

# POST COVID-19 CONDITION

## OCSO BIWEEKLY SCAN OF EVIDENCE #23

May 7-20, 2022

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### SCOPE

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

### CURRENT STATE OF KNOWLEDGE

According to the World Health Organization (WHO), post COVID-19 condition (PCC) refers to persistent symptoms occurring 12 weeks or more after an acute COVID-19 infection, which persist or reoccur for a minimum of 8 weeks. The most common symptoms include fatigue, cognitive problems (e.g., memory, concentration), respiratory issues, and mental health issues (e.g., anxiety, depression). PCC is also referred to as long COVID, post-acute sequelae, post COVID-19 symptoms, and post-acute COVID-19 syndrome. Prior to the WHO definition, a number of studies reported on post-acute sequelae (PAS) from 4 to 12 weeks post diagnosis. While scientific knowledge on these conditions is building, there is still much that is unknown about this condition. There have been reports of more than 100 symptoms or difficulties with everyday activities.

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

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

There is currently no specific treatment for long COVID. We do not know why some people develop long COVID while others are not affected. The impacts of vaccination on PCC or PAS are important, given early estimates of the burden of PCC suggest >50% of individuals with confirmed COVID-19 infection have reported at least one PCC symptom more than 12 weeks after diagnosis. Typical therapeutic itinerary involves consultations with multiple specialists and puts emphasis on self-management (rest & relaxation, self-pacing, etc). Emerging evidence points to the importance of multidisciplinary care given the heterogeneity of symptoms associated with PCC. Multidisciplinary teams in “long COVID” clinics have been set up to include professionals from the following fields: rehabilitation, respiratory and cardiac consultants, physiotherapists, occupational therapists, psychologists, etc.

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

This week's scan includes a white [paper](#) analysis of private healthcare claims published by FAIR Health in the US, as well as a systematic review [preprint](#) examining long COVID symptomatology.

## GUIDELINES OR STANDARDS

- **WHO** 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.
  - *“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.”*
  - **WHO:** Q&A [page](#) on Post-COVID-19 Condition (February 2022).
- **US CDC** describes [Post-COVID conditions](#) as a wide range of new, returning, or ongoing health problems that people experience after first being infected with the virus that causes COVID-19. The CDC posted [Interim Guidance](#) for healthcare providers on Evaluating and Caring for Patients with Post-COVID Conditions. Post-COVID conditions can be considered a disability under the [Americans with Disabilities Act \(ADA\)](#). The CDC also released information on [Caring for People with Post-COVID Conditions](#). CDC is using [science](#) to learn more about post-COVID conditions.
- **UK NICE:** Rapid [guidelines](#) for managing the long-term effects of COVID-19 (Updated March 2022).
- **Chartered Society of Physiotherapy** in UK published its COVID-19 [rehabilitation standards](#), which includes guidance about community-based rehab for people with COVID-19 and long COVID (July 2021).
- [Guidelines](#) to help doctors manage long COVID patients published in *British Journal of General Practice* (August 2021).
- **UK NHS** [guidance](#) for Post-COVID syndrome assessment clinics (April 2021).
- **CIHI** [guidance](#) for clinicians to ensure that data supports monitoring for Post-COVID conditions.
- [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*)
- American Academy of Physical Medicine and Rehabilitation (**AAPM&R**): [Cognitive Symptoms Guidance](#) and [Breathing Discomfort Guidance](#).
- Royal Australian College of General Practitioners (**RACGP**) [guidance](#) for GPs caring for ‘long COVID’ patients.
- European Society of Clinical Microbiology and Infectious Diseases (**ESCMID**): [Rapid guidelines for assessment and management of long COVID](#)
- **ACAS** (UK-based Advisory, Conciliation and Arbitration Service): [Long COVID – advice for employers and employees](#)

## NATIONAL AND INTERNATIONAL DEVELOPMENTS (MAY 7-MAY 20)

### CANADA

- No updates.

### UK

- **(NEW)** A large UK [study](#) in *BMJ* suggests that COVID-19 [vaccination after infection](#) lowers the odds of persistent symptoms, with a 12.8% initial decline after the first dose and an 8.8% drop after the second—although the long-term effects are unclear. Published May 18<sup>th</sup>, the observational study included 28,356 participants aged 18 to 69 years in the Office for National Statistics COVID-19 Infection Survey who had received one or more doses of the AstraZeneca/Oxford adenovirus vector or the Pfizer/BioNTech or Moderna mRNA vaccines after COVID-19 infection. The study period spanned the emergence and dominance of the SARS-CoV-2 Delta variant but preceded the emergence of Omicron.

### US

- **(NEW)** A white [paper](#) was released by FAIR Health in the US analyzing Private Healthcare Claims using the Official ICD-10 Diagnostic Code. Effective October 1, 2021, ICD-10 code U09.9 was introduced for “post COVID-19 condition, unspecified.” Key findings from Paper:
  - The majority (75.8 percent) of patients diagnosed with a U09.9 post-COVID condition had not been hospitalized for COVID-19.
  - Among patients who presented with a U09.9 post-COVID diagnosis, 81.6 percent of females had not had a COVID-19 hospitalization compared to 67.5 percent of males.
  - The age group 36 to 50 was the most likely to be diagnosed with U09.9 post-COVID conditions; 34.6 percent of patients with that diagnosis were in that age group.
  - Females were more likely than males to be diagnosed with U09.9 post-COVID conditions. Females made up 59.8 percent of the population of patients with that diagnosis, while males made up 40.2 percent. By comparison, within the cohort of people diagnosed with COVID-19 in the FAIR Health repository, 53.8 percent of patients were female and 46.2 percent were male.
  - Of patients who presented with a U09.9 post-COVID condition, 30.7 percent had no identified preexisting chronic comorbidities.
  - The three diagnoses most commonly co-occurring on the same claim line with the U09.9 post COVID diagnosis in patients across all ages and genders were abnormalities of breathing (23.2 percent of patients with post-COVID conditions), cough (18.9 percent) and malaise and fatigue (16.7 percent).

## EMERGING SCIENTIFIC EVIDENCE (MAY 7-MAY 20)\*

### EVIDENCE PRODUCTS

TITLE AND AUTHOR	EVIDENCE TYPE	SUMMARY
<a href="#">Identifying who has long COVID in the USA: a machine learning approach using N3C data</a>	Systematic Review (Available in	Post-acute sequelae of SARS-CoV-2 infection, known as long COVID, have severely affected recovery from the COVID-19 pandemic for patients and society alike. Long COVID is characterised by evolving, heterogeneous symptoms, making it challenging to derive an unambiguous definition.

(Pfaff et al)	<i>Lancet Digit Health</i> )	Studies of electronic health records are a crucial element of the US National Institutes of Health's RECOVER Initiative, which is addressing the urgent need to understand long COVID, identify treatments, and accurately identify who has it? The latter is the aim of this study.
<a href="#">Cognitive disorders and sleep disturbances in long COVID</a> (Schilling et al)	Narrative Review (Available in <i>Nervenarzt</i> )	What is known about the occurrence of cognitive disorders and sleep disturbances in long COVID? What are the influencing factors and what is known about the course over time and possible underlying mechanisms? What treatment options are available? In a narrative review, the most important findings on cognitive disorders and sleep disturbances in long COVID are presented. An overview of cohort studies with data on the prevalence and influencing factors of both symptom complexes is given. Current knowledge and hypotheses on pathophysiological mechanisms are presented and an outlook on treatment approaches is given. About one in five of those affected report cognitive impairment more than 3 months after SARS-CoV-2 infection and about one third report sleep disturbances. The latter comprise symptoms of insomnia as well as hypersomnia. Cognitive impairment and sleep disturbances occur in patients with all levels of initial disease severity. There are indications of an improvement of cognitive deficits over time but further longitudinal studies are needed. In addition to the prognosis, the underlying disease mechanisms are still insufficiently understood.
<a href="#">Oxytocin, the panacea for long-COVID? a review</a> (Diep et al)	Review (Available in <i>Horm Mol Biol Clin Investig</i> )	In this hypothesis paper, authors explore the underlying mechanisms for long-COVID and how the oxytocinergic neurones could be infected by SARS-CoV-2 leading to a reduction in plasma oxytocin (OXT). They aim to review the relevance of OXT and hypothalamic function in recovery from long-COVID symptoms and pathology, through exploring the pro-health effects of the OXT neuropeptide. A review of published literature was surveyed using Google Scholar and PubMed. Numerous experimental data can be shown to correlate with OXT and long-COVID symptoms and conditions, thus providing strong circumstantial evidence to support our hypothesis. It is postulated that the reduction in plasma OXT due to acute and post-viral damage to the hypothalamus and oxytocinergic neurones contributes to the variable multi-system, remitting and relapsing nature of long-COVID.
<a href="#">Long Covid: A Systematic Review and Meta-Analysis of 120,970 Patients</a> (Di Gennaro et al)	Review (Available in <i>SSRN-Lancet prepub</i> )	Aimed to summarize the state-of-the-art literature in relation to long COVID symptomatology, using a systematic review and meta-analysis of observational studies. A systematic search in several databases was carried out up to 12 January 2022 for observational studies reporting the incidence rate of long COVID signs and symptoms divided according to body systems affected and defined using the World Health Organization criteria. Among 11,162 papers initially screened, 196 studies were included, consisting of 120,970 participants who were followed-up for a median of six months. The incidence of any long COVID symptomatology was 56.9%. General long COVID signs and symptoms were the most frequent, digestive issues the less frequent. Higher percentage of females moderated the onset of any, neurological, general and cardiovascular long COVID symptomatology, whilst higher mean age was associated with higher incidence of psychiatric, respiratory, general, digestive and skin conditions. The incidence of long COVID symptomatology was different according to continent, age and follow-up length.

## SELECT PRIMARY RESEARCH

TITLE AND AUTHOR	SOURCE	SUMMARY
<a href="#">The associations of long-COVID symptoms, clinical characteristics and affective psychological constructs in a non-hospitalized cohort</a> (Ocsovszky et al)	<i>Physiol Int</i>	Study aimed to evaluate the mid-term associations of the long-COVID symptoms and affective factors in a cohort of non-hospitalized patients. A total of 166 patients were enrolled in this study, including 119 sedentary/non-athlete and 47 athlete subjects at Post-COVID Outpatient Clinic of Semmelweis University. They found a positive association between the level of depressive symptoms and anxiety and long-COVID symptom count, while life satisfaction and social support correlated negatively with the long-COVID symptom count. Higher haemoglobin levels and lower LDL-cholesterol were also shown to be moderating factors. A regression model showed that symptoms during acute infection, depression, age, and life satisfaction are predictors of the long-COVID symptom count. The presence of pre-existing affective or anxiety problems was also associated with higher reported long-COVID symptom count. Furthermore, they found significant association between pre-existing mental health problems and the investigated psychological constructs. It appears that long COVID-19 is associated with acute symptoms and mental factors.
<a href="#">Trajectory of long covid symptoms after covid-19 vaccination: community based cohort study</a> (Ayoubkhani et al)	<i>BMJ</i>	Aim was to estimate associations between covid-19 vaccination and long covid symptoms in adults with SARS-CoV-2 infection before vaccination. 28 356 participants in the Office for National Statistics COVID-19 Infection Survey aged 18-69 years who received at least one dose of an adenovirus vector or mRNA covid-19 vaccine after testing positive for infection. Mean age of participants was 46 years, 55.6% were women, and 88.7% were of white ethnicity. 23.7% reported long covid symptoms of any severity at least once during follow-up. A first vaccine dose was associated with an initial 12.8% decrease in the odds of long covid, with subsequent data compatible with both increases and decreases in the trajectory. A second dose was associated with an initial 8.8% decrease in the odds of long covid, with a subsequent decrease by 0.8% per week. The likelihood of long covid symptoms was observed to decrease after covid-19 vaccination and evidence suggested sustained improvement after a second dose, at least over the median follow-up of 67 days.
<a href="#">LOng COvid Multidisciplinary consortium Optimising Treatments and services across the NHS (LOCOMOTION): protocol for a mixed-methods study in the UK.</a> (Sivan et al)	<i>BMJ Open</i>	Authors seek to optimise long COVID care both within and outside specialist clinics, including improving access, reducing inequalities, helping self-management and providing guidance and decision support for primary care. Study aims to establish a 'gold standard' of care by systematically analysing current practices, iteratively improving pathways and systems of care. This mixed-methods, multisite study is informed by the principles of applied health services research, quality improvement, co-design, outcome measurement and learning health systems. It was developed in close partnership with patients and with front-line clinicians.
<a href="#">Post COVID-19 condition of the Omicron variant of SARS-CoV-2</a> (Morioka et al)	<i>medRxiv</i>	No epidemiological data on post coronavirus disease (COVID-19) condition due to Omicron variant has been reported yet. This was as a single-center, cross-sectional study, that interviewed via telephone the patients who recovered from Omicron COVID-19 infection (Omicron group), and surveyed via self-reporting questionnaire those patients infected with other strains (control group). Data on patients' characteristics, information regarding the acute-phase COVID-19, as well as presence and duration of COVID-19-related symptoms were obtained.

<p><a href="#">Persistent Post COVID-19 Symptoms and Functional Status after 12-14 weeks of recovery, Tamil Nadu, India, 2021</a> (Rubeshkumar et al)</p>	<p><i>J Infect</i></p>	<p>The knowledge about long COVID-19 is evolving day by day. Multiple articles published in the Journal of Infection discussed the persistent symptoms, quality of life, and functional status post recovery. Long COVID symptoms were reported in 12 countries and none were from LMIC. The proportion of the Indian Population who have been experiencing the symptoms following the recovery is unknown. Understanding the burden of post COVID-19 symptoms is vital in planning the health systems for essential Post COVID care. Authors assessed the burden of persistent post COVID-19 symptoms and functional status after 12-14 weeks among those recovered from COVID-19 in Chennai, Tamil Nadu, India.</p>
<p><a href="#">Exploring invisibility and epistemic injustice in Long Covid-A citizen science qualitative analysis of patient stories from an online Covid community</a> (Ireson et al)</p>	<p><i>Health Expect</i></p>	<p>Aim of this organic research is to explore the physical and epistemic challenges of living with Long Covid. Unlike any previous pandemic in history, online Covid communities and 'citizen science' have played a leading role in advancing our understanding of Long Covid. As patient-led research of this grassroots Covid community, a team approach to thematic analysis was undertaken of 66 patient stories submitted online to covid19-recovery.org at the beginning of the Covid-19 pandemic between April and September 2020. The overriding theme of the analysis highlights the complexities and challenges of living with Long Covid. Our distinct themes were identified: the life-changing impact of the condition, the importance of validation and how, for many, seeking alternatives was felt to be their only option. Long Covid does not easily fit into the dominant evidence-based practice and the biomedical model of health, which rely on objective indicators of the disease process. Patient testimonies are vital to understanding and treating Long Covid, yet patients are frequently disbelieved, and their testimonies are not taken seriously leading to stigma and epistemic injustice, which introduces a lack of trust into the therapeutic relationship.</p>
<p><a href="#">Long COVID Optimal Health Program (LC-OHP) to Enhance Psychological and Physical Health: Protocol for a Feasibility Randomized Controlled Trial</a> (Al-Jabr et al)</p>	<p><i>JMIR Res Protoc</i></p>	<p>Despite the negative impact of long COVID on people's lives and functioning, there is no validated treatment or even rehabilitation guidance. What has been recommended thus far is the adoption of holistic management approaches. The Optimal Health Program (OHP) is a brief 5-session, plus booster, psychosocial program designed to support mental and physical well-being that has been used effectively for a range of chronic conditions. This study examines the feasibility and acceptability of employing an especially customized version of OHP (long COVID OHP LC-OHP]) to improve psychological and physical health of people with long COVID.</p>
<p><a href="#">The Impact of COVID Vaccination on Symptoms of Long COVID: An International Survey of People with Lived Experience of Long COVID. Strain</a> (Sherwood et al)</p>	<p><i>Vaccines</i></p>	<p>Aimed to survey people living with long COVID, evaluating the impact of their first COVID vaccination on their symptoms. Patients with long COVID were invited to complete a web-based questionnaire through postings on social media and direct mailing from support groups. 900 people participated in questionnaire, of whom 45 had pre-existing myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) but no evidence of COVID infection, and a further 43 did not complete the survey in full. The demographics and symptomology of the remaining 812 people were similar to those recorded by the UK Office of National Statistics. Following vaccination, 57.9% of participants reported improvements in symptoms, 17.9% reported deterioration and the remainder no change. Larger improvements in symptom severity scores were seen in those receiving the mRNA vaccines compared to adenoviral vector vaccines.</p>

<p><a href="#">Respiratory muscle dysfunction in long-COVID patients</a> (Hennigs et al)</p>	<p><i>Infection</i></p>	<p>Independent of initial disease severity or pathological pulmonary functions tests, fatigue, exertional intolerance and dyspnea are among the most common COVID-19 sequelae. Hypothesized that respiratory muscle dysfunction might be prevalent in persistently symptomatic patients after COVID-19 with self-reported exercise intolerance. In a small cross-sectional pilot study (n = 67) of mild-to-moderate (non-hospitalized) and moderate-to-critical convalescent (formerly hospitalized) patients presenting to our outpatient clinic approx. Findings point towards respiratory muscle dysfunction as a novel aspect of COVID-19 sequelae.</p>
<p><a href="#">Prevalence of vitamin D deficiency among patients attending Post COVID-19 follow-up clinic: a cross-sectional study.</a> (Hussein et al)</p>	<p><i>Eur Rev Med Pharmacol Sci</i></p>	<p>Limited data currently available has suggested that vitamin D deficiency may play a role in COVID-19 cases. However, to our knowledge, no study has examined the frequency of vitamin D deficiency in post-COVID-19 cases and its effect on the symptom severity. The aim of this study is to both screen the frequency of vitamin D deficiency in post-COVID-19 syndrome patients and to study its relation to persistent symptoms. A cross-sectional, single-center study was conducted involving all cases attending post-COVID-19 follow-up clinic from November 2020 to May 2021. The study included 219 post-COVID-19 cases, 84% had deficient vitamin D levels (&lt; 20 ng/dL); 11.4% had insufficient level (20-30 ng/dL) and only 4.9 % reported normal level. There was no link between levels of vitamin D with either the acute or post-COVID-19 symptoms in the studied groups. Despite the prevalence of vitamin D deficiency among the study population, no association was observed between the levels of vitamin D and post-COVID-19 symptoms.</p>
<p><a href="#">Persistent serum protein signatures define an inflammatory subset of long COVID</a> (Talla et al)</p>	<p><i>bioRxiv</i></p>	<p>Attempts to classify subsets of PASC by symptoms alone have been unsuccessful. To molecularly define PASC, authors evaluated the serum proteome in longitudinal samples from 55 PASC individuals with symptoms lasting ≥60 days after onset of acute infection and compared this to symptomatically recovered SARS-CoV-2 infected and uninfected individuals. These findings help to resolve the heterogeneity of PASC, identify patients with molecular evidence of persistent inflammation, and highlight dominant pathways that may have diagnostic or therapeutic relevance.</p>
<p><a href="#">Neuropsychiatric symptoms in post COVID-19 long haulers</a> (Alghamdi et al)</p>	<p><i>Acta Neuropsychiatr</i></p>	<p>Aimed to screen for the neuropsychiatric signs detected 6 months after infection by SARS-CoV-2 and to determine whether vaccination has an effect on them. An online survey was conducted among participants who had been diagnosed with laboratory-confirmed SARS-CoV-2 infection. A total of 2218 individuals, including 1358 females and 860 males, with an age range of 12-70 years, submitted their responses. The respondents experienced cognitive dysfunction, mood alteration, depression, tinnitus, sleep disorders, and loss of taste and smell, with prevalence rates ranging from 18.9% (tinnitus) to 63.9% (loss of taste and smell). More respondents who received two doses of BNT162b2 vaccine showed persistent symptoms than those in the other groups. Disease severity and female sex were identified as potential determinants of the development and persistency of such symptoms. Post-COVID neuropsychiatric symptoms were present in considerable percentages of the study participants with SARS-CoV-2 infection, persisting for &gt;6 months in up to 7.6% of the participants.</p>

<p><a href="#">Predictors of Submaximal Exercise Test Attainment in Adults Reporting Long COVID Symptoms</a> (Romero-Ortuno et al)</p>	<p><i>J Clin Med</i></p>	<p>Adults with long COVID often report intolerance to exercise. Cardiopulmonary exercise testing (CPET) has been used in many settings to measure exercise ability but has been conducted in a few long COVID cohorts. Eighty participants were included. Findings suggest that exercise tolerance in adults with long COVID has potential to improve over time. Longitudinal research should assess the extent to which this may occur and its mechanisms.</p>
<p><a href="#">Post-acute health care burden after SARS-CoV-2 infection: A retrospective cohort study among 530,892 adults</a> (McNaughton et al)</p>	<p><i>medRxiv</i></p>	<p>Aim was to assess the burden of post-acute health care use after a positive versus negative polymerase chain reaction (PCR) test for SARS-CoV-2. Retrospective cohort study of community-dwelling adults January 1, 2020 to March 31, 2021 in Ontario, Canada, using linked population-based health data. Individuals with a positive SARS-CoV-2 PCR test were matched 1:1 to individuals who tested negative based on hospitalization, test date, public health unit, sex, and a propensity score of socio-demographic and clinical characteristics. The health care utilization rate was the number of outpatient clinical encounters, homecare encounters, emergency department visits, days hospitalized, and days in long-term care per person-year. Among 530,232 unique, matched individuals, mean age was 44 years, 51% were female, and 0.6% had received <math>\geq 1</math> COVID-19 vaccine dose. The mean rate of health care utilization was 11% higher in test-positive individuals. Post-acute health care utilization after a positive SARS-CoV-2 PCR test is significantly higher compared to matched test-negative individuals. Given the number of infections worldwide, this translates to a tremendous increase in use of health care resources. Stakeholders can use these findings to prepare for health care demand associated with long COVID.</p>
<p><a href="#">STIMULATE-ICP-CAREINEQUAL - Defining usual care and examining inequalities in Long Covid support: protocol for a mixed-methods study (part of STIMULATE-ICP: Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways</a> (Ramasawmy et al)</p>	<p><i>medRxiv</i></p>	<p>Individuals with Long Covid represent a new and growing patient population. In England, fewer than 90 Long Covid clinics deliver assessment and treatment informed by NICE guidelines. However, a paucity of clinical trials or longitudinal cohort studies means that the epidemiology, clinical trajectory, healthcare utilisation and effectiveness of current Long Covid care are poorly documented, and that neither evidence-based treatments nor rehabilitation strategies exist. In addition, and in part due to pre-pandemic health inequalities, access to referral and care varies, and patient experience of the Long Covid care pathways can be poor. In a mixed methods study, we therefore aim to: (1) describe the usual healthcare, outcomes and resource utilisation of individuals with Long Covid; (2) assess the extent of inequalities in access to Long Covid care, and specifically to understand Long Covid patients' experiences of stigma and discrimination. Methods and analysis A mixed methods study will address our aims. Qualitative data collection from patients and health professionals will be achieved through surveys, interviews and focus group discussions, to understand their experience and document the function of clinics. A patient cohort study will provide an understanding of outcomes and costs of care. Accessible data will be further analysed to understand the nature of Long Covid, and the care received.</p>

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

## COMMENTARIES, LETTERS AND OPINION PIECES (MAY 7-MAY 20)

- [Are vaccines a potential treatment for long covid? \(BMJ\)](#): Vaccination to reduce risk of reinfection remains important for people with long covid, and evidence so far suggests that benefits are likely to outweigh any harms. Three outcomes are possible after vaccination: no change in symptoms (most likely), improvement (best case), or deterioration (worst case). Unfortunately, many unknowns remain about the long term prognosis of long covid, including the effect of booster vaccines or recurrent covid-19. More research is needed on the link between antibody titres and symptoms over time before we can hope to predict the effects of vaccination on individuals.
- [Stop dismissing the risk of long covid \(Washington Post\)](#): Vaccines seem to help reduce the risks of long covid, but they don't make it uncommon. Again the data are highly variable. A Veterans Affairs study estimates vaccination lowers the risk by 13 percent, while two British studies estimate a 40 to 50 percent lower risk. Maybe the best study, involving more than 240,000 U.S. patients, suggests vaccines cut the risk of long covid from roughly 17 percent to 3 percent. That is not rare. Worse still, we have no treatments for the condition, and NIH has yet to establish a platform to rapidly conduct robust clinical trials to evaluate treatments, such as prolonged antiviral use, immune modulators and other shots in the dark such as anti-cholesterol drugs or antidepressants.

## MEDIA HIGHLIGHTS (MAY 7-MAY 20)

### CANADA

- [Over 75% of long COVID patients in the U.S. not hospitalized for initial illness, study finds \(Globe and Mail\)](#): A large new study has analyzed data from the first few months after the code took effect, and the results paint a sobering picture of long COVID's serious and ongoing impact on people's health and the U.S. health care system.
- [Half of patients hospitalized with COVID-19 still experiencing at least one symptom two years later \(CTV News\)](#): Two years after being hospitalized with COVID-19, survivors of the virus are still not back at the same level of health as those who never caught it, according to a new study. And half of those patients are still experiencing at least one virus-related symptom, suggesting that long COVID might end up affecting patients for even longer than anticipated. The research, published in journal [The Lancet Respiratory Medicine](#), follows 1,192 patients hospitalized with COVID-19 in Wuhan, China between early January 2020 and late May 2020.

### GLOBAL

- [The pandemic's true health cost: how much of our lives has COVID stolen? \(Nature News\)](#): Theo Vos, an epidemiologist at the Institute for Health Metrics and Evaluation (IHME) at the University of Washington has presented unpublished data to US authorities to help them get a handle on how the lingering symptoms could affect people's ability to work. The findings suggest that in 2020 and 2021, an estimated 4.6 million people in the United States had symptoms that persisted for at least three months. The group's definition of long COVID revolves around three clusters of symptoms, centring on fatigue, cognitive problems and ongoing respiratory issues. More than 85% of these cases came as a result of a bout of COVID-19 that did not require hospital treatment.
- [Can AI Identify Patients With Long COVID? \(Psychology Today\)](#): Patients with long COVID have persistent or n symptoms for more than four weeks after a SARS-CoV-2 infection. There are no tests for long COVID, which has made it a challenge for healthcare professionals to identify it. In a new [study](#), AI (artificial intelligence) learning has accurately identified long COVID using data from electronic health records.

## POST COVID-19 CONDITION RESOURCES

- **(NEWLY ADDED)** [Lullabies for long COVID \(UK\)](#): An online program developed in collaboration with the English National Opera could help with rehabilitation, by improving mental health and symptoms of breathlessness.
- **(NEWLY ADDED)** [Solve Long Covid Initiative \(US\)](#): The Solve ME/CFS Initiative is a non-profit organization that serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid and other post-infection diseases.

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

**Note:** Previous OCSO Post COVID-19 Condition Scans can be found [here](#).