JOHNS HOPKINS COVID LONG STUDY

SPRING 2023 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 22,000 individuals from across the United States and close to 370 individuals from around the globe.

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

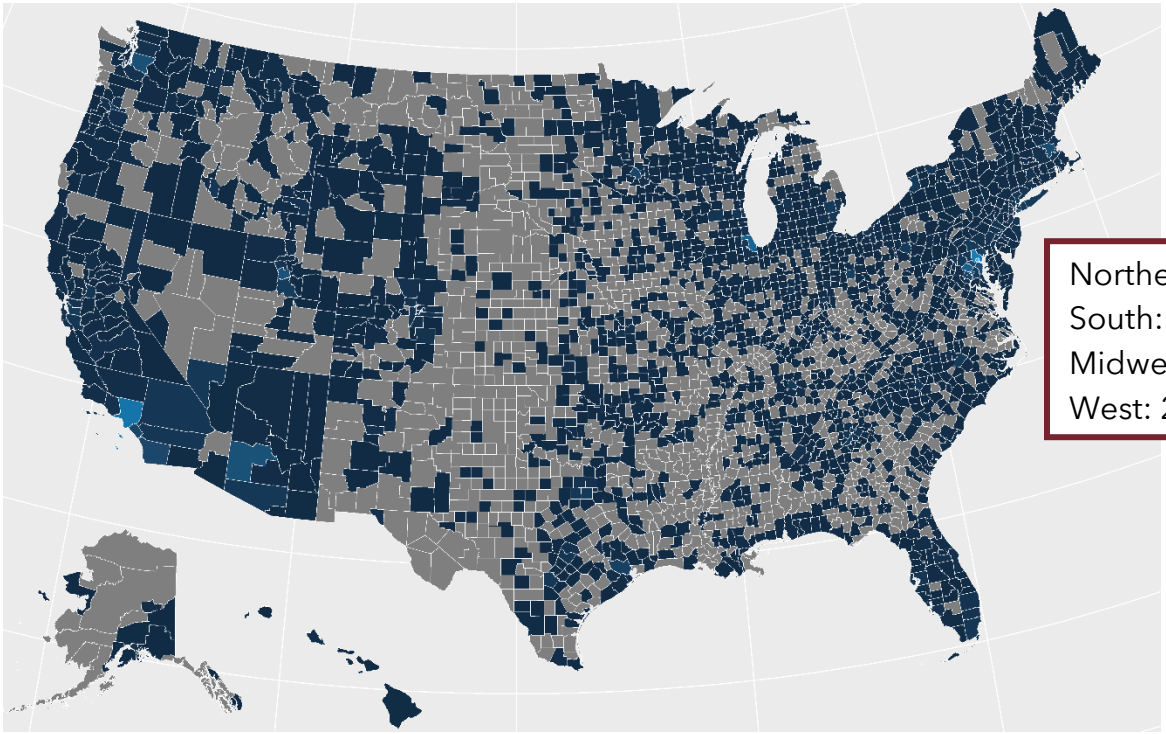
PRINCIPAL INVESTIGATOR CORNER

As spring comes to an end and we move into summer, we are examining the invaluable data you all have provided and are also applying for grants so we can do even more. We are grateful for each of you and welcome our new participants, as together, we can understand the impact of COVID. Accumulating data (especially data over time) is time consuming to analyze, but it allows us to answer more specific and meaningful scientific questions. We appreciate your patience as we work through this process! Currently we are focusing on understanding how those of you with long COVID have symptoms that come and go over time. We are also looking into brain fog to better understand what it means and how those with long COVID, COVID that has fully resolved, and those who never had COVID may experience it differently. We will continue to learn from the data that you have provided and will do the data justice by telling your story.

RECRUITMENT UPDATES

On August 22, 2022, we opened up our global survey to English speakers from all countries around the world and are currently working to translate our survey into Portuguese (Brazil) and Vietnamese. Other translations are forthcoming. As of April 12, 2023, we have recruited 22,340 individuals across 53 states and territories in the United States. We have also recruited 368 individuals across 38 different countries globally. We have had 6,383 individuals complete their first follow-up survey, 4,345 individuals complete their second follow-up survey, and 2,910 individuals complete their third 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, 39% are from Australia, 22% are from Canada, 13% are from the United Kingdom, and 8% 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. The Atlantic interviewed our investigators on long COVID. Check out the interviews here and here!

WHO WE ARE



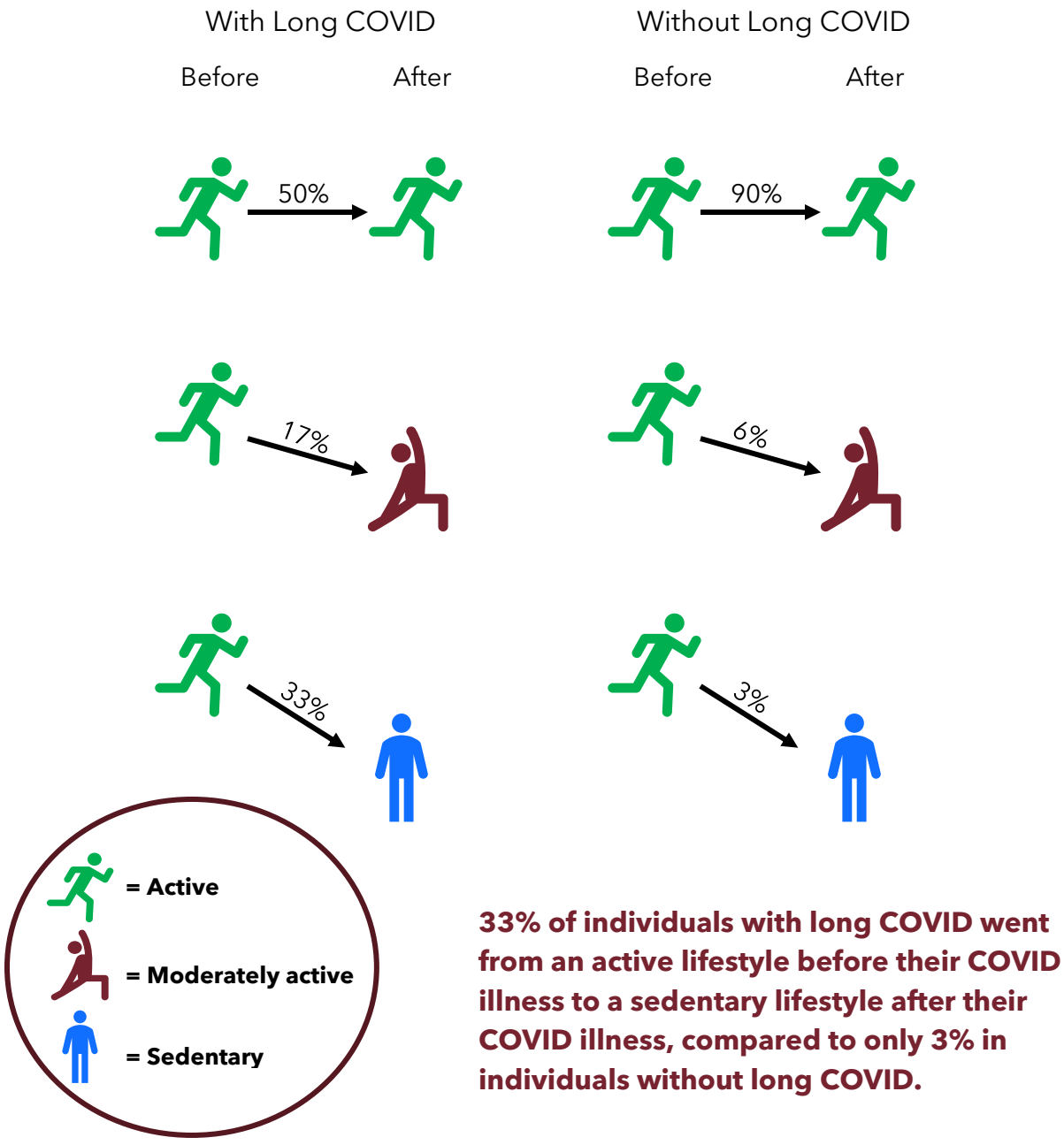
Northeast: 19%
South: 39%
Midwest: 21%
West: 21%

**Darker colors represent more survey responses*

Oceania: 47%
Europe: 25%
Canada: 22%
Asia: 3%
South America: 2%
Africa: 1%
Mexico: 1%

WHAT WE HAVE LEARNED

Activity level before and after COVID-19 illness in individuals with and without long COVID

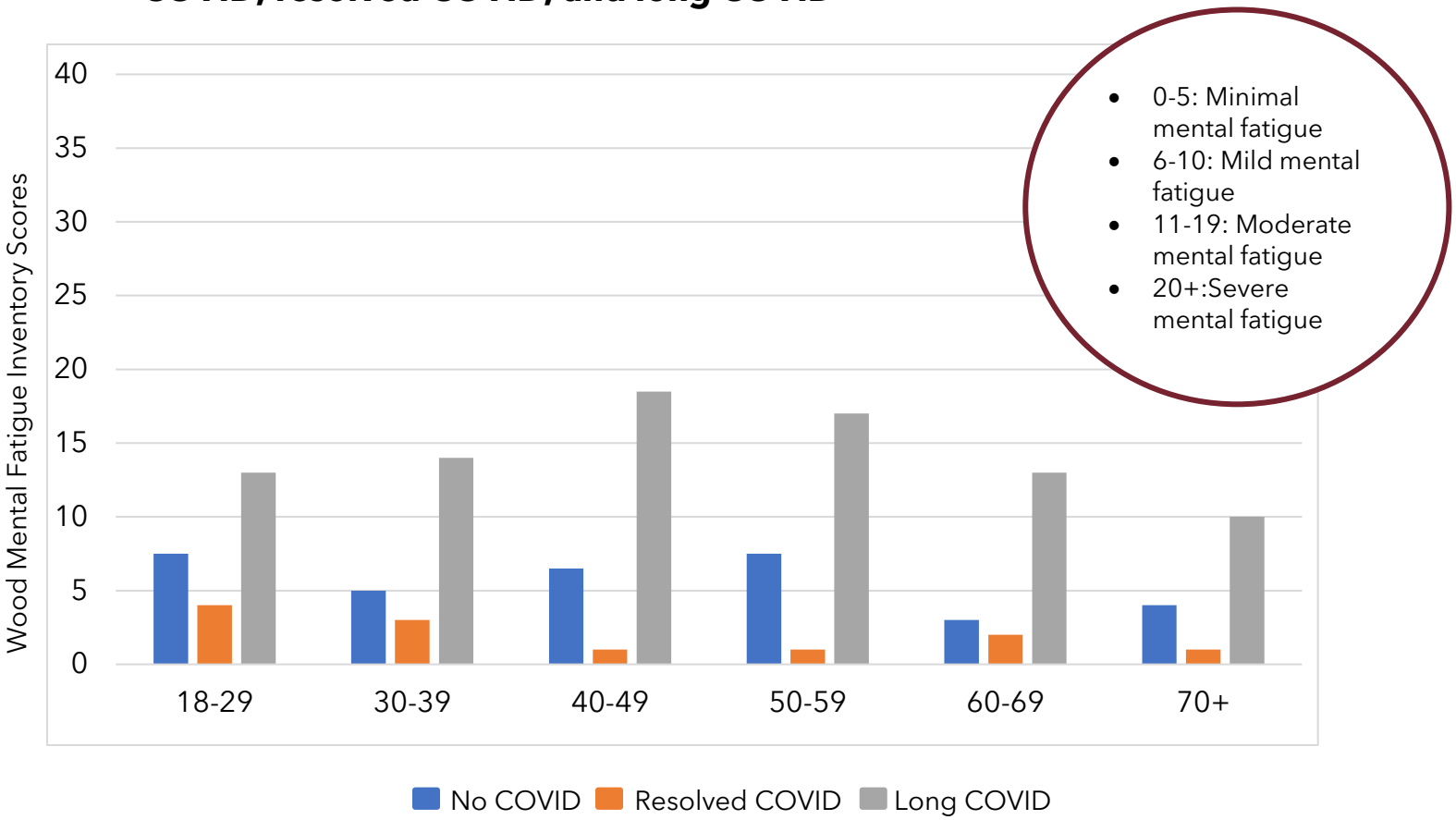


33% of individuals with long COVID went from an active lifestyle before their COVID illness to a sedentary lifestyle after their COVID illness, compared to only 3% in individuals without long COVID.

- Activity level was assessed using the total leisure activity score determined by the Godin-Shepard Leisure-Time Physical Activity Questionnaire.
- Figure represents 4,278 individuals with long COVID and 586 individuals without long COVID.

WHAT WE HAVE LEARNED

Mental fatigue scores by age category in individuals without COVID, resolved COVID, and long COVID



How to interpret the graph:

The above graph shows the score at which half of the mental fatigue scores are above it and half of the mental fatigue scores are below it. We looked at six different age categories and compared scores across three groups of individuals: no COVID, resolved COVID, and long COVID. Here you can see that across all age categories, those with long COVID have greater levels of mental fatigue when compared to the other two groups.

Definitions:

No COVID: Individuals without a history of COVID-19 illness.
Resolved COVID: Individuals with a history of COVID-19 illness who did not report experiencing any new/continuing symptoms 12 weeks after their initial illness.
Long COVID: Individuals with a history of COVID-19 illness who reported at least one new/continuing symptom 12 weeks after their initial illness.
Mental fatigue score: Scores are based on the Wood Mental Fatigue Inventory.

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.*