



**U.S. Department of Labor's
Understanding and Addressing the
Workplace Challenges
Related to Long COVID
National Online Dialogue**

**July 11 – August 15, 2022
Summary Report**



Table of Contents

Introduction.....	2
Background.....	2
Online Dialogue Topics.....	3
Key Themes and Takeaways.....	5
Dialogue Submission Summary.....	10
Top Dialogue Submissions by Vote.....	10
Top Calls to Action Determined by Participant Votes	10
Top Informational Contributions Determined by Participant Votes	13
Most Active Dialogue Submissions	15
Top Trending Dialogue Submissions	16
Most Popular Dialogue Submissions	19
Outreach Efforts.....	26
ePolicyWorks Email and Social Media Outreach	26
Independent Online Dialogue Promotion.....	27
Online Dialogue Participant Summary.....	29
Contributions to the Online Dialogue	29
Visitors, Registrants and Participants in the Online Dialogue	30
Online Dialogue Registration Questions	32
Review and Analysis of Online Dialogue Contributions.....	34
Appendix A: Resources Shared in the Online Dialogue	35
Organizations and Not-for-Profits.....	35
Reports and Resources.....	35
State, National and International Government Resources	36
News Articles, Blogs and Webinars (by date)	36
Appendix B: Potential Partners Identified in the Online Dialogue	38

Introduction

Background

In June 2022, the Centers of Disease Control and Prevention (CDC) stated that 40% of adults in the United States reported COVID-19 in the past, and nearly one in five of those (19%) are currently experiencing ongoing symptoms—commonly known as *long COVID* and its associated conditions. In these cases, symptoms can last weeks, months, or even years and can include shortness of breath, fatigue, brain fog, heart palpitations, headaches, anxiety and depression among nearly 200 reported symptoms. Per guidance from the U.S. Department of Health and Human Services and the U.S. Department of Justice, a person with long COVID is considered to have a disability if the person's condition or any of its symptoms is a "physical" or "mental" impairment that "substantially limits" one or more major life functions. Under these conditions someone with long COVID is protected from discrimination under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Patient Protection and Affordable Care Act.

The U.S. Department of Labor (DOL) is committed to supporting the rights of all workers with long COVID, as well as their employers. So, as part of an effort to better understand workplace challenges related to long COVID, DOL initiated an ePolicyWorks online dialogue in the summer of 2022.

From July 11 to August 15, the ePolicyWorks national online dialogue, *Understanding and Addressing the Workplace Challenges Related to Long COVID*, gathered ideas on how to support employers and employees facing long COVID related workplace issues. The dialogue contributed to efforts by DOL, the U.S. Surgeon General and the U.S. Centers for Disease Control and Prevention's (CDC) to provide the resources and supports an individual with long COVID needs to be able to successfully stay at work and/or return to work. In addition, the dialogue sought to obtain insight into ways DOL, the Surgeon General and CDC can support the nation's diverse array of workers, employers and policymakers as they address issues around long COVID.

The dialogue utilized ePolicyWorks' crowdsourcing technology to gather input from subject matter experts and key stakeholders, including long COVID advocacy groups, disability organizations, employers and other members of the public. Among the topics explored were various long COVID-related challenges faced by employees and employers, and how to best reach stakeholders and potential partners to support DOL, CDC and the Surgeon General in their response. In addition, the dialogue aimed to collect information on issues individuals with long COVID may be experiencing when accessing employee disability benefits. The dialogue provided an innovative opportunity for stakeholders to play a key role in informing the government's efforts to best meet the needs of people with long COVID, including those from historically underserved communities.

During the national online dialogue, more than 4,000 stakeholders visited the dialogue website to view, share, comment and vote on ideas in five topic areas related to issues around long COVID in the Workplace: (1) Employer Challenges & Solutions; (2) Employee Challenges & Solutions; (3) Informing Stakeholders; (4) Employee Benefit Challenges and (5) Identifying Partners. Based on the input from these stakeholders, the dialogue identified several key themes and takeaways that will assist policymakers as they work to create resources, programs and policies to address long COVID. The key themes and takeaways included providing accommodations for workers with long COVID, creating an education campaign around long COVID in the workplace and supplying employers, especially small business, with the resources and information they need.

Online Dialogue Topics

The *Understanding and Addressing the Workplace Challenges Related to Long COVID National Online Dialogue's* five topics were associated with different areas of interest for the host agencies, as well as DOL's Office of Disability Employment Policy (ODEP). The topics included several related question and prompts:

1. Employer Challenges & Solutions

What challenges are employers facing when supporting employees with long COVID? Please share your experiences, insights and possible solutions to workplace challenges posed by long COVID, as well as policies or programs to help employers retain employees with long COVID.

2. Employee Challenges & Solutions

What challenges do employees with long COVID face in the workplace, and how can we help overcome these? Please share your experiences as well as any policies, practices or resources that might minimize employment and financial struggles resulting from long COVID.

3. Informing Stakeholders

Which organizations should be part of developing solutions for those affected by long COVID? Please share national, state and local organizations representing communities most affected by long COVID and others working on issues related to solving the long COVID workplace challenge.

4. Employee Benefit Challenges

If you are a worker with long COVID, have you experienced challenges in obtaining disability benefits from your employer-sponsored disability plans? If so, what type of challenges are you facing? What reasons are being given for the denial of benefits?

5. Identifying Partners

How can DOL best inform employees and employers about the latest long COVID research, emerging practices and resources? Please share names of blogs, newsletters and other communication channels through which DOL can inform those effected by long COVID.

Key Themes and Takeaways

Based on an analysis of the ideas and comments posted to the dialogue, the following key themes, policy recommendations and takeaways emerged:

Employees with Long COVID Need Reasonable Accommodations and Workplace Flexibility

There is an apparent lack of understanding about long COVID as a disability under the Americans with Disabilities Act (ADA) and the rights and responsibilities of employees and employers, as well as what resources exist around accommodations.

Many in the dialogue agreed that the first step in addressing long COVID in the workplace is offering reasonable accommodations. They pointed out that, like other disabilities, long COVID limits a person's ability to perform his/her essential work functions.

It was clear from the ideas submitted that those with long COVID experience times of the day when they are less cogent and have low energy. One participant suggested that "when an employee/contractor has this experience and then finds themselves in long COVID, the employer should be required to allow accommodations, as with any other disability, so that collaboration and deliveries can be flexible with the illness."

Many stressed that human resource departments should start the accommodations process as soon as possible. Preventative measures taken early would alleviate many disabling symptoms. In the long run, providing accommodations to those with long COVID could also lead to an increase in employee retention.

The major accommodation mentioned was workplace flexibility. One contributor noted that employees "have proven ability to work remotely, [those with long COVID] should be provided that option for times of episodic flare ups which [they] cannot predict." Now that working remotely has proven successful, one contributor suggested that "it should be mandated that employees with ongoing health challenges and disabilities be allowed to work from home as an acceptable workplace accommodation."

Other accommodations mentioned were controlled climate workspaces, a new or different workstation, time to reacclimate and restore focus on work tasks, decreased stimulation, intermittent time away and limits to excessive walking or exertion on the job.

One participant shared, "[I am] going on 9 months with long COVID and I know my employment will run out soon as I cannot perform my day-to-day tasks. Though my employer (university) has been very compensating to my condition, there is not an option to declare disability for myself to travel for treatment as there is no treatment (research) in Alaska. My insurance will not cover COVID-related treatment, so my primary provider has to prescribe tests and treatments that are not related. This is frustrating and discouraging for my challenging future ahead."

Another mentioned that as a high school teacher, "I have struggled to work full-time through long COVID. My symptoms worsen with stress and physical/mental activity. All of my energy currently goes to making it through four days of work. By the fifth day, I often cannot get out of bed. On most days, I do not complete household chores and do very little parenting, conserving all my energy for teaching."

Overwhelmingly, dialogue participants wanted to keep working. One participant stated, "if I could pace myself and take mental and physical breaks as needed [I could continue to work]. My symptoms vary greatly from day-to-day and hour-to-hour, but I would still like to work in some capacity."

Some participants were not aware that the Federal Government has resources around accommodations and asked for government disability employment guidance/resources as well as other information about their rights under the ADA.

Employers Need Education Regarding Long COVID Symptoms and Disability Qualifications

There is a need for education around long COVID and its symptoms, as well as guidance related to reasonable accommodation requests for long Covid, specifically flexible work schedules, and qualifications for short-term (STD) and long-term disability (LTD).

Overwhelmingly, participants stressed that there is a need for employers to understand long COVID and its on-again/off-again symptoms. They stressed that many individuals with long COVID have chronic fatigue, brain fog and ongoing breathing issues, and these "episodes" can happen without warning.

Several ideas were submitted about providing long COVID training for employers and employees. Many felt that employers and co-workers have little-to-no understanding of how prolonged, unpredictable, insidious and debilitating long COVID is. They felt that there was a clear need for training and resources that could help others understand they have employees and co-workers experiencing long COVID and that small adjustments (e.g., waiting just a little for someone to finish speaking) can make a very big impact. One person suggested that "long COVID training for employers and employees needs to be produced, communicated and potentially made mandatory."

One person suggested designating a human resources representative to be in charge of dealing with employee issues around long COVID. This HR professional could be educated on how to handle all COVID-related care obstacles for both employers and employees.

Employers Need to Give Those with Long COVID the "Benefit of the Doubt" When It Comes to Accommodations

Individuals with long COVID are experiencing issues with accommodations requests (i.e., in demonstrating disability).

One participant stressed that long COVID sufferers who did not meet the original criteria (age, confirmed exposure, etc.) to be tested or hospitalized must be given the benefit of the doubt and presumption of infection regarding their original diagnosis. The government can accomplish this by placing the burden of proof on the employer to prove otherwise.

A number of participants discussed the challenges they faced in getting documentation of their symptoms from doctors and health care workers. One person shared their experience stating, "my company-sponsored disability plan covered the first few weeks and then asked for more verification from every doctor I had seen. That added up to a lot of doctors."

Employee Benefits Need to Be Updated for Those with Long COVID, Including Short-Term and Long-Term Disability

Many workers have issues and concerns related to long COVID as an episodic disability and struggle with approvals for STD and LTD.

Several participants discussed the challenges around obtaining employee disability benefits. They wanted to see more guidance provided to private disability insurers to align with the ADA's definition of long Covid as a disabling illness. They also requested that the government investigate whether people with long COVID are being approved for short term disability (STD), long term disability (LTD) or Social Security Disability Insurance (SSDI).

One individual who was approved for LTD, yet when he increased his work hours, he lost his benefits. When his employer cut his hours again because of the pandemic, he was told because he had been off of LTD for more than three months, his claim would need to be considered as a brand-new claim. The individual was then approved under reservation of rights, only to be denied a week later. This story was not unique and presents a special challenge for benefit providers. Another person shared that individuals with long COVID may not be eligible for STD unless they stop working entirely. If someone with long COVID tries to work full time with accommodations, but is unable and decides to work part-time, he/she may find that working can make long COVID symptoms much worse. And since he/she is working, he/she would not qualify for any LTD benefits.

For long COVID, like many other disabilities, it is common to have ups and downs. Several people posted ideas about creating legislation that would require LTD plans to re-open previous claims in the case of relapse. It was suggested in the dialogue that DOL eliminate the "under reservation of rights" loophole to Employee Retirement Income Security Act (ERISA) law. This allows LTD plans to indefinitely leave people in limbo. People could have to pay back LTD payments they've received, which could wreak havoc on families' finances. One participant suggested addressing this by creating funds or offering loans for people who were denied benefits so that they have stability while they are waiting.

Another person suggested creating employee support groups to navigate the disability benefit processes as well as the health care process potentially funded by government grants.

Finally, there was the suggestion to add long COVID to the Compassionate Allowance Illnesses identified on the list of quick qualifiers for Social Security with special circumstances and to allow others to access their 401K to support themselves while dealing with long COVID work absences.

Small Business Employers and Their Employees with Long COVID Need Support

Small businesses do not have the resources they need to provide reasonable accommodations for individuals with long COVID and, as a result, struggle to retain employees that suffer from long COVID.

There were discussions about how long COVID affects small businesses/employers. One participant discussed her situation with her small business employer. She stated, "we don't have disability or FMLA or anything. I'm lucky to have health insurance that I pay for myself with post income tax dollars. Regardless, there is a struggle for small employers to offer anything to their employees who are sick. Big corporate benefits would be so awesome. "

One participant suggested a tax credit or some incentive for small business to keeping those with long COVID.

One employee who wanted to continue working noted that his employer did not support remote work and stated, "the thought of getting up and having to make myself professional and presentable is beyond me, I feel like I could be fired just for asking for a simple accommodation and no one will want to hire a sick person. Small businesses need to be educated on reality."

A retired HR professional suggested creating an online resource for employers to share ideas and solutions about how to retain and support those experiencing long COVID.

FMLA and SSDI Need to Be Updated in Consideration of Long COVID

One individual stressed that people with long COVID need rest/care and noted that the uncertain recovery time is longer than anything anyone is used to. In lieu of a cure, they need SSDI.

Participants highlighted the need to update paperwork requirements for Family and Medical Leave Act (FMLA) and disability benefits to reflect the unknown nature of long COVID, both in symptoms and illness timeline. Patients have been told by their doctors that "we don't know what the long COVID timeline is or what testing will be needed" but are held to the standards of repetitive, tedious, antiquated forms.

One dialogue participant gave an example of how updating FMLA could support the return to work for many suffering with long COVID. This individual was able to use accumulated sick leave

to reduce his work schedule to only 20 hours a week without losing his full-time salary. With his workload reduced he was able to attend the treatment that was recommended by the long COVID clinic and rest during the rest of his time off. This combination of treatment and rest allowed the dialogue participant to almost completely recovery from long COVID. It took 6 months of a part time schedule for this recovery to happen, but the individual was eventually able to return to full-time work. He was able to access to this benefit through his employer, but many low wage or part-time workers do not have this resource. He recommended that DOL assess what is available through LTD and FLMA to determine whether more is needed to provide every employer with the ability to give employees paid time off to recover from long COVID or to manage long COVID symptoms with the hope of eventually returning to full-time employment.

Employers and Employees Need More Data on COVID Leave Policies and Disability Related Benefits

Several participants asked for COVID-related leave policy information. They stated that employers would find current employer trend data on COVID-specific leave policies helpful when shaping their own policies. One participant stated that when DOL promulgated the Families First Coronavirus Response Act (FFCRA) and Emergency Family and Medical Leave policies, employers received a clear-cut directive on how eligible companies should respond to employees impacted by COVID diagnoses, school closures, etc. Since those leaves have expired but COVID has not, many employers who are not required to provide leave via state or local mandates question whether their current policies meet their employees' needs and are competitive with other companies in their industries while being financially viable. It was noted that the Bureau of Labor Statistics does have some data that employers can use, but it was suggested that additional statistics be added such as: whether time off is available for employees diagnosed with long COVID; whether time off is available for dependents or family members' diagnosis of long COVID; and whether there is paid or unpaid leave or industry telecommuting accommodations.

Dialogue Submission Summary

Top Dialogue Submissions by Vote

Below are the top dialogue submissions determined by participant voting. These contributions include *calls to action* with implementable ideas, as well as *informational* posts describing organizations, initiatives and other resources of reference that support the topics discussed in the dialogue.

The listings in the following section include minor typographical corrections, which have in no way impacted the substance or the intention of the revised posts.

Top Calls to Action Determined by Participant Votes

Launch national public information campaign: Stop. Rest. Pace.

Topic: Employee Challenges & Solutions

80 Up Votes | 0 Down Votes | 80 Net Votes

Comments: 17

Followers: 3

Resting and pacing are the core recommendation from health providers who specialize in treating post-infectious syndromes. We need a national public information campaign that empowers employees and employers with better information about how to manage activity and accommodate disability from infection-associated chronic illnesses. Returning to work too quickly, without adequate accommodations, or using inappropriate graded exercise therapy can increase the likelihood of the illness worsening into a long-term disability. If accurate public health information is more widespread, it will help us in our goals to safely rejoin the workforce and pursue our dreams without sacrificing health.

Many people with long COVID report experiencing post-exertional malaise (PEM), that is a worsening of symptoms after physical and cognitive exertion. Symptom onset can be immediate or delayed for hours or days. PEM is a hallmark symptom of myalgia encephalomyelitis/chronic fatigue syndrome (ME/CFS).

While graded exercise may be useful in people who are deconditioned after surgery or a severe illness, graded exercise does not address the metabolic dysfunction and atypical reactions to activity that lead to PEM symptoms in people with ME/CFS or long COVID. A national public information campaign providing guidance on pacing to manage PEM, as well as warnings against graded exercise therapy is urgently needed to prevent harm and protect the health of people with infection-associated chronic illness experiencing post-exertional malaise.

["Stop. Rest. Pace."](#) is a public information campaign developed by #MEAction, a patient-led advocacy organization with experience in infection-associated chronic illness.

The CDC recommends [pacing](#) for people with ME/CFS and long COVID managing post-exertional malaise.

The DOL's Job Accommodation Network recommends [pacing](#) to manage PEM in people with ME/CFS.

National Awareness & Education Campaigns on Long COVID & Associated Conditions (LCAC) Now!

Topic: Employee Challenges & Solutions

68 Up Votes | 0 Down Votes | 68 Net Votes

Comments: 2

Followers: 2

Much of the American public is not aware of long Covid, despite a conservative estimate of 1 in 5 developing long COVID. Because of this, many are not able to identify their newly developed health issues as related to COVID-19 infection, especially if they had mild or asymptomatic infections. This, therefore, results in cases of long Covid not being documented, which results in both a lack of governmental action and a lack of education within medical fields. With a lack of national public messaging and education on long COVID, many take place in risky behaviors putting them, their families and their co-workers at risk of COVID-19 and therefore long COVID.

1. General Public Education

- a. Long COVID commercials, billboards, social media and print campaigns, posters within public transportation facilities and in medical offices, workplaces and schools. (HHS, CDC, Local Health Depts & long COVID orgs partnering). These should include phone numbers and websites people can call to self-report as a Longhailer and receive resources and be added to the National Long Covid Database.*
- b. Quality long Covid messaging from national leadership and trusted community partners with messaging designed by and guided by long COVID org partners.*

2. Mandatory Employer Education (Reaches employee and employer):

- a. 1 in 5 COVID-19 infections = long COVID. Our data shows 2/3 have filed or were preparing to file for social security disability. This created an enormous stress on the labor force and the individual's losing income, and employers losing employees. Keep in mind even those able to work have reduced "efficiency and productivity."*
- b. What is long COVID and its associated conditions (LCAC) and what does it mean for an employee to have a complex chronic illness with waxing and waning symptoms needing work accommodations with a flex-type schedule?*
- c. What resources should you have available to an employee with long COVID and what are you responsible for providing as well as how far does a "reasonable" accommodation" have to go?*

- d. *If an employee should have to cease employment, how should you assist them in the process of seeking benefits such as workers compensation, short or long-term disability, or social security disability?*

3. *Mandatory Provider Education*

- a. *(CEU's/CME's) for medical providers (Physicians, P.A's, N.P's, R.N's and those working at Post Covid Centers/ COE's and study sites, including RECOVER and other federally and state funded facilities), as many have never heard of the conditions associated with long Covid and are not providing quality patient care, in addition to there not being enough specialists in these fields to treat the number of Longhauers.*
- b. *Educational efforts will ensure providers are identifying and documenting long COVID and its associated conditions, therefore/ hopefully, treating them correctly/ as able to, not advising patients to "push through it", "exercise harder," "blame anxiety or depression," or tell them it's "psychosomatic," or force them back to working conditions that further exacerbate their medical conditions forcing them to be unable to work at all. Providers, employers and employees should be working as a team to create a plan or care, and a flexible work schedule that can accommodate the employee, allowing them to successfully perform their job as they are able to.*
- c. *Should the employee no longer be able to work, this same team needs to work to ensure the employee has easy, fair, swift access to resources and benefits and is not retaliated against for seeking benefits.*
- d. *Will further help other employees with complex chronic illnesses.*
- e. *Will help contribute to the consistent use of long Covid diagnostic codes within medical facilities, allowing researchers to better identify the population affected for proper long-term planning and funding allocation, including feeding data into a National Long COVID Database for reporting long COVID cases.*

4. *Mandatory Lawmaker Education- Lawmakers are responsible for maintaining and creating policies that deliver quality health care and necessary resources to sustain everyday quality of life for hundreds of millions in the United States. The COVID-19 Pandemic has taken over 1 million lives and contributed to at least 18-72 million long COVID cases to date (7-26-22) in the United States alone, 2.5 years into the pandemic. As patients, we were the first to and have continued to report on how Long COVID has impacted the economy and workforce, yet our government continues to not grasp the seriousness and scale of its impact or take precautions from allowing it to further impact us all more or help those already impacted. Discussing long COVID at one off hearings, where Longhauers get to discuss their experience for a total of maybe 5 minutes each is not sufficient, so we propose the following:*

- a. *Lawmakers undergo mandatory education on long COVID and its associated conditions through bi-monthly, 2-hour lectures led by:*

- i. *Credible long COVID and associated condition patient advocacy organizations representatives and advocates.*
- ii. *Credible medical providers treating long COVID patients and patients with associated medical conditions*
- iii. *Credible researchers investigating long COVID and/ or its associated conditions or previous post-viral illnesses pandemics.*
- iv. *Credible allies (lawmakers, public health officials, other government officials)*
- b. *The appropriate committees and members should make themselves available and seek out the above experts for further information and partnership in global education through parts 1-3 above.*
- c. *Members serving on committees specific to the coronavirus should make an effort to make it to every single one of the very few meetings actually held on the topic.*
- d. *Lawmakers should form long COVID task forces within their district and become members of our state advocacy teams, and partner with our members to learn more about their needs and what they can do for their constituents.*

Provide short-term disability insurance policies

Topic: Employee Benefit Challenges

65 Up Votes | 0 Down Votes | 65 Net Votes

Comments: 20

Followers: 4

Resting and pacing are the core recommendation from health providers who specialize in treating post-infectious syndromes. Being required to work can increase the likelihood of the illness worsening into a long-term disability. Having access to short-term disability policies through an employer, union or other insurance programs would help many people with a range of disabling chronic illnesses including long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). If we better recognize chronic illnesses as an intermittent disability, it'll help us in our goals to rejoin the workforce and pursue our dreams without sacrificing health.

Top Informational Contributions Determined by Participant Votes

The COVID-19 Longhauler Advocacy Project

Topic: Informing Stakeholders

136 Up Votes | 0 Down Votes | 136 Net Votes

Comments: 16

Followers: 8

The COVID-19 Longhailer Advocacy Project is a grassroots, patient-led, non-profit organization formed in June 2020 ([Meet the team here](#)). Our mission is to advance the understanding of Long COVID and expedite solutions and assistance for Longhailers and their families through advocacy, education, research and support. The organization has 50 state groups plus D.C. and 9 special populations groups including pediatrics, teens, pregnancies and family planning, single parents and caretakers, educators, BIPOC, first responders and military personnel, healthcare workers and researchers, and fundraising and financial assistance + advocacy teams for all which you are encouraged to join and get involved.

Our organization was the first of anyone to report on the economic cost of long COVID and its impact to the labor force ([open-letter](#)) as well as outline a strategic and comprehensive plan for addressing the needs of the long COVID community in January 2022, and we expanded this work in July 2022 based off current case counts and long COVID estimates, which you can find outlined in [our letter to the Select Committee on the Coronavirus Crisis here](#).

We have been on the front lines for the long COVID community advocating for our everyday needs such as, but not limited to better protection measures, financial assistance, expansion of social security, workplace accommodations, long COVID public education and awareness campaigns, a long COVID task force, provider education on long COVID and its associated conditions, better access to quality medical care and so much more! We have been extremely, extremely thorough and detailed in collecting these needs from, and outlining these needs for the community. We have presented these needs to various government and health agencies such as the White House COVID Response Team, Various Divisions within HHS, the NIH and RECOVER Initiative and lawmakers.

We discuss the barriers to employment, medical care, resources and assistance and then discuss the numerous ways in which we can address the barriers Longhailers face, laying out a step by step guide, based on community feedback and experience such as but not limited to; national education and awareness campaigns; counting, documenting and planning for long COVID; Long COVID Assistance Programs (LCAP); Long COVID Care Programs (LCCP); Long COVID Research Programs (LCRP); Expansion of Social Security Disability to include Long COVID and Associated Conditions (LCAC); and other long-term assistance programs for longhailers and future pandemic patients.

We, too, are sick patients fighting right alongside you for the exact same needs, living through the exact same experiences. We, too, are desperate for action, angry, frustrated at the lack of medical knowledge and resources available. Our work is based on the experience we have personally gained through our own journey but from also LISTENING TO AND LEARNING FROM

ALL OF YOU. We are dedicated to ensuring the needs of the long COVID community are met and millions are not left behind for decades to come, impacting generations.

The Myalgic Encephalomyelitis Action Network (#MEAction)

Topic: Informing Stakeholders

78 Up Votes | 0 Down Votes | 78 Net Votes

Comments: 20

Followers: 7

#MEAction is an advocacy organization fighting for recognition, education and research so that, one day, all people with ME, long COVID and other infection-associated chronic illnesses will have support and access to compassionate and effective care. We are people with ME and long COVID, caregivers, family members and allies. We operate in both the US and UK.

[Preliminary studies](#) are now showing that nearly half of people with long COVID are presenting with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). ME/CFS is triggered by infection in [up to 80% of cases](#). Other viral infections have triggered ME/CFS in [10-12% of individuals](#) overall. Other coronaviruses like SARS and MERS have led to even [higher rates of ME/CFS](#).

#MEAction should be part of developing solutions for those affected by long COVID and ME/CFS and infection-associated chronic illnesses as a patient-led, community-accountable organization committed to disability justice.

*<https://www.meaction.net/>
info@meaction.net*

Most Active Dialogue Submissions

Below are the most active dialogue submissions from the *Understanding and Addressing the Workplace Challenges Related to Long COVID Online Dialogue*. "Most active" is determined based on the total number of participant views, comments, votes and followers the post receives over the course of the dialogue.

Four of the most active submissions (1) *The COVID-19 Longhailer Advocacy Project*; 2) *The Myalgic Encephalomyelitis Action Network (#MEAction)*; 3) *Launch national public information campaign: Stop. Rest. Pace*; and 4) *Provide short-term disability insurance policies* were also the top submissions by vote. See the [Top Dialogue Submissions by Vote](#) section for a full description of each submission.

Detailed below is the fifth most active submission, which includes minor typographical corrections that have in no way impacted the substance or the intention of the revised post.

Increase Long COVID SSDI Coverage

Topic: Employee Challenges & Solutions

27 Up Votes | 0 Down Votes | 27 Net Votes

Comments: 1

Followers: 1

I've been suffering with long Covid since getting infected in March 2020. Healthy 36-year-old. I spent two years pushing through horrifying symptoms to stay employed before trying to get disability leave.

Most people aren't and won't be fortunate enough to have access to workplace accommodations, nor employer sponsored STD/LTD, and frequently private insurers are denying us this coverage.

This is why SSDI MUST BE SIGNIFICANTLY EXPANDED FOR LONG COVID.

When you have long Covid and push through like I did, you slowly kill yourself. I deteriorated significantly and wound-up bed bound and unable to care for myself. I now have Postural Orthostatic Tachycardia Syndrome (POTS), dysautonomia, mitochondrial dysfunction, Mast Cell Activation Syndrome (MCAS), [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(MECFS\)](#), metabolic disorder, and my lungs utilize oxygen similar to a person in their 80s. I have no idea if I'll ever recover.

Enhanced leave policies, flex time, benefits for health insurance coverage, and work from home are all helpful, but we know nebulous.

People with long Covid need rest, care, and the uncertain recovery time is longer than anything we are used to. In lieu of a cure, we need SSDI.

Top Trending Dialogue Submissions

Below are the submissions that were trending (i.e., receiving the most views, votes and comments) at the conclusion of the *Understanding and Addressing the Workplace Challenges Related to Long COVID* Online Dialogue.

Three of the top trending submissions have been highlighted in the Top Dialogue Submissions by Vote and Most Active Dialogue Submissions sections above. Detailed below are the other two top trending submissions, which include minor typographical corrections, that have in no way impacted the substance or the intention of the revised posts.

National Dashboard to Report Non-Compliance & Submit Evaluations of Coordinator Competency, Accommodation Efficacy & Support.

Topic: Employee Challenges & Solutions

65 Up Votes | 0 Down Votes | 65 Net Votes

Comments: 3

Followers: 3

Far too many Longhaulers cannot access workplace accommodations. In a COVID-19 Longhailer Advocacy Project Poll in April 2022 run over three days, 400 people responded. Of the 23% working who requested accommodations, 58% said they were denied. 59% said the accommodations they had or were receiving were just not enough.

1. *Create a national training program for LCAC → Accommodations Policy Coordinator (APC)*
 - a. *Require medical systems, police, fire and EMS departments (including applicable city and county employers) and school districts to maintain a salaried year-long position responsible for long COVID education, workplace accommodations, and disability paperwork related to long Covid and its associated conditions (LCAC)*
 - b. *Require employers with 300+ employees to maintain a salaried year-long position responsible for long COVID education, workplace accommodations, and disability paperwork related to long Covid and its associated conditions (LCAC).*
 - c. *Require employers with <300 employees maintain one trained leadership staff/ member of human resources per 100 employees via a six hour (3 hours, taken every 6 months) yearly certification course that will be responsible for handling all claims related to Long COVID and helping employees navigate resources available to them.*
2. *Employers implement an APC. Given 1 in 5 who get COVID-19 will develop long COVID and current public messaging is that “everyone will get COVID-19,” every single workplace will have Longhaulers working for them, and every single workplace will lose workers due to LCAC. They must have personnel prepared to handle multiple applications and consistent applications for accommodations and other forms of assistance and disability. Workplaces over “X” employees may need to be assigned “X” APCs per 100 employees.*
 - a. *Employers and employees should be able to hold an open, bi-directional dialogue about the employees’ needs and accommodations and work to create a plan that captures those needs. The employee should monitor the efficacy of this plan daily and weekly and report back to HR at the 2-week mark where the plan can then be revised as needed, and repeated as needed, without penalty to the employee.*
 - i. *Sample Evaluation Questions*
 1. *How are the accommodations helping your symptom management?*
 2. *How are the accommodations helping your work efficiency & efficacy?*

3. *How are the accommodations helping with your commute to & from work?*
 4. *How are the accommodations helping with home life after work?*
 5. *Are the accommodations meeting your expectations? What can we expand or alter to better fit your needs?*
 6. *What symptoms cannot be helped by the accommodations?*
- b. *APCs are also responsible for completing and filing paperwork with workers' compensation, short and long-term disability, social security disability, and waivers for other types of assistance programs that may be needed. (This is why "X" APCs / "X" Employees is an important figure to compute considering 1 in 5 develop long COVID, and current public messaging is saying, eventually, everyone will get COVID-19. We need to prepare for the very long-term consequences, not yet realized.)*
3. *After DOL develops a plan in partnership with a patient led long COVID organization, APCs should begin to implement that plan, which will include education to those who will need and be utilizing this very program.*
 4. *HHS/DOL launches the national dashboard to report non-compliance and submit evaluations of APC competency, efficacy of accommodations, and the overall support you are receiving which includes your treatment in the workplace as someone with LCAC. This dashboard can and should be expanded to things like workers' compensation issues, refusal to assist with short-term, long-term and social security disability applications, and offer a follow-up service (EEOC is way too slow to respond, and people do not want to litigate) or possibly impose penalties on employers. We would love to see this serve as a pilot, like many recommendations coming from us, to be expanded to the chronic illness and disability community as a whole.*

Capturing Dynamic Disability in Social Security & Other Forms of Disability & Assistance.

Topic: Employee Challenges & Solutions

64 Up Votes | 0 Down Votes | 64 Net Votes

Comments: 3

Followers: 3

Patients with long COVID and its associated conditions (LCAC) may experience periods of functional health lasting days, weeks, months and or even years. However, as is often seen in other chronic illnesses and disabilities, relapses can occur at any time leading to complete, temporary or LTD. The process for obtaining disability benefits does not allow for any flexibility to keep up with people's changing health needs in situations such as these, and people do not have the capacity to start anew in the lengthy application and approval process.

A rolling eligibility system is needed to accommodate the many who experience dynamic health conditions like LCAC. This would allow Longhaulers and their families to receive support and

alleviate the financial burden placed on them that can intermittently be experienced, placing them and their families into irreversible financial hardships due to resources that are inaccessible to them during the times most needed. This understanding of the unpredictability of LCAC is not currently captured by the current system, which is what we need to work on capturing not only for LCAC but for everyone.

Most Popular Dialogue Submissions

Below are the top two most popular submissions from each of the online dialogue's five topic areas. "Most popular" is determined based on the submission's total number of participant up votes, comments and followers at the conclusion of the dialogue.

The submissions listed in the following section include minor typographical corrections, which have in no way impacted the substance or the intention of the revised posts.

Most Popular Submissions from the Employer Challenges and Solutions Topic

1. Disability Support and Job Protection

25 Up Votes | 0 Down Votes | 25 Net Votes

Comments: 5

Followers: 1

In speaking with my HR colleagues, a lot of private insurance disability carriers are rejecting long COVID claims from employees, taking advantage of long COVID not necessarily having a singular "test" to validate per se and because the symptoms look different for everyone afflicted with it, while they continue to receive employer payments as a vendor. All of the employees I know of who have received their disability pay has been after needing to appeal and after weeks of no pay from these disability vendors who drag out the appeals process hoping the employees give up. It is unfortunate especially because a lot of these employees who get sick with COVID and develop long COVID afterwards are not always protected by FMLA if they haven't been employed for 12 months with the company, nor do many of them continue to receive any pay from their employer considering their policy.

It would be great if the government could take a more active role in monitoring these private disability insurance companies who act as judge and jury in these appeal cases and ensure there are at the very least more swift responses. If employees with long COVID receive some financial support, then they are more likely to take the time they need out of the office to begin to recover, and when they are ready to return, they will be that much more productive and healthy vs. feeling like they need to return right away but are absent or not productive and not feeling well.

I also think it would be great if employers played a more active role in the accommodation process after an employee has COVID. Many states now have paid COVID sick leaves for 2 weeks or what not, but it would be great to see this be a mandate by the government plus also having employers actively ask their employees returning from a COVID leave what support they may need in returning to the office—encouraging breaks and easing back into their work vs. needing to do all the work they missed for 2 weeks plus whatever new comes up which is unfortunately the case for many workers who take time away from work.

Lastly, it would be great if there was more information out there as to what can help while the medical community searches for answers. For example, Physical Therapy has been great for many long COVID care centers within hospitals. Adderall is helpful for some to be able to focus and gain energy in the workplace. Breath work and meditation and a healthy lifestyle have also been important pieces as it relates to mental health support.

2. Flexible work - including part-time & job sharing may support both long Covid sufferers & caregivers to stay in paid work

20 Up Votes | 0 Down Votes | 20 Net Votes

Comments: 1

Followers: 1

I am the host of the podcast "Job Sharing and Beyond"

My focus is on creating part-time positions including job-shared jobs across all job levels. This will enable professionals to stay in the paid workforce despite not being able to work a full-time job for a variety of reasons.

I believe that organizations that start offering these fractional positions will not only enable professionals impacted by long COVID to continue to stay in the paid workforce, but it will also attract caregivers or other members of the workforce who have had to opt out when they could not find part-time work.

Given that long COVID sufferers often do not have a lot of energy, offering remote positions that are part-time or maybe project-based work with fewer weekly hours may be most ideal.

Unilever has created U-Work, a program enabling professionals to stay with them on a monthly retainer but with more flexible work choices. While this program was created not with long COVID in mind, it may present a great starting point.

<https://www.forbes.com/sites/avivahwittenbergcox/2021/05/23/flexibility-for-all--unilevers-vision-of-the-future-of-work/?sh=6851be9775c6>

I have recently come across several articles about long COVID and its implications on the workforce and some ideas for managers. There was also a congressional hearing about long COVID today.

<https://sloanreview.mit.edu/article/how-managers-can-support-employees-with-long-covid/>

<https://www.ft.com/content/63dcc4d1-8b53-4110-bd44-10e3d1d98585>

<https://fortune.com/2022/07/19/long-covid-congressional-hearing-labor-force-health/>

Also, this article shares why in the USA part-time work (beyond an entry-level) is not that frequently available. There is definitely a stigma attached that if someone cannot work a full-time position, they may be less motivated, ambitious and skilled. Adding a large new segment to this part of the workforce that is not care responsibility focused but due to long COVID, may reduce the stigma as it will impact all parts of the labor market - from tech to healthcare and across all genders. <https://www.businessinsider.com/corporate-america-companies-part-time-jobs-work-layoffs-great-resignation-2022-6>

On my podcast, I have spoken with international experts about various forms of flexible work and what it takes to create these best practice examples.

<https://podcasts.apple.com/ca/podcast/jobsharing-and-beyond/id1505170119>

Most Popular Submissions from the Employee Challenges & Solutions Topic

- 1. Launch national public information campaign: Stop. Rest. Pace.** *(The full description of this submission can be found under [Top Dialogue Submissions by Vote](#))*
80 Up Votes | 0 Down Votes | 80 Net Votes
Comments: 17
Followers: 3
- 2. National Awareness & Education Campaigns on Long COVID & Associated Conditions (LCAC) Now!** *(The full description of this submission can be found under [Top Dialogue Submissions by Vote](#))*
68 Up Votes | 0 Down Votes | 68 Net Votes
Comments: 2
Followers: 2

Most Popular Submissions from the Informing Stakeholders Topic

- 1. The COVID-19 Longhailer Advocacy Project** *(the full description of this submission can be found under [Top Dialogue Submissions by Vote](#))*

136 Up Votes | 0 Down Votes | 136 Net Votes

Comments: 16

Followers: 8

- 2. The Myalgic Encephalomyelitis Action Network (#MEAction)** *(the full description of this submission can be found under [Top Submissions by Vote](#))*

78 Up Votes | 0 Down Votes | 78 Net Votes

Comments: 20

Followers: 7

Most Popular Submissions from the Employee Benefit Challenges Topic

- 1. Provide short-term disability insurance policies** *(the full description of this submission can be found under [Top Submissions by Vote](#))*

65 Up Votes | 0 Down Votes | 65 Net Votes

Comments: 20

Followers: 4

- 2. Capturing Dynamic Disability in Social Security & Other Forms of Disability & Assistance.** *(The full description of this submission can be found under [Trending Submissions](#))*

64 Up Votes | 0 Down Votes | 64 Net Votes

Comments: 3

Followers: 3

Most Popular Submissions from the Identifying Partners Topic (a full list of partners that were submitted by dialogue participants can be found in [Appendix B](#))

- 1. The COVID-19 Longhailer Advocacy Project**

103 Up Votes | 1 Down Votes | 102 Net Votes

Comments: 18

Followers: 12

The COVID-19 Longhailer Advocacy Project is a grassroots, patient-led, non-profit organization formed in June 2020 ([Meet the team here](#)). Our mission is to advance the understanding of long COVID and expedite solutions and assistance for Longhailers and their families through advocacy, education, research and support. The organization has 50 state groups plus D.C and 9 special populations groups including pediatrics, teens, pregnancies and family planning, single parents and caretakers, educators, BIPOC, first responders and military personnel, healthcare workers and researchers, and fundraising

and financial assistance + advocacy teams for all which you are encouraged to join and get involved.

Our organization has put forth the only strategic outline and comprehensive plan for addressing the needs of the long COVID community. We have been on the front lines for the long COVID community advocating for our everyday needs such as, but not limited to better protection measures, financial assistance (we are the only organization who has put this at the forefront of our advocacy), expansion of social security, workplace accommodations, long COVID public education and awareness campaigns, a long COVID task force, provider education on long COVID and its associated conditions, better access to quality medical care and so much more! We have been extremely, extremely thorough and detailed in collecting these needs from, and outlining these needs for the community. We have presented these needs to various government and health agencies such as the White House COVID Response Team, Various Divisions within HHS, the NIH and RECOVER Initiative and lawmakers.

After two years of waiting for the government to help us, and develop a plan, we realized it was not coming unless we were able to present why action was imminently needed, so we got to work for millions. We began with our groundbreaking [report and open letter](#) sent to national leadership, which was the first report ever on issues on the economic impact of long COVID. We expanded our report and then included our Comprehensive and Systematic Approach to Long-Term Planning and Desired Outcomes for the Long COVID Community, which we then included into the Letter for the Record we submitted to the Select Committee on the Corona Virus Crisis Hearing on "[Understanding and Addressing Long COVID and Its Consequences.](#)"

In this letter, we built off the data collected and utilized in our earlier reporting and current "documented" case counts, which sit right around 90 million, a shameful 73% (38M) increase in just 7 months (1/3 the time it took for 52M "documented cases"), from the 52M cases at the time of that initial letter's calculations in December 2021, only utilizing "documented" cases. We discuss the barriers to employment, medical care, resources and assistance and then discuss the numerous ways in which we can address the barriers Longhaulers face, laying out a step by step guide, based on community feedback and experience such as but not limited to; national education and awareness campaigns; counting, documenting and planning for long COVID; Long COVID Assistance Programs (LCAP), Long COVID Care Programs (LCCP), Long COVID Research Programs (LCRP), Expansion of Social Security Disability to include Long COVID and Associated Conditions (LCAC), and other long-term assistance programs for longhaulers and future pandemic patients.

Need we remind you that we, too, are sick patients fighting right alongside you for the exact same needs, living through the exact same experiences. We, too, are desperate for action, angry and frustrated at the lack of medical knowledge and resources available. Our work above is based on the experience we have personally gained through our own journey but from also LISTENING TO AND LEARNING FROM ALL OF YOU, THE COMMUNITY IN NEED. The reasons why our guidelines resonate with so many is because we listened, and we pulled from much of our prior work below, that we did along our journey, which we also encourage you to check out below.

[We began our work with one of the first long COVID studies to be done in June 2020 which compared confirmed and unconfirmed cases. We then completed the first experiences and needs survey for the long COVID community in October 2020. We created various resources such as our comprehensive guide for Longhaulers and providers, a COVID competent providers list and several public service announcements, all of which you can find on our website, where we also just launched a Long COVID Dashboard and will shortly be launching a Long COVID Resource Map. We co-drafted the Treat Long COVID Act and a \$60M/yr. appropriations request which includes long COVID associated conditions (LCAC). We have provided language to 5 other bills and 2 other budget items to support the long COVID community and a \$125M/yr. appropriations request in the Senate, echoing the House version. We published a groundbreaking report and open letter to national leadership calling for the immediate formation of Long COVID Assistance Programs and a Long COVID Task Force and created a Roadmap to Successful Outcomes for Longhaulers. We also co-founded the Long COVID Alliance, and we became members of the Disability Economic Justice Collaborative and National Network for Long COVID Justice. We have met, and continue to meet, with various government and health agencies to try to educate them about the needs of the long COVID community, reinforcing the necessity for meaningful, weighted patient engagement at every stage, of every action, for long COVID and its associated conditions. Our president and founder also serves on the NIH'S RECOVER Initiative's Ancillary Studies Oversight Committee and on the Long COVID Research Fund's Advisory Board and was also just a recipient of the Amelia Moore Sparkle Award for Compassionate Advocacy from Dysautonomia International].

We hope that after reviewing how deeply committed and involved we are in the Long COVID community's long-term well-being, and the well-being of all those with complex, chronic illnesses, that you will support us and vote for us for involvement in this project moving forward.

2. Partnering with Covid-19 Longhaulers Advocacy Project

38 Up Votes | 1 Down Votes | 37 Net Votes

Comments: 2

Followers: 3

Since the early days of the pandemic, when no one listened to us when we said we were not recovering from the virus, patients led the discussion on long Covid. Organizations like the Covid-19 Longhaulers Advocacy Project formed to speak for those too sick to do so themselves. No step forward should be taken without working directly with those whose very decisions this committee will affect. Partnering with patient-led advocacy groups like C-19 LAP is fundamental to directly addressing the concerns of those living with post-acute sequelae of COVID-19 (PASC).

Outreach Efforts

To ensure a wide range of participants in the online dialogue, DOL, along with the other host agencies, conducted numerous strategic outreach efforts, including distributing targeted eblasts, publishing announcements in DOL newsletters, and posting on @USDOL's Twitter and other social media accounts. In addition, ePolicyWorks conducted its own outreach via the @ePolicyWorks Twitter account and through emails to targeted groups, such as the registrants of previous disability and stay-at-work/return-to-work (SAW/RTW)-focused ePolicyWorks online dialogues, long COVID advocacy organizations, healthcare organizations, organizations that represent employers and workers, state and local government officials, and other key stakeholders, including members of the disability community.

ePolicyWorks Email and Social Media Outreach

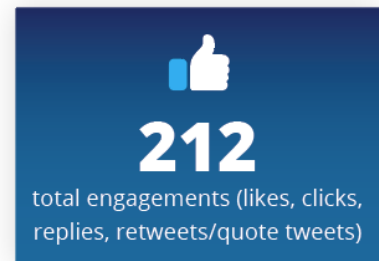
ePolicyWorks conducted six distinct email campaigns over the course of the dialogue. The campaigns included the following:

1. Dialogue launch announcement (general invite)
2. Three separate targeted dialogue announcements (one to disability advocacy groups, one to historically underserved population advocacy and worker equity groups, and one to previous dialogue registrants)
3. Outreach to media outlets and health publications to raise awareness of the dialogue
4. Dialogue "last week" reminder to current dialogue registrants
5. Dialogue "last week" reminder to the ePolicyWorks community
6. Dialogue "last day"

In total, 33,676 emails were sent to ePolicyWorks stakeholders with an open rate of more than 20%, which is several percentage points better than recent ePolicyWorks dialogue outreach campaigns and higher than the industry average of 17%. The individuals who opened the emails were informed of the dialogue and also learned about DOL's efforts to support workers with long COVID and their employers. In addition, 11.5% of individuals who opened one of the outreach emails clicked on a link in the email.

- Total emails delivered: **33,676**
- Total emails opened: **6,792 (20.2%)**
- Total number of clicks on links in emails (excluding multiple clicks of the same link): **774 (11.5%)**

In addition to email distribution, ePolicyWorks posted 25 tweets to its Twitter account throughout the dialogue. The 25 tweets resulted in 3,802 impressions and 212 interactions (likes, clicks, replies, retweets or quote tweets).



- Number of impressions from all @ePolicyWorks *Long COVID* dialogue promotional tweets: **3,802**
- Total engagement with @ePolicyWorks *Long COVID* dialogue tweets (likes, clicks, replies, retweets or quote tweets): **212**

Independent Online Dialogue Promotion

Beyond outreach by ePolicyWorks, the department and the host agencies, as well as many other public and private organizations promoted the online dialogue through Facebook, LinkedIn, Twitter, emails, blogs, newsletters and action alerts. Below is a sampling of the organizations that disseminated details regarding the online dialogue:

- Association of University Centers on Disabilities (AUCD)
- The Campaign for Disability Employment (CDE)
- The Council of State Governments (CSG) Disability Employment Policy
- Kessler Foundation
- Maryland Department of Education Division of Rehabilitation Services
- The Myalgic Encephalomyelitis Action Network #MeAction
- National Rehabilitation Information Center (NARIC)
- Pandemic Patient
- Respectability

In addition to promotion by advocacy groups and other organizations, several major publications and news outlets covered the dialogue and shared links to the dialogue in articles, newscasts and online bulletins. These included, but are not limited to:

- The Bismarck Tribune [federal government wants to crowdsource solutions.](#))
- The Boston Globe ("[How is long COVID affecting people in the workplace? The](#)

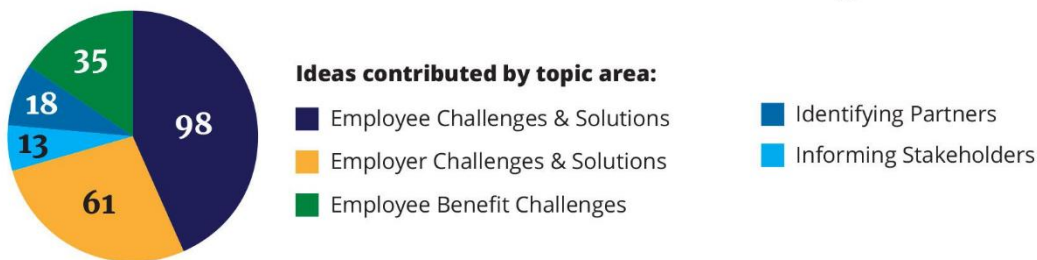
- Business Insurance (“[Department of Labor to tackle long COVID workplace challenges?](#)”)
- D (Dallas) Magazine
- Government Executive
- HR Drive
- Inside Health Policy
- National Public Radio (NPR)
- WorkCompCentral (“[Feds Seeking Input on Long-COVID Workplace Challenges.](#)”)
- Workers Comp Executive
- Safety and Health Magazine

Online Dialogue Participant Summary

The *Understanding and Addressing the Workplace Challenges Related to Long COVID* Online Dialogue opened on July 11, 2022, and closed at the end of the day on August 15, 2022. Detailed below is information on contributions to the dialogue, including submissions, comments and votes, along with the number of online dialogue views and registrants, participation rates and profile information provided by registrants during the registration process.

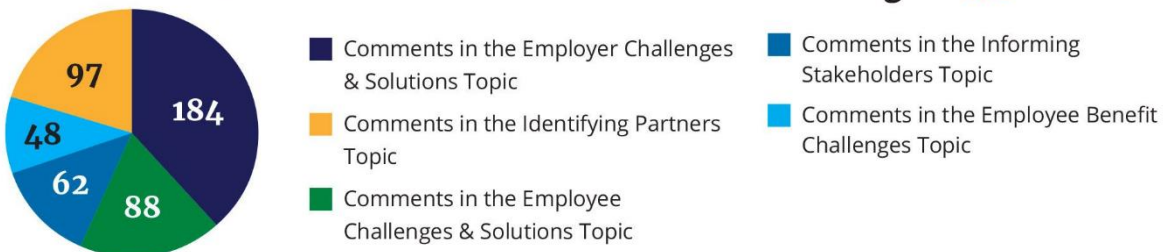
Contributions to the Online Dialogue

Total number of ideas in the online dialogue: 225



- Ideas in the Employer Challenges & Solutions Topic - **98**
- Ideas in the Employee Challenges & Solutions Topic - **61**
- Ideas in the Informing Stakeholders Topic - **13**
- Ideas in the Employee Benefit Challenges Topic – **18**
- Ideas in the Identifying Partners Topic – **35**

Total number of comments in the online dialogue: 479



- Comments in the Employer Challenges & Solutions Topic - **184**
- Comments in the Employee Challenges & Solutions Topic - **88**
- Comments in the Informing Stakeholders Topic - **62**
- Comments in the Employee Benefit Challenges Topic - **48**
- Comments in the Identifying Partners Topic - **97**

Total number of votes in the online dialogue: 3,481



- Votes in the Employer Challenges & Solutions Topic – **1,403**
- Votes in the Employee Challenges & Solutions Topic - **535**
- Votes in the Informing Stakeholders Topic - **532**
- Votes in the Employee Benefit Challenges Topic - **314**
- Votes in the Identifying Partners Topic - **697**

Visitors, Registrants and Participants in the Online Dialogue

From July 11 to August 15, 2022, the *Understanding and Addressing the Workplace Challenges Related to Long COVID Online Dialogue* could be viewed by visiting LongCOVIDatWork.IdeaScale.com. Visitors to the website could access all the submissions, including ideas, comments and votes in the online dialogue, as well as detailed information on how ePolicyWorks dialogues work and step-by-step instructions on how to participate.

In addition, the dialogue provided vital information on long COVID including the Department of Health and Human Services’ current reports and action plans, the Department of Labor’s detailed benefit guides and SAW/RTW resources. Links to resources from the CDC and the U.S. Equal Employment Opportunity Commission, as well as information from the Center for American Progress, the Brookings Institute and the National Law Review, were shared during the crowdsourcing exchange.

All this information was available to anyone who visited the website LongCOVIDatWork.IdeaScale.com, but in order to participate in the dialogue—i.e., submit an idea, comment or vote—individuals had to complete the registration process. The registration process entailed completing an online form that asked registrants to share the community with which they identify, their occupation, their type of location and their stakeholder group. Though all questions were mandatory, the form allowed participants to choose more than one answer and/or choose “other.”

After the form was submitted, registrants were asked to verify their email to complete the process. Once an individual’s email was verified by IdeaScale, they could create a password, log in and add ideas, as well as comments and votes on ideas submitted by others.

For the following dialogue metrics, “**visitors**” are defined as all individuals who visited the dialogue website, whether or not they chose to complete the registration process. As mentioned above, during the dialogue, all visitors to the website could view all ideas, comments, votes and resources. For the metrics, “**Registrants**” are those who successfully verified their email and created a password and “**Participants**” include anyone who submitted an idea or commented or voted on an idea submitted by another.

- Total number of visits to the online dialogue: **4,180 visits**
- Total number of page views: **14,741 pages**
- Average number of times visitors came to the online dialogue: **2.39 sessions**
- Average length of time they spent visiting the online dialogue: **7:40 minutes**
- Average pages they viewed during a visit to the online dialogue: **3.53 pages**
- Total number of registrants in the dialogue: **617 individuals**
- Total number of registrants who participated by contributing an idea, comment or vote: **393 (64% of registrants)**
- Total number of registrants who contributed ideas: **155**
- Total number of registrants who contributed comments: **120**
- Total number of registrants who contributed votes: **309**
- Total number of states represented by dialogue registrants: **50, the District of Columbia and the U.S. Territories**



4,180
dialogue visits

Page views: **14,741**
Avg. time: **7:40 minutes**



617
registrants

15% of visitors registered



393
participants

64% of registrants participated

Online Dialogue Registration Questions

When registering for the *Understanding and Addressing the Workplace Challenges Related to Long COVID Online Dialogue*, registrants were asked if they would like to share information about their community, occupation, location and stakeholder group. Registrants were given prepopulated choices and could choose all that applied to them including a choice titled "other." Below is a summary of the responses from dialogue registrants.

Industry or Government Represented



Telecommunications
Education **Federal Government**
Retail **Healthcare** Mining Real Estate
Energy **Financial Services** Agriculture
Defense **Construction** **Technology** **Manufacturing**
Arts/Entertainment Transportation Hospitality
Food & Beverage **State or Local Government** Banking

- 145 registrants selected Healthcare
- 84 registrants selected Education
- 42 registrants selected State or Local Government
- 40 registrants selected Tech
- 35 registrants selected Federal Government
- 26 registrants selected Arts/Entertainment
- 20 registrants selected Construction/Labor/Workforce
- 16 registrants selected Financial Services
- 12 registrants selected Manufacturing
- 11 registrants selected Transportation
- 10 registrants selected Retail
- 9 registrants selected Energy
- 9 registrants selected Food & Beverage
- 7 registrants selected Hospitality
- 6 registrants selected Agriculture

- 6 registrants selected Defense
- 6 registrants selected Telecommunications
- 4 registrants selected Banking
- 2 registrants selected Real Estate
- 1 registrant selected Mining

Stakeholder Group

- 305 registrants selected Employee
- 95 registrants selected Advocacy Organization
- 61 registrants selected Employer
- 53 registrants selected Non-profit
- 36 registrants selected Health Care Providers
- 29 registrants selected Federal Government
- 26 registrants selected State or Local Government
- 22 registrants selected Research or Educational Institution
- 8 registrants selected Private Insurers
- 130 registrants selected Other

Community Represented

- 382 registrants selected White
- 66 registrants selected Black
- 50 registrants selected Latino
- 43 registrants selected Asian
- 22 registrants selected Tribal Community
- 126 registrants selected Other/Do Not Wish to Disclose

Location

- 248 registrants selected Suburban
- 220 registrants selected Urban
- 98 registrants selected Rural
- 44 registrants selected Other/None of the Above

Review and Analysis of Online Dialogue Contributions

Over the course of the *Understanding and Addressing the Workplace Challenges Related to Long COVID Online Dialogue*, participants from across the U.S. shared thought-provoking and innovative ideas and recommendations on ways the department can ensure it is providing the resources and tools employers and employees need to address the workplace challenges of long COVID. The results will help inform future priorities and funding opportunities and ensure that the department is addressing the needs of employers and employees from diverse backgrounds. In addition, the information gathered through will help shape the government’s understanding of the workplace issues people with long COVID face.

The range and depth of the ideas submitted and discussed during the online dialogue demonstrate the immense value of engaging citizens in collaboration efforts. People who have experienced long COVID, their employers, disability advocates, health care professionals, non-profits, state and local government representatives and other stakeholders jointly contributed 225 ideas, 479 comments, 3,482 votes, 82 resources ([Appendix A](#)) and 21 potential DOL partners ([Appendix B](#)) to the dialogue.



Appendix A: Resources Shared in the Online Dialogue

Organizations and Not-for-Profits

- [Academy of Cardiovascular and Pulmonary Physical Therapy](#)
- [Academy of Orthopedic Physical Therapy, Occupational Health Special Interest Group \(OHSIG\)](#)
- [Association of People Supporting Employment First](#)
- [Body Politic](#)
- [College and University Professional Association for Human Resources](#)
- [Disability Management Employer Coalition](#)
- [Dysautonomia International](#)
- [Long Haul Voices, Unfixed](#)
- [#MEAction Network](#)
- [Patient-Led Research Collaborative](#)
- [Society of Human Resource Management](#)
- [The COVID-19 Longhauler Advocacy Project](#)

Reports and Resources

- [An Open Letter to President Biden, Cabinet and Congressional Leadership and Key Government Agencies, The COVID-19 Longhauler Advocacy Project](#)
- [Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, National Library of Medicine, February 10, 2015](#)
- [C-19 Longhauler Advocacy Project \(Facebook Group\)](#)
- [Clinical Guidance to Optimize Work Participation After Injury or Illness: The Role of Physical Therapists, March 3, 2021](#)
- [Connect With Us, The COVID-19 Longhauler Advocacy Project](#)
- [Hybrid Workplace Strategy, Centric](#)
- [Increase Mental Clarity and Focus, Brain Health Sciences](#)
- [Join #MEAction's Campaign to Tell Those with Long COVID to #StopRestPace, #MEAction Network](#)
- [Legislative Advocacy, APSE](#)
- [LFR-Coronavirus Subcommittee Hearing, The COVID-19 Longhauler Advocacy Project, July 19,2022](#)
- [List of Human Resource Professional Associations & Organizations, Jobstars](#)
- [Mental Morbidities and Chronic Fatigue in Severe Acute Respiratory Syndrome Survivors, JAMA Network, December 14, 2009](#)
- [National Dashboard to Report Non-Compliance & Submit Evaluations of Coordinator Competency, Accommodation Efficacy & Support, The COVID-19 Longhauler Advocacy Project](#)
- [Post-Infective and Chronic Fatigue Syndromes Precipitated by Viral and Non-Viral Pathogens: Prospective Cohort Study, September 16, 2006](#)
- [Survey Questions to Measure Long COVID Prevalence and Impact on Work, Patient-Led Research Collaborative](#)

- [Use of Cardiopulmonary Stress Testing for Patients with Unexplained Dyspnea Post-Coronavirus Disease, ScienceDirect, December 2021](#)
- [Using Self-ID to Create a More Inclusive Workplace, Google Diversity, Equity & Inclusion](#)
- [Why Do I Still Have Thyroid Symptoms? Kharrazian Resource Center](#)
- [Working with Long COVID, CIPD, February 8, 2022](#)

State, National and International Government Resources

- [Accommodating Employees with COVID-19 or Long COVID, Job Accommodation Network](#)
- [Council of State Administrators of Vocational Rehabilitation](#)
- [Creating Inclusive Work Places, The Employer Assistance and Resource Network on Disability Inclusion](#)
- [Disability Employment: Stay-at-Work/ Return-to-Work, National Conference of State Legislatures](#)
- [Engaging Employees to Measure Success: Innovative Approaches to Encouraging Self-Identification of Disability, NASA](#)
- [Managing Post-Exertional Malaise \(PEM\) in ME/CFS, Centers for Disease Control and Prevention](#)
- [Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Job Accommodation Network](#)
- [Policy Interpretation Ruling, Social Security Administration, April 3, 2014](#)
- [Regulations, Occupational Health and Safety Administration](#)
- [Stay at Work/ Return to Work, Employer Assistance and Resource Network on Disability Inclusion \(EARN\)](#)
- [Stay at Work/ Return to Work, Office of Disability Employment Policy](#)
- [Testimony Before the Select Subcommittee on the Coronavirus Crisis, Hannah Davis, July 19, 2022](#)
- [The Long COVID Experience, House Committee on Energy and Commerce, Subcommittee on Health, April 28, 2021](#)
- [U.S. Bureau of Labor Statistics, Occupational Requirements Survey](#)

News Articles, Blogs and Webinars (by date)

- [Northern Ireland Sick Note Law Changed to Allow More Staff to Issue Them, BBC News, July 19, 2022](#)
- [1 million Americans Have Left the Labor Market Because of Long COVID. A House Subcommittee Will Hear Expert Testimony Today, Fortune, July 19, 2022](#)
- [Study Reveals Benefits of Hybrid Working for Disabled Workers but Some Fear Choice Between Health and Career Progression, phys.org, July 11, 2022](#)
- [COVID's Chronic Effects Loom Increasingly Large, Financial Times, July 7, 2022](#)
- [Long COVID and the Workplace: What Employers Could Do Better, VaccinesWork, June 16, 2022](#)
- [What is Neurofatigue and How Does it Relate to Brain Injury and PTSD? Brainline, June 9, 2022](#)

- [Want a Part-Time Job? Here's Why Corporate American Won't Hire You, Insider, June 8, 2022](#)
- [Got COVID? Doctors Warn Powering Through It- Even from Home - Can Worsen Health Toll, Los Angeles Times, July 7, 2022](#)
- [Long COVID is a New Disability Affecting Millions of Workers- and ' A Moment of Essential Innovation' for Employers, One Lawyer Contends, Fortune, June 5, 2022](#)
- [Hybrid Work: Making It Fit with Your Diversity, Equity, and Inclusion Strategy, McKinsey & Company, April 20, 2022](#)
- [Supporting Employee Caregivers Starts with Better Data, Harvard Business Review, April 15, 2022](#)
- ["Take a planned approach to managing Long COVID in the workforce - new SOM guide," Supporting Occupational Health and Wellbeing Professionals, April 8, 2022](#)
- [Plasma Metabolomics Reveals Disrupted Response and Recovery Following Maximal Exercise in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, JCI Insight, March 31, 2022](#)
- [Accommodating Disabilities in Remote and Hybrid Work, Forbes, March 30, 2022](#)
- [How Managers Can Support Employees with Long COVID, MIT Sloan Management Review, March 14, 2022](#)
- [Chronic Illness Tips! Pacing Doesn't Have to be Scary, Jessica Kellgren-Fozard \(Video\), March 11, 2022](#)
- [COVID-19 Likely Resulted in 1.2 million More Disabled People by the End of 2021- Workplaces and Policy will Need to Adapt, Center for American Progress, February 9, 2022](#)
- [When COVID-19 'Brain Fog' Hit, They Turned to a Language App, Discover, February 1, 2022](#)
- [Is ' Long COVID' Worsening the Labor Shortage? Brookings, January 11, 2022](#)
- [Mixmag: Researchers Study Music App to Treat Brain Fog, UC News, January 8, 2022](#)
- [Leveraging Self-ID Campaigns to Increase Percentages of Professionals with Disabilities, Veterans & LGBTQ, DiversityInc, 2022](#)
- [Long COVID's Catch 22: Too Sick to Work, Yet Not Quite Disabled, Bloomberg Law, November 18, 2021](#)
- [Flexibility for All: Unilever's Vision of the Future of Work, Forbes, May 23, 2021](#)
- [10 Tips for COVID-19 Long-Haulers Seeking Disability Benefits, The Mighty, November 14, 2020](#)
- [Understanding Your LTD Policy's Mental/Nervous Limitation, California Insurance Lawyer Blog, October 11, 2019](#)
- [How I Use an App to Manage My Fatigue After Brain Injury, Brainline, June 19, 2019](#)
- [How Can Organizations Host Effective Self-ID Campaigns? Getting Hired, May 16, 2019](#)
- [10 Apps That Can Help You Be Productive, Even When Brain Fog Takes Over, The Mighty, March 28, 2018](#)
- [Navigating Social Security Disability and ERISA Benefits- What Should You Be Aware Of? McKennon Law Group PC \(No Date\)](#)
- ["Job Sharing and Beyond with Karin Tischler" \(Podcast\)](#)
- [Chronic Illness, Karen Hill \(Full Video Playlist\)](#)

Appendix B: Potential Partners Identified in the Online Dialogue

[Academy of Cardiovascular & Pulmonary Physical Therapy](#)

[American Physical Therapy Association](#)

[Association of People Supporting Employment First \(APSE\)](#)

[Body Politic](#)

[College and University Professional Association for Human Resources](#)

[Council of State Administrators of Vocational Rehabilitation](#)

[COVID-19 Longhailer Advocacy Project](#)

[COVID Care Group](#)

[Disability Management Employer Coalition](#)

[Dysautonomia International](#)

[Job Accommodation Network \(JAN\)](#)

[#MEAction Network](#)

[National Organization for Rare Disorders](#)

[Open Medicine Foundation](#)

[Pandemic Patients](#)

[Patient-Led Research Collaborative](#)

[Physios for M.E.](#)

[Society for Human Resource Management](#)

[Solve M.E.](#)

[Survivor Corps](#)

[Workwell Foundation](#)