



## **Report on Second Pan-Canadian Long COVID Impact Survey 4 May 2022**

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***

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, and is reaching out to other organizations with an interest in the lasting and long-term impacts of COVID-19.

As such, the alliance first ran a survey of COVID long-haulers in Canada from May 5th to May 26<sup>th</sup>, 2021. The survey results were consistent with other scientific findings and patient surveys. The results demonstrated the broader impacts of Long COVID on quality of life: on health, society and the economy. At the time of publication, the survey was the largest publicly available survey of people living with Long COVID in Canada. A full report can be found on VINEx's [website](#).

The report which follows details the results of a follow-up survey of more than 1,000 COVID long-haulers in Canada. The survey was launched on March 23rd and closed on April 13th, 2022, and had a particular focus on the brain health impacts of Long COVID. It was prepared by [VINEx](#) and distributed through the [COVID Long-Haulers Support Group Canada](#) and [Neurological Health Charities Canada](#) (NHCC) membership.

The findings confirm that the brain health impacts of Long COVID exist and persist for Canadians from coast-to-coast and negatively impact their daily life and ability to work. The most frequently reported brain health impacts include difficulty concentrating and thinking, short-term memory loss, sleep disturbances, headaches, dizziness, and depression.

All survey data has been inputted independently by survey participants. In the survey answers where symptoms are self-reported, these symptoms do not necessarily in themselves constitute a medical diagnosis.

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. (May 2022). *Report on Second Pan-Canadian Long COVID Impact Survey*.

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Viral Neuro Exploration ([VINEx](#)), [COVID Long-Haulers Support Group Canada](#), et les [Organismes caritatifs neurologiques du Canada \(OCNC\)](#) se sont alliés pour sensibiliser le public, et cibler et accroître 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, et s'adresse à d'autres organisations qui s'intéressent aux impacts durables et à long terme de la COVID-19.

À ce titre, l'alliance a d'abord mené un sondage auprès de personnes atteintes de COVID longue au Canada du 5 au 26 mai 2021. Les résultats du sondage étaient en accord avec d'autres résultats scientifiques et des enquêtes auprès de patients avec la COVID longue. Les résultats ont démontré les impacts plus larges de la COVID longue sur la qualité de vie : sur la santé, la société et l'économie. Lorsque publié, le sondage était le plus grand sondage publiquement disponible de personnes vivant avec la COVID longue au Canada. Le rapport complet peut être [consulté](#) sur le site Web de VINEx.

Le rapport qui suit détaille les résultats d'un sondage de suivi mené auprès de plus de 1 000 personnes vivant avec la COVID longue au Canada. Le sondage, qui a été lancé le 23 mars et s'est terminé le 13 avril 2022, s'est particulièrement intéressé aux effets sur la santé du cerveau de la COVID longue. Il a été préparé par VINEx et distribué par l'intermédiaire des membres du COVID Long-Haulers Support Group Canada et des Organismes caritatifs neurologiques du Canada (OCNC).

Les résultats confirment que les impacts sur la santé du cerveau de la COVID longue existent et persistent pour les Canadiens d'un océan à l'autre et ont un impact négatif sur leur vie quotidienne et leur capacité à travailler. Les effets sur la santé du cerveau les plus fréquemment signalés sont les suivants : difficulté à se concentrer et à réfléchir, perte de mémoire à court terme, troubles du sommeil, maux de tête, étourdissements et dépression.

Toutes les données du sondage ont été saisies indépendamment par les participants. Dans les réponses au sondage, les symptômes sont autodéclarés, et ces symptômes ne constituent pas nécessairement un diagnostic médical.

Toute donnée utilisée à partir du 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 les Organismes caritatifs neurologiques du Canada. (Avril 2022). *Rapport sur le deuxième sondage pancanadien sur l'impact de la COVID longue.*

## **II. Highlights**

- The survey received responses from 1,050 long-haulers in nine provinces and one territory.
- More than **60%** of respondents are **between the age of 40 and 59**.
- Over **87%** of respondents identified as **women**. This is consistent with studies which demonstrate that women are [disproportionately](#) affected by Long COVID, by as much as a [4 to 1 ratio](#). **10.5%** of respondents identified as a **visible minority or member of a minority cultural community**.
- **Only a quarter** of respondents **were initially believed and received appropriate care** when they described their Long COVID symptoms to a healthcare professional.
- **Over 80%** of respondents said Long COVID has had a **negative or very negative impact on their brain health**.
- For those experiencing **neurological or psychiatric symptoms**, **more than 80%** said it has **negatively or very negatively impacted their daily life**.
- **Close to 75%** of long-haulers surveyed have **sought medical care for their neurological or psychiatric symptoms**.
- **Over 70%** 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.

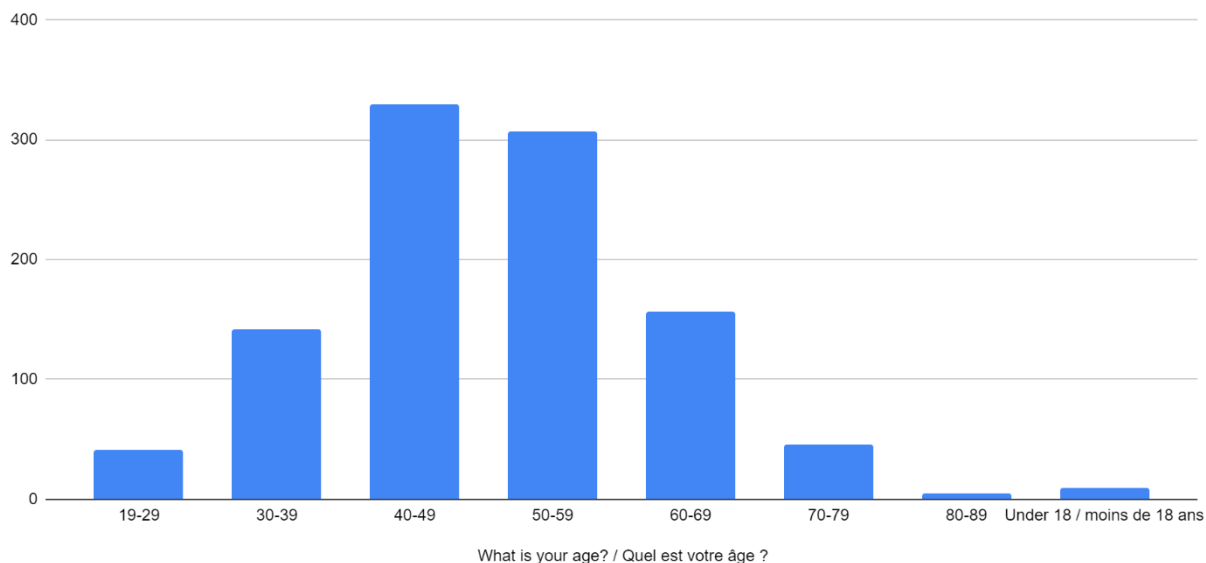
## **III. Context**

The survey questions were sent out in the format of a link to a dedicated Google Form. Survey questions were sent out in English and in French. Participants with Long COVID could respond to survey answers from March 23rd to April 13th, 2022 inclusive.

Survey questions and answers are listed below under their own heading with a separate analysis. Although the survey reached 1,050 respondents, not all respondents answered all questions.

#### IV. Survey Results

##### What is your age?



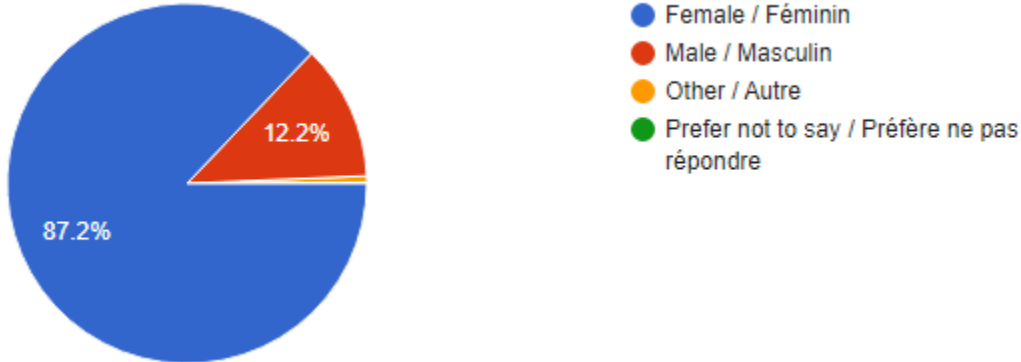
Participants ranged in age from under 18 to over 90. More than 60% were aged 40 to 59. This is consistent with other surveys, as individuals with Long COVID tend to skew towards people in their middle years.

##### Where do you live? / Où demeurez-vous ?

Province	Number of respondents
Alberta / L'Alberta	204
British Columbia / La Colombie-Britannique	142
Saskatchewan / La Saskatchewan	32
Manitoba / Le Manitoba	27
Ontario / L'Ontario	340
Quebec / Le Québec	220
New Brunswick / Le Nouveau-Brunswick	16
Nova Scotia / La Nouvelle-Écosse	38
Prince Edward Island / L'Île-du-Prince-Édouard	0
Newfoundland and Labrador / Terre-Neuve-et-Labrador	6
Nunavut / Nunavut	0
Northwest Territories / Territoires du Nord-Ouest	0
Yukon / Yukon	6
Other	8

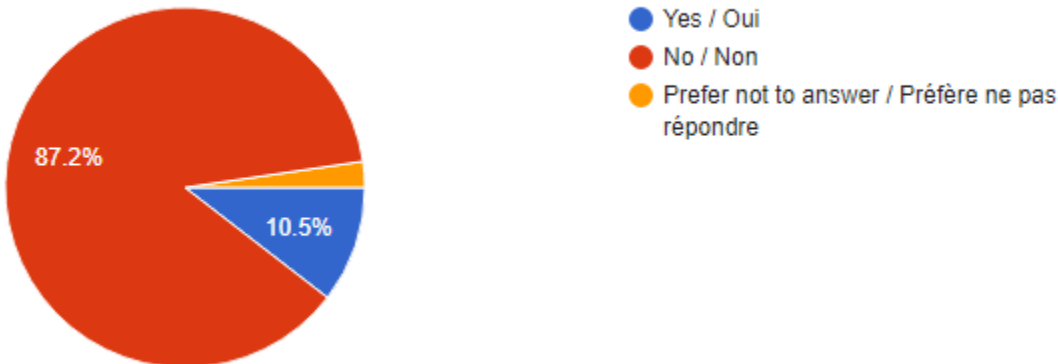
More than 50% of people surveyed are from Ontario and Quebec. The survey received responses from long-haulers in nine provinces and one territory. Responses were roughly proportional to the demographic weight of each province and territory in the Canadian federation.

**What is your gender?**



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. This is consistent with studies which demonstrate that women are disproportionately impacted by Long COVID by as much as a 4 to 1 ratio.

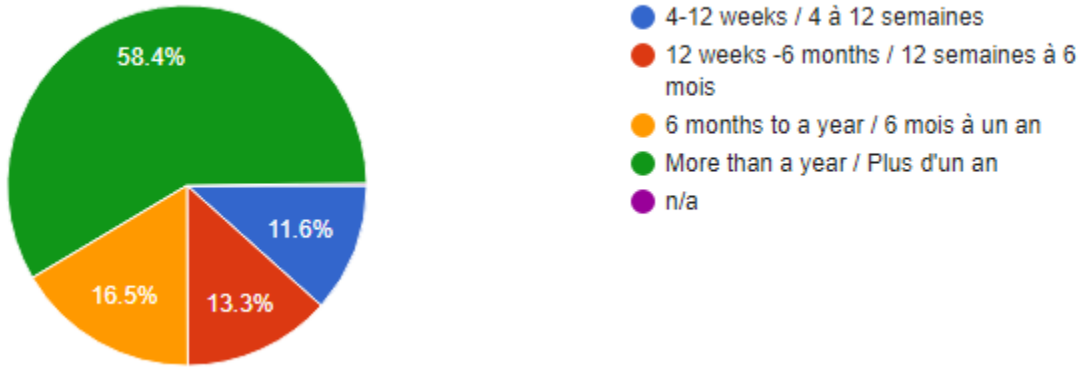
**Are you a visible minority or member of a minority cultural community?**



Survey participants were asked to self-identify as being a visible minority or member of a minority cultural community. The terms were not defined. 10.5% of respondents identified as a visible minority or member of a minority cultural community.

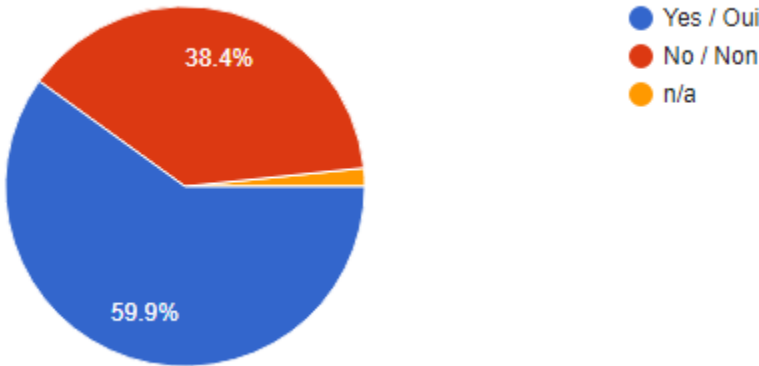
However, we recognize that the percentage may be undercounted given the survey sample. The survey might not have reached visible minorities or members of a minority cultural community in a proportion comparable to their shares of the Canadian population.

### How long have you been experiencing Long COVID symptoms?



Close to three quarters of long-haulers surveyed have experienced Long COVID symptoms from six months to a year, and close to 60% have experienced symptoms for more than a year.

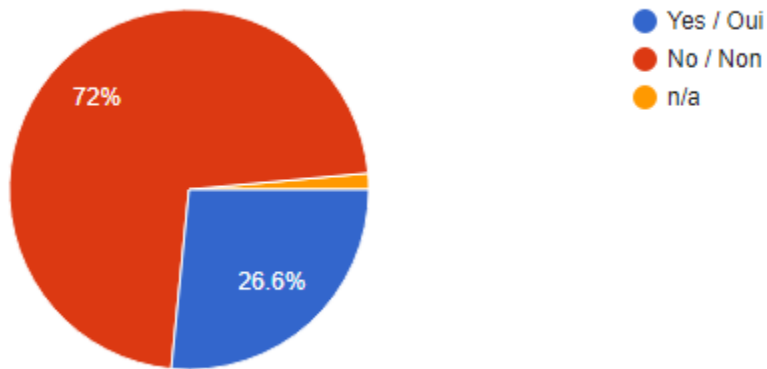
### Have you received a Long COVID diagnosis from a health care provider?



Nearly 60% of respondents received a Long COVID diagnosis from a healthcare provider. It should be noted that in the early days of the pandemic, COVID-19 and Long COVID diagnoses were limited, and for those who did present to a physician, the range of Long COVID symptoms and lack of diagnostic criteria made it difficult for them to get answers. The WHO only offered a clinical case [definition](#) of Long COVID in October 2021.

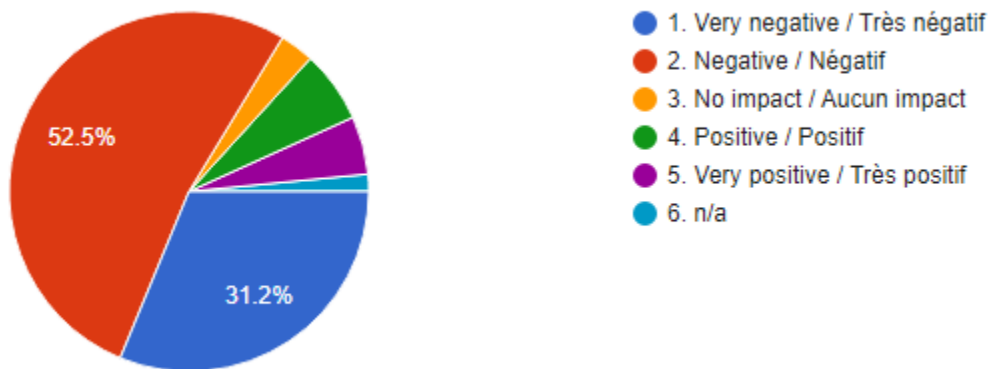


### Have you received or had access to Long COVID-specific treatment?



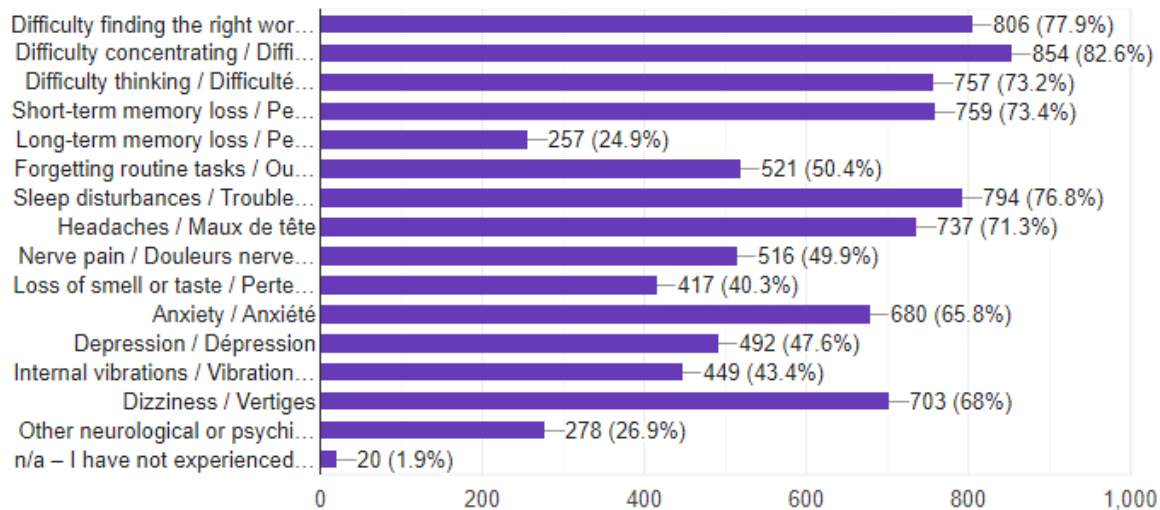
Less than 30% of surveyed long-haulers have received or had access to Long COVID-specific treatment. This demonstrates an immense unmet need across the country.

### Has Long COVID had an impact on your brain health? If so, please rate the brain health impact on a scale of 1 to 5.



More than 80% of respondents say Long COVID has had a negative or very negative impact on their brain health.

**Which of the following brain health (neurological or psychiatric) symptoms have you experienced? Choose all that apply.**



There have been more than 200 symptoms associated with Long COVID. The question asked respondents to list their brain health (neurological or psychiatric) symptoms from a list. The symptoms were self-reported, and the respondents could select all that applied. The most frequently reported brain health impacts include difficulty concentrating and thinking, difficulty finding the right words, sleep disturbances, short-term memory loss, headaches, dizziness, anxiety, forgetting routine tasks, and depression.

***If you had any additional neurological and/or psychiatric symptoms not included in the above list, please list them here.***

Long-haulers surveyed were also able to describe neurological and psychiatric symptoms in a free-form answer: there were no leading questions or choices from which to select symptoms. 353 people chose this option (out of these some answered not applicable or n/a).

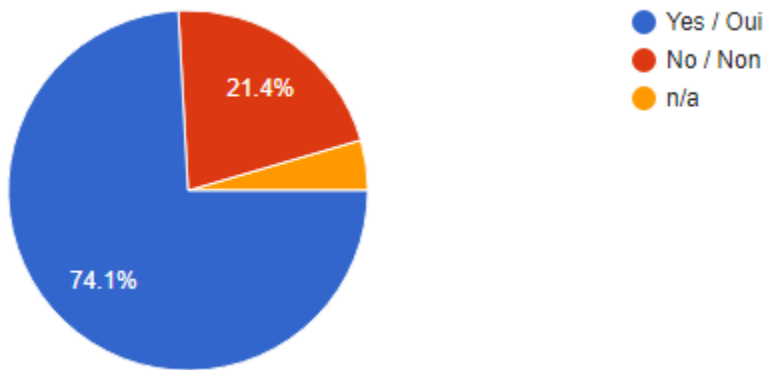
Answers ranged from synonyms or catch all terms to symptoms listed in the previous question, (for example brain fog, difficulty reading or head pain) to symptoms that had not been listed. These include tinnitus, blurry vision and eye pain, balance issues, panic attacks and mood changes.

Some anonymized answers include:

- “Depression, suicidal ideation, stroke, adjustment disorder.”
- “Feeling drunk 24/7, severe head pressure, vestibular migraines.”

- “Buzzing/vibration sensation in brain, numbness in face, aura/blurry vision.”
- « Problème avec les fonctions exécutives: d’organisation, de planification, d’activation. »
- “Difficulty processing verbal conversations.”
- “Feeling of electrical sparks on my scalp, intermittent facial numbness, difficulty writing, cannot multi-task, sensitivity to noise and bright lights.”

**If you are experiencing neurological or psychiatric symptoms, have you sought medical care?**



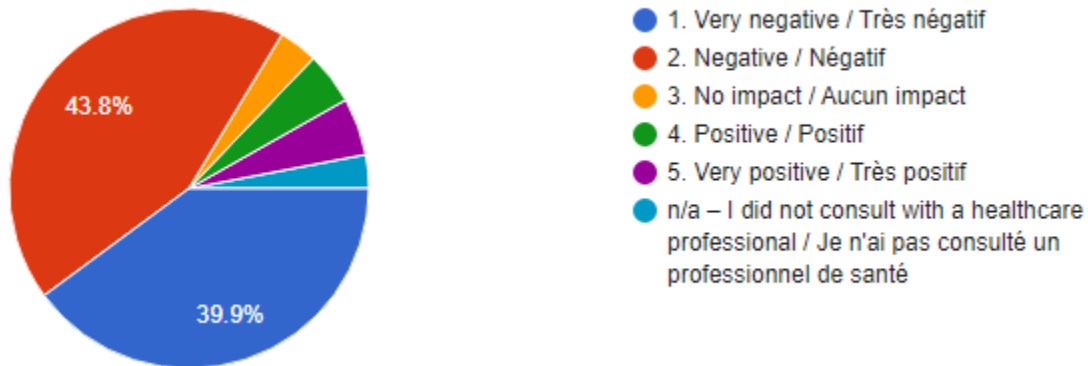
Close to 75% of long-haulers surveyed have sought medical care for their neurological or psychiatric symptoms.

**Were you believed when you initially described your symptoms to a healthcare professional? If so, did you receive appropriate care?**



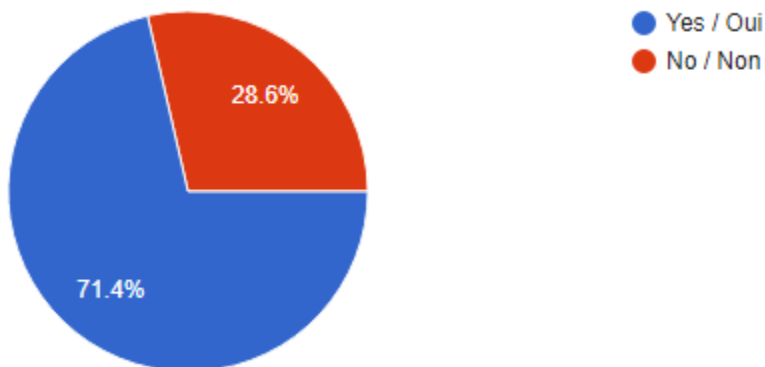
Only a quarter of respondents were initially believed and received appropriate care when they described their symptoms to a healthcare professional.

**If you are experiencing neurological or psychiatric symptoms, have they had an impact on your daily life? If so, please rate the impact on a scale of 1 to 5.**



For those experiencing neurological or psychiatric symptoms, more than 80% say it has negatively or very negatively impacted their daily life.

**Have you had to take a leave from work?**



Over 70% had to take leave from work as a result of living with Long COVID. This suggests a large impact on the labour force.

**If you answered yes to taking a leave from work, please share how long you have been on leave, if you have left the workforce, or if you have been accommodated by your employer.**

Long-haulers surveyed were also able to use a free-form answer to this question. There were no leading questions or choices from which to select. There were 756 responses to this question.

The vast majority of answers show long-haulers took leave for months at a time, often three months and above. Some had to take leave for more than a year, take early retirement, close their businesses or leave the workforce entirely. Several respondents answered that they have sought accommodation for reduced working hours or have been on and off work periodically.

Some anonymized answers, edited for clarity, include:

- “I was off 6 months. I’m still at only 24 hours per week. I’m trying slowly, with monthly increases, to be there more”
- “I am a business owner. I have had to make my own accommodations and rely on my assistant for just about everything.”
- “I really have been on and off work since being sick in March 2020. I was first off work for three months, then back. I have weeks where I have to be off. I then I got COVID again in November 2021. It’s not just brain health, it’s the total exhaustion. [...] I am a charge nurse so the brain thing gets in the way lots of times. And exhaustion, but I really have been working a lot. As far as seeking treatment, I feel like there is not much they can do at this point. I’m just trying to stay active eat healthy take my vitamins, and rest!”
- “I had to switch to online learning and sometimes only lasted 30 minutes. Now I am doing half days and only afternoons. I never went back to in-person learning after Christmas. [...] My doctor is trying to refer me to a specialist and is supportive, but there are not a lot of resources.”
- “As a self-employed freelancer, I’ve had to majorly scale back what projects I feel I can do. Often, it is only the low-paying ones that I end up keeping. The high-paying ones require too much energy or inflexible time commitment.”
- « Je suis travailleur autonome. J’ai dû m’absenter trois mois et puis cinq mois sur deux ans. Le reste du temps, j’ai diminué mes activités de moitié et plus. »

### ***Acknowledgements***

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