POST COVID-19 CONDITION

OCSO SCAN OF EVIDENCE #13

Dec 4-Dec 15, 2021

SCOPE

This 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.

There are currently no preventative strategies or prognostic markers. 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. Internationally, 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 guide for primary care physicians on management of post-COVID symptoms, a model framework for projecting the prevalence and impact of long COVID in the UK, as well as a article published in *Nature* on the promotion of non-evidence-based therapeutics within patient-led long COVID support groups.

EMERGING GUIDELINES OR STANDARDS

- The **World Health Organization** has developed a clinical case definition 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. A separate definition may be applicable for children.
    - "*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.*"

- The U.S. **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.

- Rapid guidelines for healthcare professionals by UK **NICE** (Updated November 2021).

- 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.

- Guidance 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*)

- (NEW) American Academy of Physical Medicine and Rehabilitation (AAPM&R): Cognitive Symptoms Guidance and Breathing Discomfort Guidance.

NATIONAL AND INTERNATIONAL DEVELOPMENTS

CANADA

- In Canada, **11 public clinics** identified so far:
  - Alberta: Rockyview General Hospital, Peter Lougheed Centre, Primary Care Network: Edmonton North
  - British Columbia: Abbotsford Regional Hospital, Jim Pattison Outpatient Care and Surgery Centre, Vancouver General Hospital, St. Paul's Hospital
  - Ontario: Halton Healthcare Post COVID-19 Syndrome Clinic, London Health Sciences Centre, Toronto Rehabilitation Institute (UHN)
  - Quebec: Montreal Clinical Research Institute Post-COVID-19 Clinic, Clinique ambulatoire post-COVID
  - There are also **39 private clinics across Canada**.
- Lifemark Health Group: Post COVID-19 Rehabilitation and Recovery Program.
- Alberta Health Services: Resource for rehabilitation and allied health providers working with Post-COVID-19 patients.
- Hôtel-Dieu Grace Healthcare: COVID Recovery program.
- Nova Scotia Health: My COVID Recovery – your source of health information after having COVID-19.
- The Other Pain Clinic Inc COVID Rehab & Survivorship Program (Alberta).
- Saskatchewan Health Authority: Long-COVID information repository.
- (NEW) Clinician Resource: Post-COVID-19 Recovery Care Pathway (accessible through Pathways).
- (NEW) Mental Health in "Long-COVID" – A Resource for GPs.

PHAC AND PARTNER ACTIVITIES:

- Monitoring latest research and evidence on Post COVID-19 condition and engaging with national and international experts.
  - **PHAC** published a living systematic review on the prevalence of Post COVID-19 condition. 2 new reviews are also being undertaken to gain a better understanding of 1) risk factors associated with the condition and 2) possible interventions to prevent the condition.
- PHAC is exploring data sources for **surveillance**
  - Canadian Primary Care Sentinel Surveillance System
  - Initial environmental scan of provincial/territorial initiatives examining impact of COVID-19 on vulnerable populations using administrative health data.
- **CIHR COVID-19 Rapid Research Funding Opportunity** (May 2020)
  - Over 10 projects directly examining long-term implications of COVID-19 (Figure 2, *Appendix*).
  - Canadian COVID-19 Prospective Cohort Study ($**~2.7M**): Evaluating early to 1-year outcomes in 2000 patients across AB, BC, ON, & BC with COVID-19 infection.
- **CIHR Op Grant: Emerging COVID-19 Research Gaps & Priorities - Post COVID-19 condition** (March 2021)
  - Select funded projects can be found in *Appendix (Figure 3*).

UK

- NIHR awarded **£19.6M** to 15 projects across the UK to help diagnose and treat long COVID.
- NHS England and NHS Improvement provided **£70 million** to expand long COVID services beyond Post-COVID Assessment Clinics to strengthen treatment and rehabilitation.
- Additional funding for ICSs adding to £24 million already provided to **89** specialist Post-COVID Assessment Clinics around England, bringing total investment in 2021/22 to **£94 million**. NHS will also establish specialist long COVID services for children and young people.
- NHS: Your COVID Recovery tailored rehabilitation program enabling patients to be monitored by local rehabilitation teams.
- PHOSP COVID study is a national consortium investigating long term impacts of COVID-19 on health outcomes for patients hospitalised due to COVID-19.
- Up to 1 in 7 (14%) children and young people who caught SARS-CoV-2 may have symptoms linked to the virus
. 15 weeks later, according to preliminary findings from the world's largest study on long COVID in children.
- UK Collaborative on Development Research highlighted there's over **121** long COVID projects, involving **$205 million** funding investment, with the top funder being UKRI (as of July 2021).
- Guidance for people suffering from long COVID has been launched by the NHS 24 (Scotland).
- UK Office for National Statistics reported first dose of a COVID-19 vaccine was associated with 13% decrease in self-reported long-COVID symptoms among those who already had the condition. Second dose yielded a further 9% drop relative to the first.
- (NEW) 3.26%, of healthcare workers in the UK are estimated to have long Covid, according to the Office for National Statistics.
- (NEW) Around 1 in 50 people in the UK self-reported experiencing long COVID.

US

- **Post-Acute Sequelae of SARS-COV-2 Infection Initiative (NIH PASC): $1.15B/4 years**
- NIH has invested in longitudinal studies to record recovery paths of ~40,000 adults and children in a 'meta-cohort', to observe who develops long-term effects and who doesn't.
- Based on media reports, there are **80 post-COVID-19 clinics in the U.S.**. A Becker's Hospital Review article (Aug 2021) stated that **44** hospitals and health systems have launched post-COVID-19 clinics. 11.1 million Americans are living with long COVID, according to the American Academy of Physical Medicine & Rehabilitation.
- Virtua Health: "Care After COVID" program.
- **$40 million** multi-year study from Children's National Hospital and NIAID examining long-term effects of COVID-19 and multisystem inflammatory syndrome in children.
- NIH created REsearching COVID to Enhance Recovery (RECOVER) Initiative and awarded **$470 million** to create a national study population of volunteers, as well as support studies on long-term effects of COVID-19.
- Brown School of Public Health launched long COVID initiative to examine social and economic impacts of long COVID.
- NIH to study long-term effects of COVID-19 in pregnancy by following up to 1,500 pregnant patients with COVID-19 and their offspring for 4 years, as part of NIH's RECOVER initiative.
- NIH to study effects of COVID-19 infection on 1000 children over 3 years as part of RECOVER initiative.
- (NEW) John Hopkins Medicine: Long-Term Effects of COVID-19.

EMERGING SCIENTIFIC EVIDENCE

EVIDENCE PRODUCTS (*DEC 4-DEC 15, 2021*)

TITLE AND AUTHOR	EVIDENCE TYPE	SUMMARY
Addressing post-COVID symptoms: A guide for primary care physicians (Vance et al)	Review (Available in *J Am Board Fam Med*)	A reference guide for management of post-COVID symptoms was created for PCPs. Educational materials were created for clinicians to share with patients. This article reviews several common complaints including respiratory, cognitive, and neurological symptoms, chronic fatigue, dysautonomia, and anosmia and presents recommendations for management. Conclusions: Data on long-term effects of COVID-19 are still emerging, and rapid dissemination of this data to front-line PCPs is crucial.
Proposed subtypes of post-COVID-19 syndrome (or long-COVID) and their respective potential therapies (Yong et al)	Review (Available in *Rev Med Virol*)	Effects of COVID-19 do not always end in the acute phase. Depending on study referred, about 10%–30% (or more) of COVID-19 survivors may develop post-COVID-19 syndrome (PCS), characterised by persistent symptoms lasting for 3 months or more after acute COVID-19. While pathophysiological mechanisms of PCS have been extensively described elsewhere, subtypes of PCS have not. This review proposes and characterises six subtypes of PCS based on the existing literature. The subtypes are non-severe COVID-19 multi-organ sequelae (NSC-MOS), pulmonary fibrosis sequelae (PFS), myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS), post-intensive care syndrome (PICS) and medical or clinical sequelae (MCS). The subtyping proposed herein aims to provide better clarity on the current understanding of PCS.

SELECT PRIMARY RESEARCH (*DEC 4-DEC 15, 2021*)

TITLE AND AUTHOR	SOURCE	SUMMARY
A model framework for projecting the prevalence and impact of Long-COVID in the UK (Martin et al)	*PLoS One*	Objective of paper is to model lost Quality Adjusted Life Years (QALYs) from symptoms arising from COVID-19 disease in UK population, including symptoms of 'long-COVID'. Scope includes QALYs lost to symptoms, but not deaths, due to acute COVID-19 and long-COVID. Assuming a 60% final attack rate for SARS-CoV-2 infection in the population, we modelled 299,730 QALYs lost within 1 year of infection (90% due to symptomatic COVID-19 and 10% permanent injury) and

		557,764 QALYs lost within 10 years of infection (49% due to symptomatic COVID-19 and 51% due to permanent injury). The UK Government willingness-to-pay to avoid these QALY losses would be £17.9 billion and £32.2 billion, respectively. Additionally, 90,143 people were subject to permanent injury from COVID-19 (0.14% of the population).
Long-Term Outcomes after Severe COVID-19 Infection: A Multicenter Cohort Study of Family Member Outcomes (McPeake et al)	*Ann Am Thorac Soc*	Study aimed to evaluate the long-term outcomes of family members of patients who had survived severe COVID-19 infection. We undertook a multicenter, prospective observational cohort study across seven critical care units in five hospitals in Scotland. Nineteen (40.4%) family members described symptoms of anxiety; 12 (63.2%) had symptoms of moderate or severe anxiety. Symptoms of depression were noted in 10 (21.3%) family members. Problems with sleeping were reported in 20 (42.6%) family members via the Insomnia Severity Index. Family members of critical care survivors in this cohort experienced high levels of anxiety and depression in the post hospital discharge phase.
Risk factors associated with long covid syndrome: A retrospective study (Asadi-Pooya et al)	*Iran J Med Sci*	Investigated long COVID syndrome, and risk factors associated with it. 4,681 patients were studied, 2915 of whom (62.3%) reported symptoms. The most common symptoms of long COVID syndrome were fatigue, exercise intolerance, walking intolerance, muscle pain, and shortness of breath. Women were more likely to experience long-term COVID syndrome than men, which was significant.
Persistent symptoms and decreased health-related quality of life after symptomatic pediatric COVID-19: A prospective study in a Latin American tertiary hospital (Fink et al)	*Clinics*	Aim was to prospectively evaluate demographic, anthropometric and health-related quality of life (HRQoL) in pediatric patients with laboratory-confirmed coronavirus disease 2019 (COVID-19). Pediatric patients with COVID-19 showed a longitudinal impact on HRQoL parameters, particularly in physical/school domains, reinforcing the need for a prospective multidisciplinary approach for these patients.
Skeletal muscle mass, sarcopenia and rehabilitation outcomes in post-acute COVID-19 patients (Gobbi et al)	*J Clin Med*	Study investigated impact of existence of sarcopenia upon admission to a post-acute COVID-19 patient rehabilitation unit on body composition and functional and respiratory capacity at discharge. Thirty-four post-acute COVID-19 patients were referred to our Rehabilitation Unit from different COVID Hospitals in northern Italy. Upon admission, the prevalence of sarcopenia among our patients was 58%. In all of the 34 patients, we observed a trend of improvement in all of the respiratory, body composition, muscle strength and functional parameters considered.
Is central sensitisation the missing link of persisting symptoms after COVID-19 infection? (Goudman et al)	*J Clin Med*	Study explored the presence of symptoms of central sensitisation, and the association with functional status and health-related quality of life, in patients post COVID-19 infection. This survey indicated the presence of symptoms of central sensitisation in more than 70% of patients post COVID-19 infection, suggesting towards the need for patient education and multimodal rehabilitation, to target nociplastic pain.
Perceived and Real Work Capacity of Patients with Post-COVID Symptoms after Mild Acute Course: A Analysis of the Rehabilitation Needs Questionnaire (RehabNeQ) (Lemhöfer et al)	*Phys Med Rehab Kuror*	Aim of analysis was to show real and perceived work ability of patients with Post-COVID syndrome. 58.7 % were able to work at the time of the interview. Perceived ability to work was reported as an average of 5.1 points out of a possible 10. Women showed an average of 6.2 points and men 4.7 points. 59.1 % of respondents in this group indicated difficulty in obtaining necessary therapies. 41.3% individuals were unable to work at the time of the survey, due to sequelae following COVID-19 disease. The mean age of the group was 46.6 years. 51.6% of the 31 subjects reported being continuously unable to work since infection. In this group, 64.5 % had difficulties in obtaining therapies that they considered necessary.
Post-COVID-19 Long Hauler Clinical Program: Change in Health-Related Quality-of-Life (Brodsky et al)	*Glob Adv Health Med*	An Integrative Medicine Center created a post–COVID-19 myalgiac encephalomyelitis (ME) program in response to a July 2020 Centers for Disease Control and Prevention document that described fatigue and other functional symptoms. 12 participants (31%) completed a baseline and follow-up survey. Mean SF-12 physical component summary scores improved 5 (SD 9) and mental component summary scores improved 4 (SD 9) in patients who completed baseline and follow-up surveys. Case studies of two patients who completed the

		SF-12 at baseline and after 4 weekly treatments illustrate the program's standardized treatment approach
Long COVID in inflammatory bowel diseases (Salvatori et al)	*J Clin Med*	We evaluated the frequency of long COVID in patients with inflammatory bowel diseases (IBD). IBD patients afferent for scheduled visits to our tertiary referral center at the Tor Vergata University Hospital, Rome, were recruited from 7 September to 22 October 2021. Fifty-three out of 528 IBD patients (10%) have had a SARS-CoV-2 infection. Of these, 21 patients (40%) developed long COVID, and asthenia was the more frequent symptom as it occurred in nearly two-thirds of patients. Patients with long COVID were more frequently females, while other clinical and demographic characteristics did not differ between patients with Long COVID and those without long COVID. Long COVID appears to be common in IBD patients even though it does not influence the IBD course.
Characteristics of Patients Referred to a Cardiovascular Disease Clinic for Post-Acute Sequelae of SARS-CoV-2 Infection (Wang et al)	*medRxiv*	Study describes the characteristics, diagnostic evaluations, and cardiac diagnoses in patients referred to a cardiovascular disease clinic designed for patients with post-acute sequelae of SARS-CoV-2 infection (PASC) from May 2020 to September 2021. Of 126 patients, average age was 46 years, 43 were male. Patients presented on average five months after COVID-19 diagnosis. 30 (24%) patients were hospitalized for acute COVID-19. Severity of acute COVID-19 was mild in 37%, moderate in 41%, severe in 11%, and critical in 9%. Patients were also followed for PASC by pulmonology (53%), neurology (33%), otolaryngology (11%), and rheumatology (7%). Forty-three patients (34%) did not have significant comorbidities. The most common symptoms were dyspnea (52%), chest pain/pressure (48%), palpitations (44%), and fatigue (42%), commonly associated with exertion or exercise intolerance. A number of cardiovascular diagnoses were identified.
Persistent Symptoms Among Frontline Health Workers Post-acute COVID-19 Infection (Wose Kinge et al)	*medRxiv*	Sought to identify persistent symptoms of COVID19 in frontline workers at Right to Care (RTC) South Africa who have past the acute phase of illness with a view to establishing rehabilitation programs for its employees and the community at large. Headache, body ache, fatigue, loss of smell, dry cough, fever, and loss of appetite were the most common reported symptoms at time of diagnosis. Persistent symptoms were characterized by fatigue, anxiety, difficulty sleeping, chest pain, muscle pain and brain fog, being the six most reported.
Long Covid: Online patient narratives, public health communication and vaccine hesitancy (Miyake et al)	*Digit Health*	Adopted a mixed methods approach involving quantitative and qualitative analyses of 1.38 million posts mentioning long-term symptoms of Covid-19, gathered across social media and news platforms between 1 January 2020 and 1 January 2021, on Twitter, Facebook, Blogs, and Forums. Results indicate that the negative impacts arise mostly from conflicting definitions of Covid-19 and fears around the Covid-19 vaccine for long Covid sufferers. Key areas of concern are: time/duration; symptoms/testing; emotional impact; lack of support and resources.
Long-term Health Ailments among COVID-19 recovered patients in South Asian Countries: A Descriptive Cross-sectional Study (Mythili et al)	*Research Square prepub*	Objective of study is to find prevalence of various health ailments among COVID recovered population from South Asian countries. Descriptive cross-section study was conducted among 384 COVID-19 recovered population in South Asian Countries through randomized survey. Among 384 samples, 68% of patients had post COVID-19 long term extreme tiredness and 64% of patients reported with sleeplessness. 73% of patients had fever and smell loss during COVID-19. 64% had reported body pain and cough when they had infection. 42% of patients were healthy ones without any comorbidity prior to COVID.
Post-COVID-19 conditions in Ecuadorian patients: an observational study (González-Andrade et al)	*Lancet Reg Health Am*	Paper compares post-COVID symptoms in 3 patient groups with mild, moderate, and severe infections in Ecuadorian outpatients. 64.3% of patients had symptoms between 4 to 6 weeks after infection, 21.1% showed ongoing symptoms between 6 to 12 weeks, and 14.6% had symptoms for more than 12 weeks. Most common symptom was fatigue in 67.3% of patients, followed by headache in 45.2%, body pain in 42.3%, and sleep disorders in 36.5%.

COVID-19: Post-recovery long-term symptoms among patients in Saudi Arabia (Khodeir et al)	*PLoS One*	Aim of present study was to identify these symptoms, their severity, and their duration as a first step in building a system to classify post-recovery long-term symptoms of coronavirus disease 2019 (COVID-19). Most common symptoms included general fatigue and weakness (73% each), with moderate severity of neurological symptoms including mood changes (41%) and insomnia (39%). Among the special senses, loss of smell and taste of marked severity were reported by 64% and 55% among respiratory symptoms, cough of mild severity (47%), and dyspnea of moderate severity (43%). Loss of appetite of moderate severity was reported in 42%, and diarrhea, abdominal pain, and nausea of mild severity were reported by 53%, 50%, and 44% of respondents, respectively.
Changes in the trajectory of Long Covid symptoms following COVID-19 vaccination: community-based cohort study (Ayoubkhani et al)	*medRxiv*	Aimed to estimate associations between COVID-19 vaccination and Long Covid symptoms in adults who were infected with SARS-CoV-2 prior to vaccination. The likelihood of long Covid symptoms reduced after COVID-19 vaccination, and the improvement was sustained over follow-up period after second dose.
Population-Based Estimates of Post-acute Sequelae of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) Infection (PASC) Prevalence and Characteristics (Hirschtick et al)	*Clin Infect Dis*	Objective was to estimate prevalence and correlates of post-acute sequelae of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection (PASC). The analytic sample (n = 593) was predominantly female (56.1%), aged ≥45 years (68.2%), and non-Hispanic White (46.3%) or Black (34.8%). Thirty- and 60-day COVID-19 were highly prevalent (52.5% and 35.0%), even among non-hospitalized respondents (43.7% and 26.9%) and respondents reporting mild symptoms (29.2% and 24.5%). Respondents reporting very severe (vs mild) symptoms had 2.25 times higher prevalence of 30-day COVID-19 and 1.71 times higher prevalence of 60-day COVID-19.Hospitalized (vs non-hospitalized) respondents had ~40% higher prevalence of both 30-day COVID-19.
Post-sequelae one year after hospital discharge among older COVID-19 patients: a multi-center prospective cohort study (Fang et al)	*J Infect*	Objective was to systematically evaluate prevalence of post-sequelae and chronic obstructive pulmonary disease assessment test (CAT) scoring one year after hospital discharge among older COVID-19 patients, as well as potential risk factors. Of the 1233 eligible cases, 630 (51.1%) reported at least one sequelae. Top six post-sequelae included fatigue (32.4%), sweating (20.0%), chest tightness (15.8%), anxiety (11.4%), myalgia (9.0%), and cough (5.8%).Disease severity during hospitalization and follow-up time were independently associated with risk of post-sequelae, while disease severity during hospitalization was significantly associated with increased risk of emerging sequelae.

COMMENTARIES, LETTERS AND OPINION PIECES (DEC 4-DEC 15, 2021)

- **Long COVID-The New "Invisible" Illness: How School Nurses Can Support the Nursing and Educational Teams for Student Success *(NASN Sch Nurse):*** School-age children are not immune to COVID-19 or the pronounced and persistent symptoms associated with a long-COVID diagnosis. Students may present with a variety of symptoms affecting their physical, cognitive, and mental health. The school community should be educated on the school-based interventions and recommendations for creating an individualized safe and successful return to school plan. As we await approval for vaccinations in school-age children younger than 12 years and continue to reposition ourselves to the waves of this pandemic and new variants of the virus, understanding the medical and educational long-term effects on our students may be a long-term need.

- **Promotion of non-evidence-based therapeutics within patient-led Long COVID support groups *(Nature):*** Given the current lack of understanding of the disease etiology of long COVID and lack of any proven treatment options, patients are desperate for any offered hope. Long COVID support groups provide important and essential services, supporting patients and advocating for recognition and care. Through the establishment of an administrator-moderated code of conduct, it would be possible to eliminate dangerous misinformation and the promotion of non-evidence-based therapeutics, ensuring the safety and integrity of patient-led long Covid support groups, as well as patient-led support groups for other medical conditions.

MEDIA HIGHLIGHTS

CANADA

- **Why are they still sick? The latest clues in the mystery of COVID-19 long haulers (Global News):** "We know that COVID 19 can cause, or can lead to increased risk of new-onset diabetes and new-onset kidney disease. And what we know about these diseases that are really chronic diseases that don't go away," said Al-Aly, who is also chief of research and development service at the VA Saint Louis Health Care System.

- **Females more likely than males to experience long-term COVID-19 symptoms, small study suggests (CTV News):** A new report suggests females experience significantly different symptoms than males in the weeks and months following a COVID-19 infection. The new research, published last month as a pre-proof in the journal Mayo Clinic Proceedings, found that among the first 108 patients to the Mayo Clinic's Post-COVID-19 Care Clinic in Minnesota, 75 per cent of them were females.

GLOBAL

- **What We've Learned About Identifying And Treating Long-Haul COVID (NPR):** It's estimated that over half of the 270 million people diagnosed with COVID-19 worldwide since December 2019 will experience post-COVID symptoms. Long covid is testing not just the medical system, but also government safety nets that are not well suited to identifying and supporting people with a newly emerging chronic disease that has no established diagnostic or treatment plan. Insurers are denying coverage for some tests, the public disability system is hesitant to approve many claims, and even people with long-term disability insurance say they are struggling to get benefits.

- **'Scary and confusing': When kids suffer from long COVID-19 (Association of American Medical Colleges):** Even months after COVID-19 infection, children can suffer an array of symptoms from difficulty concentrating to trouble breathing. Some are finding hope at new long COVID-19 clinics created just for kids. Older children seem to fare worse, but that may be partly because of their ability to articulate concerns, says Yonts, who has seen kids as young as 3 in her clinic. Research further suggests that symptoms may recede — and then come back.

- **Long Covid among staff adding to healthcare pressures, say NHS leaders (Independent):** NHS bosses have warned the high prevalence of long Covid among staff is adding to rising healthcare pressures, amid growing concern that the new omicron variant could further drive infections and absences in the workforce. Some 40,000 of healthcare workers in the UK are estimated to have long Covid, according to the Office for National Statistics. This figure has risen by 5,000 since July.

POST-COVID-19 RESOURCES

- COVID Long Haul (Canada): 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 support group and a Report on Pan-Canadian Long 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.

- Survivor Corps (US): 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.

- The Center for Chronic Illness (US): 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.

- Blooming Magnolia (US): 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.

- Patient-Led Research Collaborative (Global): Group of Long COVID patients working on patient-led research around the Long COVID experience.

- CANCOV- Patient resources (Canada): CANCOV is a research platform grounded in a prospective longitudinal 1-year cohort study of patients infected with COVID-19.

- COVID Patient Recovery Alliance (CPRA) (US): 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 report outlines recommendations for federal policymakers to promote recovery.

- British Lung Foundation (UK): UK-based charity sharing resources on navigating the NHS, breathlessness support, movement and energy support for long COVID patients.

- Webinar - Implications of Long COVID (Canada): October 2021 CADTH webinar with expert panel discussing what is known know about long COVID, long COVID clinics, and what needs to be done to ensure quality of care.

- Living with Long COVID (US): COVID-19 Long-Haulers and Post-COVID Support Community.

- Pre-populated literature searches: Long COVID search (LitCovid) and Long COVID search (NIH)

NEWLY ADDED RESOURCES:

- ECDC: Webinar on post-COVID-19 condition in children (December 7).

APPENDIX

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

Figure 1. **CIHR Funded Operating Grant: Emerging COVID-19 Research Gaps & Priorities - Post COVID-19 condition (Select Studies)**

Name	Institution Paid	Project Title	CIHR Funding Contribution	Funding Term
Gershon, Andrea S; Aaron, Shawn D; Gupta, Samir; Lavoie, Kim; Leung, Janice; Sin, Donald; Stickland, Michael K; To, Teresa	Sunnybrook Research Institute (Toronto, Ontario)	The Canadian Respiratory Research Network Long COVID-19 Study	$500,000	1 year
Raj, Satish R	University of Calgary	Muticentre Assessment of Cardiovascular Hemodynamics and Autonomic Dysfunction with Long COVID	$277,613	1 year
Sander, Beate H; Janjua, Naveed Z; Kwong, Jeffrey C; Mishra, Sharmistha; Sbihi, Hind	University Health Network (Toronto)	Predictors and burden of post-acute COVID-19 syndrome (long-COVID) with a focus on equity	$499,645	1 year
Weatherald, Jason; Granton, John T; Mak, Susanna	University of Calgary	Pulmonary vascular disease in patients with Long COVID	$292,092	1 year
Archambault, Patrick; Berger Pelletier, Elyse; Graves, Donna Lorraine; McGavin, Colleen B; Dainty, Katie N; Hohl, Corinne M; Perry, Jeffrey J; Rosychuk, Rhonda J	Université Laval	Investigating the Post-Acute Sequelae of SARS-CoV-2 Infections: a Patient Oriented Canadian COVID-19 Emergency Department Rapid Response Network (CCEDRRN) Study	$499,945	1 year
Corbeil, Jacques; Lambert, Jean-Philippe	Université Laval	COVID-19 persistent symptomatology: an investigation of the metabolomic and proteomic underpinning	$394,000	1 year
Nacul, Luis; Levin, Adeera; Mckay, Rhonda J; Song, Xiaowei	University of British Columbia	A double blind randomized trial of low-dose naltrexone for post-covid fatigue syndrome	$742,331	1 year
Leong, Darryl	McMaster University	Post-Acute Complications of COVID-19: An International Cohort Study (PACS) Note in a previous iteration, proposal was titled PACMAN as indicated in some Letters of Support	$495,684	1 year
Law, Susan K	Trillium Health Partners (Mississauga, ON)	Living with long-COVID. Patient experience to inform policy makers and care providers	$275,969	1 year
Hatcher, Simon; Orpana, Heather M; Werier, Joel M	Ottawa Hospital Research Institute	In people with Long Covid does adding a digital health platform to usual care improve outcomes at three months compared to usual care alone? The Enhancing Covid Rehabilitation with Technology (ECORT) randomised controlled trial	$922,869	1 year
Mukherjee, Manali; Svenningsen, Sarah; Tselios, Konstantinos	McMaster University	SARS-CoV-2 triggers Autoimmunity: implications for the pathogenesis of Post-Acute COVID-19 Syndrome - (AI-PACS)	$0 CIHR External Partner (PHAC) Contribution-$499,245	1 year
Cheung, Angela M; JÃ¼ni, Peter; Tomlinson, George A	University Health Network (Toronto)	The RECLAIM (REcovering from COVID-19 Lingering symptoms Adaptive Integrative Medicine) trial	$1,000,000	1 year
Ramanathan, Sheela; Piche, Alain	Université de Sherbrooke	Clinicopatholgical correlates of long COVID and potential interventions for improving the quality of life	$490,000	1 year
Ho, Chester; O'Connell, Petra; Zilkie, Tracey A	University of Alberta	Implementing the Provincial Post COVID-19 Rehabilitation Framework for Screening & Transitions in Alberta: A Pragmatic Evaluation	$499,883	1 year
Baker, Andrew J; Dos Santos, Claudia C	Unity Health Toronto	Autoimmunity as a novel mechanism in post-COVID syndrome	$0 CIHR External Partner (PHAC) Contribution-$269,500	1 year

Gross, Douglas P; Lam, Grace Y; Skolnik, Kate; Weatherald, Jason	University of Alberta	Exploring Rehabilitation Needs and Access to Services for Long COVID	$152,778	1 year
Yeung, Rae S; Benseler, Susanne; Haddad, Elie	Hospital for Sick Children (Toronto)	Post COVID hyperinflammation: A syndrome beyond the name	$0 CIHR External Partner (PHAC) Contribution- $499,170	1 year
Pasquier, Jean Charles; Beaulieu, Jean-François; Chaillet, Nils; Laforest-Lapointe, Isabelle; Piche, Alain; Robitaille, Julie	Universite de Sherbrooke	Évaluation de l'efficacité des probiotiques sur les affections post-COVID-19.	$997,273	1 year
Swayne, Leigh A; Tremblay, Marie-Ève	University of Victoria (British Columbia)	Understanding and treating the adverse effects of COVID-19 on the brain	$293,000	1 year
Kendall, Claire; Hawken, Steven; Tanuseputro, Peter	Bruyère Research Institute	Health equity and the post COVID-19 condition	$221,728	1 year
Green, Robin E; Cheung, Angela M	University Health Network (Toronto)	An intervention to teach self-management skills for persisting symptoms of COVID-19: Minimizing impact of symptoms on everyday functioning and on healthcare usage/utilization - A randomized controlled trial	$330,562	1 year
Falcone, Emilia L	Institut de recherches cliniques de Montréal	Identification of microbial factors to modulate immune dysregulation and treat post-COVID-19 syndrome.	$0 CIHR External Partner (PHAC) Contribution- $493,955	1 year
Quinn, Kieran L; Chan, Timothy; Cheung, Angela M; Ghassemi, Marzyeh; Herridge, Margaret S; Mamdani, Muhammad; Razak, Fahad; Rosella, Laura C; Verma, Amol	Sinai Health System (Toronto)	Improving the recognition and care of patients with long-term health complications of COVID-19	$499,998	1 year
O'Brien, Kelly K; Brown, Darren A; Bergin, Colm J; Erlandson, Kristine M; Vera, Jaime	University of Toronto	Long COVID and Episodic Disability: Advancing the Conceptualization, Measurement and Knowledge of Episodic Disability with people living with Long COVID	$204,205	1 year
Roy, Jean-Sébastien; Paquette, Jean-Sébastien; Perreault, Kadija	Université Laval	Better understanding physical and cognitive impairments and functional limitations in people suffering from long COVID to support the development of adapted interventions	$293,100	1 year
Sin, Donald	University of British Columbia	Biomarker Discovery for the Post-COVID Pulmonary Syndrome	$499,500	1 year
Beauchamp, Marla K; Costa, Andrew P; Duong, Mylinh; Ho, Terence; Kruisselbrink, Rebecca; Raina, Parminder S	McMaster University	The McMaster Multi-Regional Hospital Coronavirus Registry (COREG): Extending a Rapid Research Platform to Inform the Clinical Management of COVID-19 'long haulers'	$497,800	1 year
Paterson, Theone; Gicas, Kristina M	University of Victoria (British Columbia)	Investigating Neuropsychological Consequences of COVID-19 on Adults, and Examination of Associated Risk and Resilience Factors	$199,121	1 year
Graff-Guerrero, Ariel; Gerretsen, Philip	Centre for Addiction and Mental Health (Toronto)	Long COVID-19 on the human brain	$932,475	1 year
Graham, Simon J; Chen, Jing J; Gilboa, Asaf; MacIntosh, Bradley J; Schweizer, Tom A; Sekuler, Allison B	Sunnybrook Research Institute (Toronto, Ontario)	Post-Acute Sequelae of COVID-19: An Electroencephalography and Magnetic Resonance Neuroimaging Study of the Elderly in our Communities	$500,000	1 year