

# **2024 GEAR Group:**

# Long COVID as a Chronic Disease: Assessment and Mitigation Resources and References Document

# **NACDD GEAR Groups**

GEAR Groups explore their topic through case presentations, short didactic presentations, and active discussions throughout four 90-minute video conferences. A facilitator and strategist guide each discussion to explore opportunities for improvement through partnerships, promising interventions or policies, data, and evaluation.

# Long COVID as a Chronic Disease: Assessment and Mitigation

Some people who have been infected with the virus that causes COVID-19 can experience long-term effects from their infection, known as Long COVID or Post-COVID Conditions (PCC). Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 infection. In July 2021, Long COVID was added as a recognized condition that could result in a disability under the Americans with Disabilities Act (ADA). The cases brought to this GEAR Group will take a nuanced look at the reality of how Long COVID shows up within chronic disease prevention, management, and programming as well as promising and/or innovative strategies to assess for, measure, and mitigate Long COVID. Case presentations or proposals may elevate approaches for assessment and mitigation of Long COVID as well as how to conceptualize, approach, or treat Long COVID as a chronic disease. Meetings were held March 5, 12, 19, and 26, 2024.

# **Participating states**

- Idaho
- Kentucky
- Maryland
- Michigan

- Minnesota
- Utah
- Vermont
- West Virginia

# **Resources and References**

The following resources were shared amongst the participants during the four-week GEAR Group in March 2024. The linked articles or resources do not necessarily represent the official views of individual participants, participants' respective organizations, or NACDD.

#### **Advocacy/Grassroots Groups**

- 1. ME Action
  - a. ME Action Network Dropbox
- 2. Solve M.E.
- 3. Survivor Corps

#### **Chronic Disease Connection**

- 4. Cardiovascular Manifestations of the Long COVID Syndrome
- 5. Looking at the Data on Smoking and Post-COVID-19 Syndrome—A Literature Review
- 6. The bidirectional association between diabetes and long-COVID-19 A systematic review



#### **Communications Resources**

- 7. NACDD Communications Guide
- 8. NACDD Communications Resources

#### **Communications Examples**

- 9. Long COVID YouTube playlist
- 10. Symptom graphics
- 11. Work-related messaging and resources
- 12. Phone survey
- 13. General messaging
- 14. Cover article for Minnesota Physician magazine
- 15. Press release

#### **Community Engagement/Storytelling**

- 16. Accessible and Adaptive Communication
- 17. Arts-Focused Approaches to Public Health Communications (Webinar)
- 18. Arts-Focused Approaches to Public Health Communications (Resources)
- 19. Community Engagement Toolkit: A Participatory Action Approach Towards Health Equity and Justice
- 20. CSPI Resource Hub Training: The Stories We Tell
- 21. Engaging Community Residents with Lived Experience: Common Concerns & What to do About Them
- 22. Engaging People with Lived Experience to Improve Federal Research, Policy, and Practice
- 23. Engaging People with Lived Experience Toolkit
- 24. Foundations of Community Engagement: Advancing Community Engagement in Public Health Practice
- 25. HHS health+ Long COVID Human-Centered Design Report
- 26. MPHI Community Engagement and Collective Impact
- 27. Narratives and Health Equity: Expanding the Conversation
- 28. The power of public health storytelling (University of Michigan)
- 29. Voices of Long COVID

#### Disabilities/Ableism

- 30. For patients with disabilities, this doctor prioritizes independence and fun
- 31. Resources for People with Long COVID
- 32. The Lancet: Structural ableism in public health and healthcare: a definition and conceptual framework

### **Funding**

33. Michigan Health Endowment Fund: Special Projects & Emerging Ideas

#### **General Information**

- 34. Implementation of the Government-wide Response to LONG COVID An update from the Office of Long COVID Research and Practice | February 2024
- 35. Long COVID and Fatiguing Illness Recovery Program ECHO
- **36.** International Long COVID Awareness
- 37. Post COVID-19 condition (Long COVID)
- 38. Risk Factors Associated With Post-COVID-19 Condition



Promoting Health. Preventing Disease.

#### **Health Systems**

- 39. CDC's Healthcare Appointment Checklist for Post-COVID Conditions
- 40. Coding long COVID: characterizing a new disease through an ICD-10 lens
- 41. Evaluation and Supporting Children and Adolescents Presenting with Post-COVID Conditions
- 42. Providing Health Care and Screenings for Individuals with Disabilities

#### **Related Conditions**

43. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

#### Research

- 44. CDC Household Pulse Survey data on Long COVID
- 45. CDC Science behind Long COVID
  - a. <u>CDC: Track PCC (Tracking the Burden, Distribution, and Impact of Post COVID-19 Conditions in Diverse</u> Populations for Children, Adolescents, and Adults)
- 46. Michigan COVID-19 Recovery Surveillance Study
- 47. NIH opens long COVID trials to evaluate treatments for autonomic nervous system dysfunction
- 48. RECOVER: Researching COVID to Enhance Recovery
  - a. RECOVER Caveat/Consideration: <u>'Underwhelming': NIH trials fail to test meaningful long Covid</u> treatments after 2.5 years and \$1 billion

#### Schools/Education

- **49.** Long COVID under Section 504 and the IDEA: A Resource to Support Children, Students, Educators, Schools, Service Providers, and Families
- 50. School Accommodations

#### **State Grant**

51. 2024 Long COVID Network & Capacity Building Grants: Request for Proposals (MN)

#### **State Statute**

52. 2023 Minnesota Statutes: 145.361 LONG COVID AND RELATED CONDITIONS; ASSESSMENT AND MONITORING

#### State Webpages/Resources

- 53. California Department of Public Health: Post-COVID Conditions (or Long COVID)
- 54. Minnesota Department of Health: Long COVID A Post COVID Condition
- 55. New York State Department of Health: Long COVID
- 56. Utah Department of Health: Long COVID Resources
- 57. Washington State Department of Health: Long COVID

### **Survey Questions**

- 58. Long COVID Questions in NHANES 2022
- 59. Maryland Behavioral Risk Factor Surveillance System (BRFSS)



# Workplace Accommodations: Employer and Health Care Provider Guidance

- 60. JAN: Accommodation and Compliance: Long COVID
- 61. Providing Sufficient Medical Documentation in Support of a Patient's Accommodation Request
- 62. Supporting Employees with Long COVID: A Guide for Employers