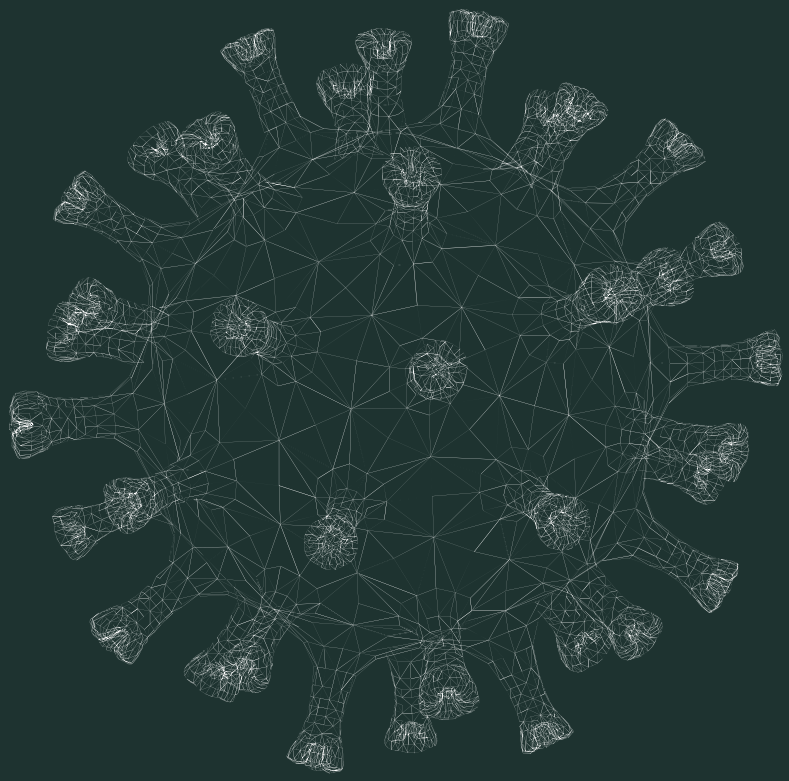
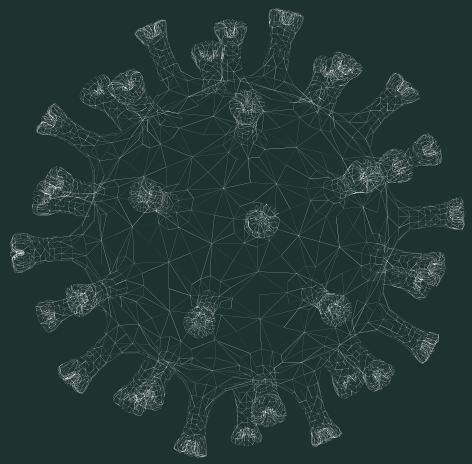
Long COVID in Utah

October 2024





Utah Department of
Health & Human
Services

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Executive summary

Long COVID is an infection-associated chronic condition that includes a wide range of symptoms lasting months to years that is just starting to be understood. It can significantly impact a person's quality of life and well-being. Diagnosis is challenging because there is no simple test or validated screening tool. Treatment options are limited and do not guarantee resolution of the illness. Our understanding of what Long COVID is and how to define it is being continually refined.

About 1 out of every 12 Utahns is experiencing Long COVID, and facing the physical, mental, emotional, and financial impacts that can arise. There is a significant unmet need to acknowledge and support these patients and their caregivers.

The Utah Department of Health and Human Services is using data to better understand and communicate the impact of Long COVID and provide information about how to care for and prevent Long COVID. This report aims to make progress in both of these areas, providing information for medical providers, patients, and the general public to ensure all Utahns have fair and equitable opportunities to live healthy and safe lives.

Long COVID in Utah

→ **1 in 12 Utahns are currently experiencing long-term symptoms.**

→ **Long COVID is more common among women, people in their 40s and 50s, and people who did not get vaccinated against COVID-19. In addition, people identifying as Hispanic/Latino or LGBTQ were more likely to report having Long COVID.**

→ **People with Long COVID report poorer physical health and greater rates of depression, anxiety, social isolation, and financial hardship.**

What can you do?

A detailed list of resources is linked in the "Action steps" section of this report.

COVID-19 vaccination is the best tool we have to reduce the risk of Long COVID. Talk to your doctor or pharmacist about being up-to-date on your COVID-19 immunizations.

If you have Long COVID, talk to your doctor about how to care for your symptoms. There are clinics specializing in Long COVID care and programs that can help you access supportive services. Long COVID can be an ADA-protected disability, which means you have the right to reasonable accommodations at work or school.

If you provide clinical care, increase your understanding of how to diagnose and treat Long COVID with free CME credits through CDC and the Bateman Horne Center.

What is Long COVID?

It's important to know:

→ Anyone can develop Long COVID.

→ There is no simple test and no known cure.

→ Some treatments or therapies may help improve symptoms.

→ The best way to lower your risk is keeping up-to-date on COVID-19 vaccinations.

Long COVID is a condition that some people develop after a COVID-19 infection. It can be disabling in its most severe form. It includes a wide range of symptoms lasting at least three months, sometimes improving or worsening over time. Common symptoms include fatigue, memory problems, lightheadedness, shortness of breath, fast heartbeat, chest pain, and changes in taste or smell. **Anyone can develop Long COVID**, but people who had a severe COVID-19 infection or who are not up-to-date on their COVID-19 vaccinations are more likely to develop it. Many people recover within one year, but some people only partially recover or do not meaningfully recover.

There are no simple tests to diagnose Long COVID. Routine labs and medical imaging are frequently normal. Tests can be done to help determine if the symptoms are due to Long COVID and rule out other causes. Getting correctly diagnosed often depends on a person's ability to describe their symptoms and a clinician's willingness to believe the patient. Many patients feel dismissed by medical providers.[1,8]

Diagnosis can be especially difficult for people with communication challenges, including children, people with disabilities, or people who do not speak English as their primary language.

There is no single treatment for Long COVID. Some people are able to manage their symptoms through medication, physical or occupational therapy, or other treatments. Others may not see any improvement with their symptoms.

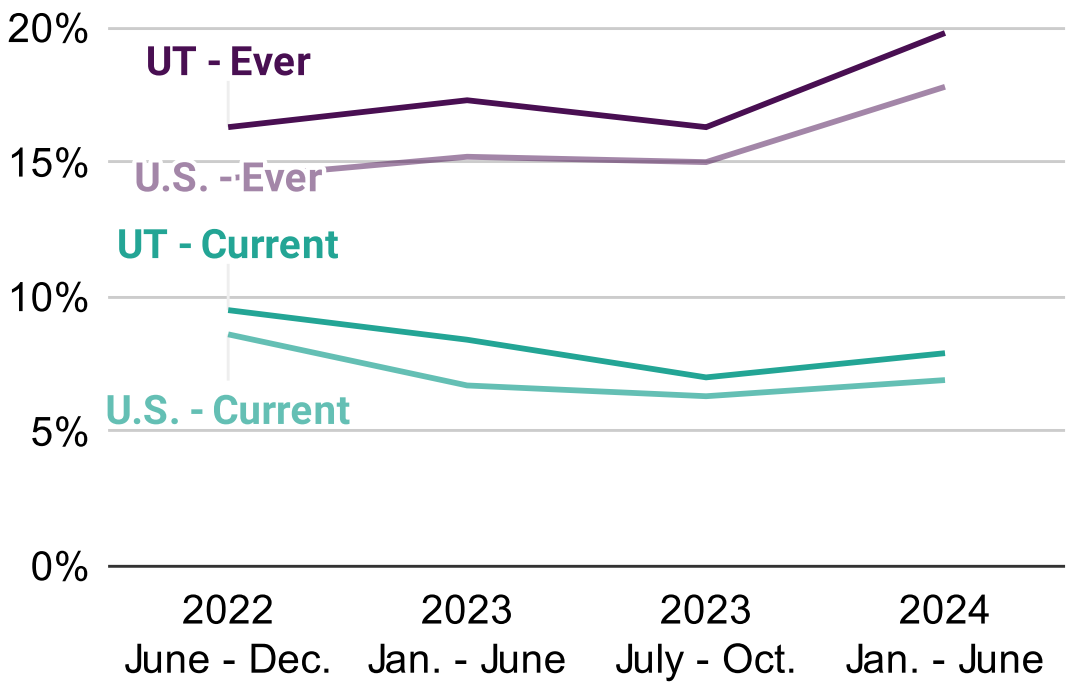
Long COVID is an infection-associated chronic condition that scientists and medical experts are just beginning to understand. Although infection-associated chronic conditions are not new (persistent Lyme disease, multiple sclerosis), they are not well-understood yet. There are ongoing trials to help us better diagnose, treat, and prevent Long COVID.

What do we know about Long COVID in Utah?

How common is Long COVID in Utah?

Long COVID is a common outcome of a COVID-19 infection. The most recent data available show that in 2024 nearly 1 in 5 adults in Utah (19.8%) had ever experienced Long COVID (Table 1). Currently, 8.3% of Utah adults report they have Long COVID symptoms, or about 1 in 12 adults (Figure 1). Compared to other states, Utah consistently experiences a high prevalence of Long COVID. Utah has the 11th highest prevalence of adults who have ever experienced symptoms, and the 9th highest of people who are currently experiencing symptoms in the United States.

Figure 1. Percent of adults in Utah and U.S. who ever had and currently have Long COVID



Studies nationally and in Utah show Long COVID is more common among women and people in their 40s and 50s.[8] In Utah, women account for 63% of people who report long-term symptoms, though they make up only 50% of Utahns overall. People with Long COVID tend to be somewhat younger than the population overall. The average age of people with long-term symptoms is 46.8 years, compared to 51.4 years, which is the average age of adults in the state of Utah.

National and local data also show that people identifying as Hispanic/Latino, LGBTQ, or having a disability experience Long COVID at higher rates. These communities suffered from higher rates of COVID-19 and continue to face significant barriers to fair and equitable opportunities to live safe and healthy lives.[8] For example, in Utah, 17% of people with Long COVID identify as Hispanic/Latino while only 14% of all Utahns identify as Hispanic/Latino. This higher level is likely related to socioeconomic factors like work in in-person jobs with limited paid sick time, inadequate access to health insurance or healthcare, and a shortage of culturally-competent providers.[6,15] We also saw that a higher proportion of those with Long COVID identify as LBGTQ (13%) than the overall percent of Utahns who identify this way (10%). This may be due to a higher prevalence of underlying health conditions, delayed care-seeking in avoidance of stigmatization in medical settings, and disproportionate negative economic impacts of the pandemic.[3,5,13] Adults with long-term symptoms are more likely to describe themselves as having a disability (38% versus 26%). National data shows people with a pre-existing disability may be more likely to develop Long COVID due to a range of barriers to quality care or being at higher risk for severe COVID-19.[4,16] The prevalence of Long COVID is similar in urban, rural, and frontier areas in Utah, although data is limited.

How are patients experiencing Long COVID?

Utahns with Long COVID have poorer physical health, mental health, and are more socially isolated compared to Utahns overall. Utahns with long-term COVID symptoms more frequently describe their general health as fair or poor (25.2% versus 14.0%) (Table 2). Chronic pain is more common (45.2% versus 30.7%) but opioid use for pain is not meaningfully different (15.7% versus 14.8%). When asked about their health over the past 30 days, more people with Long COVID report at least 14 days of poor mental health (28.8% versus 16.5%) or poor physical health (19.6% versus 11.3%). People with Long COVID are more than twice as likely to report difficulty concentrating or remembering (24.0% versus 11.1%). Social isolation is also more common among people with Long COVID (44.7% versus 33.0%), as is depression (42.5% versus 26.5%).

> "I feel like I have been robbed of my life. While most of the heart and lung issues have subsided, the ME/CFS [Myalgic encephalomyelitis/chronic fatigue syndrome] and brain fog have not. I still am able to work but only because I have an incredible employer who lets me work from home as needed and adjust my work hours on crash days. I have used up all of my sick leave. I have no energy left to live my life—you know things like making dinner for my kids, taking them on outings, etc. All I do is survive."
>
> —Long COVID patient in Utah

Among Utahns with more severe disease

Long COVID encompasses a spectrum of symptoms. To better understand the range of experiences in Utah, we surveyed 627 Utah adults with Long COVID (see Appendix B for detailed methodology). We analyzed the responses by severe or mild symptoms. “Severe symptoms” included those who reported their symptoms were so severe they significantly impacted their daily activities (57%). “Mild symptoms” included people who reported little to no impact on their daily activities (43%). **People with more severe physical symptoms also had more significant mental health challenges, financial challenges, and difficulty getting quality clinical care.**

Mental health impacts

Depression and anxiety were about 2 times as common in people with severe Long COVID compared to people with mild symptoms, though they were frequently seen in both groups. When asked questions that screen for depression, 29% of people with mild symptoms screened positive compared to 63% of those with severe symptoms. Similarly, when asked questions assessing anxiety, 36% of people with mild symptoms screened positive for anxiety, whereas 58% of people with severe symptoms screened positive.

> “It’s a terrible thing to not have the energy to enjoy life.”
>
> —Long COVID patient in Utah

Financial impacts

People experiencing Long COVID frequently had to work fewer hours or exit the workforce entirely, and experienced significant financial hardship. This was very common among people with severe symptoms in our survey.

Survey respondents with severe Long COVID were twice as likely to have to reduce their hours at work or school, or stop working entirely (80% versus 39%). Financial hardship was also more common among people with more severe symptoms compared to less severe symptoms. They were more likely to have a reduced household income (56% versus 30%), cut spending on essential items like food and clothing (72% versus 47%), use savings (63% versus 39%), or borrow money or take out a loan (35% versus 22%).

Disability status and supports

People with severe Long COVID were twice as likely to identify as disabled compared to the people with mild symptoms, but were largely unaware of the support and legal protections this diagnosis can confer. Only half of people with severe disease self-identify as disabled, despite significant limitations to daily activities. In the group with less severe disease, 26% of people identified as disabled, which is similar to the population of adults in Utah overall. Overall, 42% of respondents in our survey self-identified as having a disability. Among these respondents, 1 in 5 indicated Long COVID was their only disability. Only 28% of respondents who identified as disabled were aware that Long COVID may qualify them for accommodations and protections at work under the Americans with Disabilities Act or for supportive services like Social Security Disability Insurance or Medicaid.

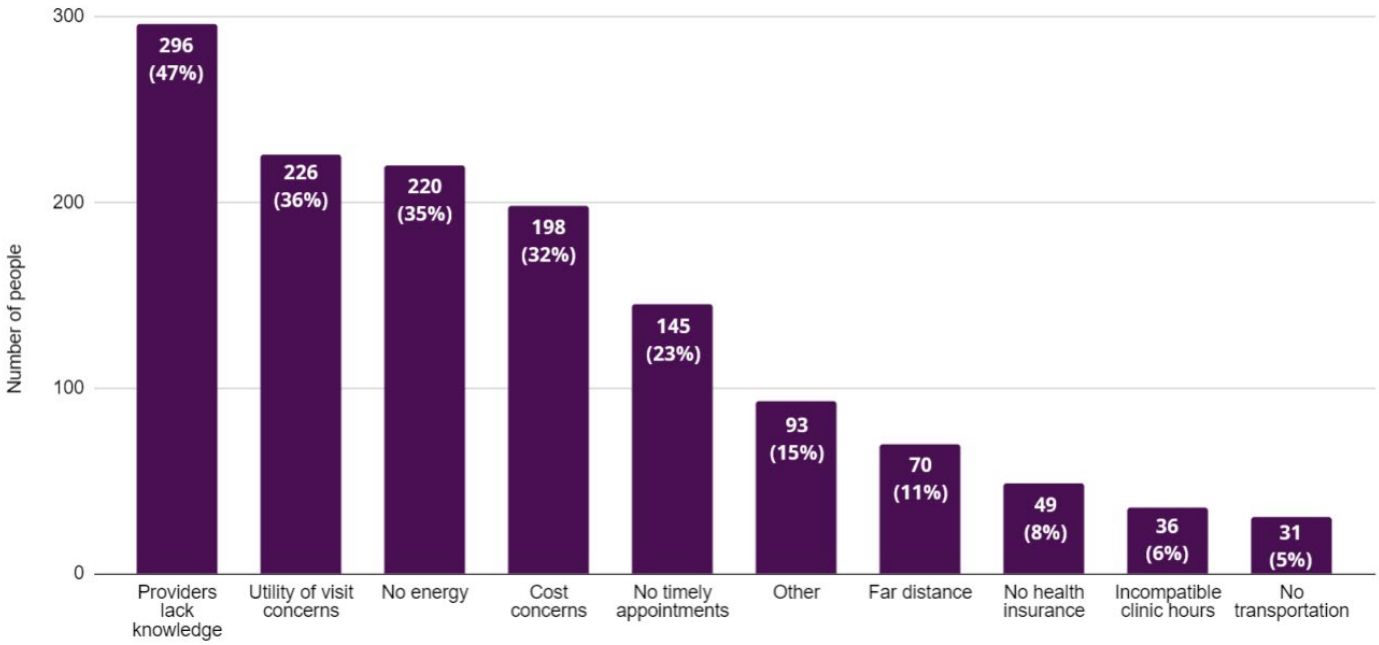
Medical care-seeking behaviors and barriers

Though primary care was the most frequently sought care for both groups, more medically and financially intensive care was common especially among people with severe symptoms. Compared to people with less severe Long COVID, people with severe Long COVID were 1.5 times more likely to seek care in an emergency department (33% versus

22%), 2 times as likely to have an overnight hospital stay (13% versus 6%), 3.3 times as likely to seek care in a Long COVID clinic (25% versus 7%), and 1.9 times more likely to seek care from a specialist (54% versus 29%).

Many people found it difficult to find adequate care. Barriers to adequate care most commonly reported by patients were finding providers who understand Long COVID (47%), feeling the visit would not be useful (36%), lacking energy to attend the appointment (35%), concerns about cost (32%), and lack of appointments available in the near term (23%) (Figure 2).

Figure 2. Barriers to care for Long COVID among adult Utahns



"We need help. We need clinicians who listen and take us seriously. I just want my life back."

—Long COVID patient in Utah

Statements from Long COVID patients in Utah

“

I’m not even close to living the life I lived before. I ran 5-6 miles a day. I can’t even jog 1 mile. Fatigue, pain, fear…and migraines that last days. I worked 3 days a week. I’ve been unable to maintain that schedule due to fatigue, weakness and dizziness. I’ve been attempting to try returning to work 1 day a week for a half a day.

It was horrible! At its worst, a good day was being able to get out of bed in the morning, shower and fix breakfast before collapsing on the couch; a bad day was not being able to get out of bed at all.

It would be helpful if doctors didn’t gaslight me when I explain my symptoms/condition and trusted I know my body better than they do. Long COVID is real, but too many just think we are wanting attention when we really want help!

I have no idea what my new normal is. Trying to reinvent myself. I am always fatigued, and brain fog is difficult.

Please help us—we feel forgotten. Our lives have been completely disrupted.

”

Long COVID art by patients

Long COVID patients in Utah are expressing their experiences through art.

Ella Udell
Meet my Monster Project
2024

Her porcelain body illustrates the fragile nature of chronic illness. She is both held together and held up by string, emphasizing fragility and disjointedness when seizures take control, and the loss of coherency between her mind and body (dysautonomia). Cracks in her torso represent life-saving surgical ports.

Crashing through the floor is an aggressive tentacled monster—Long COVID—in her house becaue no place feels safe. Causing extreme fatigue, it pulls her down until she fears she'll disappear. The bookcase represents her previous scholarship. Now she struggles to follow a simple Nancy Drew novel.

The window overlooking her garden imbues this harrowing scene with a sense of hope. In spite of her symptoms, the difficulty of getting care, and the length of recovery, she made it her mission to fight back and never let this monster win.

Ella Udell
Meet my Monster Project
2024

Reminiscent of a bat reliant on echolocation, episodic blindness leaves this patient trapped in a dark and confusing world, which often forces him to find alternative methods of navigating his environment. Red, hot, itchy hives cover his body and the dramatic hair loss he has experienced after developing Long COVID brings him much shame and distress. In the patient's extreme joint pain while the burden of the ball and chain represent the oppressive fatigue that drags him down. Syringes have also been included as the patient feels like a lab animal—hopelessly poked and prodded without concrete answers—which is deeply demoralizing.

Ella Udell
Meet my Monster Project
2022

My monster is part trapdoor spider: it lives in a hidden burrow underground and stalks me. With little time to react, I feel myself suddenly snatched, pulled from beneath and dragged down into this chimera's lair. Once there, piercing fangs bite into my body and paralyzing venom shoots through my veins. My blood thickens and I lay helpless, the weight of my fatigue and pressure on my brain too heavy to fight back.

My monster is part hyena as it always seems to mock me. The hyena also represents the loopy brain fog and frequent maniacal migraines.

My monster has one blind eye that represents the sudden literal blindness I sometimes experience as well as bizarre visual events that no one can explain.

My monster is one part rabbit. I feel like a lab animal constantly injected, poked, prodded, jerked around.

My monster is not evil or malicious but rather confused, clunky and unpredictable.

This monster has been with me since 2020.

Ella Udell
Meet my Monster Project
2024

Illuminated by the light of the fire, bruised and decaying flesh stretches tightly over her skeletal figure to convey her drastic weight loss triggered by everything tasting and smelling like rotten flesh following her acute COVID infection. Bloodied nails are embedded in her emaciated muscles to represent the sharp jolts of pain that course through her body. The patient holds her heart in her hands as when she experiences tachycardia, it feels like, “my heart could literally burst from my chest.”

Her skin is bare against the burning flames and the biting menace of ice as she has lost much of her ability to regulate termperature, which has left her feeling like being in a fire in the middle of winter. Her chronic brain fog is represented through the thick smoke that surrounds her.

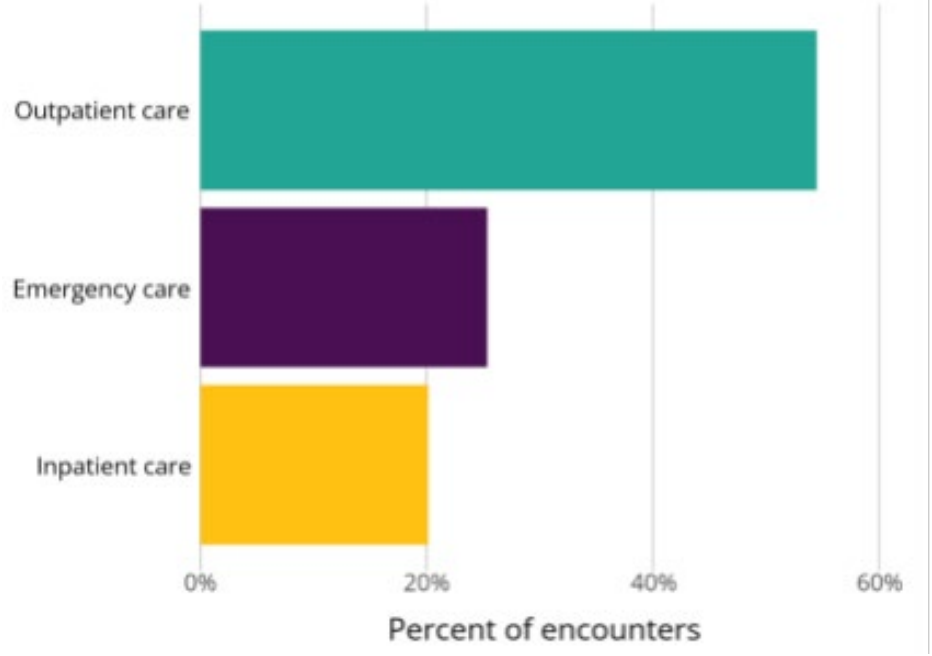
Amy Cuddeback
The Crushing Aftermath of COVID-19
2021

Who is accessing clinical care?

Clinic and emergency department visits

The Utah Department of Health and Human Services collects information about the reason people visit emergency rooms across the state, as well as the reason for a subset of inpatient and outpatient visits. Among patients with visits for Long COVID, outpatient clinic visits were more common than emergency department or inpatient visits (Figure 3). Taken together, the number of visits for long COVID appears to be decreasing year over year (Figure 4). The majority (60%) of encounters were among females and middle-aged adults (Figure 5). Children are represented in this data, unlike all other data reported here. They are a small, but important group of people seeking care with unique needs and treatments.

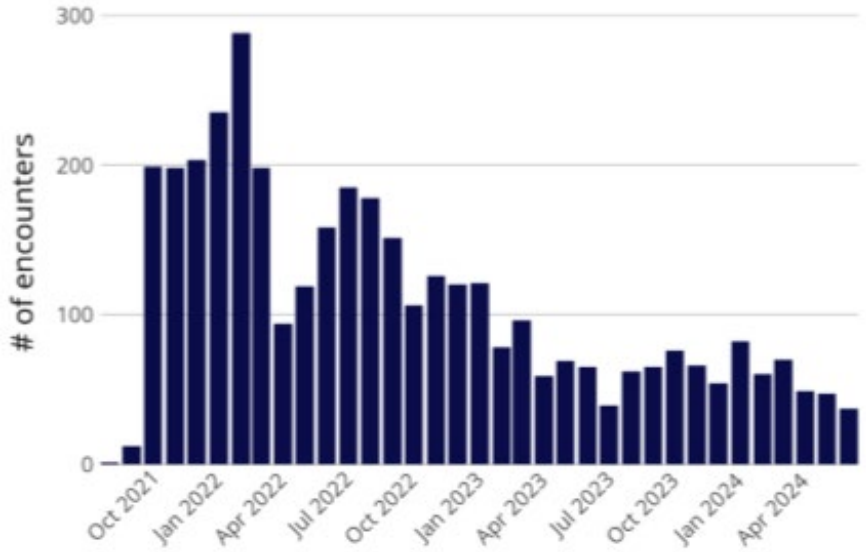
Figure 3. Long COVID-associated visits in outpatient, emergency department, and inpatient settings in Utah, August 2021 - June 2024



Hospital and clinic visits

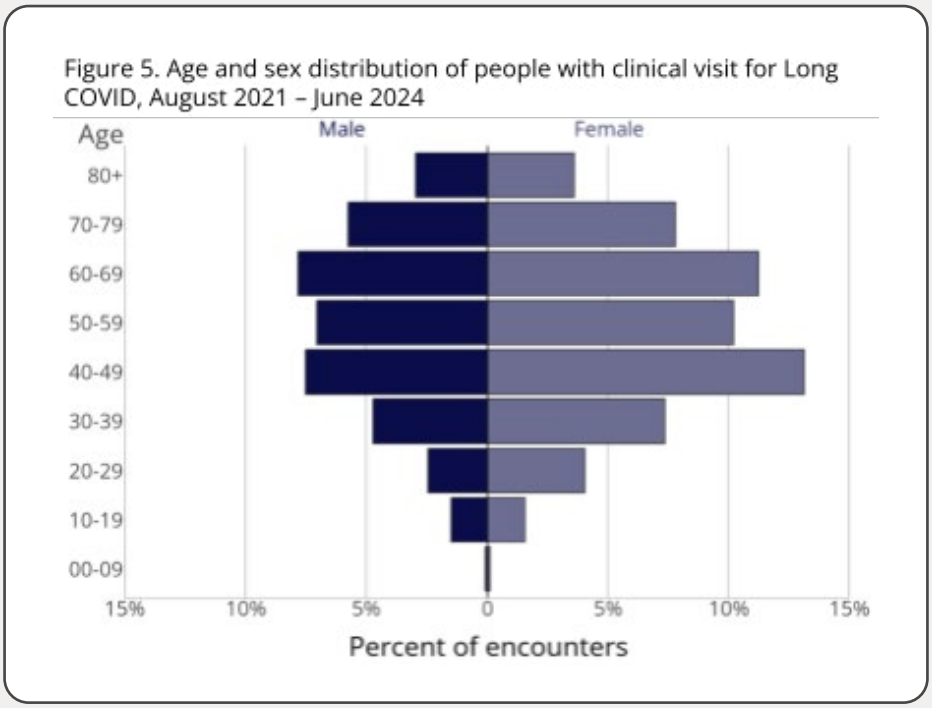
Focusing on the two largest healthcare systems in Utah, Intermountain Healthcare and University of Utah, we found an average of 227 Utahns with a documented Long COVID diagnosis sought healthcare services each month over a one-year period from June 2023 to May 2024. The average age of these individuals was 52 years (standard deviation 18 years). The majority (90%) were white, followed by Hispanic/Latino and all other races (5% each, respectively).

Figure 4. Number of monthly encounters with Long COVID ICD-10 discharge code, August 2021 - June 2024



Our data suggest some people may face more barriers to diagnosis or clinical care than others. Only 5% of those accessing care identify as Hispanic/Latino despite 17% of people surveyed reporting long-term symptoms identifying as Hispanic/Latino. Similarly, although the majority (55%) of care seekers were female, they may still be under-represented given that 63% of people reporting long term symptoms are female. Importantly, these data are a limited snapshot of all Long COVID-related

visits. These data only include people in reporting healthcare systems who were correctly diagnosed and charted correctly. Many people are formally not diagnosed with Long COVID by a doctor and visits may not be coded correctly in medical charts.



Action steps

The best way to protect yourself from Long COVID is to be up-to-date on your COVID-19 immunizations.[2,11,12] Being up-to-date on your COVID-19 immunizations helps both reduce the risk of getting sick from COVID-19 and reduce the risk of later developing Long COVID.

The only way to fully prevent Long COVID is by not getting a COVID-19 infection. This means actions like masking in crowded indoor settings or improving indoor ventilation can also be helpful. Prevention is important since there is no cure for Long COVID.

People with Long COVID need support to help them through the pain and isolation that often comes with this long term illness. With 1 in 5 Utahns ever affected by Long COVID, it is likely that if you haven't experienced it, you know someone who has.

> "How can I find help? Will it get better? Will I be able to continue working? Does Long COVID count as a disability?"
>
> —Long COVID patient in Utah

Resources for patients about their rights, clinical options, and supports available:

→ *Utah Department of Health and Human Services* maintains an up-to-date web page with information about Long COVID and resources. https://coronavirus.utah.gov/covid19-long-haulers/

→ *University of Utah's Long Hauler Clinic* is accepting new patients for in person and telehealth visits. They will provide care to any adult who lives in Utah up to $5,000 in medical expenses, regardless of insurance status. https://healthcare.utah.edu/locations/covid-19-clinic

→ *Intermountain Pediatric Long COVID Navigation Clinic* provides care to children. https://intermountainhealthcare.org/primary-childrens/programs-specialties/long-covid/

→ *Take Care Utah* will connect Utahns with a mobility limitation (or other disability) to supportive services. https://takecareutah.org/linkage-co-ordinator-project/

→ *The Disability Law Center* offers educational self-advocacy documents on the right to fair housing, reasonable accommodations at work, and other topics. https://disabilitylawcenter.org/get-help/resources/

→ *The Job Accommodation Network* provides information about accommodations in the workplace including examples of accommodations for specific symptoms. https://askjan.org/disabilities/Long-COVID.cfm

→ *Utah 211* is a free, confidential service that can connect you to services such as housing and utility assistance, food resources, and legal aid. https://utah211.org/

Accurate assessment of this complex condition is essential for patients to get the care they need and the resources they may be entitled to. **Specific resources for medical providers** include *the Bateman Horne Center* in Utah and the *CDC*. They both provide information on clinical assessment and management, as well as free continuing medical education credits:

The Bateman Horne Center:
https://batemanhornecenter.org/providers/long-covid/

CDC:
https://www.cdc.gov/covid/hcp/clinical-overview/index.html

> "With effort and much work, meds, cost, and time I have defined a new normal. I only was successful because my employer, family, and friends believed, supported, and encouraged me every step of the way."
>
> —Long COVID patient

Acknowledgments

Primary author

Rachel Kubiak, PhD, MPH (Contractor for DHHS, Office of State Epidemiologist)

Contributing authors

Leisha Nolen, MD, PhD (DHHS, Office of State Epidemiologist)

Amelia Johnson, DrPH (DHHS, Office of State Epidemiologist)

Eric Walls (DHHS, Office of Communicable Diseases)

Teri Bills (DHHS, Office of Communicable Diseases)

Randon Gruninger, MPH (DHHS, Syndromic Surveillance)

Sia Gerard, MPH (DHHS, Syndromic Surveillance)

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Author notes

The views expressed in this report do not necessarily reflect the official policies of the Utah Department of Health of Health and Human Services nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. government.

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Table 1. Prevalence of Long COVID among adults in Utah and United States, 2022-2024

	Utah			USA		
	%	(95% CI)		%	(95% CI)	Rank
Ever had Long COVID						
Overall	17.4	(16.8-18.0)		15.5	(15.4-15.6)	11th
2022 Jun-Dec	16.3	(15.2-17.6)		14.4	(14.2-14.6)	11th
2023 Jan-Jun	17.3	(16.2-18.5)		15.2	(14.9-15.4)	8th
2023 Jul-Oct	16.3	(15.1-17.6)		15.0	(14.8-15.3)	11th
2024 Jan-Jun	19.8	(18.4-21.1)		17.8	(17.6-18.1)	9th
Currently experiencing symptoms						
Overall	8.3	(7.9-8.8)		7.2	(7.2-7.3)	9th
2022 Jun-Dec	9.5	(8.6-10.5)		8.6	(8.4-8.8)	12th
2023 Jan-Jun	8.4	(7.6-9.3)		6.7	(6.5-6.8)	4th
2023 Jul-Oct	7.0	(6.2-7.8)		6.3	(6.1-6.5)	16th
2024 Jan-Jun	7.9	(7.0-8.8)		6.9	(6.8-7.1)	11th

Data source: Household Pulse Survey public use files. Available at: https://www.census.gov/programs-surveys/household-pulse-survey/data/datasets.html

Table 2. Characteristics of adults experiencing Long COVID in Utah, 2022

	Population with Long COVID (n=784)		Utah overall (n=9826)		
	n	Adjusted %	n	Adjusted %	p-value
Demographic characteristics					
Age (years)					0.006
18-29	130	25.3	1477	25.2	
30-39	136	22.2	1510	20.0	
40-49	188	21.9	1686	17.4	
50-64	200	21.5	2221	20.0	
65+	122	9.1	4091	17.3	
Female	485	63.3	4898	50.0	<0.001
Race-ethnicity					0.83
White, non-Hispanic	623	75.3	8035	76.2	
All other races, non-Hispanic	30	7.4	442	9.4	
Hispanic/Latino of any race	113	17.3	1100	14.4	
Health status and conditions					
Self-defined general health					<0.001
Excellent, very good	327	42.6	5241	54.5	
Good	267	32.2	3088	31.4	
Fair, poor	189	25.2	1475	14.1	
Physical health not good for 14+ days out of last 30	157	19.6	1193	11.3	<0.001
Mental health not good for 14+ days out of last 30	199	28.8	1366	16.5	<0.001
Depression	311	42.5	2328	26.5	<0.001
Difficulty concentrating or remembering	93	24.0	587	11.1	<0.001
Experiences chronic pain	156	45.2	1253	30.7	<0.001
Opioid use for chronic pain	25	15.7	197	14.8	0.44
Experiences social isolation always, usually, or sometimes	310	44.7	2465	33.0	<0.001

Data source: Utah Behavioral Risk Factor Surveillance System (BRFSS), Utah Department of Health and Human Services, 2022

Appendix A: List of data sources for reported statistics

Overall prevalence of ever and currently experiencing Long COVID (p.5, Figure 1, Table 1): Household Pulse Survey 2023

Prevalence of Long COVID by sociodemographic characteristics, beliefs, and behaviors (p.6-7, Table 2): Utah Behavioral Risk Factor Surveillance System (BRFSS), Utah Department of Health and Human Services, 2022

Impacts of severe Long COVID (p.8-10, Figure 2): Survey of long-term symptoms after COVID-19, Utah Department of Health and Human Services, 2023-2024

Hospital utilization (p.17-19, Figures 3-5): Syndromic surveillance, Utah Department of Health and Human Services, 2021-2024; electronic case reporting, Office of Communicable Diseases, Utah Department of Health and Human Services, 2023-2024

Quotes from Long COVID patients throughout: Survey of long-term symptoms after COVID-19, Utah Department of Health and Human Services, 2023-2024

Long COVID illustrations: Courtesy of Ella Udell and Amy Cuddeback

Appendix B: Description of data sources

Behavioral Risk Factor Surveillance System

To better describe and understand the prevalence of Long COVID in Utah, we used data collected as part of the Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is a well-established national telephone survey conducted every year to measure health beliefs, behaviors, and conditions. Participants are selected through random, stratified sampling. Population-level prevalence estimates are generated through a complex weighting structure.

In 2022, several questions were incorporated into the BRFSS in Utah to assess whether a person had a prior COVID-19 infection, had long-term symptoms after this infection, and what the most significant symptom was. These questions were as followed:

1. Has a doctor, nurse, or other health professional ever told you that you tested positive for COVID-19?

- ❍ Yes
- ❍ No
- ❍ Don't know/not sure
- ❍ Refused

2. [If Yes] Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19?

- ❍ Yes
- ❍ No
- ❍ Don't know/not sure
- ❍ Refused

3. [If Yes] Which of the following was the primary symptom that you experienced? Was it…?

- ❍ Tiredness or fatigue
- ❍ Difficulty thinking or concentrating or forgetfulness/memory problems (sometimes referred to as “brain fog”)
- ❍ Difficulty breathing or shortness of breath
- ❍ Joint or muscle pain
- ❍ Fast-beating or pounding heart (also known as heart palpitations) or chest pain
- ❍ Dizziness on standing
- ❍ Depression, anxiety, or mood changes
- ❍ Symptoms that get worse after physical or mental activities
- ❍ You did not have any long-term symptoms that limited your activities
- ❍ Loss of taste or smell
- ❍ Some other symptom
- ❍ Don’t know/not sure
- ❍ Refused

In these analyses, we report the number of responses to indicate the sample size. We used weighted percentages as prevalences and used these to compare between groups. To test for statistical significance, we used the chi-square test for categorical data and Student’s t-test to compare means.

Electronic case reporting

We used electronic case reporting (eCR) data to get a better understanding of healthcare access trends for Long COVID patients. Using eCR, data related to specific reportable conditions is automatically transmitted to DHHS from medical systems (University of Utah, Intermountain Healthcare), which cover approximately 80% of the state's population. The reportable ICD-10 code for Long COVID is U09.9 – post-COVID-19 condition, unspecified. This code was used to identify Long COVID cases. However, case capture is technically challenging and there is potential for false query matches based on the search string 'U09.9' or, conversely, positive matches may be missed. This report used data from clinic visits occurring from June 2023 to May 2024, aggregated monthly.

Household Pulse Survey

We used publicly available data from the Household Pulse Survey to describe the prevalence of Long COVID in Utah and compare it to national data. It is a short online survey of adults in the U.S. conducted by the U.S. Census Bureau and the CDC National Center for Health Statistics. For this report, we aggregated data collected from June 1, 2022 through June 24, 2024. We applied person-level survey weights to adjust for non-response and to match Census Bureau population estimates of age, sex, race and ethnicity, and educational attainment.

The relevant Long COVID questions are:

1. Have you ever tested (using a rapid point-of-care test, self-test, or laboratory test) positive for COVID-19 or been told by a doctor or other health care provider that you have or had COVID-19?

- ❍ Yes
- ❍ No

2. [If ever tested positive] Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19?

Long term symptoms may include: Tiredness or fatigue, difficulty thinking, concentrating, forgetfulness, or memory problems (sometimes referred to as “brain fog”), difficulty breathing or shortness of breath, joint or muscle pain, fast-beating or pounding heart (also known as heart palpitations), chest pain, dizziness on standing, menstrual changes, changes to taste/smell, or inability to exercise.

- ❍ Yes
- ❍ No

3. [If ever tested positive] Do you have symptoms now?

- ❍ Yes
- ❍ No

4. [If had long term symptoms] Do these long-term symptoms reduce your ability to carry out day-to-day activities compared with the time before you had COVID-19?

- ❍ Yes, a lot
- ❍ Yes, a little
- ❍ Not at all

To estimate the proportion of people who have ever had Long COVID, we used the number responding “Yes” to having any new symptoms lasting three months or longer as the numerator. To estimate the proportion of people who currently have Long COVID, we took the number responding “Yes” to the question “Do you have symptoms now?” as the numerator. The denominator comprised the people responding to the relevant numerator question, plus the number of people who said “no,” they had never had a COVID-19 infection.

More information about the survey is available here: https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm

Data is publicly available here: https://www.census.gov/programs-surveys/household-pulse-survey/data/datasets.html

Survey of long-term symptoms after COVID-19

In 2022, the Utah Department of Health and Human Services (DHHS) designed a questionnaire to better understand the experiences and needs of people experiencing Long COVID across the state. The survey used questions from validated scales (Generalized Anxiety Disorder-2, Patient Health Questionnaire-2), Long COVID surveys conducted by other states, BRFSS, and questions written by DHHS staff. It was field tested and approved by the DHHS IRB (DHHS IRB No. 687). All materials (flyers, consent form, questionnaire) were available in English and Spanish.

Eligible participants had to be at least 18 years of age, living in the state of Utah, believe they had at least one prior COVID-19 infection, and had/have experienced new symptoms after their infection lasting three months or longer.

The survey was available online through REDCap and in paper form from December 2023 through May 2024. It was disseminated primarily online via social media by partnering organizations, patient support groups, and individuals in these networks. DHHS promoted the survey on social media (using paid ads) for two weeks in March 2024. Paper flyers were created for dissemination in clinics likely to have Long COVID patients, local health departments, and community organizations. Community health workers were trained on the survey and encouraged to share it with their communities.

We analyzed the data using a complete case analysis (only participants who reached the end of the survey) and excluded participants who did not answer the question “Do these long-term symptoms reduce your ability to carry out day-to-day activities compared with the time before you had COVID-19?” as an indicator of disease severity. We provide descriptive statistics here.

Over the six-month survey period, 627 people completed the survey from 26 out of 29 counties across the state. The majority of respondents were female (81%) and white, non-Hispanic/Latino (87%). We characterized “severe Long COVID” or “severe symptoms” as a response of “Yes, a lot” to the question “Do these long-term symptoms reduce your ability to carry out day-to-day activities compared with the time before you had COVID-19?”. We characterized “mild Long COVID” or “mild symptoms” as a response of “Yes, a little” or “No, not at all” in response to that same question.

Syndromic surveillance

We used syndromic surveillance to better understand who and how Long COVID patients are accessing healthcare over time. The syndromic surveillance database in Utah, ESSENCE, includes all emergency departments (n=48), and select urgent care and primary care departments (n ~75). Through an established, automated process, participating facilities transmit authorized demographic and clinical data to DHHS in near real-time.

Patients presenting to a participating medical facility from August 1, 2021 to June 31, 2024 and attributed the ICD-10 code for Long COVID (U09.9) as part of their discharge diagnosis are represented in this report. August 1, 2021 is the first instance of U09.9 in this database. The total number of encounters was 3,808 over this time period, among 3,047 unique persons. Figure 3 includes all encounters (if a person went to the emergency department and then was admitted to the hospital, a visit to both settings is shown here). Figures 4 and 5 depict unique persons.