Community Engagement Alliance (CEAL) Against COVID-19 Disparities Update

Monica Webb Hooper and George Mensah
Racial and Ethnic Minorities are Disproportionately Affected by COVID-19*

Risk for COVID-19 Infection, Hospitalization, & Death by Race/Ethnicity¹

<table>
<thead>
<tr>
<th>Rate ratios compared to White Persons</th>
<th>American Indian or Alaska Native</th>
<th>Asian</th>
<th>Black or African American</th>
<th>Hispanic or Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cases</td>
<td>1.6x</td>
<td>0.7x</td>
<td>1.1x</td>
<td>2.0x</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>3.3x</td>
<td>1.0x</td>
<td>2.9x</td>
<td>2.8x</td>
</tr>
<tr>
<td>Death</td>
<td>2.4x</td>
<td>1.0x</td>
<td>1.9x</td>
<td>2.3x</td>
</tr>
</tbody>
</table>

*Note that the CDC data shown does not include Pacific Islander populations which is another population disproportionately affected by COVID-19

¹ Table Source CDC as of May 26, 2021: Risk for COVID-19 Infection by Race/Ethnicity (CDC)
To understand factors that contribute to the disproportionate burden of COVID-19 in underserved communities and establish effective, community-engaged strategies to enhance education, awareness, trust, access, and inclusion of underserved communities in COVID-19 treatment and prevention strategies to reduce disparities.
CEAL Overview

NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities was established to lead outreach and engagement efforts in underserved ethnic and racial minority communities disproportionately affected by the COVID-19 pandemic and in overall vaccine and therapeutic trials in the future.

COMMUNITIES OF FOCUS

- African Americans/Blacks
- Hispanic/Latinos
- American Indians/Alaskan Natives
- Asian Americans, Native Hawaiians and Pacific Islanders

Establish Partnerships within the Community
Address Misinformation within Communities of Color
Grow an Understanding and Trust in Science
Accelerate the Uptake of Beneficial Treatments

Deploy a set of public messages that present accurate information about COVID-19.

Create mechanisms, processes, and structures to conduct urgent community-engaged research and outreach within the target community.
The Alliance includes a diverse ecosystem of partners and trusted leaders across the country to engage communities.

**Core Partners in the CEAL Alliance**

- Faith-Based Organizations
- Researchers
- Policymakers & Government Agencies
- Academic Health Centers
- Historically Black Colleges & Universities
- Community-Based Organizations
- Pharmacy Networks
- Professional Societies/Foundations
- Health Professional Organizations
CEAL Teams conduct a variety of activities to engage communities of focus.

**Establish Partnerships with Communities**
- DMV Youth voices: CEAL teams will engage youth and young adults in advisory roles for message development.

**Address Misinformation**
- MI & NC Crowdsourcing messaging ideas that resonate with the community.

**Increase Trust in Science**
- CA, LA, AL, TN & MI Hosting townhalls with community health workers & professionals targeting at-risk groups.

**Accelerate Uptake of Beneficial Interventions**
- GA’s Morehouse School of Medicine holds vaccination Saturdays; >1,700 residents vaccinated.

Original Teams:
- Alabama
- Arizona
- California
- Florida
- Georgia
- Louisiana
- Michigan
- Mississippi
- North Carolina
- Tennessee
- Texas

2021 Additions:
- Arkansas
- Colorado
- DMV
- Illinois
- Massachusetts
- Missouri
- New Mexico
- New York
- Pennsylvania
- Puerto Rico

Lead P.I. Institution Location
Disparities in U.S. Vaccination Levels\(^1\) Relative to COVID-19 Burden:

Across US states, Latino/Hispanic and African American/Black populations have received a smaller share of vaccinations compared to their share of cases and percentage of the total population.

\(^1\)Source KFF: Latest Data on COVID-19 Vaccinations Race/Ethnicity
May 26, 2021
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May 26, 2021
How CEAL is Reaching Communities

The CEAL initiative and its grantees (aka “CEAL Research Teams”), collectively referred to as the CEAL Alliance, are reaching communities of color in the following ways:

- Prioritizing Communities Hardest Hit by COVID-19
- Diverse Partnership Network
- Resource/Content Development
- CEAL Website
- Social Media
- Events at Local, State, and National Levels
Across the Alliance, CEAL has leveraged its experience and lessons learned to create useful resources—including videos, social media posts, handouts, and fact sheets—available on the CEAL website to facilitate outreach to communities about critical topics.

Learn more: covid19community.nih.gov

**Vaccines**
This section includes general information on vaccines and how the COVID-19 vaccine will work to protect people who get the vaccine and their family and friends.

**Diversity & Inclusion**
Participants in any clinical trial should represent the patients who will use the drug or vaccine being tested. This section includes resources about removing barriers and including ethnic/racial minorities in COVID-19 trials.

**Clinical Trials**
Understanding what it means to participate in a clinical trial is an important first step for people considering volunteering. This section includes information around clinical trials.

**COVID-19 Basics**
Preventing the spread of COVID-19 is one of the most powerful ways we can fight it. This section includes information to help understand what COVID-19 is and how to protect yourself and others.
Insights Derived from CEAL Teams

In the first six months of the program, CEAL Research Teams surfaced insights related to the pandemic and public health interventions through engagement with communities.

- General COVID-19 Misinformation
- Widespread Vaccine Misinformation
- Elevated Vaccine Hesitancy
- Expand Reach via Trusted Sources
- Need for COVID-19 Prevention
- Adverse Impacts on Mental Health
- Low Vaccine Confidence
- Inequitable Vaccine Access

*Derived from more than 100 engagement activities, including focus groups, interviews, and listening sessions*
CEAL REACH

In the first six months, the original 11 CEAL research teams in the Alliance had remarkable reach including:

- **Over 25,800 interactions** with community members through CEAL Research Team outreach efforts (e.g., community forums, town halls, social media engagements)

- More than **3.4 million people reached** with messages or educational materials about COVID-19 through CEAL events, social media and distributed educational materials

- More than **1,650 connections** with COVID-19 clinical trial Principal Investigators and Organizations
CEAL Community Engagement Spotlights

The following examples show the diverse ways CEAL research teams are engaging with communities.

Clinical Trial Collaboration – Mississippi

INCREASING DIVERSITY IN CLINICAL TRIALS

- Partnered with University of Mississippi Medical Center (UMMC) to register participants in COVID-19 clinical trials
- Reached 64% African American enrollment across all COVID-19 clinical trials (vaccine and therapeutic), and 80% African American enrollment in the UMMC vaccine clinical trial

Partnering with Promotores – Texas

BUILDING INFRASTRUCTURE FOR HEALTH EQUITY

- Developed trainings for community health workers (CHWs) about clinical trials and vaccines.
- Identified issues caused by language barriers with underserved communities.
- Discovered that poor translation of material adds to the mistrust that exists within the Brown and Black Communities.
- Trained 900+ Promotores/CHWs
CEAL Community Engagement Spotlights

The following examples show the diverse ways CEAL research teams are engaging with communities

Working with State Government – Arizona

PARTNERING TO INCREASE ACCESS

- Partnered with Arizona’s Medicaid agency to leverage COVID-19 vaccinators through the Department of Health to do home-based or congregate care-based vaccinations

- Worked to update the statewide COVID-19 database so that universities can better analyze the data and understand how to best respond

- Partnered with the Arizona State Health Department to share Arizona CEAL’s data and assessment information to develop social media and communications materials

Online Education – Louisiana

COMBATTING MISINFORMATION/MISTRUST

- Identified key myths and misperceptions about COVID-19 through a community needs assessment

- Established a LA CEAL Website and social media platforms to address key misperceptions and myths about COVID-19 and to support COVID-19 vaccination and clinical trial decision-making

- Resulted in over 49,000 impressions/community contacts in the first six months of the project
Vaccine enthusiasm across the US among Black or African American and Hispanic or Latino adults has changed over time. This demonstrates that perspectives on vaccine acceptance can change, highlighting the importance of both listening to the needs of communities and tackling misinformation.
Building Confidence in COVID-19 Vaccines: Leveraging Trusted Community-Based Relationships

The intent to vaccinate has increased most among Blacks…

…yet vaccination rates remain low among Black and Hispanic populations.

Race/ethnicity

November 2020:
42% African American
61% White

February 2021:
61% African American
69% White

Strategic community outreach efforts using trusted partnerships are vital for improving confidence and acceptance of COVID-19 vaccines.
COVID-19 Research: Includes People Like Me

CEAL launched the Scientific Pathway to highlight the diverse representation across each phase of the scientific process.

View the Scientific Pathway at: https://covid19community.nih.gov/about/scientific-pathway

Dr. Lisa A. Cooper
Bloomberg Distinguished Professor, Johns Hopkins Bloomberg School of Public Health

“As a safety monitor in the COVID-19 clinical trials, it is my responsibility to protect volunteer participants and make sure their safety is the highest priority. My role allows me to ease any concerns raised by family and friends and make sure they continue to trust the science. I can say with the utmost confidence that this vaccine is safe and effective.”
Lessons Learned: Implications for Community Engagement

- **Leadership goes beyond scientists** – local leaders (e.g., local influencers, faith leaders, local government officials) are instrumental to reaching communities in effective ways.

- **Collaboration and co-creation with community partners** to accurately represent the needs of communities increases the effectiveness of engagement.

- **Disaggregation of race/ethnicity data** is critical to uncover disparities hidden in existing data.

- **Simultaneous development in multiple languages** is critical to meet community needs.

- **Significant demand exists for expertise** in community engagement and community-engaged research.

- **There is potential for exponential impact** as trusted relationships are established and bolstered in disproportionality affected communities.
CEAL as a Platform to Support Community-Engaged Research

CEAL leadership has received several requests from clinical trial teams for assistance on increasing inclusive participation in community-engaged research, including help with:

- Enhancing community engagement in research
- Developing basic tools and techniques to enhance outreach with and messaging to racial and ethnicity minority communities
- Building partnerships with communities

CEAL can be a repeatable resource to help the research ecosystem work with communities to address disparities.
The Vision for CEAL

WHERE CEAL IS TODAY...

...An immediate response to address COVID-19 Disparities

CEAL serves as an alliance to respond to the COVID-19 pandemic, until the pandemic is declared over

WHERE CEAL IS HEADING...

...An approach to address COVID-19 disparities long-term

CEAL continues to prioritize COVID-19 response and transitions to pandemic recovery and resilience

AND

...A scaled alliance to promote community engagement and inclusive participation across NIH

CEAL serves as a scaled alliance approach across NIH to advance health equity in trans-NIH research priorities
Guiding Principles to Combat COVID-19 through Community-Engaged Research and Outreach

1. **Move at the speed of TRUST!**
2. Build and sustain trusting relationships through community-engaged research.
3. Work with trusted voices and trusted messengers at the national and local levels.
4. Address social determinants of health.

[Image: COVID19COMMUNITY.NIH.GOV]
People of CEAL

CEAL researchers and community partners are made up of people from the communities the Alliance is serving.

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<thead>
<tr>
<th>CEAL Steering Committee Co-Chairs</th>
<th>CEAL Interest Group Co-Chairs</th>
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<tr>
<td>Rita Carreón</td>
<td>Dr. Karina Walters</td>
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<tr>
<td>Dr. Lisa Cooper</td>
<td>Dr. Michelle Kahn-John</td>
</tr>
<tr>
<td>Rev. Kendrick E. Curry</td>
<td>Dr. Keawe Kaholokula</td>
</tr>
<tr>
<td>Dr. Ricardo Muñoz</td>
<td>Dr. Grace Ma</td>
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<tr>
<td>INCLUSIVE PARTICIPATION</td>
</tr>
<tr>
<td>Dr. Amelie Ramirez</td>
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<td>Dr. Karen Winkfield</td>
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<td>COMMUNICATION</td>
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<td>Dr. Susan Eggly</td>
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<td>Dr. Joseph Cappella</td>
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<td>NEED ASSESSMENT &amp; EVALUATION</td>
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<tr>
<td>Dr. India Ornelas</td>
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<td>Dr. Gbenga Ogedegbe</td>
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# Acknowledgements

## New CEAL Research Team Principal Investigators
- NM: Lisa M Cacari-Stone
- IL: Molly Martin
- CO: Donald Nease Jr
- AR: Pearl McElfish
- NY: Chau Trinh
- MO: Matthew Kreuter
- PR: Vivian Colon
- MA: Benjamin Linas
- DMV: Cheryl Himmelfarb
- PA: Jose A Bauermeister

## Existing CEAL Research Team Principal Investigators
- AZ: Sai Parthasarathy
- GA: Tabia Akintobi
- NC: Anissa Vines
- MS: Caroline Compretta
- CA: Arleen Brown
- TN: Paul Juarez
- FL: Olveen Carrasquillo
- MI: Erica Marsh
- LA: M Krousel-Wood
- AL: Mona Fouad
- TX: Jamboor Vishwanatha

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**CEAL Research Teams have partnerships with hundreds of community-based organizations**
Thank You