



JOHNS HOPKINS COVID LONG STUDY

Fall 2022 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 18,000 individuals from across the United States and close to 300 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

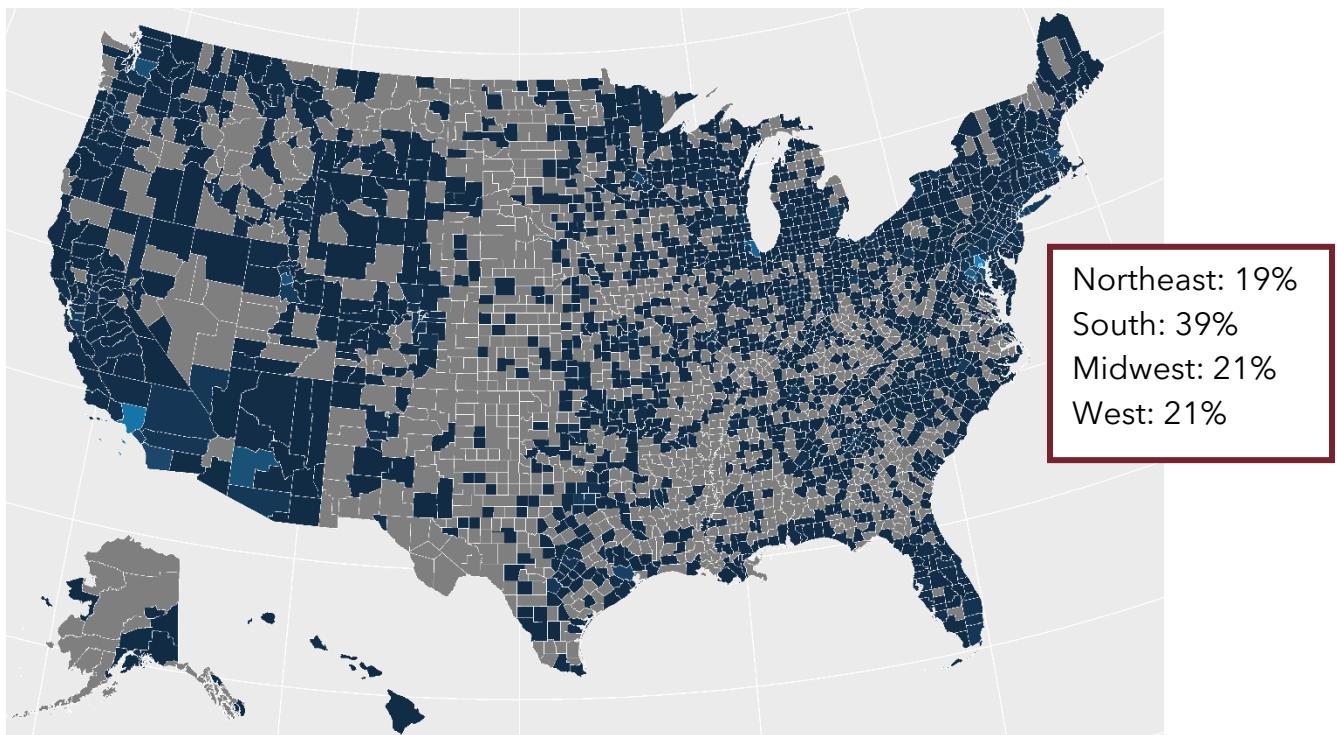


Happy New Year! As 2023 begins, we are hopeful that we will learn more and be able to share our findings about COVID and long COVID. We are grateful for all of the new participants who have joined our study to better understand the impact of COVID on our lives. We are especially thankful for those of you who are working with us long term so that we can understand how COVID symptoms, diagnoses, and other factors change over time. We know that these questions can take time and are sometimes tedious, but collectively they are so powerful and have provided tremendous insight. You may be one voice, or one answer, but together you are helping to shed more light on the impact of this virus in the short and long term. Most recently, we have focused on long COVID disability. We have shared some preliminary data from that analysis on pages 4-5 of the newsletter. You can also view a pre-print version of our long COVID disability manuscript by clicking [here](#).

RECRUITMENT UPDATES

On August 22, 2022, we opened up our global survey to English speakers from all countries around the world. Other translations are forthcoming. As of December 14, 2022, we have recruited 18,117 individuals across 53 states and territories in the United States. We have also recruited 288 individuals across 33 different countries globally. We have had 6,070 individuals complete their first follow-up survey and 3,661 who have completed their second 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 participations, 43% are from Australia, 22% are from Canada, and 10% are from the United Kingdom. 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.

WHO WE ARE

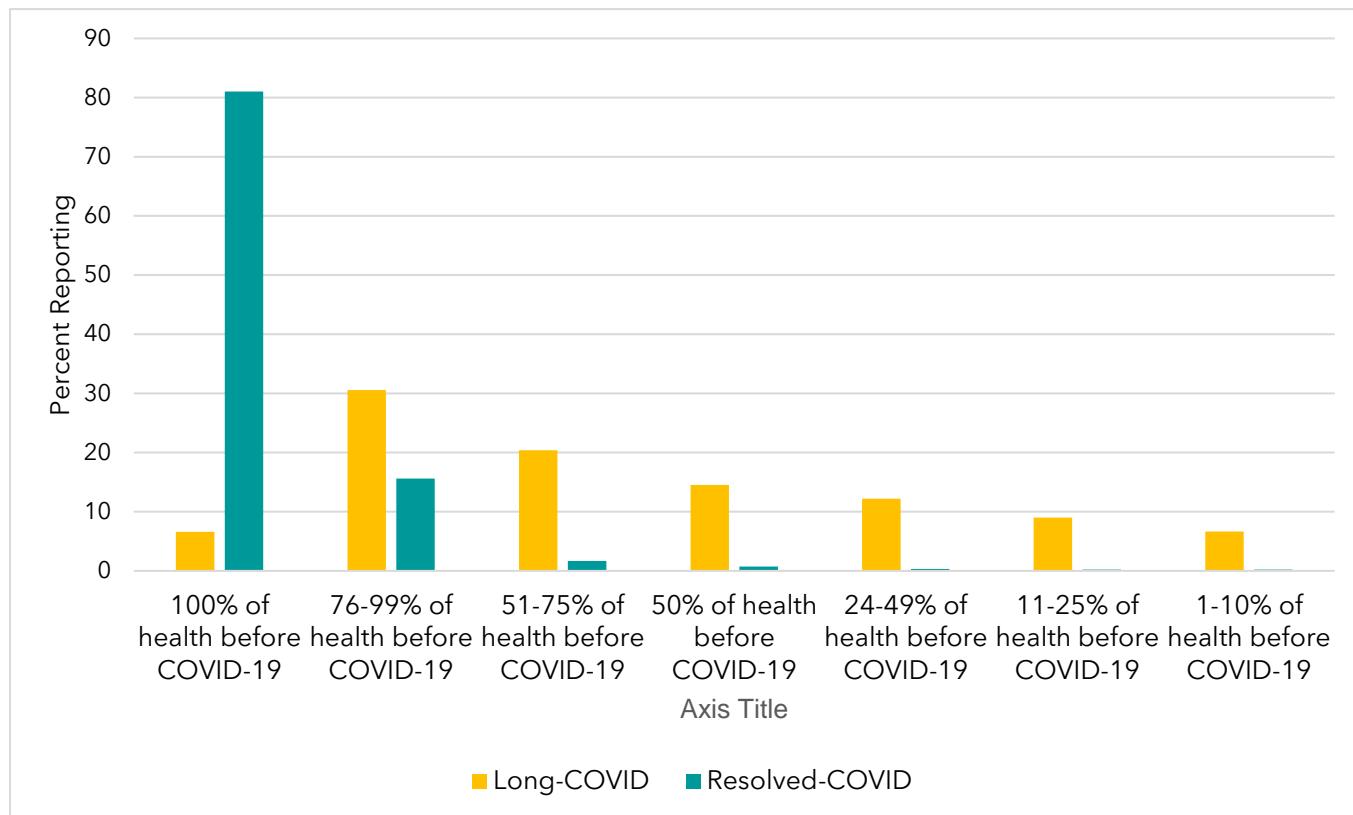


*Darker colors represent more survey responses



WHAT WE HAVE LEARNED

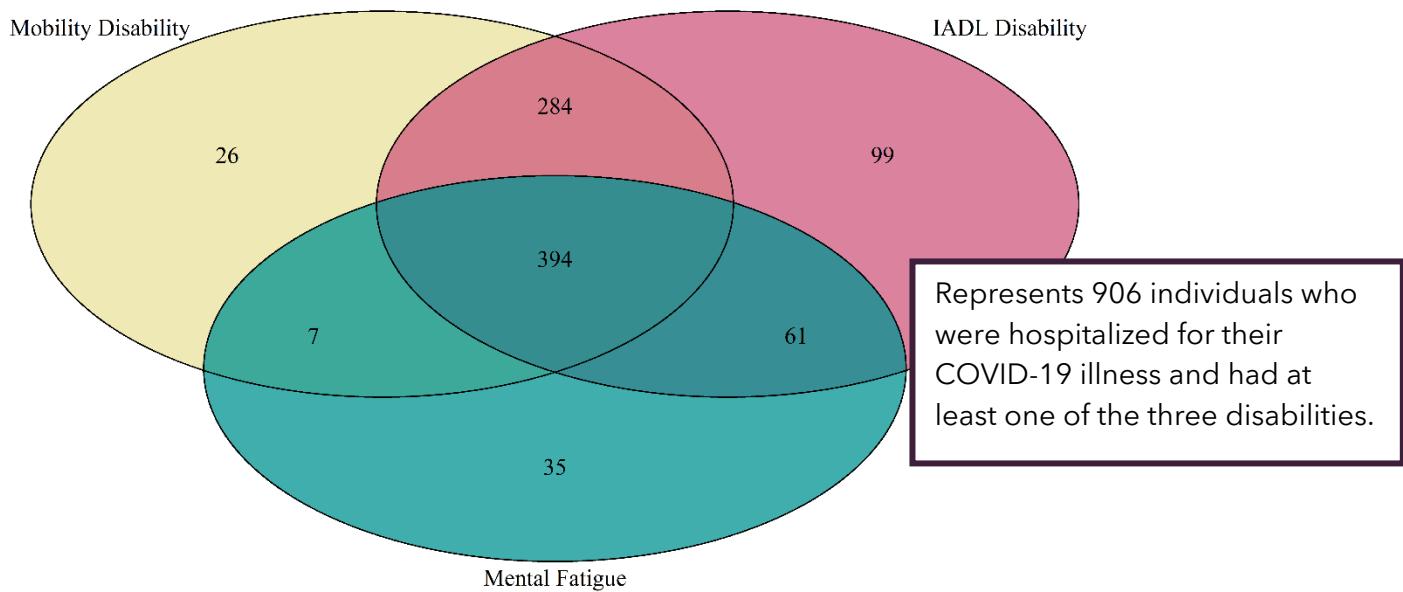
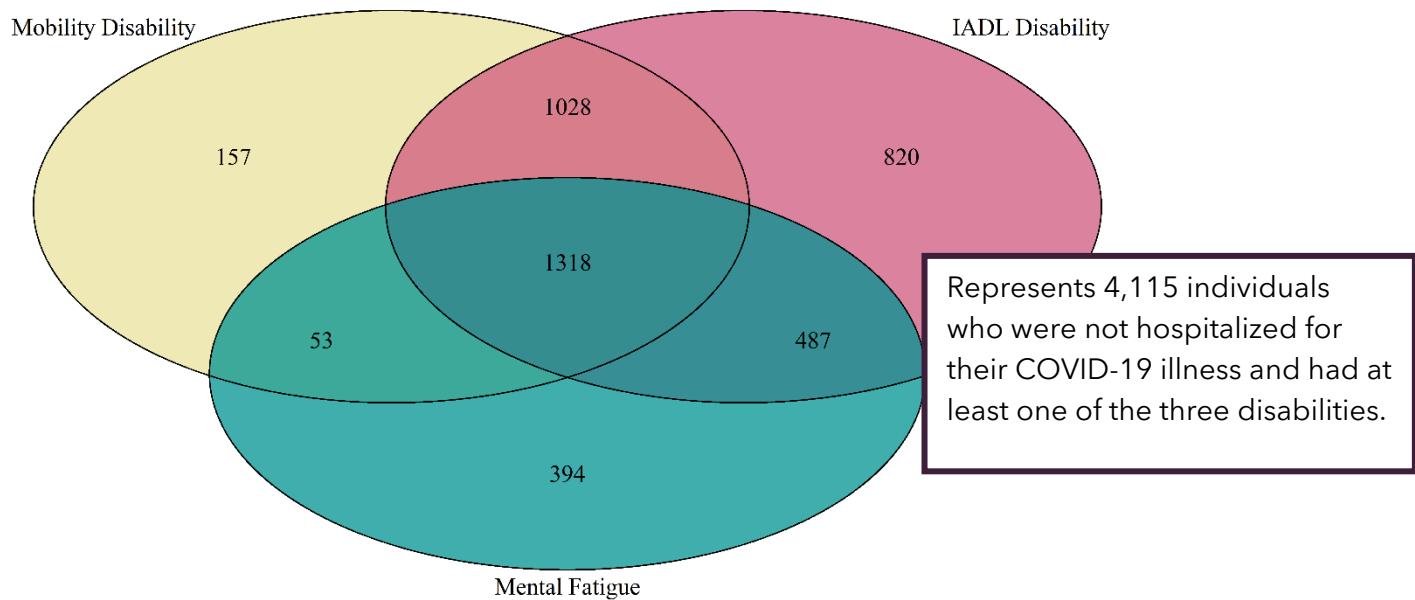
Self-Reported Changes in Health Status Since COVID-19



We classified individuals as having long-COVID or resolved-COVID using the WHO definition:

- Long-COVID: Individuals who had at least 12 weeks between COVID-19 infection and the date they completed our survey who reported new or persistent symptoms (met WHO definition for long COVID).
- Recovered-COVID: Individuals who had at least 12 weeks between COVID-19 infection and the date they completed our survey who did not report new or persistent symptoms (did not meet the WHO definition for long COVID).

WHAT WE HAVE LEARNED



- Mobility disability: Some or greater level of difficulty walking up 10 stairs and/or walking $\frac{1}{4}$ of a mile
- Instrumental activities of daily living (IADL) disability: Some or greater level of difficulty with heavy housework
- Mental fatigue: Scoring 20 or higher 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.*