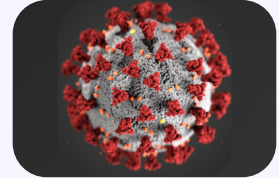


HEALTH EXPERIENCES RESEARCH CANADA SUMMER NEWSLETTER

CURRENT MODULES

Three modules are near completion to be launched this year:

1. Experiences of Long COVID. Our module on experiences of long COVID, funded by the Canadian Institutes of Health Research (CIHR), will be launched this summer (Linda Rozmovits and Michelle Marcinow), based on 42 interviews with adults across 8 provinces and territories. We received a secondary grant from another CIHR-funded project to conduct interviews with decision makers responsible for leading service changes for long COVID in provinces and territories across Canada.
2. 'From the heart': women's experiences of heart failure. This CIHR-funded module is also in the final preparatory stages to launch this summer (Heather Lannon, Jane Sandercock, Jason Nie and Michelle Marcinow), based on 30 interviews with women across 7 provinces.
3. Mental health and pregnancy. We have now completed 32 interviews across 4 provinces about experiences of mental health problems during and after pregnancy (Ilja Ormel and Ana Keller). Analysis will be completed in the coming months and we will secure additional funding to prepare and launch a module.



OTHER PROJECTS INVOLVING PERSONAL EXPERIENCES

- Medical cannabis and chronic pain. Our team has been involved in a few medical cannabis-related initiatives. The narrative synthesis on patient experience of medical cannabis has now been resubmitted – with huge thanks to Martina Breuning (Germany) for taking the lead on this one, and to Jason Nie for stellar support! Lorraine Smith (AU) and Susan received two University of Sydney – University of Toronto collaboration awards to conduct focus groups, interviews and symposia with stakeholders in each of our countries. We note that (perhaps coincidentally) the recent report of the federal expert review of the Canadian Cannabis Act seems VERY well aligned with the recommendations of our Fall 2023 roundtable. We have been inspired to resubmit our proposal for a module on patient experience of using medical cannabis for chronic pain – likely Fall 2024.
- Transitions and health during war: experiences of Ukrainian refugees. Our team helped to organize (with Lorraine Smith and Joel Montanez) a training initiative to support qualitative researchers interviewing people from Ukraine displaced due to war (planning a follow-up perhaps Fall 2024). With special thanks to our Ukrainian partner organizations and Alona Lypovsky (student with lived experience who provided essential contextual and cultural background for this session). We received a small grant to conduct five interviews for the pilot study of Ukrainian refugees, data collection is complete and analysis in process.
- Pregnancy and birth during COVID. Susan supported a small hospital-based project on patient experience of birth during COVID, led by first-time nursing researchers. Paper has been accepted for publication.
- Experience-based co-design in paediatric intensive care. Susan is a co-investigator on an experience-based co-design project and is transitioning to PI. A challenging but insightful project!
- Experiences of rehab personnel caring for patients in a COVID-19 hot zone. (Susan, Dahlia Kairy, Joel). Data analysis underway by 2 graduate students (Rosemarie Boudreau and Rebecca Benyk).
- Sharing the lessons of a lifetime with an orphan disease during the process of assisted dying. Joel, Nicolas Gulino. Recruiting.
- Sharing family experiences during the process of assisted dying. (Rosemarie, Joel). Project accepted as part of Rosemarie's Individualized Master's Program.

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UNSUCCESSFUL PROPOSALS

As always, we are learning from our unsuccessful attempts to obtain funds for health experiences initiatives. In 2023/24, we wrote grants which ranked well but not high enough to receive funding from granting agencies on women's experiences of gynaecologic cancers, using arts-based approaches for conversations on dying and death with young adults, and experiences of Ukraine refugees of transition and health. Try, try again!!

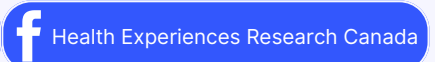
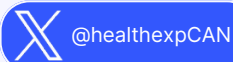
IN THE WORKS

We are developing a proposal for a module on women veterans' experiences of chronic pain to submit June 2024 (led by [Émilie Dionne](#)). We are planning to develop a proposal to obtain network/infrastructure funding for Health Experiences Research Canada, and to resubmit a medical cannabis and chronic pain proposal. Together with DI colleagues from eligible countries – Germany ([Christine Holmberg](#) and [Luisa Wagenschwanz](#)), UK ([Sue Ziebland](#), [Lisa Hinton](#) and [Anna Dowrick](#)), Japan ([Rika Sato](#), [Rie Toyomoto](#), [Ryoko Hatanaka](#), [Setsuko Sugano](#), and [Takuya Matsushige](#)), and our Canadian team ([Susan Law](#), [Ilja Ormel](#), [Matthew Hunt](#), and [Kenneth Southall](#)), an application was submitted to the ORA8 opportunity to explore how social scientists can better collaborate across countries in times of public health crises. Funding decisions in September 2024. Fingers crossed!

WEB AND SOCIAL MEDIA UPDATES

Since 2018, over 125,000 people have accessed our web site, with about 6,400 users in 2024 so far. The majority of people visiting healthexperiences.ca appear to be based in France (interestingly!), with significant numbers from Canada and the United States. Since January 2024, our website has accrued over 15,000 pageviews and has been accessed from 121 countries around the world. Our social media presence, particularly on Instagram, has seen remarkable growth and engagement over the past year. We've experienced an 835% increase in impressions (views) and a massive surge in the number of accounts reached (+4,533%). Engagement has also soared, with a 200% increase from non-followers and a 120% increase from followers. Our Instagram followers are predominantly female (80%), aged 35-44, with a strong presence across Canada, and from the US, Brazil, the UK, and France. Currently, we have 266 followers on Instagram and counting! On LinkedIn, a singular repost by a team member sharing content from the Health Experiences page garnered 1,674 impressions, showcasing the potential of cross-platform promotion - an initiative we will explore further as we refine our social media strategy. We have also been resharing our work through the DIPEX LinkedIn page, which has helped increase impressions for our LinkedIn content. Instagram remains our primary platform, and we also maintain an active presence on Facebook, Twitter, and LinkedIn. Introducing Reels and short-form video content has significantly boosted our reach on Instagram. Additionally, we have started posting content in both English and French on Instagram and Twitter to broaden our reach and inclusivity. We encourage any/all to follow us on Instagram, Facebook, Twitter, and LinkedIn to stay updated with our work! With thanks to [Ryan Caulfeild](#), [Yousra Lakhani](#), and [Graham Gould](#) for their stellar support on these activities.

Follow us on social media:



DIPEX INTERNATIONAL COLLABORATORS MEETING, Czechia

[Heather Lannon](#) and [Susan Law](#) attended the 2023 DI meeting in beautiful Czechia. Susan presented with [Lorraine Smith](#) on the development of the training session for the Ukrainian refugee project, Susan presented on the session organized with Canadian journalists on lessons for qualitative researchers and, Heather presented on our progress with the heart failure project.

HEALTH EXPERIENCES RESEARCH CANADA SUMMER NEWSLETTER

HERC TEAM UPDATES

WELCOME TO OUR NEW TEAM MEMBERS:



Émilie Dionne
Co-Director



Kenneth Southall
Research Associate



Jane Sandercock
Research Associate



Fredrick Vokey
Research Professional



Rosemarie Boudreau
Student - Bishop's U



Kayla Krolikowski
Student - Western U



Graham Gould
Student - Western U



Daniela Senese
Student - Western U



Maxime Gilbert
Student - Bishop's U



Rebecca Benyk
Student - Bishop's U



Alona Lypovsky
Student - Bishop's U

Welcome to Jane Sandercock, Research Associate, who has joined us to support the analysis and publication of our heart failure module, as well as to Kenny Southall, Research Associate, working to support our work with Ukrainian refugees. Most recently, Fredrick Vokey, Research Professional at Université Laval joins us as part of Emilie's team (see below). Michelle Marinow has been on maternity leave – congrats on the arrival of her baby boy Max! In the Fall of 2023, our team welcomed three undergraduate students for their practicum in their final year of health studies at the University of Western Ontario – Graham Gould, Kayla Krolikowski, and Daniela Senese. They have been helping with our social media, literature reviews for various projects, the medical cannabis project, and a review of patient engagement training initiatives in Ontario. A very special welcome to Emilie Dionne who has been a member of various project teams and has officially joined Susan as Co-Director of Health Experiences Research Canada. Emilie is a sociopolitical scientist, feminist thinker, and qualitative health researcher at the VITAM Research Centre in Sustainable Health (Centre de recherche en santé durable) in Quebec City, and adjunct professor in the Department of Sociology at Université Laval. Her research interests include person-centred care, ethics of vulnerability, critical qualitative methodology, feminist bioethics, participatory action research. Wonderful to welcome Emilie to the leadership for HERC – we have many plans in the making for the future of our team and work, so stay tuned.

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SELECTED CONFERENCE PRESENTATIONS – 2023/24

- Nie JX, Smith L, Clark H, Kalocsai C, Schwartz R, Smith N, Gould G, Law S. Access to medical cannabis in Canada: exploring policy, clinical and patient advocacy perspectives. Poster presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.
- Law S, Lypovsky A, Montanez J, Ormel I, Smith L. Interviewing people with traumatic experience: an approach to preparing qualitative researchers for an international Ukrainian refugee project. Oral presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.
- Nie JX, Smith L, Clark H, Kalocsai C, Schwartz R, Smith N, Gould G, Law S. Access to medical cannabis in Canada: exploring policy, clinical and patient advocacy perspectives. Poster presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.
- Gilbert M, Law, S., Dahlia K, Pytka-Jones R, Ormel I, Montanez J. "I would not want my leg back": Living Experiences of Adult Amputees. A Pilot Study. Poster presentation. March 2024.
- Law S, Lypovsky A, Montanez J, Ormel I, Smith L. Interviewing people with traumatic experience: an approach to preparing qualitative researchers for an international Ukrainian refugee project. Oral presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.
- Sandercock J, Lannon H, Nie JX, Marcinow M, Montague J, Ratz, J, Law S. From the heart: Canadian women's lived experiences of heart failure. Oral presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.
- Law S, Rozmovits L, Christopoulos T, Weeks L, Cheung A, Gibbens M, Décary S. Improving health system design for people with long COVID or Post-COVID Condition: perspectives and experiences of change leaders in Canada. Oral presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.
- Ganty P, Ware M, Busse J, Law S. The role of cannabinoids in current pain practice and future implications. Panel presentation at the 2024 Canadian Pain Society Annual Symposium. Ottawa, Ontario, Canada. May 27-30, 2024.
- DIPEX International Collaborators Meeting 2023. From the heart: Canadian women's lived experiences of heart failure. Lannon H, Law S. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.
- DIPEX International Collaborators Meeting 2023. Interviewing people with traumatic experience - Refugee project: Experiences of Ukraine displaced persons due to war. Law S, Smith L. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.
- DIPEX International Collaborators Meeting 2023. Are there lessons for qualitative researchers from journalists? Law S. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.
- DIPEX International Collaborators Meeting 2023. The persistence of stigma in the lived experiences of people using medical cannabis: a scoping narrative review of the qualitative literature. Breuning M, Nie J, Schlesinger M, Smith L, Lavie-Ajayi M, Babinski S, Law S. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.
- Public Health Palliative Care International Conference 2024. Using narrative data to engage young adults in conversations about dying and death. Smith, K., Law, S., Blanchard, P., Widger, K., & Stajduhar, K. October 2024, Switzerland. Accepted.
- University of British Columbia Women's Health Trainee Research Conference. From the heart: Canadian women's experiences of heart failure. Lannon H, Marcinow M, Nie J, Wright D, Law S. Virtual conference, June 14, 2023. Poster presentation.
- Canadian Association of Perinatal and Women's Health Nurses (CAPWHN) National Conference. A qualitative study of the lived experiences of pregnant persons during the early phases of the COVID-19 pandemic. Hoosein S, Winchester P, Smith N, Law S. Winnipeg, Manitoba, April 27-28, 2023. Poster presentation. Research Week. Bishops University, March 2024.



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PUBLICATIONS – since previous newsletter (students underlined)

- Breuning M, Nie J, Schlesinger M, Smith L, Lavie-Ajayi M, Babinski S, Law S. The persistence of stigma and other challenges in the lived experiences of people using medical cannabis: a thematic synthesis of the qualitative literature. Submitted to *Journal of Psychoactive Drugs* May 23, 2024.
- Montanez J, Dahlia K, Gilbert M, Ormel I, Gulino N, Pytko-Jones R, Law S. "I would not want my leg back": Living experiences of adult amputees. Submitted to *Rehabilitation Psychology*, March 17, 2024. Revisions requested May 2024.
- 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. Submitted to the *Journal of Patient Experience* October 20, 2023. Accepted for publication with minor revisions May 14, 2024.
- Marcinow M, Sandercock J, Cadel L, Singh H, Guilcher S, Dowedoff P, Maybee A, Law S, Fancott C, Kuluski K. A qualitative study exploring how patient engagement activities were sustained or adapted in Canadian healthcare organizations during the COVID-19 pandemic. *PLOS ONE* 2023, 18(3): e0282890. <https://doi.org/10.1371/journal.pone.0282890>
- Macarthur C, Van Hoorn R, Lavis J, Straus S, Jones N, Bayliss L, Terry AL, Law S, Victor C, Prud'homme D, Riley J, Stewart M. Training and capacity development in patient oriented research: Ontario SPOR SUPPORT Unit (OSSU) initiatives. *Res Involv & Engagem* (2023) 9:5. <https://doi.org/10.1186/s40900-023-00415-8>
- Maclean A, Hunt K, Brown A, Evered JA, Dowrick A, Fokkens A, Grob R, Law S, Locock L, Marcinow M, Smith L, Urbanowicz A, Verheij N, Wild C. Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: validated, diverted and rejected candidacy. *Social Science & Medicine – Qualitative Research in Health* 2023: 100207. <https://doi.org/10.1016/j.ssmqr.2022.100207>
- Rozmovits L, Marcinow M, Ormel I, Tang T, Mansfield E, Kuluski K, Marwaha S, Law S. Living with long-COVID in the community during the first wave of the pandemic: Lessons for healthcare providers and policy makers. *Patient Experience Journal* 2023; 10(1): 115-123. doi: 10.35680/2372-0247.1714.
- Charlebois K, Law S. Optimizing the discharge process from internal medicine: understanding the challenges faced by clinicians and staff. *Health and Social Care in the Community*, 2022; 00, 1-10. <https://doi.org/10.1111/hsc.14023>
- Rennick J, Buchanan F, Cohen E, Carnevale F, Dryden-Palmer K, Fontela P, Patel H, Razack S, St-Saveur I, Law S. Towards enhancing Pediatric Intensive Care for Children with Medical Complexity (ToPIC CMC): A mixed methods study protocol using Experience-Based Co-Design. *BMJ Open*, 2022; 12:e066459. <http://dx.doi.org/10.1136/bmjopen-2022-066459>

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