



**Report on Pan-Canadian Long Covid Impact Survey  
June 8<sup>th</sup> 2021**

The survey and report were made possible by an alliance of Viral Neuro Exploration (VINEx), COVID Long-Haulers Support Group Canada, and Neurological Health Charities Canada.

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## ***I. Executive Summary / Sommaire exécutif***

Despite growing scientific evidence and increased media attention, the symptoms and impacts of Long COVID – where COVID-19 symptoms last weeks or months after the initial infection – are still not well understood. Viral Neuro Exploration ([VINEx](#)), [COVID Long Haulers Support Group Canada](#), and [Neurological Health Charities Canada](#) (NHCC) formed an alliance 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 alliance ran a survey of COVID long-haulers in Canada from May 5<sup>th</sup> to May 26<sup>th</sup> 2021 inclusive. The survey was sent through the networks of each alliance member to reach people with lived experience. The questions reflect the priorities of the alliance members in their efforts to better understand COVID-19's long-term impact on Canadians, and on the economy and society. The survey comprises answers from 1,048 respondents from all 10 provinces and three territories.

Survey results are consistent with other scientific findings and patient surveys, 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. Select publications are referenced at the end of this report for further reading.

The survey questions, answers and analysis below give valuable insights into the health, social and economic impacts of Long COVID on Canadians from coast to coast. They reveal the effect of Long COVID on brain health and the consequences on the public health sector and labour force.

All survey data has been inputted independently by survey participants.

Any data used from the report must reference the survey and the members of the alliance. The report should be cited as: Viral Neuro Exploration (VINEx), COVID Long Haulers Support Group Canada, and Neurological Health Charities Canada. (June 2021). *Report on Long COVID Impact Survey*.

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Malgré les preuves scientifiques croissantes et l'attention accrue des médias, les symptômes et les impacts de la COVID longue, où les symptômes de la COVID-19 (après l'infection initiale) durent des semaines ou des mois, sont encore mal compris. [VINEx](#) (une exploration multidisciplinaire de la connexion entre les virus et le cerveau), le [COVID Long Haulers Support Group Canada](#), et les [Organismes caritatifs neurologiques du Canada](#) (OCNC) se sont alliés pour accroître la sensibilisation et le financement de la recherche et des soins sur la COVID longue. L'alliance s'appuie sur la science, la recherche clinique et les expériences vécues par les groupes de patients, et cherche à collaborer avec d'autres organisations intéressées par les impacts à long terme de la COVID-19.

L'alliance a mené un sondage auprès des personnes souffrant de la COVID longue au Canada du 5 au 26 mai 2021 inclus. Le sondage a été envoyé par le biais des réseaux de chaque membre de l'alliance afin d'atteindre les personnes ayant une expérience vécue. Les questions reflètent les priorités des membres de l'alliance dans leurs efforts pour mieux comprendre les impacts à long terme de la COVID-19 sur les Canadiens, l'économie et la société. Le sondage comprend les réponses de 1 048 personnes provenant des 10 provinces et des trois territoires.

Les résultats du sondage sont cohérents avec d'autres résultats scientifiques et sondages auprès des patients, notamment le fait que la COVID longue affecte de manière disproportionnée les femmes d'âge moyen. Il s'agit du plus grand sondage public disponible à ce jour auprès des personnes vivant avec la COVID longue au Canada. D'autres publications sont disponibles à la fin de ce rapport pour une lecture plus approfondie.

Les questions et réponses du sondage, ainsi que l'analyse ci-dessous, donnent un aperçu précis des répercussions sanitaires, sociales et économiques de la COVID longue sur les Canadiens d'un océan à l'autre. Ils révèlent l'effet de la COVID longue sur la santé du cerveau et les conséquences sur le système de santé publique et la main-d'œuvre.

Toutes les données du sondage ont été saisies de manière indépendante par chacun des répondants.

Toute donnée reprise de ce rapport doit faire référence au sondage et aux membres de l'alliance. Le rapport doit être cité comme suit : Viral Neuro Exploration (VINEx), COVID Long Haulers Support Group Canada, et Organismes caritatifs neurologiques du Canada. (Juin 2021). *Rapport sur le sondage sur l'impact de la COVID longue.*

## **II. Highlights**

- The survey ran from May 5<sup>th</sup> to May 26<sup>th</sup> 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 recognize 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.*

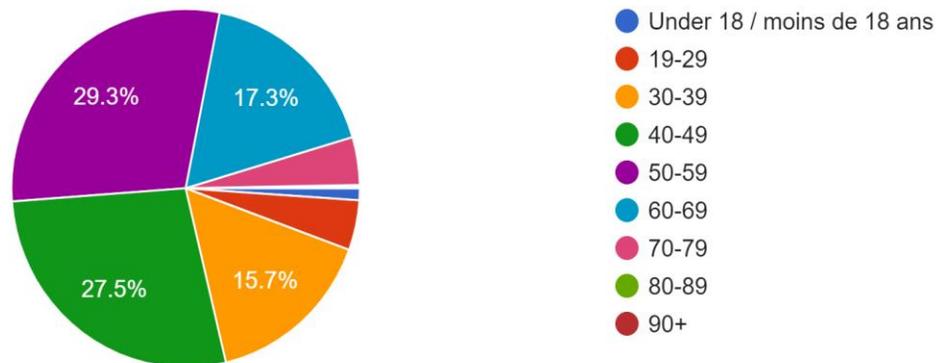
### III. Context

The survey questions were sent out in the format of a link to a dedicated Google Form through the networks of the three alliance members: VINEx, COVID Long Haulers Support Group Canada, and NHCC. Survey questions were sent out in English and in French. Participants with Long COVID could respond to survey answers from May 5<sup>th</sup> to May 26<sup>th</sup> 2021 inclusive. The questions were generated by different alliance priorities, in terms of scientific findings, clinical research, and lived experiences from patient groups. Survey questions and answers are listed below under their own heading with a separate analysis. Although the survey reached 1,048 respondents, not all respondents answered all questions. The comments from participants quoted at the end of this report were not edited and appear as were submitted.

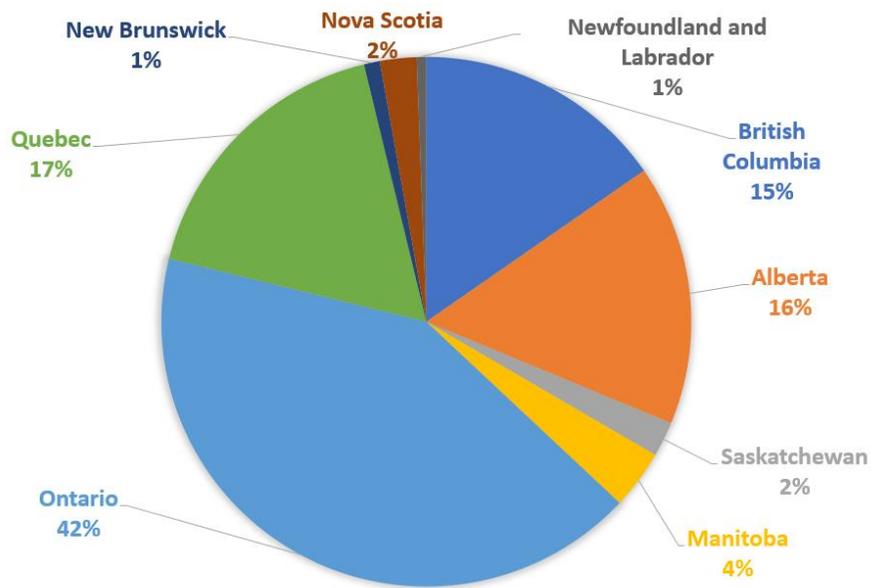
### IV. Demographics

What is your age? / Quel est votre âge ?

1,020 responses



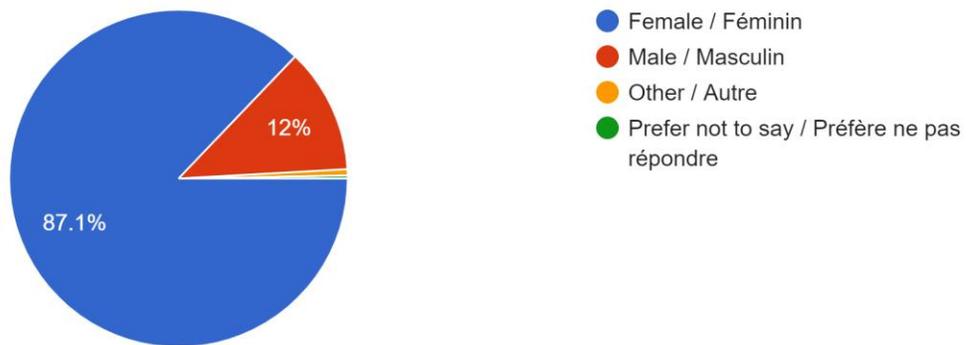
Participants ranged in age from under 18 to over 90. Nearly 60% were aged 40 to 59. This is consistent with other surveys, as individuals with Long COVID, where COVID-19 symptoms last weeks or months, tend to skew towards people in their middle years.



Survey participants were from all ten provinces and three territories. Responses were roughly proportional to the demographic weight of each province and territory in the Canadian federation.

### What is your gender? Quel est votre genre ?

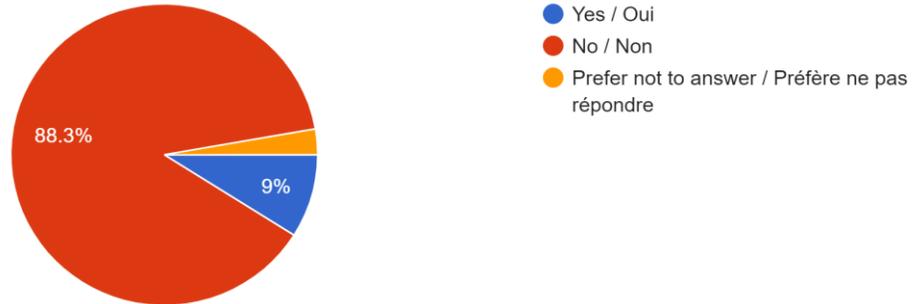
1,017 responses



Survey participants were asked to self-identify their gender, a social construct, as opposed to sex, a biological category. More than 87% of respondents identified as women. The survey responses suggest the burdens of Long COVID disproportionately affect women. It could be that the survey reached more women than other genders; however numerous studies suggest that women are more proportionately affected by Long COVID. See resources section at the end for a selection of publications that discuss potential hypothesis.

Are you a member of a minority cultural community? / Êtes-vous membre d'une communauté minoritaire culturelle ?

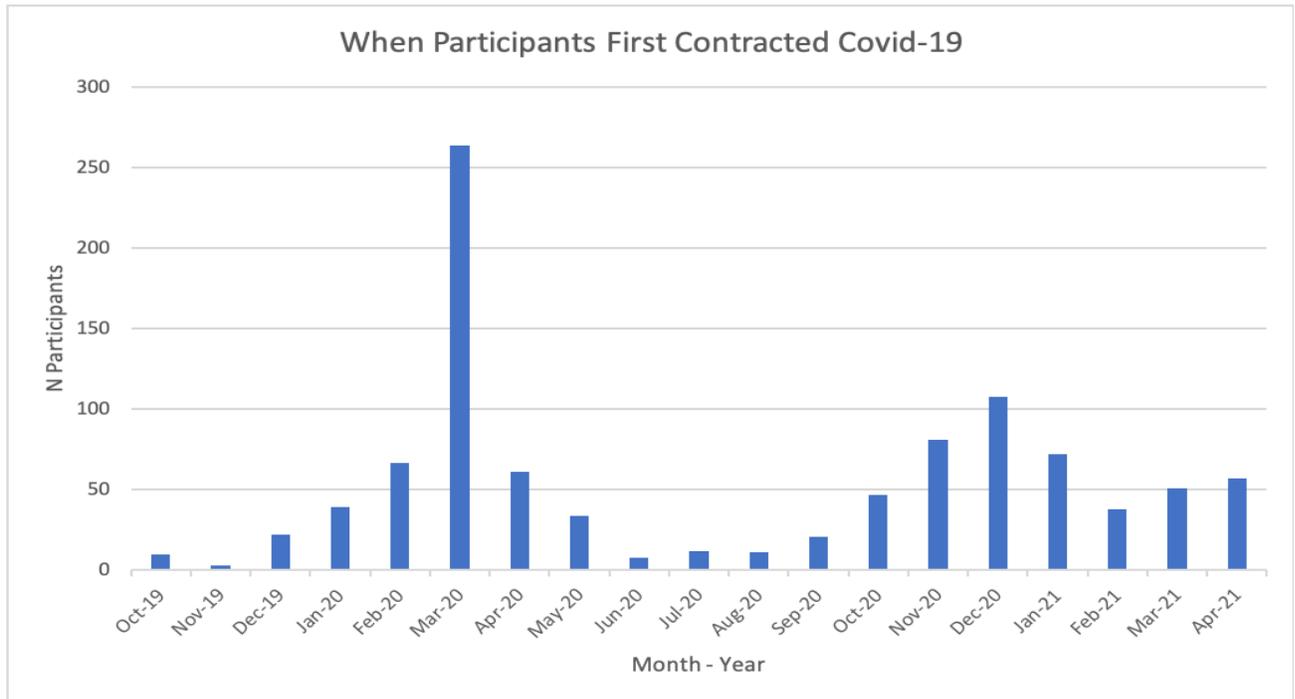
1,016 responses



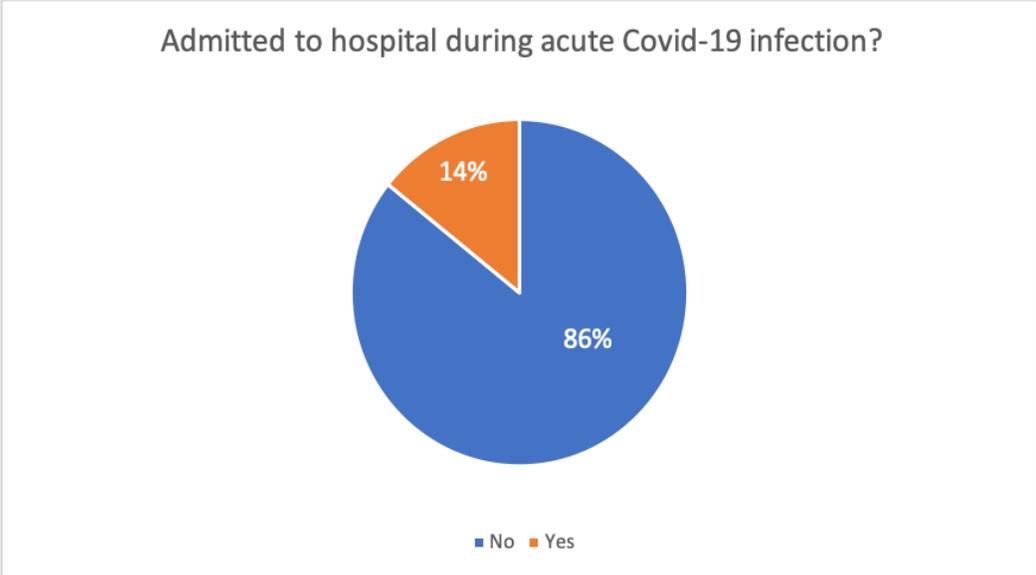
Survey participants were asked to self-identify as being part of a minority cultural community or not. The term was not defined, and could therefore include cultural, ethnic, and/or visible minorities. Members of cultural minorities represented 9% of participants.

However, we recognize 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.

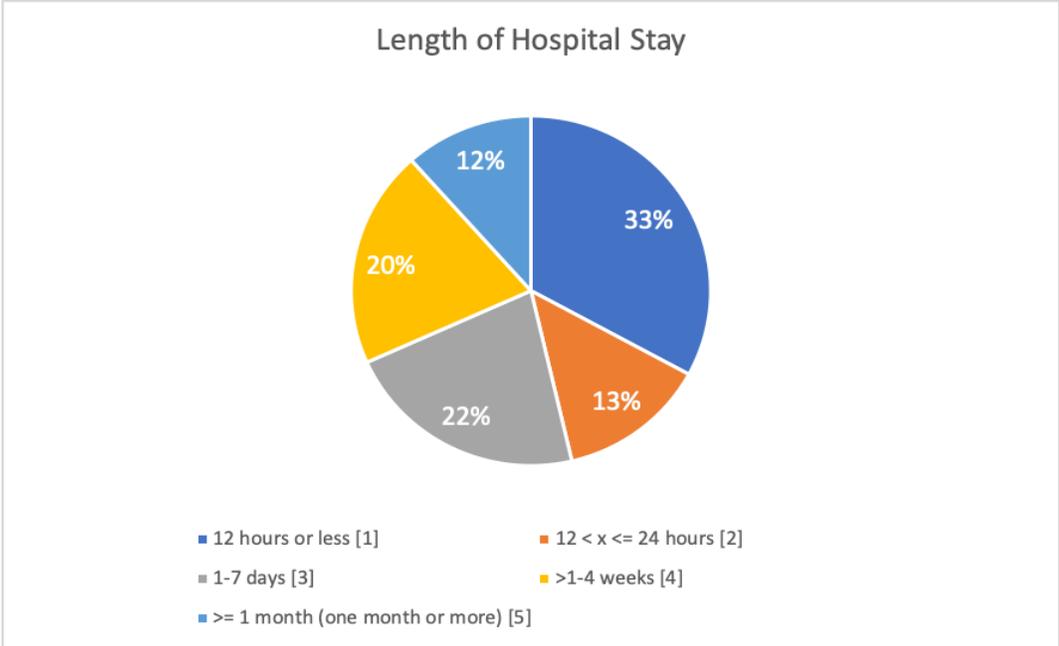
#### V. Initial Infection, Testing and Hospitalization



The majority of participants (more than 250) responded they contracted COVID-19 (likely or confirmed) in March of 2020. It should be noted that respondents may not have had access to COVID-19 tests at the times of their initial infection. A second peak is observed in December 2020 which is in line with a peak in overall reported Covid-19 cases in Canada as a whole.



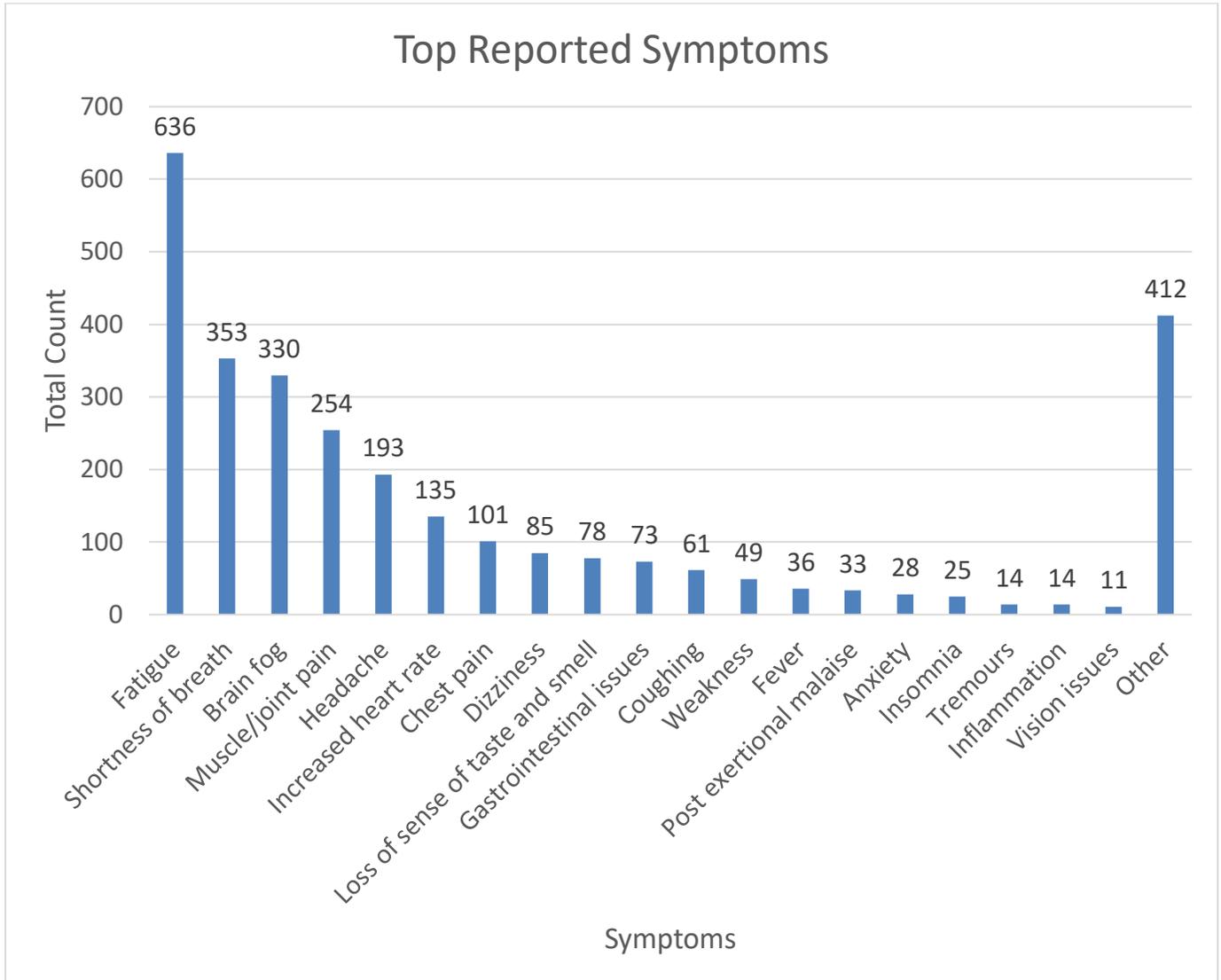
More than 85% of participants were not admitted to hospital during their initial infection.



Of the 14% who were hospitalized during the acute phase of Covid-19 infection, 46% of survey participants were hospitalized for 24 hours or less; 20% were hospitalized for one to four weeks; and 12% were hospitalized for more than one month. This is a large spread, but due to the minority percentage (14%)

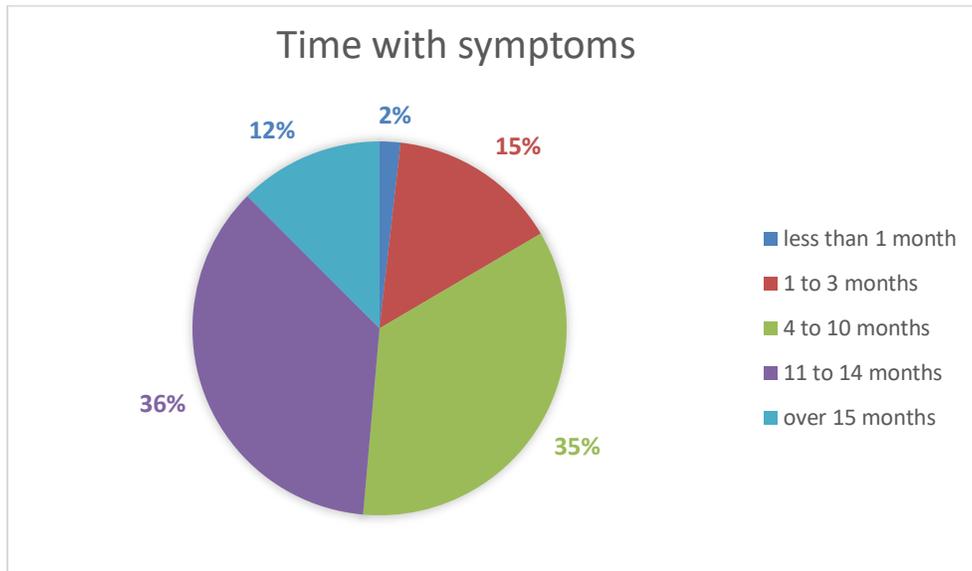
who were hospitalized in the first place, of which almost half stayed in the hospital for less than 24 hours, hospitalization time is not necessarily related to existence, severity or longevity of post-COVID syndrome symptoms.

## VI. Symptoms



There have been more than 200 symptoms associated with Long COVID. The question asked respondents to list their top three symptoms. The top 20 symptoms reported by survey respondents are listed in the graphic above. The symptoms were self-reported. The respondents described symptoms in a free-form answer: there were no leading questions or choices from which to select symptoms. 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.

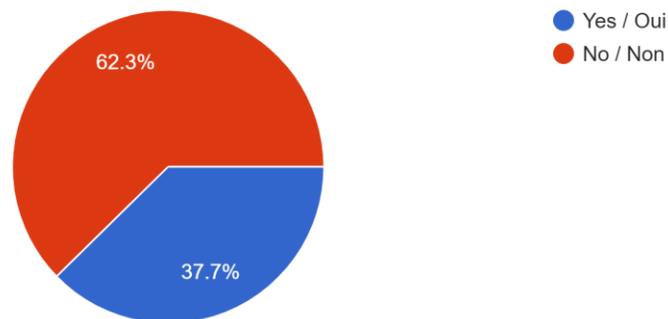


COVID long-haulers are individuals with COVID-19 symptoms that last weeks or months. Over 80% of respondents experienced symptoms for more than three months, and almost 50% experienced symptoms for 11 months or more.

### VII. Prior Long-term Health Conditions

Prior to having COVID-19, were you diagnosed with another long-term health condition? / Avant d’avoir la COVID-19, avez-vous été diagnostiqué avec une autre maladie de longue durée ?

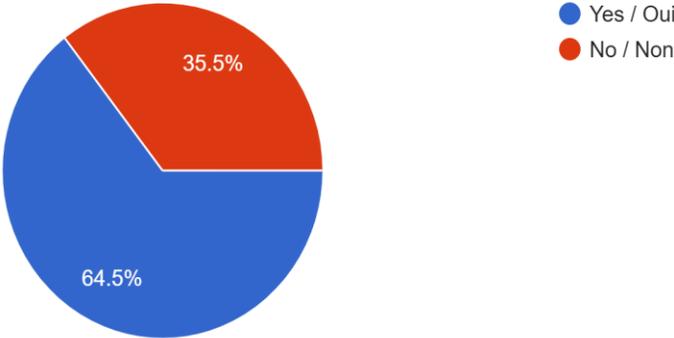
1,030 responses



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

Has your long-term health condition changed after having COVID-19? / Est-ce que votre maladie de longue durée a changé après avoir attrapé la COVID-19 ?

781 responses

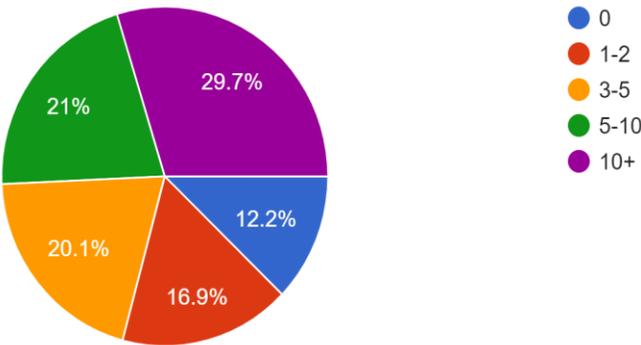


Nearly 65% of participants stated that their long-term health condition changed after having COVID-19. When asked how it has changed, in a free-form answer, the vast majority stated that their long-term health condition worsened or became more severe.

**VIII. Visits to Healthcare Facilities**

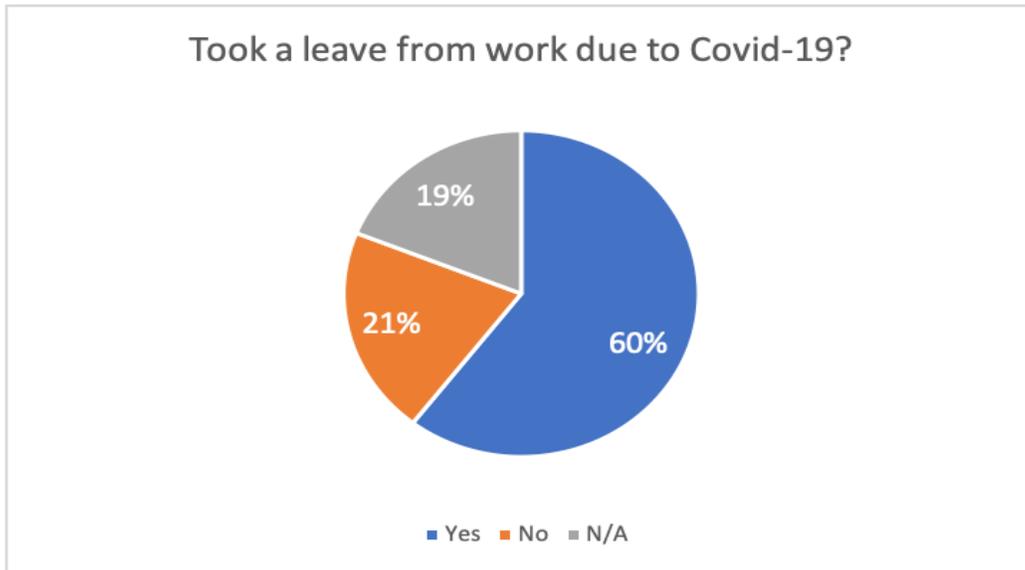
How many times have you received care at a healthcare clinic (for example, a physician's office, hospital, outpatient clinic, or a private option) r...cernant des symptômes persistants de la COVID-19 ?

1,029 responses

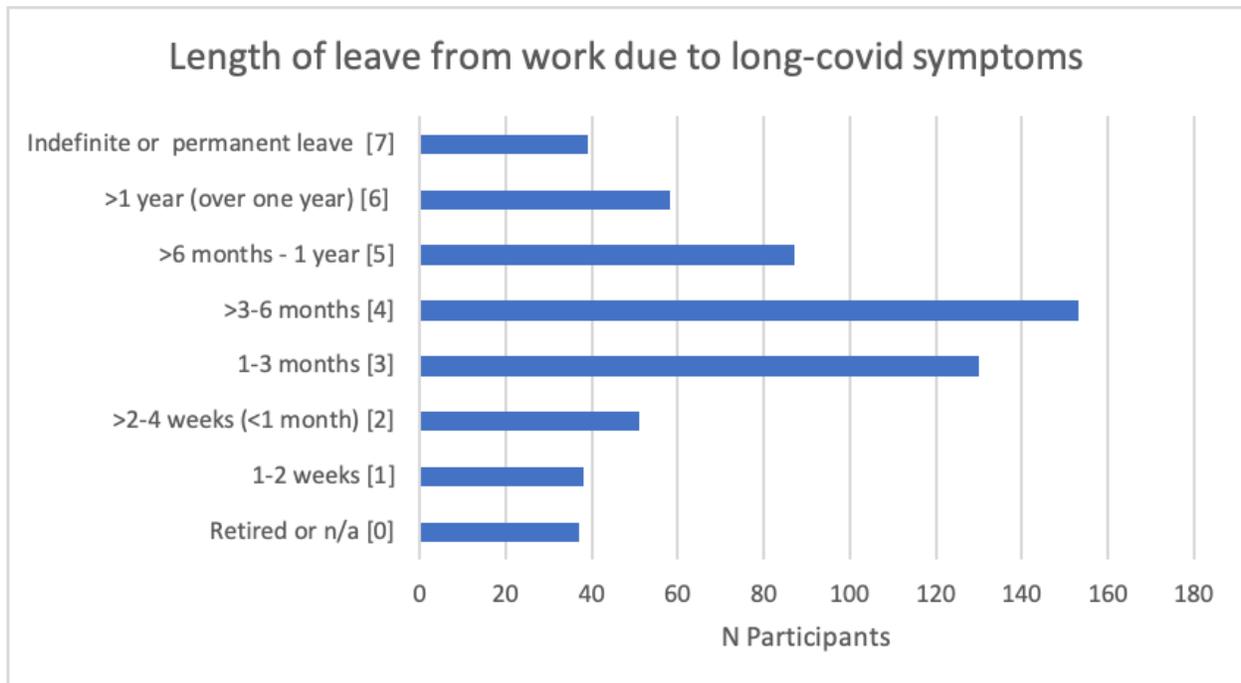


Nearly half of respondents received care for long-lasting symptoms in a healthcare clinic more than five times. Nearly a third received care more than 10 times. This suggests consequences on the public healthcare sector, as well as the need for interdisciplinary COVID-19 care clinics.

**IX. Time Off Work and Disability**

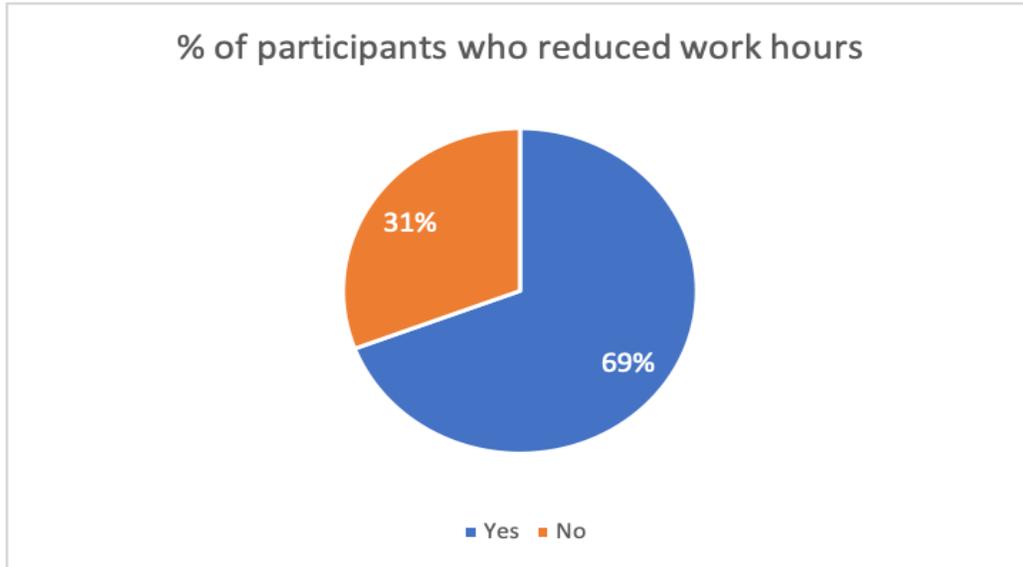


A majority (60%) of survey respondents had to take a leave from work at some point due to COVID-19 (acute infection or associated long-term symptoms).

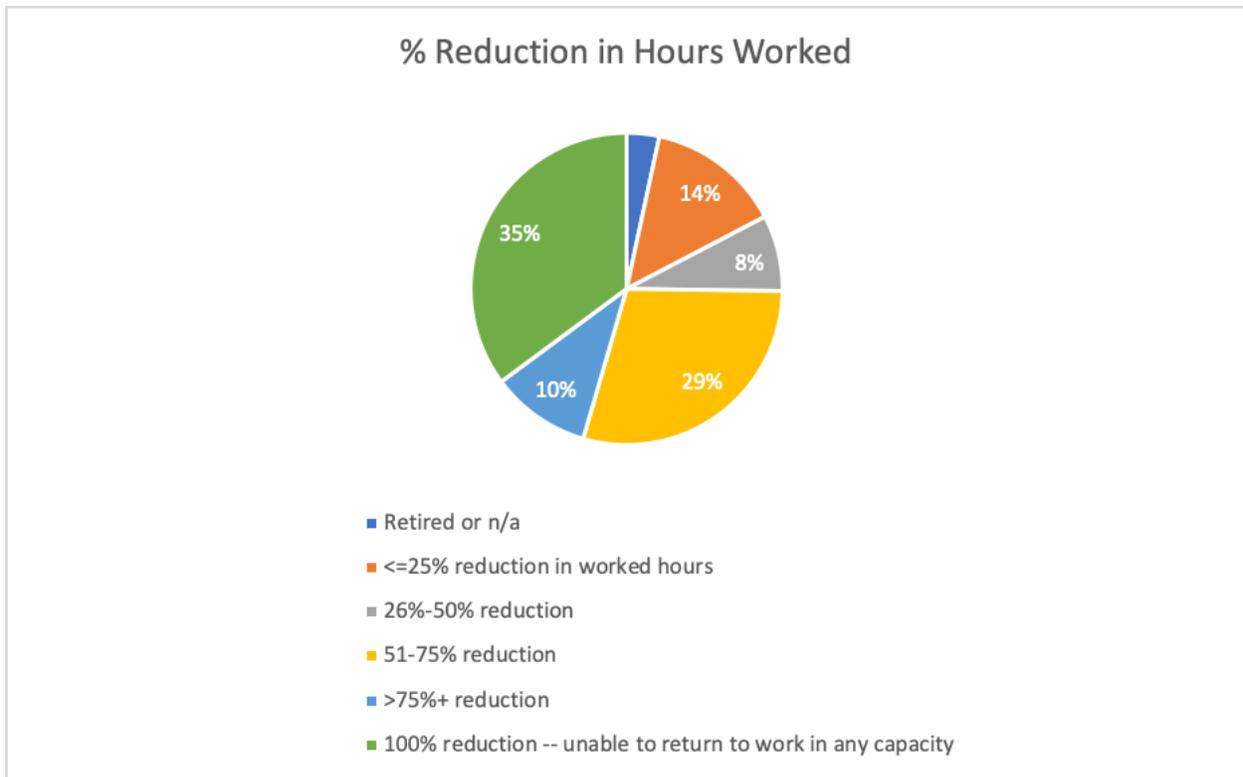


In terms of length of leave from work, the top three choices among participants were three to six months' leave, one to three months' leave, and six months' to one year's leave. These are all substantial amounts

of time that affect workplaces and government benefit payouts. Unfortunately, out of the 593 responses to this question, 40 are on indefinite or permanent leave.



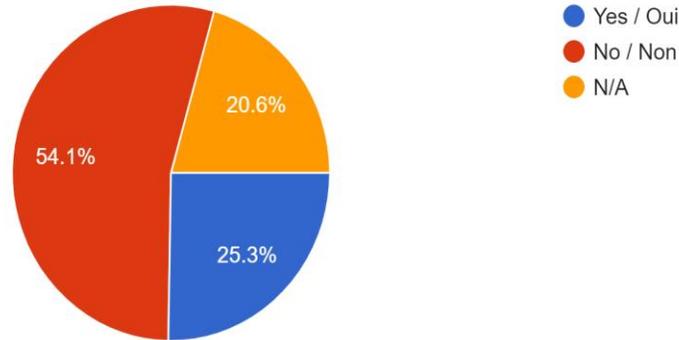
Nearly 70% of 718 respondents to this question had to reduce work hours in some capacity as a consequence of living with Long COVID. That is a large impact on the labour force. There may be some of the other 31% who may have wanted to reduce work, or were not given the opportunity due to employer or income limitations.



35% of the 444 respondents to this question have been unable to return to work in any capacity. This is detrimental to their quality of life, income-earning capacity, and employer, and may require them to rely on income support programs provided by the government. The second most common answer (29%) was a still substantial reduction of 51%-75%.

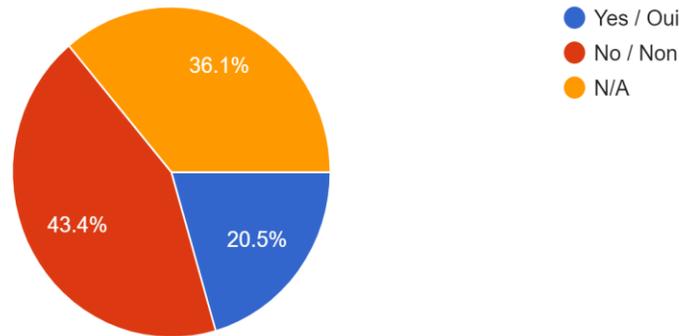
Have you had to access disability insurance? / Avez-vous dû recourir à l'assurance invalidité ?

1,013 responses



Have you been able to access disability insurance? / Avez-vous pu bénéficier d'une assurance invalidité ?

971 responses



A quarter of respondents had to access disability insurance. Nearly 44% had not been able to access disability insurance at the time of the survey.

### ***X. Open-ended Questions***

The survey concluded with two open-ended questions: 'How has living with Long COVID impacted your family?' and 'Is there anything else that you would like to share about your experience living with Long

COVID?' A selection of answers are listed below. They have been kept anonymous to protect participant privacy and have not been edited.

### *A. Impact on Family*

'I had to move back in with my parents.'

'I'm very dependent on family for daily living, e.g. groceries, meals, housekeeping, etc.'

'It has made life very difficult. My fiance has to constantly take care of me because some days I am not able to myself. We aren't able to do the things we used to do such as going for long walks, on adventures or even being out for a whole day. We have to plan everyday ensuring I have rest times. It has effected my mood a lot as well as I am always feeling defeated.'

'I am not able to fulfill my role as a wife, mother or make money to contribute financially. I require help with tasks that I didn't before. It is stressful for my kids to see their mom unwell.'

'I can hardly look after myself. I used to be an endurance athlete. I have no desire to do anything as I feel worse.'

'I was the primary keeper of the house and family schedule as well as worked full time. I am none of those things now. My children see me spend my day moving between bed and couch and my husband has had to take over all cleaning, shopping and care giving on top of his full time job. The impact has been huge.'

'Stress and sadness. My wife has to do more chores. We pay for house cleaning and landscaping since I can't do anything anymore.'

'I am only able to do a fraction of the things that I used to. I am a single mom and haven't had the energy to do the things that I used to with the kids so I feel like we're missing out on a lot of quality time together. I haven't been able to work so it has been financially stressful and because there are so many unknowns it's been emotionally stressful as well.'

### *B. Other comments*

'It's scary that we don't really know enough about this disease and I'm worried for my life expectancy now.'

'Helpful to have a group to share experiences. A lot of people give advice when have no experience - blame the victim. Doctor says nothing they can do, when I'm not sure that's accurate.'

'I feel as though I have aged ten years in one + year of Covid. I am no longer the person I once was. I was denied a Covid test back in March 2020 even though I was symptomatic. By the time I was able to get

tested in late May 2020, my result was negative. However, I have been diagnosed by my doctor as having had Covid after everything else was ruled out. Covid has been detrimental in my life.'

'This has been the most difficult year. I am only 27 years old and I can't go for a long walk or take care of myself some days. Doctors have dismissed me from day one. If a doctor told me the right things, I maybe would have been better by now. It's very discouraging and all we need is for someone to listen to us and help us navigate through this illness.'

'A lot of things have been difficult but the most difficult is not being believed or heard by health care professionals. Or being dismissed as "having anxiety". Also, I feel like I am a completely different person than I was prior to getting Covid-19.'

'I have been fortunate enough to work from home and only work half days. As a result of fatigue, brain fog and memory loss, my work is not reliable. My husband and I work together. Partially, as a result of my struggles we have decided that it is best to retire, which we are doing as of the end of June 2021. If I were not suffering from long haulers, we likely would have continued to work for another couple of years.'

'It's been absolutely debilitating. So much more frustrating to hear about the magical 14 day quarantine or death but nothing about the recovering.'

'We need proper supports in Canada. While I am fortunate to have a fantastic medical team, they have no support. I did not have the elusive positive test (though all physicians firmly believe it was a false negative) so I don't qualify for any of the post covid clinics. It is frustrating to watch other countries quickly mobilize to get people with post covid back to work as quickly as possible and Canada acts like it isn't even happening. This is a huge drain on the medical system let alone the work force. The impacts are far reaching and significant.'

## ***XI. Conclusion***

A pan-Canadian survey of more than 1,000 COVID long-haulers-individuals with COVID-19 symptoms that last weeks or months after the initial infection-reveals the impact of Long COVID on brain health. This is the largest publicly available survey of people living with Long COVID in Canada to date. 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. Survey responses suggest economic, health and societal costs of COVID-19 with consequences on the health sector and labour force. Survey results are consistent with other scientific findings, including that Long COVID is disproportionately impacting women in their middle years.

## ***About the Alliance Members***

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.

## ***References for Further Information***

VINEx Select Publications and Resources: <https://rocketscience.health/vinex/publications-and-resources/>

### *Long COVID and Women*

Covid-19: Middle aged women face greater risk of debilitating long term symptoms:

<https://www.bmj.com/content/372/bmj.n829>

Long COVID: The Impact on Women and Ongoing Research:

<https://swhr.org/long-covid-the-impact-on-women-and-ongoing-research/>

Why do most 'long-haul' COVID-19 sufferers seem to be women? The case for more sex-inclusive research:

[https://www.thestar.com/life/health\\_wellness/2021/03/11/why-do-most-long-haul-covid-19-sufferers-seem-to-be-women-the-case-for-more-sex-inclusive-research.html](https://www.thestar.com/life/health_wellness/2021/03/11/why-do-most-long-haul-covid-19-sufferers-seem-to-be-women-the-case-for-more-sex-inclusive-research.html)

## *Long COVID*

Long Covid in adults discharged from UK hospitals after Covid-19: A prospective, multicentre cohort study using the ISARIC WHO Clinical Characterisation Protocol:

<https://www.medrxiv.org/content/10.1101/2021.03.18.21253888v3.full-text>

Report: What Does COVID-19 Recovery Actually Look Like:

<https://patientresearchcovid19.com/research/report-1/>

Post-acute COVID-19 syndrome:

<https://www.nature.com/articles/s41591-021-01283-z>

High-dimensional characterization of post-acute sequelae of COVID-19:

<https://www.nature.com/articles/s41586-021-03553-9>

NIH launches new initiative to study “Long COVID”:

<https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid>

Nearly \$100M in Long COVID Funding Introduced in Congress:

<https://www.prnewswire.com/news-releases/nearly-100m-in-long-covid-funding-introduced-in-congress-301301363.html>

## ***Acknowledgements***

Viral Neuro Exploration (VINEx), COVID Long Haulers Support Group Canada, and Neurological Health Charities Canada (NHCC) would like to sincerely thank all survey participants.

## **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 27<sup>th</sup> 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 2<sup>nd</sup> 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 5<sup>th</sup> to May 26<sup>th</sup> 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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## **Un sondage pancanadien révèle les effets néfastes à long terme de la COVID sur la santé du cerveau**

### **Les réponses suggèrent des coûts économiques, sanitaires et sociétaux ayant des conséquences sur le système de santé et la main-d'œuvre**

3 JUIN 2021 - Un sondage pancanadien mené auprès de plus de 1 000 personnes souffrant de la COVID longue, c'est-à-dire des personnes dont les symptômes durent des semaines ou des mois, révèle l'impact de la COVID longue sur la santé du cerveau. D'un océan à l'autre, les troubles cognitifs ou le « brouillard cérébral » figurent parmi les symptômes les plus fréquemment signalés, avec la fatigue et l'essoufflement. Parmi les autres symptômes liés au cerveau figurent les maux de tête, les vertiges et l'anxiété. Plus de 80 % des personnes interrogées ont ressenti des symptômes pendant plus de trois mois, et près de 50 % pendant 11 mois ou plus. Bien que les vaccins et la distanciation physique soient importants pour prévenir et atténuer la COVID-19, le sondage suggère que l'impact de la COVID-19 sur la santé du cerveau durera au-delà de la pandémie.

Un rapport détaillé sur le sondage est à venir et sera disponible sur les sites web des membres de l'alliance nommés ci-dessous. Les résultats de l'enquête sont cohérents avec d'autres [résultats scientifiques](#), notamment le fait que la COVID longue affecte de manière disproportionnée les femmes d'âge moyen. Il s'agit du plus grand sondage public disponible à ce jour auprès des personnes vivant avec la COVID longue au Canada.

« Nous espérons que les données recueillies dans le cadre de ce sondage mettront en lumière les implications de la COVID longue sur la santé du cerveau. La sensibilisation par le biais d'expériences vécues et de collaboration avec des patients soulignera l'urgence d'agir en finançant la recherche et la réadaptation des gens souffrant de la COVID longue », a déclaré Susie Goulding, fondatrice du COVID Long-Haulers Support Group Canada.

Le sondage est le résultat d'une alliance entre [VINEx](#) (Viral Neuro Exploration), le [COVID Long Haulers Support Group Canada](#) et les [Organismes caritatifs neurologiques du Canada](#) (OCNC) pour accroître la sensibilisation et le financement de la recherche et des soins sur la COVID longue. L'alliance s'appuie sur la science, la recherche clinique et les expériences vécues par les groupes de patients, et cherche à collaborer avec d'autres organisations intéressées par les impacts à long terme de la COVID-19.

« Le sondage souligne les observations antérieures selon lesquelles la COVID-19 peut causer des dommages neurologiques qui persistent des mois après l'infection initiale. Il indique clairement que le Canada doit agir sur la santé du cerveau dans un contexte COVID et post-COVID », a déclaré Deanna Groetzinger, directrice des Organismes caritatifs neurologiques du Canada.

Selon le sondage, près de la moitié des personnes interrogées a reçu des soins pour des symptômes de longue durée dans une clinique de santé plus de cinq fois. Près d'un tiers a reçu des soins plus de 10 fois. Six personnes sur 10 ont dû s'absenter de leur travail en raison de la COVID longue, pendant des semaines ou des mois, ce qui a parfois conduit à une retraite anticipée. Les réponses suggèrent des coûts économiques, sanitaires et sociétaux continus ayant des effets d'entraînement sur le système de santé publique et la main-d'œuvre.

« Nous devons faire de l'étude des impacts viraux sur le cerveau une priorité, en commençant par les survivants de la COVID-19, car ceux-ci ont besoin de réponses. Un ou plusieurs essais cliniques d'une ampleur suffisante, avec des patients suivis dans le temps, permettraient de générer les données nécessaires pour mieux comprendre la COVID longue et les conséquences neurologiques et psychologiques de cette infection. Ce que nous apprendrons en poursuivant les recherches sur la COVID longue accélérera également notre compréhension de la manière dont les virus et les futures pandémies peuvent affecter la santé du cerveau, notamment en tant que déclencheurs possibles de maladies neurodégénératives », a déclaré [Inez Jabalpurwala](#), directrice mondiale de VINEx.

En plus de son alliance avec le COVID Long Haulers Support Group Canada et les OCNC, VINEx est devenu un membre international de la [Long COVID Alliance](#) aux États-Unis. Cette alliance, dirigée par SOLVE M.E., a joué un rôle central dans la législation bipartite [déposée](#) le 27 mai dernier, qui prévoit un financement de près de 100 millions de dollars américains pour la recherche et l'éducation dans le domaine de la COVID longue.

On estime actuellement que 25 à 35 % des patients atteints de la COVID-19 subissent des effets à long terme liés au virus. En date du 2 juin, le nombre de cas de COVID-19 au Canada s'élevait à 1 383 214, ce qui signifie que de 345 803 à 484 125 personnes pourraient vivre ou avoir vécu avec la COVID longue au pays.

### Le sondage en chiffres



Le sondage s'est déroulé du 5 au 26 mai 2021 et a été complété par **1 048** personnes atteintes de COVID longue dans toutes les dix provinces et les trois territoires.



L'âge des personnes sondées allait de moins de **18 ans** à plus de **90 ans**. Près de **60 %** étaient âgés de **40 à 59 ans**.



Plus de **87 %** des personnes sondées se sont identifiées en tant que femmes. Les membres des minorités culturelles représentaient **9 %** des répondants\*.



Avant d'avoir la COVID-19, près de **63 %** des personnes interrogées **ne souffraient pas** d'une maladie de longue durée.



**57%** des personnes sondées ont reçu un test COVID-19 positif. Il convient de noter que les répondants peuvent ne pas avoir eu accès aux tests COVID-19 au moment de leur infection initiale.



Plus de **85 %** des participants **n'ont pas** été admis à l'hôpital lors de leur infection initiale.



Près de **70 %** des personnes interrogées ont dû prendre congé du travail. Plus de la **moitié** ont dû réduire leurs heures de travail, **74 %** d'entre eux ayant réduit leurs heures de **50 %** ou plus.

*\*Nous reconnaissons que le pourcentage de répondants appartenant à des minorités culturelles peut être sous-estimé compte tenu de l'échantillon du sondage. Le sondage n'a peut-être pas rejoint les minorités culturelles dans une proportion comparable à leur part de la population canadienne.*

## À propos des partenaires du sondage

En avril 2020, Rocket Science Health, une société privée de dispositifs médicaux axés sur la santé du cerveau, a lancé [VINEx \(Viral Neuro Exploration\)](#), une initiative visant à attirer l'attention et à investir dans la façon dont les virus affectent le système nerveux central et la santé du cerveau. VINEx a été constitué en organisme indépendant à but non lucratif en novembre 2020. Si la crise de la COVID-19 crée une urgence et constitue le point de mire initial, la vision de VINEx s'inscrit dans une perspective à plus long terme et concerne d'autres coronavirus connus et inconnus, ainsi que d'autres virus. Pour concrétiser sa vision, VINEx rassemble des leaders d'opinion de la communauté des chercheurs pour mener des projets concrets là où la collaboration, la coordination et l'investissement sont nécessaires.

Le [Covid Long Haulers Support Group Canada](#) sensibilise le public aux effets de la COVID-19 sur les personnes atteintes de la COVID longue, tant sur le plan symptomatique que financier et économique. Il fait pression pour que les responsables gouvernementaux et le public reconnaissent l'existence de cette maladie et veut faire comprendre que les personnes atteintes de la COVID longue ne sont pas guéries. Il attire aussi l'attention sur des lacunes de financement à combler, que ce soit pour effectuer des recherches longitudinales fiables, ou pour prodiguer des soins de réadaptation individualisés aux personnes atteintes de la COVID longue. Grâce à ses efforts de partage d'expériences vécues avec les médias visant la création d'un élan, le groupe espère amener le changement.

Les [Organismes caritatifs neurologiques du Canada](#) forment une coalition d'organismes qui représentent les personnes touchées par une maladie, un trouble ou une lésion du cerveau au Canada. Les OCNC jouent un rôle de premier plan aux fins de l'évaluation et de la promotion de nouvelles possibilités de collaboration en matière de sensibilisation, d'éducation et de recherche en vue d'améliorer la qualité de vie des personnes touchées par une affection du cerveau. Les OCNC sont ouverts aux organismes caritatifs et aux organismes sans but lucratif qui s'intéressent particulièrement aux affections du cerveau.

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