# COVID-19 Health Equity Task Force

Long COVID, PPE, Testing and Therapeutics Subcommittee Interim Recommendations

June 25, 2021

# Subcommittees and Task Force mission

**This Task Force under the Executive Order ---- is responsible to make recommendations for mitigating the health inequities caused or exacerbated by the COVID–19 pandemic and for preventing such inequities in the future.**

The four sub-subcommittees work intensely and effectively to provide:

A. Recommendations for how agencies and State, local, Tribal, and territorial officials can **best allocate COVID–19 resources**, in light of disproportionately high rates of COVID–19 infection, hospitalization, and mortality in certain communities and disparities in COVID–19 outcomes by race, ethnicity, and other factors, to the extent permitted by law;

B. Recommendations for agencies with responsibility for disbursing COVID–19 relief funding regarding **how to disburse funds in a manner that advances equity**; and

C. Recommendations for agencies regarding **effective, culturally aligned communication, messaging, and outreach to communities of color and other underserved populations** - In addition to addressing equity data shortfalls.

# Thank you to our SMEs for engaging with the Task Force on Long COVID, PPE, Testing and Therapeutics!

| Name | Institution |
|---|---|
| Dr. Kimberly Prather | UC San Diego |
| Hannah Davis and Lisa McCorkell | Patient-Led Research Collaborative |
| Karen Harris, Diana Berrent, and Natalie Lambert | Indiana University School of Medicine |
| Jennifer Possick | Yale School of Medicine |
| Dr. Jeremy Faust | Harvard Medical School |
| Marija Pantelic and Nisreen Alwan | Authors of "The stigma is real for people living with long covid." |
| Dr. Stephen Feagins | Mercy Health's Long COVID program |
| Jason Maley | Harvard Medical School and Massachusetts Institute of Technology |
| Fiona Lowenstein; Angela Meriquez Vázquez; Chimére L. Smith | Co-Founder Body Politic COVID-19 Support Group |
| Kristin Urquiza | Founder: Marked By COVID |

# Interim Recommendations by Theme

## Mandate Data Collection, Research, and Transparency

- Set a national research agenda centering on health equity and COVID-19, with minoritized, marginalized, and underrepresented populations co-designing agenda and adequately represented as participants

- Create a national coordination of research standards and standardized methods to disseminate research

- Conduct research to understand eligibility, patient knowledge, and access to therapeutics and how they may differ across communities

- Establish Long COVID health equity learning community infrastructure to collaborate on exchange of knowledge for Long COVID centers and clinics

- Create data transparency related to the demographics of those receiving therapeutics

## Increase Awareness and Access to Services

- Collaborate with major professional associations to build awareness, educate, and solicit more data from the public on Long COVID.

- Launch an interagency-led campaign that focuses on Long COVID patient's rights and support services

- Ban coverage limits for Long COVID and ensure treatment regardless of insurance status to extend existing protections during the pandemic.

- Provide funding for Specialty Clinics to disseminate medical equipment to patients, expanding access to preventive treatment for Long COVID

# Interim Recommendations by Theme (cont.)

## Protect Workers and the Workplace

- Create a tip line for employees to address health and safety violations by employers.

- Pass the public policies that invest in children and families (e.g. American Families Plan) and ensure benefits extend to minorities, marginalized, and medically underserved communities with Long COVID

- Pass public policies that create jobs and rebuild the countries infrastructure (e.g., American Job Plan) and ensure benefits support the needs of minorities, marginalized, and medically underserved communities with Long COVID

- Enhance temporary disability benefits to support minorities, marginalized, and medically underrepresented, individuals with long COVID

## Engage Communities

- Collaborate with community-based organizations and providers to create a Long COVID Technical Assistance Center to learn more about the condition and resources

- Create a public-private partnership to fund healthcare providers and community-based organizations serving communities most affected by Long COVID

- Expand the recruitment of and funding for Community Health Workers that are referring people impacted by Long COVID to community resources

# Data, Analytics, and Research Subcommittee

- Chair: Joneigh Khaldun

- Members: James Hildreth, Andy Imparato, Victor Joseph, Homer Venters

- Staff: Martha Okafor, Phillip Blanc, Shondelle Wilson-Frederick, Jamie Babin, Beverly Udegbe, Maya McCoy

# Problem Statements

**PROBLEM STATEMENT 1**
Given the potential scale of Long COVID issues in the population, and the growing evidence of the disproportionate impact of Long COVID symptoms on minoritized and marginalized populations, the federal investment in studying Long COVID is inadequate. There is a lack of evidence-based research and insufficient data to understand and respond to Long COVID.

**PROBLEM STATEMENT 2**
As research progresses and more treatments for COVID are available, access and administration of therapeutics are not equitably dispersed across populations.

**PROBLEM STATEMENT 1**

Given the potential scale of Long COVID issues in the population, and the growing evidence of the disproportionate impact of Long COVID symptoms on minoritized and marginalized populations, the federal investment in studying Long COVID is inadequate. There is a lack of evidence-based research and insufficient data to understand and respond to Long COVID.

1.  **The Federal Government should set a national research agenda centering on health equity and COVID-19**

The research agenda should be shaped with input from minoritized, marginalized, and medically under-served communities, and research participants should encompass a diverse group of participants across these communities as well as pediatric populations so that data can be disaggregated for these high-risk populations.

The government should promote public-private partnerships and investments in a variety of research methods (e.g., clinical trials, case-control studies, longitudinal studies, real-time technology solutions) to meet research aims, such as:

- ○ Understand the cause, biomarkers, prevalence, rates of diagnosis, and treatment effects associated with Long COVID morbidities and mortality;

- ○ Understand how racism and discrimination are associated with symptoms, disease progression, severity of Long COVID for minoritized, marginalized, and medically under-served populations;

Given the potential scale of Long COVID issues in the population, and the growing evidence of the disproportionate impact of Long COVID symptoms on minoritized and marginalized populations, the federal investment in studying Long COVID is inadequate. There is a lack of evidence-based research and insufficient data to understand and respond to Long COVID.

2. **The Federal Government should create a national coordination of research standards** and a standardized method to disseminate research, diagnostic, and therapeutic practices related to Long COVID to support informed and inclusive clinical decision making.

As research progresses and more treatments for COVID are available, access and administration of therapeutics are not equitably dispersed across populations.

1. **Create data transparency related to the demographics of those receiving therapeutics** (e.g., monoclonal antibodies) —understand who has access, who is providing services, who receives/is eligible for therapeutics; rates of associated hospitalization pre and post therapeutic administration.

2. **The Federal Government shall sponsor a research project** to compare infection rates to monoclonal antibody use and severity of illness across marginalized and minoritized populations, in addition to variability of monoclonal antibody use and Long COVID incidence.

3. **The Federal Government should conduct research to survey the general population** to understand eligibility, patient knowledge, and access to therapeutics and how they may differ across communities (e.g., home based, nursing home, outpatient facilities).

# Discussion

# Healthcare Access and Quality Subcommittee

- Chair: Tim Putnam

- Members: Mayra Alvarez, Pritesh Gandhi, James Hildreth, Vincent Toranzo, Mary Turner, Homer Venters, Bobby Watts

- Staff: Martha Okafor, Phillip Blanc, Shondelle Wilson-Frederick, Jamie Babin, Tag Quijano

OASH | Office of the Assistant Secretary for Health

OMH | U.S. Department of Health and Human Services Office of Minority Health

# Problem Statements

**PROBLEM STATEMENT 1**
There is a shortage of treatment resources for the growing population of patients experiencing Long COVID. The absence of cohesive agreement in the medical community on diagnosing Long COVID has led to the lack of access to and funding for high-quality treatment options, especially for minoritized, marginalized, and medically underserved populations that are disproportionately impacted by symptoms.

**PROBLEM STATEMENT 2**
Treatment for Long COVID is being disproportionately denied by health insurance providers and medical professionals, leading to disproportionately poor Long COVID prognosis for minoritized, marginalized, and medically underserved populations.

**PROBLEM STATEMENT 3**
Racism results in minoritized populations being misdiagnosed, less likely to receive an accurate diagnosis of Long COVID, and less likely to receive appropriate and high-quality care compared to their non-minoritized peers. Without addressing these pre-existing disparities, misdiagnosis will continue to be exacerbated with Long COVID.

# Problem Statements

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|---|---|---|
| **PROBLEM STATEMENT** | **4** | There is a lack of clear guidance around PPE use, reuse, equitable dissemination, and rationing that contributed to an increase in the spread of illness and death among health care professionals and all workplaces serving minoritized, marginalized, and medically underserved populations. The lack of lack of federal oversight and standards and increased cost of PPE all led to the delay or cancellation of non-emergent health care services. |
| **PROBLEM STATEMENT** | **5** | COVID-19 testing still is not widely available in some areas.  As variant strains continue to develop and a significant portion of the population remains unvaccinated, equitable access to testing is crucial to preventing the spread of COVID-19 in minoritized, marginalized, and medically underserved populations. |

# Problem Statements

**PROBLEM STATEMENT 6**

People experiencing homelessness are not often able to get the rest they need because many shelters require clients to leave the facility during the day.  Being able to rest and having access to treatment are important factors related to ameliorating Long COVID.

**PROBLEM STATEMENT 7**

Many Long COVID patients in rural and remote areas do not have the ability to travel for treatment and support or have access to telemedicine due to a lack of access to internet-enables devices, stable/quality internet, or support to increase familiarity with technology options.

**PROBLEM STATEMENT 1**

There is a shortage of treatment resources for the growing population of patients experiencing Long COVID. The absence of cohesive agreement in the medical community on diagnosing Long COVID has led to the lack of access to and funding for high-quality treatment options, especially for minoritized, marginalized, and medically underserved populations that are disproportionately impacted by symptoms.

1. **The Federal Government should communicate unified ICD-10 Codes for Long COVID** so that medical providers can accurately classify the diagnosis, treatment, and billing for Long COVID. This is intended to prevent patients that are being denied coverage for the diagnosis and treatment of Long COVID.

2. **The Federal Government should expand the recruitment of and funding for Community Health Workers** that are referring people impacted by Long COVID to community resources, such as healthcare, housing, and food in addition to providing resources to assist them with signing up for health insurance coverage, including Medicaid and other forms of coverage.

3. **The Federal Government should provide funding to encourage both targeted training for providers serving minoritized, marginalized, and medically underserved communities, focused on Continuing Medical Education (CME)** for COVID that is also inclusive of Long COVID.

**PROBLEM STATEMENT 1**

There is a shortage of treatment resources for the growing population of patients experiencing Long COVID. The absence of cohesive agreement in the medical community on diagnosing Long COVID has led to the lack of access to and funding for high-quality treatment options, especially for minoritized, marginalized, and medically underserved populations that are disproportionately impacted by symptoms.

4. **The Federal Government should mandate that any funding for multidisciplinary post-COVID care centers to treat Long COVID populations must simultaneously require these centers to accept patients regardless of insurance coverage and deliver training for providers treating patients in safety net health systems** like FQHCs, Indian Health Service and Rural Health Clinics.

5. **The Federal Government should provide funding for clinics, Federally Qualified Health Centers (FQHCs), Indian Health Service and Rural Health Clinics to disseminate medical equipment (e.g. pulse oximeters, spirometers etc.) to patients**, expanding access to treatment to prevent the exacerbation of Long COVID by enabling patients to monitor symptoms and promote rehabilitation safely at home.

**PROBLEM STATEMENT 1**

There is a shortage of treatment resources for the growing population of patients experiencing Long COVID. The absence of cohesive agreement in the medical community on diagnosing Long COVID has led to the lack of access to and funding for high-quality treatment options, especially for minoritized, marginalized, and medically underserved populations that are disproportionately impacted by symptoms.

6. **The Federal Government shall continue to update and disseminate standards and protocols** for diagnosis and management of Long COVID.

7. **Increase staffing in areas with health professional shortages to treat minoritized, marginalized, and medically underserved populations**, and in areas with the highest COVID-19 infection rates. Dramatically increase funding for education in medical fields and graduate medical education for people raised in or committed to serve health professional shortage areas, HPSA. Expand National Public Health Service Corps, Public Service Loan Forgiveness, and Public Health Service Act Title VII and Title VIII grants, scholarships, and loan forgiveness.

# PROBLEM STATEMENT 2

Treatment for Long COVID is being disproportionately denied by health insurance providers and medical professionals, leading to disproportionately poor Long COVID prognosis for minoritized, marginalized, and medically underserved populations.

1. **Create more inclusive health insurance disability policies that recognize Long COVID** as a health condition with a diagnostic schema that identifies people who have Long COVID without a positive COVID test.

2. **Ensure that the pediatric patient population has access to primary care providers** and clinics that treat Long COVID.

3. **The Federal Government should consult with the appropriate healthcare professionals** to ensure that Long COVID treatment incorporates patient-centered approaches and adequate clinical encounter time to optimize the quality of life and function in affected patients.

4. **The Federal Government should explicitly ban coverage limits for Long COVID and ensure treatment regardless of insurance status** to extend existing protections during the pandemic.

**PROBLEM STATEMENT 3**

Racism results in minoritized populations being misdiagnosed, less likely to receive an accurate diagnosis of Long COVID, and less likely to receive appropriate and high-quality care compared to their non-minoritized peers. Without addressing these pre-existing disparities, misdiagnosis will continue to be exacerbated with Long COVID.

1. **Healthcare providers should be required to complete ongoing training addressing unconscious and explicit bias that utilizes standardized metrics to monitor and report the effectiveness of the training over time.** Training requirements should be part of CMS provider compliance training.

2. **Patients should receive access to treatment for Long COVID, irrespective of whether they received a positive test for acute COVID**, for which they were or were not hospitalized. The patient population should be inclusive of people living in congregate settings such as carceral institutions and inpatient psychiatric settings.

**PROBLEM STATEMENT 4**

There is a lack of clear guidance around PPE use, reuse, equitable dissemination, and rationing that contributed to an increase in the spread of illness and death among health care professionals and all workplaces serving minoritized, marginalized, and medically underserved populations. The lack of lack of federal oversight and standards and increased cost of PPE all led to the delay or cancellation of non-emergent health care services.

1. **The Federal Government should maintain an adequate stockpile and create a rapid emergency production plan** for PPE for healthcare providers and all essential workers.

2. **The Federal Government should develop and enforce the standards used to produce PPE during public health emergencies requiring such equipment.**

3. **Leverage available federal funding tools to provide temporary funding for vaccine uptake in employees of congregate settings**, such as long-term care facilities, hospitals, End-Stage Renal Disease (ESRD) facilities, shelters, and prisons. Vaccine uptake in these settings protects employees, residents, and patients, all of which are often from minoritized, marginalized, and medically underserved communities.

**PROBLEM STATEMENT 5**

COVID-19 testing still is not widely available in some areas. As variant strains continue to develop and a significant portion of the population remains unvaccinated, equitable access to testing is crucial to preventing the spread of COVID-19 in minoritized, marginalized, and medically underserved populations.

1. **The Federal Government should partner with COVID-19 test kit manufacturers to expand at home COVID-19 test kits with results that are entered into a public health data system**, expanding access to communities not able to access traditional testing sites while providing access to data that builds transparency around spreadable diseases.

2. **The Federal Government should develop policies that require public and private health insurance to cover COVID-19 testing** and ensure testing is at no cost to the patient if the patient is uninsured.

## PROBLEM STATEMENT 6

People experiencing homelessenss are not often able to get the rest they need because many shelters require clients to leave the facility during the day.  Being able to rest and having access to treatment are important factors related to ameliorating Long COVID.

1. **The Federal Government should issue guidance to recipients of Emergency Solutions Grants (ESG) funds** to address how and why shelters should allow people to rest as needed.

2. **The Federal Government should encourage and incentivize state homeless service providers and state, tribal, and local Continua of Care to address homelessness**, to ensure that the people experiencing homelessness with Long COVID have places to rest during the day by extending shelter operations to include daytime hours and/or expanding day-time drop-in center capacity.

**PROBLEM STATEMENT 6**

People experiencing homelessness are not often able to get the rest they need because many shelters require clients to leave the facility during the day. Being able to rest and having access to treatment are important factors related to ameliorating Long COVID.

3. **The Federal Government should establish funding for Medical Respite (also known as Recuperative Care) programs**, which provide safe places for people experiencing homelessness to receive medical care and wrap around services to stabilize their health and recover from conditions such as Long COVID; Encouragement and support should be extended to communities seeking to convert hotels used to house people experiencing homelessness during the pandemic to these programs.

4. **The Federal Government should provide public health intervention funding to address barriers to care** such as transportation to treatment centers from homeless shelters to increase access to quality treatment for Long COVID for minoritized, marginalized, and medically underserved populations with a special focus on populations experiencing homelessness.

**PROBLEM STATEMENT 7**

Many Long COVID patients in rural and remote areas do not have the ability to travel for treatment and support or have access to telemedicine due to a lack of access to internet-enables devices, stable/quality internet, or support to increase familiarity with technology options.

1. **Leverage telehealth and telephone visits where medical resources are limited** and ensure that providers are reimbursed at equitable rates.

2. **Provide government incentives and equipment to Long COVID providers** who offer care within known remote, tribal, and medically underserved areas, including funding, machines, therapeutics, and training.

3. **The Federal Government should prioritize access to in person care** when possible and expand access and reimbursement for telemedicine and telephone visits when in person care is not feasible or would delay treatment.

# Discussion

# Structural Drivers and Xenophobia Subcommittee

- Chair: Haeyoung Yoon

- Members: Mayra Alvarez, Sara Bleich, Jessica Cardichon, Richard Cho, Jo Linda Johnson, Victor Joseph, Octavio Martinez, Mary Turner, Bobby Watts

- Staff: Martha Okafor, Phillip Blanc, Shondelle Wilson-Frederick, Jamie Babin, Sydney Gray

# Problem Statements

**PROBLEM STATEMENT 1** Various underserved communities are more likely to be exposed to, contract, and have trouble recovering from COVID-19 and Long COVID due to continued and persistent exposure, lack of adequate ventilation, and/or overcrowding.

**PROBLEM STATEMENT 2** AAPI individuals in the healthcare sector are experiencing on-the-job discrimination and harassment due to rising anti-Asian xenophobia, along with both systemic and institutional racism.

**PROBLEM STATEMENT 3** The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

## PROBLEM STATEMENT 1

Various underserved communities are more likely to be exposed to, contract, and have trouble recovering from COVID-19 and Long COVID due to continued and persistent exposure, lack of adequate ventilation, and/or overcrowding.

1. **The Federal Government should provide funding and guidance to ensure safe ventilation practices and evaluate air-quality standards** for publicly provided housing, shelters, and centers. These settings support minorities, marginalized, and medically underserved communities who are at risk of Long COVID and its ongoing effects.

**PROBLEM STATEMENT 2** AAPI individuals in the healthcare sector are experiencing on-the-job discrimination and harassment due to rising anti-Asian xenophobia, along with both systemic and institutional racism.

1. **Building upon the executive order and Presidential Memorandum to combat systemic racism, the Federal Government should work with the public and private hospitals and the health care industry to address discrimination faced by AAPI health care professionals** as its continued negative impact on the treatment of COVID and Long COVID for AAPI individuals, among others.

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

1. **Congress should pass public policies that invest in children and families – such as the American Families Plan – and ensure that the benefits to support the needs of minoritized, marginalized, and medically underserved communities with long COVID and their overburdened, unpaid caregivers.**

   a. Work with Congress to expand the coverage of the Healthy Families Act to cover all employees and pass the legislation to establish the national sick leave standards to extend sick leave for those diagnosed with long COVID.

   b. Provide national paid leave to all, including those with long COVID.

   c. Provide more direct support to children and families who continue to be vulnerable, not just to the impacts of COVID, as initially scoped, but also the adverse impacts of long COVID on education, career, wealth, and wellness.

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

*(continued)*

d.  Work with Congress to make the Childcare Tax Credit (through ARPA) beyond 2021 for family members who assume caregiving responsibilities for a child or dependent adult child diagnosed with long COVID

e.  Establish a tax credit to offset the cost of family care that starts in 2021 and extends beyond, covering family members who assume caregiving responsibilities for a spouse, non-child dependent, and/or elder diagnosed with long COVID

f.  Establish and fund a homemaker and home health aide care program to support overburdened, unpaid caregivers (at no cost to them) of those with diagnosed long COVID that sends trained home health aides equipped to help assess and support daily living needs (Modeled off of VA Homemaker Home Health Aide Care.)

g.  Build on the FY22 ED budget request to increase the number of school nurses and professional counselors to support children in k-12 who have long COVID and children whose parents have long COVID, to also support higher education.

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

2. **Congress should pass public policies that create jobs and rebuild the country's infrastructure – such as the American Jobs Plan – and ensure that the benefits to support the needs of minoritized, marginalized, and medically underserved communities with long COVID and their overburdened, unpaid caregivers.**.

   a. Ensure that patients with long COVID have workplace protections by enforcing existing laws (Americans with Disabilities Act, Family & Medical Leave Act), increase paid leave available for those with long COVID.

   b. The US Department of Labor and the US Equal Employment Opportunity Commission should issue information and guidance for employers to remind them of their obligations under ADA and Rehabilitation Act of 1973 (Rehab Act) when it comes to requests for leave.

   c. In the American Jobs Plan, develop a Long COVID job reentry program with state, local governments, federal government, and private industry (private/public), that dedicates funding, training, placement support and open roles, as well as other resources specifically to women, genderqueer, two-spirit, and nonbinary folks with set-aside support for intersectional groups within these, including Black, Indigenous, and other people of color.

**PROBLEM STATEMENT 3**

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

3. **Enhance temporary disability benefits to support minorities, marginalized, and medically underrepresented, individuals with long COVID**.

   a. **Improve and expand the current Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs**, including: speeding up application processing times; removing waiting periods before payment and Medicare/Medicaid coverage; reducing work requirements necessary to qualify; including Long COVID in the list of medical conditions accepted by Social Security Administration, include allowances for temporary, partial, and/or situational impairment as qualifying disabling conditions; and increasing benefits to 100% Federal Poverty Level (FPL).

**PROBLEM STATEMENT 3**

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

*(continued)*

b.  **The Federal Government should help adults with Long COVID learn about and navigate the Social Security Disability benefit system and the accompanying healthcare programs** so they can get the support and care they need as they experience work disruptions. Recognizing that a number of adults with Long COVID may not qualify for federal disability benefits, the Federal Government should provide flexible funding to the States to provide income support and health care benefits that can provide relief for individuals who are waiting for eligibility determinations or who have been found ineligible for federal disability benefits.

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

4. **The Federal Government should clarify its educational accommodations for those experiencing Long COVID**, including eligibility requirements for special education and related services, in addition to helping students and caregivers navigate the systems and programs that exist to support them.

   a. For children with Long COVID and their families, the Federal Government should clarify their eligibility for special education and related services under IDEA and their right to access appropriate services and supports under Supplemental Security Income, Medicaid and other programs. In the areas where there are gaps in federal programs designed to support children with disabilities and chronic health conditions, the Federal Government should provide flexible funding to States to help fill these gaps for families dealing with Long COVID.

**PROBLEM STATEMENT 3**

The experience of having long COVID has caused outsized negative financial, health, physical, and social impacts due to a lack of benefits and/or support securing available benefits, the added strains and dependency on others with their continued illness, and the longstanding and insufficient support for people with disabilities across their lifespan.

5. **The federal government should create an updated FAQ to clarify that people who have faced financial hardship due to long-COVID are eligible for rental assistance** through the Emergency Rental Assistance Program (ERAP 1 and ERAP 2) today and after the federal emergency declaration for COVID-19 ends.

# Discussion

# Communications and Collaborations Subcommittee

- Chair: Mayra E Alvarez

- Members: Andy Imparato, Jo Linda Johnson, Rachel Levine, Octavio Martinez, Vincent Toranzo

- Staff: Martha Okafor, Phillip Blanc, Shondelle Wilson-Frederick, Jamie Babin, Swathi Srinivasan

**OASH** | Office of the Assistant Secretary for Health

**OMH** | U.S. Department of Health and Human Services Office of Minority Health

# Problem Statements

**PROBLEM STATEMENT** **1** The lack of an accepted definition of Long COVID, limited availability of information, absence of a common language to discuss the condition and a fragmented and siloed pre-pandemic health care infrastructure led to increased bias, discrimination, hesitation, doubt, and heightened stigmatization by marginalized populations  - both on the part of providers, and experience by patients.

**PROBLEM STATEMENT** **2** Patients, providers, and communities disproportionately affected by Long COVID have fewer workplace protections and employment opportunities, resulting in lost pay, lost jobs, and compromised health.

**PROBLEM STATEMENT 1**

The lack of an accepted definition of Long COVID, limited availability of information, absence of a common language to discuss the condition and a fragmented and siloed pre-pandemic health care infrastructure led to increased bias, discrimination, hesitation, doubt, and heightened stigmatization by marginalized populations - both on the part of providers, and experience by patients.

1. **The Federal Government should provide resources and collaborate with community-based organizations and providers** to create a Long COVID Technical Assistance Center. This would include a hotline for community members and other stakeholders to learn more about the condition, share their experiences and connect with local resources.

2. **The Federal Government should execute a robust communication campaign**, collaborating with major professional associations to build awareness, educate, and solicit more data from the public on Long COVID. This campaign should include efforts to reach marginalized communities, as well as healthcare workers that serve them.

3. **The Federal Government should establish a Federal Advisory Committee**, specifically on Long COVID, comprised of a majority of composed of Long COVID patients and include external experts in researching and treating post-infectious chronic illness and their comorbidities and disability advocates.

**PROBLEM STATEMENT 1**

The lack of an accepted definition of Long COVID, limited availability of information, absence of a common language to discuss the condition and a fragmented and siloed pre-pandemic health care infrastructure led to increased bias, discrimination, hesitation, doubt, and heightened stigmatization by marginalized populations - both on the part of providers, and experience by patients.

4. **The Federal Government should create a public-private partnership** to fund healthcare providers and community-based organizations serving communities most affected by Long COVID. Funds will support local efforts to reach marginalized communities with information, supports, and services regarding Long COVID.

5. **The Federal Government should lead the development of a Long COVID health equity learning community infrastructure**, in partnership with Long COVID centers and clinics that are developing across the country to research, understand, develop interventions, and treat Long COVID. The Long COVID health equity learning community infrastructure will facilitate collaborations and the exchange of knowledge between all Long COVID centers and clinics.

## PROBLEM STATEMENT 2

Patients, providers, and communities disproportionately affected by Long COVID have fewer workplace protections and employment opportunities, resulting in lost pay, lost jobs, and compromised health.

1. **The Federal Government should launch an interagency-led initiative** that focuses on Long COVID patients' rights and support services such as legal aid, vocational rehabilitation services, housing as well as occupational therapy. Through this initiative, the Federal Government should advance programs that help patients with Long COVID learn about and navigate these services so they can get the support and care they need as they manage the impacts of Long COVID.

2. **The Federal Government should create a tip line for employees to address health and safety violations by employers.** The tip line should provide a protected channel of communication for employees to express concerns related to Long COVID health and safety.

# Discussion