

Leading the way as a patient partner in research: examples of and tips and resources for patient-led research.



Sneha Dave

Sneha graduated from Indiana University in May 2020 where she majored in chronic illness advocacy as well as journalism. She created Generation Patient and its program the Crohn's and Colitis Young Adults Network (CCYAN) to develop support systems for adolescents and young adults with chronic conditions across the U.S. and internationally. She is proud to work with a team composed entirely of young adults with chronic conditions and also to keep Generation Patient and CCYAN independent from the pharmaceutical and insurance industries. Sneha has completed an undergraduate research fellowship in health policy at Harvard T.H. Chan School of Public Health. She has also interned at numerous places such as Pfizer in health economics and outcomes research for Inflammation and Immunology.

Sneha has spoken on Capitol Hill, featured nationally on C-SPAN, and is a past contributor for U.S. News and World Report. She has served on the Democratic National Committee Disability Policy Subcommittee and recently joined the Midwest Comparative Effectiveness Public Advisory Council, an independent appraisal committee of the Institute for Clinical and Economic Review. She also serves on the FDA Patient Engagement Collaborative and in a grantmaking committee with the Robert Wood Johnson Foundation. Sneha was awarded two academic fellowships with the Association of Health Care Journalists. For her work, she was selected as one of the most influential teenagers in 2018 by the We Are Family Foundation and was recognized as an American Association of People with Disabilities Emerging Leader in 2020.



Hannah Wei

Hannah Wei is a co-founder at the Patient-Led Research Collaborative, an international organization of Long-COVID patient-researchers and advocates at the forefront of the Long COVID patient-led movement.

Since the beginning of the pandemic, PLRC has brought together an interdisciplinary team of patients with backgrounds in medicine, neuroscience, participatory design, public policy, cognitive science, research engineering, data science, biostatistics, virology, psychiatry, neurology, pediatrics, and social epidemiology. We have collaborated with the Long COVID taskforce at the WHO, CDC and co-authored over a dozen papers, including the paper on Characterizing long COVID in an international cohort: 7 months of symptoms and their impact published in the [Lancet](#).

Hannah's background is in computer science and leading data-driven products for the technology industry. Before the pandemic, Hannah was running field research in frontier communities of West Africa and Southeast Asia for product innovation teams at Fortune 500 tech companies. She became a Long COVID patient after getting infected on an airplane in March 2020. Since then, she has dedicated her efforts to running projects PLRC and innovating on the patient-led research model.

Website: patientledresearch.com

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Moderated By



Linda Hunter

Linda Hunter is a retired executive health care leader and nurse who has worked locally, nationally, and internationally in healthcare over the last 35 years. Linda has worked with seniors in three long term care homes in Ontario – including two rural homes. She has spinal stenosis, osteoarthritis, fibromyalgia, and severe degenerative disc disease and has lived with chronic pain for over 15 years. Linda is a CIHR Patient Engagement Research Ambassador (PERA) for the Institute of Musculoskeletal Health and Arthritis with the Canadian Health Research Institutes (CIHR) and is a member of the Institute's Advisory Board. She co-developed online educational modules for patients and researchers about Patient Engagement in Research – available through CIHR-IMHA. Linda also is a Board member of the Canadian Arthritis Patient Alliance (CAPA) and is a member of the Fibromyalgia Association of Canada's Research and Education Committees.

Linda is an Essential Caregiver to her Mum, who lives with dementia, and is an executive member of the Friends and Family Council at her Mum's LTC Home.

Linda states: "It is vital that the patient voice is respected, listened to, and incorporated into change in the delivery of health care services, including research. Patients are experts about their disease and the lived experience. They are becoming more informed and knowledgeable, and it is imperative that they are included in the development of plans of what is researched." Linda is a Patient Co-Investigator for the Clinical Trails Training Platform research grant funded by CIHR called CanTrain and is the national Co-Chair of the Patient, Family and Community Member Working Group.