



JOHNS HOPKINS COVID LONG STUDY

Fall 2026 Newsletter

The Johns Hopkins COVID Long Study began in February of 2021 with the goal of learning more about the short- and long-term health impacts of COVID-19 illness. Thanks to our dedicated participants, we have heard from more than 31,000 individuals from across the United States and more than 4,500 individuals from around the globe.

Every COVID-19 story matters. We are grateful to everyone who has shared their story with us.

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PRINCIPAL INVESTIGATOR CORNER



We want to thank our study participants for their steadfast commitment to the Johns Hopkins COVID Long Study. As the fall season begins here in the United States, we wanted to check in and share some updates with you. Data collection and analysis are still in full swing, and every piece of information you've shared with us continues to shape our understanding of long COVID. We currently have one research paper under peer

review at a scientific journal, and our team is hard at work examining post-exertional malaise, along with how COVID-19 symptoms shift and evolve over time. We're looking forward to sharing more details as these projects develop, and we will continue to post updates to our [website](#). Your participation truly helps drive long COVID research forward and supports our shared goal of improving the lives of those living with this condition. No matter your experience with COVID-19 – whether you're living with long COVID, recovered fully, or never had it at all – your contribution to this study matters.

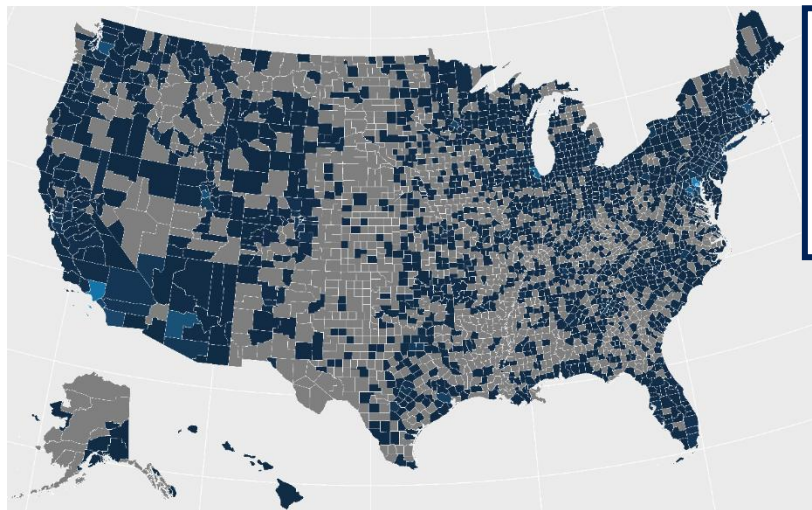
WE APOLOGIZE - SLOW SURVEY TIMES!

If you have taken the survey any time over the past several months, you may have noticed slower loading times. We have been working hard to figure this out and will be making adjustments over the next few months. We apologize for the inconvenience.

RECRUITMENT UPDATES

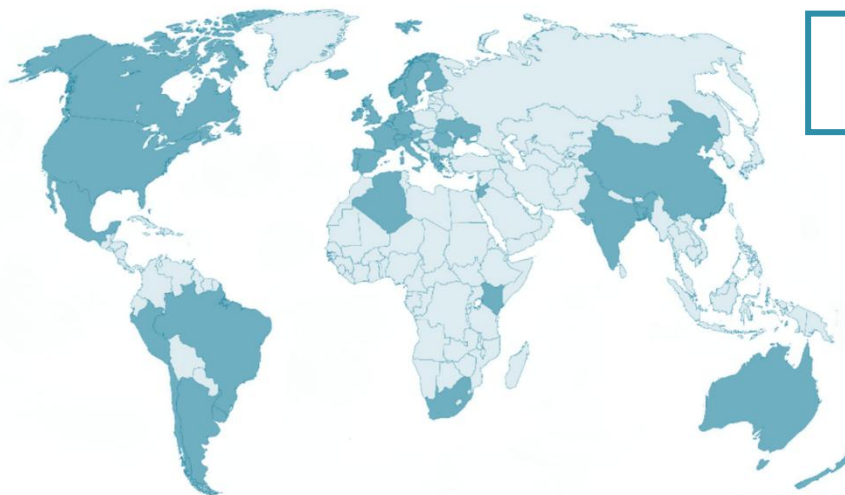
As of August 20, 2026, we have recruited 31,978 individuals across 53 states and territories in the United States and 4,596 individuals across 100 different countries globally. Additionally, we have 12,175 individuals who completed their first follow-up survey! We have recruited participants of all ages, and while the majority of our participants are white (81%), we also have participants who are Black, East Asian, South Asian, Native American/American Indian, Alaskan Native, and Native Hawaiian/Pacific Islander. Of all who have participated, 7% reported being of Hispanic, Latino, or Spanish origin. Our participants are 74% female. Of our global participants, 28% are from Canada, 20% are from Australia, 15% are from United Kingdom, and 8% are from the Germany. At the time of their initial COVID-19 illness, 99% reported having symptoms, and 83% reported new/continuing symptoms after their initial illness had cleared. If you haven't read our cohort profile paper in *BMJ Open* yet, you can read it [here](#)!

WHO WE ARE



Northeast: 19%
South: 39%
Midwest: 20%
West: 22%
Territories: <1%

**Darker colors represent more surveys responses*



Global
representation



COVID Status**
Recovered COVID: 7%
Long COVID: 42%
Indeterminate Status: 16%
non-COVID: 35%

***This breakdown is as of December 11, 2025, and represents a participant's COVID status at the time of their first survey completion (baseline). We used the [WHO](#) definition of long COVID to classify a participant as having long COVID or recovered COVID. A participant with an indeterminate status is someone we could not classify as there was not enough time between their initial SARS-CoV-2 infection and the date they completed their baseline survey to make a determination. A participant with a non-COVID status is someone who reported they never experienced a SARS-CoV-2 infection at baseline.*

WHAT WE HAVE LEARNED

Brain Fog and SARS-CoV-2: Group Comparisons Using the Brain Fog Scale*

N = 4,055
Participants

Johns Hopkins COVID Long Study

What is the Brain Fog Scale (BFS)?

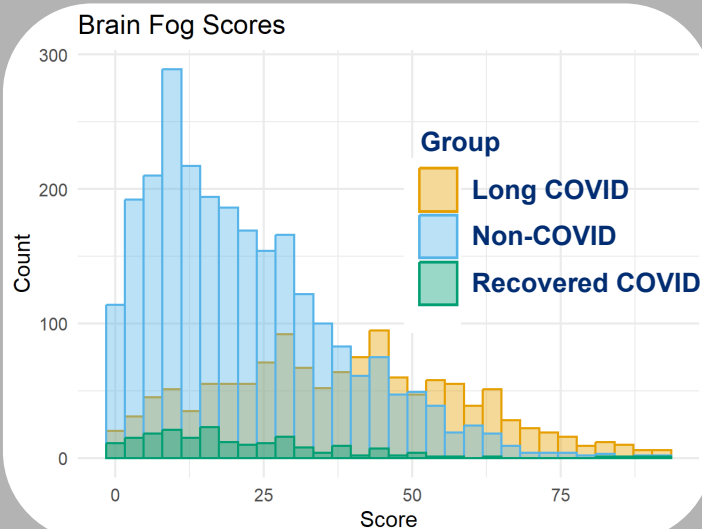
The BFS is the first validated measure of brain fog. It includes 23 questions with scores ranging from 0-92 that measure:

Mental
Fatigue

Confusion

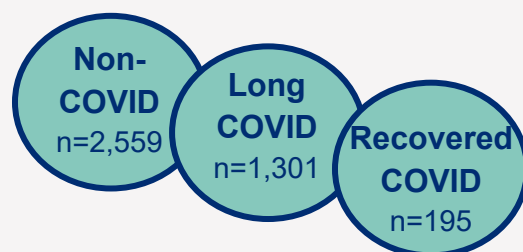
Impaired
Cognitive
Acuity

Higher scores = increased level of brain fog



Who Did We Include?

We asked participants in active follow-up to take the BFS at one time-point. The scores on each question were summed together and compared across 3 groups.**



What Did We Find?

- The majority of recovered COVID (78%) and non-COVID (74%) participants reported low levels of brain fog (0-30), compared to only 39% of participants with long COVID.
- Higher levels of brain fog (60+) were more common among participants with long COVID (15%), compared to recovered COVID (3%) and non-COVID (2%) participants.

💡 What Does This Mean?

Participants with long COVID reported considerably higher brain fog scores overall – with 61% scoring above 30.

*Debowska A, Boduszek D, Ochman M, Hrapkowicz T, Gaweda M, Pondel A, Horeczy B. Brain Fog Scale (BFS): Scale development and validation. *Pers Individ Dif.* 2024;216:112427. doi:10.1016/j.paid.2023.112427

**The three groups were defined at the time of their baseline survey, not at the time they took the Brain Fog Scale instrument. A participant was defined as long COVID if they reported new or continuing symptoms at least 12 weeks after their initial SARS-CoV-2 infection. If no symptoms were reported at this time point, they were defined as recovered COVID. If they reported never experiencing a SARS-CoV-2 infection, they were defined as non-COVID.

STUDENT SPOTLIGHT



The Johns Hopkins COVID Long Study values the contributions of PhD and master's students who join our team to assist with data cleaning, data analysis, and to pursue their thesis work using our study data. Our student investigators play a vital role in advancing our research and bringing fresh perspectives to our project. One such student investigator is Madeline Sagona.

Madeline earned her Master of Science in Genetic Epidemiology from the Johns Hopkins Bloomberg School of Public Health in 2026 and her Bachelor of Arts in Biology from Indiana University in 2021, where she graduated summa cum laude and Phi Beta Kappa.

She is currently pursuing her PhD in Sociology at Columbia University. Madeline has worked as a scientist where she dissected fruit fly brains, as a journalist where she covered cardiology news for cardiology industry professionals, and as a science writer where she wrote about topics ranging from dementia to health disparities to federal artificial intelligence policy.

Madeline was particularly interested in joining our team because she experienced a persistent post-viral illness following an Epstein-Barr Virus infection in her freshman year of college. She was eventually diagnosed with ME/CFS. Thankfully, about three years after she first became ill, her condition improved dramatically and she has remained healthy since. She hopes that better understanding of long COVID will also shed light on post-viral conditions more broadly.

As a member of our team, she has been working to shed light on how SARS-CoV-2 vaccination affects mental fatigue among people with long COVID. Specifically, she is investigating whether receiving a vaccination before a SARS-CoV-2 infection is associated with a reduction in mental fatigue among people who later develop long COVID. She hopes her findings will help people better understand the potential benefits of vaccination.

Outside of work, Madeline enjoys reading for fun, doing jiu jitsu, losing in chess, and re-watching her favorite comfort show, *Buffy the Vampire Slayer*.

RESOURCES

- American Academy of Physical Medicine and Rehabilitation: Long COVID (PASC) Resources
[Link](#)
- Centers for Disease Control and Prevention: COVID-19
[Link](#)
- Centers for Disease Control and Prevention: More Resources about COVID-19
[Link](#)
- Centers for Disease Control and Prevention: Long COVID or Post-COVID Conditions
[Link](#)
- FACT SHEET: Americans with Disabilities Act Resources to Support Individuals with Long COVID
[Link](#)
- Johns Hopkins Bloomberg School of Public Health: Coronavirus Questions and Answers
[Link](#)
- Long COVID Alliance
[Link](#)
- Survivor Corps
[Link](#)
- U.S. Department of Health & Human Services: Guidance on “Long COVID” as a Disability Under the ADA, Section 504, and Section 1557
[Link](#)
- World Health Organization: COVID-19 pandemic
[Link](#)

**Note: The Johns Hopkins COVID Long Study is a survey-based study. Resources are being offered for informational purposes only. This list is not comprehensive and does not constitute an endorsement by the Johns Hopkins University.*