

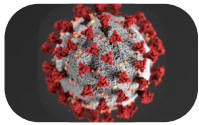


# WINTER NEWSLETTER

JANUARY 2026

Happy new year to all! As we head into the new year, we want to extend our sincere thanks to everyone who has supported our work – your continued engagement means so much. We are excited to share our updates and hope you enjoy catching up with us at HERC!

**Susan Law and Émilie Dionne, Co-Directors, HERC**



## NEW MODULES ONLINE

- **Experiences of Long COVID.** Funded by the Canadian Institutes of Health Research (CIHR). See: <https://healthexperiences.ca/long-covid/>
- **From the heart: women's experiences of heart failure.** Funded by CIHR. See: <https://healthexperiences.ca/heart-failure/>
- **Mental health and pregnancy.** Funded in part by the Royal Bank of Canada Foundation. See: <https://healthexperiences.ca/perinatal-mental-health/>

We are continuing to promote these modules through direct communications with relevant national and local organizations, healthcare professional groups and social media.

## STUDENTS & TRAINEES

We have welcomed several students (current and future) and trainees who have contributed to our research program. The first two are leading new modules with HERC!

- **Asha Ulusow** is a Research Coordinator at Women's College Hospital in Toronto and a prospective MSc student at the University of Toronto. Asha holds two grants (based at Women's College Hospital under mentorship of Dr. Mona Loutfy), entitled Harnessing Opportunities for Progress Through Patient Experience (HOPE) from the Ontario HIV Treatment Network (OHTN). She is leading, with supervision and support from HERC, a study investigating the experiences of young people living with HIV.
- **Savannah Dubé**, PhD student (co-supervised by Susan with Dr. Katie Dainty) at the School of Behavioural Health Sciences, University of Toronto. She will lead a module exploring the lived experiences of people with premenstrual dysphoric disorder in Canada, including the development of strategies for improved care. She is the recipient of three (!!) doctoral awards from CIHR, the Quebec-based FRQS, and Desjardins (financial institution in Canada).
- In 2024/2025, **Émilie Richer** joined us for a practicum placement; she was an undergraduate health sciences student at University of Western, Ontario, now starting her Master's degree in health sciences and nutrition at McMaster University. Émilie provided support for our knowledge mobilization strategy for our new HERC modules.
- Susan continues to be a mentor for an American high school student **Caitlyn Lupia**, enrolled in a high school research program. Caitlyn and her school supervisor found us through one of our perinatal mental health publications! She is focusing on perceptions and experiences of stigma in a secondary analysis of selected perinatal mental health transcripts from the HERC module.
- Susan is also an advisor for a University of Toronto medical student **Jazlyn McGuinty** who is working on a secondary analysis of women's experiences of heart failure data to explore intersectional aspects of younger women's experiences of heart failure.
- In May 2025, we enjoyed helping to host University of Oxford DPhil student **Bakita Kasadha** as a University of Toronto visiting student at the Social and Behavioural Health Sciences Division of the Dalla Lana School of Public Health.

# WINTER NEWSLETTER

JANUARY 2026



## PROPOSALS SUBMITTED FOR FUNDING

- **CIHR Project Grant** (Fall 2025). Learning from diverse peoples living with multiple sclerosis experiencing invisible symptoms in Canada. \$555,000 (3 years). Submitted October 2025. Notice of decision January 2026.
- **CIHR Project Grant** (Fall 2025). Integrating personalized risk visualization to influence health beliefs and self-management behavioural intentions in young-onset Type 2 Diabetes. \$870,000 (4 years). Submitted September 10, 2025. Notice of decision January 2026.
- **CIHR Catalyst Grant – Partnering for Impact** (Fall 2025) Designing a new community-based program for health and social care. Listening for direction from asylum seekers in Canada. Amount requested: \$124,607 (1 year). Submitted October 23, 2025. Results announced February 24, 2026.
- **SSHRC Insight Grant** (Fall 2025). Beyond the Individual: Understanding Systemic Drivers and Social Ecologies of Burnout among Diverse Canadian Health and Social Care Workers. \$375,000 (3 years). Submitted September 2025. Notice of decision April 2026.
- **MS Canada Discovery Grant** (Fall 2025). Learning from diverse peoples living with multiple sclerosis experiencing invisible symptoms in Canada. \$296,872 (2 years). Submitted October 4<sup>th</sup>, 2025. Notice of decision March 2026.

## RECYCLING DEPARTMENT!

As always, we have grants that didn't make it through so will be looking to recycle the hard work in future grant applications – on chronic pain and women military veterans, medical use of cannabis, gynaecological cancers, Ukraine refugee experiences of transition and health, and young people and death literacy.

## OTHER ACTIVITIES

- Our Japanese colleagues at DIPEX Japan asked if our Canadian team would permit the translation of our family caregiving module from English to Japanese. We are delighted that this content could be useful to others around the globe! Yes!!
- Since January 2025, a team comprised of six HEXI countries have been working together to apply to the JTC-THCS 2025 Call. An innovative, qualitative and arts-based approach was proposed to explore the impact of homecare policies on aging adults and their informal carers. Our team just recently learned that we have not been funded. We do hope, however, that our ongoing conversation over the past year will motivate us to keep working together and find another funding opportunity.
- Following the HEXI meeting in Norway, members of the Canadian and the US teams (HERC and HERN) have been meeting monthly to discuss a potential collaboration around lived experience of multiple sclerosis (MS), invisible symptoms and intersectionality. We hope to build from the US experience and recently published module on MS to develop a joint project.

# WINTER NEWSLETTER

JANUARY 2026

## HEXI INTERNATIONAL COLLABORATORS' MEETING: June 2-6, 2025, Trømsø and Sommarøy, Norway

Susan, Émilie and Fred were thrilled to attend the 2025 in-person collaborators' meeting held in northern Norway. Susan presented with Hege Andreasson on the Ukrainian refugee project and Émilie presented on the international research proposal (PI: Vinita Mahtani) submitted on enhancing community and primary care to the 2025 call from the EU Joint Transnational Call Better Care Closer to Home. We invited some Canadian colleagues working in Indigenous health research to participate in the open conference held on June 2<sup>nd</sup> in Trømsø on Indigenous health: Rani Sanderson, Director of StoryCentre Canada; Bobby Henry, Canada Research Chair in Indigenous Justice and Well-being, University of Saskatchewan; and, Chelsea Gabel, Scientific Director of the CIHR Institute of Indigenous Peoples' Health, and Associate Professor at McMaster University. We look forward to attending the next virtual collaborators' meeting in 2026, and in-person meeting in Berlin, Germany.



## WEB UPDATE

Our [healthexperiences.ca](https://healthexperiences.ca) website has had 140,443 users so far, with a total of 314,618 views across all webpages, 73% of web traffic originating through Google, with the website accessed globally, with each user viewing 2-3 pages per visit, and visits lasting 2-8+ minutes. Our web modules to date include breast cancer, family caregiving, Long COVID, heart failure in women, perinatal mental health, and patient-researcher partnerships, with additional projects, including catalyst films, posted on immigrant mental health and living with an amputation.

Our social media presence continues to demonstrate strong growth and meaningful engagement. On Instagram, we have reached 300 followers and counting, alongside a 355.6% increase in profile visits. Instagram remains our primary platform, where the introduction of Reels and bilingual posts has helped extend our reach. On LinkedIn, our followers primarily work in hospitals and health care (20.5%), higher education (14.8%), and research services (12.5%), with additional representation from government administration (3.4%) and public health (2.3%), underscoring the platform's role in professional knowledge translation. We also maintain a steady presence on X (formerly Twitter) and Facebook. We encourage readers to follow and share our content to help amplify our participants' lived experiences.

With thanks to Ryan Caulfeild and Yousra Lakhani for their support on these activities.

Follow us on social media:



# WINTER NEWSLETTER

JANUARY 2026

## HERC TEAM NEWS

**The Health Experiences Research Canada Team has grown!**

We have been delighted to welcome several new members to our national network. **Dr. Terence Tang**, General Internal Medicine physician at Trillium Health Partners has accepted the position of HERC Medical Advisor. He is also a clinician scientist with research interests in health informatics, user-centred system design and co-design, implementation and evaluation, as well as care transitions, interprofessional collaboration, AI, and compassion. We now have lead roles within our network for the Atlantic region (**Dr. Emily Gard Marshall**, Dalhousie University), Western region (**Dr. Maria Santana**, University of Calgary), and for Indigenous Health (**Dr. Rheanna Robinson**, University of Northern British Columbia). **Dr. Robert Simpson**, rehabilitation physician and clinician researcher at University Health Network and University of Toronto, has led several grant applications over the past two years with HERC for modules related to experiences of 'invisible symptoms' in multiple sclerosis and healthcare professional burnout. These individuals bring excellent track records in their own research areas, scientific leadership, and a passion for the power of personal narratives, as well as fresh ideas and terrific networks of their own that will help to expand our reach, including professional and patient connections.



Dr. Terence Tang



Dr. Emily Gard Marshall



Dr. Maria Santana



Dr. Rheanna Robinson



Dr. Robert Simpson

## PUBLICATIONS

- Minogue V, Vicary P, Law S. Chapter 2: Bridging the gap: moral and ethical issues within Patient and Public Involvement in research – tensions and dilemmas. In: John Salsberg and Virginia Minogue (Editors), Meaningful and Safe: The ethics and ethical implications of patient and public involvement in health and medical research. Ethics International Press, UK. September 20, 2024. Print Book ISBN: 978-1-80441-545-0; eBook ISBN: 978-1-80441-546-7.  
<https://ethicspress.com/products/meaningful-and-safe?INTEGRITY>
- Rennick J, Southall K, Carnevale F, Dryden-Palmer K, Patel H, Dagenais M, Buchanan F, Avery S, Razack S, St-Saveur I, Cohen E, Fontela P, Law S. Exploring care experiences and identifying practice change priorities to enhance pediatric intensive care for children with medical complexity using Experience-Based Co-Design. BMJ Open 2025, 15(5): e096181.  
<https://bmjopen.bmj.com/content/15/5/e096181.full> or <https://doi.org/10.1136/bmjopen-2024-096181>
- Montanez J, Kairy D, Gilbert M, Gulino N, Ormel I, Pytka-Jones R, & Law S. (2025). "I would not want my leg back": Living experiences of adult amputees following intensive functional rehabilitation. Rehabilitation Psychology. Advance online publication. <https://doi.org/10.1037/rep0000617>
- Hoosein S, Winchester P, Babinski S, Smith N, Bahvsar P, Law S. An exploratory qualitative study of perinatal experiences in an acute setting during early phases of the COVID-19 pandemic. Patient Experience Journal 2024; 11(3): 85-96. <https://doi.org/10.35680/2372-0247.1896>.



# WINTER NEWSLETTER

JANUARY 2026

## CONFERENCE PRESENTATIONS (students underlined)

- Law S, Gould G, Krowlikowski K, Senese D, Graves L, Riley J, Macarthur C. Learning for learning health systems: an environmental scan of training opportunities in Ontario, Canada. International Conference on Integrated Care, April 13-15, 2026, Birmingham UK. Submitted as oral presentation October 17<sup>th</sup>, 2025. Notice of decision December 20<sup>th</sup>, 2025.
- Whitney C, Grob R, Mahtani-Chugani V, Dixon S, Law S. Beyond “Passing the Tissue Box”: Navigating the ethical landscape of “empathetic load” in qualitative research through compassionate action. Submitted to the 2026 World Congress of Bioethics, July 8-10<sup>th</sup>, 2026, Johannesburg, South Africa.
- McGuinty J, Mansfield E, Tang T, Law S. Understanding the lived experiences of young women with heart failure in the Canadian healthcare system. CSIM/ACP Atlantic Provinces Chapter 2025 Meeting, October 15-17, Halifax, Nova Scotia. Poster presentation.
- Law S, Ormel I, Lypovsky A, Montanez J, Southall K, Makarenko D, Naumova D, Smith L. Learning from the experiences of Ukraine refugees in Canada – an initiative to train qualitative researchers and conduct pilot interviews with refugees in Canada. Oral presentation at the North American Refugee Health Conference (NARHC), Niagara Falls, ON. September 11-13, 2025.
- Law S, Dionne E. Engaging arts students. Oral presentation at 2024 Virtual DIPEX International Collaborators’ Meeting. November 26, 2024.
- Law S, Smith L, Breuning M. DI International Collaborations – Medical Cannabis and Chronic Pain. Oral presentation at 2024 Virtual DIPEX International Collaborators’ Meeting. November 26, 2024.
- Lannon H, Sandercock J, Marcinow M, Nie J, Law S. From the heart: Canadian women’s experiences of heart failure. Poster presented at the 2024 Canadian Cardiovascular Congress, Vancouver BC. October 2024.
- Macarthur C, Law S, Graves L, Krowlikowski K, Gould G, Senese D, Riley J. Learning for Learning Health Systems. Oral presentation to the OSSU Learning Health System Working Group. October 11, 2024.
- Law S, Rozmovits L, Marcinow M, Ormel I, Reid R, Hayes A, Pindera L, Gutnick D, Patino A, Curran J, Tang T, Mansfield E, Kuluski K, Marwaha S, Dionne E. Living with Long COVID. Learning from lived experiences to inform patients, policy and practice. Poster presented at the 2024 Long COVID Web Symposium, Edmonton AB, October 1-4, 2024.
- Christopoulos T, Décarý S, Senese D, Krowlikowski K, Gould G, Giannarakos A, Law S. What has been the health system response to organize care delivery for people living with Long COVID/Post-COVID Condition (PCC)? A scoping review. Poster presented at the 2024 Long COVID Web Symposium, Edmonton AB, October 1-4, 2024.
- Macarthur C, Law S, Graves L, Krowlikowski K, Gould G, Senese D, Riley J. Learning for Learning Health Systems. Oral presentation to the OSSU Training and Capacity Development Working Group. July 15, 2024.
- Nunes da Silva J, MacDonald S, Law S, Gopaul U, Bayley M, Munce S. Influences of sex and gender-related variables on willingness to participate in stroke research studies. Poster presentation at the Rehabilitation Sciences Institute's Research Day. Toronto, Ontario, Canada. May 30, 2024. Award: Research Excellence Award from Rehabilitation Sciences Institute – related to the project as a whole and what Juliana has achieved with it.

## HEALTH EXPERIENCES INTERNATIONAL

The international collaboration that has been known as DIPEX International (DIPEX was the acronym for the Database of Individual Patient Experience) has been renamed to Health Experiences International, with new web link: <https://healthexperiencesinternational.org/>



healthexperiences.ca  
experiencesante.ca

# WINTER NEWSLETTER

JANUARY 2026

## CONTACT US

To join our network or to suggest ideas for future research activities: please write to Susan Law [[susan.law@utoronto.ca](mailto:susan.law@utoronto.ca)] or Émilie Dionne [[emilie.dionne3.ciussscn@ssss.gouv.qc.ca](mailto:emilie.dionne3.ciussscn@ssss.gouv.qc.ca)], co-directors, HERC.

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sponsors and collaborators!**



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