

Taking an alternative path in (self) research: a discussion with case studies and examples about responsible self-research and other non-traditional pathways to do research as a patient.



Alex Haagaard

Alex Haagaard is a design researcher who specializes in disability-inclusive UX and digital service design. They earned their Master of Design from OCAD University in Toronto, studying knowledge gathering practices of emergency medical professionals for the purposes of healthcare information design. During this time, they also increasingly struggled with what one doctor derisively described as "a myriad of nonspecific symptoms," which made publishing and networking as an early career researcher challenging. In 2016, they began to work full-time pursuing a diagnosis and medical care, an experience which they describe as the "world's worst paying, least prestigious design research fellowship." After two years of fighting to access care, they realized that if they wanted effective treatment, they would have to make it themselves. Researching the neurophysiology of histamine and identifying novel plant-based compounds, they successfully produced their own sleep cycle in 2018.

Since then, they have been working with companies to develop and advocate for accessible design processes, including neglected modes of accessibility experienced by people with chronic pain and illness. They also work as a patient advocate and currently co-chair the Chronic Pain Network's Knowledge Mobilization and Implementation Science committee.



Dana Lewis

Dana Lewis founded the open source artificial pancreas movement (known as "OpenAPS"), making safe and effective automated insulin delivery (AID) technology available (sooner) for people with diabetes around the world. She authored the book, "Automated Insulin Delivery: How artificial pancreas "closed loop" systems can aid you in living with diabetes", to help more people understand automated insulin delivery systems, in addition to a series of children's books such as "Understanding Automated Insulin Delivery: A basic book for kids, family, and friends of people living with diabetes". She is now an independent diabetes researcher and her peer-reviewed publications have been cited more than 1,500 times in the last five years.



Sara Riggare

Sara Riggare (MSc, PhD) is a patient leader and patient researcher at Uppsala University in Sweden. She has made it her mission to bring patients, researchers, healthcare, industry, and policymakers closer together to improve health for all. Sara has been living with Parkinson's disease for over 35 years and her research is focused on personal science, self-tracking, Quantified Self, and patient-led research. Sara develops models for selfcare in chronic disease based on her own experiences from managing Parkinson's disease.

Moderated By

Trudy Flynn



Trudy Flynn is a medically retired Nurse from Nova Scotia. She was diagnosed with Fibromyalgia over 31 years ago. She controls her Fibromyalgia with exercise, is a long distance runner and follows the slow but steady mantra. Trudy started being involved in research as part of a Clinical Trial in 2009 through the Nova Scotia Pain Clinic, which led to her first experience with actual Patient Engagement in 2014 as part of the steering committee for the CIHR – James Lind Alliance Adult Fibromyalgia Priority Setting Partnership. Trudy was a Patient Representative at the Canadian Pain Summit in Toronto in September, 2014 and it was at this Summit, listening to Researchers that Trudy realized how important Knowledge Translation and Patient Engagement were to making research relevant to the community the research is supposed to serve. As a result of this realization Trudy became a Research Ambassador for CIHR – IMHA and later a Patient Engagement Research Ambassador (PERA).

In 2017, Trudy coauthored a paper published in the Canadian Journal of Pain, called "A paradigm change to inform Fibromyalgia research priorities by engaging patients and health care professions". In 2018 Trudy wrote about her James Lind experience in an article titled "The James Lind Alliance: Identifying the Top 10 Canadian Research Priorities for Fibromyalgia – a Patients Perspective" for the CIHR website. In 2019 Trudy was a key contributor for the Fibromyalgia Section of the IMHA Online Resource Library.

In 2019 Trudy joined the Maritime SPOR Support Unit (MSSU) to help promote and participate in Patient Engagement in the Maritime Provinces, where she is currently the Co-Chair of the Patient Public Partner Council and serves on many MSSU committees.

In 2021 Trudy helped establish Fibromyalgia Association Canada (FAC), a nationwide organization led by people with fibromyalgia for people with fibromyalgia. Trudy is currently the Chair of the Board of Directors at FAC.