POST COVID-19 CONDITION

OCSO BIWEEKLY SCAN OF EVIDENCE #7

Sept 11th- Sept 24th 2021

SCOPE

This monthly 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. (NEW) 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.

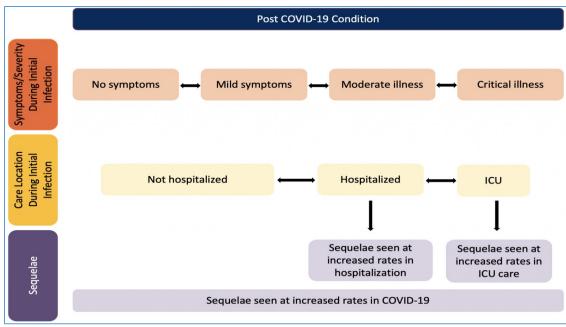
There are currently no preventative strategies or prognostic markers. Typical therapeutic itinerary involves consultations with multiple specialists and puts emphasis on self-management (rest & relaxation, self-pacing, etc.) Emerging evidence points to the importance of multidisciplinary care given the 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. 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. (NEW) It is reported that 10% of adults are unable to return to work in the long term.

This month's scan includes a Science Brief from the Ontario Science Table on Post COVID-19 Condition and its expected burden for Ontario, as well as preliminary findings from the world's largest study on long COVID in children suggesting up to 1 in 7 children and young people who caught SARS-CoV-2 may have symptoms linked to the virus 15 weeks later.

EMERGING GUIDELINES OR STANDARDS

- The World Health Organization proposed the updated terminology 'Post COVID-19 Condition.' The WHO conducted a Delphi survey to come to a consensus on the clinical case definition of Post-COVID 19 condition. A webinar was held on June 15 to present the consensus clinical case definition from the global Delphi exercise, and to understand the mechanisms that may cause post COVID-19 condition, and the care models to manage it. WHO is working with researchers to streamline data collection and reporting on Post COVID-19 condition. The project, Post-COVID Condition Core Outcomes, will survey patients to establish what core patient outcomes need to be measured to understand the condition.
- 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. (NEW) 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 were published in UK NICE in December 2020 (Figure 1, Appendix).
- The 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 were published in August 2021 in *British Journal of General Practice*.
- UK **NHS** guidance for Post-COVID syndrome assessment clinics (April 2021).
- **CIHI** <u>guidance</u> 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).



Source: Understanding the Post COVID-19 Condition (Long COVID) and the Expected Burden for Ontario. Ontario Science Table. Sept 14, 2021.

NATIONAL AND INTERNATIONAL DEVELOPMENTS

CANADA

- In Canada, **11 public clinics** have been 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: London Health Sciences Centre, Toronto Rehabilitation Institute (UHN)
 - Quebec: Montreal Clinical Research Institute Post-COVID-19 Clinic, Clinique ambulatoire post-COVID (in French only)
 - (NEW) There are also 39 private clinics across Canada.
- Lifemark Health Group has a Post COVID-19 Rehabilitation and Recovery Program with locations across 6 provinces.
- Alberta Health Services developed a <u>resource</u> to support rehabilitation and allied health providers across the care continuum working with patients recovering from symptoms of COVID-19.
- Hôtel-Dieu Grace Healthcare launched a COVID Recovery program to help people suffering from effects of COVID-19.
- Nova Scotia launched a <u>website</u> with information on managing or treating the lingering symptoms of COVID-19.
- <u>The Other Pain Clinic Inc COVID Rehab & Survivorship Program</u> in Alberta aims to treat people with post COVID symptoms to allow them to have a better quality of life. The program also has a virtual care option.

PHAC AND PARTNER ACTIVITIES:

- Monitoring latest research and evidence on Post COVID-19 condition and engaging with national and international experts.
 - PHAC maintains a living systematic <u>review</u> on the prevalence of Post COVID-19 condition, with also 2 new reviews being undertaken to gain a better understanding of 1) risk factors associated with the condition and 2) possible interventions to prevent the condition.
 - **CPHO** released a statement about Post COVID-19 Condition on July 7th, 2021.
 - Web content on Post COVID-19 Condition is published on the Government of Canada's website.
- 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).
 - <u>Canadian COVID-19 Prospective Cohort Study</u> (\$~2.7M): Evaluating early to 1-year outcomes in 2000 patients across AB, BC, ON, & BC with COVID-19 infection.
- CIHR Emerging COVID-19 Research Gaps and Priorities Funding Opportunity (March 2021)
 - Specific research focusing on identifying, defining & addressing Post COVID-19 condition to understand biological
 & psychological impacts. Select funded projects can be found in *Appendix (Figure 3*).

UK

- NIHR & UKRI:
 - Previous calls: ~£25M to better understand long-term effects of COVID-19 on physical & mental health
 - Current call: ~£20M focused on non-hospitalized adults & children with post COVID-19 condition
 - NIHR awarded £19.6M to 15 projects across the UK to help diagnose and treat long COVID.
- NHS England and NHS Improvement will provide £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 <u>Post-COVID Assessment Clinics</u> around England, bringing total investment in 2021/22 to £94 million. NHS will also establish specialist long COVID services for <u>children and young people</u>.

- UK Office for National Statistics released <u>experimental statistics</u> on long COVID showing overall UK prevalence estimate of **1.7%**. Research shows **2 million** people in England may have had long COVID, with women and lower-income people particularly susceptible.
- NHS <u>Your COVID Recovery</u> platform is an online, tailored rehabilitation program that enables patients to be monitored by local rehabilitation teams to ensure they are on track with their care.
- The PHOSP COVID study is a <u>national consortium</u>, led by experts in the UK, to investigate long term impacts of COVID-19 on health outcomes for patients who were hospitalised due to COVID-19. Data that is collected during the study will be used <u>globally</u>, collaborating with the <u>European Respiratory Society</u> and <u>Canadian Thoracic Society</u>, to understand the long terms impacts of COVID-19 on health worldwide.
- (NEW) 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.

USA

Post-Acute Sequelae of SARS-COV-2 Infection Initiative (NIH PASC): \$1.15B/4 years

- Focus: Understand biological basis of PASC & factors contributing to vulnerability
- Current call: Recovery Cohort Studies, Clinical Science, Data Resource & PASC Biorepository Cores
- NIH has invested in longitudinal studies to record the 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 <u>media</u> reports, 80 post-COVID-19 clinics were actively engaging with COVID-19 patients as of March 2021.
 64 of these clinics surveyed have seen a combined total of ~10,000 patients. A <u>Becker's Hospital Review</u> article (Aug 2021) stated that 44 hospitals and health systems have launched post-COVID-19 clinics. <u>11.1 million</u> Americans are living with long COVID, according to the American Academy of Physical Medicine & Rehabilitation.
- Virtua Health offers a nationwide "<u>Care After COVID</u>" program to help those experiencing post COVID symptoms.
- A **\$40 million** multi-year <u>study</u> from Children's National Hospital and NIAID examining long-term effects of COVID-19 and multisystem inflammatory syndrome in children.
- (NEW) NIH has created the <u>REsearching COVID to Enhance Recovery (RECOVER) Initiative</u> and awarded \$470 million to create a national study population of volunteers, as well as support studies on long-term effects of COVID-19.

EMERGING SCIENTIFIC EVIDENCE

EVIDENCE PRODUCTS (SEPT 11- 24, 2021)

| TITLE | EVIDENCE TYPE | SUMMARY |
|--|--|---|
| Long-term side effects and lingering symptoms post COVID-19 recovery (Zarei et al) | Review (Available in <i>Rev</i> <i>Med Virol</i>) | This review examines the long-term impact of COVID-19 on different organ systems from different clinical studies. Understanding risk factors and signs and symptoms of long-term consequences after recovery from COVID-19 will allow for proper follow-up and management of the disease post recovery. |
| "LONG COVID": An insight (Ahmad et al) | Systematic Review (Available in Eur Rev Med Pharmacol Sci) | This review analyzed available literature on long COVID, its pattern, and the long-term effects on survivors. Databases searched until May 2021. 20 articles analyzed in paper. Most common prevalent long-term symptoms included persistent fatigue and dyspnea in almost all of the studies. Among neurological manifestations headache, peripheral neuropathy symptoms, memory issues, concentration, and sleep disorders also commonly observed. Mental health issues affecting mental abilities, mood fluctuations namely anxiety and depression, and sleep disorders commonly seen. Appropriate clinical evaluation required in long COVID cases. |

| Long COVID patient symptoms and its evaluation and management (Shrestha et al) | Review (Available in J Nepal Med Assoc) | The consequences of COVID-19 infections follow major organ damage, and induction of immunological and hormonal systems dysfunction. This communication proposes evaluation and management of chronic COVID-19 patients with efficient assessment of commonest symptoms, targeted physical examination and organ function testing, and interventions based on specific organ functional status, and experience with similar chronic immune syndromes. |
|--|--|--|
| How Common Is Long COVID in Children and Adolescents? (Zimmerman et al) | Review (Available in Pediatr Infect Dis J) | In children, the risk of COVID being severe is low. However, the risk of persistent symptoms following infection with SARS-CoV-2 is uncertain in this age group. Reviewed 14 studies to date reporting persistent symptoms following COVID in children and adolescents. Almost all studies have limitations, including lack of clear case definition, variable follow-up times, inclusion of children without confirmed SARS-CoV-2 infection, reliance on self- or parent-reported symptoms without clinical assessment, nonresponse and other biases, and absence of control. Of the 5 studies which included children and adolescents without SARS-CoV-2 infection as controls, 2 didn't find persistent symptoms to be more prevalent in children and adolescents with evidence of SARS-CoV-2 infection. Long-term SARS-CoV-2 infection—associated symptoms are difficult to distinguish from pandemic-associated symptoms. |

SELECTED PRIMARY RESEARCH (SEPT 11- 24, 2021)

| TITLE | SOURCE | SUMMARY |
|--|---------------|---|
| Intriguing New Faces Of Covid-19: Persisting | Cardiol Young | Study evaluated persisting Covid-19-related symptoms and assessed cardiac findings in order to determine impact of Covid-19 on children's |
| Clinical Symptoms And | | cardiovascular health. Clinical symptoms (chest and back pain, dizziness, |
| Cardiac Effects in | | headache, palpitation, fatigue, shortness of breath, loss of balance, |
| <u>Children</u> | | coughing) of 37% of cases persisted at least 1 month after Covid-19 |
| (Erol et al) | | recovery. |
| Long-Term Symptoms | MMWR Morb | CDC administered a survey to a nationwide sample of U.S. adults aged ≥18 |
| Among Adults Tested for | Mortal Wkly | years to compare prevalence of long-term symptoms (those lasting >4 |
| SARS-CoV-2 - United | Rep | weeks since onset) among persons who self-reported ever receiving a |
| States, January 2020- | | positive SARS-CoV-2 test result with prevalence of similar symptoms |
| <u>April 2021</u> | | among persons who reported always receiving a negative test result. Two |
| (Wanga et al) | | thirds of respondents who received a positive test experienced long-term |
| | | symptoms often associated with SARS-CoV-2 infection. Compared with |
| | | respondents who received a negative test result, those who received a |
| | | positive test result reported a significantly higher prevalence of any long- |
| | | term symptom , fatigue, change in sense of smell or taste, shortness of |
| | | breath, cough, headache, and persistence (>4 weeks) of at least one |
| | | initially occurring symptom. Compared with respondents who received a |
| | | negative test result, a larger proportion of those who received a positive |
| | | test result reported believing that receiving a COVID-19 vaccine made |
| | | their long-term symptoms better. |

| Chemometric analysis of the global pattern of volatile organic compounds in the exhaled breath of patients with COVID-19, post-COVID and healthy subjects. Proof of concept for post-COVID assessment (Zamora-Mendoza et al) | Talanta | Objective was to evaluate application of electronic nose and chemometric analysis to discriminate volatile organic compounds between patients with COVID-19, post-COVID syndrome and controls in exhaled breath samples. This technology, due to its simplicity, low cost and portability, can support strategies for identification and follow-up of post-COVID patients. |
|--|---------------------------|---|
| A multidisciplinary approach to evaluate the presence of hepatic and cardiac abnormalities in patients with post-acute COVID- 19 syndrome—a pilot study (Bende et al) | J Clin Med | This study aims to evaluate presence of cardiac and liver alterations in patients with post-acute COVID-19 syndrome using transthoracic echocardiography (TTE) and liver elastography (LE). Considering presence of pulmonary injury during COVID-19, patients divided into 2 groups. Although none had altered systolic function, we evidenced pulmonary hypertension, diastolic dysfunction, increased liver stiffness, viscosity, and steatosis in around one-third of the patients, with significantly higher values in subjects with pulmonary injury compared to those without. |
| Health-Related Quality of Life in Survivors of Severe COVID-19 of a University Hospital in Northern Portugal (Fernandes et al) | Acta Medica Portuguesa | Study aimed to characterize COVID-19 survivors of critical illness and to evaluate health-related quality of life and disability following hospital discharge. Retrospective case-series study included COVID-19 survivors admitted to Intensive Care of a University Hospital. Follow-up evaluation performed between 30th and 90th day after discharge. Based on COVID-19 survivors-reported outcomes after critical illness, mobility, pain/discomfort, and anxiety/depression were main problems persisting 1-3 months after hospital discharge. |
| Persistent intestinal dysbiosis after SARS- CoV-2 infection in Brazilian patients (Ferreira Junior et al) | Research Square | Study aimed to evaluate intestinal microbiota of patients infected with SARS-CoV-2 with different clinical manifestations and post-COVID-19 (post-COV) periods, and correlate use of antibiotics during acute disease. Patients who took antibiotics during the COVID-19 course showed decreased richness of gut microbiota, even months after disease resolution. We hypothesized persistent dysbiosis and indiscriminate use of antibiotics during pandemic may be associated with long COVID syndromes, suggesting involvement of gut-lung axis. |
| A covid-19 rehabilitation prospective surveillance model for use by physiotherapists (Postigo-Martin et al) | J Clin Med | Article presents a COVID-19 prospective surveillance model based on sensitive and easily used assessment tools. Model provides guidelines to rehabilitation professionals working with patients who require rehabilitation after suffering from COVID-19. A COVID-19 prospective surveillance model is proposed for use by rehabilitation professionals and includes both face-to-face and telematic monitoring components. This model should facilitate early identification and management of long-term COVID-19 sequelae. |
| One year after mild covid-19: The majority of patients maintain specific immunity, but one in four still suffer from long-term symptoms (Rank et al) | J Clin Med | Persistent complications, including headache, concentration difficulties and loss of smell/taste, were reported by 61% of participants and decreased over time to 28% 1 year after COVID-19. |

| Clinical Characteristics and the Long-Term Post- recovery Manifestations of the COVID-19 Patients—A Prospective Multicenter Cross- Sectional Study (Mohiuddin Chowdhury et al) | Front Med | Clinical information and associated complaints of COVID-19 illness confirmed by reverse transcription-polymerase chain reaction (RT-PCR) were collected directly from patients. Regular follow-ups obtained on phone every 2 weeks following recovery for 20 weeks. Post-COVID-19 persisting symptoms/complaints found among 21.4% of symptomatic patients, which persisted for ≥20 weeks and had a significant relationship with duration of COVID-19 illness and existing comorbidity. |
|---|-----------------------|---|
| Cross-sectional survey on long term sequelae of pediatric covid-19 among italian pediatricians (Parisi et al) | Children | Purpose of work was to present data from a survey addressed to Italian pediatricians concerning the impact of long-COVID among children who recovered from SARS-CoV-2 infection. Persistence of symptoms found in <20% of children. Fatigue most mentioned symptom (75.6%). |
| Patients' Experiences of "Long COVID" in the Community and Recommendations for Improving Services: A Quality Improvement Survey (Razai et al) Long COVID and Chronic Fatigue Syndrome: A survey of elderly female | J Prim Health Care | Aim of survey was to explore patients' acute and post-acute "long" COVID-19 symptoms, their experiences of community services and recommendations for improving these services. 49% of patients reported at least 1 post-acute COVID-19 symptom. Many patients felt isolated and fearful, with scant information about community resources and little safety netting advice. Patients also expected more from primary care with 56% recommending regular phone calls and follow up from healthcare staff as most important approach in recovery. Study aimed to investigate post COVID 19 symptoms amongst elderly females and whether they could be a risk factor for developing Chronic Fatigue Syndrome (CFS) later on. |
| survivors in Egypt (Aly et al) | | |
| Severe Fatigue in Long COVID: Web-Based Quantitative Follow-up Study in Members of Online Long COVID Support Groups (Van Herck et al) | J Med Internet Res | Objectives of study was to assess severity of fatigue over time in members (n=239) of online long COVID peer support groups with confirmed diagnosis approximately 3 and 6 months after onset of infectious symptoms, and assess whether members of these groups experienced mental fatigue, physical fatigue, or both. Vast majority of patients had severe fatigue at 10 weeks and 23 weeks after onset of infectious symptoms. No significant differences found in prevalence of normal, mild, and severe fatigue. Both physical and mental fatigue present. |
| Post-acute sequelae of COVID-19: Evidence of mood & cognitive impairment (Lamontagne et al) | BBI - Health | Depressive symptoms found in post-acute sequelae of COVID-19 (PASC) sample. Reward processing and cognitive functioning impaired in PASC phase. PASC associated with impaired executive function, but not orienting or alerting. Stress did not moderate PASC effects. Protracted inflammatory responses may contribute to post-acute psychiatric sequelae. |

COMMENTARIES, LETTERS AND OPINION PIECES (SEPT 11- 24, 2021)

Breakthrough Infections in Vaccinated People Less Likely to Cause 'Long COVID' (NIH Blog): Dr. Francis Collins highlights how people who are fully vaccinated also are substantially less likely to develop Long COVID Syndrome. Findings in Lancet Infectious Diseases are latest from COVID Symptom Study. Researchers in UK found fully vaccinated individuals who developed breakthrough infections were half as likely as unvaccinated people to report symptoms of Long COVID Syndrome lasting at least 4 weeks after infection.

- Long covid must be recognised as occupational disease, says BMA (BMJ): The UK government must recognise long covid as an occupational disease and invest in its monitoring, research, and treatment, doctors have said. In a motion passed at the BMA annual representative meeting, doctors called on the body to "seek the recognition of occupationally acquired acute covid and long covid in doctors as an occupational disease." They also called for a multidisciplinary approach to the management of long covid that includes primary, specialist, and occupational medicine. A GP called for the UK to follow the lead of the governments of Belgium, Canada, Denmark, France, Germany, and Spain which have recognised covid-19 as an occupational illness and compensated healthcare workers.
- In for the long-haul? Seropositivity and sequelae 1 year post COVID-19 (BMC Med): COVID-19 leads to long-lasting sequelae, now termed long-COVID. Xiong et al follow a cohort of 333 health care workers with severe COVID-19 and a median age of only 36 years after 5, 8, and 11 months. Almost one third of these showed persistent symptoms of long-COVID 1 year after COVID-19 with a decline in muscular strength, flexibility as well as agility and dynamic balance. Larger, systematic studies quantifying overt and subtle COVID sequelae based on objective criteria as well as assessing the persistence and robustness of immunity are needed. Because "long-COVID" is projected to impact several body systems, test batteries must be comprehensive, quantitative and sensitive enough to detect subtle differences between such groups and to adequately define the disability associated with sequelae of the infection. With projected millions of "long haulers" in the workforce, investigators will need to consider using non-invasive testing, organ damage biomarkers and sample biobanking to elucidate the extent of the post-pandemic impact of COVID-19 and define the burden of long-COVID.

MEDIA HIGHLIGHTS (SEPT 11-24, 2021)

CANADA

- Much about 'long COVID' remains a mystery, 18 months into the pandemic: CBC News notes that
 international studies suggest 10-20% of COVID patients have lingering sickness at the 3-month mark. Medical
 director of the disease's recovery clinic at Vancouver General Hospital, Dr. Schwartz, states "the treatment is
 truly the vaccination. I hate to say it like that, but if you don't get COVID-19, you won't get the long-haul
 symptoms."
- School disruption, 'long COVID,' all factors in choice to vaccinate young kids (Tam): Toronto Star reports that Dr. Teresa Tam said Health Canada will be looking at the data carefully to determine if the vaccine is safe for children, but that's not the only factor parents will have to weigh up. Children's risk of serious illness and death from COVID-19 are low compared to the rest of the population, but Tam warned rare incidents can become more common as the virus spreads. She also points to the impacts of "long COVID," which is still being studied, and the importance of limiting disruptions to school as things to consider.

GLOBAL

- Study of up to 40,000 people will probe mysteries of Long Covid: Science reports the NIH has awarded a \$470 million grant to probe one of the mysteries of COVID-19: the debilitating symptoms that many people experience weeks or months after their infection clears. The study will enroll up to 40,000 adults and children newly and previously infected with SARS-CoV-2 to explore the causes of these post infection effects, dubbed Long Covid, and look for clues to treatments and prevention.
- What is the proper treatment for long COVID? New clinics seek answers: USA Today highlights how as more people survive COVID-19 infections yet continue to suffer, health care has begun to respond with multidisciplinary clinics that connect patients with a range of experts. Demand exceeds supply at many clinics, an ongoing challenge, said Dr. Peter Staats, who serves on medical advisory board for Survivor Corps. Doctors find themselves engaging in trial and error to figure out what works. Many have long waiting lists. People most disadvantaged by long-term COVID-19, experts say, are those who are generally the most disadvantaged: rural residents, people of color, those without financial resources, those uncomfortable with or not trusting of medical care.
- Long Covid Has Created an Unexpected Health-Care Burden, says NIH Director: BNN Bloomberg reports how long-term symptoms of Covid-19 affecting millions of Americans are "a deep mystery" that is troubling scientists and straining the health-care system, according to Dr. Francis Collins.

POST COVID-19 CONDITION ADVOCACY AND SUPPORT GROUPS

- <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. They also have a COVID long-haulers <u>support</u> group. COVID Long Haulers: <u>Report on Pan-Canadian Long COVID Impact Survey (PDF) (June 2021)</u>
- <u>BC ECHO for Post-COVID-19 Recovery (Canada)</u>: Based on the <u>global ECHO model</u>, the BC ECHO for Post-COVID-19 Recovery is a virtual learning community of specialists and community health-care providers who use instructive and case-based learning to improve care for patients recovering from <u>symptoms post-COVID-19</u>.
- <u>Long Covid Support (UK)</u>: 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 in the U.S. connecting, supporting, and mobilizing COVID-19 Survivors to support medical, scientific and academic research. They have a <u>list</u> of Post-COVID Care Centers (PCC) on their site 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.
- CANCOV: Patient resources (Canada)

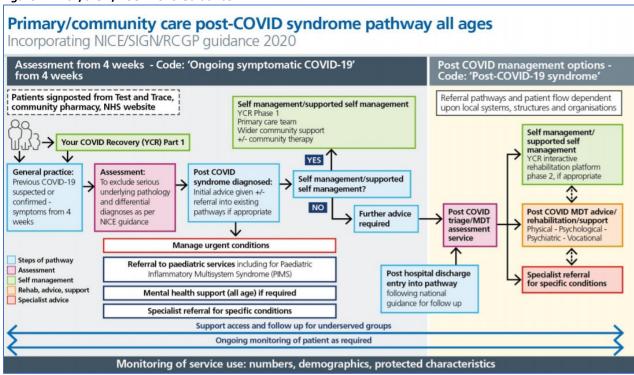
NEWLY ADDED RESOURCES:

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

APPENDIX

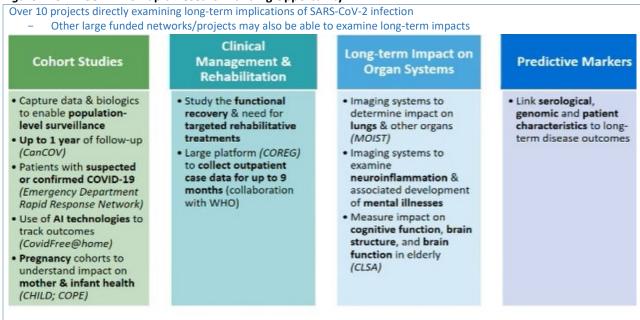
Note: Previous OCSO Post COVID-19 Condition Scans can be found here.

Figure 1. NICE/SIGN/RCGP 2020 Guidance



Source: National Health Service (NHS). National quidance for post-COVID syndrome assessment clinics, Version 2, 26 April 2021.

Figure 2. CIHR COVID-19 Rapid Research Funding Opportunity



Source: CIHR Knowledge Mobilization Forum. June 10, 2021

Figure 3. <u>CIHR Funded Operating Grant: Emerging COVID-19 Research Gaps & Priorities - Post COVID-19 condition</u> (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; Jüni, 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 | 1 year |
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| | . , | | External Partner (PHAC) Contribution- \$499,170 | |
| 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 |