# Public Health Surveillance of Long COVID

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## **Overview**

- 1. What is long COVID?
- 2. Why long COVID disease surveillance?
- 3. What is being planned for long COVID disease surveillance?
  - a. ICD-10 code U09.9 post COVID condition, unspecified

# **Long COVID diagnosis**

## **Symptoms**

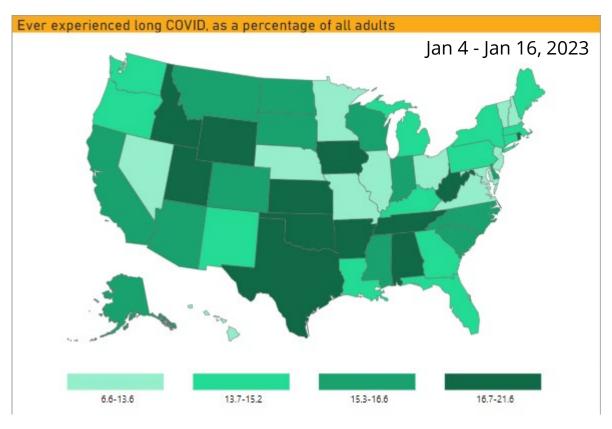
- Must begin within 3 months of COVID-19 infection and last ≥4 weeks
- Very varied
- Range in severity
- Appears most but not all people slowly recover

## Laboratory testing

- No laboratory-confirmed COVID-19 infection requirement
- No long COVID test
- Long COVID diagnosis is based on clinical symptoms after ruling out other causes

# **Long COVID Epidemiology**

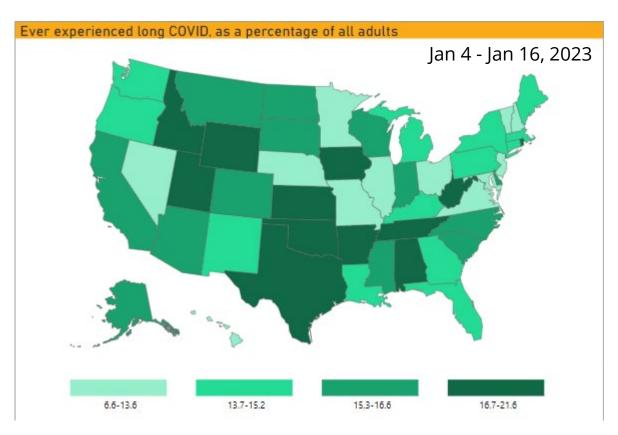
- Long COVID is common
- Impacts 5-30% of people who had a COVID-19 infection



1. CDC Household Pulse Survey. Accessed 16 February, 2022. https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm

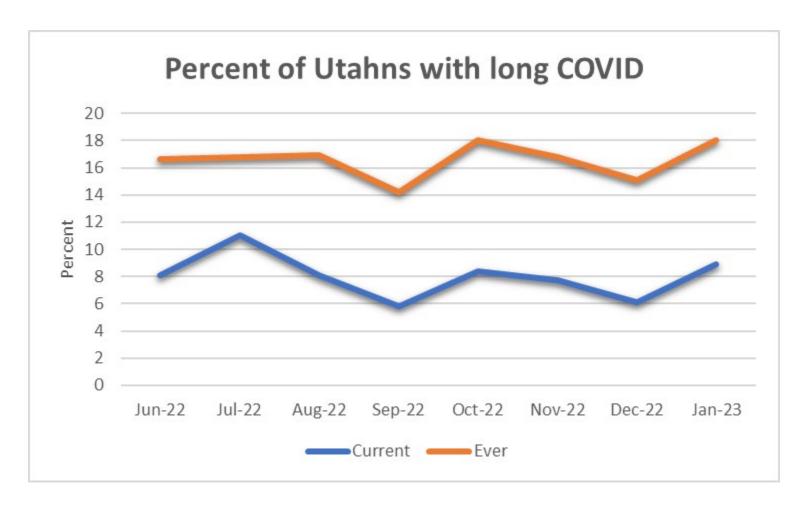
# **Long COVID Epidemiology**

- Long COVID is common
- Impacts 5-30% of people who had a COVID-19 infection
- Disproportionately affect some populations
  - Adults
  - Women
  - Unvaccinated people
  - People with severe disease



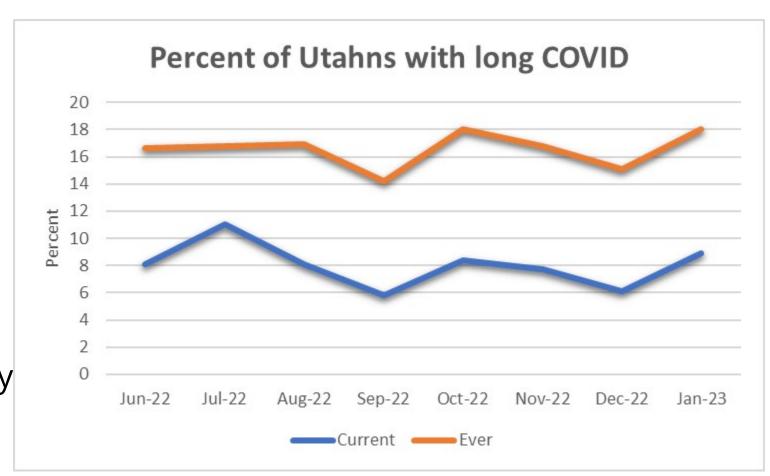
# **Long COVID Epidemiology in Utah**

- ~18% ever had long
   COVID
- ~8% prevalence



# **Long COVID Epidemiology in Utah**

- ~18% ever had long
   COVID
- ~8% prevalence
- 74% (95% CI 64-83)
   report <u>any</u> activity
   limitations
- 24% (95% CI 13-39%)
   report <u>significant</u> activity
   limitations

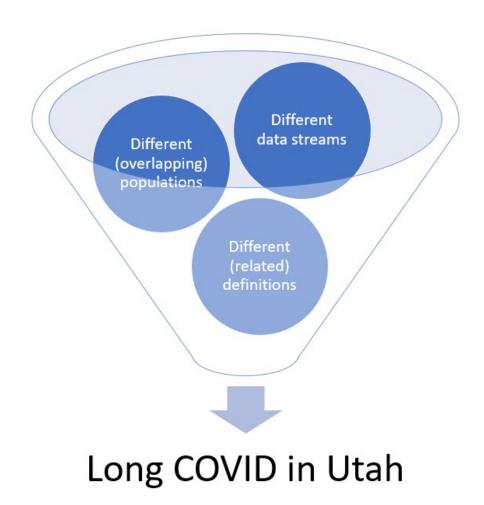


# **Long COVID surveillance - Why?**

- 1. Large number of impacted people
- 2. Impact on quality of life
- 3. High cost
  - a. 44% of people with long COVID exited the labor force, 51% worked fewer hours.<sup>1</sup>
  - b. If treatment is similar to treatment of myalgic encephalomyelitis (chronic fatigue syndrome), estimated cost could be about \$9000 per person annually.<sup>2</sup>
- 4. High burden on healthcare system
- Uneven distribution
- 6. High public/media/political interest

- 1. COVID-19 Longhauler Advocacy Project. Mathematical breakdown and formulas for long COVID calculations. Published January 10, 2022. Accessed May 5, 2022. https://www.longhauler-advocacy.org/calculations-formulas
- 2. Jason LA, Mirin AA. Updating the National Academy of Medicine ME/CFS prevalence and economic impact figures to account for population growth and inflation. *Fatigue*. 2021;9(1):9-13. doi:10.1080/21641846.2021.1878716

# **Long COVID surveillance - Overview**



# **Long COVID surveillance - Goals**

## **Overarching Goals**

- 1. Characterize the burden of long COVID in Utah
- 2. Identify gaps and best practices in diagnosis and treatment to ensure equitable access for all Utah
- 3. Provide data that helps long COVID programs plan and advocate for funding

# **Long COVID Information Systems**

# **Electronic Medical Records**

- Demographics, care needs
- Goal to establish realtime system with U09.9 ICD-10 code
- U of U Long Hauler
   Clinic one-time look

## **Emergency room visits**

- U09.9 discharge code
- Syndromic surveillance

# Nationwide survey (BRFSS)

- 2 survey questions
- Population-based survey

**Long COVID** 

#### **Insurance claims**

- U09.9 ICD-10 code
- Hospital billing including Medicaid

## Patient Surveys (proposed)

- Prevalence
- Severity
- Duration
- Access to care

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## **Resources in Utah**

## **Long COVID Clinics**

Name	Referrals	Virtual	In-person	Website
COVID Long Hauler Clinic, UofU	(T) 801-213-0884; (F) 801-213-1147	X	X	https://healthcare.utah.edu/locations/covid-19-clinic
Long COVID Clinic, IHC	(T) 801-408-5888; iCentra		X	
Pediatric Long COVID Navigation Clinic, IHC	(F) 385-297-2750; iCentra	X		https://intermountainhealthca re.org/primary- childrens/programs- specialties/long-covid

Clinician Lecture Series: Long COVID and Post-Viral Syndrome series, co-produced by UofU and Bateman Horne Center - <a href="https://physicians.utah.edu/echo/long-covid">https://physicians.utah.edu/echo/long-covid</a>
Peer Support: COVID-19 Recovery Support Group, UofU - <a href="https://nursing.utah.edu/grief-support-groups">https://nursing.utah.edu/grief-support-groups</a>

# Thank you!

Help us care for people with long COVID in Utah. Let us know of any resources you have identified and please use U09.9 as the diagnosis code when you are treating people with long COVID.

Rachel Kubiak Long COVID Surveillance Lead dcpcdcfrwk@utah.gov

# What is long COVID?

- Syndrome following acute COVID-19 infection
- Disability protected under ADA
- Goes by many names
  - Long COVID
  - Long-haul COVID
  - Chronic COVID
  - Post-acute COVID-19
  - Post-acute sequelae of SARS-CoV-2 infection (PASC)

# **Long COVID symptoms**

- General
  - Fever
  - Fatigue
  - Impaired daily functioning/mobility
- Neurologic
  - Brain fog
  - Headache
  - Insomnia
  - Change in smell or taste
  - Lightheadedness
  - o Paresthesia
- Mental health
  - Depression
  - Anxiety

- Respiratory
  - Dyspnea
  - Cough
  - Chest pain
  - Palpitations and/or tachycardia
- Digestive
  - Diarrhea
  - Stomach pain
- Other
  - Arthralgia
  - Myalgia
  - Rash
  - Menstrual cycle irregularities
  - Erectile dysfunction