TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

Rehabilitation Science
Research Network
for COVID

Rehabilitation Science Research Network for COVID
2025 International Forum on COVID Rehabilitation Research

Friday April 25, 2025
500 University Avenue, Room 140 & Online (Zoom)
Rehabilitation Sciences Building
University of Toronto
Toronto, Ontario

ACKNOWLEDGEMENTS

The Rehabilitation Science Research Network for COVID is funded by Temerty Faculty of Medicine, University of Toronto. The 2025 International Forum on COVID Rehabilitation Research is supported by the Canadian Institutes of Health Research and presented in collaboration with Long COVID Physio, Fisiocamera, and Long COVID Web.

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PATIENT-LED
RESEARCH
COLLABORATIVE

LONG
COVID
PHYSIO

FISIO
CAMERA

LONG COVID WEB

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

UHN Toronto Rehabilitation Institute

REHABILITATION SCIENCES INSTITUTE
UNIVERSITY OF TORONTO

Speech-Language Pathology
UNIVERSITY OF TORONTO

Occupational Science
& Occupational Therapy
UNIVERSITY OF TORONTO

Physical Therapy
UNIVERSITY OF TORONTO

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Welcome to the 2025 International Forum on COVID Rehabilitation Research!

On behalf of the organizing committee, we are pleased to welcome you to the **2025 International Forum on COVID Rehabilitation Research**. Over 170 participants and presenters from over 15 countries, including people with lived experiences, health care professionals, researchers, and representatives from community organizations with an interest in COVID rehabilitation will be attending this event. Working together, we aim to advance rehabilitation science, practice, and policy to enhance the well-being of people affected by COVID and their families.

This Forum, hosted by the Temerty Faculty of Medicine **Rehabilitation Science Research Network for COVID,** aims to facilitate knowledge transfer and exchange (KTE), collaborations and partnerships in COVID rehabilitation research and practice. The Forum is an international collaboration with multiple partners and members of the Network who have been instrumental in advancing evidence and practice in COVID rehabilitation.

We are delighted to count community leaders, clinicians, trainees, and researchers amongst the Forum participants, who are champions in this evolving area of research and practice.

We look forward to hearing from over 25 speakers from Canada, the United States, and the United Kingdom who have dedicated their time and expertise to sharing recent emerging evidence and their lived experiences with Long COVID and rehabilitation research and practice.

We gratefully acknowledge funding from the **Temerty Faculty of Medicine** for their support of this Forum and the Rehabilitation Science Research Network for COVID. Finally, we thank the speakers, and members of the Forum Implementation Team who worked tirelessly with us to plan this event. Thank you for your ongoing contributions to the Network. We look forward to the day ahead!

Sincerely,

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PROGRAM at a GLANCE

2025 INTERNATIONAL FORUM ON COVID REHABILITATION RESEARCH

Friday April 25, 2025; 9:00am-5:00pm EDT

Online (Zoom) and In-Person (500 University Ave, Room 140, University of Toronto)

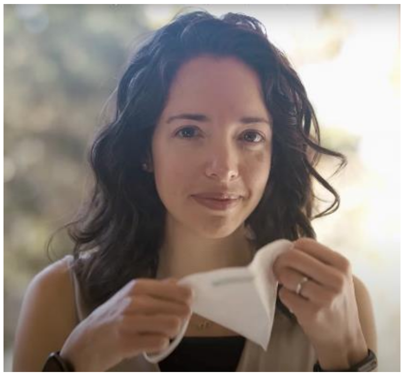
Time	Topic
8:30-9:00	**Arrival and Registration**
9:00-9:20	**Land Acknowledgement, Welcome and Introductions** **Jill Cameron**, Co-Director, Rehabilitation Science Research Network for COVID **Mary Forhan**, Executive Chair, Rehabilitation Sciences, Temerty Faculty of Medicine, University of Toronto
9:20-9:30	**Introduction to the Rehabilitation Science Research Network for COVID and Research Priorities in COVID Rehabilitation** **Jill Cameron & Kelly O'Brien,** Co-Directors, Rehabilitation Science Research Network for COVID
9:30-10:30	**Keynote Session - Wearables and Rehabilitation in Long COVID: Research and Personal Reflections from a Patient-Researcher** **Dr. Julia Moore Vogel,** Contributor at the Patient Led Research Collaborative and Senior Program Director, Scripps Research, Schaghticoke, New York, USA
10:30-10:50	**Break and Poster Viewing**
10:50-12:00	**Panel Discussion 1 - Mobilizing Research Evidence into Rehabilitation Professional Curricula to Inform Safe Rehabilitation in Long COVID** **Panelists:** • **Euson Yeung**, Department of Physical Therapy, Temerty Faculty of Medicine, University of Toronto • **Jessica DeMars**, Breathewell Physio, Nelson, British Columbia • **Josée Séguin**, Canadian Association of Occupational Therapists (CAOT), Ottawa, Ontario • **Mark Rutledge**, Advisory Committee Member, Rehabilitation Science Research Network for COVID, Whitehorse, Yukon • **Hannah Wei**, Patient-Led-Research Collaborative, Ottawa, Ontario • **Susie Goulding**, COVID Long Haulers Support Group Canada, Cambridge, Ontario • **Jaimie Coleman**, Department of Physical Therapy, Temerty Faculty of Medicine, University of Toronto **Moderator:** **Lisa Caldana**, Rehabilitation Science Research Network for COVID, Temerty Faculty of Medicine, University of Toronto
12:00-1:10	**Lunch and Poster Viewing**

Time	Topic
1:10-2:10	**Research Evidence Session 1 - Health and Disability across Acute and Long COVID Illness Trajectories** 1. **Abnormal Post-exertional Recovery in People Living with Long Covid: Insights from Two-Day Cardiopulmonary Exercise Testing -** Todd Davenport, Doctor of Physical Therapy Program, University of the Pacific, Stockton, California, USA 2. **Can automated language analyses identify cognitive deficits in Long COVID? -** Tijana Simic, Department of Speech-Language Pathology, University of Toronto & Kathleen Fraser, National Research Council of Canada, Ottawa, Ontario 3. **People's experiences of attempts to return to work and school with Long COVID: Findings from qualitative research conducted in the UK -** Alice MacLean, University of Stirling, Stirling, Scotland, UK 4. **Establishing a Framework of Measurement for Long COVID Research and Practice: Updates from a Scoping Study Involving Evidence Review and Consultation -** Kiera McDuff & Julia Nathanson, Department of Physical Therapy, Temerty Faculty of Medicine, University of Toronto
2:10-3:20	**Research Evidence Session 2 - Rehabilitation across COVID Care Continuums** 1. **Understanding the Impacts of Post-Exertional Malaise in Individuals with Long COVID Participating in a Physical Rehabilitation Trial -** Tania Janaudis-Ferreira, School of Physical and Occupational Therapy, Faculty of Medicine and Health Sciences, McGill University, Montreal, Quebec 2. **Update on CANCOV, RECLAIM and Long COVID Web (from an investigator perspective) -** Angela Cheung, University Health Network and University of Toronto, Toronto, Ontario 3. **Long COVID and One's Ability to Work -** Samantha Hancock, DAN Department of Management & Organizational Studies, Western University, London, Ontario 4. **Camelia: Canadian Learning Health Systems for Infection-Associated Chronic Conditions -** Simon Decary, Faculty of Medicine and Health Sciences, University of Sherbrooke, Sherbrooke, Quebec
3:20-3:40	**Break**
3:40-4:40	**Panel Discussion 2 - Navigating the Maze of the Continuum of Care for Long COVID Rehabilitation** **Panelists:** • **Sue Birch,** PossAbility, Toronto, Ontario • **Elizabeth Racz,** Realize, Toronto, Ontario • **Michelle DiLauro,** Toronto Rehabilitation Institute, Toronto, Ontario • **Fran Wolfe,** Baycrest Centre for Geriatric Care, Toronto, Ontario • **Cara Kaup,** Long COVID Physio, Edmonton, Alberta **Moderator:** **Alexandra Rendely,** Physiatrist, University Health Network, University of Toronto, Toronto, Ontario
4:40-5:00	**Bringing it all Together, Wrap-Up, Evaluation, Thank You & Acknowledgements**

Keynote Session – Speaker: Dr. Julia Moore Vogel

Wearables and Rehabilitation in Long COVID: Research and Personal Reflections from a Patient-Researcher

9:30-10:30am



Julia Moore Vogel

Dr. Julia Moore Vogel is a Contributor at the Patient Led Research Collaborative and a Senior Program Director at Scripps Research. She is using her over four years of lived experience with Long COVID and Myalgic Encephalomyelitis to conduct research that aims to address Long COVID and other infection-associated chronic illness symptoms through efforts such as the Long COVID Wearable Study. She is also the co-Principal Investigator for The Participant Center of the *All of Us* Research Program, overseeing efforts to accelerate medical breakthroughs through an inclusive health research program, and the ImmunoCARE Study, which aims to improve COVID-19 outcomes for immunocompromised individuals. She previously managed genomics initiatives at the New York Genome Center and The Rockefeller University. She has a PhD in Computational Biology and Medicine and an MBA both from Cornell.

Key messages:

1. Health care providers must carefully consider post-exertional malaise (PEM) in any post-COVID rehabilitation activities.
2. Physical Therapists can be powerful partners in Long COVID symptom management.
3. Wrist-worn wearables can support people with Long COVID in quantifying and managing their symptoms, including reducing PEM.

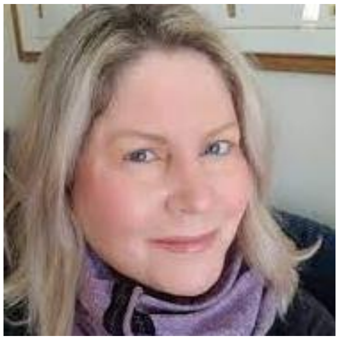
Panel Discussion 1

Mobilizing Research Evidence into Rehabilitation Professional Curricula to Inform Safe Rehabilitation in Long COVID

10:50am-12:00pm

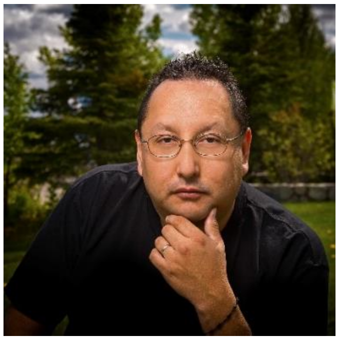
Aim of Session: To discuss the need, strategies and process for integrating evidence on safe and effective rehabilitation assessment and treatment approaches in Long COVID into rehabilitation professional curricula.

Panelists



Susie Goulding

Susie Goulding is from Ontario, Canada, and became a Long Hauler after contracting Covid-19 in March of 2020. Realising there was a lack of information available to Covid-19 survivors and a need for a non-judgmental and safe online platform for Long Haulers to congregate and connect for support she founded the Covid Long-Haulers Support Group Canada. Her advocacy work, research involvement and media presence provincially and nationally has connected her internationally with other groups and organizations.



Mark Rutledge

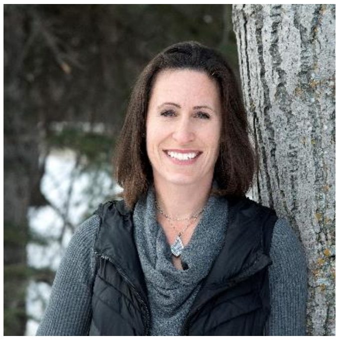
Mark Rutledge is a graphic designer by profession. He lives, works and plays on the traditional territories of the Kwanlin Dün First Nation and the Ta'an Kwach'an Council with his family. He contracted COVID-19 while attending his son’s high school graduation ceremony in June 2021. Weeks after his recovery from COVID-19, he began to experience a myriad of physical and cognitive symptoms. He continues to battle with the Yukon healthcare system and government that doesn’t believe Long COVID exists. He feels fortunate to have met some clinicians that have believed and supported him, and is now receiving more specialized care. Mark has been a champion of the cause in the North, where the healthcare system is beyond capacity and is struggling to keep pace with the ever-increasing demand of Yukoners.

Josée Séguin

Josée Séguin is an Occupational Therapist and Director of Knowledge Translation Program at the Canadian Association of Occupational Therapists (CAOT). She leads the national knowledge translation activities including CAOT conference, professional development, resources, publications (Canadian Journal of Occupational Therapy / OT Now practice magazine) and initiatives such as Primary Care and Post COVID-19 Conditions. She has a Master’s in Rehabilitation Sciences (MSc) and is a doctoral candidate in Rehabilitation and Health Leadership (DScRHL) at Queen’s University.

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, and more. PLRC has 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 projects at PLRC and innovating on the patient-led research model.

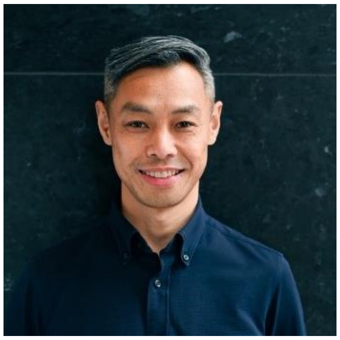


Jessica DeMars

Jessica graduated from the University of Alberta in 1998 with a Bachelor of Science Degree in Physical Therapy (with distinction). She practiced in the private setting and continued her education with numerous post-graduate courses. In 2006, her focus shifted toward learning about the impact breathing has on health. Since that time, she has attended numerous courses and gained in-depth knowledge in treating chronic and complex disease. The Canadian Instructor for the New Zealand-based BradCliff Method®, Jessica has also traveled across Canada presenting and lecturing on the impacts of dysfunctional breathing on health and has been invited to speak at numerous events. With the onset of the Covid-19 pandemic, Jessica quickly recognized the implications of Long COVID on the population and has pivoted to creating programming that delivers the best available evidence for both those living with Long COVID and health care professionals working with this population. She has become an ally and an advocate, taking on the role of Co-Director of Advocacy for the Long COVID Physio executive board. She has developed several courses and webinars on Long COVID to assist with knowledge translation to allied health professionals.

Jaimie Coleman

Jaimie Coleman is an Assistant Professor (Teaching Stream) in the Department of Physical Therapy, University of Toronto. Within the MScPT program, Jaimie is the Graduate Coordinator and is the co-lead for the cardiorespiratory course. Jaimie was involved in curating the physiotherapy and occupational therapy resources pages for the covidcarelearning.ca continuing professional development website, a trusted resource for clinicians being redeployed to alternate practice areas during the height of the pandemic. Jaimie was also involved in summarizing current guidelines for the management of patients with Long COVID for exercise professionals. Jaimie is currently a PhD student in health professions education research within the Institute of Health Policy & Management at U of T where her research focuses on mechanisms of effort regulation in on-line learning environments.



Euson Yeung

Dr. Euson Yeung is an education researcher working to advance health professions education, with a particular focus on Physical Therapy education and curriculum development. His work explores innovative instructional strategies, competency-based education, and evidence-informed curriculum design to enhance teaching and learning in the health professions. Dr. Yeung collaborates with educators, clinicians, and institutions to develop and refine curricula that prepare future healthcare professionals for clinical excellence. Through his research, he aims to advance best practices in health professions education, ensuring that graduates are well-equipped to meet the evolving demands of patient care and interdisciplinary collaboration.

Moderator

Lisa Caldana

Lisa Caldana is a Registered Physiotherapist and is also the Academic Co-lead of Clinical Education in the Department of Physical Therapy. Lisa has worked as a physiotherapist in a variety of clinical and administrative practice areas across the continuum of care. She completed the Advanced Clinician Practitioner in Arthritis Care program in 2018 and completed a Masters of Health Sciences degree in Translational Research at the University of Toronto. Lisa is very interested in advancing COVID research and helping individuals experiencing persistent symptoms from COVID access the proper resources and healthcare services.

Research Evidence Session #1

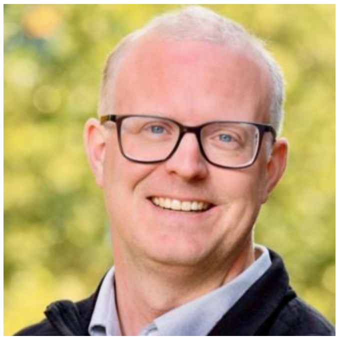
Health and Disability across Acute and Long COVID Illness Trajectories

1:10-2:10pm

Aim of Session: To foster knowledge transfer and exchange on evidence related to 1) understanding experiences of episodic disability; and 2) assessing episodic disability.

Todd E. Davenport

Abnormal Post-exertional Recovery in People Living with Long COVID: Insights from Two-Day Cardiopulmonary Exercise Testing



Todd E. Davenport is Professor and Chair in the Department of Physical Therapy at University of the Pacific in Stockton, California. He earned bachelor's degrees in psychology and exercise science (sports medicine) from Willamette University, Doctor of Physical Therapy from the University of Southern California, Master of Public Health from the University of California at Berkeley, and Doctor of Philosophy in Sport, Health, and Exercise Sciences from the University of Portsmouth. Dr. Davenport is a scientific advisor to the Workwell Foundation and Chair of Long COVID Physio. His research involves the systems-level physiology and clinical recognition of post-exertional neuroimmune exhaustion.

Key messages:

- Long COVID symptomatology has a basis in bioenergetic impairment—the inability to create and utilize energy at the cellular level.
- The bioenergetic impairment of Long COVID can be demonstrated using two-day cardiopulmonary exercise testing.
- Two-day cardiopulmonary exercise testing supports the presence of an abnormal exercise recovery response in people with Long COVID.

Tijana Simic & Kathleen Fraser

Can automated language analyses identify cognitive deficits in Long COVID?

Tijana Simic

Tijana Simic is an Assistant Professor and Graduate Faculty Member in the Department of Speech-Language Pathology and Rehabilitation Sciences Institute, and the director of the Language Rehabilitation and Cognition (LaRC) lab. She obtained her PhD in 2019 from the Rehabilitation Sciences Institute in Toronto, and completed a postdoctoral fellowship at the Centre de Recherche de l'Institut de Gériatrie de Montréal, affiliated with the Université de Montréal. She also holds a Master of Health Science (SLP) and is a registered Speech-Language Pathologist.

Kathleen Fraser

Kathleen Fraser is a computer scientist in the Digital Technologies Research Centre at the National Research Council Canada. Her research focuses on the use of natural language processing in healthcare applications, as well as assessing and mitigating social bias in artificial intelligence systems. Dr. Fraser received her PhD in computer science from the University of Toronto in 2016, and subsequently completed a post-doc at the University of Gothenburg, Sweden. She was named an MIT Rising Star in Electrical Engineering and Computer Science in 2015, and was awarded the Governor General's Gold Academic Medal in 2017. She has been a research officer at the Natural Research Council since 2018, and also holds a position as adjunct research professor at Carleton University.

Key messages:

- Long COVID affects roughly 1.4 million Canadians, and results in debilitating long-term symptoms. These include cognitive- and communicative difficulties, such as word-finding difficulties and trouble following conversations. These difficulties are not easily captured via standard cognitive testing.
- Based on studies in preclinical dementia and concussion, a more sensitive measure of cognitive deficits may be through automated computational analysis of language samples (e.g., story retelling).
- We are using automated machine learning methods to analyse and compare the language production of individuals with- and without Long COVID. This talk presents preliminary data from this work. This is the first known study to use automated analyses of language samples to address the communication needs of individuals living with Long COVID.

Alice MacLean

People's experiences of attempts to return to work and school with Long COVID: Findings from qualitative research conducted in the UK

Dr. Alice MacLean is a research fellow at the Institute for Social Marketing of Health, University of Stirling. Alice specializes in qualitative research. Her principal research interests span people's lived experiences of illness, help-seeking and behavior change across the life course, gender and health, and wellbeing within families. Alice has worked on several studies of people's experiences of Long COVID since 2021. She has also played a major part in producing evidence-based web resources on adults' experiences of Long COVID (https://hexi.ox.ac.uk/Long-Covid-In-Adults/overview) and of Long COVID within families (https://hexi.ox.ac.uk/Family-experiences-of-Long-Covid/overview). Alice is currently leading a mixed-methods study which explores the impact of Long COVID on people working in critical public sector service occupations in Scotland.

Key messages:

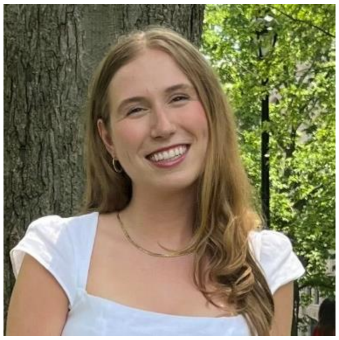
- Adults with Long COVID reported regret and guilt about not being able to return to work, and worried about the financial implications of losing their job. Children with Long COVID also voiced a strong wish to be able to return to school full-time, which represented a key part of being able to return to 'normal'.
- Existing policies and practices to support return to work and/or school after illness are not fit for purpose for episodic disabilities like Long COVID as they do not take account of the fluctuating, episodic and sometimes invisible nature of the condition. Participants highlighted the importance of being listened to and believed.
- Emerging findings from our ongoing study of the impact of Long COVID on critical public sector service occupations suggest that the potential to return to meaningful forms of work varies by occupation. It can also vary within occupation and can be linked to effective and creative line management.

Kiera McDuff & Julia Nathanson

Measurement of Disability Outcomes in the context of Long COVID – Updates from the Measurement and Assessment Paradigm of Long COVID (MAP-LC) study

Kiera McDuff

Kiera McDuff is a Physiotherapist with clinical experience in acute care, working with a variety of patients with complex health conditions. She is also Manager of the Episodic Disability and Rehabilitation Research Lab at the University of Toronto, where she has been actively involved in Long COVID and rehabilitation research for three years. Kiera is passionate about the role of physiotherapists in supporting the health and wellbeing of people living with chronic health conditions across their lifespan and is interested in exploring the rehabilitation needs of people living with Long COVID.



Julia Nathanson

Julia Nathanson is a Research Coordinator in the Episodic Disability and Rehabilitation Research Lab at the University of Toronto. In 2024, she completed her undergraduate degree at McGill University, studying psychology and political science. Julia is interested in researching the accessibility and efficacy of healthcare interventions, and engaging community organizations in her work.

Key messages:

- There is a need to advance the selection, utility, and interpretation of outcome measures for people living with Long COVID and their caregivers in clinical practice and research.
- Consultants reported familiarity with a range of patient-reported outcome measures, performance-based outcome measures, and patient-reported experience measures used among people living with Long COVID and their caregivers.
- Consultants had greater familiarity with outcome measures for adults living with Long COVID compared to children living with Long COVID or caregivers of people living with Long COVID.

Research Evidence Session #2

Rehabilitation across Acute COVID-19 and Long COVID Care Continuums

2:10-3:20pm

Aim of Session: To foster knowledge transfer and exchange on evidence related to COVID Rehabilitation research, specifically; i) identifying and examining safe approaches to rehabilitation; ii) examining the role, implementation and impact of models of rehabilitation care; iii) assessing access to safe, timely and appropriate rehabilitation and other health care provider services.

Tania Janaudis-Ferreira

Understanding the Impacts of Post-Exertional Malaise in Individuals with Long COVID Participating in a Physical Rehabilitation Trial

Dr. Tania Janaudis-Ferreira is an Associate Professor with the School of Physical and Occupational Therapy at McGill University and a Scientist with the Research Institute of the McGill University Health Centre in Montreal, Canada. The overarching goal of her research program is to improve rehabilitation care and outcomes in individuals with chronic conditions such as COPD, Long COVID and solid organ transplant patients. She has been awarded several national grants as a principal investigator from the Canadian Institutes of Health Research, Long COVID Web, Quebec Respiratory Health Network, Canadian Lung Association, Canadian Society of Transplantation, Kidney Foundation of Canada and Canadian Donation and Transplantation Research Program.

Learning objectives:

- Identify the barriers and complexities involved in delivering effective and safe physical rehabilitation to individuals with Long COVID.
- Discuss key findings of a Canadian randomized controlled trial on virtual rehabilitation on Long COVID, including those related to PEM.

Angela Cheung

Update on CANCOV, RECLAIM and Long COVID Web (an investigator perspective)

Professor Angela M. Cheung is a senior physician scientist at University Health Network, University of Toronto. She is the co-lead principal investigator (PI) for CANCOV (the national COVID-19 longitudinal cohort study across 5 provinces and 18 sites), RECLAIM (the REcovering from COVID-Lingering symptoms Adaptive Integrative Medicine platform trial), and Long COVID Web (the national research network for post COVID-19 condition (PCC)). She takes an interdisciplinary approach to examine the genetic, multi-omic and clinical factors for PCC and to develop novel curative treatments. She has advised the Ontario Science Table, Public Health Agency of Canada, Canadian Immunity Task Force, Canadian Institutes of Health Research, Canadian Agency for Drugs and Technologies in Health and the Chief Science Advisor’s Task Force on PCC.

After this session, participants will be able to:

- Describe the findings of CANCOV non-ICU cohorts.
- Explain the design of the RECLAIM adaptive platform trial.
- Access the various resources of Long COVID Web.

Samantha Hancock

Long COVID and One's Ability to Work

Dr. Samantha Hancock is an Assistant Professor in the DAN Department of Management and Organizational Studies at Western University. She holds a PhD in Management, specializing in Organizational Behaviour and Human Resource Management. Her research explores workplace inclusion for equity-deserving groups such as individuals living with Long COVID, neurominorities, and women. Through her work, she aims to advance understanding and practices that foster more inclusive and supportive organizational environments.

Key messages:

- The return-to-work process for individuals with Long COVID is not straightforward. It is often very individualized and does not follow a linear path.
- Being able to work from home is a major contributing factor in individuals' success in returning to work.
- Among those who have returned to work, productivity looks much different than it did before Long COVID.

Simon Décary

IACC Models of Rehabilitation Care

Simon Décary is an Assistant Professor in health services and rehabilitation at University of Sherbrooke in Quebec. He is involved in Long COVID research since 2020, having evaluated integrated care models for Long COVID. He was appointed as co-scientific director of Long COVID Web in 2023, a CIHR funded network to coordinate Long COVID research in Canada with Dr. Angela Cheung as nominated principal investigator. In 2025, he was appointed president of the Quebec national strategy for infection-associated chronic conditions, overseeing the transition of an integrated care model delivering care for over 4000 patients with Long COVID and chronic Lyme disease.

Key messages:

- The province of Quebec successfully implemented an integrated care model of 15 sites delivering care to thousands of patients between 2020-2025.
- A new care model and research platform is being develop to cover infection-associated chronic conditions, starting with Long COVID, chronic Lyme and myalgic encephalomyelitis.
- The project CAMELIA will aim to expand a national patient registry and a capacity-building platform to train a sustainable healthcare workforce.

Panel Discussion #2

Navigating the Maze of the Continuum of Care for Long COVID Rehabilitation

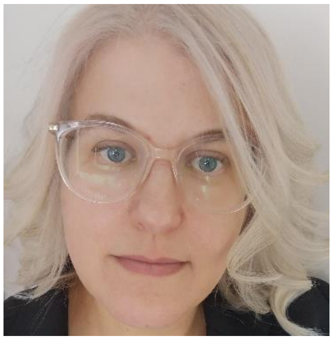
3:40-4:40pm

Aim of Session: To explore the experiences of navigating rehabilitation services in the context of Long COVID. Using an exemplar of a rehabilitation Long COVID clinic, panelists will specifically highlight important considerations for need and models of rehabilitation programs, services and models of care delivery. The panel will include researchers, clinicians, educators, members of community, and persons with lived experiences.

Panelists

Sue Birch

A Certified Disability Management Professional (CDMP) with 30 years experience in workers' compensation, Sue worked as Assistant Director in the Board's Return to Work Program. After developing ME/CFS in 2010, she embarked on her own prolonged and difficult return to work journey. Understanding that people with post-viral illness need more than a typical 4-week graduated return to work plan, and that other supports are needed, Sue founded *PossAbility: ME, Long COVID & Work* to identify work accommodations, job modifications, assistive devices, and strategies to help people with ME/CFS and Long COVID stay in the workforce, when able.



Elizabeth Racz

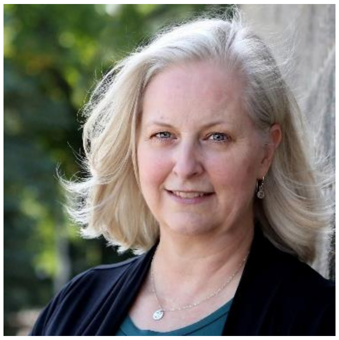
Elizabeth Racz is the Manager, Research Initiatives at *Realize*, a national non-profit organization that is a leader and catalyst for improving the health and well-being of people living with HIV and other episodic disabilities, across the lifespan in Canada. Her experience spans research in HIV, transplant, cardiac care, and COVID-19, including mixed methods, qualitative, and community-based designs. Elizabeth has worked from bench-side to bedside and beyond, implementing programs and advocating for evidence-based policy change at provincial and national levels. Elizabeth is a patient advisory board member for international clinical trials, as well as a research reviewer for a PCORI.

Michelle DiLauro

Michelle DiLauro is an Occupational Therapist with diverse clinical experience supporting individuals with acquired brain injury, oncology, chronic pain and complex musculoskeletal conditions. Currently, she supports outpatient COVID rehabilitation through her role as a rehabilitation Service Coordinator in the Musculoskeletal and Multisystem Outpatient Program at the University Health Network's Toronto Rehab. Michelle is passionate about enhancing patient and family experience across the care continuum and enabling care partnerships. She holds a Status-Only Appointment as a Lecturer with the Department of Occupational Sciences and Occupational Therapy at the University of Toronto.

Fran Wolfe

Fran Wolfe graduated from the University of Toronto Post Masters/Nurse Practitioner program in 2009. She currently works on the Outreach and Interprofessional Primary Care Team (IPCT) at the Baycrest Center. Fran provides the medical management for those living in the community as well as supports a program for those waiting at home for long-term care or needing slow stream rehabilitation. Fran noticed that some individuals' symptoms did not resolve in a few weeks and felt the need to provide support to those who continued to suffer from Long Haul Covid as the scientific evidence emerged. Today she is sharing her experiences about the support group she, as an NP has been running for these survivors since 2021.



Cara Kaup

Cara Kaup contracted COVID-19 in March 2020 and has been living with Long COVID for 5 years. She worked as pediatric Physical Therapist for over 30 years. She is no longer able to work and is now on permanent disability. Cara invests what little energy she has in educating and advocating for adults and children living with Long COVID. She is a patient advisor for several Long COVID initiatives in Alberta, Canada and internationally, with a primary focus on safe rehabilitation. As well, she has served on the board for Long COVID Physio since its inception in July 2021.

Moderator

Alexandra Rendely

Dr. Alexandra Rendely is a physical medicine and rehabilitation physician at the University Health Network's Toronto Rehab and a clinician in quality and innovation at the University of Toronto. During her residency training at the University of Toronto she completed a year long fellowship in health journalism through the Dalla Lana School of Public Health. Prior to attending McMaster Medical School she worked for television and radio stations as a sports journalist. Currently Dr. Rendely works as a musculoskeletal physiatrist with an inpatient and outpatient practice and a special interest in COVID rehabilitation. She co-runs the Interdisciplinary Virtual COVID Rehab Clinic at Toronto Rehab. She advocates for rehabilitation and related topics as a freelance health journalist and is the host of MSK Matters, a medical education podcast.

Forum Implementation Team & Contributors

Laura Bassi

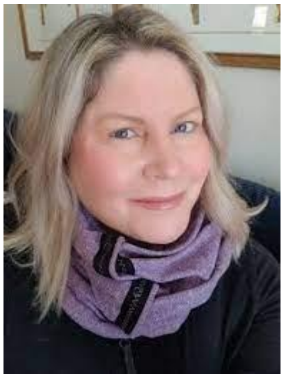
Laura Bassi is a physio-illustrator. She works as an OMPT Physiotherapist in a private studio in Ferrara, Italy. She is the creator of Fisiocamera, a fully visual health-communication service, through which she helps organizations, professionals and researchers in translating their ideas and researches into forms of visual art through various communication tools (drawings, animations, graphics). She collaborated with many organizations like Nuffield Department of Clinical Neurosciences, IFOMPT and Long COVID Physio creating the “Long COVID Physio Video Series''. She is also regional coordinator of the Mindful Self-Compassion Italian Community.

Lisa Caldana

Lisa Caldana is a Registered Physiotherapist and is also the Academic Co-lead of Clinical Education in the Department of Physical Therapy. Lisa has worked as a physiotherapist in a variety of clinical and administrative practice areas across the continuum of care. She completed the Advanced Clinician Practitioner in Arthritis Care program in 2018 and completed a Masters of Health Sciences degree in Translational Research at the University of Toronto. Lisa is very interested in advancing COVID research and helping individuals experiencing persistent symptoms from COVID access the proper resources and healthcare services.

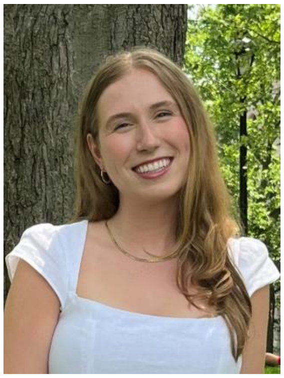
Jill Cameron

Dr. Jill Cameron (she/her) is Professor and Vice Chair Research in the Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute in the Temerty Faculty of Medicine at the University of Toronto. Her primary research interest is to understand the experiences and needs of family members who assume the role of caregiver for individuals with disability. Dr. Cameron aims to enhance models of health care delivery such that caregivers receive timely and relevant support across the care continuum. Ultimately, her research aims to enhance the health and wellbeing of people affected by disability and their caregivers.



Susie Goulding

Susie Goulding is from Ontario, Canada, and became a Long Hauler after contracting Covid-19 in March of 2020. Realising there was a lack of information available to Covid-19 survivors and a need for a non-judgmental and safe online platform for Long Haulers to congregate and connect for support she founded the Covid Long-Haulers Support Group Canada. Her advocacy work, research involvement and media presence provincially and nationally has connected her internationally with other groups and organizations.



Julia Nathanson

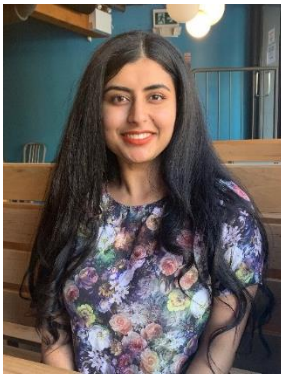
Julia Nathanson is a Research Coordinator in the Episodic Disability and Rehabilitation Research Lab at the University of Toronto. In 2024, she completed her undergraduate degree at McGill University, studying psychology and political science. Julia is interested in researching the accessibility and efficacy of healthcare interventions, and engaging community organizations in her work.

Behdin Nowrouzi-Kia

Behdin Nowrouzi-Kia, OT Reg. (Ont.), PhD, FRSA, is an Occupational Therapist and assistant professor at the Department of Occupational Science and Occupational Therapy. He holds the Inaugural Emily Geldsaler Grant Early Career Professorship in Workplace Mental Health. Dr. Nowrouzi-Kia is also an affiliate scientist at the Krembil Research Institute, Toronto Western Hospital, University Health Network and a Collaborating Scientist at the Centre for Addiction and Mental Health. Dr. Nowrouzi-Kia uses an occupational lens to systematically study occupations related to workability, work disability prevention, and return to work.

Kelly O'Brien

Dr. Kelly O'Brien is a Physical Therapist and Professor in the Department of Physical Therapy, at the University of Toronto, cross appointed to the Institute of Health Policy, Management and Evaluation (IHPME) and Rehabilitation Sciences Institute (RSI). She holds a Canada Research Chair (Tier 2) in Episodic Disability and Rehabilitation. Kelly is a Co-Director of the Rehabilitation Science Research Network for COVID, and member of the Long COVID Physio Research Committee. Her research is focused on episodic disability and rehabilitation among people living with episodic conditions.



Meera Premnazeer

Meera Premnazeer completed her Honours Bachelor of Science in Human Biology and Psychology and her Master of Science in Occupational Therapy at the University of Toronto (UofT). As a PhD Student at the Rehabilitation Sciences Institute (RSI) at UofT, Meera's research is focused on improving healthcare delivery for people with stroke and their caregivers across Canada. Her passion and research center around the area of patient- and family-centered care. Meera has received the Toronto Rehabilitation Institute Student Scholarship, Gwen Bell Endowment Fund from RSI, and more recently the Rehabilitation Science Research Network for COVID Trainee Award. She is also a recipient of the Canadian Occupational Therapy Foundation Future Scholar Award.

Alexandra Rendely

Dr. Alexandra Rendely is a physical medicine and rehabilitation physician at the University Health Network's Toronto Rehab and a clinician in quality and innovation at the University of Toronto. During her residency training at the University of Toronto she completed a year long fellowship in health journalism through the Dalla Lana School of Public Health. Prior to attending McMaster Medical School she worked for various television and radio stations as a sports journalist. Currently Dr. Rendely works as a musculoskeletal and sports medicine physiatrist with an inpatient and outpatient practice and a special interest in COVID rehabilitation. She co-runs the Interdisciplinary Virtual COVID Rehab Clinic at Toronto Rehab. She advocates for rehabilitation and related topics as a freelance health journalist and is the host of MSK Matters, a medical education podcast.

ACKNOWLEDGEMENTS

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Physical Therapy
UNIVERSITY OF TORONTO

Abstracts

1. Episodic Disability Framework in the Context of Long COVID: Community-Engaged International Study

O'Brien KK*, Brown DA, McDuff K, St. Clair-Sullivan N, Chan Caursone S, Thomson C, McCorkell L, Wei H, Goulding S, O'Hara M, Roche N, Stokes R, Kelly M, Cheung AM, Erlandson KM, Harding R, Vera JH, Bergin C, Bannan C, Torres B, Malli N, Avery L, Solomon P. Episodic Disability Framework in the Context of Long COVID: Community-Engaged International Study [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objectives: The Episodic Disability Framework (EDF) characterizes the multidimensional and episodic nature of health-related challenges experienced by an individual. Our aim was to examine the applicability of the Episodic Disability Framework to conceptualize the health-related challenges experienced among adults living with Long COVID.

Methods: We conducted a community-engaged international qualitative study involving online semi-structured interviews. We recruited adults who self-identified as living with Long COVID via community organizations in Canada, Ireland, United Kingdom, and United States. We purposively recruited for diversity in age, gender identity, ethnicity, sexual orientation, and time since initial COVID-19 infection. We used an interview guide informed by the EDF to explore experiences of health-related challenges and how they were experienced over time. We conducted a group-based content analysis.

Results: Of the 40 participants, the median age was 39 years (Interquartile Range:32–49); majority were white (73%), heterosexual (75%), women (63%), living with Long COVID for ≥1 year (83%). Consistent with the EDF, disability was described as multidimensional and episodic in nature. Experiences of disability were aligned with the 3 components of the EDF: 1) dimensions of disability (physical, cognitive, mental-emotional health challenges, difficulties with day-to-day activities, challenges to social inclusion, uncertainty); 2) contextual factors (intrinsic and extrinsic) that exacerbate or alleviate dimensions of disability; and 3) triggers that initiate episodes of disability.

Conclusions: The Episodic Disability Framework provides a way to conceptualize disability experienced by adults living with Long COVID. The Framework provides guidance for future measurement of disability, and health and rehabilitation approaches to clinical practice, research, and policy.

2. Long COVID Physio Forum: Priorities for Long COVID Rehabilitation

McDuff K*, Brown DA, Gross DP, Faghy MA, Davenport TE, Audette J, Bassi L, Bull M, Cobbing SE, Décary S, Flynn A, Jeyes F, Kaup C, Martin M, Ngeh E, Putrino D, Saravia A, Shiloff-Rogers A, Skiffington H, Skipper L, Vogel JM, O'Brien KK. Long COVID Physio Forum: Priorities for Long COVID Rehabilitation [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objectives: Long COVID Physio (LCP) is an international patient-led association of physiotherapists living with Long COVID and allies offering peer support, education and advocacy for Long COVID rehabilitation. In 2022, LCP hosted an international forum. One aim of the Forum was to identify priorities in Long COVID and rehabilitation.

Methods: We conducted an international consultation on priorities for Long COVID and rehabilitation among people living with Long COVID, clinicians, researchers, and other key interest-holders (henceforth referred to as "consultants") who registered for and attended the LCP International Forum. We collected feedback from consultants using web-based questionnaires, the Zoom chat from the forum, and posts on an online platform (Padlet) during the forum. We analyzed data using group-based content analytical techniques. Priorities were organized into 4 categories: research, practice, education, and policy.

Results: There were 794 consultants representing 34 countries, including 47% (n = 376) living with Long COVID. Seventeen priorities for Long COVID overlapped and spanned research (epidemiology, socioeconomics, pathophysiology, characterizing disability, health equity, establishing diagnostic criteria, intervention studies), practice (safety, person-centered approaches), education (for people living with Long COVID, employers, policy makers, and health care professional students), and policy (accessibility of care, supports for people living with Long COVID and caregivers, public health messaging). Most priorities focused on Long COVID and rehabilitation; however, some extended beyond the scope of rehabilitation (e.g., pharmacological interventions).

Conclusions: These priorities will help guide research, practice, education, and policy, to advance health outcomes for people living with Long COVID.

3. Mental health of caregivers to adults with COVID: Scoping review

Sessford JD*, Dodwell A, Elms K, Gill M, Premnazeer M, Scali O, Roque M, Cameron JI. Mental health of caregivers to adults with COVID: Scoping review [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objectives: Family caregivers (FCGs) are critical to the health and wellbeing of people affected by COVID/long COVID. Protecting mental health of FCGs is essential to sustaining their caregiving role. The objective of this scoping review was to synthesize identified risks factors and protective factors for mental health of FCGs to adults with COVID/long COVID.
Methods: Using the Joanna Briggs Institute (JBI) methodology, the search was conducted across Medline, CINAHL, and PsycINFO. Original studies conducted since the pandemic began were included. Participants were adult FCGs to adults with COVID in the community, and studies reported mental health outcomes and related factors. Search results were managed online using Covidence. An Excel spreadsheet was used for extracted data, including study characteristics, demographics, and factors associated with positive/negative mental health outcomes. For qualitative studies, these factors were categorised via qualitative content analysis. Quantitative data was summarised in a table.
Results: Of 3,474 identified articles, 22 met inclusion criteria (14 quantitative, seven qualitative, one mixed-methods). Across all study designs, risk factors included limited support, financial burden, family challenges, unpredictable nature of COVID, inexperience, isolation, and unpleasant experiences. Protective factors included accessing support services, self-reinforcement, coping strategies, professional help, and online intervention.
Conclusions: Quantitative and qualitative research identified common mental health risk factors and protective factors for FCGs to adults with COVID. These factors may inform development of supports and services for FCGs to people with COVID, such as online interventions. Studies did not distinguish acute versus long COVID.

4. Sensibility of the Episodic Disability Questionnaire Among Adults with Long COVID

Nathanson J*, McDuff K, Brown DA, Chan Carusone S, Townsend L, Bannan C, O'Hara M, Goulding S, Thomson C, Kelly M, O'Connell S, O'Donovan I, Wei H, Cheung AM, Vera JH, Erlandson KM, Bergin C, Harding R, St. Clair-Sullivan N, Avery L, Soares L, Malli N, Roche N, Stokes R, Martin J, O'Brien KK. Sensibility of the Episodic Disability Questionnaire Among Adults with Long COVID [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objectives: The Episodic Disability Questionnaire (EDQ) is a 35-item patient-reported outcome measure that describes presence, severity and episodic nature of disability across six dimensions: i) physical, ii) cognitive, iii) mental-emotional health, iv) difficulties with day-to-day activities, v) social inclusion, and vi) uncertainty about future health. We developed a 21-item Long COVID EDQ Supplement (LC-EDQ Suppl) for use with the EDQ to describe disability experienced by adults living with Long COVID. Our aim was to assess the sensibility of the EDQ and LC-EDQ Suppl for this population.
Methods: We conducted a community-engaged web-based survey with adults living with Long COVID in Canada, Ireland, the United Kingdom (UK), and the United States (US). We administered the EDQ and LC-EDQ Suppl, and an 18-item sensibility questionnaire assessing their face and content validity, ease of usage and format. Sensibility scores ranged from 1 (highly disagree) to 7 (highly agree). We considered the EDQ and the LC-EDQ Suppl sensible if median sensibility scores were >5/7 for >80% of the items.
Results: Of the 798 participants (Canada: 43%; UK: 23%; US: 22%; Ireland: 12%), most identified as female (82%), median age of 47 years (25th,75th percentile: 37,56), median of 2 years (1,3) living with Long COVID, and 366/788 (46%) were unable to work or lost their job due to Long COVID. Median sensibility scores were >5/7 for 16/18 (89%) items on the sensibility questionnaire.
Conclusions: The EDQ and LC-EDQ Suppl demonstrated sensibility among this sample. Further property assessment is needed in the context of Long COVID.

5. Myalgic Encephalomyelitis in Long Covid – Is it just fatigue?

Kontaxakis A*, Athanasiou N, Petta V, Gounopoulos P, Konstantinidou E, Stavropoulou G, Petrou E, Antoniou A, Barmpouti E, Ntinopoulou E, Spetsioti S, Spaggoulakis D, Katsarou M, Iasonidou E, Karitinou M, Asimakos A, Paraskevi K. Myalgic Encephalomyelitis in Long Covid – Is it just fatigue? [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objective: The global prevalence of Long Covid is estimated at 400 million people, with a financial burden of $1 trillion. More than half of those are thought to satisfy Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) criteria, an infection associated chronic condition which is still largely neglected. We aimed to describe the level of function and characteristics of Long Covid patients with ME/CFS.
Methods: Patients attending our Long Covid clinic, who satisfy the Canadian Consensus Criteria for ME/CFS were assessed. Scales completed for quality of life were SF-36, EuroQoL-5D-5L, fatigue: Fatigue Severity Scale, balance: ABC scale, physical activity: IPAQ, cognitive function: MoCA, dyspnea: CAT. Cardiovascular autonomic dysfunction was tested through a modified Ewing battery.
Results: 35 patients were enrolled with a mean age 46.5 (±11.6), 85.7% were women, 88.6% had a mild infection and 32.3% had multiple Sars-CoV-2 infections. Mean symptom duration was 2 years (±0,9) while 51,5% was diagnosed with dysautonomia. The burden on quality of life was major: physical function subscale of SF-36 was 33,5% (±8.9) and mental health one 33.9% (±9.8), Euro-QoL-VAS: 57% (±18.1), fatigue in FSS: 51.2 (±12.1). In ABC: 34% reported balance impairment, in MoCA 26.3% were impaired and 41% had severe dyspnea in CAT.
Conclusion: Disability in ME/CFS is more severe than in sensory impairment and cancer as depicted in the literature with findings that were replicated in our cohort. The co-existence of cognitive dysfunction, dysautonomia, malaise, dyspnea and balance impairment necessitate individualized rehabilitation interventions and support.

6. Community-Engaged Long COVID Research: Processes, Evaluation and Recommendations

O'Hara ME*, McDuff K, Wei H, McCorkell L, Thomson C, Kelly M, Goulding S, O'Donovan I, O'Connell S, Stokes R, Malli N, St. Clair-Sullivan N, Chan Carusone S, Cheung AM, Erlandson KM, Bannan C, Townsend L, Bergin C, Vera JH, Harding R, Avery L, Brown DA, O'Brien KK. Community-Engaged Long COVID Research: Processes, Evaluation and Recommendations [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objective: We aimed to describe the processes of undertaking a community-engaged Long COVID research study, evaluate the community-engaged approach, and identify recommendations for community-engaged patient-oriented Long COVID research.
Methods: Guided by the 4PI (Principles; Purpose; Presence; Process; Impact) Framework and Patient-Led Research Scorecards, we evaluated community engagement practices of our research using a multi-stage consultation with team members. We conducted an online group-based discussion among team members with lived experiences of Long COVID and administered a web-based Scorecard questionnaire to all team members, to evaluate the collaboration in terms of i) patient burden, ii) governance, iii) integration into the research process, and iv) organization readiness. Score range: -2(non-collaboration) to +2(ideal collaboration).
Results: Of the 10 team members who completed the questionnaire, five identified as having lived experiences of Long COVID. Median scores ranged from +1 to +2 for all domains. Five team members with lived experiences participated in the community engagement discussion. Key practices and principles that enabled meaningful community engagement included shared decision-making, respect and empathy, flexible and multiple options for engagement on the research team, ease of remuneration for community partners, reminders of team meetings, and embedding the work within lived experiences of community members. Areas for consideration included establishing terms of reference for team process; trauma-informed practices; more concise and clear email communication; and intentional diversity of representation of the patient population on the team.
Conclusions: Our community-engaged approach enhanced the quality and relevance of the study to community while highlighting areas to enhance meaningful engagement.

7. Exploring rehabilitation using nonlinear dynamical neurofeedback in persons experiencing Long COVID cognitive impairment, fatigue and other persistent symptoms

Luctkar-Flude M*, Walker S, Brooks M, Flude B, Tyerman J, Exploring rehabilitation using nonlinear dynamical neurofeedback in persons experiencing Long COVID cognitive impairment, fatigue and other persistent symptoms [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objective: Long COVID, or post-COVID-19 condition, affects many individuals with persistent symptoms like cognitive impairment, fatigue, and emotional distress, impacting their quality of life. Current management mainly relies on supportive care, highlighting the need for novel therapies. Neurofeedback is a non-invasive therapy that promotes brain self-regulation through auditory feedback, showing improvement in symptoms such as cognitive impairment, fatigue, and emotional distress in other patient populations, including cancer survivors. We propose using neurofeedback to address persistent symptoms of Long COVID. This nurse-led study aimed to assess the feasibility of nonlinear dynamical neurofeedback as a rehabilitation strategy to alleviate cognitive impairment, fatigue, and other symptoms in individuals with Long COVID.
Methods: A quasi-experimental, repeated measures design was used. Participants received 20 sessions of NeurOptimal nonlinear dynamical neurofeedback over 10 weeks. Symptoms were assessed at four time points using standardized measures of cognitive function, fatigue, sleep quality, and psychological symptoms.
Results: Of the 20 recruited participants, 16 completed all sessions and assessments. Repeated measures ANOVA showed significant reductions in cognitive dysfunction, fatigue, sleep problems, anxiety, and depression from pre-intervention to post-intervention ($p = .001$), with improvements maintained at the 10-week follow-up.
Conclusions: This feasibility study suggests that nonlinear dynamical neurofeedback is both feasible and acceptable for individuals with Long COVID. Preliminary findings indicate potential benefits, supporting further research through randomized controlled trials and the integration of neurofeedback into rehabilitation programs.

8. Understanding a Danish Long COVID Rehabilitation Intervention

Brøns Nielsen T*, Gregersen Oestergaard L, Hawkins J, Vinther Nielsen C, Leth S, Hee Laursen C, Sørensen D. Understanding a Danish Long COVID Rehabilitation Intervention [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and objective: While studies on long COVID rehabilitation are increasing, research on how interventions function remains limited. According to the British Medical Research Council's framework for complex interventions, understanding the effects requires exploration of underlying mechanisms and programme theories. A large Danish municipality developed and implemented an out-patient intervention, The Long COVID Rehabilitation Intervention, theorised to work through identity transformation, a person-centred approach, peer support and patient education. This study aimed to explore interactions between mechanisms, context and outcomes of the intervention to confirm or refine the initial programme theories.
Methods: This qualitative study was conducted with a realist perspective. Data included 12 individual patient interviews, a focus group interview with health professionals and individual interview with the rehabilitation centre manager. The analysis followed a realist analytical approach, to confirm or refine the initial programme theories.
Results: The programme theories required refinements to their contexts and mechanisms. The study highlighted the interconnectedness of the theories, with identity transformation as the central theory, supported by a person-centred approach, peer support and patient education. Contextual factors, including a supportive social network, work and reflection space with health professionals and peers, enabled mechanisms such as feeling acknowledged, acceptance of the situation and motivation to implement the strategies, explaining the identified outcomes.
Conclusions: The preliminary findings suggest how, for whom and under which circumstances the intervention worked. Ongoing analysis will further refine these insights, contributing to the development of effective and safe long COVID rehabilitation and informing the broader post-viral rehabilitation field.

9. Person and Family Centered Care for Long COVID: Qualitative Study

Wu N*, Bellerose J*, O'Brien KK, Kokorelias K, Sessford J, Premnazeer M, Scali O, Goodridge D, Gross D, Rotenberg S, Singh H, Cheung AM, Lam G, Ho C, Wasilewski M, Quinn K, Leighton J, Law S, McDuff K, Rendely A, DiLauro M, Ruggiero L, Wolfe F, Churchill K, Séguin J, Goulding S, Rutledge M, Wright H, Ornstein M, Cameron JI. Person and Family Centered Care for Long COVID: Qualitative Study [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background: Long COVID (LC) is a multisystem condition affecting 10-39% of COVID-19 survivors. Adults with LC (AwLC) face diagnostic delays, inadequate treatment, and medical gaslighting, leading to negative healthcare experiences. Caregivers of AwLC experience high stress and burnout due to unpredictable symptoms and demanding care responsibilities. Healthcare providers (HCPs) struggle with limited LC knowledge, causing care delays and reduced patient trust. Person- and Family-Centered Care (PFCC) aims to address these challenges by prioritizing collaboration between individuals, families, and HCPs, emphasizing patients' needs, preferences, and family dynamics.

Objective: To explore the experiences and perceptions of AwLC, caregivers, and HCPs regarding PFCC in the context of LC.

Methods: This qualitative descriptive study uses virtual, semi-structured interviews with AwLC (n = 3), caregivers (n = 3), and HCPs (n = 3). Participants are recruited through online support groups and long COVID online networks, with additional participants identified through snowball sampling. Interviews explore the topics of care planning, family and HCP collaboration, family contexts influencing care, supportive policies and procedures, educational needs, and care coordination strategies. Data will be analyzed using thematic analysis, ensuring rigor through reflexive journaling, audit trail, and rich descriptions.

Results: Two of nine interviews are complete. Findings will provide insight into key topics explored, identifying challenges and opportunities for PFCC involving AwLC, caregivers, and HCPs.

Conclusion: We anticipate that the findings will contribute to the co-design of a PFCC model aimed at improving care experiences, informing policy, and ultimately, enhancing the well-being of adults and caregivers affected by LC.

10. Pre-COVID to Now: Changes in Self-Reported Health Outcomes in Long-COVID

Jamal M*, Simic T, Fraser K, Torreiter S, Hamelinck DM. Pre-COVID to Now: Changes in Self-Reported Health Outcomes in Long-COVID [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objective: Long-COVID (LC) affects 1.4 million Canadians, causing debilitating symptoms such as fatigue and cognitive-communication difficulties1,2. Standard cognitive-linguistic assessments often inadequately capture these impairments 2,3. This study examines pre- to post-COVID changes in a broad profile of symptoms in individuals with LC.

Methods: LC participants completed the Modified COVID-19 Yorkshire Rehabilitation Scale (C19-YRSm), as part of a larger study evaluating cognitive-linguistic deficits in LC. The C19-YRSm is a self-report measure assessing 30 LC-related physical, cognitive, and psychological symptoms, comparing pre-COVID and current symptom severity. Participants completed the survey via REDCap, with responses verified during virtual Zoom meetings. Wilcoxon signed-rank tests were used to analyze differences in symptom severity; alpha was set at (α=0.05/30=0.0017) using Bonferroni correction for multiple comparisons.

Results: To date, 18 participants completed the study (17 female), with a mean age of 50.3 years (SD=15.2, range=29-85), and an average of 18 years of education (SD=3.7, range=12-26). Participants were on average 30.9 months (SD=11.3, range=18-59) post-onset of COVID-19 infection. Analyses reveal significant differences in self-reported functioning for 18/30 symptoms, with the greatest change in symptom severity pre-COVID to present in: fatigue, instrumental activities of daily living, memory, post-exertional malaise, concentration, and communication; symptom severity did not vary with age or time post-onset.

Conclusions: Our findings demonstrate that cognitive-linguistic difficulties are among the most frequently reported symptoms to be severely impacted in LC. We are conducting ongoing investigations into these deficits to determine whether language can be a biomarker of LC and to develop sensitive diagnostic tools.

11. Long COVID and Disability: Does Gender Play a Role?

Hee Laursen C*, Brøns Nielsen T, Leth S, Schiøttz-Christensen B, Vinther Nielsen C, Langagergaard V, Sørensen L, Sørensen D, Gregersen Oestergaard L. Long COVID and Disability: Does Gender Play a Role? [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background and Objective: Long COVID impact daily functioning and activities, yet gender-specific disparities are not well-explored despite the known influence of sex and gender on health. We hypothesised that traditional gender roles contribute to distinct challenges for women and men. This study aims to investigate 1) the gender differences in sociodemographic characteristics, work status, sick leave and mental fatigue, and 2) the experienced and prioritised problems with activities of daily living (ADL) across genders and compare these ADL problems between women and men.

Methods: We included 780 long COVID patients (567 women, 213 men) referred to occupational therapy at a Danish long COVID outpatient clinic. Sociodemographic characteristics, work status, and sick leave were self-reported. Mental fatigue was assessed using the Mental Fatigue Scale, ADL problems using the Canadian Occupational Performance Measure. Gender differences were analysed using chi-squared, Wilcoxon, or t-tests. To further explore prioritised ADL problems, a qualitative deductive content analysis was conducted.

Results: More women had a medium or higher education (55% vs. 37%). Sick leave was high, with a slight female predominance (57% vs. 50%). Mental fatigue was prevalent in both genders, with women reporting more severe symptoms. Both men and women reported significant challenges in ADL problems, but gender differences were minor, with more women reporting difficulties in household management, quiet recreation, and socialisation. Both genders prioritised ADL problems related to work, physical activities, social interaction, and fulfilling the nurturer role.

Conclusion: ADL problems faced by women and men were generally similar, significantly impacting their daily lives.

12. COVID-19 Impact on Adults with Long-term Neurological Conditions: A Scoping Review

Ugwuodo E*, Campbell P, Cowie J, Paul L. COVID-19 Impact on Adults with Long-term Neurological Conditions: A Scoping Review [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background: Long-term neurological conditions (LTNC) affect one in three individuals worldwide. COVID-19 significantly impacted the management and rehabilitation of adults living with LTNC. The third or voluntary sector, played a critical yet frequently neglected role during the pandemic; but their perspectives are seldom reported.

Objectives: To identify and synthesize the views and experiences of adults with LTNCs during the pandemic described in third-sector reports.

Methods: A scoping review was conducted using Arksey and O'Malley's five-step framework and reported following PRISMA-SCR guidelines. Relevant LTNC third-sector websites were systematically identified using key terms from the ICD-11 taxonomy. Websites were individually searched, and relevant COVID-19 reports were retrieved. Data related to unmet needs and interventions were extracted. Qualitative data was coded through thematic analysis using the International Classification of Functioning, Disability, and Health framework. Findings were brought together in a narrative synthesis supported by evidence tables.

Results: Systematic searches identified 257 potentially relevant reports from 159 individual third-sector charities. Ninety-seven reports representing 41 charities met the selection criteria. Most reports focused on the experiences of adults diagnosed with neurocognitive disorders, especially dementia. Key themes included considerable disruption in healthcare services, unequal access to digital technologies, and social isolation. Neurological charities provided flexible support packages to adults with LTNC through telerehabilitation, community-led initiatives, and client advocacy.

Conclusion: There was a widespread report of unmet needs in mental health, physical functioning, social interactions, and community engagement. Addressing the digital divide and enhancing emergency preparedness strategies is essential for mitigating future challenges.

13. Effects of a Self-Management Program in Post-COVID Syndrome Individuals with and without ME/CFS Symptoms

Sarmento A, Adodo R, Sanchez-Ramirez DC*. Effects of a Self-Management Program in Post-COVID Syndrome Individuals with and without ME/CFS Symptoms [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background: Self-management strategies may help alleviate symptoms and enhance functional outcomes in patients with Post-COVID-19 syndrome (PCS).

Objective: We investigated the effect of a 6-week home-based self-management program on individuals with PCS and compared results between those with and without ME/CFS symptoms.

Methods: Adults with PCS were assessed in person for lung function, exercise capacity (6-minute walking test [6MWT] and sit-to-stand [STS]), quality of life (EQ-5D-5L and SF-36), dyspnea (modified Borg scale), fatigue (Fatigue Severity Scale), and presence of ME/CFS symptoms (DePaul Symptom Questionnaire – short form). Participants received personalized recommendations complemented by the WHO Rehabilitation self-management leaflet and a smart watch to monitor their physical activity levels and heart rate. A weekly follow-up call was given to the participants to address any questions or concerns. Reassessments were performed in person, and participants also rated their satisfaction and perceived program's impact on their overall health using a Likert scale ranging from 0 to 4 (positive).

Results: Twenty individuals with PCS (75% females, age 53 ± 12 years) were included. Significant improvements in the predicted STS values ($p = 0.049$) and domains of usual activities of the EQ-5D-5L ($p = 0.027$) and vitality of the SF-36 ($p = 0.034$) were observed after the program. Satisfaction and impact of the program on overall health were 3.35 ± 0.79 and 3.15 ± 1.10, respectively. Eight participants (40%) reported experiencing ME/CFS symptoms. In comparing the two groups, participants without ME/CFS symptoms showed significant improvement in the mobility domain of the EQ-5D-5L after the program ($p = 0.046$), while no other differences were observed between the groups.

Conclusion: A 6-week self-management program demonstrated improvements in exercise capacity and quality of life of individuals with PCS.

14. Heart Rate Response to and Recovery from 6-Minute Walking Test in Post-COVID Syndrome Individuals with and without ME/CFS Symptoms

Sarmento A, Sanchez-Ramirez DC*. Heart Rate Response to and Recovery from 6-Minute Walking Test in Post-COVID Syndrome Individuals with and without ME/CFS Symptoms [Poster presentation]. 2025 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada. April 25, 2025.

Background: Post-COVID-19 syndrome (PCS) has emerged as a significant health concern worldwide, with some individuals experiencing symptoms of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Objective: We investigated the heart rate (HR) response of PCS individuals with and without ME/CFS symptoms during and immediately after the 6-minute walk test (6MWT). HR kinetics during recovery after the test were also compared between groups.

Methods: Adults with PCS were assessed for presence of ME/CFS symptoms (DePaul Symptom Questionnaire – short form). The 6MWT was conducted with participants wearing a smart shirt (Hexoskin) to monitor HR response; baseline and recovery HR values were collected one minute before and two minutes after the test, respectively, with participants seated at rest. For between-group comparisons during and after the 6MWT, absolute HR values were smoothed using a random walk algorithm and averaged at one minute. HR kinetics during recovery was analyzed by applying least-squares fitting to HR values, allowing us to extract the coefficient of determination (r2), slope, and time constant of decay (τ, tau). The distance covered in the 6MWT was normalized according to age-and sex-specific predicted values.

Results: Twenty-seven individuals with PCS (81.5% females, age 53 ± 10 years) were assessed, of whom 14 reported ME/CFS symptoms. No significant between-group differences were found in age, body mass index, lung function, and 6MWT distance. A MANCOVA (adjusted for baseline HR and percentage of predicted 6MWT distance) showed significantly lower HR values in individuals with ME/CFS symptoms at the 6th minute of the 6MWT compared with those without ($p = 0.03$). Although differences in HR recovery at minutes 1 and 2 were not statistically significant between groups, individuals with ME/CFS symptoms presented a time constant two-fold higher during recovery ($\tau = 7.28s$, slope = -0.233, $r2 = 0.971$) than those without ME/CFS symptoms ($\tau = 3.63s$, slope = -0.380, $r2 = 0.991$); slopes were also significantly different between groups after the 6MWT ($p < 0.001$).

Conclusion: The results suggest an altered cardiovascular regulation with attenuated HR recovery in PCS individuals with ME/CFS symptoms compared to those without.

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