TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

Rehabilitation Science Research Network for COVID

Rehabilitation Science Research Network for COVID

2024 International Forum on COVID Rehabilitation Research

Forum Report

Friday April 19, 2024
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 2024 International Forum on COVID Rehabilitation Research is hosted in collaboration with FisioCamera, Long COVID Physio, and Long COVID Web.

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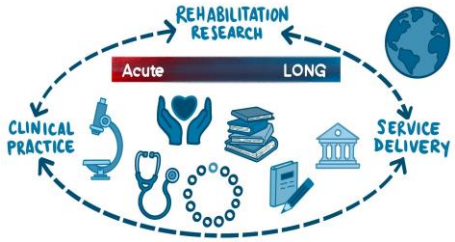
Executive Summary

The Rehabilitation Science Research Network for COVID hosted the **2024 International Forum on COVID Rehabilitation Research** on Friday April 19, 2024. 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) FisioCamera, Long COVID Physio, and Long COVID Web. 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 **375 registrants** for the Forum from **over 20 countries** (**~20% increase in registration compared with the 2023 Forum**). Of the 375 registrants, at least 216 (58%) attended the Forum synchronously (up to 166 people at a time online; 50 people in-person) (Figure 1). 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.

Twenty-seven speakers were invited to present on research, clinical and community practice related to COVID rehabilitation research at the one-day Forum. The Forum included **3 Keynote Sessions** (1 podium presentation; 2 panel sessions), and **2 Research Evidence Sessions**.

Keynote Session 1, delivered by Dr. Mark Faghy, was entitled, *Unlocking the mystery of Post-Exertional Malaise in Long COVID.* This Keynote presentation was supported by Long COVID Web. **Keynote Session 2** was a panel discussion entitled, *Community engagement in rehabilitation research – a year in review*. The aim of this panel discussion 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. **Keynote Session 3** was a panel discussion entitled, *Bridging Research Evidence with Real World: Community, Clinical and Policy Perspectives on Navigating the Maze of the Continuum of Care, Living with Long COVID*. The aim of this panel discussion was to highlight translation of research to practice from an interdisciplinary perspective, centered on a case study presented by a panelist living with Long COVID. The **first Research Evidence Session** focused on *Health and Disability across Acute and Long COVID Illness Trajectories*. The **second Research Evidence Session** focused on *Rehabilitation across Acute COVID-19 and Long COVID Care Continuums*.

New Features in 2024

We implemented new features to the 2024 Forum; 1) an abstract submission for **poster presentations**; and 2) **Special Grand Rehab Rounds*, Identifying Long COVID in clinical practice: would you recognize it if you saw it?***, with Jessica DeMars (PT). We selected three award winners for the poster presentations (Best Abstract Award, Best Trainee Abstract Award, and People's Choice Poster Award) (Agarwal *et al.*, 2024; Akbar *et al.*, 2024; Kim *et al.*, 2024). The Rounds were hosted as a one-hour event the day prior to the Forum. And 3) a social media strategy in collaboration with Fisiocamera including key messages throughout the day.

Forum evaluations (n=68) indicated that the Forum presented relevant and interesting research and information, had engaging speakers, and provided opportunities for collaboration among attendees. The median score for overall satisfaction with 2024 International Forum on COVID Rehabilitation Research (n=64) was 9/10 (min-max: 3-10). Forty-four attendees (44/64; 69%) said 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.

To access the Forum video recordings, please see the Forum's page on the Network's website or visit the Network YouTube Channel.
For more information about the Forum, please contact the Network Coordinator at rehab.covid@utoronto.ca.

Context

Long COVID is a prevalent and disabling condition that has impacted millions of people worldwide (Chen et al., 2022; Mandel et al., 2024; O'Mahoney et al., 2023). Some of the most common symptoms of Long COVID are fatigue, coughing, difficulty breathing, cognitive impairment, and general weakness (Canada, 2022). 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 disability experienced by individuals living with Long COVID also has broader impacts on their caregivers, friends, and family members (Muldrew, Fee, & Coates, 2022), as well as impacts on the workforce and economy.

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 physiotherapists, occupational therapists, and speech-language pathologists) address or prevent disability focused on the physical, mental-emotional, cognitive and social domains of health and disability. They 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 Post-Exertional Malaise (PEM) or Post-Exertional Symptom Exacerbation (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 to enhance research innovation and excellence in COVID-19 rehabilitation research. The Network engages with persons with lived experiences, caregivers, researchers, clinicians, educators, trainees, representatives from community organizations, and policy stakeholders in this collaborative. 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.

Last year, the Network held its inaugural International Forum on COVID Rehabilitation Research. Over 250 people, representing over 20 countries, participated in the Forum either virtually or in-person. This included people with lived experiences, health care professionals, policy makers, and researchers with an interest in COVID rehabilitation. The Forum included over 20 presenters from Canada, the United Kingdom, and the United States. Presentations included two Keynotes and two Research Evidence Sessions. The primary output from the 2023 Forum was the Framework of Research Priorities in COVID Rehabilitation. As a living document, this year, we aimed to revisit the Framework and invite Forum attendees to share feedback on which priorities were already being addressed, which were not being addressed, and which additional priorities were missing from the Framework.

Introduction

On Friday April 19, 2024, the Rehabilitation Science Research Network for COVID hosted the **2024 International Forum on COVID Rehabilitation Research** in hybrid format, online via Zoom and in-person at the Rehabilitation Sciences Building, University of Toronto.

This one-day Forum was hosted in collaboration with Network members and partners including (but not limited to) FisioCamera, Long COVID Physio, and Long COVID Web. 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. Content presented at this Forum consisted of three Keynote Sessions, two Research Evidence Sessions, and poster presentations. Details of the evidence presented in these sessions can be found in the *Summary of Evidence Presented at the Forum*.

New in 2024

Abstract Submission and Poster Presentations: A new component of this year's Forum is that the Network put out a call for submissions for **poster presentations** for the 2024 International Forum on COVID Rehabilitation Research. There were 9 posters presented as part of the Forum program (6 in-person and online; 3 online only). An abstract review committee comprised of Network Advisory Committee members with a combination of lived experiences, clinical experience, and research experience rated the abstracts and selected one for a **Best Abstract award** (Experiences living with Long COVID among racialized communities in Canada – Dr. Nadine Akbar) and one for a **Best Trainee Abstract award** (Long COVID and Rehabilitation: Experiences of Physical Therapists in Canada – Chantal Lin). Attendees at the Forum (n=97) voted for one poster to be selected for a **People's Choice Poster Award** (Participant Satisfaction with a Virtual Rehabilitation Program in Long COVID – Kriti Agarwal).

Special Grand Rehab Rounds: The Network hosted a **Special Rehab Grand Rounds**, *Identifying Long COVID in clinical practice: would you recognize it if you saw it?*, with Jessica DeMars (PT). The Rounds were

hosted as a one-hour event the day prior to the Forum (April 18, 2024). People who attended both events provided feedback that it was a beneficial complement to the Forum.

Social Media: The Network developed **social media posts in collaboration with Fisiocamera** to highlight key messages shared by speakers at the Forum, using illustrations, on 'X' (formerly Twitter). A member of the Network Advisory Committee and a communications staff from the University of Toronto Department of Physical Therapy (a partner of the Network) **'live-Tweeted'** using the pre-made posts with illustrations by Fisiocamera, and additional posts featuring photos and key quotes from the day of the Forum. In total, the Network shared **29 posts during and following the Forum** featuring content related to the Forum. The posts received strong engagement on 'X' and **the Network's Twitter page (@UofTCOVIDRehab) gained over 1000 new followers** on the platform between the Forum (April 19) and April 25.

Research Priorities in COVID Rehabilitation: Attendees at the 2024 International Forum on COVID Rehabilitation Research were invited to share feedback on the Framework of Research Priorities in COVID Rehabilitation (**Appendix A**) that was developed by the Network through 5 consultations between 2022-2023. Online attendees shared feedback using notes on an online platform (Jamboard) while in-person attendees posted sticky-notes on a printed poster of the Framework **(Appendix A)**. Participants were asked to post green notes to indicate research priorities in the Framework that were already being addressed, red/pink notes to indicate gaps or research priorities that were on the framework that were yet to be addressed, and yellow notes to indicate research priorities that were not currently captured in the Framework. After the Forum, Network staff conducted content analysis of the sticky notes to identify common themes and new priorities. Twenty (20) notes were posted either in-person or on the online platform. Some notes addressed reflections on the Framework from the perspective of the broader context of COVID and rehabilitation and research and clinical practice, while other notes reflected the content of the Forum specifically. Some notes addressed reflections on the target populations, methodological considerations, or knowledge mobilization sections of the Framework, rather than the research priorities. In general, feedback from attendees was that the priorities in the Framework remain relevant to the current context of COVID and rehabilitation. However, gaps and opportunities to expand the Framework were addressed.

Approach

The 2024 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 Forum Implementation Team.

Forum Implementation Team

The Forum Implementation Team included the Network Co-Directors, Program Coordinator, two members of the Advisory Committee, and two Research Coordinators from the Department of Physical Therapy, and was supported by the Information Technology (IT) Director in the Rehabilitation Sciences Institute at the University of Toronto. The purpose of the Forum Implementation Team was to oversee the promotion of the Forum and implementation of the Forum program.

This Team met on 3 occasions between January and April 2024 to discuss implementation of the Forum. Specific activities included: developing a timeline and materials for Forum promotion; advertising the Forum; finalizing catering, travel and accommodation details; discussing the evaluation process and developing an evaluation questionnaire (**Appendix B**); discussing registration options; finalizing and

distributing participant and speaker invitations; establishing opportunities and planning for rapporteurs; liaising with speakers prior to the Forum; posting on social media during the Forum; determining specific outcomes of the Forum and developing a Knowledge-Translation and Evaluation strategy post-Forum.

Invitations and Advertisement of the Forum
A list of invitees was developed, which included: researchers, clinicians, and persons with lived experiences with COVID and Long COVID and their caregivers. We distributed invitations to Network members and partner organizations via email. Registration was open using Microsoft Forms in November, 2023. The Forum Program Agenda (**Appendix C**) and Forum poster (**Appendix D**) were also displayed on the Network's X (previously Twitter) account (@UofTCOVIDRehab) to promote the Forum, introduce the speakers, as well as provide reminders regarding registration. Registration for the Forum was free, with the aim to facilitate access and attendance to the Forum.

Forum Program
The Forum Implementation 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
Twenty-seven (27) speakers were invited to present on research, clinical and community practice related to COVID rehabilitation research at the one-day Forum (7 online; 20 in-person). Speakers were invited based on guidance from the Network's Advisory Committee and the Framework of Research Priorities on COVID Rehabilitation. Seven of the speakers presented across one of two Research Evidence Panel sessions. Keynote Session 1 featured one speaker. Keynote Sessions 2 & 3 each consisted of 7 panelists and a moderator, respectively. There were 2 co-moderators for the Q&A periods following each session (one for moderating in-person discussion, another to monitor the Zoom chat).

Pre-Forum Planning Zoom Meetings
In March 2024, the Forum Implementation Team held 5 pre-Forum Zoom meetings, one for each of the Research Evidence Panel Sessions and Keynote Sessions, respectively. The purpose of these Zoom meetings was to enable speakers, panelists, and moderators 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.

Testing Hybrid Nature of Forum
In April 2024, the Forum Implementation Team met with the IT Director, Rehabilitation Sciences Sector, to test Zoom audio/visual for the Forum. The Zoom audio/visual was tested 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. All speakers provided permission for their presentation to be recorded and shared on the Network's online platforms. Speaker videos were 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 2024. Results from the evaluation forms from the Forum were compiled into a report (see **Appendix E** for details).

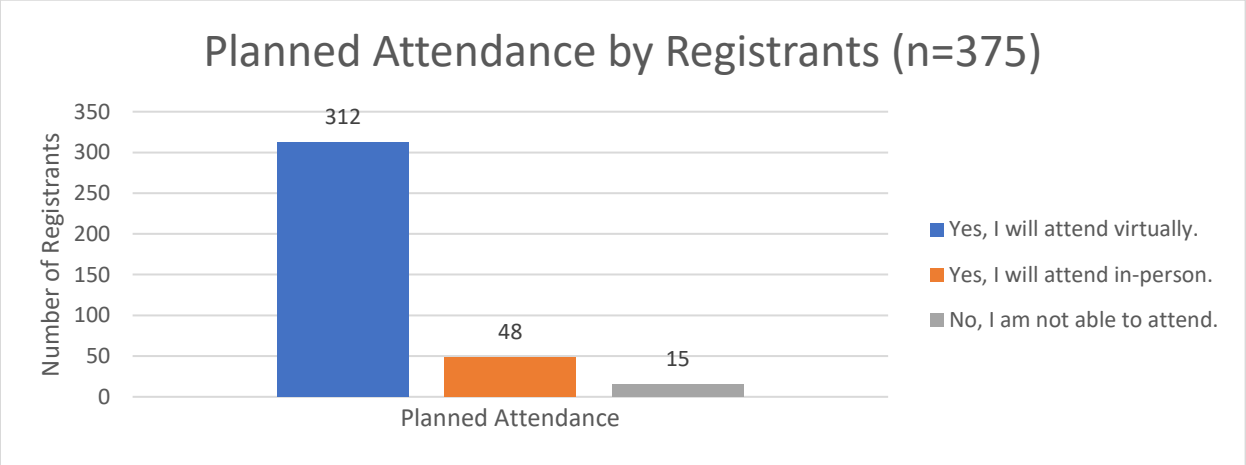
Forum Overview

The Rehabilitation Science Research Network for COVID hosted the **2024 International Forum on COVID Rehabilitation Research** on Friday April 19, 2024. 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) FisioCamera, Long COVID Physio, and Long COVID Web. 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.

Forum Registrants and Attendees

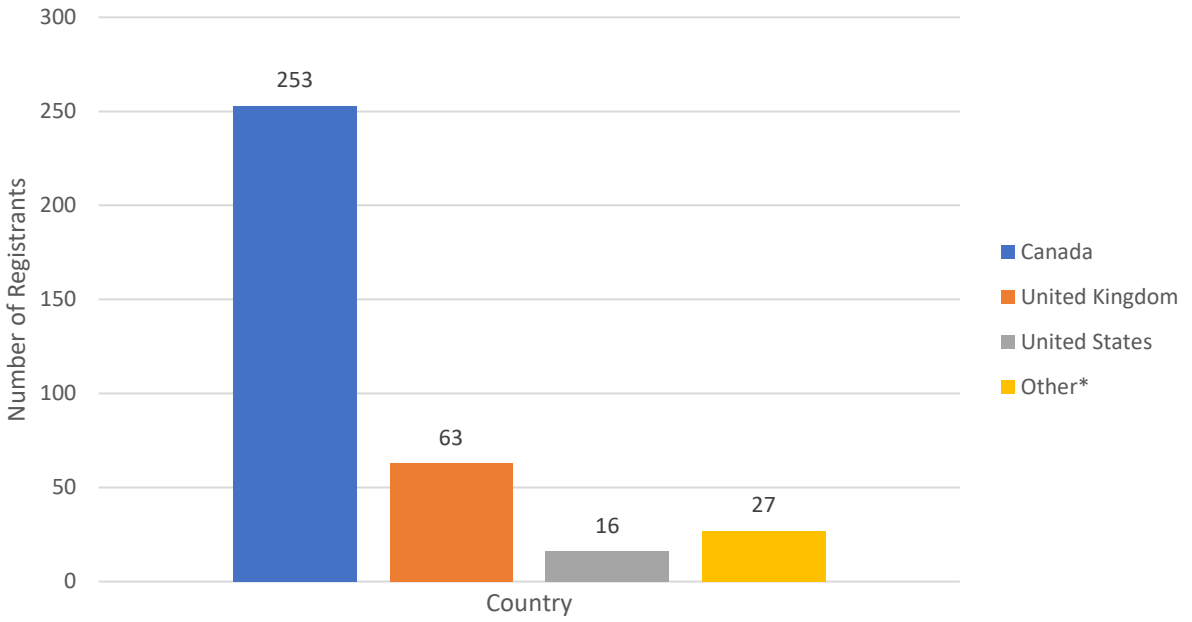
There were **375 registrants** for the Forum from **over 20 countries** (**~20% increase in registration compared with last year's Forum**). Of the 375 registrants, at least 216 (58%) attended the Forum synchronously (up to 166 people at a time online; 50 people in-person). However, this is likely an under-estimation of the number of online attendees as not all attendees attended for the whole day. The **majority of registrants planned virtual attendance (312; 83%)** (Figure 1).

Figure 1: Planned Attendance by Registrants



Most registrants were from Canada (253; 70%), followed by the United Kingdom (63; 18%) and the United States (16; 4%) (Figure 2).

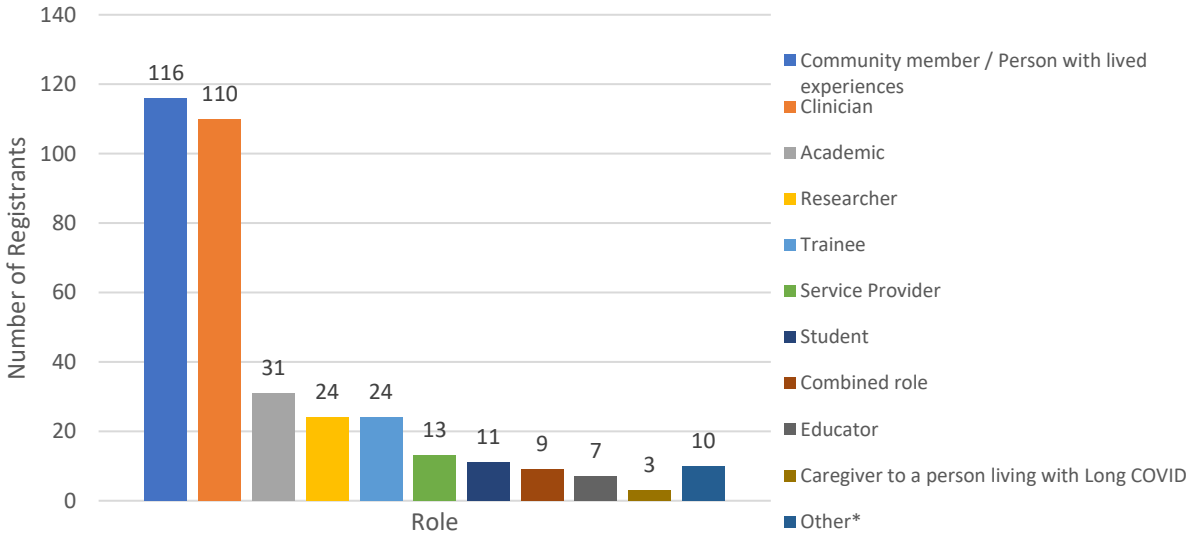
Figure 2: Number of Registrants by Country



*Other countries included: Australia, Egypt, Finland, France, Germany, Greece, India, Ireland, Isle of Man, Netherlands, Poland, Qatar, Saudi Arabia, Spain, Turkiye, United Arab Emirates, and Yemen

Registrants were asked about their primary role. The **most common role was community member or person living with Long COVID (116; 32%), followed by clinician (110; 31%), and academic (31; 9%)** (Figure 3).

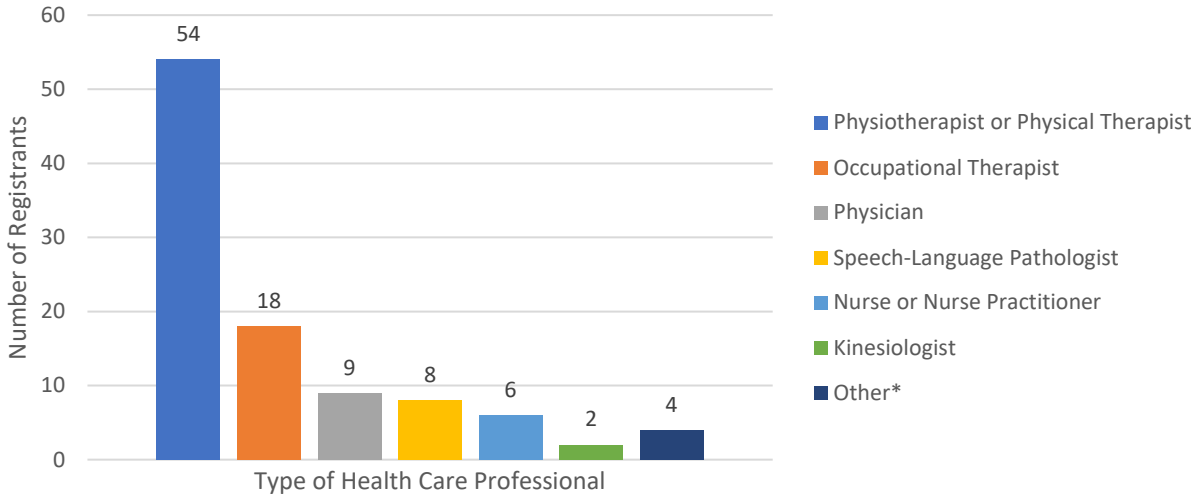
Figure 3: Role of Registrants



*Other included: BScN, Communications, Employee, Health System Leader, Long COVID Implementation Lead, Retired GP, Trustee at Long COVID Charity, U of T Staff, and Volunteer at LC Support.

Of the 110 clinicians, 101 (92%) specified the type of health profession they belonged to. **Most were physiotherapists (54; 53%), followed by occupational therapists (18; 18%), and physicians (9; 9%)** (Figure 4).

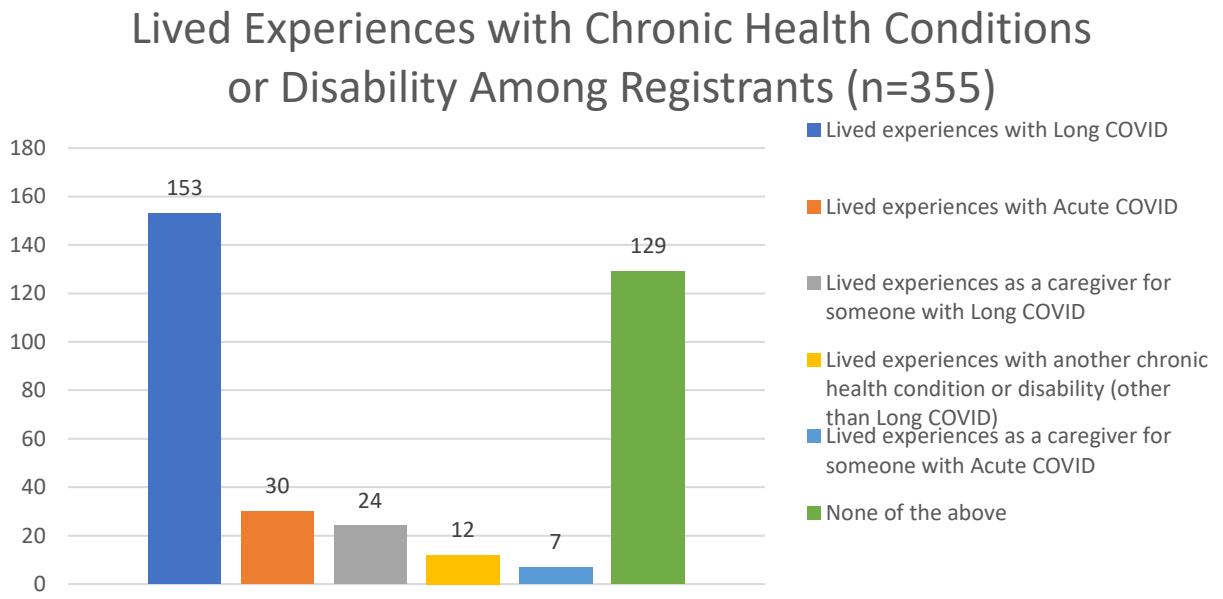
Figure 4: Types of Health Care Providers that Registered for the Forum



*Other included: Consultant Clinical Psychologist, Massage Therapist, Nurse and Social Worker, and Social Worker.

Registrants were also asked about whether they had lived experiences with COVID-19, Long COVID, as a caregiver to someone living with COVID or Long COVID, or other chronic health conditions. There were 355/375 (95%) registrants who responded to this question; of which, **153 (43%) registrants reported that they were living with Long COVID** (Figure 5).

Figure 5: Lived Experiences with Chronic Health Conditions or Disability Among Registrants



Summary of Evidence Presented at the Forum

Access all of the recordings from the Forum here.

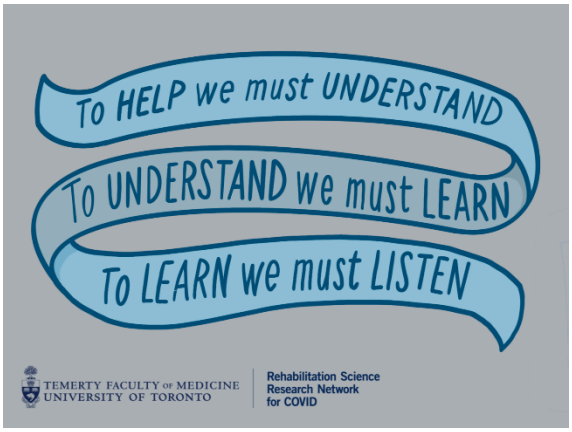
The following is a summary of evidence presented in each session of the Forum, key messages provided by panelists and speakers to accompany their sessions, and illustrations by Fisiocamera to accompany the key

messages. The illustrations and key messages in this report were posted on the Network's X account (@UofTCOVIDRehab) during the Forum, in coordination with each session.

Keynote Session 1

Unlocking the mystery of Post-Exertional Malaise in Long COVID

Dr. Mark Faghy – Professor, School of Human Sciences, University of Derby, United Kingdom



"Long COVID is a multi-system and complex pathophysiologic condition that requires true interdisciplinary collaborations to develop effective collaborations that are safe and well tolerated. To do this we must work closely with patients to increase the understanding of the lived experience. To help we must understand, to understand we must learn and to learn we must listen." – Dr. Mark Faghy

Key messages from this presentation included:

1) Long COVID has a complex pathophysiologic pathology, which must be acknowledged and screened for in any attempts to profile and improve Long COVID outcomes.
2) Exercise and physical rehabilitation in Long COVID has its place if detailed screening/risk profiling is in place and appropriate monitoring is used continuously.
   - Long COVID patients have a reduced threshold of tolerance for physical activity. Post-exertional malaise is easily triggered.
3) The path to recovery is not linear, we need to open minded, adaptive and informed.

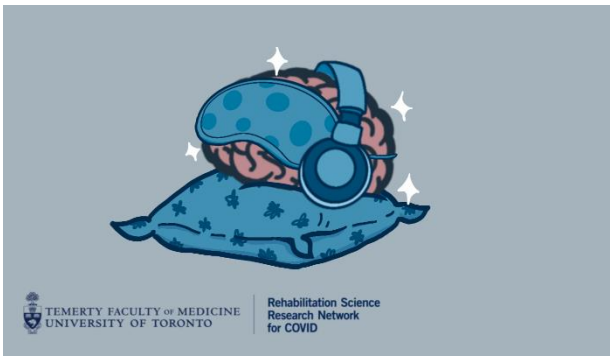
The presentation included discussion of how cardiopulmonary exercise testing (CPET) can be used safely to understand the physiology behind PEM.

Keynote Session 2

Community engagement in rehabilitation research – a year in review – Panel discussion

Panelists: Margaret O'Hara (Long COVID Support UK); **Linda Li** (Department of Physical Therapy, University of British Columbia); **Hannah Wei** (Patient Led Research Collaborative and Advisory Committee); **Sammie McFarland** (Long COVID Kids and Advisory Committee); **Susie Goulding** (COVID Long Haulers Support Group Canada and Advisory Committee); **Mark Rutledge** (Advisory Committee member); **Lindsay Skipper** (Long COVID Physio, UK)

Moderator: Kiera McDuff (Rehabilitation Science Research Network for COVID)



"Cognitive impairment is debilitating and often overlooked in Long COVID as is the role of Occupational Therapy. More research is needed as to how to differentiate between cog impairment, PESE and POTS. Cognitive rest needs to be encouraged; true rest does not have to be earned!" – Helen Skiffington

Keynote Session 2 was a panel discussion entitled, *Community engagement in rehabilitation research – a year in review.* This panel discussion involved 7 speakers (3 in-person; 4 online) and 1 moderator. The aim of this panel discussion 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.

Key messages from this panel session included:

1) Patient-engagement should feel safe and respectful and should not be tokenistic
2) The 4Pi Framework can be used to guide patient engagement
    a. 4 'P's stand for: principles, purpose, presence, process
    b. 'i' stands for: impact
3) It is important to evaluate patient-burden associated with participating in research (consider the costs associated for patient partners – energy, emotion, time, etc.)
4) Ongoing challenges with respect to patient-engagement in Long COVID research include:
    a. There is substantial room for improvement with respect to engaging children and young adults living with Long COVID
        i. Broadening methodologies outside of traditional research to include art mediums, such as poetry, singing, writing) can help to empower children to share their experiences
    b. Remote and rural communities continue to face barriers to accessing research and clinical care for Long COVID
5) Online platforms can be helpful for facilitating access to research for patients (e.g. support groups on Facebook, Citizen Science platform)
6) Patients should be involved in reviewing and evaluating research proposals (ex: patient-advisory council for Long COVID Web is involved in reviewing every application for funding)
    a. Ensures that important considerations like risk of PEM are not overlooked in study designs
7) Patients should be involved in every stage of research, including design, implementation, analysis, and knowledge translation to ensure research is relevant to the patient population
8) There are important safety considerations when engaging people living with Long COVID in research
    a. Masking and COVID-testing to avoid exposing people to risk of infection when participating in research

b. Screening protocols to monitor for PEM

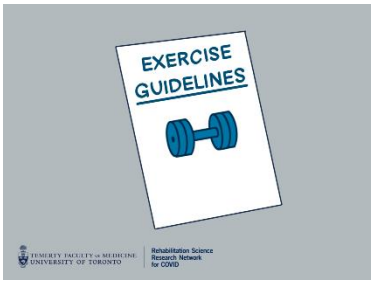
The panel session included discussion of the patient-led scorecards as a potential tool for evaluating patient-engagement in research.

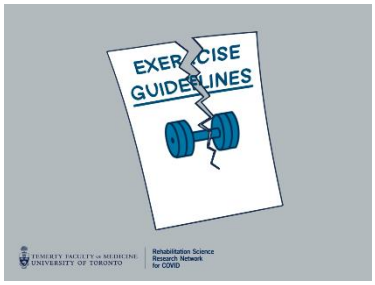
Keynote Session 3

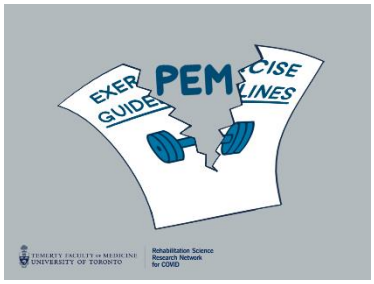
Bridging Research Evidence with Real World: Community, Clinical and Policy Perspectives on Navigating the Maze of the Continuum of Care, Living with Long COVID – Panel discussion

Panelists: Nisa Malli (Patient Led Research Collaborative); **Chester Ho** (MD, University of Alberta); **Adam Brown** (PT, Cornerstone Physiotherapy); **Jessica DeMars** (PT, Breathe Well Physio); **Michelle DiLauro** (OT, Toronto Rehab Institute, University Health Network); **Helen Skiffington** (OT, Long COVID Physio, UK); **Alexandra Rendely** (MD, University Health Network)

Moderator: Katie Churchill (Rehabilitative Care Alliance)







"Believe your patients when they tell you they cannot exercise/be active. PEM breaks all the rules of exercise/physical activity that we have been taught; and despite evidence to show that exercise is harmful, it is still difficult as clinicians for us to acknowledge it." – Jessica DeMars, PT

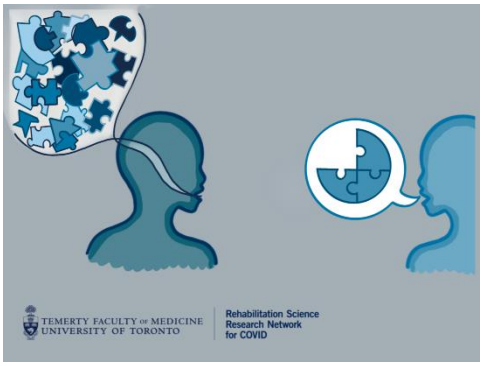
Keynote Session 3 was a panel discussion entitled, *Bridging Research Evidence with Real World: Community, Clinical and Policy Perspectives on Navigating the Maze of the Continuum of Care, Living with Long COVID.* This panel discussion involved 7 speakers (5 in-person; 2 online) and 1 moderator. The aim of this panel discussion was to highlight translation of research to practice from an interdisciplinary perspective, centering a case study presented by a panelist living with Long COVID. The value of patient narratives as a tool for research and knowledge translation was emphasized through the telling of a case study in narrative format.

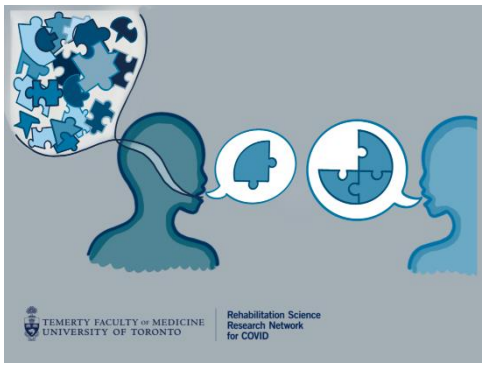
The case study portrayed one of many potential trajectories while living with Long COVID. Living with Long COVID involves many ups and downs. Although recovery is possible for some people living with Long COVID, it does not happen in a single moment; instead it takes lots of trial and error over time.

Key messages from this panel session included:

1) There is a need for more connection between health care providers and people living with Long COVID
2) There is a need for education of physicians and other health care providers on Long COVID symptoms and assessment and management strategies

    a. Education should include: how to screen for red flags (e.g. PEM, POTS, etc.), common triggers of PEM, pacing as a management strategy, etc.
3) Current Long COVID services in Canada are very limited and under-funded
4) Long COVID clinics and models of care should be interdisciplinary and patient-centred
    a. Ex: intake assessments should be interdisciplinary so that patients do not need to repeat their stories numerous times with different providers within the same model of care
5) Wearable technology and other means of symptom and activity tracking can provide helpful information to guide patient-centred interventions
6) There are management strategies that can help to reduce symptom burden for people living with Long COVID
    a. Ex: addressing sleep may help to reduce fatigue and improve cognitive function; compensatory strategies like post-it notes and checklists can help mitigate cognitive impairments; pacing strategies can help reduce frequency and severity of PEM
7) Health care providers can support people living with Long COVID with return to work
    a. Write detailed reports and letters that explain symptoms and the impact of those symptoms on function to communicate to employers, disability assessors, etc.
    b. Provide recommendations to adapt work for people living with Long COVID (e.g. later starting times, work-from home options, flexible hours, pacing in the workplace, etc.)





"It is challenging to distill a large body of research and information on a diverse set of patients with Long COVID and skillfully apply it to a single individual ("N of one") through clinical reasoning." – Adam Brown, PT

Research Evidence Session 1

Health and Disability Across Acute and Long COVID Illness Trajectories

The first Research Evidence Session featured 3 speakers who presented on completed or current research studies.

Untold Stories of Immigrants with Disabilities Navigating Health and Rehabilitation Services During COVID-19 in the Greater Toronto and Hamilton Area – Dr. Chavon Niles, Assistant Professor, Department of Physical Therapy, University of Toronto

Study objectives included:

- Understand complexities and barriers accessing rehab/health/social services for racialized immigrants
- Recommendations to decrease inequities in accessing these services

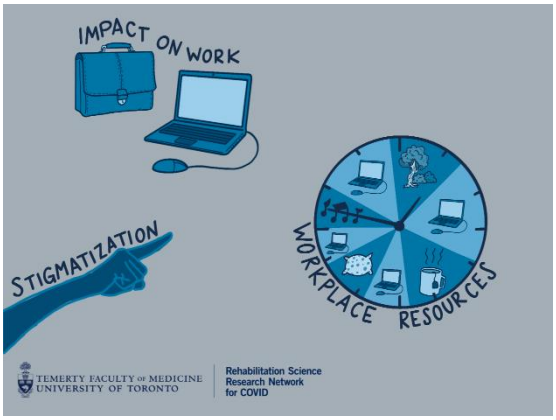
Key messages from this presentation included:

- For immigrants living with disabilities during the COVID-19 pandemic:
  - Systemic oppression shapes access to care
  - Most were only access services in times of crisis (surviving not thriving)
  - Fluency in English was a protective factor
  - Symptoms may be dismissed by healthcare providers due to status as a new immigrant - "your symptoms are because you are adjusting to Canada"

Future directions include:

- Naming implicit biases and systems of oppression and how they impact access to care
- Implementing implicit bias training within rehab/health/social services
- Seeking narratives from a more diverse profile of those with lived experiences (one way to do this is to seek participation through networks outside of hospital settings – certain groups have been historically excluded from hospital care and environments)
- Important to center and amplify community voices

From Isolation to Integration: Unveiling the Multifaceted Work Challenges Faced by Individuals with Systematic Lupus Erythematosus in the Wake of COVID-19 – Dr. Behdin Nowrouzi-Kia, Assistant Professor, Department of Occupational Science and Occupational Therapy, University of Toronto



"From our Research Science Research Network for COVID supported catalyst grant entitled, Creating a functional profile of work participation and engagement needs of patients with systematic lupus erythematosus (SLE) transitioning out of the COVID-19 pandemic: a national qualitative study, the following three themes emerged from the data: a) the illness experience and its impact on work, b) the stigmatization of illness disclosure, c) the availability of workplace resources and accommodations" – Dr. Behdin Nowrouzi-Kia

Lupus is a multisystem autoimmune disease. Symptoms of Lupus may be episodic in nature and people living with Lupus may go through periods where they can/cannot work due to their disability.

Study objectives included:

- Explore what individuals living with Lupus need in order to feel supported with return-to-work

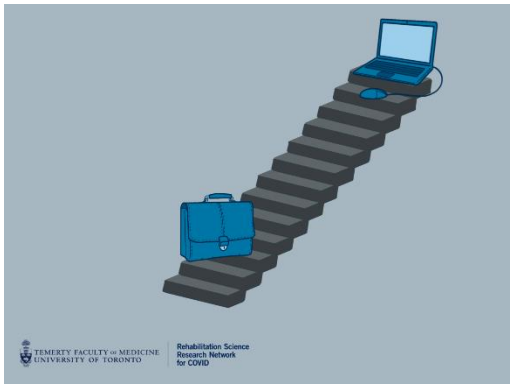
Key messages included:

- Common types of accommodations needed by people with Lupus to support return-to-work include: flexible schedules, assistive devices, ability to take time away from work
- People with Lupus constantly have to prove themselves to employers and colleagues when it comes to what they are capable of with their condition (particularly among visible minorities)
- People with Lupus experience anxiety about becoming sick and if they will be able to return-to-work
- Challenges people with Lupus experience that impact ability to work include brain fog, burnout, and pushing too hard followed by relapses in symptoms

Future directions include:

- Approaches to supporting return-to-work for people with Lupus should be multidisciplinary
- Case management supports can help support return-to-work efforts for people with Lupus
    - Occupational therapists may play a role in acting as a liaison between employers and patients, helping to arrange appropriate workplace accommodations
- Exploring how aging, perimenopause, and menopause interact with the chronic and episodic nature of Lupus

A scoping review of interventions and recommendations for enhancing work ability and facilitating return-to-work for individuals living with Long COVID – Dr. Victor Ezeugwu, Assistant Professor, Faculty of Rehabilitation Medicine, Physical Therapy, University of Alberta



"*We investigated Long COVID & Return-to-Work (RTW) in our review. Despite being crucial for rehab, RTW is challenging for those with Long COVID. Out of 14 studies that included or evaluated an intervention, 9 show promising insights. Our findings shed light on potential strategies for supporting RTW in this group."* – Dr. Victor Ezeugwu

Study objectives included:

- Synthesizing evidence on return-to-work interventions, including approaches and guidelines or recommendations

Key messages included:

- Return-to-work interventions that showed more promising outcomes were characterized by:
    - Multidisciplinary teams
    - Multimodal delivery models (e.g. online and in-person)
    - Individualized support and accommodations, including extending return-to-work timelines
    - Strategies including: Synthesize evidence of return the work interventions and approaches + guidelines and recommendations
    - Active involvement of managers and employers
- There is a lack of knowledge among employer disability managers about what return-to-work looks like in the case of episodic conditions

Future directions include:

- Differentiating between part-time and full-time return to work outcomes and considering long term measurements to account for relapses
- Developing specific approaches and guidelines regarding what "gradual and phased return to work" looks like in practice
- Educating employer disability managers about what return to work looks like in the case of episodic conditions

Research Evidence Session 2

Rehabilitation across acute COVID-19 and Long COVID Care continuums

The second Research Evidence Session featured 4 speakers who presented on completed or current research studies.

Embracing the idea that "less can be more" in long COVID rehabilitation – Dr. Diana Sanchez-Ramirez, Assistant Professor, College of Rehabilitation Sciences, University of Manitoba

Long COVID significantly impacts quality of life, functioning, and social participation.

Study objectives included:

- To understand key factors in the rehabilitation process for patients living with Long COVID

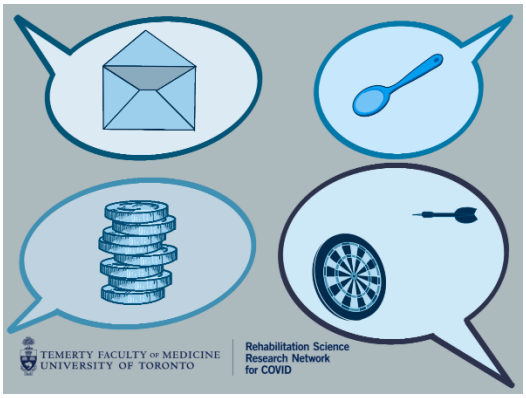
Key messages included:

- Participants want to be able to do "what they used to do" (daily life activities)
- Symptoms of Long COVID are diverse and vary between patients
- Caution must be applied when prescribing exercise as a rehabilitation intervention
    - However, when managed appropriately, exercise interventions can improve functioning, quality of life, and other key outcomes for people living with Long COVID
- Pacing and breathing strategies are rehabilitation interventions that show promising outcomes among people living with Long COVID
- Chest pain and dizziness are important symptoms to monitor during rehabilitation

Future directions include:

- Further inquiry into how to appropriately implement exercise in a way that does not cause harm to people living with Long COVID

"It's a moving target": Pacing as strategy to reduce symptom exacerbation – results from an international community-engaged study of adults living with Long COVID – Kiera McDuff, Program Coordinator, Rehabilitation Science Research Network for COVID, University of Toronto



"*Pacing is not a cure for Long COVID but is a helpful living strategy with the aim to mitigate or prevent multidimensional health challenges of Long COVID. Adults with Long COVID use many analogies to communicate about pacing.*" – Kiera McDuff, PT

Pacing is a living or rehabilitation strategy where individuals balance rest with activity to reduce impacts of PESE

Study objectives included:

- To explore experiences in pacing in adults living with Long COVID

- To explore perspectives, knowledge and experiences of adults living with Long COVID with pacing

Key messages included:

- Characteristics of pacing include that:
  - Pacing is a disability management strategy but not a cure for Long COVID
  - Pacing prevents multidimensional health challenges
  - Pacing requires balancing physical, mental and emotional activity with rest
- Learning how to pace
  - Many learned through online resources and community support
  - Challenges: judgment/lack of support from family, friends, employers and healthcare professionals
- Analogies used by participants to describe pacing included:
  - Staying within one's energy envelope
  - Budgeting energy
  - Spoon theory

Future directions include:

- Exploring how well-known pacing is as a strategy outside well-connected community support group members
- Using combined strategies of pacing and other rehabilitation strategies in the context of interventions for Long COVID

Symptom-Targeted Rehabilitation for Cognitive Complaints in Long COVID Clinical Trials – Susan Viola, Assistant Clinical Professor, Department of Speech-Language Pathology, McMaster University, Hamilton, Ontario

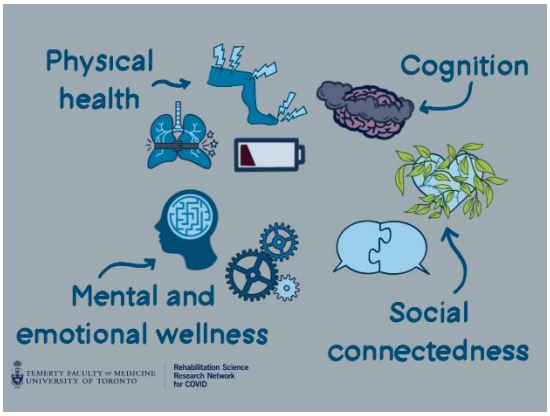
Study objectives included:

- Comparing individualized cognitive rehabilitation therapy vs educational material for feasibility and effectiveness

Key messages included:

- Common cognitive complaints among people living with Long COVID include: memory trouble, lack of mental energy, difficulty finishing or focusing on tasks, fatigue induced by attention requiring activities
- Individualized cognitive rehabilitation therapy involved identifying challenges and using those to inform individualized targets. Goal attainment scaling was used to measure progress. Rehabilitation strategies were individualized and catered to participant needs and goals.
  - Collaboration between SLP and OT professionals in delivery
    - OT: compensatory strategies: calendars, timers, energy conservation, etc.
    - SLP: word finding

'The Long COVID Education and Awareness Hub:' A public-facing resource webpage – Dr. Jaylyn Leighton, Post-doctoral Fellow, St. John's Rehab, Sunnybrook Research Institute, Toronto, Ontario



"Long COVID (and the experiences of illness/disability) not only impacts one's physical health and cognition, it also impacts one's psychosocial health (mental and emotional wellness and sense of social connectedness)." – Dr. Jaylyn Leighton

Study objectives included:

- To develop a Long COVID Education and Awareness Hub

Key messages included:

- Key messages from people living with Long COVID and caregivers:
  - People living with Long COVID and caregivers experience challenges accessing and participating in LC rehab
  - People living with Long COVID and caregivers are taking on their own care and management of conditions (there is a lack of adequate clinical support)
  - There is a need for psychosocial wellness support
- Key messages from healthcare providers:
  - Care providers lack adequate research and support
  - Care providers felt unprepared to clinically manage Long COVID
  - Best practices: affirming experiences, peer support
- Output is the www.livinglongcovid.ca Project
  - Education: about strategies to manage Long COVID
  - Advocacy: spreading awareness (docuseries to be launched soon)
    - Health and Social Care Reform and Care Integration
  - Peer Support: interactive map of Canada identifying peer support groups

Future directions include:

- Ensuring long term upkeep of this project

The Forum provided an opportunity for speakers and attendees 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.

Evaluations

In total, **68 Forum evaluations** were completed by attendees. See Table 1 for characteristics of attendees who completed evaluations. See **Appendix E** for more details on the results of the Forum evaluations.

Table 1: Characteristics of Attendees Who Completed Evaluations (n=68)

Characteristics of Attendees Who Completed Evaluations (n=68)	N (%)
Attended online	52 (24%)
In which country do you currently reside?	
Canada	51 (75%)
United Kingdom	6 (9%)
United States	4 (6%)
Other (Germany, India, Ireland, Poland, United Arab Emirates, Yemen)	7 (10%)
Which of the following best describes your primary role? (n=67)	
Community member (e.g. person with lived experiences with COVID and/or Long COVID or their parents, partners, and caregivers)	22 (33%)
Clinician	16 (24%)
Academic (e.g. located at an academic institution)	9 (13%)
Trainee (e.g. MSc, PhD, or Post-doctoral Fellow)	7 (10%)
Researcher	6 (9%)
Other (Educator, Caregiver and retired OT, Project Manager in Research (PhD), Service Provider, Student (e.g. Occupational Therapy student, Physical Therapy student, etc.))	7 (10%)
I belong to the following health professional group (n=16)	
Physiotherapist	6 (38%)
Occupational Therapist	5 (31%)
Other (Kinesiologist, Massage Therapist, Physician, Social Worker, Speech-Language Pathologist)	5 (31%)
Has lived experiences with: (n=67)	
Long COVID	24 (35%)
Acute COVID	5 (14%)
Caregiver to someone with Long COVID	5 (14%)
Caregiver to someone with acute COVID	4 (6%)
Another chronic health condition or disability (other than Long COVID)	3 (4%)
None of the above	26 (39%)

The median score for overall satisfaction with 2024 International Forum on COVID Rehabilitation Research (n=64) was 9/10 (min-max: 3-10). See Table 2 for the median satisfaction scores for each of the five sessions included in the 2024 International Forum on COVID Rehabilitation Research.

Table 2: Median Rating of Satisfaction with Sessions at the 2024 International Forum on COVID Rehabilitation Research (n=60)

Median Rating of Satisfaction with Sessions at the 2024 International Forum on COVID Rehabilitation Research (n=60)	Median (Min-max)
Keynote Session #1 - Unlocking the mystery of Post-Exertional Malaise in Long COVID… (Dr. Mark Faghy)	9 (3-10)
Keynote Session #2 – Panel Discussion: Community engagement in rehabilitation research – a year in review (n=56)	8.5 (2-10)

Median Rating of Satisfaction with Sessions at the 2024 International Forum on COVID Rehabilitation Research (n=60)	Median (Min-max)
Research Evidence Sessions (Part 1) (Dr. Chavon Niles, Dr. Behdin Nowrouzi-Kia, Dr. Victor Ezeugwu) (n=52)	8.5 (2-10)
Research Evidence Sessions (Part 2) (Dr. Diana Sanchez-Ramirez, Kiera McDuff, Susan Viola, Dr. Jaylyn Leighton) (n=49)	9 (5-10)
Keynote #3 - Panel Discussion: Bridging Research Evidence with Real World (n=53)	9 (2-10)

Attendees were asked to rate their agreement with whether the 2024 International Forum on COVID Rehabilitation Research met its stated objectives (See Table 3 for the results). The median knowledge on COVID and rehabilitation research *before* attending the Forum (n=62) was median 7/10 (min-max: 2-10); *after* the Forum (n=62) it was median 8/10 (min-max: 4-10).

Table 3: Ratings of Satisfaction with 2024 International Forum on COVID Rehabilitation Research (n=65)

Ratings of Satisfaction with 2024 International Forum on COVID Rehabilitation Research (n=65)	N (%)
The Forum achieved its goal of advancing knowledge transfer and exchange in COVID rehabilitation research and practice.	
Strongly Agree	31 (48%)
Agree	21 (32%)
Neutral	7 (11%)
Disagree	3 (5%)
Strongly Disagree	3 (5%)
The Forum achieved its goal of advancing collaborations and partnerships in COVID rehabilitation research and practice.	
Strongly Agree	25 (38%)
Agree	23 (35%)
Neutral	14 (22%)
Disagree	1 (2%)
Strongly Disagree	2 (3%)
The presenters were knowledgeable and communicated their ideas clearly.	
Strongly Agree	35 (54%)
Agree	23 (35%)
Neutral	4 (6%)
Disagree	1 (2%)
Strongly Disagree	2 (3%)
There was adequate time allocated for informal discussion amongst Forum participants. (n=64)	
Strongly Agree	22 (34%)
Agree	24 (38%)
Neutral	13 (20%)
Disagree	3 (5%)
Strongly Disagree	2 (3%)
I made new contacts which will be helpful in my everyday work. (n=63)	
Strongly Agree	10 (16%)
Agree	14 (22%)

Ratings of Satisfaction with 2024 International Forum on COVID Rehabilitation Research (n=65)	N (%)
Neutral	31 (49%)
Disagree	3 (5%)
Strongly Disagree	5 (8%)

Forty-four attendees (44/64; 69%) said they would be able to apply the content covered in the Forum to their work. Examples of content they would apply to their work included:

- Improved understanding of the perspectives of those who are living with Long COVID
- Applying info covered at the Forum to advocacy and support initiatives for people living with Long COVID
- Applying info covered at the Forum to future research study design and grant writing
- Applying info covered at the Forum to guide clinical decision-making when working with people living with Long COVID
- Applying info covered in the Rounds to develop educational materials for other healthcare professionals, students, or patients

Attendees were asked to share what were the 2-3 most important take home messages that they heard at the 2024 International Forum on COVID Rehabilitation Research. Common themes included:

- Importance of including patients, clinicians, and researchers in efforts to better understand Long COVID
- Pacing is challenging and the goal of pacing may be symptom-stabilization instead of progression of activity
- There is a need to make Long COVID resources more accessible (e.g. across Canada, to minority groups, etc.)
- It is important to screen for post-exertional malaise (PEM) when working with people living with Long COVID

General feedback on the Forum was positive overall. A few comments on overall impressions of the Forum include:

"Fantastic organization!!! Loved the emails and then reminder with zoom link. Loved how quick you put references in the chat when they were being talked about. Loved the Grand Rounds idea the day before for a detailed topic and discussion. Excellent facilitators/moderators. Great time keeping. I really appreciated the patient focus even though it was a research conference. People with LC felt acknowledged and heard."

"Great job. Allowing the posters to be viewed electronically was done very effectively as well."

"It really could be a two-day conference! I would love to see a couple of sessions that are just open discussions (ie not scripted) - maybe it is patient experiences, or maybe it is clinical experience."

"Thank you for providing such a well integrated hybrid meeting in which it was clear that long covid researchers both understand the data and are willing to take steps to protect themselves and others by masking. Even if ventilation in the room was amazing, just having that solidarity so clearly modeled by leaders in the field was incredibly valuable - it really sends a message that people doing the research understand the impact and value of such simple gestures of solidarity and care."

Highlighted Needs and Conclusion

This report summarizes the planning, implementation, content, and evaluation of the **2024 International Forum on COVID Rehabilitation Research**.

The evidence presented at the Forum highlights the following needs:

- Increased access to health care, disability, and employment supports for people living with Long COVID and their caregivers
- Research and education (e.g., for rehabilitation providers and other health care professionals, patients, etc.) on:
    - How to screen for post-exertional malaise (PEM)
    - Existing insurance and disability supports for people living with Long COVID
    - Cognitive impairments experienced by people living with Long COVID, how to assess them, and how to manage them
    - Specific assessment and intervention strategies to implement when working with people living with Long COVID
    - How to support people living with Long COVID to safely stay in, return to, or leave work
- Clinical trials to assess safe rehabilitation interventions for people living with Long COVID
- Building capacity for safe and accessible interdisciplinary Long COVID care

Overall, the 2024 International Forum on COVID Rehabilitation Research was a successful event that built on feedback received from last year's inaugural Forum. All registrants received a link to the Forum presentations on the Network YouTube Channel.

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

References

Agarwal, K.*, Beauchamp, M., Bourbeau, J., Ross, B., Benedetti, A., Rizk, A., Barreto, L., Sedeno, M., Tansey, C. M., Cloutier, J., Lopez, J., Zucco, R., Janaudis-Ferreira, T. (2024, April 19). Participant Satisfaction with a Virtual Rehabilitation Program in Long COVID [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Akbar, N.*, Phadke, S., Mehelay, S., Godinho, A., Fakolade, A., Finlayson, M., Phan, R., Lall, R., & Tough, K. (2024, April 19). Experiences living with Long COVID among racialized communities in Canada [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Chen, C., Haupert, S. R., Zimmermann, L., Shi, X., Fritsche, L. G., & Mukherjee, B. (2022). Global prevalence of post-coronavirus disease 2019 (COVID-19) condition or long COVID: a meta-analysis and systematic review. The Journal of infectious diseases, 226(9), 1593-1607.

Davis, H. E., Assaf, G. S., McCorkell, L., Wei, H., Low, R. J., Re'em, Y., ... & Akrami, A. (2021). Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. EClinicalMedicine, 38.

Government of Canada. (2023). COVID-19 epidemiology update: Summary. *2023*(July 13). Retrieved from https://health-infobase.canada.ca/covid-19/#a2

Kim, C.*, Lin, C.*, Wong, M.*, Al Hamour Al Jarad, S., Gao, A., Kaufman, N., McDuff, K., Brown, D. A., Cobbing, S., Minor, A., Chan Carusone, S., O'Brien, K. K. (2024, April 19). Long COVID and Rehabilitation: Experiences of Physical Therapists in Canada [Poster Abstract]. 2024 International Forum on COVID Rehabilitation Research, Toronto, ON, Canada.

Mandel, H., Yoo, Y., Allen, A., Abedian, S., Verzani, Z., Karlson, E., ... & Moffitt, R. (2024). Long COVID incidence in adults and children between 2020 and 2023: a real-world data study from the RECOVER Initiative. Research Square.

Muldrew, D. H., Fee, A., & Coates, V. (2022). Impact of the COVID-19 pandemic on family carers in the community: a scoping review. Health & Social Care in the Community, 30(4), 1275-1285.

O'Brien, K. K., Brown, D. A., McDuff, K., Clair-Sullivan, N. S., Solomon, P., Carusone, S. C., ... & Harding, R. (2023). Conceptualising the episodic nature of disability among adults living with Long COVID: a qualitative study. BMJ global health, 8(3), e011276.

O'Mahoney, L. L., Routen, A., Gillies, C., Ekezie, W., Welford, A., Zhang, A., ... & Khunti, K. (2023). The prevalence and long-term health effects of Long Covid among hospitalised and non-hospitalised populations: A systematic review and meta-analysis. EClinicalMedicine, 55.

Soriano, J. B., Murthy, S., Marshall, J. C., Relan, P., & Diaz, J. V. (2022). A clinical case definition of post-COVID-19 condition by a Delphi consensus. The Lancet infectious diseases, 22(4), e102-e107.

World Health Organization. (2023). Rehabilitation. *2023*(July 13). Retrieved from https://www.who.int/news-room/fact-sheets/detail/rehabilitation

World Physiotherapy. (2021). World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long-Covid: physical activity and exercise.

Appendix A – Framework of Research Priorities in COVID Rehabilitation and Attendee Feedback on the Framework

Figure 1: Framework of Research Priorities in COVID Rehabilitation

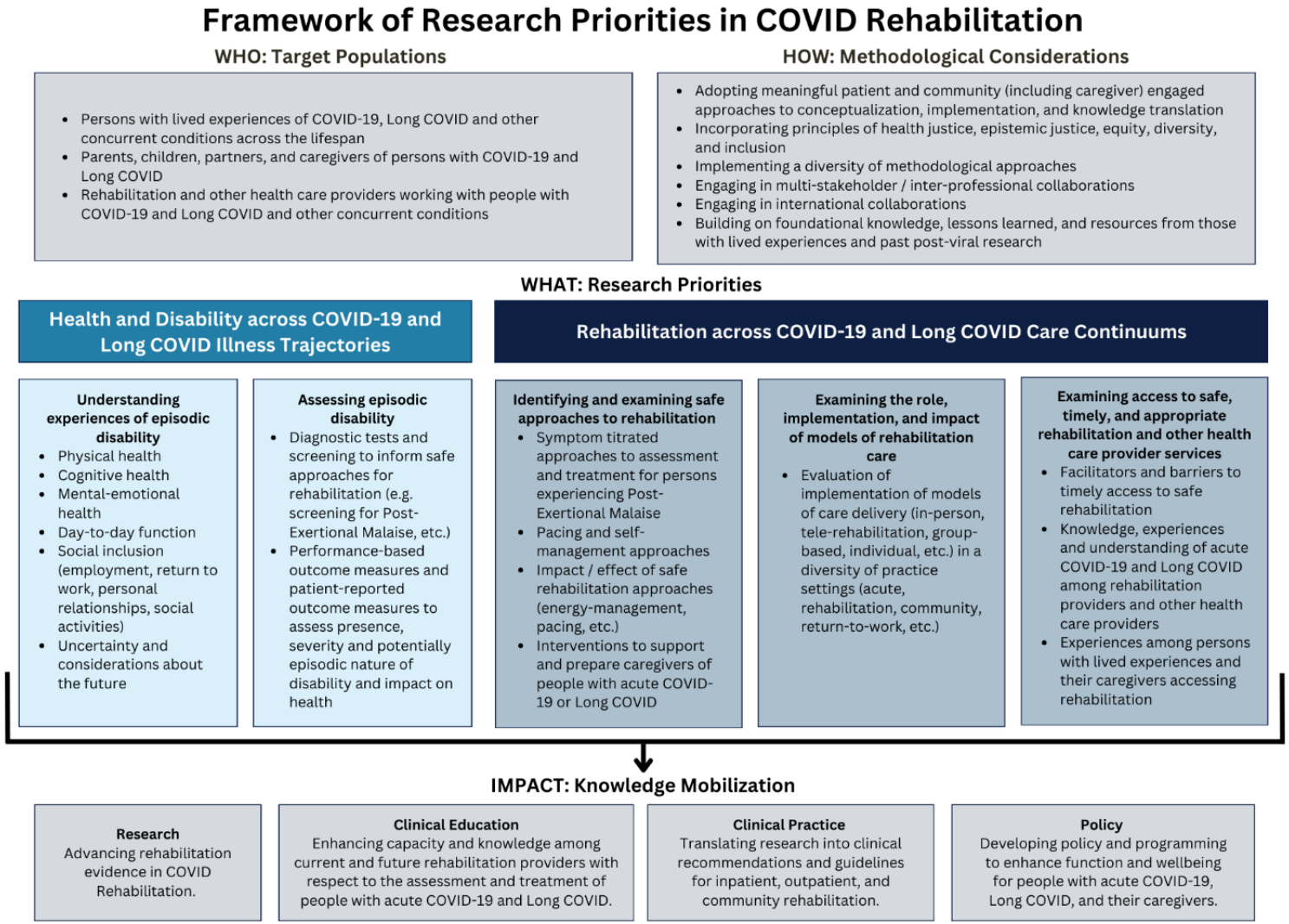


Figure 2: Export of Jamboard with Online Attendees' Feedback on the Framework of Research Priorities in COVID Rehabilitation

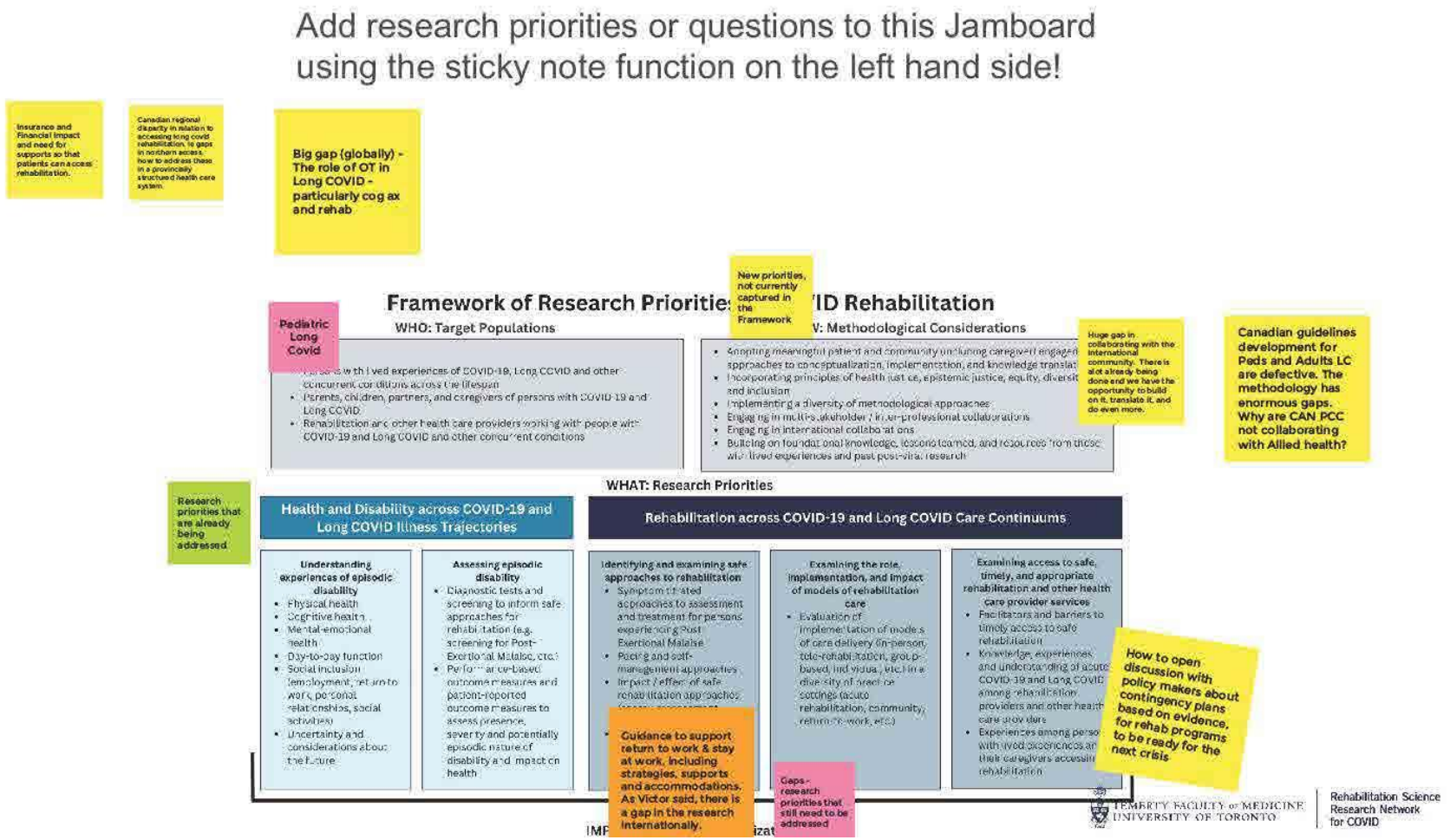
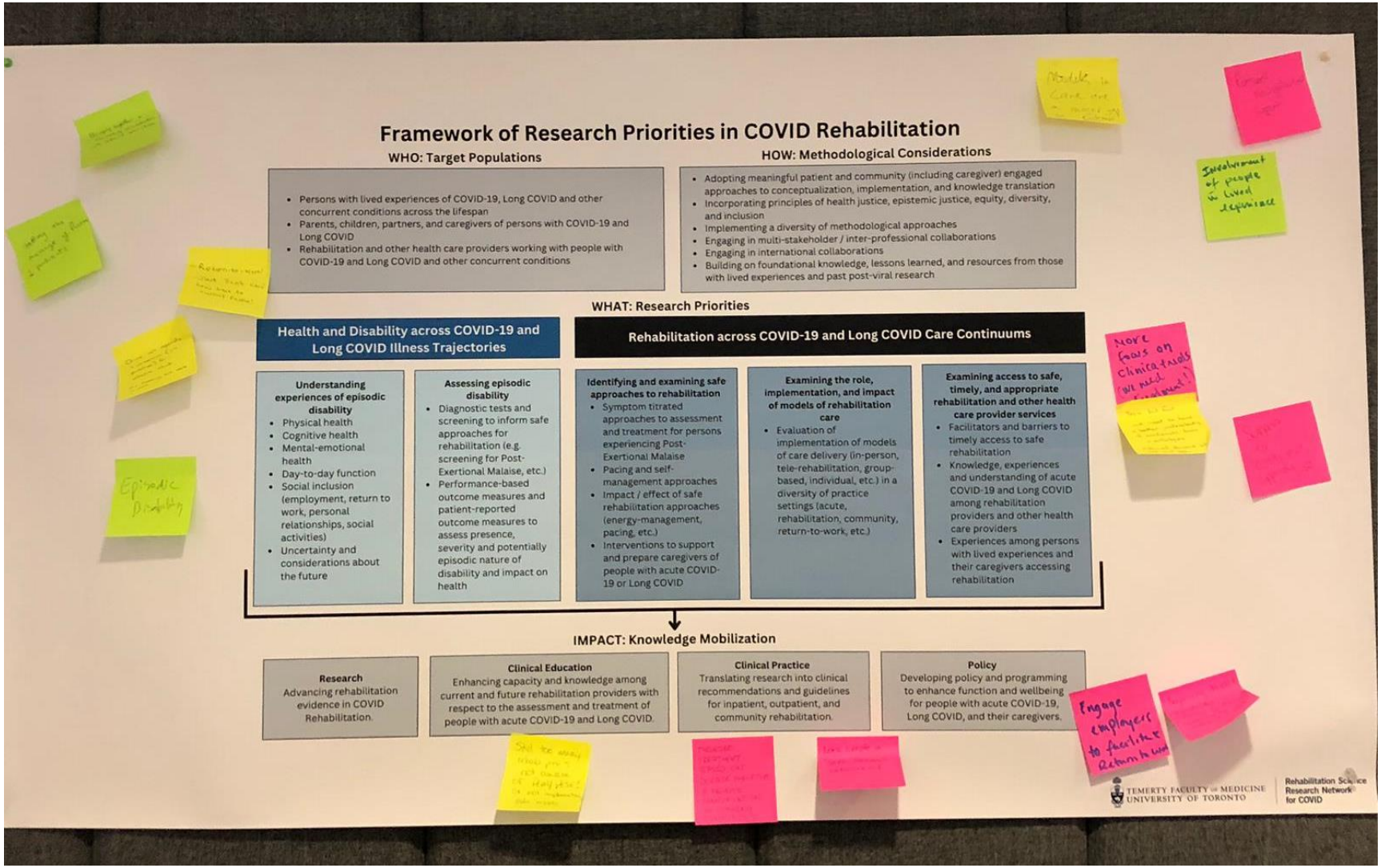


Figure 3: Photo of In-Person Attendees' Feedback on the Framework of Research Priorities in COVID Rehabilitation



Appendix B – Forum Evaluation Questionnaire

Evaluation Survey – 2024 International Forum on COVID Rehabilitation Research

April 19, 2024

Please share your feedback on the Rehabilitation Science Research Network for COVID: 2024 International Forum on COVID Rehabilitation Research!

Thank you and acknowledgments

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 think the **Forum implementation committee:** Nisa Malli, Sabrina Poirier, Katie Churchill, Alexandra Rendeley, Laura Bassi, Jessica Martin, Zeal Kadakia, 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 **FisioCamera, Long COVID Physio, and Long COVID Web**.

Respondent Info

1. Please select one. I attended the Forum:
   - In-Person
   - Online

2. In which country do you currently reside?
   - Australia
   - Canada
   - Chile
   - Germany
   - Hong Kong
   - India
   - Ireland
   - Japan
   - Mauritius
   - New Zealand
   - Nigeria
   - Pakistan
   - Qatar
   - St. Lucia
   - South Korea
   - Switzerland
   - United Kingdom
   - United States of America
   - Other

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.

4. Please select one. I belong to the following **health professional group**:

Note: this question is conditional upon the answer to question 3 being "Clinician."

- 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

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

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 condition or disability** (other than Long COVID)
- Lived experiences as a **caregiver for someone with 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:

Note: this question is conditional upon the answer to question 6 being "Lived experiences with another chronic condition or disability (other than Long COVID)."

8. Were you an invited **speaker, panelist, or presenter** at the International Forum on COVID Rehabilitation Research?

- Yes

- No

9. 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 the 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

Feedback on 2024 International Forum on COVID Rehabilitation Research

10. How would you rate your **overall** satisfaction with the 2024 International Forum on COVID Rehabilitation Research?

0 Not at all satisfied	1	2	3	4	5	6	7	8	9	10 Extremely satisfied

11. Which sessions were you able to **attend or view**? Please select all that apply.
- Keynote Session #1 – Unlocking the mystery of Post-Exertional Malaise in Long COVID… (Dr. Mark Faghy)
- Keynote Session #2 – Panel Discussion: Community engagement in rehabilitation research – a year in review
- Research Evidence Sessions (Part 1) (Dr. Chavon Niles, Dr. Behdin Nowrouzi-Kia, Dr. Victor Ezeugwu)
- Research Evidence Sessions (Part 2) (Dr. Diana Sanchez-Ramirez, Kiera McDuff, Susan Viola, Dr. Jaylyn Leighton)
- Keynote #3 – Panel Discussion: Bridging Research Evidence with Real World: Community, Clinical and Policy Perspectives on Navigating the Maze of the Continuum of Care, Living with Long COVID

12. If applicable, how would you rate your **overall** satisfaction with **Keynote Session #1 – Unlocking the mystery of Post-Exertional Malaise in Long COVID… (Dr. Mark Faghy)**?

0 Not at all satisfied	1	2	3	4	5	6	7	8	9	10 Extremely satisfied

13. If applicable, how would you rate your **overall** satisfaction with **Keynote Session #2 – Panel Discussion: Community engagement in rehabilitation research – a year in review**?

0 Not at all satisfied	1	2	3	4	5	6	7	8	9	10 Extremely satisfied

14. If applicable, how would you rate your **overall** satisfaction with **Research Evidence Sessions (Part 1) (Dr. Chavon Niles, Dr. Behdin Nowrouzi-Kia, Dr. Victor Ezeugwu)**?

0 Not at all satisfied	1	2	3	4	5	6	7	8	9	10 Extremely satisfied

15. If applicable, how would you rate your **overall** satisfaction with **Research Evidence Sessions (Part 2) (Dr. Diana Sanchez-Ramirez, Kiera McDuff, Susan Viola, Dr. Jaylyn Leighton)**?

0 Not at all satisfied	1	2	3	4	5	6	7	8	9	10 Extremely satisfied

16. If applicable, how would you rate your **overall** satisfaction with **Keynote #3 – Panel Discussion: Bridging Research Evidence with Real World: Community, Clinical and Policy Perspectives on Navigating the Maze of the Continuum of Care, Living with Long COVID**?

0 Not at all satisfied	1	2	3	4	5	6	7	8	9	10 Extremely satisfied

17. To what extent do you agree with the following statements?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a) The Forum achieved its goal of advancing knowledge transfer and exchange in COVID rehabilitation research and practice.	○	○	○	○	○
b) The Forum achieved its goal of advancing collaborations and partnerships in COVID rehabilitation research and practice.	○	○	○	○	○
c) The presenters were knowledgeable and communicated their ideas clearly.	○	○	○	○	○
d) There was adequate time allocated for informal discussion amongst Forum participants.	○	○	○	○	○
e) 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?

Note: conditional upon response to question 18 being 'Yes.'

20. If not, please explain?

Note: conditional upon response to question 18 being 'No.'

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

0 Not at all knowledgeable	1	2	3	4	5	6	7	8	9	10 Extremely knowledgeable

22. Please rate your knowledge on COVID and rehabilitation research **after** attending the Forum.

0 Not at all knowledgeable	1	2	3	4	5	6	7	8	9	10 Extremely knowledgeable

Feedback for future Forums on COVID rehabilitation research

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 2024 International Forum on COVID Rehabilitation Research. If you have any questions, please contact the Rehabilitation Science Research Network for COVID's Program Coordinator, Keira McDuff, at rehab.covid@utoronto.ca. **Please click submit before exiting this page to ensure the submission of your response.**

Appendix C – Forum Program

Forum Program at a Glance	
Time (EDT)	**Topic**
9:00-9:30am	**Registration (Coffee, Tea & Light Pastries Provided)**
9:30-9:40am	**Land Acknowledgement & Welcome from the Rehabilitation Sciences Sector and Temerty Faculty of Medicine**
9:40-10:00am	**Overview & Aims of the Forum** **Jill Cameron** (Department of Occupational Science and Occupational Therapy) & **Kelly O'Brien** (Department of Physical Therapy), Co-Directors, Rehabilitation Science Research Network for COVID, University of Toronto **Welcome from Long COVID Physio** **Todd Davenport,** Chair, Long COVID Physio, University of the Pacific, Stockton, California **Welcome from Long COVID Web** **Angela Cheung,** Co-Lead, Long COVID Web, University Health Network, Toronto, Ontario
10:00-10:40am	**Keynote Session #1 – Unlocking the mystery of Post-Exertional Malaise in Long COVID…** **Mark Faghy,** Professor, School of Human Sciences, University of Derby, UK
10:40-11:00am	**Break & Poster Viewing in the Lobby**
11:00am-12:00pm	**Keynote Session #2 – Panel Discussion: Community engagement in rehabilitation research – a year in review** Aim of Session: To build capacity learning from persons with lived experiences about their experiences and perspectives engaging in COVID rehabilitation research, to reflect on the PLRC score cards (1 year on) and to discuss recommendations, considerations and best practices for engaging in COVID rehabilitation research. **Panelists: Margaret O'Hara** (Long COVID Support UK); **Linda Li** (Department of Physical Therapy, University of British Columbia); **Hannah Wei** (Patient Led Research Collaborative and Advisory Committee); **Sammie McFarland** (Long COVID Kids and Advisory Committee); **Susie Goulding** (COVID Long Haulers Support Group Canada and Advisory Committee); **Mark Rutledge** (Advisory Committee member); **Lindsay Skipper** (Long COVID Physio, UK) **Moderator: Kiera McDuff** (Rehabilitation Science Research Network for COVID)
12:00-1:20pm	**Lunch & Poster Viewing in the Lobby (and Online)**
1:20-2:00pm	**Research Evidence Session Part 1 – Health and Disability across Acute and Long COVID Illness Trajectories** Aim of Session: To foster knowledge transfer and exchange on evidence related to 1) understanding experiences of episodic disability; and 2) assessing episodic disability. 1. **Chavon Niles,** Assistant Professor, Department of Physical Therapy, University of Toronto 2. **Behdin Nowrouzi-Kia**, Assistant Professor, Department of Occupational Science and Occupational Therapy, University of Toronto

Forum Program at a Glance	
Time (EDT)	**Topic**
	3. **Victor Ezeugwu,** Assistant Professor, Faculty of Rehabilitation Medicine, Physical Therapy, University of Alberta
2:00-2:20pm	**Break & Poster Viewing in the Lobby**
2:20-3:10pm	**Research Evidence Session Part 2 – Rehabilitation across Acute COVID-19 and Long COVID Care Continuums** 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. 1. **Diana Sanchez-Ramirez**, Assistant Professor, College of Rehabilitation Sciences, University of Manitoba 2. **Kiera McDuff,** Program Coordinator, Rehabilitation Science Research Network for COVID, University of Toronto 3. **Susan Viola**, Assistant Clinical Professor, Department of Speech-Language Pathology, McMaster University, Hamilton, Ontario 4. **Jaylyn Leighton**, Post-doctoral Fellow, St. John's Rehab, Sunnybrook Research Institute, Toronto, Ontario
3:10-4:20pm	**Keynote Session #3 – Panel: Bridging Research Evidence with Real World: Community, Clinical and Policy Perspectives on Navigating the Maze of the Continuum of Care, Living with Long COVID** **Panelists: Nisa Malli** (Patient Led Research Collaborative); **Chester Ho** (MD, University of Alberta); **Adam Brown** (PT, Cornerstone Physiotherapy); **Jessica DeMars** (PT, Breathe Well Physio); **Michelle DiLauro** (OT, Toronto Rehab Institute, University Health Network); **Helen Skiffington** (OT, Long COVID Physio, UK); **Alexandra Rendely** (MD, University Health Network) **Moderator: Katie Churchill** (Rehabilitative Care Alliance)
4:20-4:30pm	**Next Steps, Wrap-Up, Announcements of Poster Awards, & Evaluations**

Appendix D – Forum Poster

TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

Rehabilitation Science Research Network for COVID

2nd International Forum on COVID Rehabilitation Research

Friday April 19, 2024
9:30am-4:30pm EDT

FREE Hybrid event
(Zoom & in-person)
Rehabilitation Sciences Building
500 University Avenue, Room 140,
University of Toronto

Keynote Speaker:
DR. MARK FAGHY
Associate Professor,
School of Human Sciences,
University of Derby, UK

SCAN TO REGISTER

The Rehabilitation Science Research Network for COVID is funded by the Temerty Faculty of Medicine, University of Toronto.

Appendix E – Additional Detail from Forum Evaluations

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

- Lack of resources
- Not currently working
- Difficult to know how to apply the research that was presented to their clinical practice

Additional examples of take-home messages from the Forum:

- Importance of virtual care and cautious approaches to rehabilitation for people living with Long COVID
- Return to work is unlikely to be linear for people living with Long COVID
- Progress to date on COVID rehabilitation and clinical practice does not look the same for everyone (e.g., more marginalized populations face more barriers, not all communities or countries have the same resources, etc.)

Responses when asked, **"What topics or issues would you like to see covered in future Forums, workshops or webinars?":**

- Insurance policies and resources available for people living with Long COVID
- Perspectives of clinicians who are treating patients from other countries
- Caregiver support
- How interdisciplinary teams function and respect and build off of each member's strengths in the context of COVID rehabilitation
- Details on practical aspects of pacing strategies for people living with Long COVID
- Brain fog and cognitive impairments: assessment and management
- Case studies on the structure, key learnings, successes and challenges of existing Long COVID clinics
- Return to work
- Relationship between Long COVID and other related conditions (e.g. post-vaccine injury, other post-viral illnesses, etc.)
- Cardiopulmonary Exercise Testing (CPET) protocols and foundational results to date
- Depression and anxiety experienced by people living with Long COVID (without psychologizing Long COVID)

Suggestions for format of future Forums and events:
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).

A few respondents suggested adding a half day or full day to allow the information to be spread out over a longer period of time.