

## New Research Study Identifies Return-to-Work Barriers for Workers Living With Long COVID and Potential Solutions from Workers' Perspectives

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Members of the Patient-Led Research Collaborative (PLRC) have published a new study entitled [“Return-to-work with long COVID: An Episodic Disability and Total Worker Health® analysis.”](#) The study was released by *Social Science & Medicine*, a leading social science journal. This international study of workers with long COVID investigates the barriers and facilitators to returning to work while living with this chronic illness from the perspective of these workers.

Elisabeth Stelson, a PhD Candidate at the Harvard T.H. Chan School of Public Health who is a PLRC member and the lead author on the study, explains: “What we heard from people living with long COVID is that it is critical for employers to build in flexibility and accommodations for workers who have these fluctuating symptoms. However, that’s not enough. We need to also be looking at factors beyond the workplace that affect workers ability to engage in work. One of the main hurdles workers in this study experienced is that healthcare providers did not recognize that their patients had long COVID. Healthcare providers are often the gatekeepers to accessing workplace accommodations, workers compensation, and sick leave. Without this medical documentation, workers can’t access the supports they need.”

This qualitative study systematically analyzed the return-to-work experiences of 510 workers with long COVID who were randomly sampled from a larger survey conducted by PLRC. Analysis of participant statements identified four primary themes in experiences of individuals trying to return to work with this chronic condition: 1) People living with long COVID both need and want to return to work for financial reasons as well as to find meaning in their lives; 2) how long COVID symptoms fluctuate and are managed depend on how their jobs and homelife are organized; 3) there is strong disbelief in and stigma of long COVID at work and in medical settings; and 4) support of medical providers is key to successful return-to-work. The study provides concrete recommendations to support workers with long COVID return to work, which may be key to addressing the [contribution of long COVID to workforce shortages identified in recent economic analyses](#).

Lisa McCorkell, a co-founder of PLRC and a co-author of the study, reflects on how this research could be put into action: *“Flexible hours and working remotely can help some workers with Long COVID pace themselves and stay in the workforce. This is critical for workers’ own financial well-being, and, according to previous disability research, is also good for business.”*

This study has several notable strengths, including its large sample size which is unusual for qualitative research. The analysis is also informed by Episodic Disability Theory. Stelson described why this perspective is critical to studying not only long COVID, but other disabilities as well: “We typically think of disability as a constant condition when in reality many people with disabilities experience fluctuations in symptoms and severity over time, which interacts with the environments they live in. Considering disability as a static state overlooks the how individuals with disabilities can contribute and lead in their work and social lives. If we recognize the role of the larger environment, we can identify ways to help people living with disabilities live their fullest lives. This reorientation is important given the growing rates of chronic illness and

disability globally, in part due to aging populations as well mass-disabling events like the COVID-19 Pandemic.” This study is also informed by [Total Worker Health®](#), a holistic approach to improving worker health and wellbeing promoted by the National Institute of Occupational Safety and Health (NIOSH).

Members of the research team were all individuals either living with or caring for somebody with long COVID. According to Hannah Wei, also a PLRC co-founder and co-author of the paper: *“The patient-led approach to research in this study likely increased trust and recruitment with participants. If we do research this way, we can hear what matters most for the people most affected. Employment and return-to-work is a key issue for many people living with long COVID, and we need to make sure we support this growing portion of the workforce.”*

For questions, please contact [team@patientledresearch.com](mailto:team@patientledresearch.com).

**About Patient-Led Research Collaborative:** Patient-Led Research Collaborative (PLRC) is a multi-disciplinary group of people with lived experience of Long COVID, formed together in April 2020 through the Body Politic COVID-19 Support Group, and were the [first to conduct research](#) on Long COVID. PLRC’s work thus far has resulted in the [identification](#) of key symptoms, timeline, comorbidities, and possible treatment options for Long COVID, as well as a \$4.8 million fund for biomedical research with awards decided by patients, a publication of patient-generated hypotheses, and research into the impact of reinfections, identifying Long Covid phenotypes, Long Covid impact in LMIC countries, and others. They have presented their work to the World Health Organization, United States House of Representatives, National Institutes of Health, and Centers for Disease Control and Prevention, and have influenced Long COVID clinical guidelines and legislation. For more on PLRC, visit [patientledresearch.com](https://patientledresearch.com).