

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)
COVID-19 HEALTH EQUITY TASK FORCE (HETF)**

5th MEETING (Virtual)

June 25, 2021

Members Present

Marcella Nunez-Smith, M.D., M.H.S. (Chair)
Mayra Alvarez, M.H.A.
Sara Bleich, Ph.D.*
Jessica Cardichon, Ed.D., J.D.*
Richard Cho, Ph.D., M.P.H.
Pritesh Gandhi, M.D., M.P.H.*
James Hildreth, Ph.D., M.D.
Andrew Imparato, J.D.
Jo Linda Johnson, J.D.*
Victor Joseph
Joneigh Khaldun, M.D., M.P.H., F.A.C.E.P.
Octavio Martinez, M.D., M.P.H., M.B.A., F.A.P.A.
Shannon Pazur, J.D.*
Tim Putnam, D.H.A., E.M.S.
Vincent Toranzo
Mary Turner, R.N.
Homer Venters, M.D.
Bobby Watts, M.P.H., M.S.
Haeyoung Yoon, J.D.

Members Absent

Rachel Levine, M.D.*

*Federal ex-officio members

Federal Staff

CAPT Samuel Wu, Pharm.D., Designated Federal Officer, Office of Minority Health
Martha Okafor, Ph.D., Executive Director, Office of the Assistant Secretary for Health

Invited Presenters

Bruce Siegel, M.D., M.P.H., President & CEO
America's Essential Hospitals
Margot Gage Witvliet, Ph.D., Assistant Professor
Lamar University

Call to Order, Welcome and Introductions

CAPT Samuel Wu

Designated Federal Officer, Office of Minority Health

CAPT Wu opened the fifth meeting of the COVID-19 Health Equity Task Force (HETF) by welcoming attendees to the meeting and wishing them a happy Pride Month and recognizing the historic first Federal commemoration of the Juneteenth. He stated that the focus of this meeting was on the inequities and impact of Long COVID, and the access to personal protective equipment (PPE), testing, and therapeutics that are related to this pandemic. He reminded attendees that the meeting was being live streamed and recorded, that the recording would be available for viewing at a later time, and, additionally, all materials presented in the meeting would be available at minorityhealth.hhs.gov/hetf. CAPT Wu noted that American Sign Language (ASL) interpreter services were available for the meeting and closed captioning was available at both hhs.gov/live and the Office of Minority Health YouTube channel. He welcomed members of the public to provide comments as stated in the meeting notice published in the Federal Register by emailing COVID19HETF@hhs.gov no later than 7 days after the meeting.

Opening Remarks

Marcella Nunez-Smith, M.D., M.H.S.

Chair, COVID-19 Health Equity Task Force

Dr. Nunez-Smith opened the meeting by welcoming everyone and restating the objective of the Task Force, to provide recommendations for mitigating health disparities caused or exacerbated by the COVID-19 pandemic and preventing such inequities in the future. Additionally, she reminded the Task Force that their purpose is to consider guidance specific to culturally responsive best practices regarding language, access and sensitivity toward Asian Americans, Native Hawaiians, and Pacific Islanders in the Federal Government's response.

Dr. Nunez-Smith shared that the Administration has made notable progress distributing vaccines around the country, including to the communities that most urgently need them. More specifically, she summarized the most current data revealing that 65 percent of all adults have received at least one shot, including 87 percent of seniors. Other encouraging signs of progress show that hospitalizations and deaths, particularly among older persons, is trending down. Additionally, 70 percent of adults over 27 years of age will have received at least one shot by July 4th. She noted that areas needing urgent improvement include increasing immunization uptake among persons 18 to 26 years of age and those who are medically underserved. She raised the concern that all persons who are unvaccinated remain at risk for COVID-19 and will also remain at risk for localized surges. Dr. Nunez-Smith emphasized that vaccinations save lives and, as the Delta variant is highly contagious and on track to become the dominant variant in the United States, this too should be a compelling motivator to get vaccinated, as should avoiding post-COVID syndrome or Long COVID.

Dr. Nunez-Smith pointed out that while vaccinations remain top of mind in the country and around the globe, equitable access to PPE, testing, and therapies must be prioritized. She also stated that key to understanding who is at greatest risk is elevating the crossroads of intersectional and disaggregated data. Dr. Nunez-Smith remarked that these data will also help to

understand where resources and interventions should be targeted and to take the necessary steps to center equity across the groups that are most affected.

In keeping with the Task Force's mission, Dr. Nunez-Smith announced that today's attention turns to two important priorities: equitable access to PPE, testing, and therapies and post-COVID syndrome, otherwise known as post-acute sequelae of SARS-CoV-2 infection, or Long COVID. She shared lessons learned from challenges encountered by frontline and healthcare workers as well as those regarding equitable access to testing. She further described that data also demonstrate differential access and uptake in terms of COVID-19 therapies. She noted that it is imperative that everyone have access to the scientific discoveries, including those on the testing and therapeutic fronts.

Describing the limited research to date on the mental, physical, social, and emotional impact on post-COVID conditions, Dr. Nunez-Smith remarked that these factors are often compounded by grief and bereavement. She also commented that there are insufficient data to accurately estimate the number of people who are affected. She reminded the Task Force that one of the day's key tasks was to better understand the potential for inequities and the burden of Long COVID in access to state-of-the-art care and to provide interim recommendations for mitigating these inequities. In addition to problems with diagnosis and care, the issues facing those suffering from Long COVID symptoms are multifactorial. Housing, financial, nutritional, and employment insecurities have a profound impact on anyone's ability to heal and move forward. She lifted the notion that those who are under the chronic stress of poverty or who have already been severely affected by this pandemic will continue to need proactive support to achieve wellness.

In closing, Dr. Nunez-Smith reviewed the meeting agenda and recognized the contributions of the Federal staff, Task Force members, subcommittee members, and subject matter experts who have contributed to the body of recommendations thus far.

After the opening remarks, CAPT Wu performed a roll call of HETF members and announced a quorum for the meeting.

Panel Presentations and Discussion

Two members of the public health community were invited to address the Task Force. Dr. Bruce Siegel spoke about PPE, testing, and therapy and the issue affecting the nation's safety net system and the patients that rely on its care. Dr. Margot Gage Witvliet, a social epidemiologist, shared her own personal experience with Long COVID, her fight for fair treatment, and the insights it has provided her into where the current systems need improvement. The presentations were each followed by a brief discussion period.

*Bruce Siegel, M.D., M.P.H.
President & CEO
America's Essential Hospitals*

Dr. Siegel expressed that while we are making progress as it relates to the COVID-19 pandemic, more work is needed in terms of health, social inequities, and our response to the COVID-19 pandemic. Paraphrasing President Biden's Executive Order, he highlighted the urgent need for

improved racial, ethnic, language, and other data to inform best practices. Dr. Siegel recognized that prior meetings of the Task Force have also exemplified the lack of complete data disaggregated by race, ethnicity, and language that are needed to ensure an equitable pandemic response and recovery. He further stated that the unconscionable rates of infection and death among Blacks, Latinx, and other people of color have emphasized the urgency of this need.

Turning to testing, Dr. Siegel explained that patients served by America's Essential Hospitals have a higher probability for severe disease due to comorbidities and social risk factors that create barriers to accessing testing. Dr. Siegel referred to a June 8, 2021 study published in the Journal of the American Medical Association illustrating that White and affluent patients with access to telehealth services were less likely to be hospitalized compared to patients of color, non-Native English speakers, and Native Americans who initiated testing through emergency rooms, as these patients often lacked access to telehealth and/or primary care services. The study also revealed that patients who initiated a COVID-19 test via telehealth or an outpatient encounter had lower rates of subsequent inpatient and intensive care unit (ICU) services compared to persons who were tested by way of an emergency department visit. Dr. Siegel remarked that the Medical University of South Carolina sought an equitable solution to testing through the creation of a statewide COVID-19 testing network that reached geographically vulnerable communities. As a result, 50 percent of all COVID-19 tests were administered to Black patients, who represent a quarter of the state's overall population.

In addition to accessible testing, Dr. Siegel illuminated the importance of a steady and equitable supply chain to administer COVID-19 testing supplies such as swabs, nasal transfer media, and reagents. He explained that many essential hospitals have faced acute PPE shortages and were outbid in the "mad scramble" to acquire items like N95 masks early in the pandemic. He pointed out that hospitals, dependent on Medicaid for most of their financing or hospitals with 50 percent or more self-pay patients are at greater risk of supply chain disparities for items that are critical to frontline healthcare workers and their patients.

Regarding therapeutics, Dr. Siegel shared that barriers to the equitable allocation of therapeutics include inadequate access to information, the inability to schedule therapies, or a lack of availability of therapeutics nearby their respective community. Fortunately, states such as Minnesota can serve as a model to help other states replicate their framework, which called for each region within the State to have several locations designated to administering monoclonal antibody infusions and placed consideration on geographic and demographics factors as well as population needs when they developed their framework. Dr. Siegel also noted the need for healthcare systems and infusion facilities to accept referrals from outside their system of care and among persons who lack connection to a specific health system or regular primary care provider.

As it relates to infrastructure, Dr. Siegel noted that many essential hospitals lack the infrastructure needed to prepare for and appropriately respond to COVID-19 surges because of their financial state. Dr. Siegel stressed the importance of investing in America's safety net system and ensuring that these investments are directly targeted to the need(s), persons served, and to account for the financial disadvantage of their payor mix. Additionally, Dr. Siegel asked that the HETF recommend increasing funding for hospital preparedness programs,

improving surveillance systems to support early detection and intervention, and strengthening America's safety net system to better respond to future pandemics and other public health emergencies.

Discussion

Dr. Martinez asked about data and metrics, where Dr. Siegel had pointed out we have fallen short for decades across the board, and if there is a compelling rationale or argument for why we should not collect key data to address health disparities and inequities?

Dr. Siegel responded that he does not see any rationale not to collect disaggregate data. He explained that data systems are now in a place with the capability of collecting and stratifying data according to key measures. He further noted that collecting disaggregate data that represent the patient population will enable hospital systems and the country to prepare for and respond to emerging infectious diseases and outbreaks.

Ms. Turner expressed her appreciation for Dr. Siegel's portrayal of what it was like on the frontlines. As a COVID ICU nurse, she appreciated his recommendations to fully fund preparedness for the hospitals because "I never again want to have one N95 that I wear till it falls off my face."

Dr. Nunez Smith thanked Dr. Siegel for his clear, pragmatic ideas and recommendations and asked that he elaborate on how best to target provider relief.

Dr. Siegel responded that the low reimbursement rates provided by Medicaid leave vulnerable hospitals at risk for being able to adequately care for and respond to public health emergencies. The historically low Medicaid reimbursement rates is both a legacy and manifestation of structural racism. He noted that the last administration did work hard to correct reimbursement rates, but America's safety net system remains in dire financial straits. Regarding the perception that hospitals have gained financially from the Provider Relief Funds, Dr. Siegel noted that while there may have been some hospitals who financially benefited from these funds, most did not. Dr. Siegel underscored that many public and essential hospitals in America continue to struggle. He stated that consideration for resource allocations need to be made based on the number of cases and among hospitals who are dependent on Medicaid reimbursement.

Dr. Putnam touched on the issue that many hospitals and physicians are paid at significantly lower rates for publicly insured patients than many commercially insured patients. He asked Dr. Siegel to share his organization's top one or two recommendations to help understand how to address this.

Dr. Siegel responded that one thing seen over the years in the regulatory framework is a lack of emphasis on ensuring that Medicaid rates are adequate to ensure access. He urged HHS and the Centers for Medicare & Medicaid Services (CMS) to consider the adequacy of rates to ensure equivalent access to medical care for all persons.

Lessons Learned from Being Sick 15 Months With COVID-19

Margot Gage Witvliet, Ph.D.

Assistant Professor & Social Epidemiologist

Lamar University

Dr. Gage Witvliet shared that over a year ago, she deliberated for some time as to whether she should publicly share her health situation. After learning about so many other women and women of color experiencing symptoms of Long COVID yet not being believed and taken seriously, she felt compelled to come forward.

Dr. Gage Witvliet stated that prior to March 2020, she would have described herself as a healthy and vibrant female health researcher and mother. She had no prior health conditions, exercised regularly, and ate healthfully. After a plane ride, she and her family became extremely sick. While her family seemed to recover within short order, Dr. Gage Witvliet explained that her condition would become progressively worse. She shared that while she appears to be normal, even now as she speaks with the HETF, she is experiencing persistent chest pain, pins and needle sensations running down her arms, ringing in her ears, and a headache. She shared that by evening, she will “morph into a deconditioned 80-year-old woman.” Dr. Gage Witvliet explained that because of her low energy, it is imperative for her to pace herself throughout the day. Her symptoms are similar to what persons living with myalgic encephalomyelitis, or chronic fatigue syndrome experience.

Turning to the issue of education, Dr. Gage Witvliet recommended to the HETF that they advocate for continued virtual education options, especially for persons with chronic illness who are caring for school-age children. She noted that children not yet eligible for the vaccine who must return to in-person school will increase risk for infection for their caretakers living with Long COVID and other health conditions. Dr. Gage Witvliet asked that the HETF consider all family types in making decisions about returning children to in-person school and suggested that the Elementary and Secondary School Emergency Relief Fund (ESSER) may be one resource that can be leveraged to address families like hers.

Shifting to healthcare costs associated with Long COVID, Dr. Gage Witvliet stated that the financial expense is insurmountable for many persons living with Long COVID and for persons living with chronic disease. She asked that the HETF help to identify ways to reduce the burden on patients in navigating and affording healthcare, especially for persons who are not well insured and/or who are not familiar with the healthcare system.

Another area that Dr. Gage Witvliet asked the HETF to consider is fully supporting integrative medicine. She shared that as a Long COVID patient with a myriad number of providers, it is difficult to coordinate care and should be done at the provider level, not the patient level.

Discussion

Mr. Imperato reflected on how Dr. Gage Witvliet mentioned the challenges with the healthcare system and asked her to comment on her experience in navigating short-term or long-term disability benefits and getting accommodations in the workplace. He also asked if she had any recommendations for the Task Force in those areas.

Dr. Gage Witvliet responded that navigating the [system] has been arduous at best. She noted that the significant amount of redundant paperwork and telephone calls have been a challenge. In her case, she explained, she was fortunate not to have needed to apply for disability. However, she knows many patients with Long COVID who have struggled with navigating the system and receiving adequate support and appropriate care.

Dr. Martinez stated that he was glad that integrative care was mentioned. He noted that a whole-health approach to include physical, emotional, and psychological needs should be addressed in a concerted fashion. He asked Dr. Gage Witvliet if she would be willing to provide additional perspective on the mental health implications of what she or others have experienced.

Dr. Gage Witvliet disclosed that mental health professionals are part of her health team in addition to a neurologist and a cardiologist. She added that one provider issue that has caused anxiety and stress is the disbelief that she suffers from COVID-related symptoms as she appears “normal”; but even more so, Dr. Gage Witvliet stated that it is not uncommon for a healthcare provider to first test her for alcohol or other drugs before delivering care to her, which is an expression of explicit bias.

Dr. Venters asked Dr. Gage Witvliet, as a social epidemiologist, to comment on the experience of persons who are incarcerated living with Long COVID and who may not have been tested or provided a confirmed diagnosis. He questioned specifically what the implications might be for the long-term engagement of communities of color who are disproportionately overrepresented in correctional settings and what this might mean for the health system.

Dr. Gage Witvliet advised that a concerted effort must be made to provide adequate PPE, testing, and therapeutics for persons who are incarcerated and to educate communities on Long COVID.

Ms. Turner expressed concern for children who rely on school nurses for their primary health care and raised the question of how can we ensure continued access to school nursing care for virtual students.

Dr. Gage Witvliet advised that we will have to think about how we make in-school nurses accessible to student’s attending school virtually. She also suggested that nurses could perform home visits or go to already established community centers.

Introduction of Ex-officio Members

The new HETF member, Shannon Pazur, J.D., introduced herself, summarized her background, and highlighted experiences relevant to the HETF charge.

Ms. Pazur serves as senior counsel with the Office of Legal Policy of the Department of Justice. She has been with the department for about 10 years and has experience in a wide range of subject matter areas including civil rights and equity.

Subcommittee Presentations and Discussion

Dr. Martha Okafor highlighted the purpose and mission of the subcommittees and reviewed that the purpose of the four sub-subcommittees is to provide:

- (1) 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;
- (2) Recommendations for agencies with responsibility for disbursing COVID-19 relief funding regarding how to disburse funds in a manner that advances equity; and
- (3) 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.

Dr. Okafor lifted up the following common themes.

Mandate Data Collection, Research, and Transparency

- Set a national research agenda centering on health equity and COVID-19 with minority, marginalized, and underrepresented populations codesigning 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.

Protect Workers and the Workplace

- Create a tip line for employees to address health and safety violations by employers.
- Pass public policies that invest in children and families (e.g., American Families Plan) and ensure benefits extend to minority, marginalized, and medically underserved communities with Long COVID.

- Pass public policies that create jobs and rebuild the country’s infrastructure (e.g., American Jobs Plan) and ensure benefits support the needs of minority, marginalized, and medically underserved communities with Long COVID.
- Enhance temporary disability benefits to support minority, 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

Joneigh Khaldun, M.D., M.P.H., F.A.C.E.P.

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.

To address the problem statement, the subcommittee presented the following recommendations:

- (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 underserved 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; and
 - Understand how racism and discrimination are associated with symptoms, disease progression, severity of Long COVID for minoritized, marginalized, and medically underserved populations.
- (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.

Problem Statement 2: As research progresses and more treatments for COVID are available, access and administration of therapeutics are not equitably dispersed across populations.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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; and 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

Dr. Venters underscored how many minoritized and underrepresented populations have not been counted relative to Long COVID, citing the incarcerated population at the Federal and State level as an example. The undercounting impacts the programs and resources available to the incarcerated while they are in jail and when they go home.

Mr. Imperato added that many individuals with a disability delayed getting medical treatment because they were immunocompromised and did not want to take the risk associated with going into the doctor's office during the pandemic. This is an equity issue and has implications for Long COVID research.

Ms. Alvarez commended the subcommittee for their work and advocating for improved data to better understand the extent and needs of persons living with Long COVID.

Healthcare Access and Quality Subcommittee

Tim Putnam, D.H.A., E.M.S.

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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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 for COVID that is also inclusive of Long COVID.
- (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 Federally Qualified Health Centers (FQHCs), Indian Health Service (IHS), and rural health clinics (RHCs).
- (5) The Federal Government should provide funding for clinics, FQHCs, IHS, and RHCs 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.
- (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. 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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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 appropriated and high-quality care compared to their non-minoritized peers. Without addressing these preexisting disparities, misdiagnosis will continue to be exacerbated with Long COVID.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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 healthcare professionals and all workplaces serving minoritized, marginalized, and medically underserved populations. The lack of Federal oversight and standards and increased cost of PPE all led to the delay or cancellation of nonemergent healthcare services.

To address the problem statement, the Subcommittee presented the following recommendations:

- (1) The Federal Government should maintain an adequate stockpile and create a rapid emergency production plan for PPE for healthcare providers and 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 whom 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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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 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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (1) The Federal Government should issue guidance to recipients of Emergency Solutions Grants 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 and 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 daytime drop-in center capacity.
- (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 wraparound 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-enabled devices, stable/quality internet, or support to increase familiarity with technology options.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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

Mr. Toranzo stated that he supports the recommendation that the Federal Government maintains an adequate stockpile of PPE to avoid future preventable disease transmission and deaths. He also raised the notion that many people may have Long COVID, be unaware, and struggle to receive adequate care because they have not been accurately diagnosed. He went on to state that patients need to have access to treatment for Long COVID irrespective of whether they received a positive test for acute COVID or were hospitalized. Mr. Toranzo voiced his support for ensuring that pediatric patients receive appropriate care for Long COVID.

Ms. Turner stated that this pandemic has demonstrated the need for compassion and care in the in-patient setting. She commented on the extent of rural and urban clinics closing and asked that

the Task Force give consideration to advocating for funding support to ensure that people have access for both telehealth and in-patient care.

Mr. Watts pointed out the importance of medical respite. He stated that housing status is one of the strongest social determinants of health. He pointed out that people of color are overrepresented among those who are experiencing homelessness. Mr. Watts stated that homelessness is a matter of health and social equity; and he stressed that the most basic of human rights, a place to rest and heal, should be afforded to those who are most vulnerable in our country during this global pandemic. Mr. Watts strongly encouraged the Task Force to consider his recommendations.

Dr. Hildreth noted the importance of educating frontline healthcare professionals on cultural competency and how their implicit and explicit bias delays or denies care for persons of color. He noted that this is exemplified in the number of patients who present in an emergency room and are denied care until an alcohol or drug screen clears them for medical treatment.

Mr. Joseph expressed his appreciation for the emphasis put on telemedicine and the need for having affordable access to care. He commented that some patients may have to drive a long long-distance to seek care without a safe place to stay and/or meals. Consideration must be made to provide sustenance as needed and to provide access to affordable devices for telemedicine.

Dr. Martinez commented that health access and quality is also a workforce issue. He emphasized the need for recruiting and hiring a diverse, equitable, and inclusive workforce to include physicians, nurses, social workers, psychologists, etc. He noted the need to provide them with the skillsets needed for the 21st century.

Structural Drivers and Xenophobia Subcommittee
Haeyoung Yoon, J.D.

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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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 minority, marginalized, and medically underserved communities whose members are at risk of Long COVID and its ongoing effects.

Problem Statement 2: Asian American and Pacific Islander (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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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 healthcare industry to address discrimination faced by AAPI healthcare professionals as its continued negative impact on the treatment of COVID and Long COVID for AAPI individuals, among others.

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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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.
 - (d) Work with Congress to make the Childcare Tax Credit (through the American Rescue Plan Act) 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, nonchild 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 the Veteran Affairs' (VA) Homemaker Home Health Aide Care program).
 - (g) Build on the FY22 Department of Education 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.
- (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 [ADA], Family & Medical Leave Act), and increase paid leave available for those with Long COVID.
 - (b) The U.S. Department of Labor and the U.S. Equal Employment Opportunity Commission should issue information and guidance for employers to remind them

- of their obligations under ADA and the 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 individuals with set-aside support for intersectional groups within these communities, including Black, Indigenous, and other people of color.
- (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 and Social Security Disability Insurance 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 the Social Security Administration, including allowances for temporary, partial, and/or situational impairment as qualifying disabling conditions; and increasing benefits to 100% Federal Poverty Level.
 - (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.
- (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 the Individuals with Disabilities Education Act 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.
- (5) The Federal Government should create an updated Frequently Asked Questions 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

Mr. Toranzo stated that he supports increased funding for school nurses and professional counselors for the nation’s K-12 schools and educational accommodations for students experiencing Long COVID.

Mr. Imperato commended the subcommittee for the recommendations to improve the Federal disability benefit system to make it more user friendly, especially for persons living with Long COVID. He stated that these recommendations are not only appropriate for persons with Long COVID, but for the entire disability community.

Ms. Johnson highlighted the importance for employers to recognize conditions, whether someone has a diagnosis of Long COVID or not, if they have and are experiencing symptoms that require them to receive accommodations in the workplace. Employers are reminded that this is still a requirement, and the recommendations that have been made by the subcommittees on expanding protections really highlight that employers may not recognize current protections and expectations under the law.

Communications and Collaboration Subcommittee

Mayra E. Alvarez, M.H.A.

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 healthcare infrastructure led to increased bias, discrimination, hesitation, doubt, and heightened stigmatization by marginalized populations—both on the part of providers and experienced by patients.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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, comprising a majority of Long COVID patients and include external experts in researching and treating postinfectious chronic illness and their comorbidities and disability advocates.
- (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.

To address the problem statement, the Subcommittee presented the following recommendations:

- (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, and 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

Dr. Martinez reiterated that the subcommittee wants to ensure that the technical assistance center and the other recommendations provide support and services to all the different communities being discussed, including providers, because they equally are looking for direction and assistance and want to do the right thing in ensuring things are being done from a quality and equitable standpoint.

Mr. Watts pointed out that we can have benefits, but if they cannot be accessed because of barriers of understanding or bureaucracy, we are really reinforcing inequity. Those who are most educated, have the most time, and the political capital are the ones who will make their way through. So, we must reduce any potential barriers.

Public Comments

Mr. Michael Sieverts, Long COVID Alliance

Hello and thank you. I'm grateful to have the opportunity to speak today. I'm here as also a long-COVID patient. Like Dr. Gage, who spoke earlier, I'm in my 15th month of this. And there are really just two things I want to mention, really just to amplify things that have been said or mentioned earlier in the meeting, but a couple of things I want to bring out more fully.

First, on the testing issue, the access to tests. I think Dr. Gage said and others have said, especially for people in this first cohort, the, you know, who were, back in March, when testing was really sporadic, access to testing was hit or miss. The reason—another reason that is incredibly important now is that the research studies at NIH and other organizations often require a positive test for enrolling people in the studies. So whatever disparities occurred in the testing phase have the potential to be carried through the research phase, and I think you all know better

than most how much that may limit the applicability or the relevance of the results of the research. So that's the aspect of the testing issue I wanted to amplify.

And then just, the second issue is, earlier, particularly after Dr. Gage spoke, there was some discussion of the mental health aspects, and I will just say that that issue is probably even more complicated than it may seem. I say that because of the neurological impacts that COVID has. I am someone who is living with those neurological impacts, and so the fact that it's this emotionally challenging experience at the same time that you know your brain is not working right makes it a doubly challenging mental health adventure. And I think that, you know, very often, when I read about the mental health aspects of COVID, it is presented simply as, "Oh, it's so hard to be dealing with Long COVID. "Yeah, it's hard, but then there are very real neurological impacts that affect, you know, cognition, et cetera, and that is just a complicating factor in this whole awareness and understanding of what's going on to the people who are living with Long COVID.

So, those are my two points. I really appreciate the work you're doing. I'm very glad to have this opportunity to speak.

Dr. Harald Schmidt, University of Pennsylvania

Thank you very much, yeah. My name is Harald Schmidt. I am an Assistant Professor of Medical Ethics and Health Policy at the University of Pennsylvania. I want to congratulate the chair, the Task Force members, and the staff again for your incredibly important and inspiring work. And, I'm very grateful to have the opportunity to provide brief comments now on two points that I think stand in direct continuity with today's discussion and are of central relevance for the Task Force's ongoing work on the Federal Crisis Standard of Care, and they're related to new evidence and the importance of procedural, as well as substantive principles.

So, first, on new evidence, emphasizing and underlining equity concerns that colleagues and I expressed earlier, there are now three studies that quantify inequitable outcomes from using the SOFA score in combination with the widely adopted triage framework. Specifically, Deepshikha Charan Ashana and colleagues analyzed data of more than 100,000 patients at 27 hospitals in the U.S., and they found that, "81.6 percent of Black patients included in lower priority Crisis Standard of Care categories, and 9.4 percent of all Black patients, were erroneously excluded from receiving the highest prioritization. The SOFA score without creatinine reduced racial miscalibration."

So, what this means is that, in practice, under severe crisis conditions, a large number of Black patients will die by being denied ICU care despite good prognoses. And the study published just last week by Dwight Miller and colleagues directly confirms this. For data that they used, the EICU database, and the lifestyles of more than 95,000 patients admitted to more than 200 ICUs in more than 100 hospitals and found that Black patients were structurally disadvantaged, as their likelihood to die was overestimated. So, in the standards adopted by hundreds of hospitals across the U.S., 15.6 percent of Black patients were misclassified under severe shortage conditions from the highest to the second priority. And [there is] a third study that's about to be out, and that I'll share separately directly confirms these findings.

The new evidence also raises important questions about substantive and procedural elements in Federal guidance. Importantly, the underlying triage model used in these studies has been revised substantially, first in December 2020, including dropping the use of SOFA. However, the risk is that in hospitals across the country now, earlier versions will simply be filed away as-is for future use, and there's no clear incentive at this point to make further revisions. So, a clear benchmark statement by the task force on the use of SOFA and related measures, including, ideally, with recommendations for at least a core set of national uniform elements, such as the impermissibility of categorical exclusions and of racially biased frameworks, will hence be as critical for practical orientation in future pandemics as for the historic record.

And substantive side procedural guidance is also urgent. At the peak of the pandemic last year, Gina Piscitello and colleagues found that there were just 26 states that had publicly available Crisis Standard of Care. And so, a simple but clear and important recommendation would be to require all hospitals with ICU facilities to register publicly with HHS first, whether or not they have triage guidelines, and second, if so, to provide copies of all iterations in a timely manner. And the same should then be required for any state-level triage guidance, and developers of model guidance should likewise be encouraged to share their frameworks in this way.

So, to sum up, we now know that the designs of widely adopted triage guidelines enshrine major inequities. Substantive and procedural recommendations by the task force offer a unique opportunity to set the historic record straight and to enable a more equitable response in the next pandemic.

Ms. Reva Singh, American Academy of Physical Medicine and Rehabilitation (AAPM&R)

Thank you for your time today and the opportunity to speak and, most importantly, your attention to this issue. So many of the recommendations that have been made today would be really helpful, and I'm grateful to have heard them, and I hope that they are applied.

AAPM&R represents over 10,000 physiatrists, or physicians focused on physical medicine and rehabilitation, nationwide, and I'm here to ask you to address Long COVID as the crisis that it is by working with agencies across the Federal Government to create a comprehensive national plan that invests in healthcare infrastructure and ensures equitable access to care, not just to clinical care, but to other resources such as education, work accommodations, and disability evaluation and benefits.

Our members have been opening post-COVID clinics across the nation for the past year. These clinics are multidisciplinary and are an attempt to serve as a one-stop shop for patients with Long COVID to see multiple physicians, therapists, mental health professionals, and sometimes social workers. This is to help them address their illness that affects multiple organ systems and various factors of their day-to-day lives. These clinics aim to provide comprehensive and streamlined care so that individual patients are not left to coordinate their own care by juggling multiple referrals. That can be especially difficult for somebody experiencing debilitating symptoms, which is true for many Long COVID patients, as well as the disability and complex illness population before Long COVID. Currently, these clinics are primarily opening in academic medical centers, but such clinics need support so that they can be accessed by all patients across the nation. AAPM&R has gathered 26 of these post-COVID clinics to discuss best practices,

patient access barriers, and to draft and disseminate clinical guidance directly to the bedside as soon as possible.

I'm urging you to recognize Long COVID as a crisis of the pandemic. Of course, AAPM&R recognizes that acute COVID is still with us and likely to continue. However, Long COVID is well underway, as we've been hearing today, with some people suffering for a year or longer. The conservative estimate that's coming internationally is that 10 percent of people who are infected with COVID-19 will experience Long COVID symptoms. That's currently over 11 million people in the United States. And this 10 percent is of the entire COVID population, not just those who had severe cases or were symptomatic or received a positive COVID test. This has already been discussed. There are many reasons that people may have not received a positive COVID test or an antibody test.

In addition to a national crisis plan, I am asking for an immediate public statement addressed to this growing patient population to let them know that they are recognized and that help is on the way. This population is currently being dismissed, like many chronic illness patients have been, because their symptoms may be vague and variable, because this illness is unknown and new, and, again, because they may not have a COVID history in their medical record.

The issues of long-COVID, as we've been discussing all day, or all afternoon, are complex and wide reaching. Similar to Ms. Alvarez's subcommittee's recommendation for a Federal advisory committee and an interagency committee dedicated to patients' rights, AAPM&R believes that a diverse body of experts from across the government needs to be working together and with the public to ensure that efforts are not being duplicated and that there are no further gaps in equitable access to resources. Again, we think that a national crisis plan would be the most effective and efficient way to ensure this.

Thank you again for all that you do, and AAPM&R is a resource to this Task Force, and we hope to continue working with you.

Interim Recommendations Vote

Dr. Nunez-Smith introduced the voting phase for HETF members to vote on each set of interim recommendations and whether the recommendations should move forward to the next stage for refinement. Dr. Nunez-Smith opened the floor for consideration of the following interim recommendations:

- Data, Analytics, and Research Subcommittee recommendations
- Healthcare Access and Quality Subcommittee recommendations
- Structural Drivers and Xenophobia Subcommittee recommendations
- Communications and Collaboration Subcommittee recommendations

Each set of the Subcommittees' recommendations received a motion to approve that was seconded. Each motion carried with a majority vote to approve.

Closing Remarks and Next Steps

Marcella Nunez-Smith, M.D., M.H.S.

Dr. Nunez-Smith thanked the HETF members, guest speakers, public commenters, Federal staff team, and ASL interpreters for making the fifth HETF meeting a success. She also thanked the HETF subcommittee members for developing their interim recommendations and noted that the four subcommittees will continue to refine their recommendations prior to the next HETF meeting. The next meeting will focus on future pandemic relief and preparedness.

Appendix A. Written Public Comments

My name is Miranda Erlanson and I founded a support group for Texans called Covid Survivors From Texas. It is a nonprofit Texas business. My suffering has gone almost 17 months now, and there are new longhaulers joining this wretched tribe daily. I developed 17 disabilities from survivor of COVID-19. I was a Texas public school teacher. I ran marathons and now I am a professionally sick person.

We need access to the therapeutic Leronlimab to any long-haul or across United States who wants it. We pharmaceutical access immediately. We need the major universities of every state to except any insurance for a post Covid visit. We need disaster unemployment made available without 700 red flags for a person who is cripplingly sick. Play Social Security approvals without 100 different new evaluations. We need help that doesn't extend our suffering in order to receive the help. We need financial assistance immediately. We need you to talk to Dr. Yo and Dr. Patterson and Dr. Christopher Recknor, work with the scientists who have the exact precision science down to an art. Longhaulers that are in clinical trials and improving are rare. Actually I can tell you because I am one of them, 56 of us out of the entire United States participated in the most recent clinical trial to receive the CCR five drug Leronlimab. 56 people out of the entire United States. I am so thankful and I feel privileged to have participated despite severe illness and suffering. Let's make it to 3 million longhaulers who needed to get access, not just 56 of us. There's no privilege in sickness, there's no wealth in sick health. We want to get better and we want to get back to work and be a part of our communities again. We need proper supports while we rehabilitate and return to the workforce eventually. We need every drive across the US to have some type of FMLA provision for a Covid Longhailer. Let's get the others better. I already have the job that makes me better and thousands of people who would like access to it. The clinical trial data was very successful and is being presented to the FDA on June 30. Let's coordinate with the FDA to expedite this medication as a breakthrough therapy designation.

Primary Endpoint baseline thru day 56 Average

		Tingling or Numbness			
		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	1	5	1	1
Moderate	2	1	5	3	6
Mild	1	9	12	7	10
None	0	17	6	17	11
		14	37	16	25
			-23		-9
			LL better		156%

Repeated Measures p-value < 0.0001

Primary Endpoint baseline thru day 56 Average

Muscle Weakness

		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	1	5	2	4
Moderate	2	4	15	6	8
Mild	1	14	5	8	12
None	0	9	3	12	4
		25	50	26	40
		-25		-14	
		LL better		79%	

Repeated Measures p -value = 0.013

Primary Endpoint baseline thru day 56 Average

Tightness in Chest

		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	0	6	2	3
Moderate	2	4	5	5	4
Mild	1	8	7	3	9
None	0	16	10	18	12
		16	35	19	26
		-19		-7	
		LL better		171%	

Repeated Measures p -value < 0.0001

Primary Endpoint baseline thru day 56 Average

Sleep Disturbance (Insomnia)

		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	2	10	4	8
Moderate	2	1	12	4	11
Mild	1	13	4	11	7
None	0	12	2	9	2
		21	58	31	53
		-37		-22	
		LL better		68%	

Repeated Measures p -value = 0.01

CD-15: Long-Hauler Symptoms
Primary Endpoint baseline thru day 56 Average

Joint Pain & Swelling

		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	0	2	1	3
Moderate	2	4	14	9	7
Mild	1	12	9	4	7
None	0	12	3	14	11
		20	43	25	30
		-23		-5	
		LL better		360%	

Repeated Measures p -value < 0.0001

Primary Endpoint baseline thru day 56 Average

Headache

		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	1	5	3	4
Moderate	2	1	10	3	9
Mild	1	12	10	6	8
None	0	15	3	16	7
		17	45	21	38
		-28		-17	
		LL better		65%	

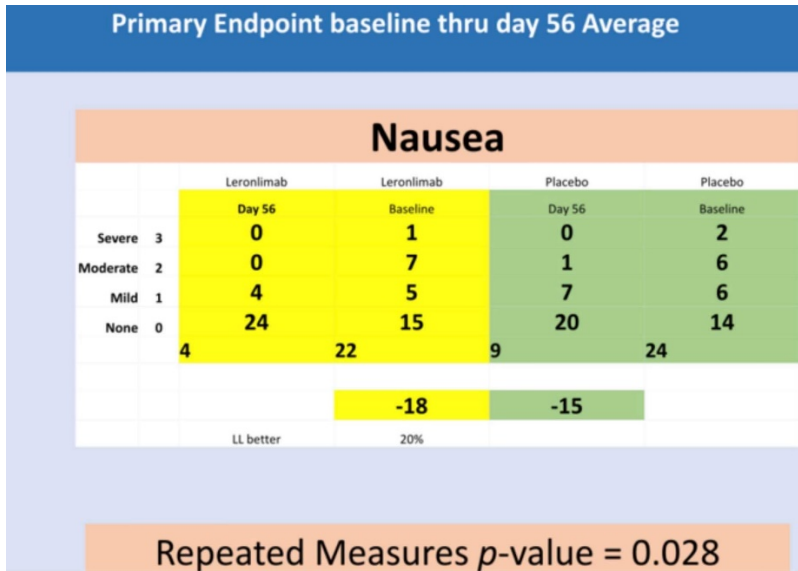
Repeated Measures p -value < 0.0001

Primary Endpoint baseline thru day 56 Average

Shortness of Breath

		Leronlimab		Placebo	
		Day 56	Baseline	Day 56	Baseline
Severe	3	0	5	2	3
Moderate	2	4	10	5	8
Mild	1	11	6	6	11
None	0	13	7	15	6
		19	41	22	36
		-22		-14	
		LL better		57%	

Repeated Measures p -value = 0.032



Best Regards,
 Miranda Erlanson
 (512) 965-9229

Founder, COVID Survivors From Texas, Inc. 501(c)3 Non-Profit
www.texancare.org

Texas Facebook Support Groups:

<https://www.facebook.com/groups/covidsurvivorsfromtexas/>
<https://www.facebook.com/groups/txlonghaulers/>

Worldwide Support Groups:

Slack: Body Politic

Facebook: Survivor Corps

Facebook: Covid Longhaulers Round 2 (infected after April 2020)

Covid Longhaulers Round 3

(Infected after Dec 2020)

To Whom It May Concern,

Thank you for the opportunity for members of the DisDATA collaborative to provide comment to the 5th COVID-19 Health Equity Task Force Meeting June 25, 2021.

DisDATA (Disability Data Advocates Taking Action) is a collaborative of researchers, disabled people, service providers, activists, and advocates promoting disability data equity. We are concerned about the lack of opportunities that the disability community has to be involved in the work of the taskforce committee and actions being planned in regard to data collection. In particular, it is imperative that all people with disabilities are able to represent their experiences and knowledge using statistically reliable, accurate and comprehensive data elements that reflect their identities and the shared values, definitions, and solutions of the disability community. (Nothing about us without us.) Any changes to current disability data collection standards for federally funded activities such as those administered by the Census, the National Center for Health Statistics, and the Centers for Medicaid and Medicare must be planned with the intentional and meaningful engagement and leadership of disability-led organizations (i.e., not token). While we appreciate the expertise of researchers, epidemiologists, and other public health professionals, and while we understand that timelines can be tight, activities must further health equity efforts of the disability community not diminish or undo those efforts. [April 2021 DisDATA statement.](#)

Sincerely,

Tom Olin, DisDATA

Thomas Hale, PhD, DisDATA

Jenn Wolff, MOT

Marsha Katz, DisDATA/ADAPT

Joel Peden, Montana Association of Centers for Independent Living

Travis Hoffman, Summit Independent Living

Lillie Greiman, MA; Meg Traci, PhD; Andrew Myers, MS; University of Montana Rural Institute for Inclusive Communities

DisDATA

Disability Data Advocates Taking Action

Immediate email contact: disdata@mso.umt.edu

DisDATA (Disability Data Advocates Taking Action) is a collaborative of researchers, disabled people, service providers, activists, and advocates promoting disability data equity.

- The COVID-19 pandemic has highlighted disability data inequity
- People with disabilities are disproportionately impacted by the pandemic and yet are unrepresented in data collection and reporting
- This inequity is compounded for disabled people in congregate settings where data is either insufficient, waived or lacking entirely
- **DisDATA** members are advocating for improved disability representation to improve disability data equity across all levels of data collection

People with disabilities are made invisible across federal policy through the lack of data collection and representation. This lack of representation creates a disability data inequity which limits the ability of researchers, disability leaders, policy makers, and service providers to make informed decisions to improve the lives of people with disabilities, and perpetuates the continued silencing of disabled voices and exclusion of disabled lives from American society.

The COVID-19 pandemic has highlighted this long-standing data disparity. People with disabilities have been disproportionately impacted by the pandemic, with the highest rates of cases and deaths, but are under-represented in data collection and reporting.

Addressing this data inequity is critical in a time when people with disabilities are disproportionately:

- [Living and dying in unsafe congregate settings](#)
 - e.g., nursing homes, licensed and unlicensed group homes, detention facilities, prisons, jails, detention centers, and other carceral facilities, intermediate care facilities, long-term care facilities, regional centers, state hospitals, acute care hospitals, rehabilitation hospitals, psychiatric hospitals, veterans hospitals, hospice facilities, assisted living facilities without individual rooms, residential treatment centers, and other congregate shelters
- Suffering and dying from COVID-19
 - [In long term care facilities](#), with at least 174,474 deaths
 - [In the community](#), the lack of disability specific indicators in case data prevents us from having even a nominal understanding of the impacts on people living in the community
 - Contracting COVID-19 and living with “long haul” consequences
- Experiencing [homelessness](#), [poverty](#) and [living with multiple marginalized identities](#)
- [Living in rural communities with limited access to services and resources](#)
- Impacted by [disasters caused by climate change](#)

The members of **DisDATA** are committed to advocating for disability representation at all levels of data collection. Disability representation means centering the inclusion of disability led organizations, disabled researchers, and disability activists and advocates in data decision making processes such as:

- Defining data priorities and identifying data disparities
- Measurement development
- Data collection and distribution
- Data analysis and knowledge translation
- Development of data driven policies, strategies and solutions

The members of **DisDATA** are committed to advocating for increased and improved access to accurate and reliable data that impacts the lives of people with disabilities. This includes but is not limited to:

- Demographic and descriptive data on people with disabilities living in **all types** of congregate settings
 - e.g., nursing homes, licensed and unlicensed group homes, detention facilities, prisons, jails, and detention centers, and other carceral facilities, intermediate care facilities, long-term care facilities, regional centers, state hospitals, acute care hospitals, rehabilitation hospitals, psychiatric hospitals, veterans hospitals, hospice facilities, assisted living facilities without individual rooms, residential treatment centers, and other congregate shelters
- Data for individuals living in congregate settings and how these data intersect with other health equity measures, including but not limited to the impact of COVID-19 on disabled residents across settings
- Data that illustrates and supports current successful emergency mitigation strategies, such as the emergency relocation, transition and diversion efforts of [Centers for Independent Living](#).
 - e.g., Timely data on the support needs of residents in congregate settings to anticipate the resource needs for emergency relocations and transitions to independent community living settings
- Comprehensive data for people with disabilities living in the community and how these data intersect with other health equity measures, including but not limited to the impact of COVID-19 on disabled residents across settings
- Comprehensive data on the movement of people with disabilities into and out of congregate settings throughout and after disasters.
- Data on how the COVID-19 pandemic has impacted the supports and services people with disabilities access and use in the community
 - Availability of home care (including provider pool, care provider wages, COVID hazard pay, and provision of personal protective equipment (PPE))
 - Housing availability, accessibility and affordability
 - Programs, policies, services, tools, and technologies that support diversion from entering congregate settings

DisDATA recognizes that without access to accurate, reliable, and usable disability data disabled people will continue to be harmed. Disability data representation is a critical component in the work to address health injustice and health equity.

If you are interested in being involved with **DisDATA**, please email: disdata@mso.umt.edu



Harald Schmidt, PhD
Assistant Professor, Department of Medical Ethics and Health Policy
Research Associate, Center for Health Incentives and Behavioral Economics
Senior Scholar, Leonard Davis Institute of Health Economics

Health Equity Task Force
Office of Minority Health
Tower Oaks Building
1101 Wootton Parkway
Suite 100
Rockville, MD 20852

Philadelphia, June 30, 2021

Dear Dr. Nunez-Smith and members and staff of the Health Equity Task Force,

Public comment – improving equity in federal crisis standards of care/ventilator rationing

I am writing to congratulate the Chair, the Task Force members, and the staff once more on your incredibly important and inspiring work and progress to date.

I would also like to thank you for the opportunity to provide a brief oral comments at the June meeting of the Task Force. I am following up here with a written version, and references to relevant sources, that I believe are of central relevance to the Task Force’s ongoing work on federal Crisis Standards of Care. The main points relate to 1) major new evidence, and 2) the importance of procedural as well as substantive principles.

First, on new evidence.

With my colleagues Drs. Amaka Eneanya and Dorothy Roberts, we published earlier this year an analysis on equity problems with the way in which widely used mortality prediction models are integrated in dominant ventilatory triage models.¹ We noted that such frameworks compound prior unfair structural disadvantage for many Black patients, chiefly, due to the way scores such as the Sequential Organ Failure Assessment (SOFA) and life expectancy are integrated. Focussing on the role of SOFA and its capture of kidney function, we offered six possible policy options toward a more just approach: improving diversity in decision processes, adjusting creatinine scores, dropping creatinine, finding alternative measures, adding equity weights and dropping measures such as SOFA.¹

On submitting our initial paper, we were not aware of any robust published data, although one of us (Dr. Eneanya) was a co-author of a study assessing SOFA’s performance among different racial groups. The vignettes that we used in our analysis to illustrate the harmful consequences of widely used triage models were directly informed by this work—ongoing at the time, published since²—and align closely with similar recent research,³ that I would like to bring to the attention of the Task Force.

Specifically, Dr. Deepshikha Ashana and colleagues analysed data of more than 100,000 Black and white patients admitted for sepsis or acute respiratory failure at 27 U.S. hospitals. The team calculated in-hospital mortality of SOFA and another score, including a version of the SOFA score without the creatinine component, to reduce the influence of race. They found that:

“81.6% of Black patients included in lower priority crisis standard of care categories, and 9.4% of all Black patients, were erroneously excluded from receiving the highest prioritization. The SOFA score without creatinine reduced racial miscalibration.”²

What this means is that in practice, under severe crisis conditions, a large number of Black patients would die, by inappropriately being denied ICU care despite good prognoses. Unsurprisingly, therefore, the authors call for more equitable mortality prediction models.

Similarly, Dr. Dwight Miller and colleagues call for such changes, in a study published earlier this month.³ The team used the eICU Database and analysed data of more than 95,000 patients admitted to 233 ICUs in 118 US hospitals. They found that the SOFA overestimates the mortality of Black patients, restricting access of Black patients to the top priority tier, under a triage model adopted by hundreds of hospitals across the US.⁴ Under severe shortage conditions—where only the top priority tier would receive treatment—15.6% of Black patients were misclassified from the highest to the second priority.³

A third study, that should be published shortly, and that I will share separately, confirms the trend that SOFA and widely adopted triage models compound prior disadvantage.

The new evidence also raises important questions about substantive and procedural elements in federal guidance.

Importantly, the underlying triage model used in these studies has been revised substantially in December 2020, including dropping the use of SOFA.⁵

However, the risk is that in hospitals across the country, earlier versions will simply be filed away ‘as is’ for future use—there is no clear incentive at this point to make further revisions (Note, for example, that New Jersey’s Directive No. 2020-03⁶ that we used as an example in our analysis, and that incorporates a version of the guideline included in the above-cited studies, still does not reflect these changes).

A clear benchmark statement by the TF on the use of SOFA and related measures—ideally with recommendations for at least a core set of nationally uniform elements (such as the impermissibility of categorical exclusions, and of racially biased frameworks)—will hence be as critical for practical orientation in future pandemics, as for the historic record.

Substance aside, procedural guidance is also urgent.

At the peak of the pandemic last year, Gina Piscitello and colleagues found that there were just 26 states that had publicly available Crisis Standards of Care.⁷

A simple, yet clear and important recommendation by the Task Force would be to require all hospitals with ICU facilities to register publicly with HHS:

- 1) whether or not they have triage guidelines, and
- 2) if so, to provide copies of all iterations in a timely manner.

Ideally, all versions would be publicly accessible via a centralized HHS portal. The same should be required for any state-level triage guidance, and developers of Model Guidance should likewise be actively encouraged to share their frameworks in this way.

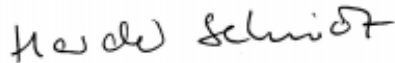
While, of course, countless details would still need to be addressed, such an arrangement would provide an incentive to establish, review, and update guidance, and offer instant transparency about adopted rules for a setting in which the stakes could not be higher.

In summary: During the pandemic's peak, many commentators felt it was the wrong time to re-examine the principles underpinning ventilator triage. Eventually, considerable variation, and a multitude of different types of frameworks and revisions emerged.^{7,8} The risk now is that a plethora of models with inequitable outcomes—including ones not reflecting key updates and robust evidence^{2,3}—is archived, to be at hand for the next pandemic. The injustice enshrined in these models should not stand.

Substantive and procedural recommendations by the Task Force offer a unique opportunity to set the historic record straight. Hopefully, they will also enable a more equitable response in the next pandemic, that will more uniformly reflect social and racial justice and the views of those who have most to lose;^{1,9} provide full transparency about all plans in place;^{7,8} and include structures that permit policy makers to be aware of major revisions to widely adopted guidelines in a systematic, timely and accurate manner.

If there would be anything that you would like to discuss further, please feel free to reach out via schmidh@upenn.edu.

Sincerely,



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