

Rehabilitation Science Research Network for COVID



TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

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

Friday April 21, 2023
500 University Avenue, Room 140 & Online (Zoom)
Rehabilitation Sciences Building
University of Toronto
Toronto, Ontario

ACKNOWLEDGEMENTS

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We also acknowledge the collaboration with partners of the Network in the Forum including Long COVID Physio, Patient-Led Research Collaborative, Rehabilitative Care Alliance, and FizioCamera.

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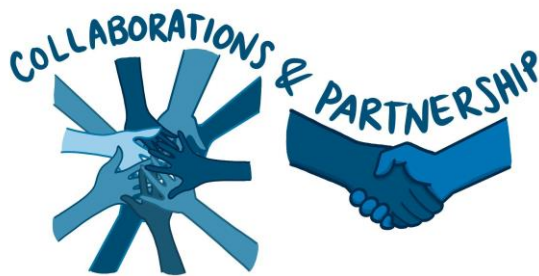
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Executive Summary

The [Rehabilitation Science Research Network for COVID](#) hosted the inaugural **International Forum on COVID Rehabilitation Research** on Friday April 21, 2023. The Forum was delivered in a hybrid format, online via Zoom and in-person at the Rehabilitation Sciences Building, University of Toronto. This Forum was a collaboration among Network members and partners including (but not limited to) Long COVID Physio, Patient-Led Research Collaborative, Rehabilitative Care Alliance, and FioCamera. This event included a range of community leaders, clinicians, trainees, and researchers who have been instrumental in advancing science, practice, and policy in COVID rehabilitation.

The objectives of the Forum were:

- 1) To facilitate **knowledge transfer and exchange (KTE)** in the field of rehabilitation research related to COVID-19, clinical practice and service delivery among persons with lived experiences and affected by COVID-19, including acute COVID-19, and Long COVID, researchers, caregivers, clinicians, educators, trainees, representatives of community organizations and policy stakeholders in Canada and internationally;



- 2) To establish new and strengthen existing research **collaborations and partnerships** in the field of COVID-19 rehabilitation;

- 3) To foster **mentorship and training** in COVID-19 rehabilitation research among faculty, clinicians and trainees;



- 4) To identify new and emerging **research priorities** in COVID-19 rehabilitation research and practice.

There were 297 registrants for the Forum from over 20 countries. Of the 297 registrants, 160 (67%) attended the Forum (125 people online; 35 people in-person). After the Forum, all registrants received a [link](#) to the Forum presentations on the [Network YouTube Channel](#). Registrants and attendees included persons with lived experiences of COVID and Long COVID, caregivers, clinicians, researchers, and representatives from community organizations, and trainees to exchange research and lessons learned in the field of COVID rehabilitation research and practice.

Eighteen speakers were invited to present on research, clinical and community practice related to COVID rehabilitation research at the one-day Forum including a Keynote Speaker Session (1 speaker), two Research Evidence Sessions (10 speakers) and a Panel Session (6 speakers and 1 moderator).

The Keynote Presentation delivered by Dr. Todd Davenport was entitled: *Back to the Future for Long COVID Research*. The first Research Evidence Session focused on *Profiling COVID-19 Rehabilitation Research across the Continuum of Care*. The second Research Evidence Session focused on *Profiling COVID-19 Rehabilitation Research across the Continuum of Care – Rehabilitation Approaches*. The Panel Session focused on *Best Practices for Community-Engaged approaches to COVID-19 Rehabilitation Research* whereby the aim was to build capacity by learning from persons with lived experiences about their experiences and perspectives engaging in COVID rehabilitation research, and to discuss recommendations, considerations and best practices for research moving forward. The Forum provided an opportunity for a range of stakeholders to respond to current research evidence and present new and emerging research evidence and experiences of COVID rehabilitation. Structured discussions and Q&A segments enabled participation throughout the day and facilitators engaged attendees both in-person and online, while adhering to the agenda (**Appendix A**).

Forum evaluations (n=46) indicated that the Forum presented relevant and interesting research and information, had engaging speakers, and provided opportunities for collaboration among attendees. The median rating of satisfaction (25th, 75th percentile) with the Forum was 9/10 (8, 10) and 39/45 (87%) of respondents indicated that they would be able to apply the content covered in the Forum to their work.

Strengths of the Forum included the hybrid online and in-person mode of delivery; the emphasis on and inclusion of the voices of people with lived experiences with Long COVID and their caregivers; high quality speakers and presentations; and opportunities for transfer and dissemination of knowledge and research. Respondents also noted the program was full and would have liked more room in the schedule for interaction and discussion. See **Appendix B** for additional detail from the evaluation responses.

This report provides an overview of the Forum and our process of summarizing the research evidence on priorities in COVID rehabilitation research.

To access the Forum recordings, please see the [Forum's page](#) on the Network's [website](#).

For more information about the Forum, please contact Kiera McDuff, Network Coordinator at rehab.covid@utoronto.ca.

Context

In Canada, there have been over 4.6 million confirmed cases of COVID-19 and over 52,000 deaths (Canada, 2023). Approximately 17% of adults who had a confirmed diagnosis of COVID-19 experience long-term symptoms with the most common including fatigue, coughing, difficulty breathing, difficulty thinking or problem solving, and general weakness (Canada, 2022). These persistent symptoms are referred to as Long COVID, Post-COVID Condition (PCC) or Post-acute sequelae of SARS-CoV2 (PASC) (Chen et al., 2022; Nalbandian et al., 2021). Long COVID is defined by the World Health Organization as occurring usually 3 months from the onset of probable or confirmed COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis ([Soriano et al., 2021](#)). Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness, and may also fluctuate or relapse over time highlighting the potentially episodic nature of the condition.

The multi-dimensional nature of disability experienced by people living with Long COVID, can adversely impact daily function, return to employment, family life, relationships, and ability to care for others (Davis et al., 2021). Persons living with COVID and Long COVID can experience disability as episodic in nature, characterized by fluctuations in presence and severity of health-related challenges (disability) that may occur both within a day, within weeks, or over a longer continuum ([O'Brien et al., 2023](#)). The medical and illness uncertainty with Long COVID further adds to the complexity of the unpredictability of episodes, their length, severity and triggers, and process of long-term trajectory, which has implications on broader health ([O'Brien et al., 2023](#)).

The COVID pandemic has implications for the health and wellbeing of caregivers. The context of the COVID pandemic, including “stay at home” messages, physical distancing requirements, decreased supports from formal care providers, and fear of contracting COVID, increased demands on family caregivers. In a recent review of family caregiver wellbeing in the context of the COVID pandemic, caregivers experienced a decline in their psychological wellbeing, concern for their own health and wellbeing, concerns about decreased supports from the formal care system, and concerns for their increased caregiving load and related demands (Muldrew, Fee, & Coates, 2022). These findings highlight the importance of research to understand and address the needs of family caregivers.

Rehabilitation has a role in preventing or addressing disability and enhancing or maintaining health outcomes across the COVID continuum of care. Rehabilitation providers (such as physiotherapy, occupational therapy, and speech-language pathology) address or prevent disability focused on the physical, mental-emotional, cognitive and social domains of health and disability, and hence are well-positioned to address episodic and multidimensional disability among people living with acute COVID and Long COVID. Rehabilitation should be safe, disability focused, goal-oriented, person-centred, focused on function, and tailored to an individual's goals, abilities, and interests ([World Health Organization, 2023](#)). Rehabilitation is not limited to cardiorespiratory approaches, exercise or physical activity. Exercise is harmful for persons with PEM or PESE, and graded exercise therapy is not a safe rehabilitation intervention to treat fatigue among people experiencing post-exertional symptom exacerbation ([World Physiotherapy, 2021](#)). Therefore, there is a need to translate knowledge of evidence to inform clinical practice, policy, and education.

Established in 2022, the [Rehabilitation Science Research Network for COVID](#) is located in the Rehabilitation Sciences Sector, with funding from the Temerty Faculty of Medicine at the University of Toronto. The Network is leading an international collaborative engaging with persons with lived experiences, caregivers, researchers, clinicians, educators, trainees, representatives from community organizations, and policy stakeholders to enhance research innovation and excellence in COVID-19 rehabilitation research. The Network aims to advance evidence-informed rehabilitation assessments, interventions, and models of care

delivery to prevent or mitigate disability and optimize health and well-being across the illness trajectory among persons with lived experiences, including persons living with acute COVID-19, persons living with Long COVID and their caregivers. The Network is guided by a multi-stakeholder Advisory Committee comprised of representatives of clinicians, researchers, policy-makers, and persons with lived experiences, who inform the priorities, objectives, and actions of the Network.

[Strategic directions of the Network](#) include: **mobilizing knowledge transfer and exchange (KTE) on rehabilitation research related to COVID-19, clinical practice and service delivery** among persons with lived experiences and those affected by acute or Long COVID, researchers, caregivers, clinicians, educators, trainees, representatives of community organizations, and policy stakeholders in Canada and internationally; and **establishing new and strengthening existing research collaborations and partnerships** locally, nationally and internationally (clinical, research, community) in the field of COVID-19 rehabilitation.

Forum on COVID Rehabilitation Research

On Friday April 21, 2023, the Rehabilitation Science Research Network for COVID hosted the inaugural **International Forum on COVID Rehabilitation Research** at the Rehabilitation Sciences Building, University of Toronto.

The one-day hybrid (in-person and online) Forum was hosted by the Network, in collaboration with [Long COVID Physio](#), [Patient-Led Research Collaborative](#), [Rehabilitative Care Alliance](#), and [FisioCamera](#), to advance these objectives within the broader scope of the Network.

The Keynote Presentation delivered by Dr. Todd Davenport was entitled: *Back to the Future for Long COVID Research*. The two Research Evidence Sessions included: 1) Profiling COVID-19 Rehabilitation Research across the Continuum of Care (5 presentations); 2) Profiling COVID-19 Rehabilitation Research across the Continuum of Care – Rehabilitation Approaches (5 presentations). The Panel Session, *Best Practices for Community-Engaged approaches to COVID-19 Rehabilitation Research*, consisted of 6 panelists with lived experiences with Long COVID who discussed their experiences and perspectives engaging in COVID rehabilitation research, and recommendations, considerations and best practices for research moving forward.

Approach

The International Forum on COVID Rehabilitation Research was supported by Temerty Faculty of Medicine, University of Toronto. The Forum involved a planning and development process led by the Network's Co-Directors and Program Coordinator, and facilitated by a Core Forum Planning Team.

Core Forum Planning Team

The Core Forum Planning Team included the Network Co-Directors, Program Coordinator, and four members of the Advisory Committee, and supported by the Information Technology (IT) Director in the Rehabilitation Sciences Institute at the University of Toronto. The purpose of the Core Planning Committee was to oversee the planning and implementation of the Forum.

This Committee met on 3 occasions between January and April 2023 to discuss planning of the Forum. Specific activities included: developing a timeline for Forum preparation; advertising the Forum; planning the Forum agenda and program; connecting with potential speakers and panelists; finalizing catering, travel and accommodation details; discussing the evaluation process and developing an evaluation form; discussing registration options; finalizing and distributing participant and speaker invitations; establishing opportunities

and planning for rapporteurs; liaising with speakers prior to the Forum; determining specific outcomes of the Forum and developing a KTE strategy post-Forum.

Invitations and Advertisement of the Forum

The Core Planning Committee developed a list of invitees, which included: researchers, clinicians, and persons with lived experiences with COVID and Long COVID and their caregivers. We distributed a 'Save-the-Date' email to Network members on December 16, 2022. Registration was open using Qualtrics in January 2023. Targeted invitations and advertisements were sent out to Network members and partners/organization representatives, in January-March 2023. The Forum Program Agenda (**Appendix A**) and Forum poster (**Appendix C**) were also displayed on the Network's Twitter account (@UofTCOVIDRehab) to promote the Forum, introduce the speakers, as well as provide reminders regarding the registration closing date. Registration for the Forum was free with the aim to facilitate access and attendance to the Forum.

Forum Program

The Core Forum Planning Team developed a [Forum Program](#), which contained the agenda, title of each speaker's presentation, key messages and biographies. The purpose of the program was to give participants the opportunity to familiarize themselves with the speakers, and to prepare them to engage in discussions during the Forum. An electronic copy of the Forum program was available to registrants online and on site at the event via a QR code.

Invited Speakers and Volunteers

Eighteen (8 online; 10 in-person) researchers, clinicians, and persons with lived experiences with COVID, Long COVID, and their caregivers spoke as part of the Forum program. Ten of those speakers presented across one of three Research Evidence Panel sessions, with one keynote speaker. The Panel Session consisted of 6 panelists and a moderator. There were 2 co-moderators for each session (one for moderating in-person discussion, another to monitor the Zoom chat).

Pre-Forum Planning Teleconferences

In March 2023, the Core Forum Planning Team held 4 pre-Forum teleconferences, one for each of the two Research Evidence Panel Sessions, one for the Panel Session and one for the Rapporteurs. The purpose of these teleconferences was to enable speakers, panelists, and rapporteurs to be acquainted with each other and discuss their topics of presentation (if applicable) before the Forum and to discuss the logistics and proceedings of the Forum.

Piloting Hybrid Nature of Forum

In March 2023, the Core Forum Planning Team met with the IT Director to pilot Zoom audio/visual for the Forum. The Zoom audio/visual was piloted in the same room from which the Forum was hosted at the Rehabilitation Sciences Building. The Forum moderators attended this trial via Zoom to become familiar with how to monitor the Zoom chat, operate the mute functions, and spotlight key speakers for online attendees.

Forum Recordings

The Forum was recorded using Zoom. Speaker videos were edited and uploaded onto the [Network's YouTube channel](#) to enable further dissemination of research knowledge on COVID and rehabilitation. Video recordings can be accessed from the [Forums page](#) on the [Network's website](#).

Post-Forum Activities

The Network's Advisory Committee met after the Forum via Zoom to debrief about the overall Forum process, discuss next steps for the knowledge translation strategy, and address post-Forum activities such as

distributing thank you letters and discussing the Forum evaluations. Thank-you letters were mailed to all speakers, rapporteurs, and the video editing team in May 2023. The evaluation forms from the Forum were compiled into a report (see **Appendix B**).

Forum Overview

The Rehabilitation Science Research Network for COVID hosted the inaugural International Forum on COVID Rehabilitation Research on Friday April 21, 2023 at the Rehabilitation Sciences Building, University of Toronto. The Forum was hybrid in nature, enabling participation both in-person and online (via Zoom). The Keynote Presentation delivered by Dr. Todd Davenport was entitled: *Back to the Future for Long COVID Research*. The first Research Evidence Session focused on *Profiling COVID-19 Rehabilitation Research across the Continuum of Care*. The second Research Evidence Session focused on *Profiling COVID-19 Rehabilitation Research across the Continuum of Care – Rehabilitation Approaches*. The Panel Session focused on *Best Practices for Community-Engaged approaches to COVID-19 Rehabilitation Research* whereby the aim was to build capacity, learning from persons with lived experiences about their experiences and perspectives engaging in COVID rehabilitation research, and to discuss recommendations, considerations and best practices for research moving forward. Structured discussions and Q&A segments enabled participation throughout the day and facilitators engaged attendees both in-person and online, while adhering to the agenda. All presentations were recorded and uploaded to the [Network’s YouTube channel](#) to enable further dissemination of research knowledge on COVID and rehabilitation.

Registrants and Attendees

There were 297 registrants, from over 20 countries, for the 2023 International Forum on COVID Rehabilitation Research. Of the 297 registrants, 160 (67%) attended the Forum (125 (78%) people online; 35 (22%) people in-person). See Table 1 for an overview of characteristics of Forum participants based on information gathered at Forum registration.

Table 1: Characteristics of Registrants for the 2023 International Forum on COVID Rehabilitation Research (n=297)

Characteristics of Registrants	N (%)
Mode of Attendance	
<i>I will attend online</i>	240 (81%)
<i>I will attend in-person</i>	49 (17%)
<i>I am not able to attend</i>	8 (3%)
Country (n=295)	
<i>Canada</i>	201 (68%)
<i>United Kingdom</i>	37 (13%)
<i>United States of America</i>	26 (9%)
<i>Switzerland</i>	6 (2%)
<i>Ireland</i>	5 (2%)
<i>India</i>	3 (1%)
<i>Germany</i>	2 (<1%)
<i>Nigeria</i>	2 (<1%)
<i>Other (e.g. Australia, Brazil, Chile, Greece, Hong Kong, Italy, Japan, Mauritius, New Zealand, Pakistan, Qatar, Saint Lucia, South Korea)</i>	13 (4%)
Stakeholder Group (n=285)	
<i>Clinician</i>	102 (36%)
<i>Researcher</i>	40 (14%)

Characteristics of Registrants	N (%)
<i>Academic (e.g. located at an academic institution)</i>	34 (12%)
<i>Community member (e.g. person with lived experiences with COVID and/or Long COVID or their parents, partners, and caregivers)</i>	33 (12%)
<i>Trainee (e.g. MSc, PhD, or Post-doctoral Fellow)</i>	16 (6%)
<i>Service Provider</i>	11 (4%)
<i>Educator</i>	6 (2%)
<i>Student (e.g. Occupational Therapy or Physiotherapy Student)</i>	5 (2%)
<i>Other (e.g. Manager, Knowledge Broker, Clinical Exercise Physiologist, Wellness Coach, University Administrator, Health Care Administrator, Community Health Navigator, Health System Influencer/Decision Maker, Case Manager, Equity Analyst, Policy Analyst, Retiree, Epidemiologist, or Blended Roles)</i>	38 (13%)
Type of Health Care Professional (n=100)	
<i>Physiotherapist</i>	59 (59%)
<i>Occupational Therapist</i>	19 (19%)
<i>Physician</i>	10 (10%)
<i>Other rehabilitation professional (e.g. Respiratory Therapist, Physical Medicine and Rehabilitation Doctor, Massage Therapist)</i>	4 (4%)
<i>Nurse</i>	3 (3%)
<i>Other (e.g. Pharmacist, Speech-Language Pathologist, Radiographer, Social Worker, Nurse Practitioner)</i>	5 (5%)
Lived experiences: (n=291)	
<i>With Long COVID</i>	59 (24%)
<i>With Acute COVID</i>	41 (14%)
<i>With another chronic health condition or disability (e.g. Rheumatoid Arthritis, Fibromyalgia, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Endometriosis, Hemiplegia, HIV, Long West Nile, Asthma, Lymes Disease, Post-viral Syndrome, Depression, Chronic pain)</i>	24 (8%)
<i>As a caregiver to someone with Long COVID</i>	19 (7%)
<i>As a caregiver to someone with acute COVID</i>	13 (5%)
<i>With none of the above</i>	135 (46%)
Invited speaker/panelist (n=293)	20 (7%)
Currently a member of the Rehabilitation Science Research Network for COVID (n=280)	41 (15%)
Interested in joining as a member of the Rehabilitation Science Research Network for COVID (n=235)	127 (54%)

After the Forum, all registrants were emailed the [link](#) to the Forum presentations on the Network YouTube Channel.

Summary of Evidence

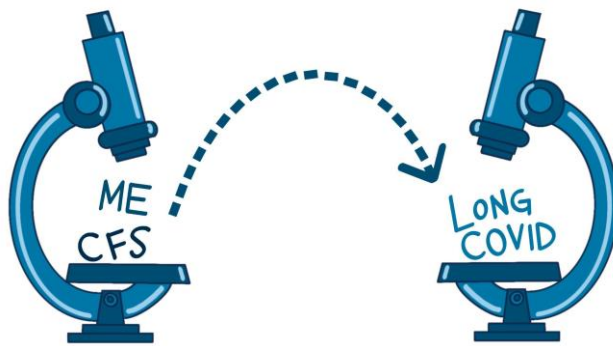
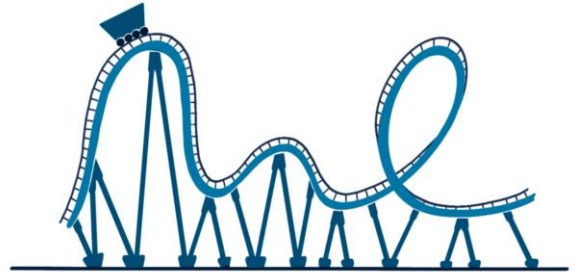
Eighteen invited speakers (8 online; 10 in-person) presented emerging evidence and their lived experiences with COVID, Long COVID and rehabilitation research and practice. There was one keynote speaker session, ten individual presentations, and a keynote panel session with question and answer periods integrated throughout. Please see **Appendix A** for the Forum Program Agenda. We provide an overview of the summary of evidence with key messages from each of the speaker presentations at the Forum.

Access all the Forum Speakers videos [here](#).

Key Messages

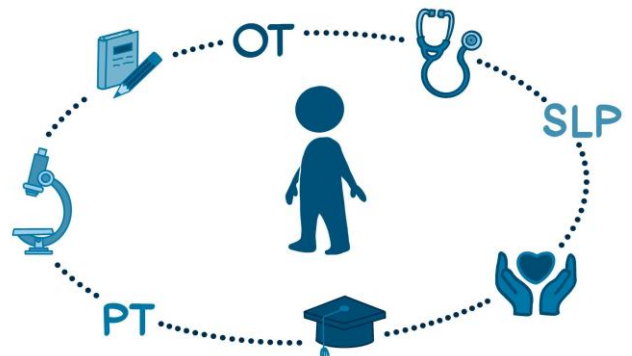
Key Messages with Associated Graphic illustrations of evidence presented at the Forum...

Key Message 1 - Disability experienced by persons living with Long COVID can be experienced as episodic, characterized by fluctuations in presence and severity of health-related challenges, which may be unpredictable in nature, occurring both within the day, and over the long-term of months and years living with Long COVID.



Key Message 2 - Rehabilitation and other health care providers and researchers can learn from other post-infectious conditions.

Key Message 3 - Person-centred care involving interdisciplinary health teams involving PT, OT and SLP may have a role in helping to prevent, mitigate or address episodes of disability among persons living with Long COVID and their caregivers.

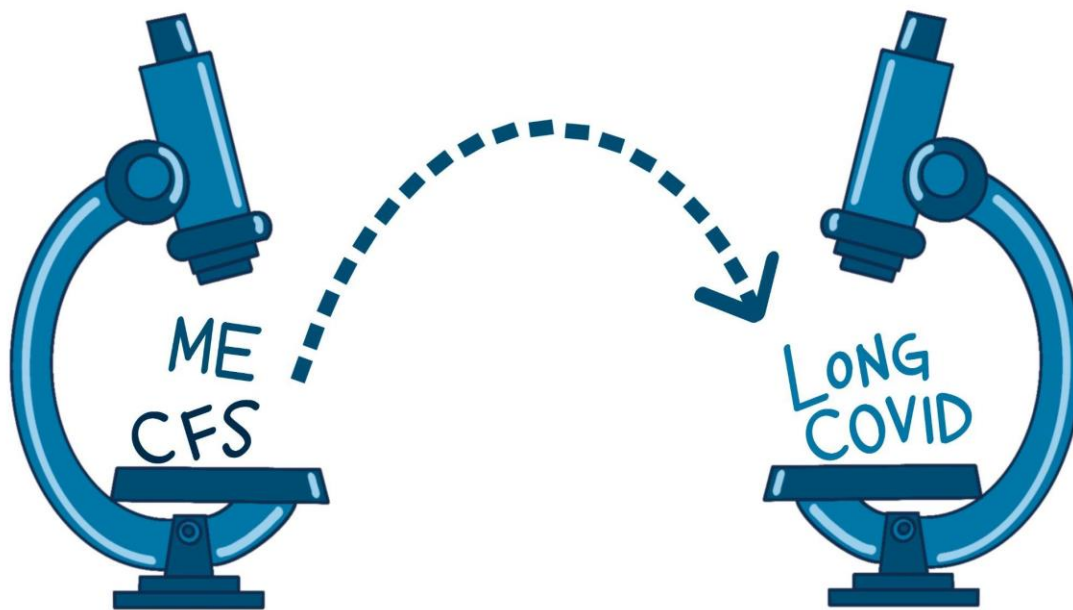


Keynote Session 1

Dr. Todd Davenport, Professor and Vice Chair in the Department of Physical Therapy at University of the Pacific in Stockton, California, presented on [Back to the Future for Long COVID Research](#).

Key messages from presentation:

- Patients know everything about what we as researchers study and what we as clinicians treat.



- Outlined operational definitions of Long COVID
 - World Health Organization ([Soriano et al., 2021](#))
 - Post-COVID Condition
 - Post-Acute Sequelae of COVID
- Described the history of how Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) has been defined and diagnosed over time, and around the world:
 - Oxford Criteria ([Sharpe, 1991](#))
 - Canadian Consensus Criteria
 - UK NICE Criteria
- It is important to carefully define Long COVID to avoid the confusion in the literature and the research that occurred with the difficulty and inconsistency in defining ME/CFS ([Davenport, Stevens, Stevens, Snell, & Van Ness, 2021](#)).
- In developing a taxonomy for Long COVID, the following should be prioritized:
 - Meaningful engagement of people with lived experiences of Long COVID
 - Base taxonomy on strong research and evidence
 - Taxonomy should allow for divergent and convergent validity
 - Taxonomy should maximize specificity and have sufficient sensibility to rule out confounding conditions like depression
 - Taxonomy should result in coherent clinical and physiological subgroupings

- Balance the need for specificity (i.e., understanding pathophysiology of specific symptoms and the needs of special populations) with an appreciation for the big picture (i.e., integration across symptoms and systems).
- There are different schools of thought about whether ME/CFS and Long COVID should be considered distinct conditions
 - This is complicated by the fact that there are many people with Long COVID who meet the diagnostic criteria for ME/CFS. More research is needed to understand how prevalent this is.
 - Post Exertional Malaise (PEM) is characteristic of ME/CFS and common in Long COVID
- PEM is not the same thing as fatigue. It can involve other symptoms, including breathing problems, cognitive dysfunction, dizziness, sore throat, headaches, etc. ([Chu, Valencia, Garvert, & Montoya, 2018](#))
- PEM can be triggered by physical and cognitive exertion. PEM is less often triggered by emotional distress ([Davenport et al., 2023](#); [Joseph et al., 2021](#); [Singh et al., 2022](#))
- There are important considerations for assessing PEM in research and clinical practice:
 - What triggers PEM?
 - How long does PEM last?
 - What symptoms are experienced with PEM? Which of those symptoms are the most severe?
- Key Findings from invasive cardiopulmonary exercise testing (iCPET) studies of PEM among patients with Long COVID and ME/CFS:
 - Decreased in oxygen consumption and ventilatory anaerobic threshold (suggestive of impairment in aerobic functioning) ([Joseph et al., 2021](#); [Singh et al., 2022](#); [Vernon et al., 2023](#))
 - Impaired systemic oxygen extraction (oxygen not leaving or getting to working cells, or getting to be used by mitochondria) ([Joseph et al., 2021](#); [Singh et al., 2022](#); [Vernon et al., 2023](#))
 - Aerobic system impairment further exacerbated by previous exertion ([Joseph et al., 2021](#); [Singh et al., 2022](#); [Vernon et al., 2023](#))
- There is a history of epistemic injustice in the context of ME/CFS. Epistemic humility is a priority and requires patients, researchers, and clinicians to work closely together ([Blease, Carel, & Geraghty, 2017](#)).
- There are special considerations to investigate a disease that breaks many of the rules we thought we knew.

Research and Evidence Session Part 1 – Profiling COVID-19 Rehabilitation Research across the Continuum of Care

Marina Wasilewski, Scientist at St. John’s Rehab Sunnybrook and Assistant Professor with the Department of Occupational Science & Occupational Therapy and the Rehabilitation Sciences Institute at the University of Toronto, presented on [*Long COVID and Disrupted Biographies: A Qualitative Study of Canadians’ Experiences*](#).



**PEOPLE WITH
LONG COVID AND
THEIR CAREGIVERS
EXPERIENCE
DISRUPTIONS IN
THEIR PERSONAL
IDENTITIES AND
PURPOSE OF LIFE**

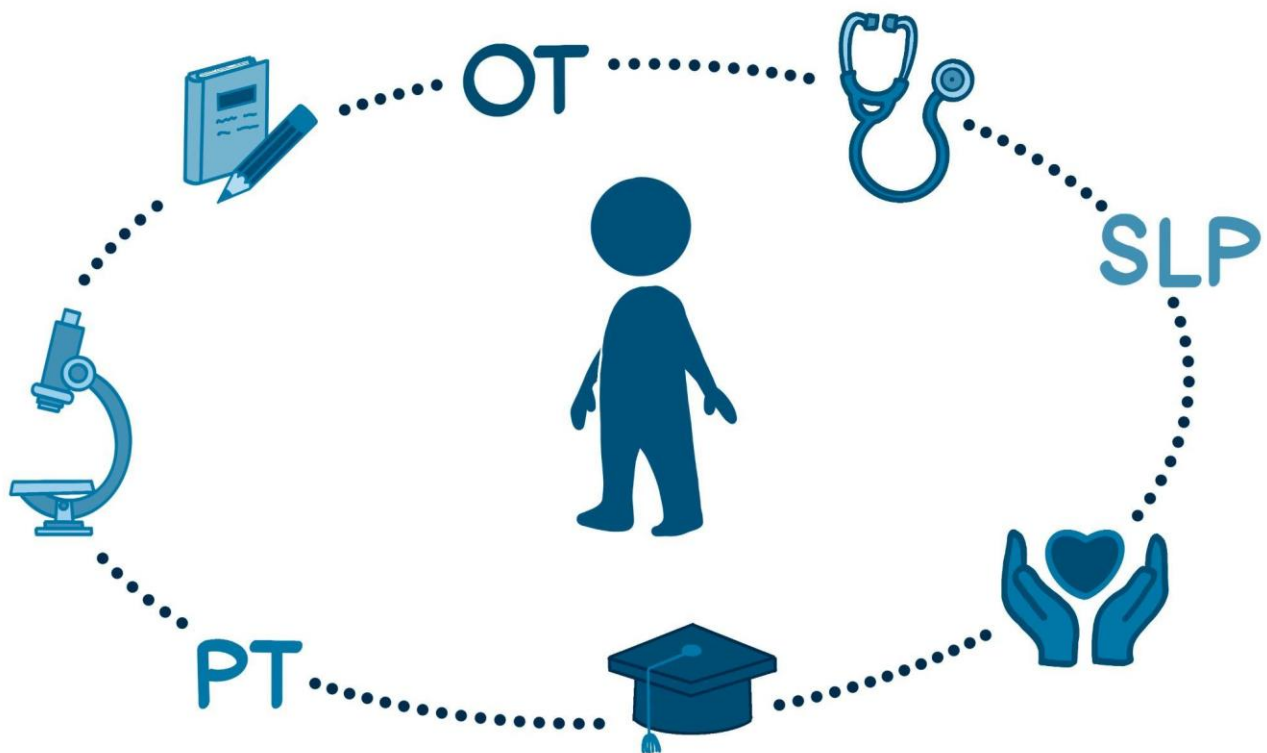


Key messages:

- Presented ongoing research with the aim to co-create a rehab strategy that would support the clinical aspects of living with Long COVID and managing Long COVID symptoms
 - Qualitative semi-structured interviews were conducted between April 2022 and February 2023 with health and social care providers who are working with people with Long COVID in any care setting, caregivers (with an even split between men and women), and people living with Long COVID
- People with Long COVID and their caregivers experience disruptions in their personal identities/biographies because of the lasting and detrimental impacts of long COVID
 - Disrupted biographies are underpinned by substantial loss and grief (e.g. loss of independence, loss of identity/personhood, and loss of meaning and purpose in life)
 - This impacted their independence, identity, and sense of meaning and purpose in life
- Disruptions entail needing to manage, shift, and adapt daily activities and roles to enable long COVID care and recovery for both people with Long COVID and their caregivers
 - This may involve adaptations to support one’s physical health (e.g. energy management strategies); caregivers carrying out tasks for people with Long COVID
 - Caregivers often experience being overwhelmed. This may impact their own health and wellbeing.

- Health care providers working with people with Long COVID also experienced disruptions in their professional roles (e.g. redeployment, confusion around what Long COVID is, altered perceptions of what pacing is and how to implement it, etc.)
- There are opportunities to:
 - Mitigate People with Long COVID (PWLC) and caregiver loss and grief stemming from disruptions in envisioned future
 - Develop caregiver-specific supports to manage new roles (combo of social, emotional, practical supports)
 - Develop (evidence-based) professional development resources for health care providers

Dr. Fiona Jones, Professor of Rehabilitation Research at St George's University of London presented on [The Listen trial- creating positive rehabilitation connections in the face of uncertainty.](#)



Key messages:

- Shared key learnings from a National Institutes of Health Research (NIHR) funded study, *LISTEN*, currently ongoing in the UK which co-designed and is now evaluating a new personalized strategy for self-management for people living with Long COVID ([Heaton-Shrestha et al., 2022](#); [Potter et al., 2023](#))
 - Aim: to evaluate the effectiveness of the LISTEN intervention for people with Long COVID on participation in routine activities, social participation, and emotional wellbeing when compared to usual NHS care
 - Eight-month co-design process involving 30 people with Long Covid and ten rehabilitation practitioners (large groups and small groups)
 - LISTEN intervention: 6 one-to-one personalized support sessions w a LISTEN trained practitioner (delivered over 10-12 weeks).
 - 56 practitioners trained to deliver the intervention

- Lessons about the key skills and support required by rehabilitation practitioners to personalize and build trust in each rehabilitation interaction
 - Practitioners were provided with descriptions of what the intervention should look like (e.g. ways to open and close sessions, exemplar sessions, crib sheets). Practitioners received eight hours of training.
- *LISTEN* study is still ongoing, but there have been key takeaways to date on how to build a ‘collective evidence base’ combining the knowledge and expertise from people with long COVID and rehabilitation practitioners.

Dr. Doug Gross, Professor in the Department of Physical Therapy at the University of Alberta, presented on [*Social Engagement and Employment among People with Long COVID*](#).

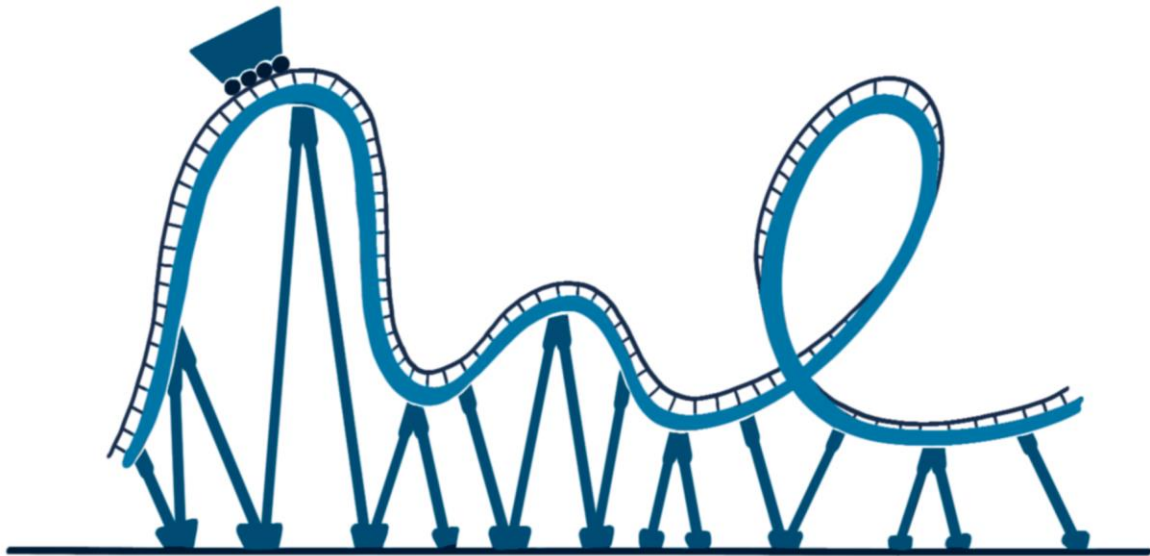


Key messages:

- Presented research involving one-on-one interviews. Conducted via Zoom/telephone. Participants were recruited from private physiotherapy clinics, public Long COVID clinics in Calgary and Edmonton, Alberta Health Services telephone advice line, and the WCB Alberta Post-COVID clinic. Interviews were also conducted with individuals not accessing rehab.
- Research questions: What are health concerns and needs leading PWLC to seek rehab? What experiences and services received, including barriers to access? How well did existing services meet or not meet health and rehabilitation needs?
- From the perspective of those with lived experiences, symptoms of Long COVID have a fluctuating, rollercoaster-like impact on health, function, and social engagement including employment.

- When navigating Long COVID services within the public health and workers' compensation systems, participants encounter barriers to access around stigma, appointment logistics, testing and 'normal' results, financial precarity, and affordability of services.
- Long COVID rehabilitation services should provide multi-disciplinary, flexible, patient-centered approaches that avoid symptom exacerbation while collaborating closely with workplaces to identify suitable accommodated duties.

Dr. Kelly O'Brien, Associate Professor in the Department of Physical Therapy with cross-appointments to the Institute of Health Policy Management and Evaluation (IHPME) and Rehabilitation Sciences Institute (RSI) at the University of Toronto, presented on [Conceptualizing the episodic nature of disability among adults living with Long COVID: Findings from an international community-engaged qualitative study](#). Kelly is a Co-Director of the Rehabilitation Science Research Network for COVID in the Temerty Faculty of Medicine at the University of Toronto.



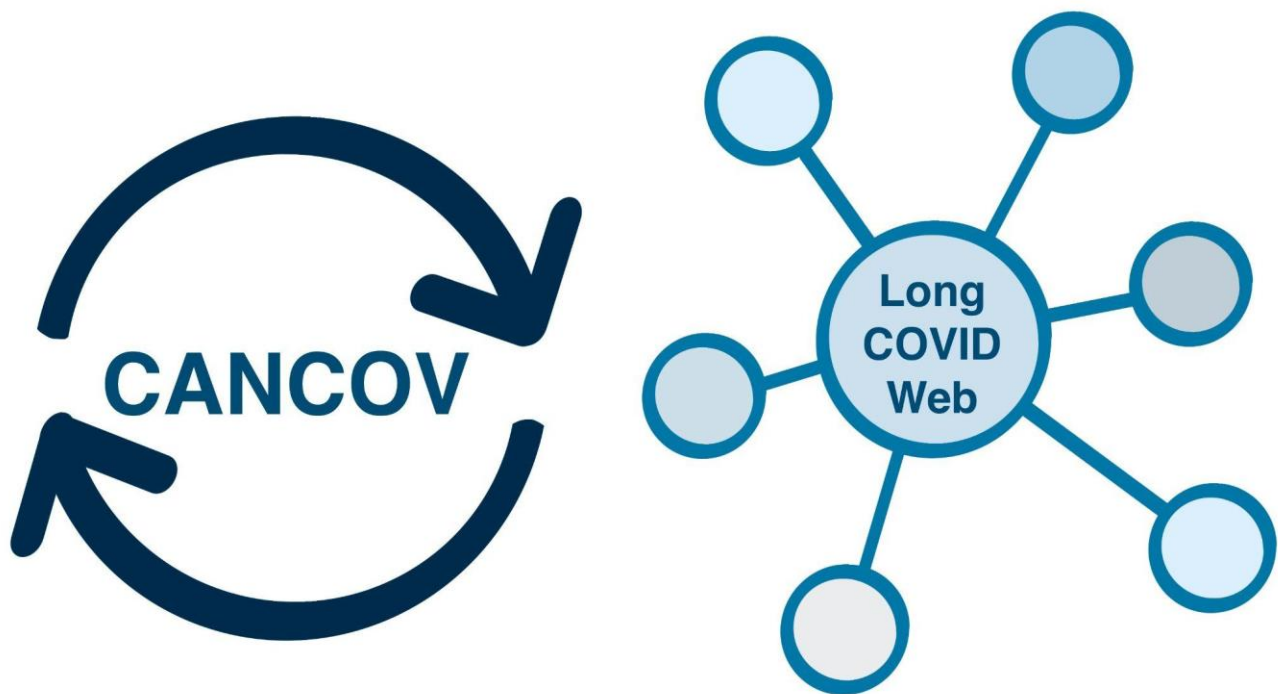
Key messages:

- Presented on a community-engaged, qualitative descriptive study, using online semi-structured interviews with 40 adults living with Long COVID (10 each in Canada, the UK, the United States, and Ireland) ([Brown & O'Brien, 2021](#); [O'Brien et al., 2022](#); [O'Brien et al., 2023](#)).
 - Study aim: To describe episodic nature of disability among adults living with long COVID.
- Episodic disability is any physical, cognitive, mental or emotional health challenges, difficulty carrying out day-to-day activities, challenges to social inclusion, uncertainty or worrying about future that an individual may experience and which may fluctuate over time ([O'Brien, Bayoumi, Strike, Young, & Davis, 2008](#); [O'Brien, Davis, Strike, Young, & Bayoumi, 2009](#)).
- Disability living with Long COVID was described by participants in this study as episodic, characterised by fluctuations in presence and severity of health related challenges, which may be unpredictable in nature,

occurring both within the day, and over the long-term of months and years living with Long COVID ([O'Brien et al., 2023](#)).

- Disability was characterized as multi-dimensional, characterized by physical, cognitive and mental-emotional health challenges, difficulties carrying out day-to-day activities, uncertainty about future health, and challenges to social inclusion which may be influenced by intrinsic (personal attributes, living strategies) and extrinsic (support, stigma) contextual factors over time ([O'Brien et al., 2023](#)).
- Uncertainty was a key component of the episodic disability experience as it intersected with the episodic nature of disability, characterised as unpredictability of episodes, their length, severity and triggers, and process of long-term trajectory, which had implications on broader health including the ability to return to employment ([O'Brien et al., 2023](#)).

Dr. Angela Cheung, Professor of Medicine and the KY and Betty Ho Chair of Integrative Medicine at the University of Toronto and co-lead for CIHR funded Long COVID Web, presented on [CANCOV Study Updates & Long COVID Web](#).



Key messages:

- Highlighted key findings from CANCOV study, which is a Canadian cohort study of people diagnosed with COVID including clinical characteristics and long-term outcomes.
 - 6 Minute Walk Test (6MWT):
 - Intensive Care Unit (ICU) patients: low 6MWT scores 1 month after discharge from ICU; improve over time.
 - Hospitalized non-ICU patients: low 6MWT scores 1 month after discharge; improved but not back to baseline at 12 months post-discharge.
 - Non-hospitalized patients: 6MWT scores improved (better than other groups), but again at 12 months post-infection, also not back to baseline.
 - Many patients have abnormally low Functional Vital Capacity (FVC) and Forced Expiratory Volume (FEV) 1 (suggestive of damage to lungs)

- This is observed in ICU patients, hospitalized non-ICU patients, and also in non-hospitalized patients
 - There may be a role for pulmonary rehabilitation to address these impairments
- Provided an overview of *RECLAIM* (Recovering from COVID lingering symptoms adaptive integrative medicine): involves 13 different interventions that included self-management, supplements, Traditional Chinese Medicine, etc.
- Introducing Long COVID Web – a national research network to advance research and clinical care of individuals affected by Long COVID.
 - Mission is to accelerate the discovery of Canadian-led science, activate learning health system that prioritized needs of individuals with Post-COVID Condition (PCC), identify best therapeutics and practices and accelerate equitable access to PCC care and maintain surveillance of impact of PCC
 - Key driving questions: How can we diagnose long COVID? How can we manage and treat long COVID? How can we access health and social services?

Keynote Session #2 – Panel discussion, *Best Practices for Community-Engaged Approaches to COVID-19 Rehabilitation Research*



Panelists: **Melissa Egan**, National Lead, Episodic Disabilities at *Realize*; **Susie Goulding**, community-member with Long COVID and founder of the Covid Long-Haulers Support Group Canada; **Alyssa Minor**, community-member with Long COVID and Physiotherapist; **Mark Rutledge**, community-member with Long COVID; **Anisha Sekar**, community-member with Long COVID and member of the Patient-Led Research Collaborative; **Hannah Wei**, community-member with Long COVID and co-founder at the Patient-Led Research Collaborative; and **Harriet Wright**, MPH with a focus in Infectious Diseases and Microbiology and a caregiver to someone with Long COVID.

Moderator: **Kiera McDuff**, Physiotherapist and Program Coordinator for the Rehabilitation Science Research Network for COVID.

Aim of Session: To build research capacity learning from persons with lived experiences about their experiences and perspectives engaging in COVID rehabilitation research, and to discuss recommendations, considerations, and best practices for engaging in COVID rehabilitation research.

Key messages:

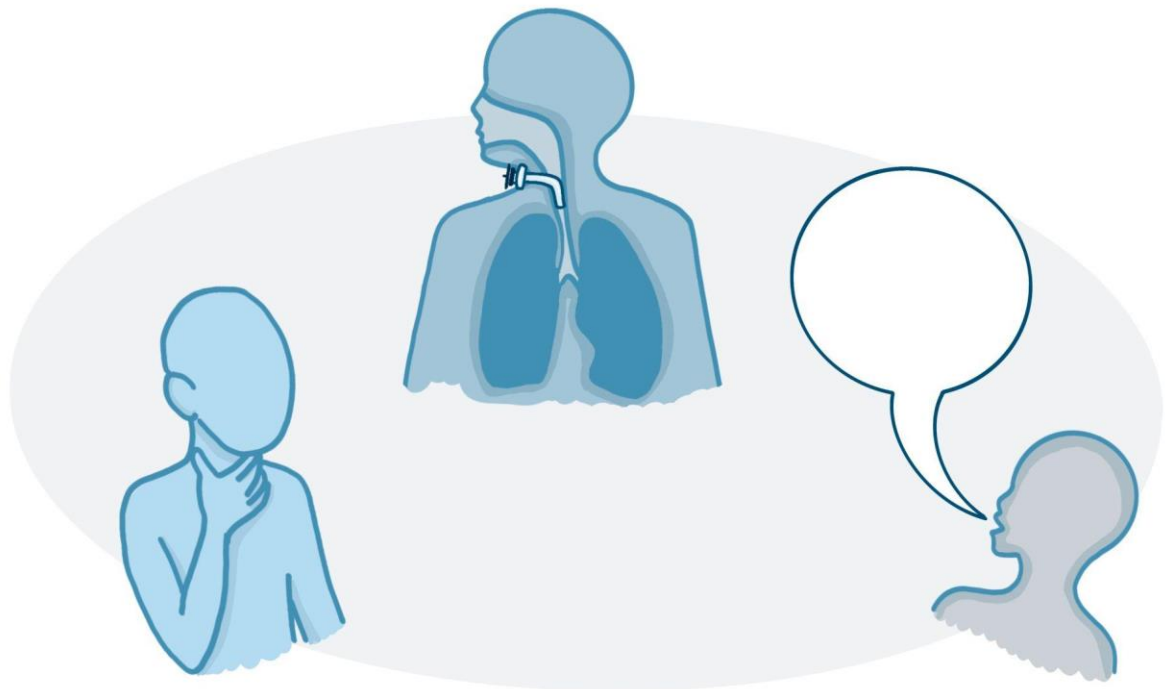
- Discussed positive and negative experiences of engaging in COVID rehabilitation research
- In the context of Long COVID, it is important to learn from the history of other post-viral illnesses and to learn from people with lived experiences
 - Reduce creating redundancies in research and wasting resources (financial/time) repeating past work/mistakes
- Co-design is important in the context of COVID rehabilitation research

- Researchers should prioritize budgeting for the involvement of patient-collaborators and groups to be involved at all stages of the research process
- It is never too early to involve patients in the research process
- Patients and community members should be involved in generating research priorities and hypotheses
- Not all patients and community-members have equal opportunity to engage in research
 - There are geographical barriers to engaging in research (e.g. those in rural and remote regions are often excluded due to distance and disconnect between those communities and research/academic institutions)
 - Technology should be optimized and utilized to help increase access to participating in research
 - Racism and discrimination create additional barriers to participating in research and engaging with clinicians
- When research teams demonstrate enthusiasm toward patient-engagement, this fosters greater and more effective collaboration
 - Researchers should maintain curiosity and be open-minded toward what can be gained through greater involvement of people with lived experiences
- Consider ways to empower people with lived experiences through the research process
 - Ask them what language they identify with and prefer
 - Address stigma and ableism – it is important to have individualized accommodations
- The [Patient-Led Research Score Cards](#) are a tool developed by Patient-Led Research Collaborative and the Council of Medical Specialty Societies to help evaluate and advance patient-led collaborative research efforts in the following areas:
 - Patient burden
 - Patient/Partner governance
 - Research organization readiness
 - Integration into research process
- There are many strategies that research teams can implement to reduce the patient burden for engaging in research
 - *“Connect with the community and meet people where they are at”*
 - Allow for flexibility in timelines
 - Online and hybrid meetings
 - Meeting earlier in the day may help to accommodate brain fog
 - Share notes in advance of and after meetings
 - Send out frequent and ongoing reminders about meetings and deadlines
 - Have a plan in place to support patients through crashes/relapses during the research process
- There are unique considerations to engaging caregivers in research as well
 - The role of ‘caregiver’ can be very all-consuming in one’s life; story-telling is a useful way to convey one’s experience and inform public-perceptions
 - Prioritize resources to help support the caregiver as well as the patient (e.g. peer-support; clinical resources)
- Addressing ableism is key to fostering community-engaged research
 - Issues of societal and institutional oppression impede community-engagement
 - Evaluating, critiquing, and dismantling ableism as it relates to research and clinical practice is necessary to enable greater involvement of patients in the research process

- Important question to ask at every stage of the research process: ‘Who is involved? Who is excluded?’ and ‘Who else can we talk to?’
- Approach to research should always be ‘human-centered’ over ‘data-centered’

Research Evidence Session Part 2 – Profiling COVID-19 Rehabilitation Research across the Continuum of Care – Rehabilitation Approaches

Dr. Stacey Skoretz, Assistant Professor and Director of the Swallowing Innovations Lab (Si-Lab) at the University of British Columbia, presented on [*Unravelling the pandemic complexities of swallowing and communication following invasive ventilation.*](#)



Key messages:

- Shared findings from a study that explored laryngeal function of patients with tracheostomy with covid-19 in the acute phase of illness ([Dawson et al., 2023](#)).
 - Aim: Understand clinician's perspective practicing in acute care assessing and managing patients with dysphagia following invasive ventilation during the pandemic
 - Themes: empowerment, fear, anxiety, learning, resilience, isolating; continual evaluation of information, restricted access to resources, and morale changes.
- Impaired airway protection during swallowing is associated with more complex and severe otolaryngological, respiratory, and physical manifestations following severe COVID-19.
- Risk stratification along with proactive and standardized multi-disciplinary assessments of swallowing and communication following invasive ventilation improves patient health outcomes.
- The roles of speech-language pathologists are still poorly understood across the healthcare system – how we navigate future care delivery for swallowing and communication can be informed through the lived experiences and resiliency of patients and front-line clinicians.

Jessica DeMars, Physiotherapist and Co-Director of Advocacy for the Long COVID Physio executive board, presented on [BREATHE: A mixed-methods evaluation of a virtual self-management program for people living with Long COVID](#).



Key messages:

- BREATHE is an education and self-management program for people with Long COVID; important element of peer-support
 - Developed to address concerns re: return to work and exercise triggering Long COVID symptoms ([Wurz et al., 2022](#)).
 - Topics included: Fatigue, post-exertional malaise (PEM) ([Twomey et al., 2022](#)), sleep, dysautonomia, return to work, etc.
- Virtual, multi-disciplinary, group-based self-management is a feasible, safe/tolerable and acceptable format for people living with Long COVID
- A virtual, group-based format may improve self-efficacy to manage chronic illness and reduce social isolation
 - Empathy, reassurance, encouragement and optimism were key
- We may need to rethink what we consider rehabilitation, and how we deliver it to people living with Long COVID

Dr. Simon Décary, Assistant Professor of Rehabilitation at University of Sherbrooke in Québec and co-lead for Long COVID Web, presented on [Integrating Rehabilitation in Care Models for Long COVID: third update of a living systematic review](#).



Key messages:

- With the prevalence of Long COVID, many countries have been driven to organize health care systems to provide care for Long COVID
 - There have been international efforts to integrate standardized assessment procedures
- Three years of international evidence propose that rehabilitation professionals are key to achieve integrated care models for Long COVID.
- Presented findings from a systematic review of care models for Long COVID rehabilitation ([Décary et al., 2021](#)).
- Canadian context - 4 care pathways:
 - Community-based referrals
 - Hospital
 - Intensive care
 - Self-referral
- Long COVID care models are interdisciplinary (20 unique health care providers identified as involved), including physiotherapy, psychiatry, pulmonary/respiratory rehabilitation, etc.
- There are gaps between emerging evidence (e.g. important screening) and what is implemented in practice
- While initial rehabilitation interventions focus on safe approaches such as pacing, emerging adapted specialty approaches are developing within care models.
- Future work will standardize rehabilitation outcome measures and practices for this population.

Dr. Jill Cameron, 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 and Co-Director of the Rehabilitation Science Research Network for COVID, presented on [Co-Designing Person and Family Centered Care for Long COVID](#).



Key messages from presentation:

- Consider the complexity of meeting the needs of diverse patient and family populations.
- Consider other models of care to integrate patient and family support across the illness trajectory.
- 1 in 4 Canadians are caregivers – unpaid labour that is estimated to save the healthcare system over 60 billion dollars annually.
 - Caregivers are essential to the sustainability of the health care system.
- It is not currently standard practice in the health care system to support or prepare caregivers across illness populations.
- Caregivers experience stress, burden, poor mental health, work-life disruptions, etc.
 - This impacts their ability to support those who they are caring for ([Cameron et al., 2016](#)).
- “Timing it right” framework (TIRF): comprehensive 5 phase approach can be used to support family from hospital to home ([Cameron & Gignac, 2008](#)).
- There are unique considerations to researching the role of caregivers:
 - Caregivers are not a homogenous group – e.g. varied emotional adaptation to providing care, sex and gender influence caregiver experiences ([Cameron et al., 2016](#); [Kokorelias, Gignac, Naglie, & Cameron, 2019](#)).
- The role of caregivers in COVID and Long COVID care has not yet been well studied or understood.

Evaluation

Forty-six (29%) of the 160 people who attended the Forum completed the evaluation survey (See **Appendix D** for the evaluation survey and **Appendix B** for a detailed report of the Evaluation Survey results). The evaluation highlighted strengths and successes and provided valuable feedback to the Network and the Forum Planning Team. See **Table 2** for a breakdown of the characteristics of those who completed the evaluation survey.

Table 2: Characteristics of Forum Evaluation Questionnaire Respondents (n=46)

Characteristics of Evaluation Survey Respondents	N (%)
Mode of Attendance	
<i>Online</i>	33 (72%)
<i>In-Person</i>	13 (28%)
Country (n=44)	
<i>Canada</i>	35 (80%)
<i>United States of America</i>	3 (7%)
<i>United Kingdom</i>	2 (5%)
<i>Other (e.g. Greece, Germany, Isle of Man, India)</i>	4 (9%)
Stakeholder Group (n=45)	
<i>Clinician</i>	16 (36%)
<i>Academic or Researcher (e.g. located at an academic institution)</i>	15 (33%)
<i>Community member (e.g. person with lived experiences with COVID and/or Long COVID or their parents, partners, and caregivers)</i>	8 (18%)
<i>Trainee (e.g. MSc, PhD, or Post-doctoral Fellow)</i>	1 (2%)
<i>Other (e.g. Facilitator for a virtual Long COVID education program, person with lived experience with ME/CFS, provincial organization, research coordinator)</i>	4 (9%)
Type of Health Care Professional (n=16)	
<i>Physiotherapist</i>	9 (56%)
<i>Physician</i>	3 (19%)
<i>Occupational Therapist</i>	2 (13%)
<i>Other (e.g. Speech-Language Pathologist, Massage Therapist)</i>	2 (13%)
Has lived experiences: (n=45)	
<i>With Long COVID</i>	11 (24%)
<i>With Acute COVID</i>	6 (13%)
<i>With another chronic health condition or disability (e.g. (chronic fatigue, ME, fibromyalgia, dyslexia, learning disability, cluster headaches)</i>	6 (13%)
<i>As a caregiver to someone with acute COVID</i>	3 (7%)
<i>As a caregiver to someone with Long COVID</i>	2 (4%)
<i>With none of the above</i>	17 (38%)
Invited speaker/panelist to the Forum (n=45)	5 (11%)

Overall Satisfaction with the Forum:

Attendees were asked to rate their overall satisfaction with the Forum on a scale of 0-10 with 0 being 'not at all satisfied' and 10 being 'extremely satisfied'. Among the 44 respondents to this question, the median rating of satisfaction (25th, 75th percentile) with the Forum was 9 out of 10 (8, 10).

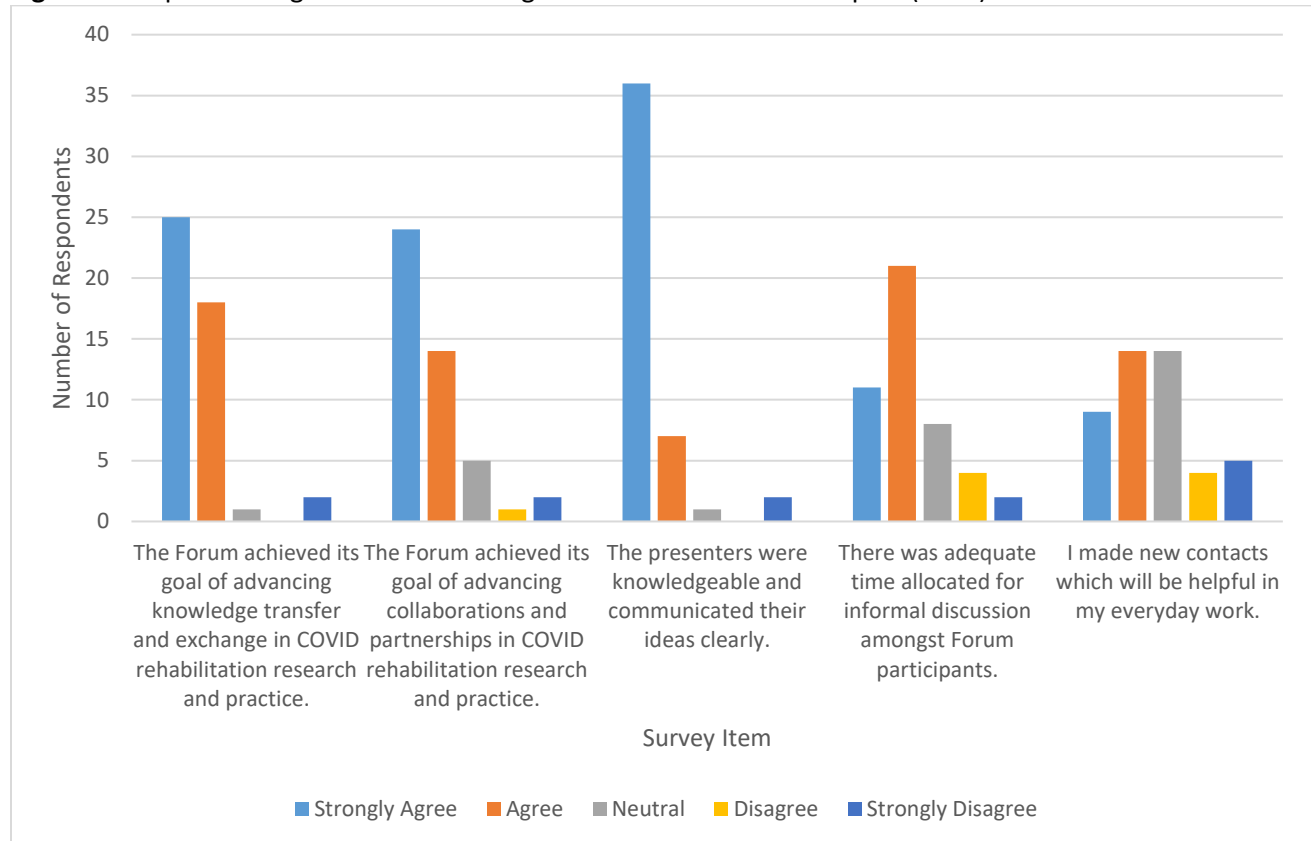
Respondents articulated several **'Take Home Messages'** from the Forum:

- It is important to continue good research related to COVID and rehabilitation. Including:
 - Post-exertional malaise
 - Investigation of rehabilitation interventions
- Greater participation from other post-infectious diseases would be beneficial
- It is important to listen to the voices of those living with Long COVID and to engage people with lived experiences in research and in design/implementation of rehabilitation programs
- The 7 grandfather teachings from the Anishinaabe tradition that Mark shared during the Keynote Panel (wisdom, love, respect, courage, honesty, humility and truth)
- It is important for clinicians and researchers to collaborate, in addition to involving those with lived experiences
- There is an important role for rehabilitation in the management of Long COVID
- There are ongoing education gaps among health care providers (including in primary care)
 - Assessment and management of Long COVID
 - Stigma
- There are similarities between ME/CFS and Long COVID
- It is important to consider PEM/PESE when working with people with Long COVID
- Long COVID is a big umbrella term and more understanding/investigation of subgroups is needed to inform clinical guidelines and best practices
- Telehealth can be used to enhance access to care
- More caregiver specific support is needed (social, emotional, practical)
- More research is needed with respect to Long COVID across the lifespan (aging population)
- The concept and characteristics of episodic disability need to be understood

Respondents were also asked to rate the extent to which they agreed with the following:

- The Forum had achieved its goals;
- The presenters were knowledgeable and communicated clearly;
- There was adequate time for informal discussion among attendees; and
- That they had made new contacts that would be helpful for their everyday work (see **Figure 1** for details).

Figure 1: Respondent Agreement Pertaining to Forum Process and Outputs (n=46)



Application to Future Work

The majority of respondents (39/45; 87%) indicated that they would be able to **apply the content covered in the Forum to their work**. Specific strategies included:

- Implementing or continuing to implement self-management interventions and education interventions for people living with Long COVID
- Sharing research presented in the Forum with colleagues and using the research shared to inform their practice
- Applying information shared in the Forum to supporting clients with Long COVID in a primary care setting, including assessment and treatment, and referrals to other services
- Screening for ME/CFS more effectively/regularly in clinical practice
- Ideas for future research
- Referencing information shared at Forum in advocacy efforts for Long COVID
- Improving/deepening involvement of people with lived experiences in research
- Motivating them to publish quality improvement work related to virtual care
- Sharing information presented at Forum with health professions students, developing curriculum
- Applying Indigenous principles to research
- Implementing methodologies (e.g. co-design) that were discussed at the Forum
- Utilizing the [PLRC score cards](#)

Strengths and Limitations of the Forum:

Respondents provided informative and encouraging comments regarding **strengths and drawbacks of the Forum**. The responses indicated that participants appreciated the hybrid (in-person and online); appreciated the emphasis and inclusion of the voices of people with lived experiences with Long COVID and their caregivers; found speakers and presentations to be high quality; and felt it was a great opportunity for transfer and dissemination of knowledge and research.

In the future, respondents indicated they would prefer more time for interactive dialogue, as well as more time for socialization between presentations. Participants also found that a lot of information was presented in a short amount of time and would prefer the Forum to be held in shorter increments over the course of a few days. Finally, some participants said that they would appreciate more information from or directed toward clinicians, with specific implications for how to practice COVID rehabilitation.

Highlighted Needs & Conclusion

This report summarizes the process and content of the inaugural *International Forum on COVID Rehabilitation Research*. The evidence presented at the Forum highlights the need for:

- A collaborative approach to research to advance evidence in COVID rehabilitation that centres those with lived experiences with COVID and/or Long COVID and their caregivers;
- COVID rehabilitation research *across the lifespan* (including pediatric, adult, and geriatric);
- Knowledge translation and mobilization of research that informs and supports health care providers in the delivery of safe, timely, and equitable COVID rehabilitation; and
- Breaking down barriers to providing care across all communities (including rural and remote communities) through the provision of virtual care and legislation that supports health care providers in being able to delivery virtual care across geographic boundaries.

This Forum also highlighted the value and importance of online and hybrid events for connecting researchers, clinicians, people with lived experiences, and their caregivers both nationally and internationally.

Ongoing research and inquiry in the field of COVID rehabilitation is needed to better understand the role of rehabilitation in supporting those living with COVID and/or Long COVID and their caregivers. Approaches to research should involve collaboration with clinicians and those with lived experiences. This Forum was successful in translating emerging research evidence and fostering connections and potential collaborations among stakeholders in COVID rehabilitation across Canada and internationally.

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Appendix A – Forum Program at a Glance

FORUM PROGRAM at a GLANCE

Friday April 21, 2023- 10:00am – 4:00pm EDT

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

Aim of Forum: To advance knowledge transfer and exchange, collaborations and partnerships in COVID rehabilitation research and practice.

Time	Topic
10:00-10:10am	<p>Land Acknowledgement & Welcome Susan Jaglal, <i>Executive Chair, Rehabilitation Sciences Sector, University of Toronto</i></p>
10:10-10:30am	<p>Overview & Aims of the Forum Kelly O’Brien and Jill Cameron <i>Co-Directors, Rehabilitation Science Research Network for COVID, University of Toronto</i> Darren Brown, PT, <i>Chair, Long COVID Physio</i></p>
10:30am-11:15am	<p>Keynote Session #1 - Back to the Future for Long COVID Research Todd Davenport <i>Professor and Vice-Chair in the Department of Physical Therapy, School of Health Sciences, University of the Pacific, Stockton, California, United States</i> <i>Scientific Advisor, Workwell Foundation; Executive, Long COVID Physio</i></p>
11:15-11:25	Break
11:25am-12:30pm	<p>Research Evidence Session – Part 1 - Profiling COVID-19 Rehabilitation Research across the Continuum of Care <u>Aim of Session:</u> To foster knowledge transfer and exchange on evidence related to COVID Rehabilitation research (7 min presentation + 3 min Q&A each)</p> <ol style="list-style-type: none"> 1. Marina Wasilewski, Assistant Professor (Status), Department of Occupational Sciences and Occupational Therapy, University of Toronto, Sunnybrook Health Sciences Centre, St. John’s Rehab Title: <i>Long COVID and Disrupted Biographies: A Qualitative Study of Canadians’ Experiences</i> 2. Fiona Jones, Professor, Kingston University and St. George’s, University of London, United Kingdom Title: <i>The Listen trial- creating positive rehabilitation connections in the face of uncertainty</i> 3. Doug Gross, PT, Professor, Faculty of Rehabilitation Medicine, Physical Therapy, University of Alberta Title: <i>Social Engagement and Employment Among People with Long COVID</i> 4. Kelly O’Brien, PT, Associate Professor, Department of Physical Therapy; Co-Director, Rehabilitation Science Research Network for COVID, Temerty Faculty of Medicine, University of Toronto Title: <i>Conceptualizing the episodic nature of disability among adults living with Long COVID: Findings from an international community-engaged qualitative study</i> 5. Angela Cheung, Professor, Dalla Lana School of Public Health (DLSPH), University of Toronto, University Health Network, Toronto Title: <i>CANCOV, RECLAIM and Long COVID Web</i>
12:30-1:15pm	Lunch

Time	Topic
1:15-2:15pm	<p>Keynote Session #2 – Panel Discussion</p> <p>Best Practices for Community-Engaged approaches to COVID-19 Rehabilitation Research</p> <p><u>Aim of Session:</u> To build capacity learning from persons with lived experiences about their experiences and perspectives engaging in COVID rehabilitation research, and to discuss recommendations, considerations and best practices for engaging in COVID rehabilitation research.</p> <p>Panelists: Hannah Wei (Patient Led Research Collaborative) Mark Rutledge (Advisory Committee Member) Harriet Wright (Advisory Committee Member) Anisha Sekar (Patient-Led Research Collaborative) Susie Goulding (COVID Long Haulers Support Group Canada; Advisory Committee Member) Alyssa Minor (Long COVID Physio), & Melissa Eagan (Realize)</p> <p>Moderator: Kiera McDuff (Rehabilitation Science Research Network for COVID)</p>
2:15-2:30	Break
2:30-3:30pm	<p>Research Evidence Session – Part 2 - Profiling COVID-19 Rehabilitation Research across the Continuum of Care – Rehabilitation Approaches</p> <p><u>Aim of Session:</u> To foster knowledge transfer and exchange on evidence related to COVID Rehabilitation research (7 min presentation + 3 min Q&A each)</p> <ol style="list-style-type: none"> Stacey Skoretz, Speech-Language Pathologist, University of British Columbia Title: <i>Unravelling the pandemic complexities of swallowing and communication following invasive ventilation</i> Michelle Kho, PT, Associate Professor, School of Rehabilitation Science, McMaster University, Canada Title: <i>COVID and Post ICU frailty and quality of life</i> Jessica DeMars, PT, Breathewell, Vancouver British Columbia, Canada Title: <i>BREATHE: A mixed-methods evaluation of a virtual self-management program for people living with Long COVID</i> Simon Décary, PT, Assistant Professor, University of Sherbrooke, Montreal, Quebec Title: <i>Integrating Rehabilitation in Care Models for Long COVID: third update of a living systematic review</i> Jill Cameron, Professor, Department of Occupational Science and Occupational Therapy; Co-Director, Rehabilitation Science Research Network for COVID, Temerty Faculty of Medicine, University of Toronto Title: <i>Co-Designing Person and Family Centered Care for Long COVID</i>
3:30-4:00pm	Wrap Up, Next Steps & Evaluation

Acknowledgements: The Rehabilitation Science Research Network for COVID is funded by Temerty Faculty of Medicine; **Forum Planning Committee:** Kelly O'Brien, Jill Cameron, Kiera McDuff, Darren Brown, Nisa Malli, Alexandra Rendely, Laura Bassi, Katie Churchill, Brittany Torres, Rob Page



Appendix B – Complete Evaluation Survey Responses 2023 International Forum on COVID Rehabilitation Research

Characteristics of Evaluation Survey Respondents

Table 1: Characteristics of Evaluation Survey Respondents (n=46)

Characteristics of Evaluation Survey Respondents	N (%)
Mode of Attendance	
<i>Online</i>	33 (72%)
<i>In-Person</i>	13 (28%)
Country (n=44)	
<i>Canada</i>	35 (80%)
<i>United States of America</i>	3 (7%)
<i>United Kingdom</i>	2 (5%)
<i>Other (e.g. Greece, Germany, Isle of Man, India)</i>	4 (9%)
Stakeholder Group (n=45)	
<i>Clinician</i>	16 (36%)
<i>Community member (e.g. person with lived experiences with COVID and/or Long COVID or their parents, partners, and caregivers)</i>	8 (18%)
<i>Academic (e.g. located at an academic institution)</i>	8 (18%)
<i>Researcher</i>	7 (16%)
<i>Trainee (e.g. MSc, PhD, or Post-doctoral Fellow)</i>	1 (2%)
<i>Other (e.g. Facilitator for a virtual Long COVID education program, person with lived experience with ME/CFS, provincial organization, research coordinator)</i>	4 (9%)
Type of Health Care Professional (n=16)	
<i>Physiotherapist</i>	9 (56%)
<i>Physician</i>	3 (19%)
<i>Occupational Therapist</i>	2 (13%)
<i>Other (e.g. Speech-Language Pathologist, Massage Therapist)</i>	2 (13%)
Has lived experiences: (n=45)	
<i>With Long COVID</i>	11 (24%)
<i>With Acute COVID</i>	6 (13%)
<i>With another chronic health condition or disability (e.g. (chronic fatigue, ME, fibromyalgia, dyslexia, learning disability, cluster headaches)</i>	6 (13%)
<i>As a caregiver to someone with Long COVID</i>	2 (4%)
<i>As a caregiver to someone with acute COVID</i>	3 (7%)
<i>With none of the above</i>	17 (38%)
Invited speaker/panelist (n=45)	5 (11%)

Satisfaction with Forum and Sessions

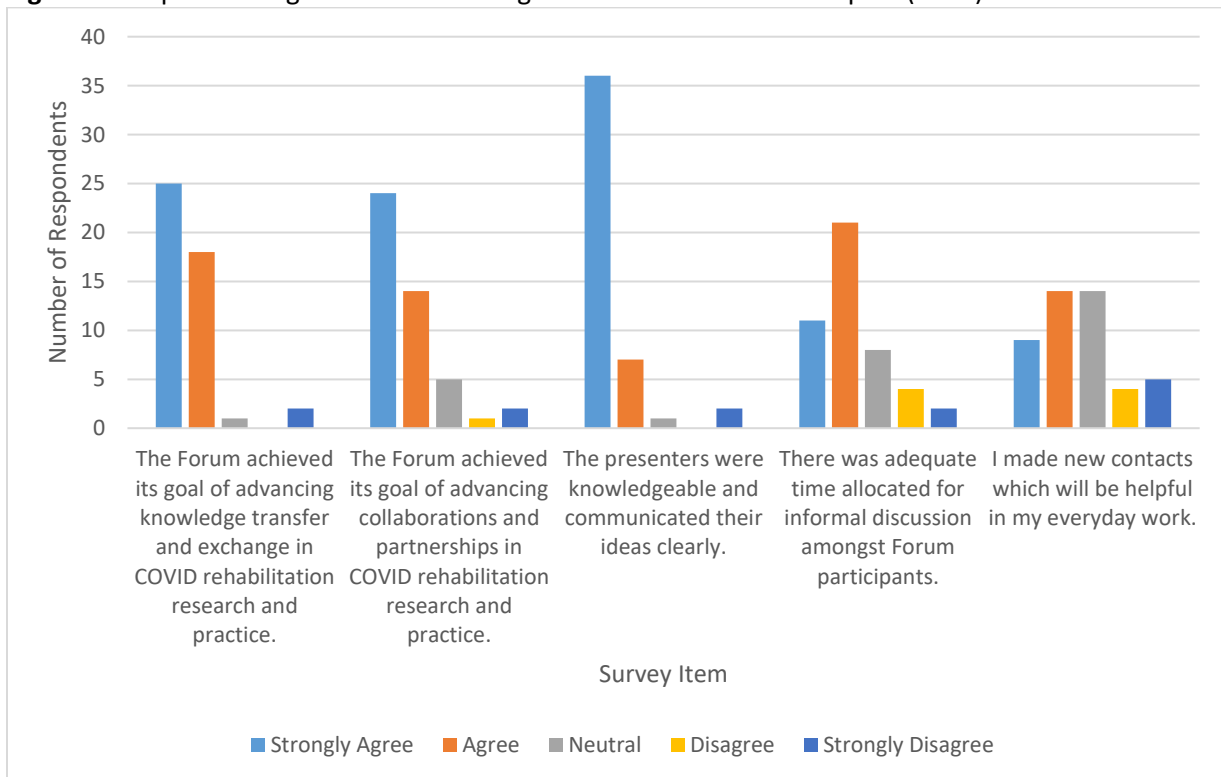
Attendees were asked to rate their overall satisfaction with the Forum on a scale of 0-10 with 0 being ‘not at all satisfied’ and 10 being ‘extremely satisfied’. 44/45 respondents to the evaluation survey responded to this question. The median (IQR) rating of satisfaction with the Forum was 9 (8, 10).

Table 2: Satisfaction with Sessions from the Forum

Session Title	Rating of Satisfaction Median (IQR)
Keynote Session #1 - Back to the Future for Long COVID Research (Dr. Todd Davenport)	10 (9,10)
Research Evidence Sessions (Part 1) (Dr. Marina Wasilewski, Dr. Fiona Jones, Dr. Doug Gross, Dr. Kelly O'Brien, and Dr. Angela Cheung)	9 (8, 10)
Keynote Session #2 – Panel Discussion: Best Practices for Community-Engaged Approaches to COVID-19 Rehabilitation Research? <i>Missing</i>	9 (8, 10) 4
Research Evidence Sessions (Part 2) (Dr. Stacey Skoretz, Dr. Michelle Kho, Jessica DeMars, Dr. Simon Décarý, and Dr. Jill Cameron) <i>Missing</i>	9 (8, 10) 5

Respondents were asked to rate their satisfaction with the sessions presented at the forum on a scale of 0-10 with 0 being ‘not at all satisfied’ and 10 being ‘extremely satisfied’.

Figure 1: Respondent Agreement Pertaining to Forum Process and Outputs (n=46)



Impact of Forum

Respondents were asked to rate their **knowledge on COVID and rehabilitation research before attending the Forum and after attending the Forum** on a scale of 0-10 with 0 being 'not at all knowledgeable' and 10 being 'extremely knowledgeable.' The median (IQR) rating of knowledge about COVID rehabilitation research was 7 (6, 8) pre-Forum, and 8 (8, 9) post-Forum.

When asked if they would be able to **apply the content covered in the Forum to their work**, 39/45 (87%) of respondents said 'yes.' Ways in which respondents stated they would be able to apply the content from the Forum to their work included:

- Implementing or continuing to implement self-management interventions and education interventions for people living with Long COVID
- Sharing research presented in the Forum with colleagues and using the research shared to inform their practice
- Apply information shared in the Forum to supporting clients with Long COVID in a primary care setting, including assessment and treatment, and referrals to other services
- Screening for ME/CFS more effectively/regularly in clinical practice
- Ideas for future research
- Reference information shared at Forum in advocacy efforts for Long COVID
- Improve/deepen involvement of people with lived experiences in research
- Motivation to publish quality improvement work related to virtual care
- Sharing information presented at Forum with health professions students, developing curriculum
- Apply Indigenous principles to research
- Implement methodologies (e.g. co-design) that were discussed at the Forum
- Utilize the PLRC score cards

Reasons respondents stated they *would not* be able to apply the content to their work included the following:

- *"There was nothing new added that I did not already know or be able to access as a Long Covid Patient living in Saskatchewan. I have been living with Long Covid since April 2020."*
- Respondent was not working at the time of the Forum
- *"The focus was rightly on first steps for identifying research priorities and a lot of discussion around patient engagement in research. of course this means that the material covered has limited applicability to clinical practice. There were some nuggets that go time thinking - the clinician in me wants more time with Tod Davenport and Simon Decary to talk about ideal program design."*
- *"Every violation of truth is not only a sort of suicide in the liar, but is a stab at the health of human society." - Ralph Waldo Emerson*
- *"My work is unrelated to Long Covid. I attended as a person living with Long Covid"*
- *"not relevant to my job function"*

What were the 2-3 most important take home messages that you heard at the International Forum on COVID Rehabilitation Research?

- It is important to continue good research related to COVID and rehabilitation. Including:
 - Post-exertional malaise
 - Investigation of rehabilitation interventions
- Greater participation from other post-infectious diseases would be beneficial

- It is important to listen to the voices of those living with Long COVID and to engage people with lived experiences in research and in design/implementation of rehabilitation programs
- There is an important role for rehabilitation in the management of Long COVID
- There are ongoing education gaps among health care providers (including in primary care)
 - Assessment and management of Long COVID
 - Stigma
- The 7 teachings that Mark shared during the Keynote Panel
- There are similarities between ME/CFS and Long COVID
- It is important to consider PEM/PESE when working with people with Long COVID
- It is important for clinicians and researchers to collaborate, in addition to involving those with lived experiences
- Long COVID is a big umbrella term and more understanding/investigation of subgroups is needed to inform clinical guidelines and best practices
- Telehealth can be used to enhance access to care
- More caregiver specific support is needed (social, emotional, practical)
- More research is needed with respect to Long COVID across the lifespan (aging population)
- The concept and characteristics of episodic disability

Recommendations for Future Forums/Events

General suggestions for future Forums/Events included:

- *"This should be the "First" International Forum - there need to be more in the future."*
- Management of 'tone-deaf' comments in the chat for online/hybrid events
- *"More time to connect over lunch etc. would be appreciated but understand the time challenges unless it was delivered over several days."*

"What topics or issues included in the Forum would you like to see covered in future Forums, workshops or webinars?"

- Inclusion of relevant quality improvement projects in addition to research
- More content on the link between Long COVID and ME/CFS
- Presentations from patients with ME/CFS
- Inclusion of presentations on interventional research for COVID rehabilitation
- Presentations that are more directly applicable to clinical skills, rehab methods. This should include presentations from clinicians, in addition to researchers ('What are they doing that helps/hinders? How can we learn from them?').
 - Including screening/assessment methods and treatments that rehab professionals can incorporate in clinical practice
 - Outcome measures that are appropriate for the varied symptoms of persons with Long COVID, e.g., for evaluating cognitive issues.
 - Self-management approach to LC
 - Cognitive rehabilitation
 - Telerehabilitation
- Focus on special populations:
 - Content on access to health care for marginalized people and non-document residents
 - People living in rural/northern areas where access to care is limited

- Parents with young children
- Geriatric (frail, cognitive impairment)
- Future forum or workshop on knowledge translation
 - *“What strategies can we employ to ensure that the majority of health care professionals (across the spectrum) are knowledgeable on Long COVID (and PEM/dysautonomia specifically)?”*
- *“More of Simon's work to support healthcare delivery models and clinical guidelines”*
- *“An overview of the history of post-infectious illness, the harms created by previous research in this field, and an overview of how to screen for MECFS, PEM and POTS in projects. This would help COVID rehabilitation researchers be aware of the past, of possible harms, give them tools to do better, and hopefully not try to recreate the wheel.”* – Respondent acknowledged that Todd’s presentation touched on this but that more detail would be helpful.
- More information on caregiver specific support for Long Covid
- Workshop to discuss further about how to include persons with lived experience in research teams and other initiatives. From the beginning and in all level of decision-making.
 - More around co-design work
- Focus on Long COVID and Work
- Focus on: 1) swallowing issues; and 2) GI issues
- Focus on: how people with long covid or other chronic illnesses will navigate services as covid precautions are removed

What topics or issues that were not included in the Forum would you like to see covered in future Forums, workshops or webinars?

- Clinical approaches – this was raised by many respondents (people are looking for this information)
 - Respiratory muscle training
 - How to diagnose and manage Long COVID and implications for rehabilitation
 - Disability claim processing – including: how to educate case workers on PESE, POTS, and focus on rehab employment trial vs. graduated return to work
 - Special considerations for management of patients with mental health challenges
 - More info on drug trials
- Long COVID and traditional Indigenous healing.
- Exploration of funding models for COVID rehabilitation
- More info about specific Long COVID symptoms and comorbidities
 - Autonomic dysfunction
 - Immune dysfunction
 - Asthma
 - Sleep apnea
 - Voice/swallowing dysfunction in non-hospitalized patients
- More information on Long COVID pathophysiology
- Occupational therapy focused research and treatment for people with long covid - energy conservation education interventions
- More on mental health challenges associated with Long COVID
- *“Allied medical services such as yoga, meditation, mindfulness, massage, acupressure, acupuncture, breathwork, interoceptive awareness, psychotherapy, etc”*

Do you have any suggestions for the format (e.g. preference for virtual vs. in-person vs. hybrid, etc.) of future Forums, workshops, or webinars?

Very consistent feedback that **hybrid/online format was well received and appreciated**. This made the Forum more accessible (both for those living with health challenges and for those who lived too far away to have otherwise attended in person).

However, a few respondents did express that there were **limitations in terms of the amount of informal networking that was able to happen** with this format. This applied both for those online and in-person. Suggestions included: breaking the Forum up over multiple days to facilitate more time in the schedule for networking, online breakout rooms, exploring technology for online interaction (i.e. chat boards, other platforms), etc.

Some respondents stated that **networking will always be somewhat hindered by virtual/hybrid formats**. As one person stated: *“I understand the limitations - but my preference is in-person. A lot of amazing researchers and clinicians attended virtually - but there is no possibility of making informal connections with them when things are virtual.”* Those who did attend in-person did express that they were happy to have been able to make in-person connections, which enhanced their networking experience.

Other respondents mentioned that **breaking the Forum up over multiple days and having shorter sessions per day** would also benefit those who faced challenges managing energy and cognitive dysfunction. However, respondents also acknowledged that recording the sessions was somewhat helpful in addressing this issue.

Finally, a few respondents suggested that the **audio/technical aspects of the Forum could be improved upon** in future events.

REHABILITATION SCIENCE RESEARCH NETWORK FOR COVID: INTERNATIONAL FORUM ON COVID REHABILITATION RESEARCH

FRIDAY APRIL 21, 2023

10:00 AM - 4:00 PM EDT

FREE EVENT - HYBRID (ONLINE & IN-PERSON)

Keynote Presentation:
*Back to the Future for
Long COVID Research*

Dr. Todd Davenport, PT,
DPT, MPH, OCS
Professor, University of the
Pacific, California
Education Co-Director,
Long COVID Physio



REGISTER



Rehabilitation Science Research
Network for COVID



TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO



Appendix D – Evaluation Form (administered electronically using Qualtrics)

Evaluation Survey - International Forum on COVID Rehabilitation Research

Please share your feedback on the Rehabilitation Science Research Network for COVID: International Forum on COVID Rehabilitation Research!

Thank you and acknowledgements

Thank you for attending the inaugural Rehabilitation Science Research Network for COVID: International Forum on COVID Rehabilitation Research! Whether you were a speaker, panelist, or attendee, we appreciate your engagement and your contributions to making this Forum a success!

Before you complete this evaluation survey, we would like to take this opportunity to thank the **Forum planning committee**: Darren Brown, Nisa Malli, Alexandra Rendely, Laura Bassi, Kelly O'Brien, Jill Cameron, and Kiera McDuff.

We would also like to acknowledge that **the Rehabilitation Science Research Network for COVID is funded by Temerty Faculty of Medicine**. The Forum was hosted in collaboration/partnership with **Long COVID Physio**.

1. Please select one. I attended the Forum:
 - In-Person
 - Online
2. In which country do you currently reside?
Drop down menu of countries
3. Please select one. Which of the following best describes your **primary role**?
 - Community member (e.g. person with lived experiences with COVID and/or Long COVID or their parents, partners, and caregivers).
 - Academic (e.g. located at an academic institution).
 - Clinician.
 - Educator.
 - Researcher.
 - Service provider.
 - Trainee (e.g. MSc, PhD, or Post-doctoral Fellow).
 - Student (e.g. Occupational Therapy student, Physical Therapy student, etc.).
 - Other (please describe):
4. Please select one. I belong to the following **health professional group**:
 - Physiotherapist or Physical Therapist.
 - Occupational Therapist.
 - Speech-Language Pathologist or Speech and Language Therapist.
 - Athletic Therapist or Athletic Trainer.
 - Physician.
 - Nurse or Nurse Practitioner.
 - Pharmacist.
 - Other (please describe):
5. Which of the following best describes your **place of work**?

- Not applicable – I am not currently working.
 - University (or other academic institution).
 - Non-Governmental Organization (NGO).
 - Community-Based or Patient-Led Organization.
 - Hospital.
 - Government.
 - Industry.
 - Other (please describe):
6. Please select the option that best describes you. I am a person with:
- Lived experiences with Long COVID.
 - Lived experiences with Acute COVID.
 - Lived experiences with another chronic health conditions or disability (other than Long COVID).
 - Lived experiences as a caregiver for someone with Acute COVID.
 - None of the above.
7. You selected that you live with a chronic health condition or disability other than Long COVID. Please describe: *(Display only if “Lived experiences with another chronic health condition or disability (other than Long COVID).” is selected for question 6.)*
8. Are you currently living with Long COVID? *(Display only if “Lived experiences with Long COVID.” is selected for question 6.)*
- € Yes
- € No
9. Were you an invited **speaker, panelist, or presenter** at the International Forum for COVID Rehabilitation Research?
- Yes
 - No
10. How did you hear about this year’s International Forum on COVID Rehabilitation Research?
- Social media (e.g. Twitter).
 - Communications through the Rehabilitation Science Research Network for COVID (e.g. email).
 - Communications through University of Toronto’s Rehab Sector (e.g. email, newsletter).
 - Communications through University of Toronto’s Temerty Faculty of Medicine (e.g. email, newsletter).
 - Word of mouth.
 - Other (please describe):
11. How would you rate your overall satisfaction with the International Forum on COVID Rehabilitation Research?

0 Not at all satisfied	1	2	3	4	5	7	8	9	10 Extremely Satisfied
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12. Which sessions were you able to **attend or view**? Please select all that apply.
- Keynote Session #1 - Back to the Future for Long COVID Research (Dr. Todd Davenport).
 - Keynote Session #1 - Back to the Future for Long COVID Research (Dr. Todd Davenport).

- Keynote Session #2 – Panel Discussion: Best Practices for Community-Engaged approaches to COVID-19 Rehabilitation Research.
- Research Evidence Sessions (Part 2) (Dr. Stacey Skoretz, Dr. Michelle Kho, Jessica DeMars, Dr. Simon Decary, and Dr. Jill Cameron).

13. If applicable, how would you rate your satisfaction with **Keynote Session #1 - Back to the Future for Long COVID Research (Dr. Todd Davenport)?**

0 Not at all satisfied	1	2	3	4	5	7	8	9	10 Extremely Satisfied
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14. If applicable, how would you rate your satisfaction with the **Research Evidence Sessions (Part 1) (Dr. Marina Wasilewski, Dr. Fiona Jones, Dr. Doug Gross, Dr. Kelly O'Brien, and Dr. Angela Cheung)?**

0 Not at all satisfied	1	2	3	4	5	7	8	9	10 Extremely Satisfied
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15. If applicable, how would you rate your satisfaction with **Keynote Session #2 – Panel Discussion: Best Practices for Community-Engaged Approaches to COVID-19 Rehabilitation Research?**

0 Not at all satisfied	1	2	3	4	5	7	8	9	10 Extremely Satisfied
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16. If applicable, how would you rate your satisfaction with the **Research Evidence Sessions (Part 2) (Dr. Stacey Skoretz, Dr. Michelle Kho, Jessica DeMars, Dr. Simon Decary, and Dr. Jill Cameron)?**

0 Not at all satisfied	1	2	3	4	5	7	8	9	10 Extremely Satisfied
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17. To what extent do you agree with the following statements?

Statement	Strongly Disagree	Disagree	Neutral		Agree	Strongly Agree
The Forum achieved its goal of advancing knowledge transfer and exchange in COVID rehabilitation research and practice.						

Statement	Strongly Disagree	Disagree	Neutral		Agree	Strongly Agree
The Forum achieved its goal of advancing collaborations and partnerships in COVID rehabilitation research and practice.						
The presenters were knowledgeable and communicated their ideas clearly .						
There was adequate time allocated for informal discussion amongst Forum participants.						
I made new contacts which will be helpful in my everyday work.						

18. Will you be able to apply the content covered in the Forum to your work?

- Yes
 No

19. If yes, how so? (*Display only if "Yes" to question 18.*)

20. If not, please explain. (*Display only if "No" to question 18.*)

21. Please rate your knowledge on COVID and rehabilitation research **before** attending the Forum.

0 Not at all knowledgeable	1	2	3	4	5	7	8	9	10 Extremely knowledgeable
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22. Please rate your knowledge on COVID and rehabilitation research **after** attending the Forum.

0 Not at all knowledgeable	1	2	3	4	5	7	8	9	10 Extremely knowledgeable
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23. What were the 2-3 most important take home messages that you heard at the International Forum on COVID Rehabilitation Research?

24. What topics or issues included in the Forum would you like to see covered in future **Forums, workshops or webinars**?

25. What topics or issues that were not included in the Forum would you like to see covered in **future Forums, workshops or webinars**?

26. **What will you change** (e.g.: clinical practice, research, education, or self-management living with Long COVID) as a result of attending the International Forum on COVID Rehabilitation Research?

27. Do you have any suggestions for the **format (e.g. preference for virtual vs. in-person vs. hybrid, etc.)** of future Forums, workshops, or webinars?
28. Please provide any **additional comments, recommendations or reflections** on the International Forum on COVID Rehabilitation Research below:

End of Survey

Thank you for completing the evaluation survey for the International Forum on COVID Rehabilitation Research. If you have any questions, please contact the Rehabilitation Science Research Network's Program Coordinator, Kiera McDuff, at rehab.covid@utoronto.ca. **Please click submit before exiting this page to ensure the submission of your response.**