge Ambassador Role and reviewing the new “Role in Action” section!

We want to hear from and connect with you!

www.uhnpiper.ca

piper@uhn.ca

Become a PiPER Member!

