



JOHNS HOPKINS COVID LONG STUDY

Spring 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 23,000 individuals from across the United States and more than 550 individuals from around the globe.

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

**Principal Investigator
Corner & Recruitment
Updates**

Page 2

Who We Are

Page 3

**What We Have
Learned**

Page 4-5

Resources

Page 6

PRINCIPAL INVESTIGATOR CORNER

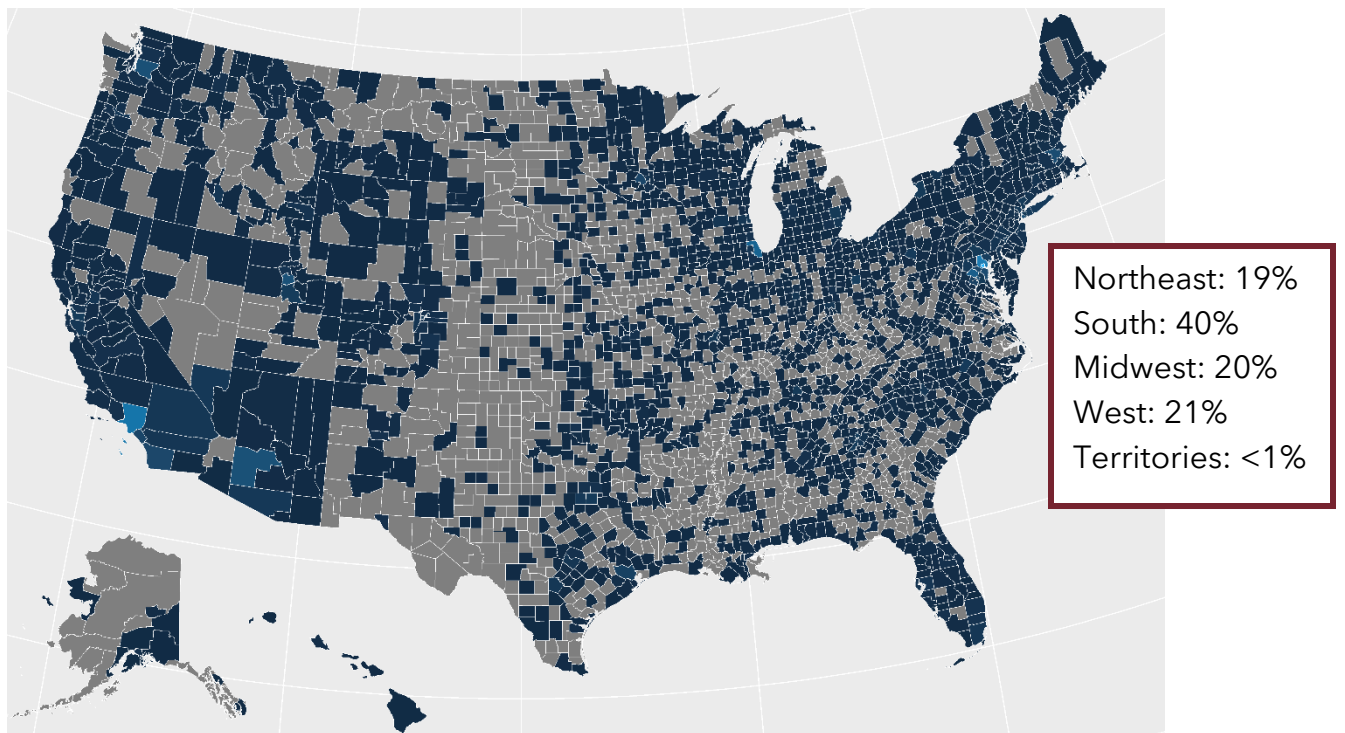


As the flowers begin to bloom and we enter spring, we are reminded how grateful we are for each of you and your continued support of our study. Some of you have been in our study for more than 3 years and others have joined just this week. Regardless of how long you have been in our study, each of you has provided invaluable data that is helping us to understand the impact of COVID-19 illness. We have many analyses in process, from looking at brain fog and how it changes over time to investigating possible connections between long COVID and hypermobility. In April we rolled out a brand new sub-study that involves collecting blood and saliva from a small group of individuals with long COVID, resolved COVID, and those who have never had COVID. This sub-study will help us to understand why some people recover and others continue to experience new and continuing symptoms over time. If our sub-study is successful, we hope to collect blood and saliva from a larger group of participants in the future. Some of you may be contacted over the next few months to learn more about participating! We appreciate your continued participation in this study and to science.

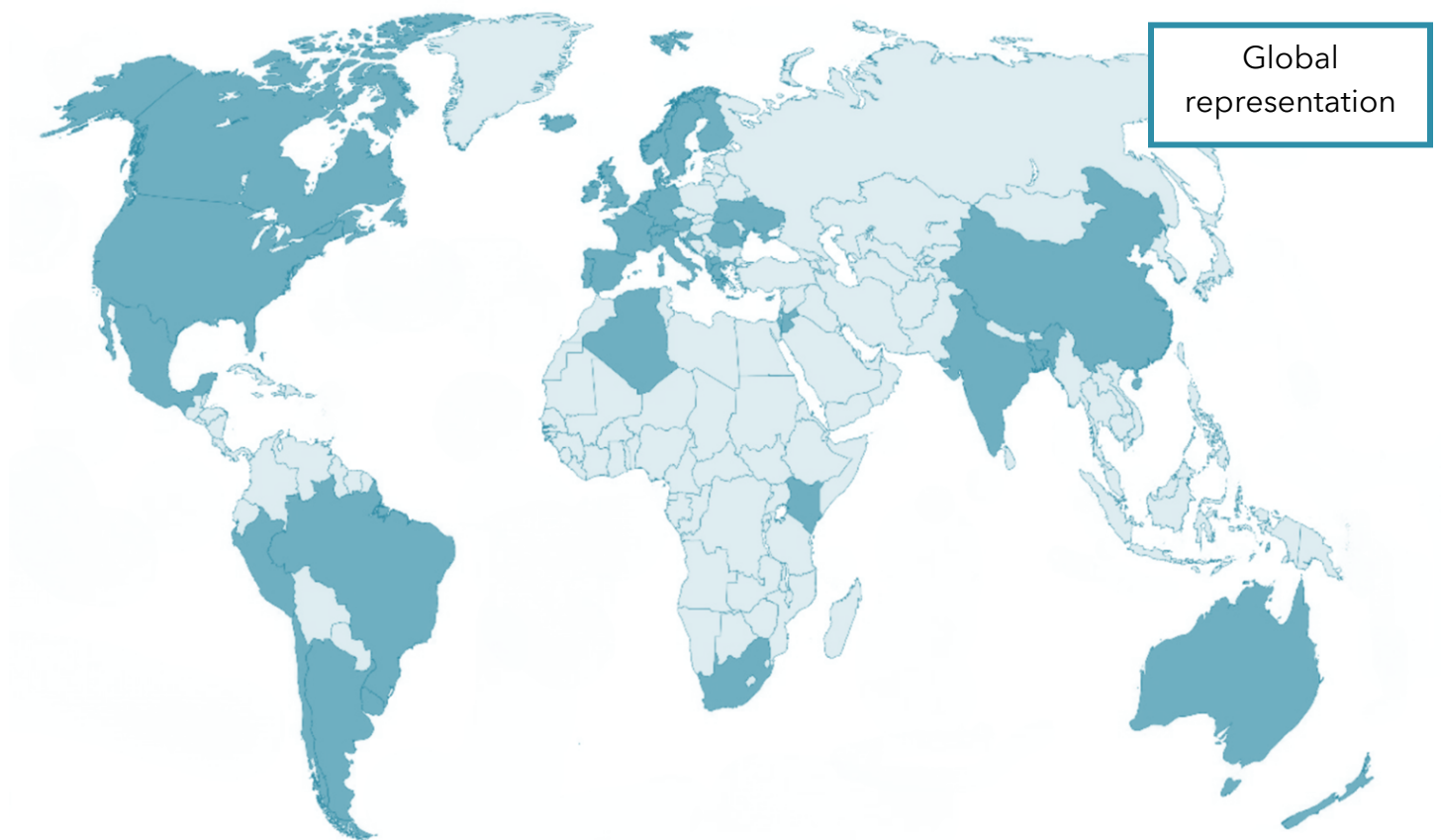
RECRUITMENT UPDATES

As of April 10, 2024, we have recruited 23,010 individuals across 53 states and territories in the United States. We have also recruited 586 individuals across 51 different countries globally. Additionally, we have had 6,750 individuals complete their first follow-up survey and 800 individuals complete their seventh follow-up survey! We have recruited participants of all ages, and while the majority of our participants are white (88%), we have also had participants who are Black, East Asian, South Asian, Native American/American Indian, Alaskan Native, and Native Hawaiian/Pacific Islander. Of all who have participated, 8% reported being of Hispanic, Latino, or Spanish origin. Our participants are 83% female. Of our global participants, 37% are from Australia, 18% are from Canada, 12% are from the United Kingdom, and 10% are from New Zealand. At the time of their initial COVID-19 illness, 99% reported having symptoms, and 86% reported new/continuing symptoms after their initial illness had cleared. If you haven't yet read our publication in *The American Journal of Medicine* on long COVID disability, you can read it [here](#)!

WHO WE ARE



**Darker colors represent more survey responses*



WHAT WE HAVE LEARNED

You spoke and we listened! Several participants have reached out and asked us to collect data on health care utilization, particularly in terms of the challenges people with long COVID face when attempting to get help for their new/continuing symptoms. Here is a preliminary look at what we found in our participants with long COVID at baseline (among 454 participants):

Do you have a primary care provider that you see regularly?

87% responded yes

Before your COVID-19 illness, how often did you see your primary care physician?

(Of those who responded 'yes')

47% responded once per year
29% responded twice per year
11% responded three times per year
6% responded four times per year
3% responded five times per year
4% responded greater than five times per year

Since your COVID-19 illness, have you tried to get care/help for your symptoms?

84% responded yes

Were you able to get care/help for your symptoms?

(Of those who responded 'yes' to trying to get care/help)

57% responded yes

43% of individuals who tried to get care/help for their symptoms were unable to get care/help.

Where did you go for care help? Select all the places you went for care/help.

(Of those who were able to get care/help)

87% responded primary care provider
20% responded urgent care/urgent treatment center
28% responded emergency room/emergency department
29% responded long COVID specialty clinic
60% responded specialist
24% responded alternative treatment provider

WHAT WE HAVE LEARNED

Of all the reasons you chose not to get care/help for your symptoms, please rate how much each of the following statements affected your decision. A rating of 1 means it did not affect your decision and a rating of 10 means it strongly affected your decision.

(Of those who responded 'no' to trying to get care/help)

I didn't know where to go for care/help.

54% said it did not affect their decision not to get care/help (rating of 1)

13% said it strongly affected their decision not to get care/help (rating of 10)

I didn't think anyone would be able to help me.

33% said it did not affect their decision not to get care/help (rating of 1)

20% said it strongly affected their decision not to get care/help (rating of 10)

I am too sick to go to the doctor.

73% said it did not affect their decision not to get care/help (rating of 1)

4% said it strongly affected their decision not to get care/help (rating of 10)

I don't have insurance / I am worried my health insurance won't cover the costs.

71% said it did not affect their decision not to get care/help (rating of 1)

4% said it strongly affected their decision not to get care/help (rating of 10)

I am worried the doctor won't believe my symptoms are real.

50% said it did not affect their decision not to get care/help (rating of 1)

7% said it strongly affected their decision not to get care/help (rating of 10)

I don't think my symptoms are serious enough to go to the doctor.

14% said it did not affect their decision not to get care/help (rating of 1)

26% said it strongly affected their decision not to get care/help (rating of 10)

I was unable to get an appointment / The waitlist was too long.

61% said it did not affect their decision not to get care/help (rating of 1)

1% said it strongly affected their decision not to get care/help (rating of 10)

The nearest location to get care/help is too far away.

76% said it did not affect their decision not to get care/help (rating of 1)

7% said it strongly affected their decision not to get care/help (rating of 10)

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.*