



## *March 2024 Newsletter*

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### **Patient partner spotlight: Linda Wilhelm**

My journey as a patient partner journey began in 1983 when at the age of 23, with a one-year-old and expecting my second child, I received a diagnosis of Rheumatoid Arthritis (RA). In 1987, after the birth of my daughter, my rheumatologist told me I would be in a wheelchair within ten years. He was wrong, it took twelve years. From my hospital bed, I began advocating for myself for access to a new medication not yet approved by Health Canada. I was given special access to etanercept and walked out of the hospital less than two weeks later. For the next six years, I had surgery every six months to repair the damage from RA. I realized how important research was for good healthcare decision-making and that patients needed to be involved if the right research questions are going to be answered; research that can change lives for people like me.

I became involved with The Canadian Arthritis Research Network who were ahead of their time and had integrated patients into every aspect of the network. When the cycle of funding for the network had finished, the Strategy for Patient-Oriented Research (SPOR) was being created and I was one of the patients engaged in developing their framework for patient engagement. In 2016, I joined the SPOR Chronic Pain Network and in 2018 the SPOR

Evidence Alliance. While my journey as a patient partner in research began twenty years prior, in 2019 I saw an advertisement for expression of interest for the Center for Research in Integrated Care and applied. I was accepted as a patient partner for PriCare, a research project looking at delivering case management in primary care for patients with complex needs. More recently I have been co-facilitating training for researchers and patients on patient-oriented research and patient engagement. I have been involved in several roles informing the government of patient priorities in healthcare, including as a former board member for a regional health authority and a member of the Department of Health former Surgical Services Advisory Committee in addition to roles on several Health Canada Advisory Committees. It is so exciting to see the amount of research happening in New Brunswick compared to twenty years ago and to see the increase of patient engagement with more patient partners engaged.

### **Project Spotlight**

#### *Patient Partner Compensation & EDI*

Health research in Canada is increasingly moving towards engaging patients in research. However, to achieve meaningful patient-oriented research, many factors need consideration, including compensating patients for their time and out of pocket expenses. The literature discusses barriers to patient partner compensation; however, much of this information does not examine the intersection between compensation and equity, diversity, and inclusion (EDI). Indeed, compensation procedures can limit inclusion for women, people of colour, and individuals with disabilities as well as Indigenous peoples and those living in low income, among others. This research aims to help fill this knowledge gap. A qualitative descriptive design is being used. Study participants will include prospective or current patient partners; academic health researchers; individuals from funding agencies; and university administration and finance representatives. Maximum variation sampling is being used to recruit a diverse sample. Participants are being asked to complete a short survey and to participate in a virtual focus group or interview. This study will help inform ways to improve patient engagement and inclusion in Canada. This in turn will help improve the outcomes for patients. Recruitment is ongoing, if interested, please reach out to [Samantha Fowler](#).

### **Staff Spotlight**

Poppy Jackson is a research assistant at the Centre for Research in Integrated Care (CRIC) and a PhD student in political science at York University. She began working at CRIC as an undergraduate student in 2018 and has continued working on a variety of projects on a part-time basis and during the summers throughout her studies. Poppy has primarily worked on scoping reviews, as well as projects related to arts-based knowledge translation strategies. Currently, she is working on a scoping review titled, [“Using Theater as an Innovative Knowledge Translation Approach for Health Research.”](#) The protocol for this project was recently published online through JBI Evidence Synthesis.

While Poppy’s graduate research is focused on international political economy and labour migration, she has enjoyed her continued work at CRIC in health research and the opportunity to continue learning and improving upon research skills, many of which have been relevant to her own studies. Through her time at CRIC, Poppy has received the opportunity to attend and present at conferences, lead projects, and mentor other students, among other things. She looks forward to continuing her work at CRIC and to keep working on professional and research skill development!



**Good News**



We would like to highlight one of our graduate students Jayda Veinot. At this year's All-Canadian awards banquet held in Edmonton, Jayda was named the winner of the Nan Copp Trophy as U SPORTS women's basketball player of the year. This is the first time someone from UNB, or any other NB university, has won this award! Congratulations Jayda!



## Upcoming Events

### QUEST - March 20th, 2024.

Join Dr. [Victoria Clarke](#) as she presents, *Introduction to reflexive thematic analysis*.

This presentation will be an opportunity to learn from and engage with an international expert on qualitative methods and thematic analysis. This promises to be an exciting introduction to the reflexive thematic analysis approach developed by Virginia Braun and Victoria Clarke! Reflexive thematic analysis offers qualitative researchers a flexible and open approach to qualitative data analysis - centering researcher subjectivity and conceptualising this as a resource for research. To become a member of the QUEST network,



please e-mail [quest-sj@unb.ca](mailto:quest-sj@unb.ca). To learn more or watch our previous events, please visit our [QUEST website](#). [Register now for this QUEST event!](#)

### **Canadian Healthcare Navigation Conference (CHNC) - May 1-2nd, 2024.**

The 4th Canadian Healthcare Navigation Conference will be held virtually on **May 1-2, 2024**, over two half days. The theme of our fourth annual conference is **Innovations in Healthcare Navigation**. [Registration is now open](#).

Individuals with lived experience are eligible to apply for a registration subsidy. There is also a discount for groups of 10 or more. Limited spots are available, contact us for details.

### **Patients Den - October 8th, 2024.**

The 2024 Patients' Den event will be held at Lilly Lake Pavilion in Saint John. This event will feature presentations from researchers vying for research awards up to \$5,000. Winners will be chosen by a panel of patient partner judges.

## **Recent Publications**

Doucet, S., Légère, K., Luke, A., & Goudreau, A. (2024). Barriers and facilitators for engaging in the practice of medical assistance in dying among providers in Canada: A scoping review protocol. *JBI Evidence Synthesis*, 22(2), 273-280. [DOI: 10.11124/JBIES-22-00278](https://doi.org/10.11124/JBIES-22-00278).

Légère, K., Luke, A., & Doucet, S. (2024). Mapping the landscape of medical assistance in dying through exploring barriers and facilitators among providers in Canada. *JBI Evidence Synthesis*, 22(2), 155-156, [DOI: 10.11124/JBIES-24-00026](https://doi.org/10.11124/JBIES-24-00026).

Hudon, C., Lambert, M., Aubrey-Bassler, K. et al. (2024). Fostering collective leadership to improve integrated primary care: Lessons learned from the PriCARE program. *Arch Public Health*, 82, 24. <https://doi.org/10.1186/s13690-024-01258-9>

Nguyen, L., Pozniak, K., Strohm, S., Havens, J., Dawe-McCord, C., Thomson, D., Putterman, C., Arafeh D, Galuppi B, Via-Dufresne Ley, A., Doucet, S., Amaria, K., Kovacs, AH., Marelli, A., Rozenblum, R., Gorter, J.W. on behalf of the CHILD-BRIGHT READYorNot™ Brain-Based Disabilities Trial Study Group. (2024). Navigating meaningful engagement: Lessons from partnering with

youth and families in brain-based disability research. *BMC*, 10(17), 1-13. <https://doi.org/10.1186/s40900-024-00543-9>

Balcom, S., Doucet, S., & Dube, A. (2024). Registered nurses and practical nurses working together: An institutional ethnography. *Journal of Qualitative Health Research*, 11(00), 2333-3936. <https://doi.org/10.1177/23333936231225201>

Jackson, P., Luke, A., Goudreau, A., & Doucet, S. (2024) Using theater as an innovative knowledge translation approach for health research: a scoping review protocol. *JBIE Evidence Synthesis*, 22(1), 2689-8381. [DOI: 10.11124/JBIES-23-00312](https://doi.org/10.11124/JBIES-23-00312)

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