



Pan-Canadian Survey Reveals Long-term Harm of COVID to Brain Health

Responses Suggest Economic, Health and Societal Costs with Consequences on Health Sector and Labour Force

3 JUNE 2021 – A pan-Canadian survey of more than 1,000 COVID long-haulers, individuals with COVID-19 symptoms that last weeks or months, reveals the impact of Long COVID on brain health. From coast to coast, cognitive impairment or “brain fog” was among the top reported symptoms, along with fatigue and shortness of breath. Additional brain-related symptoms included headaches, dizziness, and anxiety. Over 80% of respondents experienced symptoms for more than three months, and almost 50% experienced symptoms for 11 months or more. While vaccines and physical distancing are important to prevent and mitigate COVID-19, the survey suggests the impact of COVID-19 on brain health will last beyond the pandemic.

A detailed report on the survey is forthcoming and will be available on the website of the alliance members listed below. Survey results are consistent with other scientific [findings](#), including that Long COVID is disproportionately impacting women in their middle years. This is the largest publicly available survey of people living with Long COVID in Canada to date.

“It is our hope that the data collected from this survey will highlight the implications of Long COVID on brain health. Creating awareness through lived experiences and patient collaboration will magnify the urgency to act on funding for research and rehabilitation of long-haulers,” said COVID Long-Haulers Support Group Canada Founder Susie Goulding.

The survey is the result of an alliance between Viral Neuro Exploration ([VINEX](#)), [COVID Long Haulers Support Group Canada](#), and [Neurological Health Charities Canada](#) (NHCC) to build awareness and increase funding for research and care on Long COVID. The alliance leverages science, clinical research, and lived experiences from patient groups, and is reaching out to other organizations with an interest in the lasting and long-term impacts of COVID-19.

“The survey underlines earlier observations that COVID-19 can cause neurological damage which persists months after the initial infection. It clearly indicates that Canada needs action on brain health in COVID and post-COVID contexts,” said Neurological Health Charities Canada Manager Deanna Groetzinger.

According to the survey, nearly half of respondents received care for long-lasting symptoms in a healthcare clinic more than five times. Nearly a third received care more than 10 times. Six out of 10 had to take leave from work as a consequence of living with Long COVID, for weeks or months at a time,

sometimes leading to early retirement. The responses suggest ongoing economic, health and societal costs with ripple effects into the public health sector and labour force.

“We must make the study of viral impacts on the brain a priority, beginning with COVID-19 survivors who need answers. One or more clinical trials of sufficient scale, with patients followed over time, would generate data needed to better understand Long COVID and the neurological and psychological consequences of this infection. What we learn from more research on Long COVID will also accelerate our understanding of how viruses and future pandemics may affect brain health, including as possible triggers for neurodegenerative diseases,” said VINEx Global Director [Inez Jabalpurwala](#).

In addition to its alliance with COVID Long Haulers Support Group Canada and NHCC, VINEx has become an international member of the [Long COVID Alliance](#) in the United States. This alliance, led by SOLVE M.E., was central to the bipartisan legislation [introduced](#) on May 27th to provide nearly 100 million USD in Long COVID funding for research and education initiatives.

It is currently estimated that 25-35% of COVID-19 patients are experiencing the long-term effects of the virus. The COVID-19 count in Canada as of June 2nd is 1,383,214, which means that anywhere from 345,803 to 484,125 people may have been or are currently living with Long COVID in this country.

The Survey in Numbers



The survey ran from May 5th to May 26th 2021 and reached **1,048** respondents with Long COVID from all ten provinces and three territories.



Participants ranged in age from under **18** to over **90**. Nearly **60%** were aged **40 to 59**.



More than **87%** of respondents identified as women. Members of cultural minorities represented **9%** of participants*.



Before having COVID-19, nearly **63%** of respondents did **not** have a long-term health condition.



57% of participants received a positive COVID-19 test. It should be noted that respondents may not have had access to COVID-19 tests at the times of their initial infection.



More than **85%** of participants were **not** admitted to hospital during their initial infection.



Nearly **70%** of respondents had to take leave from work. **More than half** had to reduce working hours, with **74%** reducing their working hours by **50%** or more.

**We recognise that the percentage of cultural minority respondents may be undercounted given the survey sample. The survey might not have reached cultural minorities in a proportion comparable to their shares of the Canadian population.*

About

In April 2020, Rocket Science Health, a private brain-health focused medical device company, launched **Viral Neuro Exploration (VINEx)** as an initiative aimed at raising attention to, and investment in, how viruses affect the central nervous system and brain health. VINEx was incorporated as an independent non-profit in November 2020. While the COVID-19 crisis creates urgency and is the initial focus, VINEx’s vision has a longer time horizon, and will involve other known and unknown coronaviruses, and other

viruses. To achieve its vision, VINEx is bringing together thought leadership from the research community to drive actionable projects where collaboration, co-ordination and investment are needed.

The [Covid Long Haulers Support Group Canada](#) is creating awareness of the effects COVID-19 has on long-haulers, symptomatically, financially and economically. They lobby for recognition from government officials and the public and want it to be understood that long-haulers are not recovered. There is still robust, longitudinal research and rehabilitation targeted for long-haulers that need to be funded. Through their efforts of sharing lived experiences with media and creating momentum, they hope to create change.

[Neurological Health Charities Canada](#) (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions. NHCC is open to charities and non-profit organizations with a specific interest in brain conditions.

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