### COVID WEBINAR

# **Understanding Long COVID**

June 24, 2022 at 1:00 EST





Jennifer Cope, MD, MPH

Commander, U.S. Public Health Service

Team Lead and Medical Epidemiologist, Centers for Disease Control and Prevention







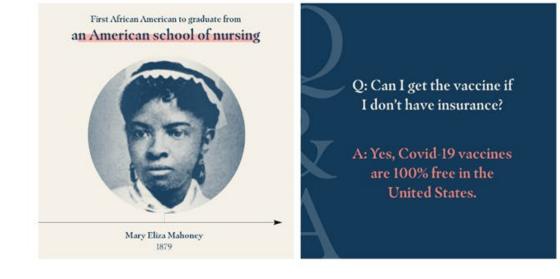


The National Nurse-Led Care Consortium (NNCC) is a non-profit membership organization that supports nurse-led care and nurses at the front lines of care.

NNCC supports comprehensive, community-based primary care and public health nursing through policy and advocacy, program development and management, technical assistance and support, and direct, nurse-led healthcare services.

Learn more at NurseLedCare.org

# CDC COVID Vaccine Project Goals



- Empower nurses with necessary information to engage care teams and communities about COVID-19 vaccines.
- Provide learning opportunities to share up-to-date guidance, support peer engagement among nursing colleagues, and strengthen the nursing role.
- Amplify the nursing voice by featuring nurse champions through our podcast and other media outlets.

Learn more at NurseLedCare.org



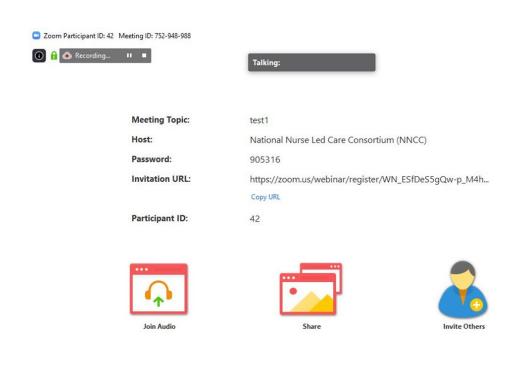
### Housekeeping Items

#### **Question & Answer**

- Click Q&A and type your questions into the open field.
- The Moderator will either send a typed response or answer your questions live at the end of the presentation.

#### **Continuing Education Credits**

- Please complete the evaluation survey after today's training.
- Certificate will arrive within 4 weeks of completing the survey.







# COVID-19 UPDATES & RESOURCES



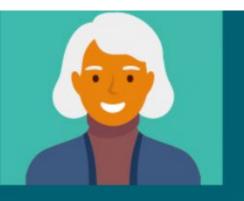
#### **COVID-19 VACCINE UPDATE**

# Who should get vaccinated against COVID-19?

Everyone ages 6 months and older



cdc.gov/coronavirus











## June 19, 2022: Interim Clinical Considerations for Use of COVID-19 Vaccines Currently Approved or Authorized in the United States

Table 2. COVID-19 vaccination schedule for people who are NOT moderately or severely immunocompromised

6 months through 11 years

Manufacturer*	Age group	Total number of doses recommended	Number of primary doses	Number of booster doses	Interval between 1st and 2nd dose <sup>†</sup>	Interval between 2nd and 3rd dose	Interval between 3rd and 4th dose
Pfizer- BioNTech	6 months– 4 years	3	3	NA	3-8 weeks	At least 8 weeks	NA
Pfizer- BioNTech	5–11 years	3	2	1	3-8 weeks	At least 5 months	NA
Moderna	6 months– 5 years	2	2	NA	4-8 weeks	NA	NA

# Infants and Young Children Do Die from COVID-19 Deaths due to COVID-19 Higher than Other Vaccine Preventable Diseases

Disease	<b>Deaths</b> (Per Year)	Date Range	<b>Age</b> (Years)
COVID-19	74-221	2020-2022	0-4
Influenza	68-87	2018-2020	0-4
Varicella	50	1970-1994 (prevaccine)	< 15
Rubella	17	1966-1968 (prevaccine)	All
Hepatitis A	3	1990-1995 (prevaccine)	< 20
Rotavirus	20-60	1999-2007 (prevaccine)	< 5

Anderson EJ, et al. Clin Infect Dis 2021; 73:336 340. doi: 10.1093/cid/ciaa1425.

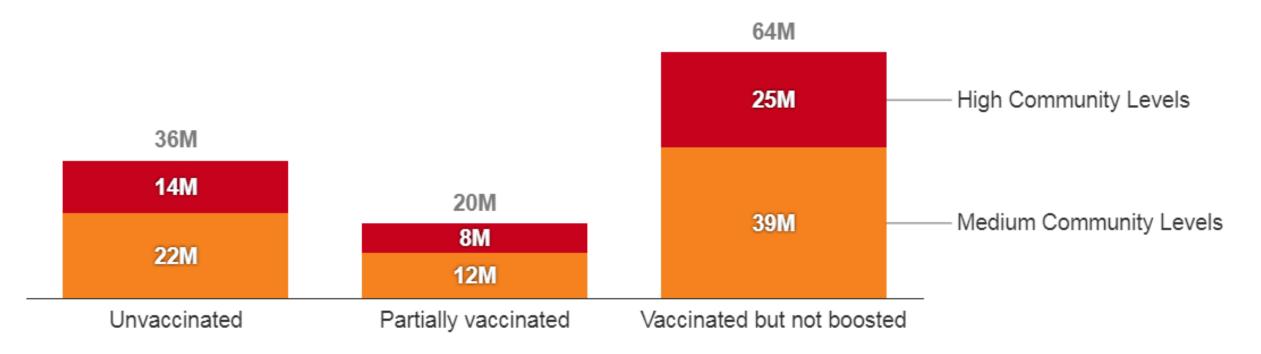
https://gis.cdc.gov/grasp/fluview/pedfludeath.html

https://www.cdc.gov/nchs/nvss/vsrr/covid\_weekly/index.htm and https://www.cdc.gov/flu/spotlights/index.htm

### June 8, 2022: Kaiser Family Foundation: How Many Are Not Up to Date with Vaccination in Counties with Elevated COVID-19 Community Levels?

120 Million People Are Not Up To Date On COVID-19 Vaccines And

Live In Counties With Elevated COVID-19 Community Levels



# June 10, 2022: COVID-19 State of Vaccine Confidence Insights Report #26

#### Major themes identified by consumers that may impact vaccine confidence:

- The impact of future and current variants on case counts, hospitalizations and deaths and the
  potential for this to occur with the emergence of the Omicron BA.2 variant.
- The safety and effectiveness of booster doses especially after the authorization of a 2nd booster dose.
- Consumer concerns about and opposition to COVID-19 vaccines for children.

#### Ways to take action:

- Explain why the 2nd booster dose is necessary and its role in preventing severe illness from COVID-19.
- Disseminate messages about community-level risk and the need to follow COVID-19 mitigation measures when needed.

#### Additional Resources

- Answers to Tough Questions on Children and Vaccines (Public Health Communications Collaborative)
- <u>FDA Meeting for <5 COVID Vaccine</u>: <u>Q&A</u> (Your Local Epidemiologist)
- FDA Advisory Committee Recommends Emergency Use Authorization of Novavax COVID-19 Vaccine for People Aged 18 Years and Older (Novavax)
- <u>Better Understanding Adult COVID-19 Vaccination Hesitancy and Refusal: The Influence of Broader Beliefs about Vaccines</u> (Int J Environ Res Public Health)





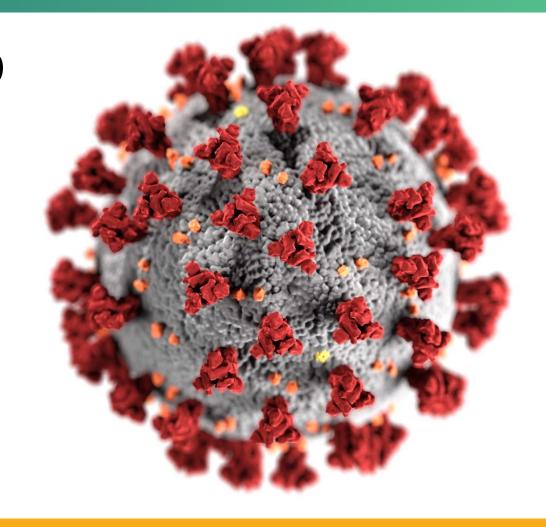
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Commander, U.S. Public Health Service

Team Lead and Medical Epidemiologist, Centers for Disease Control and Prevention

# Understanding Post-COVID Conditions

Jennifer Cope, MD, MPH
CDR, US Public Health Service
COVID-19 Response
Post-COVID Conditions Team





cdc.gov/coronavirus

### **Objectives**

- Outline a framework for understanding post-COVID conditions or long COVID
- Describe the most common symptoms of long COVID and risk factors for developing long COVID
- Discuss strategies for diagnosis and management of long COVID patients



#### Many terms are used to refer to these conditions

- Long COVID
  - Commonly used
- Post-COVID Condition(s)
  - CDC and WHO
- Post-Acute Sequelae of SARS-CoV-2 (PASC)
  - NIH terminology



# General framework for understanding long COVID or post-COVID conditions

- Umbrella term for the wide range of physical and mental health consequences
  - present for 4 or
     more weeks after
     SARS-CoV-2
     infection
  - Even among patients who had initial mild or asymptomatic acute infection

### Framework for Variety of Conditions Following SARS-CoV-2 Infection

### General Consequences of Illness and Hospitalization

- Post ICU-syndrome
- Other complications of illness and treatment

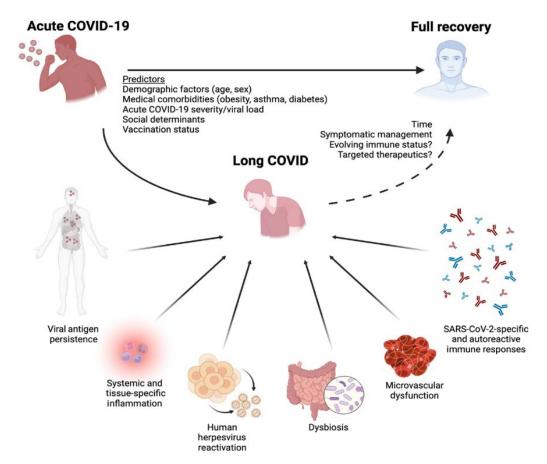
#### Post-Acute Consequences of SARS-CoV-2 Infection

- System-specific pathology (e.g., lung fibrosis, stroke)
- Clinically significant symptoms with unclear pathology (e.g., ME/CFS\*-like, dysautonomia)

Conditions frequently overlap
Patients may experience any combination



# Multiple proposed potential mechanisms for post-COVID conditions



- Proposed mechanisms could include viral persistence, systematic and tissue specific inflammation, auto immunity, microvascular dysfunction
- Whether potential risk factors differ for children is unknown

Proposed contributing mechanisms



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Peluso and Deeks. Early clues regarding the pathogenesis of long-COVID: Trends in Immunology (cell.com) 2022

### Symptoms seen in post-COVID conditions

- Dyspnea or increased respiratory effort
- Fatigue
- Post-exertional malaise and/or poor endurance
- "Brain fog," cognitive impairment
- Cough
- Chest pain
- Headache
- Palpitations and/or tachycardia
- Arthralgia
- Myalgia
- Paresthesia

- Abdominal pain
- Diarrhea
- Insomnia and other sleep difficulties
- Fever
- Lightheadedness
- Impaired daily function and mobility
- Pain
- Rash (e.g., urticaria)
- Mood changes
- Anosmia or dysgeusia
- Menstrual cycle irregularities







- Fatigue can be
  - physical, cognitive, or emotional
  - mild to severe
  - intermittent or persistent
  - affect a person's energy, motivation, and concentration
- One of the most common persistent symptoms, regardless of severity of acute COVID

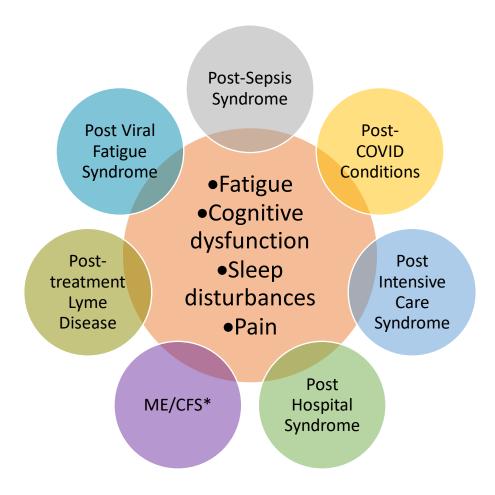
### Focus on cognitive symptoms

- Often described as "brain fog" by patients
  - Includes difficulty thinking clearly and concentrating, forgetfulness, and memory loss
- Frequently reported in post-COVID studies of both hospitalized and non-hospitalized COVID-19 patients
  - 18% of moderately to severely ill (including hospitalized) and 9% of mildly ill reported cognitive symptoms<sup>1</sup>
  - 25% report cognitive symptoms at 1 year follow-up<sup>2</sup>
  - 18% with cognitive deficits after 1 year (more among hospitalized)<sup>2</sup>
- Evidence for cognitive deficits on objective testing compared with controls<sup>3</sup>

<sup>1.</sup> Caspersen et al. European Journal of Epidemiology 2022

<sup>3.</sup> Hampshire et al. eClinical Medicine 2021

### Syndromes with post acute sequelae



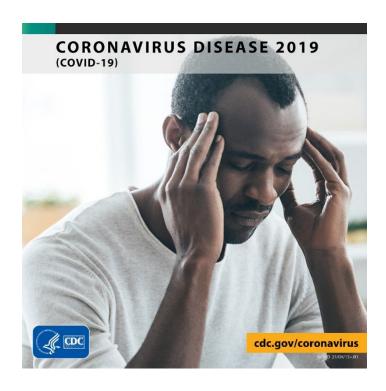


### Clinical challenges with post-COVID conditions

- Complex clinical situation presents diagnostic challenges
  - No diagnostic test
- Patient-reported symptoms are numerous
- Symptoms and debilitation often not explained by objective tests
  - Patients can be misunderstood and stigmatized
- No clinical trial data or management outcomes available



# CDC issued interim guidance for post-COVID conditions clinical care



Key Points | Evaluating and Caring for Patients with Post-COVID Conditions | CDC

- Most post-COVID conditions can be diagnosed and managed by primary care
- Many post-COVID conditions may be diagnosed based on history and physical exam, routine tests may be normal
- Consider conservative diagnostic approach in the first 4 to 12 weeks
- Symptoms persisting beyond three months should prompt further evaluation
- Listen to and validate patients' experiences and partner with patients to identify achievable health goals

U.S. ICD-10 CM code for post-COVID conditions (as of October 1, 2021)

**U09.9 Post COVID-19 condition** 



### Challenges in understanding post-COVID conditions

- Includes a wide range of physical and mental health consequences experienced by some patients
  - Spectrum of physical, social, and psychological consequences
  - Conditions are heterogenous and attributable to different underlying pathophysiologic processes
- Studies to date include different patient populations
- Assessments of occurrence of symptoms and conditions are done at varying time points following acute infection, often only once
- Many studies do not include control groups
- Severity and impact of symptoms on quality of life or daily activities not consistently reported



# There is a wide range in estimates of the prevalence of post-COVID conditions

- Self- reported symptoms range from 13.3% at ≥ 1 month to 2.5% at ≥ 3 months
- Based on electronic health record (EHR) data
  - Of non-hospitalized adults with COVID-19, 7.7% experienced one or more of 10 identified late-onset conditions 1 to 4 months post infection<sup>2</sup>
  - Frequency of at least one symptom at 6 months differs by severity of acute COVID:<sup>3</sup>
    - Overall: 73.4/1,000 patients
    - Non-hospitalized: 44.5/1,000 patients
    - Hospitalized: 217.1/1,000 patients
      - ICU: 360.5/1,000 patients

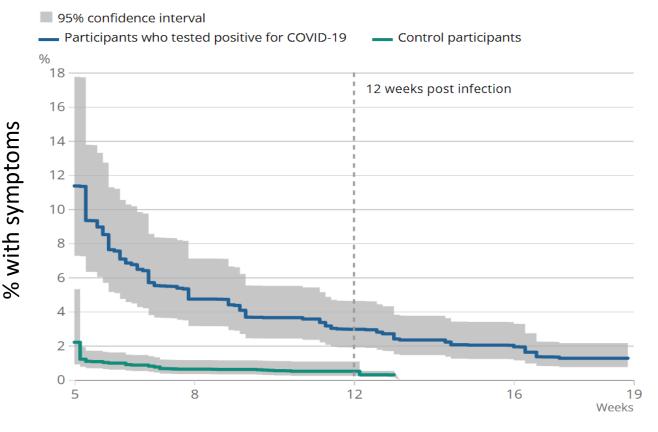


- 1. Sudre CH et al Nature Medicine 27, 626-631 (2021)
- 2. Chevinsky JR et al. Clinical Infectious Diseases 73 (S1) 2021
- Xie Y et al. Nature Communications 12, 6571 (2021)

### **Duration of post-COVID conditions can vary**

- Most patients recover in 4 weeks and the proportion reporting symptoms decreases between 4-12 weeks
- Improvement slows around 12 weeks after infection
- Women and men follow same pattern, but more women report symptoms

### UK Coronavirus Infection Survey: Report of symptoms lasting 4 or more weeks- April 2020 – August 2021





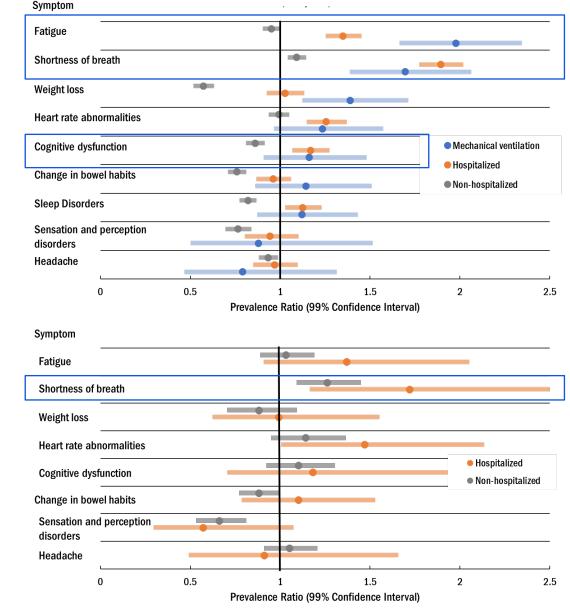
Source: Office for National Statistics - Coronavirus Infection Survey Technical article, figure 2. Office for National Statistics (ons.gov.uk)

New symptoms 31-150 days after testing positive for SARS-CoV-2

 Children and adults who tested positive for SARS-CoV-2 were more likely than patients who tested negative to have new symptoms

 Fatigue, shortness of breath, and heart rate abnormalities are more common among those who tested positive Adults (≥ 20 years)

Children and young adults (0-20 years)





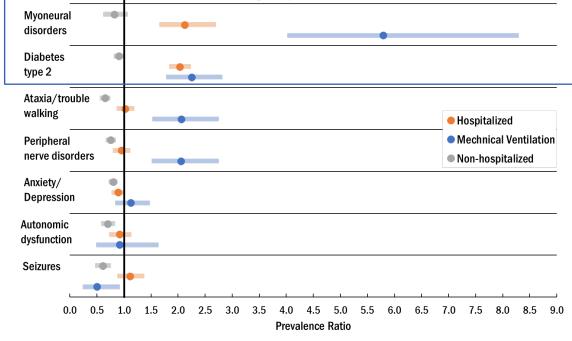
Hernandez-Romieu AC et al. JAMA Netw Open. 2022

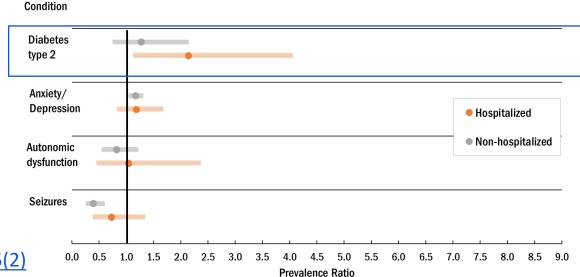
New conditions 31-150 days after testing positive for

**SARS-CoV-2** 

 Prevalence ratios of new conditions for myoneural disorders and type 2 diabetes were elevated for those with a positive SARS-CoV-2 test compared with those who tested negative Adults (≥ 20 years)

Children and young adults (0-20 years)

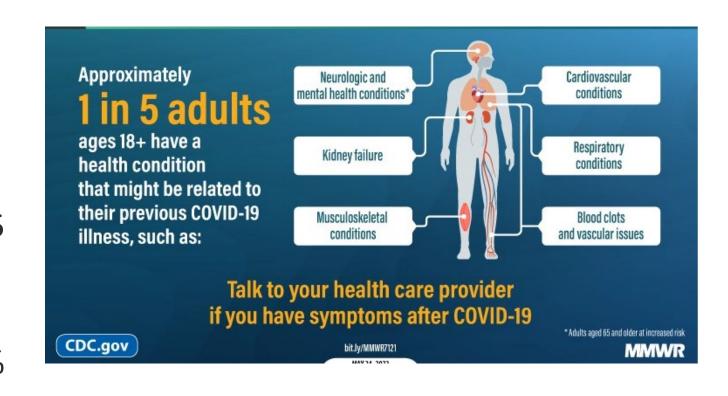






### Post–COVID Conditions Among Adult COVID-19 Survivors Aged 18–64 and ≥65 Years

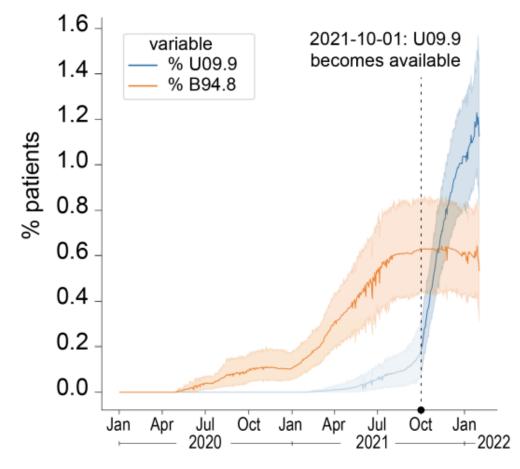
- Analysis of occurrence of 26 clinical conditions in EHRs during Mar 2020 – Nov 2021 (~63 million unique adult records)
- Patients followed for 30 365 days after their initial acute
   COVID index encounter
- 38% of case-patients and 16% controls experienced at least one incident condition





#### Use of new Post-COVID Condition ICD-10 Code U09.9

- U09.9 available for use starting
   October 1, 2021
- Previously recommended use of B94.8 (Sequelae of other specified infectious and parasitic diseases) as a placeholder
  - Plotted as a % of patients with acute COVID
- Use of U09.9 quickly exceeds B94.8 after implementation in October 2021





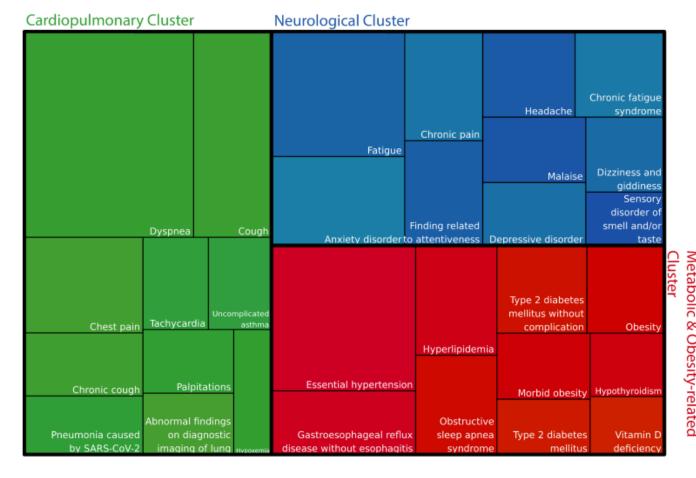
Pfaff et al. Coding Long COVID: Characterizing a new disease through an ICD-10 lens. medRxiv. April 19, 2022.

#### **Use of new Post-COVID Condition ICD-10 Code U09.9**

- Examined co-occurring diagnoses for U09.9 patients
  - U09.9 should be used in combination with condition-specific codes to establish link with COVID-19
- Found 3 distinct clusters:
   cardiopulmonary,
   neurological, and
   metabolic

#### **Cardiopulmonary cluster**

#### **Neurological cluster**





Pfaff et al. Coding Long COVID: Characterizing a new disease through an ICD-10 lens. medRxiv. April 19, 2022.

# Factors associated with an increased occurrence of post-COVID conditions

- Severity of initial infection
- Female sex
- Pre-existing conditions
- Older age
  - Increased occurrence among older adults compared to younger adults
  - Increased occurrence among adults compared to children
- Infection without evidence of vaccination
  - Lower occurrence among adults with infection after vaccination

#### DRIVERS OF INCREASED SUSCEPTIBILTIY

#### **Racial and Ethnic Minorities**

- Increased risk for exposure & severe manifestation of COVID-19
- Socioeconomic factors prevent proper selfisolation
- · Less access to primary and specialty care
- Distrust of medical institutions
- Higher rate of pre-existing conditions
- Multimorbidity

#### Clinical Complexity

- Pre-existing conditions (obesity, diabetes, heart/lung disease, etc.)
- Multimorbidity
- Severe COVID-19 manifestation
- · Prior mental health history
- Women



#### **Older Population**

- Increased risk for severe COVID-19
- · Higher rate of pre-existing conditions
- Multimorbidity

#### Rural Residents

- Increased risk for exposure to COVID-19
- · Decreased healthcare infrastructure
- Older population
- · Higher rate of pre-existing conditions
- Multimorbidity

Jiang et al. JACC Basic Transl Sci (2021) 6:796

### HEALTH DISPARITIES FOR COVID-19 LIKELY TO PERSIST WITH LONG COVID



<sup>1</sup>Thompson et al. medRxiv doi: 10.1101/2021.06.24.21259277 <sup>2</sup>Koudi et al. medRxiv doi: 10.1101/2022.01.05.22268800

# Post-COVID conditions may occur after vaccine breakthrough infections

- Study of infections after vaccination among healthcare workers in Israel found vaccine breakthrough cases were generally mild or asymptomatic, but 19% (7/36) had persistent symptoms at >6 weeks in the setting of alpha variant<sup>1</sup>
- UK Case—Control Study (n=906, 1:1 match): individuals with infections after vaccination are less likely to report prolonged symptoms (≥ 28 days) compared to persons who are unvaccinated (OR 0.51, 95% CI 0.32, 0.82)<sup>2</sup>
- Vaccines prevent post-COVID conditions by decreasing transmission, and lower the occurrence of post-COVID conditions in persons with infection after vaccination (who tend to have milder infections) than infections in persons who are unvaccinated



- .. <u>Bergwerk NEJM 2021</u>
- 2. <u>Antonelli Lancet ID 2021</u>

# **Evidence of disability associated with post-COVID conditions**

Compared with patients referred for cancer rehabilitation, post-COVID patients had poorer physical health

- More difficulty doing usual work (37.2% versus 20.4%) or participating in activities with friends (33.0% versus 18.8%)
- Reduced endurance in 6-minute walk test (distance of 303m versus 377m)

**Patient and advocacy groups'** reports have brought attention to disability associated with post-COVID conditions and the importance of including patients and caregivers in related research



### Long COVID and associated disability

- Long COVID under Americans with Disabilities Act (ADA)
  - Is a physical or mental impairment
  - Can substantially limit one or more major life activities
  - Not always a disability (must meet impairment criteria)
- Extent and duration of disability associated with persistent symptoms is being studied
  - Study of hospitalized COVID-19 patients in China found that 12% did not return to their original work by 12 months (excluded 62% who were retired or not employed before COVID-19)<sup>1</sup>

Given size of pandemic, even 1% disability at one year will have impact



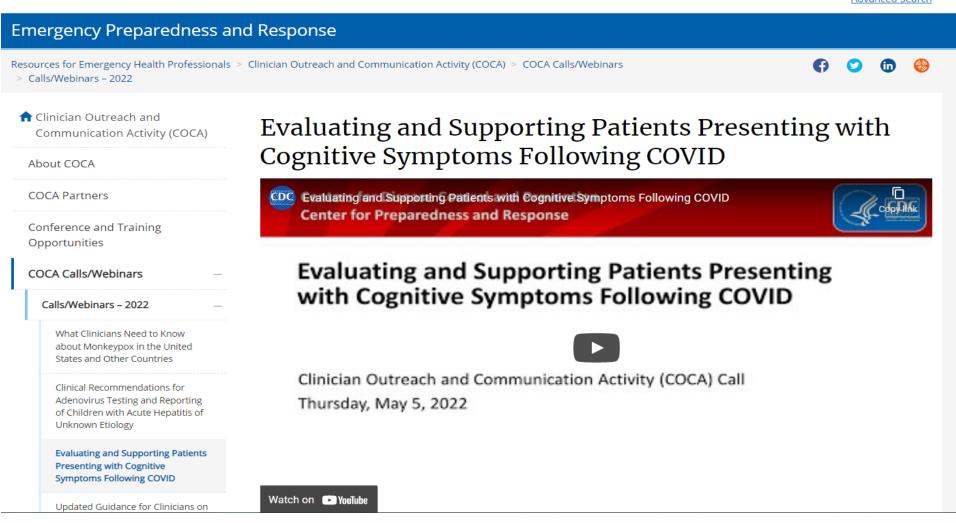
### RESOURCES







# CDC Clinician Outreach and Communication Activity (COCA) Call





To subscribe for COCA updates: https://emergency.cdc.gov/coca/subscribe.asp

# Long COVID and Fatiguing Illness Recovery Program Webinars

- 6 of 12 webinars completed
  - Sample topic: Neurocognitive manifestations of post-acute sequelae of SARS-CoV-2 (Michelle Haddad, PhD, Emory University, February 2022)
  - Next webinar: July 14, 2022
- Attendance: ~500 Zoom users per month
  - Clinicians
  - Subject matter experts
  - Patient and caregivers











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#### Long COVID & Fatiguing Illness Recovery Program ECHO

Thursday, February 10, 2022 12:00-1:00pm PST

#### **Neurocognitive Manifestations of PASC**

Michelle Haddad, PhD

Director of Post-COVID Neuropsychology Clinic Director of Inpatient Neuropsychology Departments of Rehabilitation Medicine & Neurology Emory University School of Medicine

> Agenda Presentation Slides

To register: Click Here

For resources from past sessions, click here

Please contact <u>LCecho@salud.unm.edu</u> with any questions.

This program is open to all healthcare professionals and all Long COVID and ME/CFS patient-lived experience experts interested in learning more about the treatment of Long COVID and ME/CFS.



To register: Webinar Registration - Zoom





Multidisciplinary collaborative consensus guic of SARS-CoV-2 infection (PASC) patients

Joseph E. Herrera DO, William N. Niehaus MD, Jonathan Whiteson MD, Alba MD, MBA, Talya K. Fleming MD, Soo Yeon Kim MD, Huma Nagyi MD, Sarah MD, Monica Verduzco Gutierrez MD, Jason Maley MD, Fric Herman MD, Re

First published: 04 Aug



Clinical Guidance | 🙃 Free Access

the assessment and treatment of fatigue in pi Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of breathing discomfort and respiratory sequelae in patients with post-acute sequelae of SARS-CoV-2 infection (PASC)

> Jason H. Maley MD, George A. Alba MD, John T. Barry PT, DPT, Matthew N. Bartels MD, MPH, Talya K. Fleming MD, Christina V. Oleson MD, Leslie Rydberg MD, Sarah Sampsel MPH X... See all authors ~

First published: 13 December 2021 | https://doi.org/10.1002/pmri.12744

Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cognitive symptoms in patients with post-acute sequelae of SARS-CoV-2 infection (PASC)

Jeffrey S. Fine MD, FAAPMR, Anne Felicia Ambrose MD, MS, Nyaz Didehbani PhD, Talya K. Fleming MD, Lissette Glashan MS, CCC-SLP, CBIS, Michele Longo MD, MPH ... See all authors ~



First published: 13 December 2021 | https://doi.org/10.1002/pmrj.12745



#### **Videos and Presentations**



#### RECOVER Research Review (R3) Seminar Series

The goal of the R3 Seminar Series is to catalyze a shared understanding of the research of the scientific stakeholder community within the RECOVER consortium. Working and learning together, while keeping each other up to date on the latest insights to accelerate discovery. Some R3 sessions will also inform the public about RECOVER and other research on PASC. All sessions will be recorded and posted to recovercovid.org.

#### Example seminar topics include:

- Epidemiology of Post-Acute Sequelae of SARS-CoV-2 Infection: Current Understanding and Key Questions (past event)
- Clinical Spectrum of PASC: Overview
- Commonalities with Other Disorders and Post-viral Syndromes: Focus on ME/CFS
- Clinical Spectrum of PASC: Focus on Pediatrics, including MIS-C
- Clinical Spectrum of PASC: Focus on Dysautonomia

NIH • Ongoing series began March 1, 2022



# Healthcare Provider Appointments for Post-COVID Conditions

- Listen to the patient's story
- Questions to ask:
  - What is your activity level?
  - What activities make your illness worse?
  - What improves or worsens your symptoms?
- Outline next steps:
  - Additional tests needed
  - When test results will be available
  - When to return for next visit



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

Accessible link: 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.

#### **Before the Appointment**

- ☐ Ask the new provider's office if they need **paperwork** signed so your medical records can be sent to them directly.
- ☐ Keep a **journal or a list** for a week or two to document your activities, symptoms, their severity, and anything that made you feel better or worse.
- Prepare a brief **report** that summarizes your experience and symptoms and describes your best and worst days.
- ☐ Make a list of your **current medications/supplements.**
- ☐ Make a list of questions to ask your healthcare provider. Identify which ones are a priority for you (in case time is limited).
- Make a plan for remembering your conversation with your healthcare provider — e.g., taking notes or bringing a friend.
- ☐ If needed, arrange **transportation** to your appointment.

#### **During the Appointment**

- ☐ Tell your provider the most important **symptoms or issues** you'd like to discuss.
- ☐ Answer the **provider's questions**.
- ☐ Share your **medication/supplement list**.
- ☐ Discuss your **level of activity.**
- ☐ **Ask your own questions**, starting with your priorities and issues.
- Make sure you understand the next steps, such as tests, follow-up, referrals, and future appointments.
- Ask for an **appointment summary**. If needed, ask the provider to write down or print out any instructions, medication names, or diagnoses.

#### **After the Appointment**

- ☐ Make appointments for follow up.
- □ Record future appointments, including tests, in your calendar. If others will go with you or drive you to future appointments, make sure the appointments are on their calendars too.
- ☐ Follow your **provider's instructions** to the best of your ability.
- Contact your provider's office with any questions or clarifications.
- Continue to record symptoms and keep your **journal**, so you can refer to updates or changes during your next appointment.
- Update and keep track of medications and supplements.



For more information on post-COVID conditions, please visit https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html.

# Addressing post-COVID conditions through a public health approach

#### Assess post-COVID conditions

- Provide estimates on prevalence and incidence by demographic groups,
   symptoms, and new diagnoses following COVID-19
- Characterize epidemiology, course of illness, and risk factors

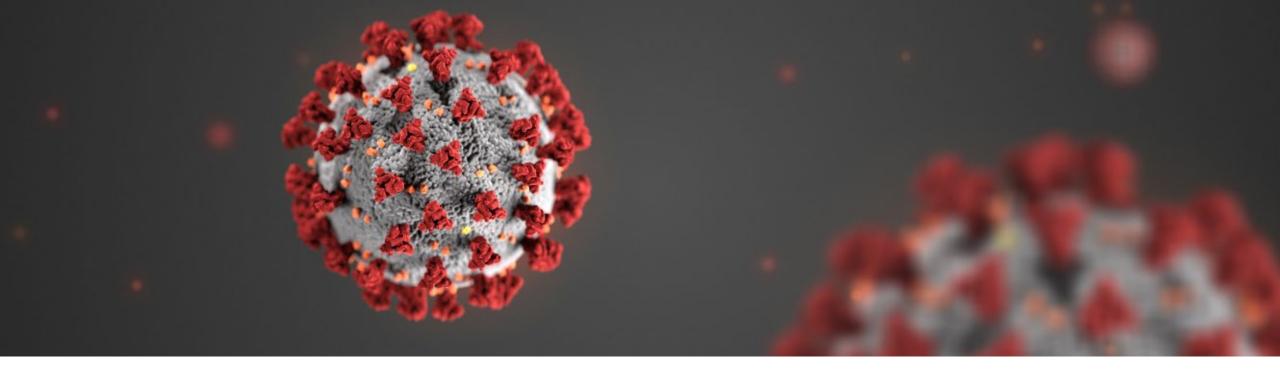
#### Identify successful interventions

- Understand vaccine effectiveness in prevention
- Provide guidance on evaluation, diagnosis, and management
- Focus on health equity to improve access to clinical care for post-COVID conditions
- Collaborate with other federal agencies and clinical organizations

#### Important take home messages

- 1. Post-COVID conditions are heterogeneous
  - Standard surveillance methods may not capture all disease
  - Epidemiologic studies must characterize different subtypes and risk factors
- 2. Post-COVID conditions will remain a public health concern into the future
  - Follow-up times will be measured in years, not weeks or months
- 3. Management of post-COVID conditions will require consistent engagement with patients and continued interagency collaboration





#### For more information:

COVID-19 Response, Epi Task Force, Post COVID Conditions Team <a href="mailto:eocevent513@cdc.gov">eocevent513@cdc.gov</a>

TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



### Q&A





# **Upcoming Learning Collaborative Community Engagement**



**Session 1: June 30th** → *Creating equitable* and effective community programs

**Session 2: July 14th** → Equitable and effective community programs: Evaluation and future steps

REGISTER HERE



Enza Rocco, JD, MSW Professor of Bioethics, Temple University



LISTEN HERE





# Nurses make change happen.

Be a part of history.

This toolkit was created to give nurses the tools to do their part in the national vaccine effort. It is designed to help you decrease vaccine hesitancy and increase vaccination rates in your community.

### https://vaccinetoolkit.phmc.org/

Find more free continuing education opportunities

### NurseLedCare.org

### THANK YOU

Special thank you to all our NNCC members who make exceptional nurse-led programming possible.



