POST COVID-19 CONDITION

OCSO BIWEEKLY SCAN OF EVIDENCE #22

April 23-May 6, 2022

SCOPE

This biweekly update presents an analysis of new evidence, guidance and issues related to post COVID-19 condition 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

According to the World Health Organization (WHO), post COVID-19 condition (PCC) refers to persistent symptoms occurring 12 weeks or more after an acute COVID-19 infection, which persist or reoccur for a minimum of 8 weeks. The most common symptoms include fatigue, cognitive problems (e.g., memory, concentration), respiratory issues, and mental health issues (e.g., anxiety, depression). PCC is also referred to as long COVID, post-acute sequelae, post COVID-19 symptoms, and post-acute COVID-19 syndrome. Prior to the WHO definition, a number of studies reported on post-acute sequelae (PAS) from 4 to 12 weeks post diagnosis. 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.

(UPDATED) There is currently no specific treatment for long COVID. We do not know why some people develop long COVID while others are not affected. The impacts of vaccination on PCC or PAS are important, given early estimates of the burden of PCC suggest >50% of individuals with confirmed COVID-19 infection have reported at least one PCC symptom more than 12 weeks after diagnosis. 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 PCC. Multidisciplinary teams in "long COVID" clinics have been set up 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. 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 <u>scoping review</u> on Post-COVID-19 Condition published by *CADTH*, as well as a <u>review</u> published in *Nutrients* examining the potential role of vitamin D in long COVID.

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).
- (UPDATED) US CDC describes Post-COVID conditions as a wide range of new, returning, or ongoing health problems that people experience after first being infected with the virus that causes COVID-19. 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.
 CDC is using science to learn more about 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 Guidance</u>.
- 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): <u>Long COVID advice for employers and employees</u>

NATIONAL AND INTERNATIONAL DEVELOPMENTS (APR 23-MAY 6)

CANADA

- (NEW) A <u>survey</u> by Viral Neuro Exploration (VINEx), Neurological Health Charities Canada and COVID Long-Haulers Support Group Canada ran between March 23-April 13, 2022 and received responses from 1,050 long haulers in 9 provinces and 1 territory. 87% of respondents identified as women and 10.5% of respondents identified as a visible minority or member of a minority cultural community. Only a quarter of respondents were initially believed and received appropriate care when they described their long COVID symptoms to a health-care professional. Over 80% of respondents say long COVID has had a negative or very negative impact on their brain health. Over 70% had to take leave from work as a result of living with long COVID, with some having to leave the workforce.
- (NEW) Alberta Health Services, along with the University of Alberta, is conducting the first large-scale <u>survey</u> on the impacts of long COVID in the province.

UK

 (NEW) <u>UK Office of National Statistics</u>: The odds of reporting long COVID symptoms 4 to 8 weeks after a first COVID-19 infection were 49.7% lower in infections compatible with the Omicron BA.1 variant than those compatible with the Delta variant among adults who were double-vaccinated when infected; after adjusting for socio-demographic characteristics.

US

• (UPDATED) Long COVID may already affect between 7 and 23 million Americans who previously had the virus, or up to 7% of the U.S. population, according to the <u>U.S. Government Accountability Office</u>.

EMERGING SCIENTIFIC EVIDENCE (APR 23-MAY 6)*

EVIDENCE PRODUCTS

TITLE AND AUTHOR	EVIDENCE	SUMMARY
	TYPE	
Cardiovascular	Systematic	A systematic search on post COVID-19 infection quantitative studies
complications and	Review	among athletes was conducted following MeSH terms in Medline,
outcomes among athletes	(Available in	Cochrane Library, Ovid, Embase and Scopus (through 15 January 2022).
with COVID-19 disease: a	BMC Sports	This study provides a low prevalence of CV complications secondary to
systematic review	Sci Med	COVID-19 infection in short-term follow-up. Early recognition and
(Alosaimi et al)	Rehabil)	continuous assessment of cardiac abnormality in competitive athletes are
		imperative to prevent cardiac complications.
Long COVID and	Review	There is accumulating evidence in the literature indicating that a number
neuropsychiatric	(Available in	of patients with COVID may experience a range of neuropsychiatric
<u>manifestations</u>	Exp Ther Med)	symptoms, persisting or even presenting following the resolution of acute
(Efstathiou et al)		COVID-19. Among the neuropsychiatric manifestations more frequently
		associated with 'long COVID' are depression, anxiety, post-traumatic
		stress disorder, sleep disturbances, fatigue and cognitive deficits, that can
		potentially be debilitating and negatively affect patients' wellbeing, albeit
		in the majority of cases symptoms tend to improve over time. Given the
		alarming effects of 'long-COVID', interdisciplinary cooperation for the

An overview of post COVID sequelae (Shukla et al)	Review (Available in J Basic Clin Physiol Pharmacol)	early identification of patients who are at a high risk of persistent neuropsychiatric presentations, beyond COVID-19 recovery, is crucial to ensure that appropriate integrated physical and mental health support is provided, with the aim of mitigating the risks of long-term disability at a societal and individual level. The clinical spectrum and long-term course of this clinical entity must be better understood. Post-COVID syndrome affects a wide spectrum of individuals (16–87%), with pneumological and cognitive symptoms being the most common. Pulmonary fibrosis was the most common organic consequence seen in post-COVID patients. Post-COVID-19 syndrome can have a major impact on the health of survivors. Working-age patients should seek rehabilitation and follow-up in interdisciplinary rehabilitation
		programmes. COVID-19-related healthcare demands will continue to climb for the foreseeable future. For COVID-19 survivors' long-term
		mental and physical health, present outpatient infrastructure will be
		utilised, scalable healthcare models will be built, and cross-disciplinary collaboration will be required.
Vitamin D: A Role Also in	Review	Vitamin D is an immunomodulatory hormone with proven efficacy
Long COVID-19?	(Available in	against various upper respiratory tract infections. Vitamin D can inhibit
(Barrea et al)	Nutrients)	hyperinflammatory reactions and accelerate the healing process in the
		affected areas, especially in lung tissue. Vitamin D deficiency has been associated with the severity and mortality of COVID-19 cases, with a high
		prevalence of hypovitaminosis D found in patients with COVID-19 and
		acute respiratory failure. Thus, there are promising reasons to promote
		research into the effects of vitamin D supplementation in COVID-19
		patients. However, no studies to date have found that vitamin D affects
		post-COVID-19 symptoms or biomarkers. Based on this scenario, this
		review aims to provide an up-to-date overview of the potential role of
		vitamin D in long COVID-19 and of the current literature on this topic.

SELECT PRIMARY RESEARCH

TITLE AND AUTHOR	SOURCE	SUMMARY
Reducing fatigue-related	Cardiovasc	Paper presents an analysis of a case series of the first 20 patients' data
symptoms in Long COVID-	Endocrinol	collected in clinical practice to evaluate the potential of a possible
19: a preliminary report of	Metab	alternative treatment for Long COVID. None of the participants had a
a lymphatic drainage		prior diagnosis of chronic fatigue syndrome, and all were new attendees
intervention		to the clinics at the time of initial assessment. The average number of
(HH et al)		treatment sessions was 9.7 in men and 9.4 in women. The reduction in
		profile of fatigue-related states (PFRS) scores was 45% in men and 52% in
		women. The highest subscale scores on average were for fatigue, with the
		lowest for somatic symptoms. All subscale scores showed, on average, a
		similar reduction of approximately 50% postintervention, with the
		reduction in score relating to a decrease in the severity of symptoms.
Modelling potential acute	BMC Public	Authors develop a model by which to estimate the potential acute and
and post-acute burden of	Health	post-acute COVID-19 burden using disability-adjusted life years (DALYs)
COVID-19 under the		associated with the re-opening of Australian borders and the easing of
Australian border re-		other public health measures, with particular attention to longer-term,
opening plan		post-acute consequences and the potential impact of permanent
(Angeles et al)		functional impairment following COVID-19. Mortality was responsible for
		72-74% of the total base case COVID-19 burden. Long COVID and post-

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		intensive care syndrome accounted for at least 19 and 3% of the total
		base case DALYs respectively. When included in the analysis, potential
		permanent impairment could contribute to 51-55% of total DALYs lost.
COVCOG 2: Cognitive and	Front Aging	Authors in study assess this sample on tests of memory, language, and
Memory Deficits in Long	Neurosci	executive function. They hypothesize that performance on "objective"
COVID: A Second		cognitive tests will reflect self-reported cognitive symptoms and that
<u>Publication From the</u>		some symptom profiles may be more predictive of cognitive performance
COVID and Cognition		than others, perhaps giving some information about the mechanism. They
Study		found a consistent pattern of memory deficits in those that had
(Guo et al)		experienced the COVID-19 infection, with deficits increasing with the
,		severity of self-reported ongoing symptoms. Fatigue/mixed symptoms
		during the initial illness and ongoing neurological symptoms were
		predictive of cognitive performance.
Pulmonary and Renal Long	Research	Authors performed proteomic and metabolomic analyses of 991 blood
COVID at Two-year Revisit	Square	and urine specimens from 144 COVID-19 patients with comprehensive
(Guo et al)	prepub	clinical data and up to 763 days of follow up. Data showed that the lungs
(Guo et al)	ргерив	and kidneys are the most vulnerable organs in long COVID patients. Study
		depicts the longitudinal clinical and molecular landscape of COVID-19 with
		; ;
		up to two-year follow-up and presents a method to predict pulmonary
Danimata was a sand	501 On an Dan	and renal long COVID.
Respiratory symptoms and	ERJ Open Res	In the COMEBAC (Consultation Multi-Expertise de Bicêtre Après COVID-
radiological findings in		19) cohort study, 478 hospital survivors were evaluated by telephone 4
post-acute COVID-19		months after hospital discharge, and 177 who had been hospitalised in an
<u>syndrome</u>		intensive care unit (ICU) or presented relevant symptoms underwent an
(Jutant et al)		ambulatory evaluation. New-onset dyspnoea and mild fibrotic lesions
		were frequent at 4 months, but the association of new-onset dyspnoea,
	_	fibrotic lesions and low D (LCO) was rare.
Coding Long COVID:	medRxiv	Authors leverage the largest publicly available HIPAA-limited dataset
<u>Characterizing a new</u>		about patients with COVID-19 in the US to examine the heterogeneity of
disease through an ICD-10		adoption and use of U09.9, the ICD-10-CM code for "Post COVID-19
lens		condition, unspecified." Results include a characterization of common
(Pfaff et al)		diagnostics, treatment-oriented procedures, and medications associated
		with U09.9-coded patients, which give us insight into current practice
		patterns around Long COVID. They established the diagnoses most
		commonly co-occurring with U09.9, and algorithmically clustered them
		into three major categories: cardiopulmonary, neurological, and
		metabolic.
Clinical features,	Research	Study aimed to characterize the clinical features of long COVID, by
therapeutic outcomes and	Square	surveying 286 patients who received care in our outpatient clinic for long
recovery period of long	prepub	COVID from May 2021 through December 2021. Results show median
COVID		number of symptoms was 2.8. Most frequent symptoms were respiratory
(Takakura et al)		manifestations (52.1%), followed by fatigue (51.4%). Respiratory
		symptoms, fatigue, and headache/arthralgia were major complaints in the
		initial phase, whereas hair loss was a major complaint in the late phase,
		suggesting that the chief complaint of patients with long COVID may vary
		temporally. The best treatment outcome was observed for pulmonary
		symptoms, and hair loss had the worst outcome. Smoking habit was an
		independent risk factor for slowing the recovery period from long COVID.
Persistent COVID-19	Nat Commun	Authors use data from rounds 3–5 of the REACT-2 study (n = 508,707;
symptoms in a community		September 2020 – February 2021), a representative community survey of
study of 606,434 people in		adults in England, and replication data from round 6 (n = 97,717; May
England		2021) to estimate the prevalence and identify predictors of persistent
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Detection of Male Hypogonadism in Patients with Post COVID-19 Condition (Yamamoto et al)	J Clin Med	symptoms lasting 12 weeks or more; and unsupervised learning to cluster individuals by reported symptoms. At 12 weeks in rounds 3–5, 37.7% experienced at least one symptom, falling to 21.6% in round 6. Female sex, increasing age, obesity, smoking, vaping, hospitalisation with COVID-19, deprivation, and being a healthcare worker are associated with higher probability of persistent symptoms in rounds 3–5, and Asian ethnicity with lower probability. Authors set up an outpatient clinic specializing in long COVID in February 2021 and have been investigating post COVID-19 condition. A retrospective analysis was performed for 39 male patients in whom serum free testosterone (FT) levels were measured out of 61 male patients who visited the clinic. Among the 39 patients, 19 patients (48.7%) met the criteria for late-onset hypogonadism. Symptoms including general fatigue, anxiety, cough and hair loss were more frequent in LOH group than in non-LOH group. Blood hemoglobin level was slightly, but significantly, lower in the LOH group. Serum level of FT was positively correlated with
SingStrong-A singing and breathing retraining intervention for respiratory and other common symptoms of long COVID: A pilot study	Can J Respir Ther	levels of blood hemoglobin and serum total protein and albumin in total population, whereas these interrelationships were blurred in LOH group. Study evaluated a breathing retraining and singing programme to address common long COVID symptoms in 21 participants who completed at least 10 classes. Participants showed significant pre-post-intervention improvements in all breathlessness symptoms, fatigue, usual activities, and pain/disability.
(Cahalan et al) Clustering analysis reveals different profiles associating long-term post-COVID symptoms, COVID-19 symptoms at hospital admission and previous medical co- morbidities in previously hospitalized COVID-19 survivors (Fernández-de-Las-Peñas et al)	Infection	Aim was to identify subgroups of COVID-19 survivors exhibiting long-term post-COVID symptoms according to clinical/hospitalization data by using cluster analysis in order to foresee the illness progress and facilitate subsequent prognosis. Anxiety/depressive levels and sleep quality were assessed with the Hospital Anxiety and Depression Scale and Pittsburgh Sleep Quality Index, respectively. Cluster analysis was used to identify groupings of COVID-19 patients without introducing any previous assumptions, yielding three different clusters associating post-COVID symptoms with acute COVID-19 symptoms at hospital admission. The identified subgrouping may reflect different mechanisms which should be considered in therapeutic interventions.
Reduced Cell Surface Levels of C-C Chemokine Receptor 5 and Immunosuppression in Long Coronavirus Disease 2019 Syndrome (Gaylis et al)	Clin Infect Dis	In an exploratory trial treating "long COVID" with the CCR5-binding antibody leronlimab, authors observed significantly increased blood cell surface CCR5 in treated symptomatic responders but not in nonresponders or placebo-treated participants. These findings suggest an unexpected mechanism of abnormal immune downmodulation in some persons that is normalized by leronlimab.
[A new challenge: post- COVID syndrome in teenagers] (Perrin et al)	Rev Med Suisse	In this specialized consultation for pediatric post-COVID syndrome, authors offer a global and multidisciplinary follow-up to patients and their families, supporting them progressively resuming physical and mental activity, and pursuing school attendance to avoid dropout.

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Persistent Lung Injury and	Front	Aim of study is to investigate the basis of pulmonary susceptibility during
Prothrombotic State in	Immunol	sequelae and the possibility that prothrombotic states may influence
Long COVID		long-term pulmonary symptoms of COVID-19. Considering the important
(Xiang et al)		role of microthrombus and arteriovenous thrombus in the process of pulmonary functional lesions to organic lesions, authors further study the possibility that prothrombotic states, including pulmonary vascular endothelial cell activation and hypercoagulability, may affect long-term pulmonary symptoms in long COVID. Early use of combined anticoagulant and antiplatelet therapy is a promising approach to reduce the incidence of pulmonary sequelae.
The Relationship between	Int J Environ	The relationship between long COVID symptoms and physical activity (PA)
Physical Activity and Long	Res	levels are unclear. In this cross-sectional study, authors examined this
COVID: A Cross-Sectional		association, and the advice that individuals with LC received on PA. New
Study		Zealand physical activity questionnaire short form (NZPAQ-SF) was
(Wright et al)		adapted to capture current and pre-COVID-19 PA levels and activities of
		daily living (ADLs). Participants reported how PA affected their symptoms,
		and what PA advice they had received; 477 participants completed the
		survey. Participants reported the effect of PA on LC symptoms as:
		worsened (74.84%), improved (0.84%), mixed effect (20.96%), or no effect
		(28.72%). Research is needed to understand how to safely return to PA
		without worsening LC symptoms.

^{*}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 (APR 23-MAY 6)

- Caring for the carers: understanding long COVID in our diverse healthcare workforce (BMJ): Healthcare workers may also be more likely than the general population to be affected by long COVID, with a disproportionate burden among ethnic minorities. A wide range of nationally funded research studies have been initiated in the UK to better understand the long term impact of SARS-CoV-2 infection on physical and mental health, and how to enhance the diagnosis and treatment of long COVID. However, these studies have largely, to date, focused on the general population, with a critical gap in research on long COVID among healthcare workers, and ethnic minority groups in particular. Research looking at the prevalence of long COVID among healthcare workers will be vital in generating key recommendations and personalised interventions for addressing social and health inequities.
- Long COVID: aiming for a consensus (*The Lancet*): There are concerns about differences in terminology, with some public health experts and policy makers avoiding the term long COVID. The use of different terms can raise worries, especially among those with lived experience of the condition who originally coined the term long COVID. Many issues have been raised by patient-researchers and other adopters of the term. One issue is epistemic injustice in medicine, including the poor recognition of patient-led expertise. Patient perspectives emphasise the tradition in medical history that those who first identify and describe a condition, name it. In the case of long COVID, it was people with lived experience of it who brought it to the world's attention and described it via a wide range of methods. The first publication on prolonged symptoms of COVID-19 was authored by patient-researchers with long COVID, later known as the Patient-Led Research Collaborative. Another issue is that the severity, features, and urgency of long COVID—as highlighted by patients—are not fully addressed within the framework of other terms and definitions.

MEDIA HIGHLIGHTS (APR 23-MAY 6)

CANADA

- Public health agency to assess how many Canadians struggle with long COVID (Globe and Mail): Federal agencies are trying to get a handle on how many Canadians may be suffering from long COVID as researchers learn more about the mysterious aftereffects of the virus. PHAC and Statistics Canada have launched a survey to try to get a broad idea of how common it is for people to feel lingering effects after COVID-19 infection, which can be difficult to identify and even harder to track. "We probably anticipate that the impact of long COVID is going to be quite substantial," Dr. Tam said at a media briefing.
- Racial bias in Canada's health care system makes diagnosing long COVID even more challenging, experts say (Globe and Mail): Black, South Asian and Indigenous people have made up the largest proportions of cases of COVID-19 and COVID-related hospitalizations in many parts of the country, and some researchers theorize that these groups also have higher rates of long COVID. But without a lab test to diagnose the syndrome, and with barriers to treatment among racialized and immigrant communities, advocates worry that studies into long COVID may be leaving out the people who are suffering the most.

GLOBAL

- The Children Left Behind by Long COVID (Bloomberg): Estimates of the number of children who face long-term symptoms are far from precise, but they probably range from 5% to 10% of those infected with the virus, says Daniel Griffin, an infectious diseases expert at Columbia University. Even at the lower end of the estimates, that translates to more than a half-million children of the 13 million so far infected. (Studies of infected adults indicate that an estimated 10% to 30% may have long COVID. There isn't much known about who gets long COVID or why, which puts it in a frustrating category of mysterious illnesses that occur after infections such as Lyme disease or mononucleosis.
- COVID Drug Paxlovid Might Also Fight Long COVID (US News): A series of case reports from researchers at the University of
 California, San Francisco (UCSF) shows some success with Paxlovid in treating patients with long COVID. One-third of people
 infected with the coronavirus are thought to develop symptoms such as fatigue, headaches and brain fog associated with long
 COVID. Paxlovid has U.S. FDA emergency use authorization to treat COVID-19 patients who are older than 65 or have underlying
 health conditions such as obesity, diabetes or cancer. The pill includes the antivirals nirmatrelvir and ritonavir.

POST COVID-19 CONDITION RESOURCES

- (NEWLY ADDED) PASC Guide (University of Michigan): A resource for people with PASC/long COVID.
- Health Education England (HEE) e-learning modules: long COVID programme
- <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.
- <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: <u>Resources on Post-COVID Condition.</u>
- Agency for Clinical Innovation (Australia): Living Evidence post acute sequelae of COVID-19.
- Pre-populated literature searches: Long COVID search (LitCovid) and Long COVID search (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.
- <u>British Heart Foundation (UK):</u> 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 <u>list</u> of Post-COVID Care Centers (PCC) and a PCCC Best Practices <u>Guide</u>.
- <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.