POST COVID-19 CONDITION

OCSO BIWEEKLY SCAN OF EVIDENCE #17 February 12-February 25, 2022

(NEW) OCSO is seeking feedback on the scan to inform its development. Please complete this short poll here by March 7.

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 <u>review</u> examining long COVID from a cardiovascular focus, a <u>UKHSA</u> evidence <u>brief</u> on the impact of vaccination on long COVID, as well as emerging <u>guidelines</u> from <u>ESCMID</u> for the assessment and management of long COVID.

GUIDELINES OR STANDARDS

- (NEW) European Society of Clinical Microbiology and Infectious Diseases (ESCMID): Rapid guidelines for assessment and management of long COVID
- The **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."
 - o (UPDATED) WHO: Q&A page on Post-COVID-19 Condition (February 2022).
- The **US CDC** describes <u>Post-COVID conditions</u> 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 <u>Interim Guidance</u> for healthcare providers on Evaluating and Caring for Patients with Post-COVID Conditions. Post-COVID conditions can be considered a disability under the <u>Americans with Disabilities Act (ADA)</u>. The CDC also released information on <u>Caring for People with Post-COVID Conditions</u>.
- Rapid <u>guidelines</u> for healthcare professionals by UK **NICE** (Updated November 2021).
- Chartered Society of Physiotherapy in UK published its COVID-19 <u>rehabilitation standards</u>, which includes guidance about community-based rehab for people with COVID-19 and long COVID (July 2021).
- <u>Guidelines</u> to help doctors manage long COVID patients published in <u>British Journal of General Practice</u> (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 <u>COVID-19</u>: <u>Clinical Guidance for Primary Care Providers Long-term symptoms / Post-acute</u> seguelae of <u>COVID-19</u> (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.
- A paper by <u>Stephenson et al.</u> published in BMJ's Archives of Disease in Childhood has produced a consensus on a definition of long COVID in children:
 - "Post-COVID-19 condition occurs in young people with a history of confirmed SARS CoV2 infection, with one or more 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-19 infection, and may fluctuate or relapse over time."

NATIONAL AND INTERNATIONAL DEVELOPMENTS (FEB 12-25)

CANADA

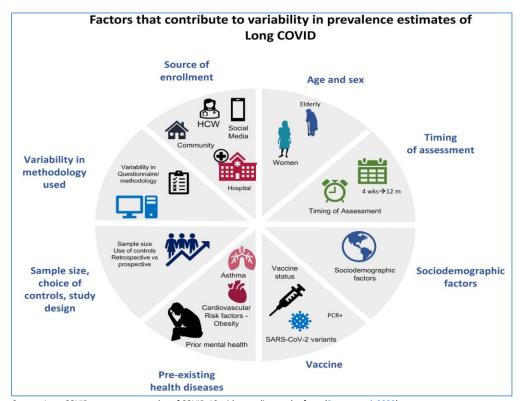
- (NEW) According to the <u>BC Ministry of Health</u>, approximately 4,200 people have been referred to long COVID clinics in BC, and about 66% of them have been accepted.
- (NEW) The University of Victoria has launched research to better understand COVID's long-term impacts on the brain.
- (NEW) The <u>Canadian Donation and Transplant Program</u> has issued a call for immunocompromised populations, such as transplant recipients, to share their experience with long COVID.

UK

• (NEW) According to a UKHSA evidence review, fully vaccinated people were half as likely to develop long covid symptoms as people who received only one vaccine dose or were unvaccinated. The review included 15 UK and international studies up to January 2022. They found that vaccine effectiveness against most post-covid symptoms in adults was highest in people over 60 and lowest in those aged 19 to 35. Being vaccinated was defined as having two doses of the Pfizer-BioNTech, Oxford-AstraZeneca, or Moderna vaccine or one dose of the Janssen vaccine.

US

• (NEW) Weill Cornell Medicine has been awarded a \$9.8 million grant from the National Institutes of Health to lead a consortium of health care institutions that are analyzing nationwide health data in an effort to unravel the complexities of long COVID.



Source: Long COVID: post-acute sequelae of COVID-19 with a cardiovascular focus (Raman et al. 2022).

EMERGING SCIENTIFIC EVIDENCE (FEB 12-25)

EVIDENCE PRODUCTS

TITLE AND AUTHOR	EVIDENCE TYPE	SUMMARY
European Respiratory Society Statement on Long COVID-19 Follow-Up (Antoniou et al)	Report (Available in Eur Respir J)	Patients diagnosed with COVID-19 associated with SARS-CoV-2 infection frequently experience symptom burden post-acute infection or post-hospitalisation. A European Respiratory Society Task Force convened and prioritised 8 clinical questions. Targeted search of literature defined timeline of long COVID-19 as 1 to 6 months post infection and identified clinical evidence in follow-up of patients. Studies meeting inclusion criteria report an association of characteristics of acute infection with persistent symptoms, thromboembolic events in follow-up period and evaluations of pulmonary physiology and imaging. This statement reviews QOL consequences, symptom burden, disability and home care follow-up. Evidence for follow-up care for patients with long COVID-19 is limited.
Clinical patterns of somatic symptoms in patients suffering from post-acute long COVID: a systematic review (Nguyen et al)	Systematic Review (Available in Eur J Clin Microbiol Infect Dis)	PubMed and Google Scholar were searched for studies on prevalence of somatic clinical symptoms lasting at least 4 weeks after onset of a PCR- or serology-confirmed diagnosis of COVID-19. 18 studies involved in-patients only with a duration of follow-up of either less than 12 weeks, 12 weeks to 6 months, or more. In these studies, fatigue (16-64%), dyspnea (15-61%), cough (2-59%), arthralgia (8-55%), and thoracic pain (5-62%) were most frequent persisting symptoms. In 19 studies conducted in a majority of out-patients, persistence of these symptoms was lower and 3-74% of patients reported prolonged smell and taste disorders. Main risk factors for persisting symptoms were being female, older, having comorbidities and severity at the acute phase of the disease.
Long COVID: post-acute sequelae of COVID-19 with a cardiovascular focus (Raman et al)	Review (Available in Eur Heart J)	This review discusses the definition of long COVID and its epidemiology, with an emphasis on cardiopulmonary symptoms. They review the pathophysiological mechanisms underlying acute and chronic cardiovascular (CV) injury, range of post-acute CV sequelae, and impact of COVID-19 on multi-organ health. Authors propose a possible model for referral of post-COVID-19 patients to cardiac services and discuss future directions including research priorities and clinical trials currently underway to evaluate efficacy of treatment for long COVID and associated CV sequelae.

SELECT PRIMARY RESEARCH

TITLE AND AUTHOR	SOURCE	SUMMARY
Impact of COVID-19	Research	Study aimed to explore the impacts of long COVID on various aspects of social life
symptoms on social aspects	Square prepub	among female long haulers. The main impacts included physical limitation,
of life among female long		financial hardship, social relationship, conflict of social roles, and social stigma.
haulers: A qualitative study		Negative effects of long COVID hindered female long haulers' recovery process.
(Aghaei et al)		Social isolation, COVID-19 associated stigma, and conflicts of social roles cause
		tremendous stress. Employers' support and social media usage may play positive
		role in their coping with impacts of long COVID on their social life.
Two months follow-up of	S Afr Fam Pract	Study aimed to describe prevalence of long COVID in mild COVID-19 patients in
patients with non-critical		Cape Town, and to document the impact of COVID-19 on patients' well-being,
COVID-19 in Cape Town,		work, and their access to long COVID treatment. It was found that 60% of patients
South Africa		with mild COVID-19 had ≥ 1 long COVID symptom, while 35% had ≥ 3 ongoing
(Mendelsohn et al)		symptoms for two months. Dyspnoea and fatigue were the most common
		symptoms. The findings revealed that 52% of employed patients missed work and
		25% of patients self-reported non-recovery from their COVID-19. Moreover, 24%
		of patients consulted a clinician for long COVID, but only 7% of patients received
		long COVID care in the public sector.

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'I can't cope with multiple	BMJ Open	UK-wide longitudinal qualitative study was used to investigate the lived
inputs': a qualitative study of		experience of 'brain fog'-the wide variety of neurocognitive symptoms that can
the lived experience of 'brain		follow COVID-19. Of 50 participants, 42 were female and 32 white British. Most
fog' after COVID-19		never hospitalised for COVID-19. Qualitative analysis revealed following themes:
(Callan et al)		mixed views on appropriateness of term 'brain fog'; rich descriptions of
		experience of neurocognitive symptoms (especially executive function, attention,
		memory and language), accounts of how illness fluctuated-and progressed over
		time; the profound psychosocial impact of the condition on relationships, personal
		and professional identity; self-perceptions of guilt, shame and stigma; strategies
		used for self-management; challenges accessing and navigating the healthcare
		system; and participants' search for physical mechanisms to explain their
		symptoms.
Persistence, prevalence, and	medRxiv	Study aimed to describe sequelae presenting more than six months after COVID-
polymorphism of sequelae		19 in non-hospitalized young adults. Young, previously healthy, individuals largely
after COVID-19 in young		recover from mild infection and the multi-system impact of the infection is less
adults		that seen in older or hospitalized patients. These results may be extrapolated to
(Deuel et al)		health-care workers and other young workforce adults. The constellation of higher
(2000, 00 01)		body mass index, dyslipidemia and lower physical endurance 6 months post
		COVID-19 is suggestive of a higher risk of developing metabolic disorders and
		possible cardiovascular complications.
Olfactory Dyefonation	Brain Sci	'
Olfactory Dysfunction,	DI UIII SCI	Study investigated mental clouding, headache, and cognitive function in adult
Headache, and Mental		patients with persistent COVID-19 olfactory dysfunction. In our cohort of adult
Clouding in Adults with Long-		patients with post-COVID-19, smell alterations persisting over 6 months, cognitive
COVID-19: What Is the Link		impairment and headache were associated with more severe olfactory loss,
between Cognition and		consistent with neuroinflammatory mechanisms mediating a variety of Long-
Olfaction? A Cross-Sectional		COVID symptoms.
<u>Study</u>		
(Di Stadio et al)		
<u>Determinants of Persistence</u>	J Infect	Prospective cohort study aimed to understand predictors of symptom persistence
of Symptoms and Impact on		in cohort of 465 COVID-19 patients followed for 9 months after disease onset.
Physical and Mental		Patients with advanced age, ICU stay and multiple symptoms at onset were more
Wellbeing in Long COVID: A		likely to suffer from long-term symptoms, which had a negative impact on both
Prospective Cohort Study		physical and mental wellbeing. 37% presented with at least 4 symptoms and 42%
(Righi et al)		complained of symptom lasting more than 28 days. At month 9, 20% of patients
		were still symptomatic, showing mainly fatigue (11%) and breathlessness (8%),
		with 18% of patients not returning to optimal pre-COVID physical health, and 19%
		showing psychological distress.
Patterns of Long COVID	J Clin Med	Study aimed to determine patterns of symptoms in convalescing COVID-19
Symptoms: A Multi-Center		patients. Six patterns of symptoms identified: cognitive, pain-syndrome,
Cross Sectional Study		pulmonary, cardiac, anosmia-dysgeusia and headache. Cognitive pattern was the
(Yelin et al)		major symptoms pattern, explaining 26.2% of the variance; the other patterns
\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \		each explained 6.5–9.5% of the variance. Cognitive pattern was higher in patients
		who were outpatients during the acute disease. Pain-syndrome pattern was
		associated with acute disease severity, higher in women and increased with age.
		Pulmonary pattern was associated with prior lung disease and severe acute
		disease. Only two patterns (cognitive and cardiac) were associated with failure to
		return to pre-COVID occupational and physical activity status. Long COVID diverse
Long COVID 10 overstance	Infact Dic Marri	symptoms can be grouped into six unique patterns.
Long COVID-19 symptoms:	Infect Dis Now	Aim was to describe persistent symptoms in long COVID-19 non-severe
clinical characteristics and		outpatients and report the 6-month clinical recovery rate. 63 patients (79%
recovery rate among non-		women, mean age: 48 years) enrolled; main symptoms (mean 81 days after acute
severe outpatients over a six-		infection): asthenia/myalgia (77%), dyspnea (51%), headaches (35%), cough (33%).
month follow-up		At 6 months (n=56), 30% had complete, 57% partial, and 13% lack of recovery.
(Seang et al)		Proportion of patients with >2 persistent symptoms was 27% at 6 months (main
		symptoms: dyspnea 54%] and asthenia/myalgia 46%]).
Assessment of 115 symptoms	Research	Retrospective matched cohort study aimed to assess which symptoms are
Assessment of 115 symptoms for Long COVID (post-COVID-	Research Square prepub	Retrospective matched cohort study aimed to assess which symptoms are associated with confirmed SARS CoV-2 beyond 12 weeks post-infection in non-hospitalised individuals, and the risk factors associated with developing persistent

<u> </u>		
<u>factors in non-hospitalised</u> <u>individuals: a retrospective</u>		symptoms. 62 symptoms were significantly associated with prior exposure to SARS CoV-2 after 12 weeks. Largest adjusted hazard ratios were for anosmia, hair
matched cohort study in UK		loss, and sneezing. Among the infected cohort, risk factors for Long COVID
primary care		included younger age, female sex, belonging to an ethnic minority group,
(Nirantharakumar et al)		socioeconomic deprivation, smoking, obesity, and a wide range of comorbidities.
Post-COVID-19 syndrome,	Curr Med Res	Aim was to know whether subjects with PCS present higher levels of inflammatory
low-grade inflammation and	Opin	markers, after a mild COVID-19. Analysed 121 mild COVID-19 cases (mean age
inflammatory markers: a	•	=45.7 years, 56.2% women). Among acute symptoms, women presented higher
cross-sectional study		frequency of fatigue (54.4% vs 30.2%). PCS affected 35.8% of women and 20.8% of
(Maamar et al)		men (p = 0.07), and the most reported symptoms were fatigue (42.8%), anosmia
		(40%), ageusia (22.8%), dyspnea (17.1%) and myalgia (11.4%).
Post-COVID-19 Memory	medRxiv	Aim was to determine prevalence of memory complaints in post-COVID-19
Complaints: Prevalence and		patients and to find potential contributing factors. Memory complaints was
Associated Factors		prevalent in 19.2% of the post-COVID patients. Multiple logistic regression showed
(Ahmed et al)		that individuals who recovered from COVID-19 within 6 to 12 months more likely
		to have memory deficits.
Immune Response To SARS-	Research	Study developed a mathematical model of the immune response to SARS-CoV-2
Cov-2 In Severe And Long	Square prepub	and revealed that typical age-related risk factors such as only a 10% decrease in
COVID-19		innate immune cell activity and inhibition of type-I interferon signaling by
(Sumi et al)		autoantibodies drastically increased the viral load. It was reported that the
		numbers of certain dendritic cell subsets remained less than half those in healthy
		donors even seven months after infection. Hence, the inflammatory response was
		ongoing. Model predicted the persistent DC reduction and showed that certain
		patients with severe and even mild symptoms could not effectively eliminate the
Fire Marrows and Albanations in	Canada	virus and could potentially develop long COVID.
Eye Movement Alterations in Post-COVID-19 Condition: A	Sensors	Video-oculography study describing potential alterations of eye movements in the post-COVID-19 condition by measuring visually guided saccades, memory-guided
Proof-of-Concept Study		saccades, and antisaccades in horizontal axis. Found that patients with post-
(García Cena et al)		COVID-19 condition had eye movement alterations mainly in centripetal latency in
(Gareia ceria et ai)		visually guided saccades, the success rate in memory-guided saccade test, latency
		in antisaccades, and its standard deviation, which suggests involvement of
		frontoparietal networks.
Symptoms After COVID-19	J Gen Intern	Cross-sectional study aimed to describe association of COVID-19 vaccination and
Vaccination in Patients with	Med	evolution of six cardinal symptoms embodying post-acute sequelae of SARS-CoV-
Post-Acute Sequelae of SARS-		2. From April 23 to July 27, 2021, an online survey was conducted with 2094
CoV-2		individuals who previously tested positive for SARS-CoV-2 infection at outpatient
(Nehme et al)		testing center of Geneva University Hospitals, Switzerland. Of symptomatic
		participants, n = 1596 reported their symptoms developed after SARS-CoV-2
		infection. Results showed that vaccination (one or two doses) was associated with
		a decreased prevalence of the six cardinal post-SARS-CoV-2 symptoms.
		Vaccination with 2 doses was associated with decreased prevalence of dyspnea
Childhand Trees		and change in taste as well as decreased prevalence of any one symptom.
Childhood Trauma Exposure	medRxiv	Childhood trauma contributes to a pro-inflammatory state in adulthood evidenced
Increases Long COVID Risk		by high morbidity and early mortality, but it has not yet been investigated as a risk
(Villanueva van den Hurk et		factor for long COVID. Early adversity is a risk-factor for long COVID, likely due to
al)		altered immune response, central sensitization, and peripheral dysfunction. Childhood trauma, a crucial social determinant of health, should be routinely
		assessed in COVID-19 survivors and may aid in determining prognosis.
Post-COVID-19 tele-survey	medRxiv	Study aimed at documenting prevalence and key associations of post-COVID
for persistent symptoms in a	meanaiv	symptoms (PCS) in India in telephonic survey among recovered patients in a single
single center hospital cohort		hospital in eastern India as well as a parallel web-survey covering a wider
in India along with a parallel		population of country.
country-wide web-survey		
(Chaudhuri et al)		

COMMENTARIES, LETTERS AND OPINION PIECES (FEB 12-25)

- How can you help me integrate my long covid care? (BMJ): Long covid clinics in the UK can be a useful way to offer an organised medical response. But, in the UK, truly integrated clinics that comprise multiple disciplines are not readily available to all. Patients have to do much of the coordinating themselves. No strict rules apply to managing long covid. Different practices suit different people, but the end goal is essentially the same. For some, individual approaches or treatments have merit, but the power comes in combining them, and aiming to find the right blend and balance.
- Defining post-COVID condition (Lancet): Villar et al. noted that the WHO Delphi exercise had relatively few participants from Africa, South America, and Southeast Asia. Although we cannot say that having a more global presence would have changed the definition, this underrepresentation of LMICs might be associated with the lack of ongoing research about this condition in low-income countries. We suggest that such research is urgently needed. For example, the COVID-19 pandemic caused an unprecedented amount of stress for people in LMICs. Still, the full scale of mental health issues related to post-COVID-19 condition remains undetermined. One of the criteria in the proposed definition is that "symptoms cannot be explained by an alternative diagnosis". Fulfilling the criterion might also be difficult in LMICs, where additional diagnostic testing might not always be available.

MEDIA HIGHLIGHTS (FEB 12-25)

CANADA

- Quebec health system unprepared to handle Omicron-fuelled long COVID cases (CBC News): Dr. Emilia Liana Falcone, an infectious disease specialist and the director of a COVID-19 clinic at the Montreal Clinical Research Institute, says it will take another 12 weeks to appreciate the extent of patients who have long COVID from Omicron. Dr. Laura Caspin and Dr. Audrey Ouaknine work at a COVID-19 clinic north of Montreal say the services offered in the province for people with persistent COVID-19 symptoms don't come close to meeting demand.
- What we know and what we still need to learn about long COVID (CBC News): Dr. Amy Tan, a family doctor and palliative care physician in Victoria, said early research indicates 10 to 25% of all people infected will end up with some sort of long COVID symptoms. But the Omicron surge has not been factored into the research, so it's unclear how many people infected by the variant will deal with long COVID. Tan says a greater commitment to research and research funding is needed. "This is where the research and academic world directly impacts clinical practice," she said. "We do need investment in research to be able to distil a robust diagnosis list, symptoms list.

GLOBAL

• Long COVID a global issue for patients and healthcare systems, UK review finds (Reuters): British researchers led by Oxford University said that the current understanding of long COVID and options to treat it is emerging as a major long-term issue for global healthcare systems after reviewing the illness' effects on patients. The review, published in the European Heart Journal, looked at direct impacts of a coronavirus infection such as myocardial infarction or inflammatory myocarditis - severe heart conditions - and long-term effects such as fatigue and mental wellbeing.

POST COVID-19 CONDITION RESOURCES

- (NEW) Agency for Clinical Innovation (Australia): Living Evidence post acute sequelae of COVID-19.
- (UPDATED) WHO: On 1 March 2022 from 1:30 3:30PM CET WHO will host a webinar focused on neurology and mental health in post COVID-19 condition.
- 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>
 COVID Impact Survey (PDF) (June 2021)
- BC ECHO for Post-COVID-19 Recovery (Canada): 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.
- Living with Long COVID (US): COVID-19 Long-Haulers and Post-COVID Support Community.