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

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Media Impact Fund Webinar
March 17, 2021
## COVID-19 and Health Disparities

<table>
<thead>
<tr>
<th>Rate ratios compared to White, Non-Hispanic persons</th>
<th>American Indian or Alaska Native, Non-Hispanic persons</th>
<th>Asian, Non-Hispanic persons</th>
<th>Black/African American, Non-Hispanic persons</th>
<th>Hispanic or Latino persons</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cases</strong>(^1)</td>
<td>1.8x</td>
<td>0.6x</td>
<td>1.4x</td>
<td>1.7x</td>
</tr>
<tr>
<td><strong>Hospitalizations</strong>(^2)</td>
<td>4.0x</td>
<td>1.2x</td>
<td>3.7x</td>
<td>4.1x</td>
</tr>
<tr>
<td><strong>Deaths</strong>(^3)</td>
<td>2.6x</td>
<td>1.1x</td>
<td>2.8x</td>
<td>2.8x</td>
</tr>
</tbody>
</table>

\(^1\) Data source: Data reported by state and territorial jurisdictions (accessed 11/27/2020). Numbers are ratios of age-adjusted rates standardized to the 2000 US standard population. Calculations use only the 52% of reports with race/ethnicity; this can result in inaccurate estimates of the relative risk among groups.


The COVID-19 Pandemic in the U.S. Disproportionately Affects Communities of Color

Interplay of clinical characteristics and social determinants of health puts minority communities at high risk for COVID-19 complications

- Heart Disease
- Hypertension
- Diabetes
- Lung Disease

Among some racial and ethnic minority groups, evidence points to higher rates of hospitalization or death from COVID-19 than among non-Hispanic white persons.

COVID-19-Associated Hospitalization Rates March 7–November 21

Rate per 100,000 Population

- American Indian or Alaska Native: 445.5
- Black: 390.8
- Hispanic or Latino: 368.5
- White: 146.4
- Asian or Pacific Islander: 135.4

Vaccine hesitancy is a continuum between complete acceptance & complete refusal

HESITANCY

ACCEPT ALL

ACCEPT BUT UNSURE

ACCEPT SOME, DELAY AND REFUSE SOME

REFUSE BUT UNSURE

“OK, I guess I’ll vaccinate”

“I don’t know”

“No, I’m not sure this is right for my child/for me”

“I don’t trust vaccines”

“I’m ready”

Courtesy: Jennifer Williams. https://www.bcemergencynetwork.ca
National Trends: Percentage of US Adults Who Say They Are Likely to Get a COVID-19 Vaccine, Apr 1 – Dec 8, 2020

Survey respondents, %

Survey period

- April 1-14
- April 15-28
- April 29-May 12
- May 13-26
- May 27-June 9
- June 10-23
- June 24-July 7
- July 8-21
- July 22-Aug 4
- Aug 5-18
- Aug 19-Sept 1
- Sept 2-15
- Sept 16-29
- Sept 30-Oct 13
- Oct 14-27
- Oct 28-Nov 10
- Nov 11-24
- Nov 25-Dec 8

In this survey, nearly two-thirds of African Americans were COVID-19 vaccine hesitant.

### African Americans/Blacks are more likely to be hesitant to COVID-19 Vaccination

<table>
<thead>
<tr>
<th></th>
<th>As soon as possible</th>
<th>Wait and see</th>
<th>Only if required</th>
<th>Definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>34%</td>
<td>39%</td>
<td>9%</td>
<td>15%</td>
</tr>
<tr>
<td><strong>Black</strong></td>
<td>20%</td>
<td>52%</td>
<td>10%</td>
<td>15%</td>
</tr>
<tr>
<td><strong>Hispanic</strong></td>
<td>26%</td>
<td>43%</td>
<td>11%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>White</strong></td>
<td>40%</td>
<td>36%</td>
<td>7%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Vaccine Intent is Lowest Among Black and Young Adults

Ad Council/Ipsos National Survey Adults 18+ Dec 15-21, 2020
1. Questions and concerns about benefits, safety, and side effects of COVID-19 vaccines.

2. Concerns about speed of the vaccine development process and representation of people “like me” in the vaccine research.

3. Misinformation: Established and new conspiracy theories about vaccines and COVID-19

4. Distrust in the political and economic motivations of the government and the companies involved.

5. Past research misdeeds that have also sewn seeds of distrust.
Background: The study initially involved 600 black men – 399 with syphilis, 201 who did not have the disease. The study was conducted without the benefit of patients' informed consent. Originally projected to last 6 months, the study went on for 40 years. Even when penicillin became the drug of choice for syphilis in 1947, researchers did not offer it to the subjects.

Tuskegee Study

Background: Doctors at the Johns Hopkins Hospital took samples of Lacks’ cancerous cells while diagnosing and treating the disease, giving some of that tissue to a researcher without Lacks’ knowledge or consent. Doctors and scientists publicly released personal details like Lacks’ name and medical records, even publishing her cells’ genome. Despite leading to milestone scientific discoveries, Lacks’ family was never consulted or compensated.

Henrietta Lacks

1 https://www.cdc.gov/tuskegee/timeline.htm; 2 https://www.nature.com/articles/d41586-020-02494-z
### Guatemala & the USPHS

**Background:** Beginning in 1946, Public Health Service investigators in a study funded by the NIH engaged in research experiments in which more than 5,000 uninformed and unconsenting Guatemalans were intentionally infected with bacteria that caused STIs. Many were never compensated and left untreated, and the NIH didn’t publish or disclose the experiments.

### Forced Sterilization

**Background:** Between the 1930s and the 1970s, approximately 1/3 of the female population of Puerto Rico was sterilized. A program endorsed by the U.S. government sent officials to rural parts of PR advocating for sterilization. Though procedures were presented to women as free family planning, women often lacked information and later regretted being sterilized.

### Deportation Fears

**Background:** In late February this year, the U.S. government’s new “public charge” immigration rule went into effect which tightly limits noncitizens’ use of programs, has left many immigrants afraid to seek any public services, including medical care, because they fear doing so could lead to deportation or prevent them from receiving permanent residency in the future.

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1. [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3828982/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3828982/)
Background: In 2003, Carletta Tilousi, a member of the Havasupai Tribe of northern Arizona, discovered that DNA samples she had donated for a genetic research project on type 2 diabetes in 1989 were in fact being used in nondiabetes-related genetic studies by researchers at ASU. A 2010 settlement included compensation but left no legal precedent.

Background: Indian Service failed to provide effective preventative services to American Indians, particularly for tuberculosis and trachoma. Serious errors were made in the treatment of Indians suffering from trachoma, and many patients underwent unnecessary procedures. Overall, the Service was critically understaffed and lacked necessary competencies.

Background: Alaska Natives and U.S. servicemen who took part in the Air Force study were given a radioactive medical tracer, iodine-131, to determine whether the thyroid gland helps humans adapt to the arctic climate. Subjects were not informed that they were taking a radioactive tracer and most thought they were receiving medical treatment.
A one-size approach does not fit all communities.

Begin by listening to the community’s needs and concerns.

Needs should be tailored to the individual or targeted and contextualized to the community.

No single intervention strategy addresses all instances of vaccine hesitancy.

Assess the 3Cs: community’s vaccine confidence, complacency, and convenience
Trends in Vaccine Hesitancy

Vaccine hesitancy among racial and ethnic minorities is not a static figure. The below graphs chart differences in vaccine hesitancy over time.

When Asked “If a COVID-19 Vaccine is Made Available to You, Will You Choose to be Vaccinated?”


Addressing Vaccine Hesitancy: Begin with the 3 Cs Model

**Confidence:**
- Refers to **trust** in the effectiveness and safety of vaccines, the system that delivers them and/or the motivations of policy-makers who make determinations about vaccines.

**Complacency**
- Refers to a low **perceived risk** of vaccine-preventable diseases and therefore it is assumed vaccines are not needed.
- Other issues are considered more important.

**Convenience**
- Refers to the degree to which the comfort, convenience, time, place, and quality of a vaccine affects uptake of the vaccine.
Count on Trusted Voices and Trusted Messengers in the Community

• Doctors, nurses, pharmacists, and other health professionals in the community
• Clergy and other faith-based organization leadership.
• Trusted voluntary organizations and institutions.
Effective Communication:
• Share accurate information from trustworthy sources.
• Use clear, concise, plain language.
• Deliver trustworthy messaging using different modes—print, video, info-graphics, in-person, social media.
• Provide information in multiple languages.
• Develop FAQs, update based on feedback and new questions.
• Use visuals with diverse representation.

Engender Trust:
• **Acknowledge** fears, concerns, and historical injustices.
• Be transparent about side effects & unknowns.
• **Use messengers experienced in effectively communicating with diverse audiences.**
• Dispel myths with facts, without being critical of individual or group beliefs.
• **Partner with trusted leaders** to share info.
• Allow people to see themselves - “someone like me”

Modified from Consuelo H. Wilkins, Vanderbilt University Medical Center
Addressing COVID-19 Vaccine Hesitancy: NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities

A trans-NIH initiative leading outreach, engagement and inclusive participation efforts in ethnic and racial minority communities disproportionately affected by the COVID-19 pandemic

11 CEAL state teams partnering with national & local organizations

- Academic Partners
- Community-Based Organizations
- Healthcare Centers & Providers
- Faith-Based Organizations
- State & Local Government Agencies
- Pharmacy Networks

NIH National Heart, Lung, and Blood Institute
Community Engagement Alliance (CEAL) Against COVID-19 Disparities

https://covid19community.nih.gov/
Online Resources to Combat Vaccine Distrust

Users can find resources—from videos and social media posts to handouts and fact sheets—on the CEAL website to facilitate outreach to communities about critical topics.

Ensuring 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.

Learning About 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.

Understanding 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.

Learn more:
covid19community.nih.gov
Online Resources

- Original content aligned with key messages
- Curated content from partners and federal agencies
- English and Spanish options available

Multiple formats increase accessibility & shareability

Printable fact sheets
Social media images and copy
Video
Infographics

In addition to vaccine information, the NIH CEAL website contains 40+ resources on the topics of inclusion, clinical trials, and COVID-19 basics.

The Journey of a Vaccine

How a new vaccine is developed, approved, and manufactured

20-100 healthy volunteers
Researchers try to answer these questions:
- Is the vaccine safe? Are there any serious side effects? Is the vaccine causing an immune response?

Several hundred volunteers
Researchers try to answer these questions:
- What are the most common short-term side effects of the vaccine?
- What is the body’s immune response?
- Are there signs that the vaccine is protected?

One thousand or more volunteers
Researchers try to answer these questions:
- How do disease sites compare between people who get the vaccine and those who do not?
- How well can the vaccine protect people from disease?

FDA approves a vaccine only if:
- It’s safe and effective.
- Its benefits outweigh the risks.

Treatment is approved by the FDA and made available to the general public.

FDA closely monitors the safety of the vaccine after the public begins using it. Researchers continue to collect data on long-term benefits and side effects.

Vaccine Adverse Event Reporting System (VAERS)

VAERS, a national monitoring program run by the FDA and the Centers for Disease Control and Prevention (CDC), is set up to look for safety problems that develop after a person gets a vaccine. Anyone can submit a report to VAERS if they or someone they know is injured, has a reaction to a vaccine, or dies.

Healthy recommendations for taking the vaccine may change as safety monitoring reveals new information about its risks.

In addition to vaccine information, the NIH CEAL website contains 40+ resources on the topics of inclusion, clinical trials, and COVID-19 basics.

How to get a vaccine for COVID-19:
- Check with local health department.
- Visit vaccines.gov for locations.
- Call 1-800-CDC-INFO (1-800-232-4636) for help.

WAS the vaccine given to COVID-19:
- It is not known whether people who have been vaccinated will no longer spread COVID-19.

COVID-19 vaccine information:
- How does it work? What can I expect? How long will it last?
- Side effects: Are they temporary or permanent? Can they be dangerous? When do they occur?
- Safety: What is the risk of getting sick from the vaccine? How does it compare to the risk of getting COVID-19?

4 Questions (and Answers) About COVID-19 Vaccines

1. Who is already home about COVID-19 vaccines?
   - The Centers for Disease Control and Prevention (CDC) is working with other federal agencies to ensure that the right people receive the COVID-19 vaccines.

   - The process for evaluating COVID-19 vaccines is rigorous and requires evidence of safety and effectiveness.

3. What is the best way to protect yourself against COVID-19 vaccines?
   - The best way to protect yourself against COVID-19 vaccines is to wash your hands often with soap and water for at least 20 seconds, wear a mask when you are around people, and practice social distancing.

4. How can we improve the accessibility of COVID-19 vaccines?
   - We can improve the accessibility of COVID-19 vaccines by making sure that they are available to people who need them, including those who have limited access to health care.
Vaccine hesitancy can change, but it requires community engagement, building trust, understanding the vaccine process, and sharing truthful information.
Thank You!