POST COVID-19 CONDITION

OCSO BIWEEKLY SCAN OF EVIDENCE #20 March 26-April 8, 2022

SCOPE

This biweekly update presents an analysis of new evidence, guidance and issues related to post COVID-19 condition (commonly referred to as 'long COVID') and synthesizes the current state of knowledge. Comprehensive lists of details and resources on this issue are available at the Office of the Chief Science Officer.

CURRENT STATE OF KNOWLEDGE

The typical duration of acute COVID-19 illness is two to four weeks. However, some patients have described debilitating symptoms persisting or recurring for weeks or months after acute illness. The range of symptoms reported is broad, and can vary from mild to more severe and debilitating effects that can affect both young and older individuals, regardless of the severity of their initial COVID-19 symptoms in the acute stage. These symptoms are often described as, Post COVID-19 condition (WHO terminology), post-acute sequelae of SARS-CoV-2 infection (PASC), and long COVID (used by patient groups). Affected individuals are commonly referred to as COVID-19 long-haulers. While scientific knowledge on these conditions is building, there is still much that is unknown about this condition. There have been reports of more than 100 symptoms or difficulties with everyday activities.

There is limited data suggesting that the condition may be more likely to develop in those:

- who were hospitalized during acute infection;
- had more than 5 COVID symptoms during the acute phase;
- have pre-existing respiratory disease;
- are older;
- · are women; and
- have other co-morbidities or have higher BMI.

Typical therapeutic itinerary involves consultations with multiple specialists and puts emphasis on self-management (rest & relaxation, self-pacing, etc). Emerging evidence points to the importance of multidisciplinary care given the heterogeneity of symptoms associated with Post COVID-19 condition. Multidisciplinary teams in "long COVID" clinics have been set to include professionals from the following fields: rehabilitation, respiratory and cardiac consultants, physiotherapists, occupational therapists, psychologists, etc.

It is anticipated that Post COVID-19 condition will have medium and long-term impact on public health in Canada. Further research with an equity lens on the predisposing conditions and risk factors is needed. Based on research to date, and reviewed by the Public Health Agency of Canada as part of a living systematic review, 56% of individuals who have had COVID-19 reported the presence of one or more symptoms 12 weeks after diagnosis. About 58% of children had 1 or more symptoms 4 weeks or more after their initial COVID-19 infection. Post COVID-19 condition will have implications for the economy, as well as federal programs including disability benefits, employment related measures and sick pay, among others. It is reported that 10% of adults are unable to return to work in the long term. The WHO has said that about one in 4 people infected with COVID-19 have experienced a post-COVID-19 condition for at least 1 month. One in 10 people experience symptoms lasting beyond 12 weeks.

This week's scan includes a bibliometric <u>analysis</u> on global trends and research hotspots for long COVID, as well as a systematic <u>review</u> preprint on risk factors and preventative interventions for Post COVID-19 condition.

GUIDELINES OR STANDARDS

- WHO has developed a <u>clinical case definition</u> of post COVID-19 condition by Delphi methodology that includes 12 domains, available for use in all settings. This first version was developed by patients, researchers and others with the understanding that the definition may change as new evidence emerges and our understanding of the consequences of COVID-19 continues to evolve.
 - "Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time."
 - WHO: Q&A page on Post-COVID-19 Condition (February 2022).
- US CDC describes Post-COVID conditions as a range of new, returning, or ongoing health problems people experience four or more weeks after first being infected with the virus that causes COVID-19. The CDC highlights the various types of post-COVID conditions such as: Multiorgan Effects of COVID-19, Effects of COVID-19 Illness or Hospitalization, and 'New or Ongoing Symptoms'. The CDC posted Interim Guidance for healthcare providers on Evaluating and Caring for Patients with Post-COVID Conditions. Post-COVID conditions can be considered a disability under the Americans with Disabilities Act (ADA). The CDC also released information on Caring for People with Post-COVID Conditions.
- UK NICE: Rapid guidelines for managing the long-term effects of COVID-19 (Updated March 2022).
- Chartered Society of Physiotherapy in UK published its COVID-19 rehabilitation standards, which includes guidance about community-based rehab for people with COVID-19 and long COVID (July 2021).
- Guidelines to help doctors manage long COVID patients published in British Journal of General Practice (August 2021).
- UK NHS guidance for Post-COVID syndrome assessment clinics (April 2021).
- CIHI guidance for clinicians to ensure that data supports monitoring for Post-COVID conditions.
- <u>Guidance</u> for Canadian Rehabilitation and Exercise Professionals on Post COVID-19 condition and rehabilitation management strategies (August 2021).
- Government of Canada: COVID-19 for health professionals Post COVID-19 condition
- Center for Effective Practice COVID-19: Clinical Guidance for Primary Care Providers Long-term symptoms / Post-acute sequelae of COVID-19 (PASC)
- Guideline S1: Long COVID: Diagnostics and treatment strategies (Wiener klinische Wochenschrift)
- American Academy of Physical Medicine and Rehabilitation (AAPM&R): <u>Cognitive Symptoms Guidance</u> and <u>Breathing Discomfort</u> Guidance.
- Royal Australian College of General Practitioners (RACGP) guidance for GPs caring for 'long COVID' patients.
- European Society of Clinical Microbiology and Infectious Diseases (**ESCMID**): Rapid guidelines for assessment and management of long COVID
- ACAS (UK-based Advisory, Conciliation and Arbitration Service): Long COVID advice for employers and employees

NATIONAL AND INTERNATIONAL DEVELOPMENTS (MAR 26-APR 8)

CANADA

- (NEW) Federal Budget 2022 proposes to provide \$20 million over five years, starting in 2022-23, for CIHR to support additional research on the long-term effects of COVID-19 infections on Canadians, as well as the wider impacts of COVID-19 on health and health care systems.
- (NEW) Government of Canada is launching a second cycle of the Canadian COVID-19 Antibody and Health <u>Survey</u> (CCAHS) led by StatsCan, PHAC and CITF. Survey will involve 100,000 Canadians and aim to estimate prevalence of post COVID-19 condition.

UK

- (NEW) Latest <u>data</u> from the Office for National Statistics shows 1.7 million people living in private households in the UK (2.7% of the population) were experiencing self-reported long COVID (symptoms persisting for more than four weeks) as of March 5. The number of people who have lived with long COVID for more than a year has risen from 685,000 to 784,000 an increase of 14.4%. 74,000 people in the UK have been suffering from the condition for at least two years.
- (NEW) Long COVID symptoms adversely affected the day-to-day activities of 1.1 million people (67% of those with self-reported long COVID), with 322,000 (19%) reporting that their ability to undertake their day-to-day activities had been "limited a lot."

US

- (NEW) US President has <u>directed government agencies</u> to take additional steps to research and treat long covid. Under a memorandum issued by Biden, they will coordinate a government-wide action plan to address long covid, which is estimated to afflict anywhere from 7.7 million to 23 million Americans, <u>according to a recent federal watchdog report</u>. Government will issue a report in 120 days detailing available services and support for those who suffer from long covid.
- (NEW) Government plans to expand a nationwide network of long covid <u>clinics</u>. Federal officials will also launch a new initiative, the "Health+ project," to solicit feedback from people living with long covid and use it to shape practices at clinics.

EMERGING SCIENTIFIC EVIDENCE (MAR 26-APR 8)*

EVIDENCE PRODUCTS

TITLE AND AUTHOR	EVIDENCE	SUMMARY
	TYPE	
One-Year Temporal	Systematic	Review aimed to explore the 1-year temporal change in prevalence,
Change in Prevalence and	Review	variety and potential risk factors of long COVID symptoms.137 studies
Characteristic of Long	(Available in	were included, covering 134,093 subjects. Prevalence of long COVID
COVID: A Systematic	SSRN Lancet	symptoms was as high as 50% since 1-month after acute phase and did
Review and Meta-Analysis	Prepub)	not show a downward trend during 1-year temporal change. Six months
(Huang et al)		or more after the acute phase, the odds ratio (OR) of population
		characteristic factors increased, such as female gender (from <6 months
		OR=1.62 to ≥ 6 months OR=1.82), while the OR value of acute phase-
		related factors (severe/critical and hospitalization) partially decreased. As
		for specific symptoms, only about one-third of symptoms were
		significantly reduced trends. However, neuropsychiatric-symptoms shows
		a stable trend, and sleep disorders and impaired concentration even
		showed an increased trend. Neuropsychiatric related symptoms showed

		a higher long-term prevalence (approximately 25%) and longer
Risk factors and preventive interventions for post Covid-19 condition: systematic reviews (Pillay et al)	Systematic Review (Available in medRxiv)	persistence trend than physical symptoms. Objective was to systematically identify and synthesize evidence around pre-existing and clinical risk factors for post Covid-19 condition, and interventions during the acute and post-acute phases of the illness that could potentially prevent post Covid-19 condition. Found small-to-moderate associations between female sex and higher non-recovery, fatigue, and dyspnea. Guidelines in relation to surveillance, screening services, and other services such as access to sickness and disability benefits, might need to focus on females and those with previously severe Covid-19 illness.
Global Trends and Research Hotspots in Long COVID: A Bibliometric Analysis (Jin et al)	Review (Available in Int J Environ Res Public Health)	784 publications were extracted from Scopus in the field of long COVID. According to bibliometric analysis, it is found that: developed countries in Europe and America were in leading positions in terms of paper productivity and citations. International Journal of Environmental Research and Public Health and Journal of Clinical Medicine were leading journals in the perspective of publications count, and Nature Medicine had the highest number of citations. Author Greenhalgh T has the highest number of papers and citations
Dietary Recommendations	Review	Review aimed to collect available evidence on the role of nutrients and
for Post-COVID-19	(Available in	their supplementation in post-COVID-19 syndrome to provide a practical
<u>Syndrome</u>	Nutrients)	guideline to nutritionists to tailor dietary interventions for patients
(Barrea et al)		recovering from COVID-19 infections.

SELECT PRIMARY RESEARCH

TITLE AND AUTHOR	SOURCE	SUMMARY
Clinical characteristics, activity levels and mental health problems in children with long coronavirus disease: a	Future Microbiol	Study aimed to establish clusters of symptoms, as well as mental and physical health effects, of children with long COVID. Researchers analyzed data from the online "Long COVID Kids Rapid Survey 2" that was collected between February and March 2021. Links to the survey were disseminated on the closed Facebook group LongCOVIDKids. Only those
survey of 510 children (Buonsenso et al)		children with symptoms lasting longer than 4 weeks were included (n=510). Results showed that fatigue, headache, muscle and joint pain, post-exertional malaise, rashes and heart palpitations were commonly reported symptoms. 25.3% of children had experienced constant COVID-19 infection symptoms, 49.4% had had periods of apparent recovery followed by return of symptoms and 19.0% had had a prolonged period of wellness followed by return of symptoms.
Long-term psychological consequences of long Covid: a propensity score matching analysis comparing trajectories of depression and anxiety symptoms before and after contracting long Covid vs short Covid (Fancourt et al)	medRxiv	Study examined when psychological symptoms first emerge following the infection with SARS-CoV-2, and the long-term trajectories of psychological symptoms comparing long and short Covid groups using longitudinal data from the UCL Covid-19 Social Study (March 2020-November 2021). Depressive and anxiety symptoms increased immediately following the onset of infection in both long and short Covid groups. The long Covid group had substantially greater initial increases in depressive symptoms and heightened levels over 22 months follow-up. Initial increases in anxiety were not significantly different between groups, but only the short COVID group experienced an improvement in anxiety over follow-up, leading to widening differences between groups.

Representation of long	Brain Behav	Google Trends data have been used to track levels of public awareness for
COVID syndrome in the	Immun Health	long COVID and some important symptoms during the course of the
awareness of the		COVID-19 pandemic. Results of this analysis clearly demonstrate the
population is revealed by		public interest in the new topic of long COVID, as documented by a
Google Trends analysis		corresponding search volume.
(Kaatz et al)		
Efficacy of Adaptogens in	Pharmaceutic	Randomized, quadruple-blind, placebo-controlled trial aimed to assess
Patients with Long COVID-	als	the efficacy of adaptogens on the recovery of patients with Long COVID
19: A Randomized,		symptoms. In this study, we, for the first time, demonstrate that
Quadruple-Blind, Placebo-		adaptogens can increase physical performance in Long COVID and reduce
Controlled Trial		the duration of fatigue and chronic pain.
(Karosanidze et al)		
Persistent symptoms after	Lancet Reg	Longitudinal study nested in the French CONSTANCES population-based
SARS-CoV-2 infection:	Health Eur	cohort to investigate the acute symptoms associated with SARS-CoV-2
Long-term implications for		infection. Using logistic regression models, the authors found a higher
health and quality of life		chance for people with SARS-CoV-2 infection, compared to those without
(So et al)		the infection, in developing dysgeusia/anosmia, dyspnea and asthenia as
		persistent symptoms. Not only the authors presented useful information
		on persistent symptoms post COVID-19 in the French population, they
		have also provided a good reference for persistent symptoms in other
		populations. Natural extension of the longitudinal study is to consider
		changes in the severity of symptoms over time, from which we can learn
		how long the "long covid" will persist.
Long COVID (post-COVID-	Arch Dis Child	Aim of this study was to derive a research definition for 'Long COVID in
19 condition) in children: a		children and young people (CYP) to allow comparisons between research
modified Delphi process		studies. 10 statements were taken forward for discussion in the
(Stephenson et al)		consensus meeting and five statements met threshold to be included in
		the research definition of Long COVID among CYP. Research definition,
		aligned to clinical case definition of WHO, is proposed as follows: Post-
		COVID-19 condition occurs in young people with a history of confirmed
		SARS-CoV-2 infection, with at least one persisting physical symptom for a
		minimum duration of 12 weeks after initial testing that cannot be
		explained by an alternative diagnosis. The symptoms have an impact on
		everyday functioning, may continue or develop after COVID infection, and
		may fluctuate or relapse over time. The positive COVID-19 test referred to
		in this definition can be a lateral flow antigen test, a PCR test or an
		antibody test.
The modified COVID-19	medRxiv	Study aimed to modify and refine the COVID-19 Yorkshire Rehabilitation
Yorkshire Rehabilitation		Scale (C19-YRS) based on psychometric properties, emerging evidence on
Scale (C19-YRSm) patient-		additional Long Covid symptoms, and feedback from a working group of
reported outcome		patients and healthcare professionals. Data were collected from 370
measure for Long Covid or		patients who completed the C19-YRS scale in a community Long COVID
Post-COVID syndrome		service in the UK. Rasch analysis revealed promising psychometric
(Sivan et al)		properties of the symptom severity and functional disability subscales,
		with both displaying good targeting and reliability, although some
TI 1 .		individual measurement anomalies were noted.
The changing	Research	Study aims to understand changes in post-COVID-19 syndrome between
characteristics of post-	Square	wave one and wave two, identify interactions between alert level and
COVID-19 syndrome:	prepub	symptoms, and investigate any predictive nature of acute symptoms for
<u>Cross-sectional findings</u>		post-acute symptomology in a young, physically-active population. Post-
from 458 consultations		COVID-19 syndrome prevalence reduced from 43% to 2% between the
using the Stanford Hall		waves. Acutely, widespread pain was more prevalent in wave two. Post-

remote rehabilitation		acutely, there was increased anxiety (p=0.10) in wave one and increased
assessment tool		sleep disturbance, memory/concentration issues and shortness of
(O'Sullivan et al)		breath/cough in wave two. Increasing alert level was associated with
		increased post-acute symptom prevalence, with sleep disturbance
		increasing at higher alert level. Acute symptoms, including fatigue, sleep
		disturbance and myalgia, were associated with multiple post-acute
		symptoms.
Post-COVID-19 syndrome	Clin Microbiol	Study sought to describe the impact of vaccination and the role of
and humoral response	Infect	humoral responses on post-COVID-19 syndrome one year after the onset
association after one year		of SARS-CoV-2. Post-COVID-19 syndrome was observed in 47.2%
in vaccinated and		(226/479) of patients after one year. There were no significant differences
unvaccinated patients		in the worsening of post-COVID 19 symptoms (22.7% vs 15.8%) among
(Peghin et al)		vaccinated (n=132) and unvaccinated (n=347) patients.
Obesity and lipid	Infection	Cross-sectional study aimed to define risk factors for long COVID
metabolism disorders		syndrome (LCS) development. 1,708/50,402 patients (3.4%) were
determine the risk for		diagnosed with LCS. In a multivariate regression analysis, lipid metabolism
development of long		disorders and obesity were identified as strong risk factors for the
COVID syndrome: a cross-		development of LCS. Besides these metabolic factors, patients' age
sectional study from		between 46 and 60 years (compared to age ≤ 30), female sex, as well as
50,402 COVID-19 patients		pre-existing asthma and depression in women, and cancer in men were
(Loosen et al)		associated with an increased likelihood of developing LCS.
PMC8960224; "Like	BMC Public	Qualitative study investigated the experience of individuals who had been
before, but not exactly":	Health	hospitalized for COVID-19, focusing on those needs and difficulties they
the Qualy-REACT		perceived as most urgent. Overall, 150 individuals consented to
qualitative inquiry into the		participate in the REACT study, and 56 individuals (60.7% male, average
lived experience of long		age 62.8 years ±11.8) were interviewed in June-July 2020, up to data
COVID		saturation. Persistent symptoms, feelings of isolation, fear and stigma,
(Schiavi et al)		emotional distress, a fatalistic attitude, and return to (adapted) life course
		were the key themes that characterized the participants' experience after
		hospital discharge.

^{*}Note: Content may have been published prior to this scan period but was only available through applying our search strategies during this period.

COMMENTARIES, LETTERS AND OPINION PIECES (MAR 26-APR 8)

- Can drugs reduce the risk of long COVID? What scientists know so far (Nature): A large UK-based trial called HEAL-COVID is testing two drugs that target the cardiovascular system in people who have been hospitalized with COVID-19. One, called apixaban, is an anticoagulant. The other, atorvastatin, is a cholesterol-lowering medication thought to reduce inflammation in blood vessels. A clinical trial called PANORAMIC has been testing the effects of the oral antiviral molnupiravir on COVID-19 severity. Although it is not the primary goal of the study, researchers will gather data from participants at three and six months after treatment which could determine whether the drug affects long-COVID risk. Two trials of Paxlovid, an antiviral drug developed by Pfizer, will include a six-month follow-up of participants.
- Joint patient and clinician priority setting to identify 10 key research questions regarding the long-term sequelae of COVID-19 (Thorax): Research Questions: What are the underlying mechanisms of long COVID that drive symptoms and/or organ impairment? What imaging techniques or scans may be able to detect and predict the development of organ problems or wider systemic issues? What happens to the immune system throughout patients' recovery from COVID-19? What can data at 6 and 12 months tell us about the long-term trajectory of illness? What blood or other laboratory tests may be able to detect and predict the development of organ problems or wider systemic issues? What is the impact of treatment(s) during the acute (initial) stage of COVID-19 on recovery? What are the

problems within the muscles associated with symptoms limiting activity/function/exercise? If so, what can be done to help? What medications, dietary changes, supplements, rehabilitation and therapies aid recovery? What can be done to support mental well-being during recovery? What is the risk of future adverse health events (eg, stroke, heart attack)?

MEDIA HIGHLIGHTS (MAR 26-APR 8)

CANADA

- Experts question research suggesting long COVID symptoms may depend on variant (CTV News): While new research suggests that symptoms linked to long COVID could vary depending on which COVID-19 variant a person is infected with, infectious disease experts say they are not completely convinced this is the case. Data is based on a study involving 428 long COVID patients treated at a post-COVID outpatient service between March 2020 and June 2021, while the original strain of SARS-CoV-2 and the Alpha variant were in circulation. It suggests that those who contracted the Alpha variant encountered different neurological and emotional symptoms when compared with those who were infected with the original strain of SARS-CoV-2. Looking at the study's design, it appears as though researchers did not confirm which variant of the virus caused infection in which patients, said Dr. Nazeem Muhajarine, an epidemiologist at the University of Saskatchewan. Instead, patients were assessed based on whether they were infected when the original strain dominated, or while the Alpha variant was dominant. This raises doubts around the accuracy of the study, Muhajarine said.
- Long COVID is affecting thousands of Canadians. These researchers are racing to understand its risk factors, treatments (Globe and Mail): In a statement, a spokesperson for CIHR said it created a dedicated pool of funds for long-COVID research last year and has so far invested nearly \$18-million in projects studying various aspects of the condition. A peer-reviewed study published in *Nature* found that people who had been infected with the virus experienced a reduction in grey matter and a greater cognitive decline compared with people who had not contracted COVID-19.

GLOBAL

• A battle is raging over long covid in children (MIT Technology Review): As of March 28, the CDC reported 7,880 cases of MIS-C in the US, which have so far resulted in 66 deaths. But there is disagreement over whether MIS-C falls under the umbrella of long covid or not. Few recent studies suggest that vaccination can reduce a child's risk of severe illness from Omicron by two-thirds. "There's been a real lack of support, understanding, research, and treatments for children," says Kane, who is a consultant respiratory physician at Manchester University NHS Foundation Trust.

POST COVID-19 CONDITION RESOURCES

- (NEWLY ADDED) <u>Voices of Long COVID (US):</u> Voices of Long Covid campaign features testimonials from a diverse group of people ages 18-29 who are suffering from long-term complications of COVID-19 infection.
- (NEWLY ADDED) <u>Dignity Health (US)</u>: COVID-19 and Chronic Illness Recovery Program based in the U.S. has helped over 2,000 people struggling with COVID long-term effects ("COVID long haulers"). Treatment is exercise-based for lingering or long-term conditions (sequelae) from having the virus.
- Altea (Switzerland): A network for sharing evidence-based information on the long-term effects of COVID-19.
- <u>Pandemic-Aid Networks</u>: Long COVID research library.
- <u>Post-COVID-19 Functional Status Scale</u>: An overview of a patient self-reported scale that helps to support assessment of functional status and recovery after the SARS-CoV-2 infection.
- Ontario College of Family Physicians: Resources on Post-COVID Condition.
- Agency for Clinical Innovation (Australia): Living Evidence post acute sequelae of COVID-19.
- Pre-populated literature searches: <u>Long COVID search</u> (LitCovid) and <u>Long COVID search</u> (NIH)
- PAHO Webinar Series on Post COVID-19 Condition launched 17 February, 2022, from 10:30 am to 12:30 pm (EST).

- <u>Body Politic COVID-19 Support Group (Global):</u> Housed on the Slack app, group members have access to dozens of different channels, which give space for more personal discussion. Some of the channels include those specifically for medical professionals, parents of children with Covid-19, LGBTQ+ individuals, BIPOC+, and different regions around the world.
- <u>Patient-Led Research Collaborative (Global):</u> Self-organized group of Long COVID patients working on patient-led research around the Long COVID experience.
- British Heart Foundation (UK): UK-based foundation with resources on long COVID.
- <u>COVID Long Haul (Canada)</u>: Canada's largest online platform for COVID survivors, their family members and anyone searching for the
 most up-to-date information about the pandemic. There is a COVID long-haulers <u>support group</u> and a <u>Report on Pan-Canadian Long</u>
 <u>COVID Impact Survey (PDF) (June 2021)</u>
- <u>BC ECHO for Post-COVID-19 Recovery (Canada)</u>: BC ECHO for Post-COVID-19 Recovery is a learning community of specialists and
 community health-care providers who use case-based learning to improve care for those recovering from symptoms post-COVID-19.
- Long Covid Support (UK): Peer support and advocacy group aiming to facilitate international peer support and campaigning in the UK for recognition, rehabilitation and research into treatments.
- Long COVID SOS (UK): Long-term sufferers formed the LongCovidSOS campaign to put pressure on the UK government to recognise the needs of those with Long Covid, and to raise awareness among the general public and employers.
- <u>Survivor Corps (US)</u>: One of the largest and fastest growing grassroots movements connecting, supporting, and mobilizing COVID-19 Survivors to support research. They have a list of Post-COVID Care Centers (PCC) and a PCCC Best Practices Guide.
- <u>The Center for Chronic Illness (US)</u>: Aims to promote well-being and decrease isolation for those impacted by chronic illness through support and education. Their online support groups are professionally-facilitated and offer psychoeducational tools for coping.
- <u>Blooming Magnolia (US)</u>: Mission is to empower others by providing a platform to strengthen & protect mental health and support
 those afflicted with Long-Covid through education and funding of therapeutic research. They have a list of support groups and
 resources on their website.
- Long COVID Alliance (US): US-based network of patient-advocates, scientists, disease experts, and drug developers who have joined together to leverage their collective knowledge and resources to educate policy makers and accelerate research to transform our understanding of post-viral illness.
- Long COVID Kids (UK/US/Canada): Parent & patient led advocacy & support group based in the UK.
- Long COVID Physio (US & UK): International peer support, education and advocacy group of Physiotherapists living with Long COVID, founded in November 2020 by Physiotherapists living with Long COVID from the UK and US.
- <u>Patient-Led Research Collaborative (Global)</u>: Group of Long COVID patients working on patient-led research around the Long COVID experience.
- <u>CANCOV- Patient resources (Canada):</u> CANCOV is a research platform grounded in a prospective longitudinal 1-year cohort study of
 patients infected with COVID-19.
- <u>COVID Patient Recovery Alliance (CPRA) (US)</u>: CPRA aims to bring together leaders in business, health care, research, academia, data and analytics, and patient advocacy to develop solutions that coordinate diverse data sources, inform models of care, and ensure adequate payment for long-COVID patients. Their <u>report</u> outlines recommendations for federal policymakers to promote recovery.
- <u>British Lung Foundation (UK)</u>: UK-based charity sharing resources on navigating the NHS, breathlessness support, movement and energy support for long COVID patients.
- <u>Living with Long COVID (US)</u>: COVID-19 Long-Haulers and Post-COVID Support Community.

Note: Previous OCSO Post COVID-19 Condition Scans can be found here.