### San Luis Obispo County

## LONG COVID-19

Findings and Analysis
November 2024



### THANK YOU

Heartfelt thanks to the 3,791 San Luis Obispo County residents who shared their experiences and insights related to COVID-19 and persistent post-COVID symptoms.

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"My doctors said I got lucky ... but, two years later, I still don't feel lucky when I look at all the covid symptoms I still carry with me. I feel exhausted, even after eight hours of sleep (if my body lets me sleep). I feel winded after a slow mile long walk with my dog. I feel frustrated when I can't form a coherent thought. I feel terrified when my chest tightens and my heart randomly stops only to begin racing so fast that I'm worried I'll have a heart attack or a stroke. My doctors say I should feel lucky, but mostly I just feel scared."

~Los Osos resident, age in their 50s

# The County of San Luis Obispo Public Health Department gathered input from residents who had COVID-19, regarding their experience with Long COVID. Their answers inform this report.

On July 11, 2022, the County of San Luis Obispo Public Health Department went live with the County's first Long Term Impact of COVID-19 form. The purpose of the form was to collect community insights to better understand the local impact that COVID-19 has had on the lives of residents.

Included in the form were questions regarding pre-pandemic illnesses and behaviors, initial COVID-19 symptoms, Long COVID-19 symptoms, healthcare access and medications sought during infection, and post-COVID-19 behavior change. Most questions used in this form were either adopted or adapted from existing health surveys developed by the US Census, University of California Los Angeles, Rare Diseases Clinical Research Network, University of California San Francisco, Johns Hopkins, and the INSPIRE study.

Limitations to these findings include the self-reported nature of the responses; bias based on the likelihood that those familiar with or experiencing Long COVID-19 are more likely to respond; bias caused by the form being available only online; and a flaw with the skip pattern of the Spanish version of the form in which irrelevant questions were not automatically skipped. Feedback from respondents indicated that "cough" was missing as a Long COVID-19 symptom option, and while it could be manually entered, it was later added. The absence of cough previously listed as an option may have impacted the findings of the top reported symptoms.

Case rates per 1,000 people are provided, though should be interpreted cautiously due to these limitations that challenge generalizability.

In total, 3,791 residents of San Luis Obispo County completed the form. Of these responses, 112 completed the form in Spanish and 3,679 completed it in English. When the form opened, it was announced to the public via news media and online channels. SLO County residents who had a reported positive test result for COVID-19 received a one-time text message informing them of the availability of the form. All information about the availability of the form was provided in English and Spanish.

"Still seven months later I am experiencing symptoms such as weakness, fatigue, a rattling in my chest when I breathe deeply, coughing, joint pain, mental confusion, brain fog and heart palpitations that were so extreme I had to visit a cardiologist. I am only 49 years old and it scares me that I am still experiencing these symptoms."

~San Luis Obispo resident in their 40s

## Many SLO County residents who tested positive for COVID-19 have since experienced symptoms of Long COVID.

The following pages include the self-reported responses from these residents. The tables below show the breakdown of respondent answers based on their initial symptomatic status. Of respondents, the majority (90%) reported being symptomatic upon their first infection with the virus that causes COVID-19. The remaining 10% reported no symptoms associated with their initial infection.

## Findings for those who were symptomatic upon initial infection (3,402 respondents)

Symptomatic During Initial Infection					
Yes, I was symptomatic	3,402				
No, I was asymptomatic	389				

Of the 3,402 respondents who reported being initially symptomatic with COVID-19, 1,954 (57%) reported having symptoms that they could not attribute to any other illness or condition after recovering from their initial COVID-19 illness. The odds of prolonged or new symptoms for those initially symptomatic are 1.8 times that for the initially asymptomatic respondents. The six most reported symptoms of Long COVID-19 following initial COVID-19 recovery included tiredness, fatigue, shortness of breath, muscle aches, headache, and loss or decreased sense of smell.

If these findings were generalized, for every 1,000 individuals that were initially symptomatic with COVID-19, we would anticipate that more than 30% of these people could experience tiredness, and approximately 25% could experience either isolated fatigue or fatigue in conjunction with tiredness.

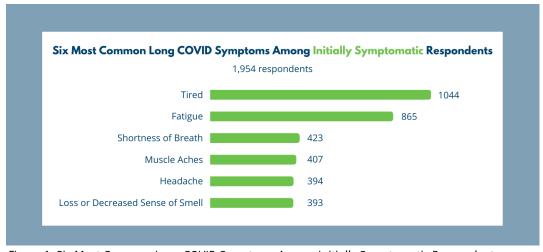


Figure 1. Six Most Common Long COVID Symptoms Among Initially Symptomatic Respondents

"Originally, I was completely asymptomatic. Then, about six weeks after infection, things went haywire. Extreme dizziness, blood pressure issues, elevated heart rate, debilitating migraines ... I have accepted this is the way it will be for the rest of my life and it's heartbreaking."

~SLO County resident

## Findings for those who were asymptomatic upon initial infection (389 respondents)

Of the 389 respondents who reported being asymptomatic but tested positive upon initial infection with the virus that causes COVID-19, 164 (42%) reported having symptoms that they could not attribute to any other illness or condition after testing positive.

The six most reported Long COVID-19 symptoms following a positive test included tiredness, fatigue, runny nose, muscle aches, and sore throat. If these findings were to be generalized, for every 1,000 asymptomatic individuals who test positive we could anticipate that more than 20% of these people could experience tiredness, and approximately 15% could experience either isolated fatigue or fatigue in conjunction with tiredness.

Regardless of whether initial infection with the virus that causes COVID-19 led to symptoms or not, the two most common symptoms reported as Long COVID-19 were tiredness and fatigue. There were also similarities in muscle aches and headaches being reported among both groups.

Of the initially asymptomatic respondents, approximately 21% reported that their activity level was somewhat less or much less than before they tested positive for the virus that causes COVID-19 . If this were to be extrapolated to the public, for every 1,000 individuals who were asymptomatic and tested positive for SARS-CoV-2, about 210 of these people would report their activity levels as being somewhat less or much less than before they tested positive.

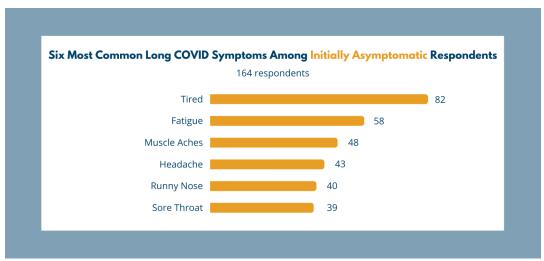


Figure 2. Six Most Common Long COVID Symptoms Among Initially Asymptomatic Respondents

"Although I'm a young healthy 21 year old female, I struggled with Covid. I had lost my sense of taste for almost a month and my smell for almost half a year. To this day it has never been the same. I had always been interested in becoming a sommelier sometime in the future as I had a really sensitive palate and sense of smell. Today I'm realistic in that not being possible for my taste and smell are not the same almost two years after ... I used to love exercise and being active and now I struggle to go for a walk. Covid, although I was lucky enough to be where I'm at today, has changed my life."

~San Luis Obispo resident in their 20s

# SLO County residents of different ages, ethnic groups, fitness levels, and areas of the county reported experiencing symptoms of Long COVID.

In an effort to reduce barriers to participation, form questions did not gather demographic information for all participants. However, many participants volunteered elements of demographic information such as age, gender, family makeup, housing status. This input indicated that people of different ages and with many other differences reported symptoms of Long COVID.

The form was available in English and Spanish. Of 3,791 residents who completed the form, 112 did so in Spanish.

Research is emerging at the state and national levels about factors that influence the risk of Long COVID. The California Department of Public Health reports:

People of any age (children, teens, or adults) can get post-COVID conditions after having COVID-19. People who had mild, moderate, or severe COVID-19 illness can develop post-COVID conditions. People who are older, obese, female, or who have underlying health conditions (co-morbidities) like Type 2 Diabetes or asthma, may have higher risks of developing post-COVID conditions. ...

Social determinants of health, such as lower income, less access to health care, and more crowded housing, can increase the risk of COVID-19 and post-COVID conditions. Additional research is needed to understand who is at higher risk of developing post-COVID conditions.

A variety of terms are used to describe the condition referred to here as long COVID, including:

- Long COVID
- Post-COVID conditions
- Long haul COVID
- Post-acute COVID-19
- Chronic COVID
- Post-acute sequelae of SARS-CoV-2 (PASC)

This terminology may evolve in time. For the purposes of this report, the terms are used interchangeably.

"The toll taken by the virus, was not (majorly) noticeable until after my quarantine period had ended. It was at that point, things got bad for me. I could not walk to the end of my driveway and back without becoming drenched in sweat and totally exhausted. My speech was impaired and even now I have trouble getting words out. My taste and smell have returned but a couple tastes do not corollate with the foods they represent. My memory (though was not perfect before) is now very bad. Muscle pain, joint pain, range of motion has severely been shortened throughout my entire body. Mentally, I have a lack of desire to do what I previously loved to do ... I have been admitted to the ICU for 4 days. Since the virus, I have had illnesses I've never have experienced before."

~Paso Robles resident in their 60s

### People experienced a wide range of symptoms attributed to Long COVID, but several symptoms were consistently more common than others.

The figure below summarizes the prevalence of symptoms reported. This includes Long COVID symptoms reported by both asymptomatic and symptomatic people. Write-in answers have not been included in this summary. These findings include tiredness ("more tired than usual") and fatigue as the most commonly-reported symptoms, followed by muscle aches, shortness of breath, and headaches. Participants selected these symptoms from a list; others (such as "brain fog") were reported in a separate write-in section. A total of 254 people reported symptoms in the "other" field. When possible, those entries were added to matching categories.

Long COVID-19 Symptoms	Total	Symptomatic People	Asymptomatic People
A new cough, or worsening of a chronic cough	388	356	32
Abdominal pain	114	105	9
Chills	128	107	21
Confusion	260	245	15
Decreased smell or change in smell	412	391	21
Decreased taste or change in taste	394	376	18
Diarrhea (>3 loose/looser than normal stools over 24 hours)	159	146	13
Fatigue	919	861	58
Feeling hot or feverish	204	181	23
Fever >100.4F (38C)	50	29	21
Hair loss	251	241	10
Headache	434	391	43
Heart palpitations	234	223	11
Joint pains	413	384	29
Mood changes (anxiety, depression, etc.)	372	352	20
More tired than usual	1122	1040	82
Muscle Aches	453	405	48
Nausea	134	121	13
Pain or tightness in your chest	241	221	20
Pink eye or conjunctivitis	25	23	2
Repeated shaking with chills	51	41	10
Runny Nose	285	245	40
Seizures	11	10	1
Shortness of Breath	448	420	28
Sleep disorder	251	234	17
Sneezing	147	122	25

"I'm still experiencing it unfortunately. It's been since Sept last year. I'm still not able to work a full work week, walk my dog, or enjoy other activities I used to. It's also been frustrating to have most at my workplace have the attitude that what I'm experiencing isn't real or isn't a big deal."

~SLO County resident

# Some people have been unable to resume their normal levels of activity, including a full return to work, following COVID-19.

Of the initially symptomatic respondents, approximately 35% reported that their activity level was somewhat less or much less than before they had COVID-19 symptoms. If this were to be generalized to the public, for every 1,000 individuals that experienced COVID-19 symptoms, about 350 individuals' activity levels may be somewhat less or much less than before they had COVID-19.

Sixty-six percent of respondents were working before they had COVID-19 symptoms. Of those, nearly a quarter reported they did not return to work or returned to work with a modified schedule/part-time after COVID-19. If generalized to the public, for every 1,000 individuals that experienced COVID-19 symptoms, we would anticipate more than 20%, or 200 people, would either not return to work or would need to modify their work schedule.

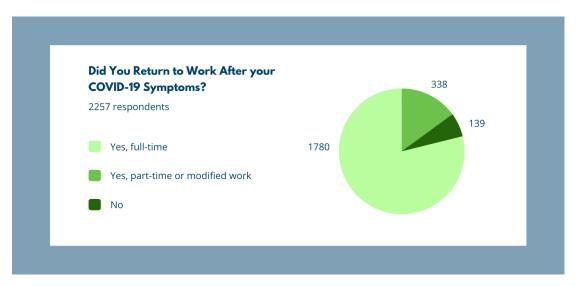


Figure 4. Did You Return to Work After your COVID-19 Symptoms?

Of the initially asymptomatic respondents, approximately 21% reported that their activity level was somewhat less or much less than before they tested positive for the virus that causes COVID-19. If this were to be extrapolated to the public, for every 1,000 individuals that were asymptomatic and tested positive for SARS-CoV-2, about 210 of these people would report their activity levels as being somewhat less or much less than before they tested positive.

"I have post acute chronic COVID. I have been hospitalized 7 times for pneumonia. Four of those times I was in the hospital for 4 days. I have an enlarged right vertical in my heart. I went to work two days a week for seven weeks prior [to] my first hospitalization. I have had severe fatigue, digestive issues including nausea, I have not been fully recovered since 2020."

~Los Osos resident in their 60s

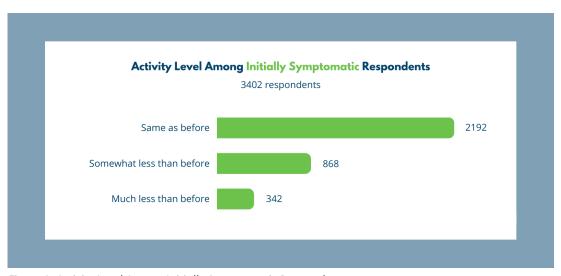


Figure 3. Activity Level Among Initially Symptomatic Respondents

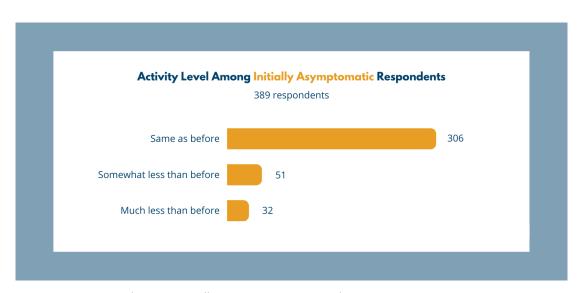


Figure 5. Activity Level Among Initially Asymptomatic Respondents

"Covid never worried me. Shortly before I tested positive I had just turned 19. I am young, I am not immunocompromised, and I've always been a very healthy kid. However, after about a month of losing my taste and smell, it still hadn't returned. Time was blurry during the pandemic so I don't remember very well, but at some point things started to come back. But they didn't come back the same. ... I used to cry sometimes because when I hug my parents I can't smell them. I didn't realize how much of a privilege my senses could be. I am a surfer and I cannot smell the ocean anymore."

~San Luis Obispo resident in their 20s

### These local findings are consistent with state trends.

The findings of this research align with preliminary findings and reports from the California Department of Public Health (CDPH). Similarities can be seen in the most reported symptoms, the approximate risk amongst individuals related to their previous COVID-19 illness or infection, and self-reported behavior changes in both CDPH and local findings.

CDPH continues to assess the impact of the virus that causes COVID-19 and how infection can lead to long-term health problems.

The National Institutes of Health is continuing large-scale research on Long COVID and many university medical centers are also conducting research in this area.

"I love to run and hike, and while I still get out, it's not the same. My energy isn't the same and I suffer with a forever cough that is exhausting and drives my family crazy! Not to mention the distorted taste and smell that has lingered for nearly 2 years ... Minus my cough, I appear to be mostly healthy on the outside. But, it's hard on the inside to feel the cough all the time, the constant lack of energy, my extra dry hair, not liking foods I once loved, and just wishing I felt like I did before Covid ... I'm hoping for my full version of recovery someday - one day at a time - and I hope everyone else recovers as well!"

~SLO County resident

While there is still much to learn about Long COVID, emerging research indicates most people recover in time. Resources for Long COVID survivors are relatively scarce but are becoming more available.

To summarize an <u>update from the Penn Medicine Post-COVID Assessment and Recovery Clinic</u>, established in spring 2020 as one of the nation's first clinics focused on post-COVID conditions:

"Recovery takes time. Often, people go to the doctor expecting a rapid resolution to their illness. You have strep throat, you go to the doctor, get your antibiotic, and then you're feeling a lot better in a day or two. But Long COVID isn't one of these situations for most people. ... A frustrating aspect of recovery from Long COVID — but one that's important to remember — is that it may not be a strictly linear process. Fatigue, for example, is often the most difficult symptom to overcome. ... Despite these ups and downs, the numbers indicate that most patients recover. A study out of Israel showed that the majority of patients who had Long COVID after a mild infection recovered within a year, and the Kaiser Family Foundation survey found that the rate people reported experiencing Long COVID steadily fell from 19 percent in June 2022 to 11 percent in January 2023."

### Resources

The following pages include informational resources and recommendations for those experiencing symptoms of Long COVID. As knowledge about Long COVID is rapidly developing, it is a good idea to check local, state, and national hubs regularly for updates. Locally, information is updated regularly at <a href="slopublichealth.org/longcovid">slopublichealth.org/longcovid</a>.

### Prevention

Long COVID can happen after any infection with the virus that causes COVID-19, even mild or asymptomatic cases. Being up to date on your COVID-19 vaccines is the first recommended step to prevent COVID-19 infection and reduces your risk of experiencing Long COVID. In a large summary study, vaccination was associated with an overall 43% reduction of Long COVID (JAMA Network: Risk Factors Associated With Post–COVID-19 Condition: A Systematic Review and Meta-analysis.) In addition to vaccination, you can reduce your risk of infection by masking in crowded places, washing your hands often, and avoiding large gatherings.

If you become infected with the virus that causes COVID-19, contact your medical provider to discuss treatment with Paxlovid.

Research is ongoing to identify strategies to reduce the development of Long COVID.

# **Healthcare Appointment Checklist for Post-COVID** Conditions | COVID-19 |

 $Accessible\ link:\ \underline{https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-COVID-appointment/index.html.}$ 

This checklist is designed to help patients and caregivers get the most out of appointments with healthcare providers for post-COVID conditions.

THE SERVICES (I.J.)	☐ If needed, arrange <b>transportation</b> to your appointment.	conversation with your healthcare provider — e.g., taking notes or bringing a friend.	time is limited).	healthcare provider. Identify which ones are a priority for you (in case	☐ Make a list of <b>questions to ask your</b>	☐ Make a list of your current  medications/supplements.    I	your experience and symptoms and describes your best and worst days.	☐ Prepare a brief <b>report</b> that summarizes	symptoms, their severity, and anything that made you feel better or worse.		Them directly.  ☐ Keep a <b>journal or a list</b> for a week	need <b>paperwork</b> signed so your medical records can be sent to	☐ Ask the new provider's office if they	Before the Appointment
		0	or print out any instructions, medication	Ask for an <b>appointment summary</b> . If needed, ask the provider to write down	referrals, and future appointments.	<b>next steps</b> , such as tests, follow-up,	your priorities and issues.	☐ <b>Ask your own questions</b> , starting with	☐ Discuss your <b>level of activity.</b>	☐ Share your <b>medication/supplement list</b> .	☐ Answer the <b>provider's questions</b> .	to discuss.	☐ Tell your provider the most important	During the Appointment
			and supplements.	☐ Update and keep track of <b>medications</b>	to updates or changes during your	☐ Continue to record symptoms and keep your <b>journal</b> , so you can refer	questions or clarifications.	Dontact voice providers, office with any	☐ Follow your <b>provider's instructions</b> to the best of your ability.	appointments are on their calendars too.	others will go with you or drive you to future appointments, make sure the	☐ <b>Record future appointments</b> , including tests, in your calendar. If	☐ <b>Make appointments</b> for follow up.	After the Appointment



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## SEEKING SUPPORT AND CARE FOR LONG COVID SYMPTOMS

### Get care right away if needed.

If you think you might be experiencing a life-threatening emergency related to COVID-19, seek medical care immediately by dialing 911. Some post-COVID health problems (such as heart attack, stroke and blood clots) require immediate care.

### Make an appointment.

If you don't have a primary care provider, you can contact your insurance provider and ask for a list of network providers that are accepting new patients. If they are unable to help, feel free to please contact our Health Care Access and Navigation team at 805-781-4838. Our team will help find additional resources.

### Document your symptoms.

Review the CDC's Healthcare Appointment Checklist for Post-COVID Conditions (available on the previous page) and bring it with you to your appointment. Keep a journal or list for a week or two to document your activities, symptoms, severity, and anything that made you feel better or worse. Bring this with you to your appointment.

### Consider seeking referrals to specialists.

Your primary doctor can assist you with referrals to specialist physicians as needed for evaluation and management of your symptoms. If the care that you need cannot be accessed locally, you may need to be referred to or consider seeking care outside of your normal network.

### Talk with others.

Talking with others about Long COVID can help improve your emotional and mental health, as well as provide support and information about available resources. See the following pages for links to discussion forums, support groups, and more.

### Learn more about Long COVID from trusted sources.

See the following pages for links to more research and information. To help or participate in Long COVID research, visit <u>recovercovid.org</u>

### LONG COVID RESOURCES

### Information Hubs

Centers for Disease Control and Prevention (CDC): Long COVID or Post-COVID Conditions <a href="https://cdc.gov/coronavirus/2019-ncov/long-term-effects">cdc.gov/coronavirus/2019-ncov/long-term-effects</a>

California Department of Public Health: Resources for People with Post-COVID Conditions <a href="mailto:cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Post-COVID-Conditions-Resources.aspx">cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Post-COVID-Conditions-Resources.aspx</a>

California Department of Public Health: Long COVID Questions & Answers cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Post-COVID-QA.aspx

### **Support Groups**

Long COVID Alliance longcovidalliance.org

Long COVID Kids longcovidkids.org

Critical Illness, Brain Dysfunction, and Survivorship (CIBS) Center <u>icudelirium.org</u>

### **Mental Health Support**

CalHope www.calhope.org

Central Coast Hotline Text or call 800-783-0607

### Research

To help or participate in long COVID research, visit <u>recovercovid.org</u> or the Patient-Led Research Collaborative at <u>patientresearchcovid19.com</u>

Long COVID research is rapidly emerging. For updates, see CDC or CDPH information hubs (previous page) or visit <u>slopublichealth.org/longcovid</u>.

Stay connected.
Knowledge about Long COVID is rapidly developing. Stay connected for updates as new information becomes available.
slopublichealth.org/longcovid   805-781-5500