

Calling Canadians to Action on Long COVID

The Problem:

The effects of [Long COVID](#) – a health condition consisting of a diverse set of symptoms that occur after the acute stage of COVID infection for a specific period of time from infection onset – are disrupting our health, our labour force and our economy. While [estimates vary](#), anywhere from [10 to 30 percent](#) of COVID-19 survivors may currently be experiencing a number of Long COVID [symptoms](#). Indeed, Statistics Canada and the Public Health Agency of Canada [released](#) the results of a national survey for Long COVID which reveal that 1.4 million Canadians are reporting lasting impacts from their initial infection¹. Globally, it is estimated that Long COVID could be directly impacting more than 185 million people. While there is no published data on the burden of Long COVID on the Canadian economy, based on US calculations, the estimated cost for a one-year period could be in the hundreds of billions of dollars². However, these figures do not capture the full range of quality-of-life impacts.

Long COVID is a multi-system condition; there have been around 200 symptoms described as associated with Long COVID. The most frequently reported are fatigue, shortness of breath and cognitive dysfunction, or “brain fog”. For some of those living with Long COVID, the consequences can be debilitating, and many of the most persistent symptoms are neurological or psychiatric. Most of those experiencing Long COVID were never hospitalized; therefore, in the early part of the pandemic, they were likely not tested for COVID-19. Numerous [studies](#) have demonstrated that women in their middle years are disproportionately impacted.

Scientists and clinicians in Canada and around the world are now studying Long COVID, but it is not yet known how or why it occurs, or in whom it is most likely to occur. There is no global consensus on the definition of Long COVID nor a single test or valid tools for diagnosing Long COVID. Vaccines and other [public health measures](#) (such as masking) offer the best protection from contracting COVID-19, and while there is [evidence](#) that they may offer some protection from Long COVID, we still need to understand the effect of vaccines on the development and expression of Long COVID.

There are currently [several theories](#) as to the causes of Long COVID symptoms – from microclots in the lungs, to the virus lingering in the body, to immune system dysfunction. The fact that Long COVID is expressed in many different organs and bodily functions adds to the complexity and the need for a large, sustained collaborative research effort to better understand this phenomenon and to develop interventions to effectively address it.

¹ While higher vaccination rates and new COVID-19 variants may lead to a lower percentage of people developing Long COVID, more research needs to be done to determine how these trends affect COVID-19 survivors.

² Recent calculations in the [Journal of the American Medical Association](#) estimate the economic loss associated with Long COVID in the US to USD 2.6 trillion. This includes estimated costs associated with loss of quality of life, lost earnings, and increased spending on medical care. For Canada, if we assume 1/9 of the population and half the incidents, the equivalent would be about USD150 billion or CAD200 billion.

There is evidence of infectious agents causing prolonged complications with long recoveries, and even triggering chronic illnesses. Epidemiologists have shown that [an elevated risk of Parkinson's](#) has accompanied several viral outbreaks throughout [history](#) from the Spanish flu to HIV, West Nile, and Japanese encephalitis. There has also been [increased interest](#) in researching whether viruses can contribute to the development of Alzheimer's disease.

What is required in Canada are nationally distributed, multidisciplinary teams to test the various hypotheses surrounding the origins and development of Long COVID; longitudinal studies that are inclusive of diverse communities, to compile an accessible body of knowledge regarding this phenomenon; adaptive trials, to create, research and then equitably deliver appropriate therapies in collaboration with existing and future global research, clinical and patient networks; and open, transparent, knowledge sharing amongst patients, policy makers, the general public, and healthcare professionals. These activities must be appropriately funded and guided by a Pan-Canadian national plan that is founded in federal, provincial and territorial collaboration and co-operation, and that will enable scaling of efforts. The knowledge and advances will also contribute to our general understanding of post-infectious and other complex chronic conditions.

While much of the focus on Long COVID has been limited to the health impacts, Canadian surveys show [see box] that it affects many aspects of our society, communities, and economy.

[VINEx](#), in collaboration with [COVID Long Haulers Support Group Canada](#), and [Neurological Health Charities Canada \(NHCC\)](#) conducted two pan-Canadian surveys of more than 1,000 COVID long-haulers to better understand the range of impacts of Long COVID.

Key findings from the surveys include:

- In both surveys, over 87% of respondents identified as women.
- Before having COVID-19, nearly 63% of respondents did not have a long-term health condition.
- More than 85% of participants were not admitted to hospital during their initial infection.
- Only a quarter of respondents were initially believed and received appropriate care when they described their Long COVID symptoms to a healthcare professional.
- In both surveys, about 70% of respondents had to take leave from work as a result of living with Long COVID, sometimes for over a year, with some having to leave the workforce. More than half had to reduce working hours, with 74% reducing their working hours by 50% or more.
- For those experiencing neurological or psychiatric symptoms, more than 80% say it has negatively or very negatively impacted their daily life.

The first survey ([report](#)) demonstrated the broader impacts of Long COVID on quality of life, with responses suggesting economic, health and societal costs with consequences on the health sector and labour force. The second survey ([report](#)) highlighted the negative brain health impacts of Long COVID.

What is being done:

In its last budget, the federal government committed [\\$20 million](#) to fund Long COVID research through the Canadian Institutes of Health Research; this was followed up by the announcement of an [open competition](#) which launched the week of October 17th. While these funds are much needed, this investment is not of sufficient magnitude to ensure a full understanding of Long COVID, nor is it tied to a comprehensive Pan-Canadian national strategy of research and care. While the [Task Force on Post-COVID-19 Condition](#) convened by Canada’s Chief Science Advisor may ultimately recommend a framework, it falls short of an actual commitment. Long COVID-specific policies, strategies and investments by Provinces and Territories are either not in place or not co-ordinated across the country. No co-ordinated and appropriately funded Pan-Canadian national network of clinical care centres or patient groups has been established to share information and create common areas of focus. Such a network would enable scaling of local and regional efforts across Canada. No comprehensive Pan-Canadian national clinical trials networks are in place to allow for investigation into potential effective interventions.

This lack of a national strategy stands in sharp contrast to what is being done in the US and UK, which have both taken an early lead on addressing Long COVID. In the US, Congress committed \$1.15 billion over four years to fund research into Long COVID through [The RECOVER Initiative](#). The RECOVER Initiative aims to enrol [40,000](#) patients in their studies by year-end. On August 3, 2022, the US Department of Health and Human Services released the [National Research Action Plan on Long COVID](#), described as “a government-wide national research agenda focused on advancing prevention, diagnosis, treatment, and provision of services and supports for individuals and families experiencing Long COVID.” In addition, a patient-driven movement to accelerate Long COVID research, [The Long COVID Research Initiative](#), has been developed. Meanwhile, [the UK has committed over £100 million to Long COVID](#). To date, [more than £50 million](#) of UK government funding has been invested in Long COVID research projects.

A Pan-Canadian strategy and investment would enable us to collaborate with other countries’ efforts, leveraging our leadership and contributions, particularly in interdisciplinary research and care, while benefiting from the latest advances around the globe.

“Each wave of the virus leaves more people with Long COVID or post-COVID condition. This obviously impacts individuals and their families but it also puts an extra burden on health systems, the wider economy and society-at-large. These challenges require action at a global, national and local level. Governments, scientists, manufacturers, WHO and citizens themselves all have their part to play.”

WHO Director-General Dr. Tedros Adhanom Ghebreyesus’s opening remarks at the COVID-19 media briefing – July 6, 2022

What needs to be done:

We call on the federal government to commit \$100 million over three years, to develop and execute a robust, comprehensive and equitable Pan-Canadian national Long COVID strategy that will include, but may not be limited to, the following components:

1. Develop a consensus definition of Long COVID that allows for cross-national and international comparisons, and develop valid tools for diagnosing Long COVID;
2. Collect economic and demographic data on the impact of Long COVID on society, the labour force and the economy. This will allow us to better understand, model and forecast the size and impact of the problem;
3. Increase funding for multidisciplinary research and longitudinal studies, in order to advance our understanding of what causes Long COVID (and how to prevent it), its natural course and duration, how to treat it, and the potential long-term impacts on human health and healthcare systems. To do this we need to:
 - Invest in a Pan-Canadian national study of sufficient scale of the Long COVID population, including those who were never hospitalized;
 - Collect multi-modal (imaging, genetics, clinical, behavioural) data, using standardized protocols and store the data on an open science platform. This would enable researchers across disciplines, between countries and around the world to share knowledge, foster collaboration and fast-track progress and allow researchers to deploy advanced analytic tools, including machine learning/AI, to analyze the data, develop new hypotheses and draw conclusions. Data should be disaggregated by age, gender, race, ethnicity, pregnancy status and other relevant factors;
 - Engage with key countries to contribute data and/or analytic tools, enabling Canadian and global investigators to enhance their collaborations;
 - Develop a Pan-Canadian national Long COVID treatment initiative to encourage and support best-in-class intervention studies and rapid scale-up of effective treatments for Long COVID;
 - Help ensure that healthcare providers and health professionals across disciplines are properly trained in diagnosis and interventions for Long Covid and are involved in the equitable care and treatment of all Canadians³ with Long COVID, regardless of their races, languages and regions;
 - Conduct adaptive trials on different therapies, including repurposed molecules.
4. Ensure a patient-centered approach through the entire process, including bringing attention to the stories of people with lived experience and countering the stigma being faced by those who are not believed because the illness is not well-defined and not always properly diagnosed;
5. Establish a Pan-Canadian network of multidisciplinary care clinics to be able to treat the different dimensions of Long COVID and foster a community of practice amongst providers and patients nationally;

³ Canadians designate all persons who live in Canada, i.e.: peoples with Canadian citizenships, immigrants, and refugees.

6. Develop a national Long COVID policy framework that includes federal, provincial and territorial authorities;
7. Develop and implement a multi-lingual communication strategy to inform and educate Canadians about Long COVID. This includes patients, medical and public health professionals, clinicians, researchers, healthcare providers, health insurers, and municipal, provincial/territorial and federal officials.

A Pan-Canadian national strategy will ensure that Canada's response to Long COVID is appropriate to the size and scale of Long COVID's impacts, bringing hope to all those who to all those who now and in the future will live with the long-term impacts of this disease.

Action and investment are needed now.

We call on the federal government to demonstrate leadership by committing \$100M over three years, to develop and deliver a robust, comprehensive and equitable Pan-Canadian national Long COVID strategy. This strategy will bring together provinces and territories to collaborate and co-operate in its development.

We invite all Canadian researchers, clinicians and affected persons to join this call to action.

Co-Leads:

Inez Jabalpurwala, Global Director, Viral Neuro Exploration (VINEx), and Executive Leader, Brain Health Nexus

Senator Stanley Kutcher, Senate of Canada

Contributors:

Magda Byma, Director, ScienceUpFirst – Canadian Association of Science Centres

Dr. Angela Cheung, Senior Scientist, University Health Network, and Professor of Medicine, University of Toronto

Dr. Tim Evans, Inaugural Director and Associate Dean, School of Population and Global Health, and Associate Vice-Principal, Global Policy and Innovation, McGill

Dr. Emilia Liana Falcone, Director, Microbiome and Mucosal Defence Research Unit, Montreal Clinical Research Institute

Susie Goulding, Founder COVID Long-Haulers Support Group Canada, National advocate, patient partner and long-hauler

Dr. Thao Huynh, Division of Cardiology, McGill University Health Centre, and Associate Professor, Department of Medicine, McGill

Dr. Tara Moriarty, Director, Moriarty Lab, University of Toronto

Dr. Manali Mukherjee, Assistant Professor, Division of Respiriology, Department of Medicine, McMaster

Dr. Andrew Nevin, Partner, West Africa Financial Services Leader and Chief Economist, PwC

Adriana Patino, Lead Administration of Long COVID Canada, National advocate and patient partner

Dr. Remi Quirion, Chief Scientist of Québec

Dr. Yanet Valdez Tejeira, Immunologist, BC Regional Lead and Director of COVID Conversations, COVID19 Resources Canada

Background articles:

Townhall articles

[Nova Scotia senator calling for more long-COVID research](#)

[A 'tsunami' of long COVID cases is about to hit, and some say the health-care system isn't ready](#)

VINEx Op-eds

[Long COVID contributing to brain health crisis disrupting labour force, economy](#)

[Why the fight against COVID-19 won't end with a high vaccination rate](#)

[Don't let the two-dose summer fool you – there is a long battle ahead against COVID-19](#)

[Canada should lead the effort to help COVID long-haulers](#)

Other mainstream articles

[Long Covid-19 may remain a chronic condition for millions](#)

[Long COVID: The invisible public health crisis fuelling labour shortages](#)

[Long COVID will have health, economic impact for years to come, says expert](#)

['There's no one long Covid': Experts struggle to make sense of the continuing mystery](#)

[Understanding long Covid will take the lived experiences of long haulers](#)

[We've got to get on top of long COVID before it drowns us](#)

[Ontario needs to develop strategy to manage long COVID, science table says](#)

[Covid-19: WHO urges action as 17 million long covid cases are estimated in Europe](#)

[Long COVID Experts and Advocates Say the Government Is Ignoring 'the Greatest Mass-Disabling Event in Human History'](#)

[One of Long COVID's Worst Symptoms is also its Most Misunderstood](#)

[The Data is Clear: Long Covid is devastating People's Lives and Livelihoods](#)