



JOHNS HOPKINS COVID LONG STUDY

Fall 2024 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 29,000 individuals from across the United States and more than 4,000 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



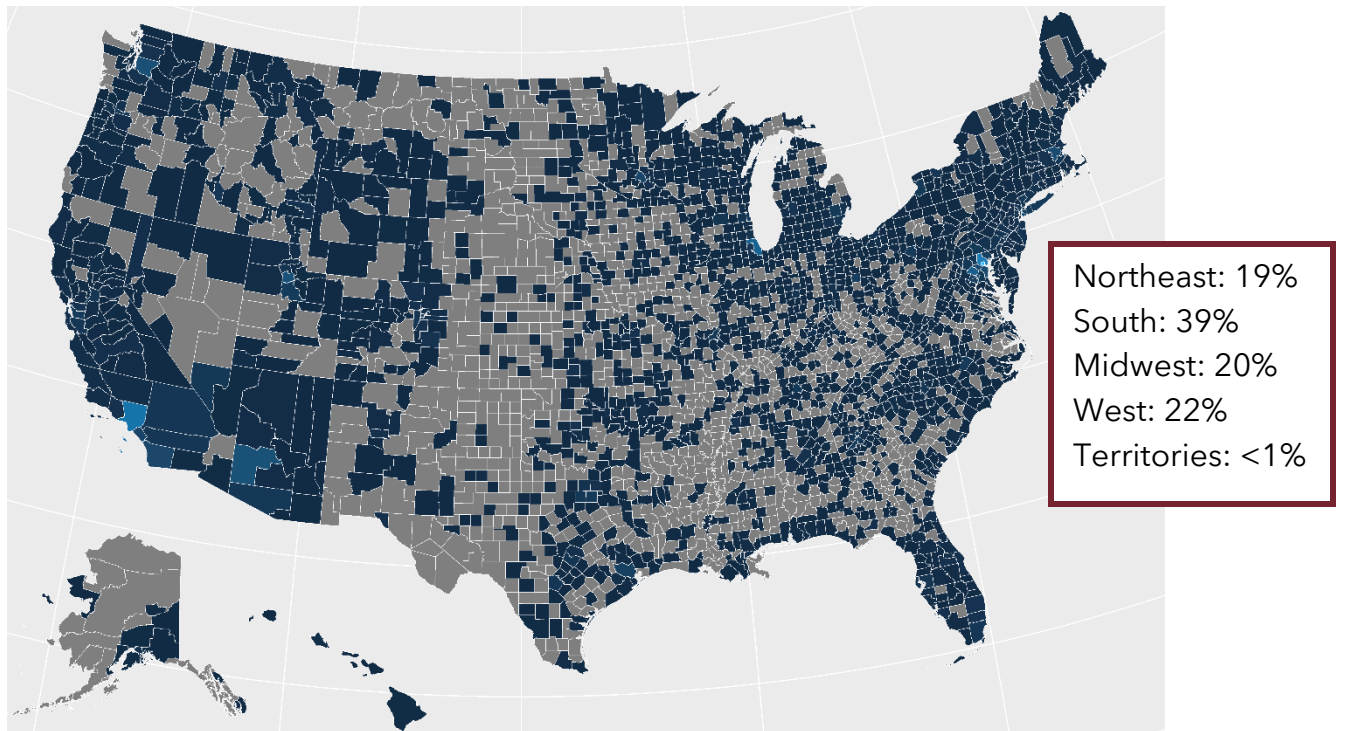
As the leaves begin to change colors and the season of thanksgiving and gratitude is upon us, we are reminded of the dedication and support that each of you have shown us as we have sought to understand the short and long term implications of COVID-19. Many of you have been in our study for four years and have poured countless hours into filling out our surveys and sharing your experiences with us.

While there is still much to learn about COVID-19 and long COVID, thanks to you, our understanding is growing. We are currently in the process of conducting a sub-study where we are helping a random sample of our participants self-collect blood and saliva from their home or work. We are hoping to identify biomarkers that can help us understand why some people get long COVID and others do not. We are also working on several analyses that we hope to share with you soon. We hope everyone has a wonderful holiday season!

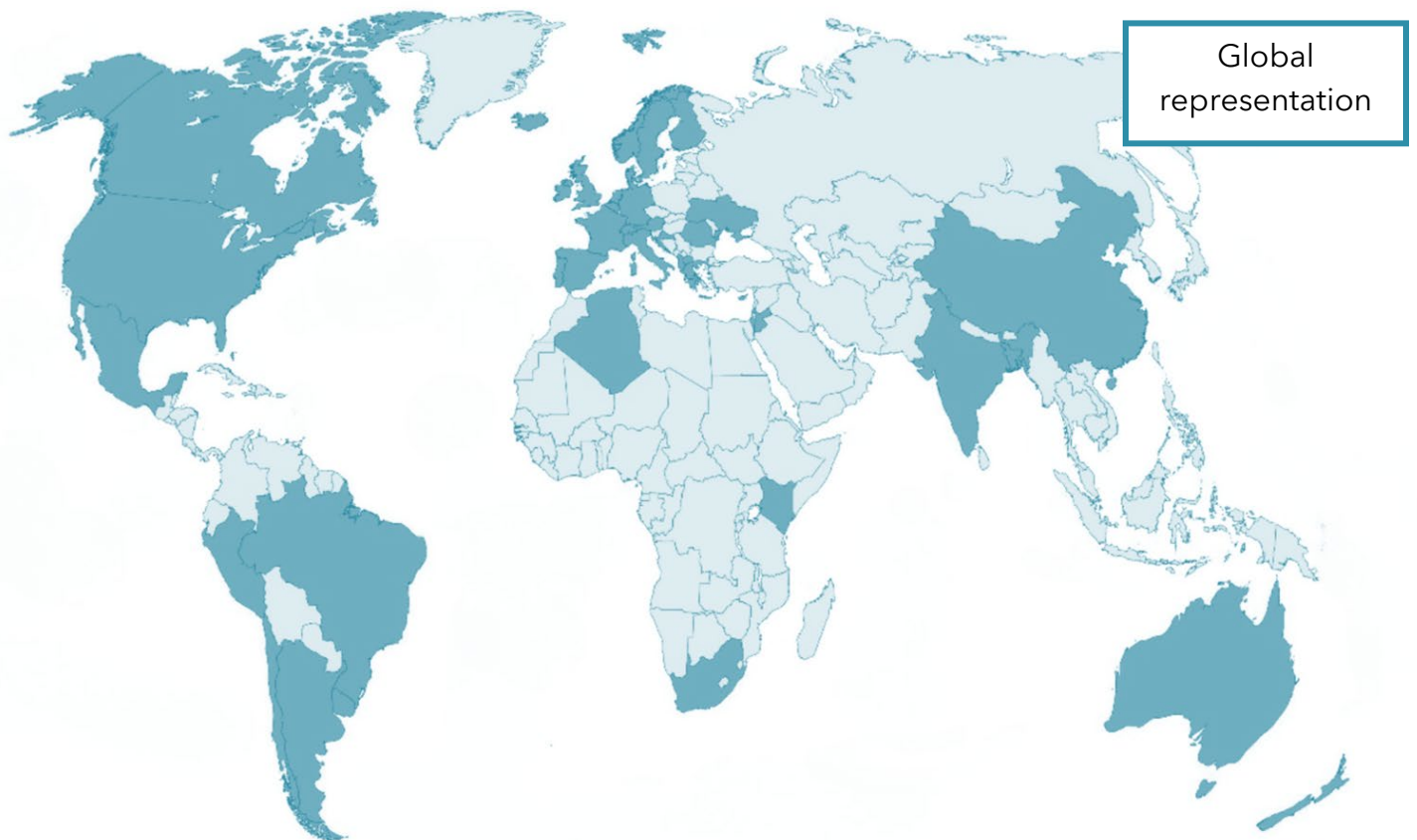
RECRUITMENT UPDATES

As of September 12, 2024, we have recruited 29,899 individuals across 53 states and territories in the United States and 4,450 individuals across 100 different countries globally. Additionally, we have 10,731 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 75% female. Of our global participants, 32% are from Canada, 14% are from Germany, 13% are from the United Kingdom, and 12% are from Australia. At the time of their initial COVID-19 illness, 99% reported having symptoms, and 85% 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



**Darker colors represent more survey responses*



WHAT WE HAVE LEARNED

At your baseline visit (first ever visit), we asked you several sets of questions related to sleep. These included questions about the amount of sleep you get, the quality of sleep you report, and a set of questions that help us understand your level of hypersomnia, or excessive daytime sleepiness.



When it comes to the amount of sleep you reported getting each night, we looked at it three different ways: 1) overall, regardless of long COVID status, 2) those classified as having long COVID at baseline, 3) those classified as being fully recovered at baseline, and 4) those with an indeterminate long COVID status at baseline*. Here is what we found:

	Overall	Long COVID	Fully Recovered	Indeterminate*
0-5 hours	9%	11%	5%	5%
6-8 hours	73%	68%	86%	82%
9+ hours	17%	21%	9%	13%



Using several questions from the Idiopathic Hypersomnia Severity Scale, we calculated a score of 0 – 14 for each participant. A higher score represents *more severe* hypersomnia (excessive daytime sleepiness) symptoms. Looking at the median score overall and in those with long COVID, fully recovered, and indeterminate status at baseline, here is what we found:

- **Overall:** score of 6
- **Long COVID:** score of 7
- **Fully recovered:** score of 4
- **Indeterminate:** score of 5

**We used the [WHO](#) definition to classify individuals as long COVID, fully recovered, or indeterminate. A person was classified as indeterminate if there was less than 3 months between their initial SARS-CoV-2 infection and the date they completed their baseline survey.*

WHAT WE HAVE LEARNED



When it comes to the quality of sleep you reported over the past *four weeks*, here is what we found:

Getting enough sleep to feel rested			
	All of the time	Some of the time	None of the time
Long COVID	2%	22%	23%
Fully Recovered	7%	19%	3%
Indeterminate	4%	25%	10%
Trouble falling asleep			
	All of the time	Some of the time	None of the time
Long COVID	13%	20%	17%
Fully Recovered	3%	19%	31%
Indeterminate	6%	21%	21%
Awakening during sleep and having trouble falling back asleep			
	All of the time	Some of the time	None of the time
Long COVID	12%	22%	14%
Fully Recovered	2%	17%	28%
Indeterminate	6%	21%	20%
Trouble staying awake during the day			
	All of the time	Some of the time	None of the time
Long COVID	7%	21%	23%
Fully Recovered	1%	12%	50%
Indeterminate	3%	16%	36%
Getting the amount of sleep you needed			
	All of the time	Some of the time	None of the time
Long COVID	3%	22%	23%
Fully Recovered	7%	20%	6%
Indeterminate	5%	23%	11%

RESOURCES

Our team has put together a list of a few resources to help you navigate the pandemic, COVID-19 disease, and long COVID.

- 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.*