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

George A. Mensah, MD, FACC

Media Impact Fund Webinar

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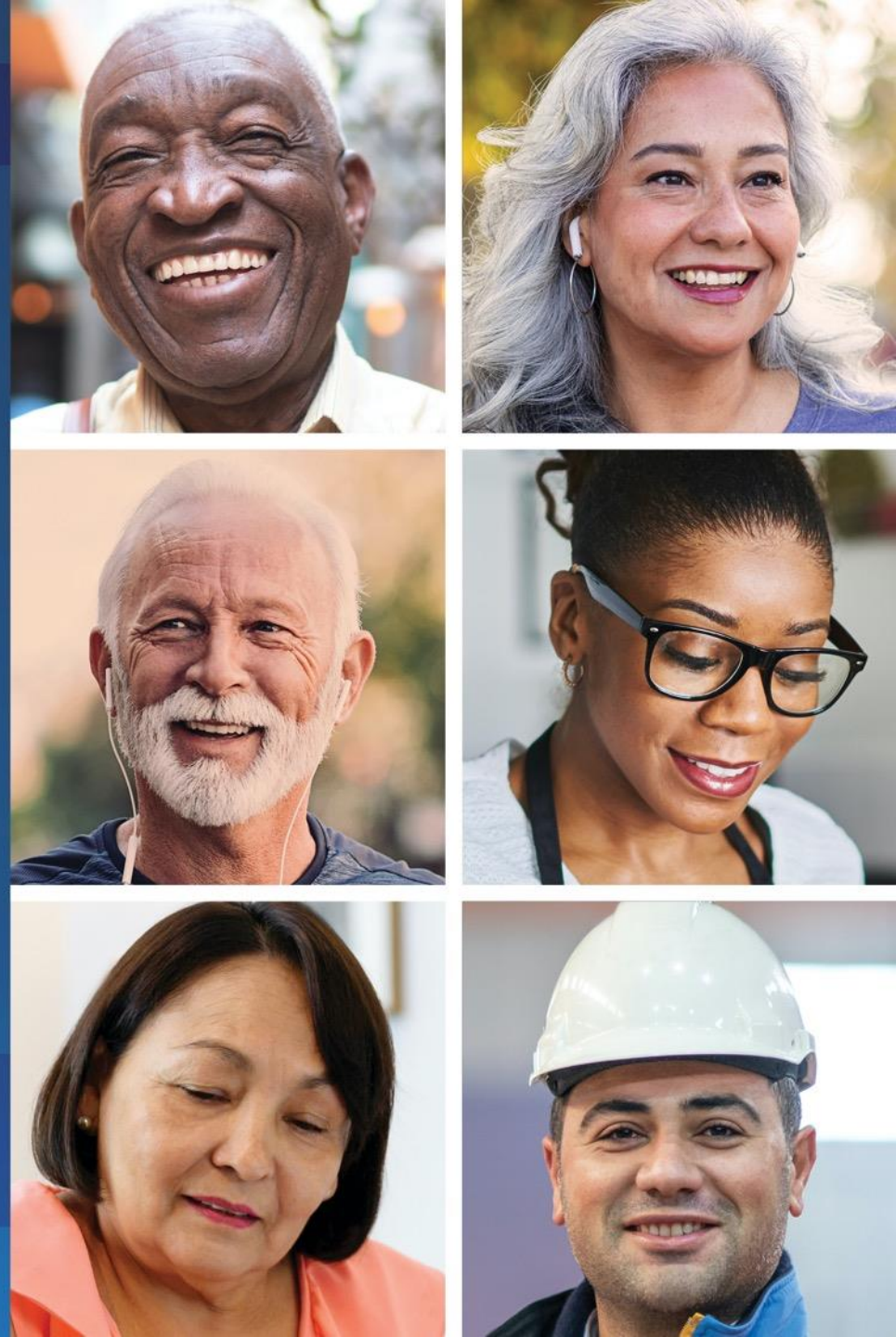
National Institutes of Health
Community Engagement Alliance

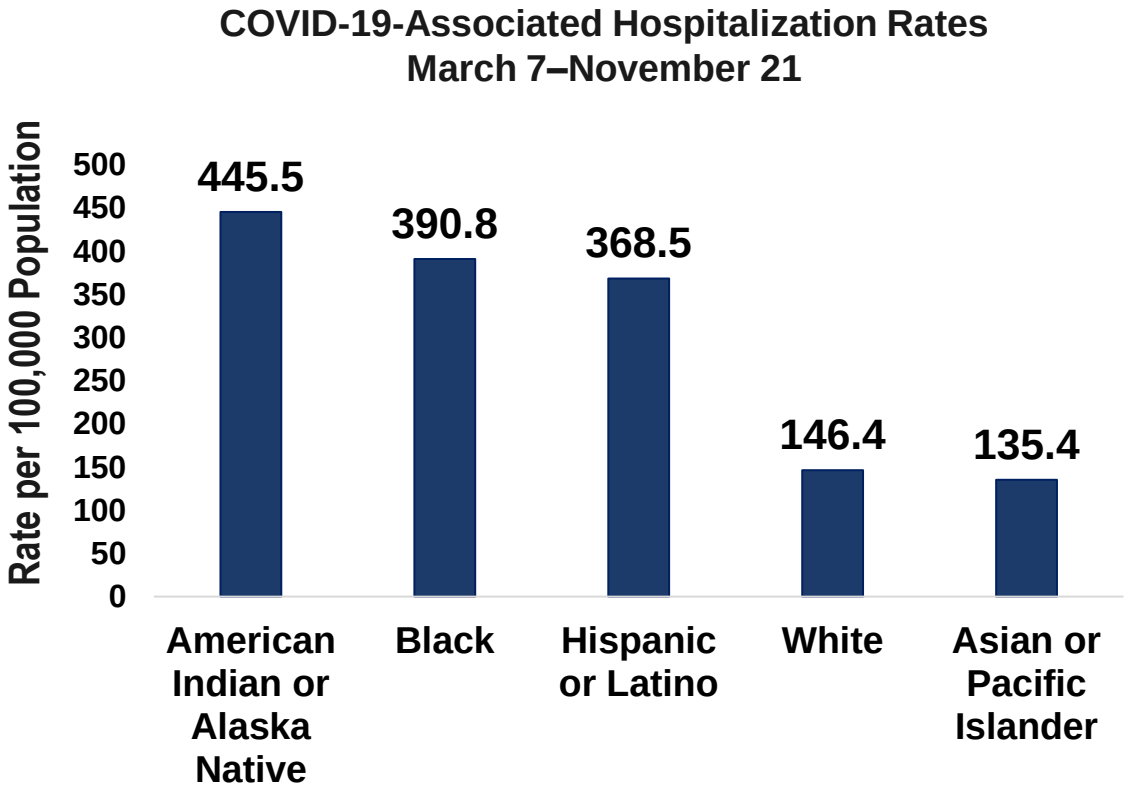


COVID-19 and Health Disparities

Rate ratios compared to White, Non-Hispanic persons	American Indian or Alaska Native, Non-Hispanic persons	Asian, Non-Hispanic persons	Black/African American, Non-Hispanic persons	Hispanic or Latino persons
Cases[1]	**1.8x**	**0.6x**	**1.4x**	**1.7x**
Hospitalizations[2]	**4.0x**	**1.2x**	**3.7x**	**4.1x**
Deaths[3]	**2.6x**	**1.1x**	**2.8x**	**2.8x**

[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.
[2] Data source: COVID-NET (https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covid-net/purpose-methods.html, accessed 11/25/2020). Numbers are ratios of age-adjusted rates standardized to the 2000 US standard COVID-NET catchment population.
[3] Data source: NCHS provisional death counts (https://data.cdc.gov/NCHS/Deaths-involving-coronavirus-disease-2019-COVID-19/ks3g-spdg, accessed 11/27/2020). Numbers are ratios of age-adjusted rates standardized to the 2000 US standard population.

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

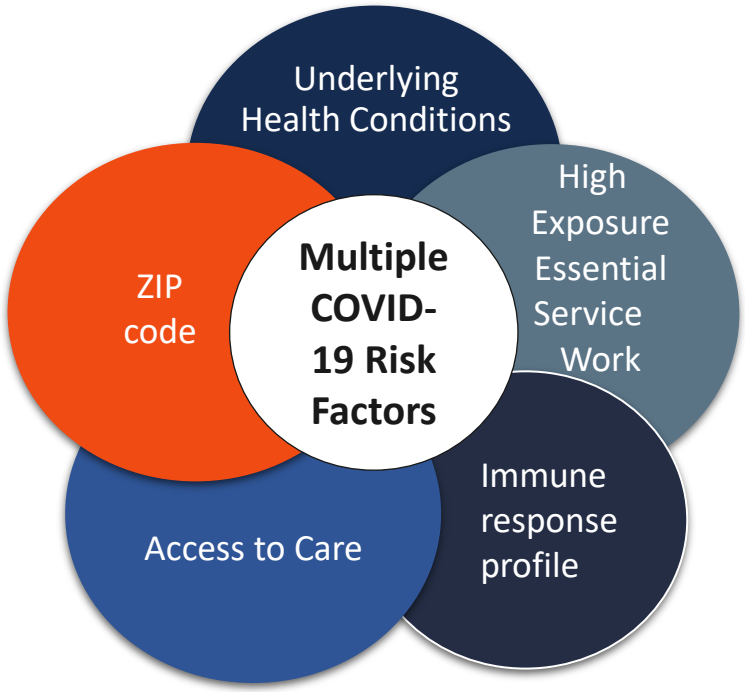


Among some racial and ethnic minority groups, evidence points to higher rates of hospitalization or death from COVID-19 than among non-Hispanic white persons.

COVID-NET

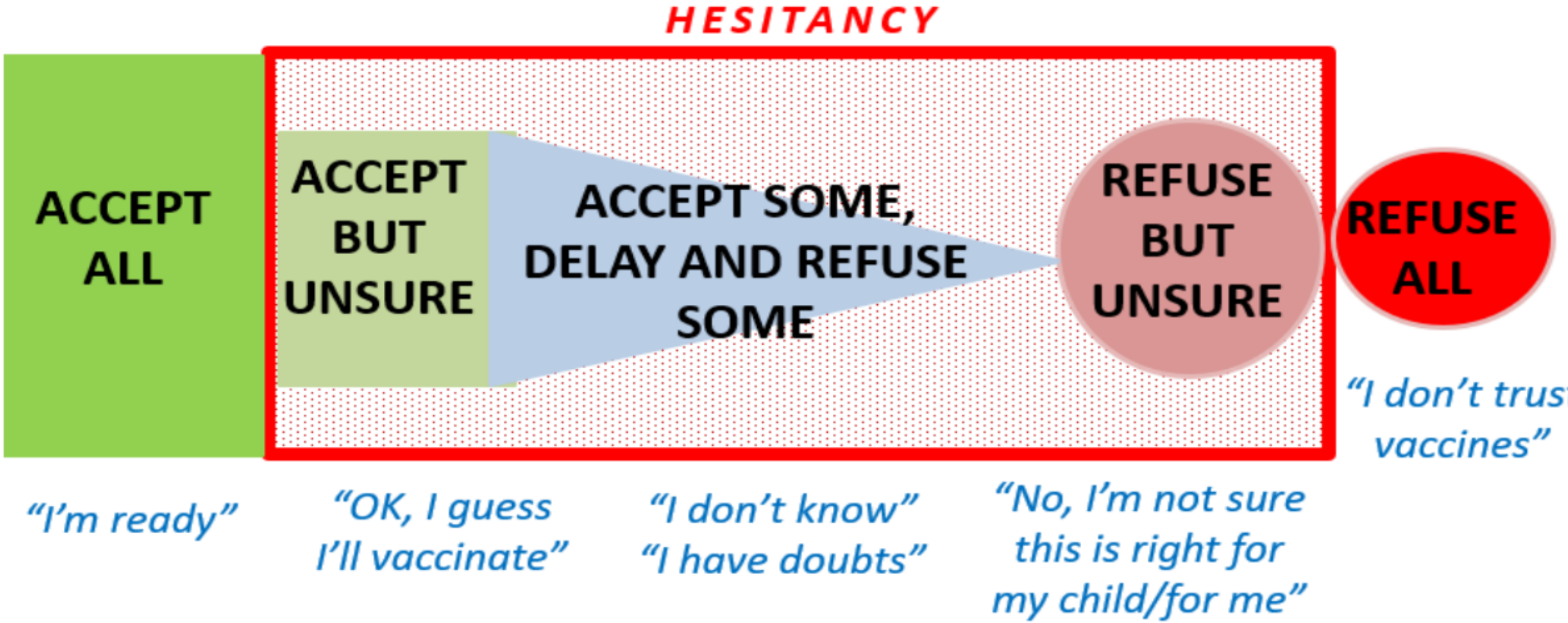
Interplay of clinical characteristics and social determinants of health puts minority communities at high risk for COVID-19 complications

- Heart Disease
- Hypertension
- Diabetes
- Lung Disease



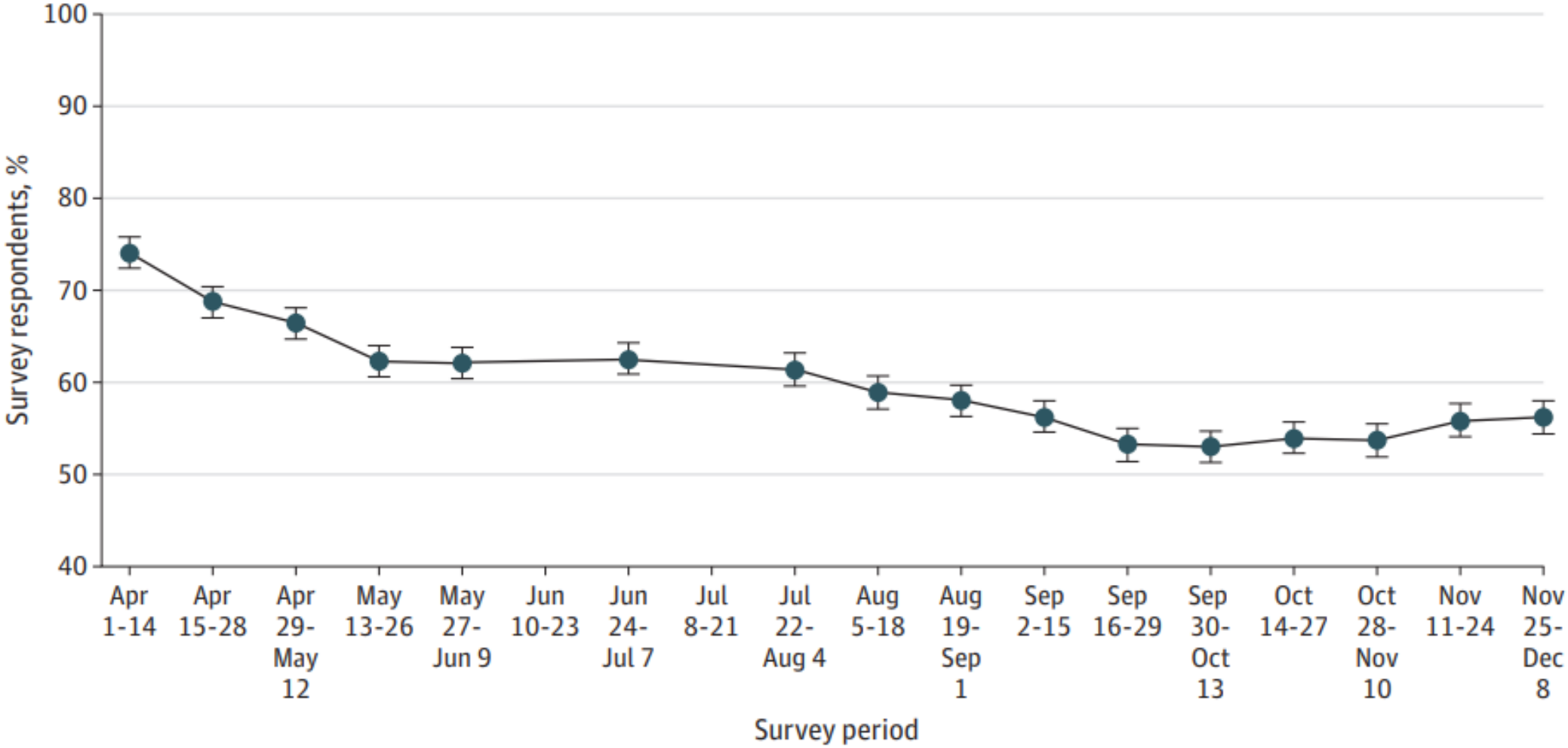
CDC, National Center for Health Statistics (NCHS), National Vital Statistics System, 2019; Yan R, et al., *Science*, 2020.

Vaccine hesitancy is a continuum between complete acceptance & complete refusal



Courtesy: Jennifer Williams. https://www.bcemergencynetwork.ca

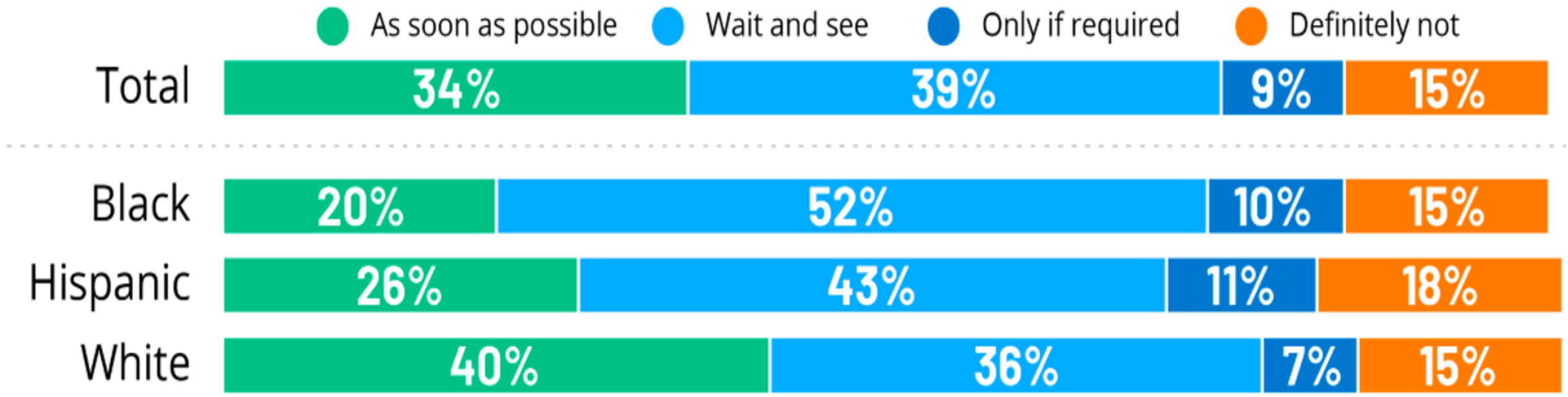
National Trends: Percentage of US Adults Who Say They Are Likely to Get a COVID-19 Vaccine, Apr 1 – Dec 8, 2020



Szilagyi, et al. *JAMA* 2020; doi: 10.1001/jama.2020.26419

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

African Americans/Blacks are <u>more likely to be hesitant</u> to COVID-19 Vaccination



SOURCE: KFF COVID-19 Vaccine Monitor (KFF Health Tracking Poll, Nov. 30-Dec. 8, 2020). See topline for full question wording.

KFF COVID-19 Vaccine Monitor

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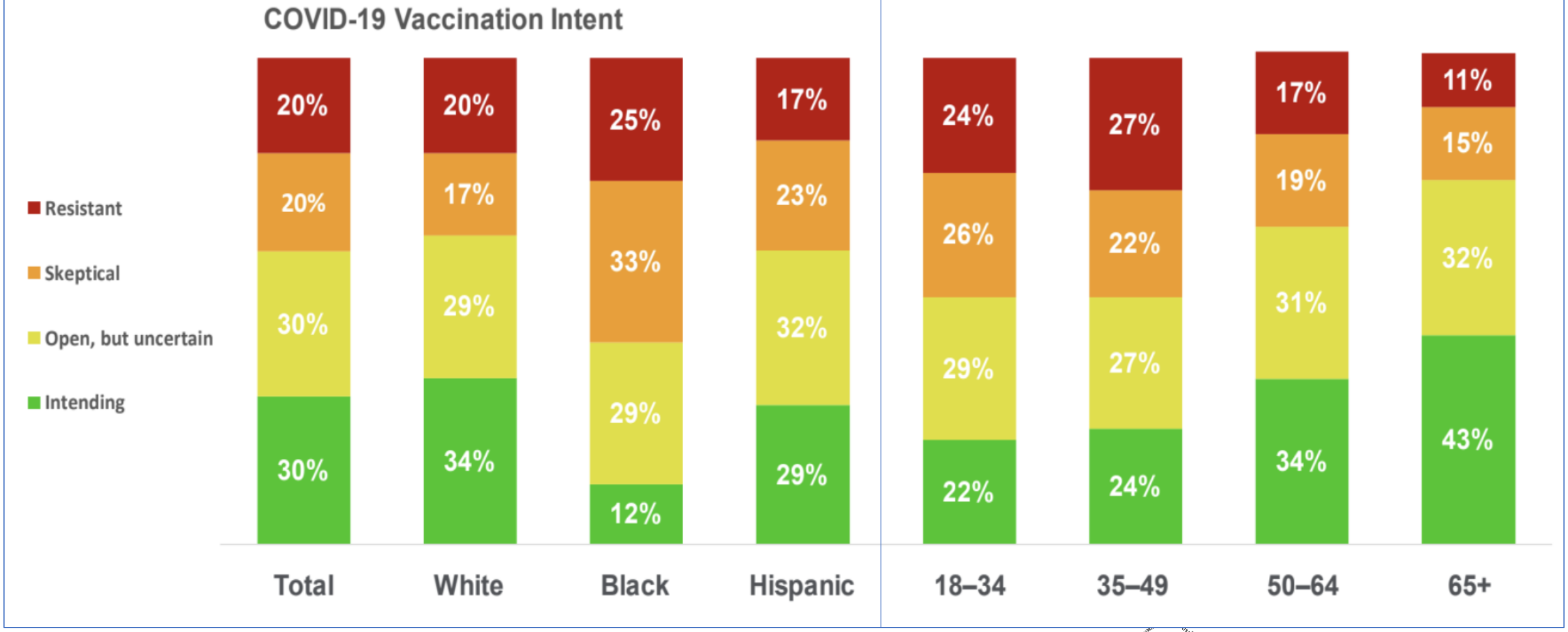
Vaccine Intent is Lowest Among Black and Young Adults



Ad Council/Ipsos National Survey Adults 18+ Dec 15-21, 2020

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Reasons for Vaccine Hesitancy in the COVID-19 Era

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**.

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History of Distrust Black and African American Communities

Tuskegee Study[1]

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.**

Henrietta Lacks[2]

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**.

[1] https://www.cdc.gov/tuskegee/timeline.htm; [2] https://www.nature.com/articles/d41586-020-02494-z

History of Distrust Hispanic and Latino Communities

Guatemala & the USPHS[1]

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[2]

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[3]

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.

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3828982/
[2] https://www.panoramas.pitt.edu/health-and-society/dark-history-forced-sterilization-latina-women
[3] https://www.statnews.com/2020/04/15/fearing-deportation-many-immigrants-at-higher-risk-of-covid-19-are-afraid-to-seek-testing-or-care/

History of Distrust: American Indian and Alaska Native Communities

Misuse of Havasupai Tribe DNA[1]

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**.

Tuberculosis and Trachoma[2]

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**.

Radioactive Iodine Testing[3]

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.

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5310710/
[2] https://www.nlm.nih.gov/nativevoices/timeline/663.html
[3] https://www.ncbi.nlm.nih.gov/books/NBK232518/

Important concepts in addressing vaccine hesitancy

- 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

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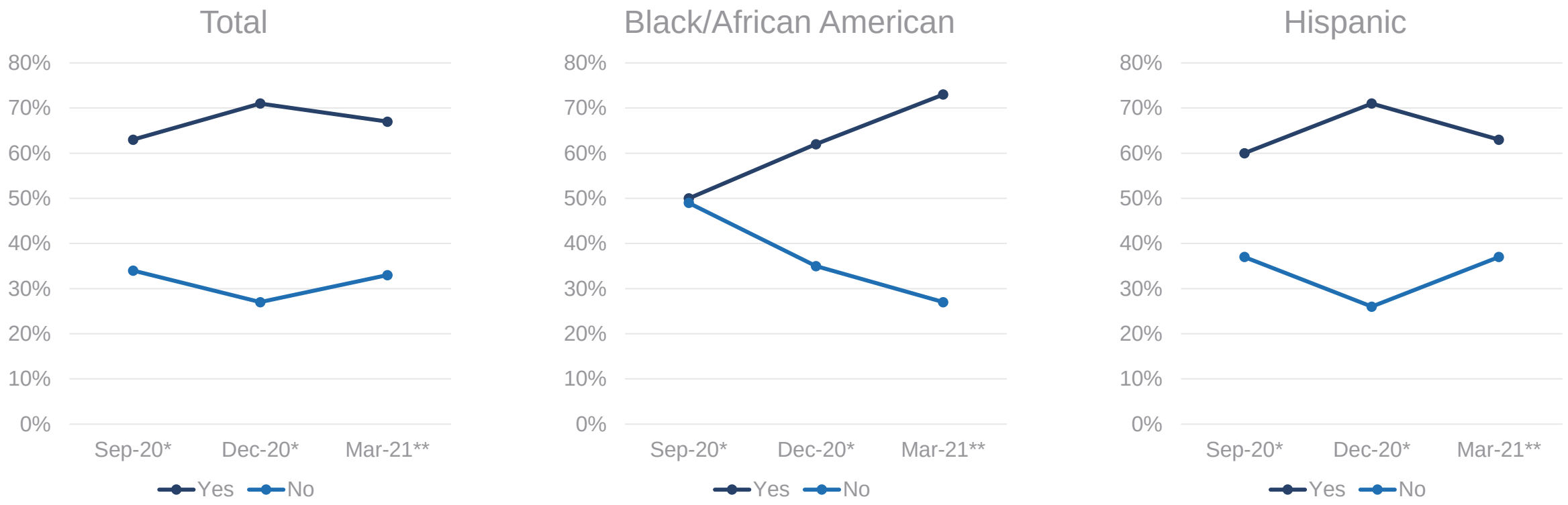
Trends in Vaccine Hesitancy

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?"



*Data Source: ***KFF COVID-19 Vaccine Monitor***: December 2020 https://www.kff.org/coronavirus-covid-19/report/kff-covid-19-vaccine-monitor-december-2020/

Data Source: ***NPR/PBS NewsHour/Marist survey*. "Little Difference In Vaccine Hesitancy Among White And Black Americans, Poll Finds" https://www.npr.org/sections/coronavirus-live-updates/2021/03/12/976172586/little-difference-in-vaccine-hesitancy-among-white-and-black-americans-poll-find

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.

Promising Strategies to Overcome COVID-19 Vaccine Hesitancy in Communities with Significant Health Disparities

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

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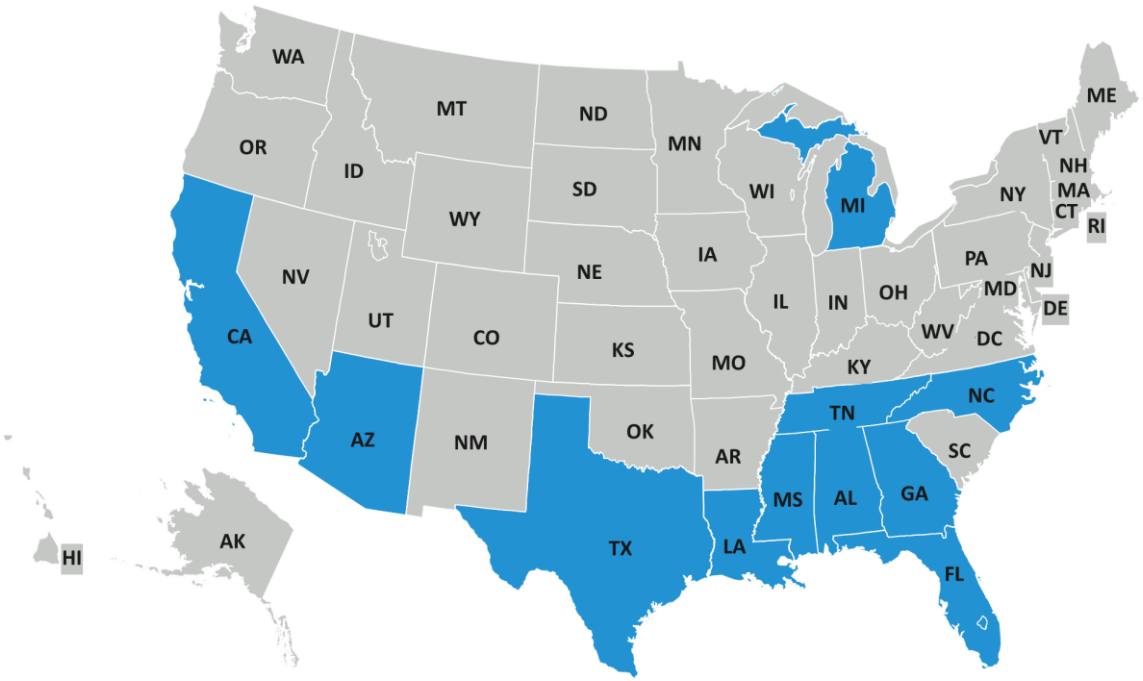
Addressing COVID-19 Vaccine Hesitancy: NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities

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/

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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.

Learn more:
covid19community.nih.gov

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.

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

Video

Social media images and copy

Infographics

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

Will the vaccine give me COVID-19?

No. The vaccines being used to prevent COVID-19 in the United States can't infect someone with the virus that causes COVID-19. None of the vaccines contain whole or live SARS-CoV-2, the virus that causes COVID-19. Getting vaccinated helps protect you by creating an antibody (immune system) response without getting you sick.

People who join ongoing vaccine trials may be exposed to SARS-CoV-2 in their everyday lives, but not as a part of the vaccine research.

The process for making a COVID-19 vaccine seemed to move really fast. How can I be sure the vaccines being used are safe and effective?

Every vaccine available to the public goes through a complete review and evaluation for safety and effectiveness by the U.S. Food and Drug Administration (FDA) before being authorized or approved. If the evidence shows a potential vaccine isn't safe or effective, it will not be used.

The SARS-CoV-2 vaccines being used have moved through all the required phases of testing, review, and evaluation faster than a typical drug or vaccine because:

1. **What we already knew about other coronaviruses like SARS-CoV-2 gave us a head start.** COVID-19 vaccines were developed based on decades of existing research about other coronaviruses.
2. **Researchers, the federal government, and drug companies came together like never before** to focus, cooperate, and share resources to create a vaccine. This kind of large-scale effort has helped make completing the different phases of testing more efficient.

Why should I get a vaccine for COVID-19?

1. **COVID-19 vaccination will help keep you from getting COVID-19.** Based on what we know about vaccines for other diseases and early data from clinical trials, experts believe that receiving a COVID-19 vaccine may also help keep you from getting seriously ill even if you do get COVID-19. Getting vaccinated yourself may also protect people around you, particularly people at increased risk for severe illness from COVID-19.
2. **COVID-19 vaccination is a safer way to help build protection.** COVID-19 can cause serious, life-threatening health problems, and there is no way to know how COVID-19 will affect you. And if you get sick, you could spread the

¿Las vacunas me transmitirán el COVID-19?

No. Las vacunas que se usan para prevenir el COVID-19 en los Estados Unidos no pueden infectar a alguien con el virus que causa el COVID-19. Ninguna de las vacunas contiene el SARS-CoV-2, el virus que causa el COVID-19, entero o vivo. Vacunarse ayuda a protegerlo al crear una respuesta de anticuerpos (sistema inmunológico) sin enfermarlo.

Las personas que participan en los ensayos clínicos que se están llevando a cabo sobre las vacunas podrían estar expuestas al virus SARS-CoV-2 en su vida cotidiana, pero no como parte de la investigación de la vacuna.

El proceso para hacer una vacuna contra el COVID-19 parece haber avanzado muy rápido. ¿Cómo puedo estar seguro de que las vacunas que se han desarrollado son seguras y eficaces?

Todas las vacunas disponibles para el público pasan por una revisión y evaluación completas de seguridad y eficacia por parte de la Administración de Alimentos y Medicamentos de los Estados Unidos (FDA, por sus siglas en inglés) antes de ser autorizadas o aprobadas. Si se encuentra evidencia de que una posible vacuna no es segura o efectiva, no se utilizará.

Las vacunas contra el SARS-CoV-2 que se están utilizando han pasado por todas las fases requeridas de pruebas, revisión y evaluación. Este proceso ha sido más rápido que un medicamento o vacuna típica por lo siguiente:

1. **Lo que ya sabíamos sobre otros coronavirus como el SARS-CoV-2 nos dio una ventaja.** Las vacunas contra el COVID-19 se desarrollaron utilizando como base décadas de investigación existente sobre otros coronavirus.
2. **Los investigadores, el gobierno federal y las compañías farmacéuticas se unieron como nunca antes** para concentrarse, cooperar y compartir recursos para crear la vacuna. Este tipo de esfuerzo a gran escala ha ayudado a completar las diferentes fases de las pruebas de manera más eficiente.

¿Por qué debería vacunarme contra el COVID-19?

1. **La vacuna contra el COVID-19 lo ayudará a evitar contraer el coronavirus.** Según lo que sabemos sobre las vacunas para otras enfermedades y los primeros datos de los ensayos clínicos, los expertos creen que recibir una vacuna contra el COVID-19 también puede ayudar a evitar que se enferme gravemente incluso si contrae el COVID-19. Vacunarse también puede proteger a las personas que lo rodean, sobre todo a las personas que tienen un mayor riesgo de enfermarse gravemente por el COVID-19.
2. **La vacuna contra el COVID-19 es una forma más segura de ayudar a generar protección.** El COVID-19 puede causar problemas de salud graves y potencialmente mortales, y no hay forma de saber cómo le afectará. Y si se enferma, podría transmitir la enfermedad a amigos, familiares y otras personas a su alrededor. Si bien contraer el COVID-19 puede ofrecer alguna protección natural o inmunidad, el riesgo de, el riesgo de

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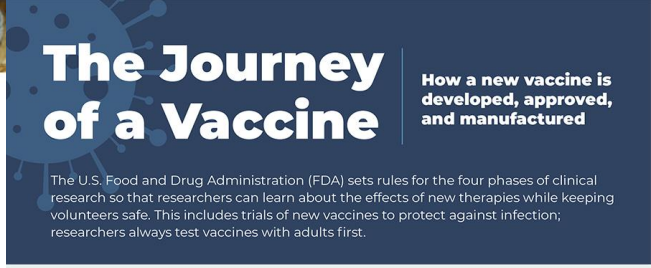
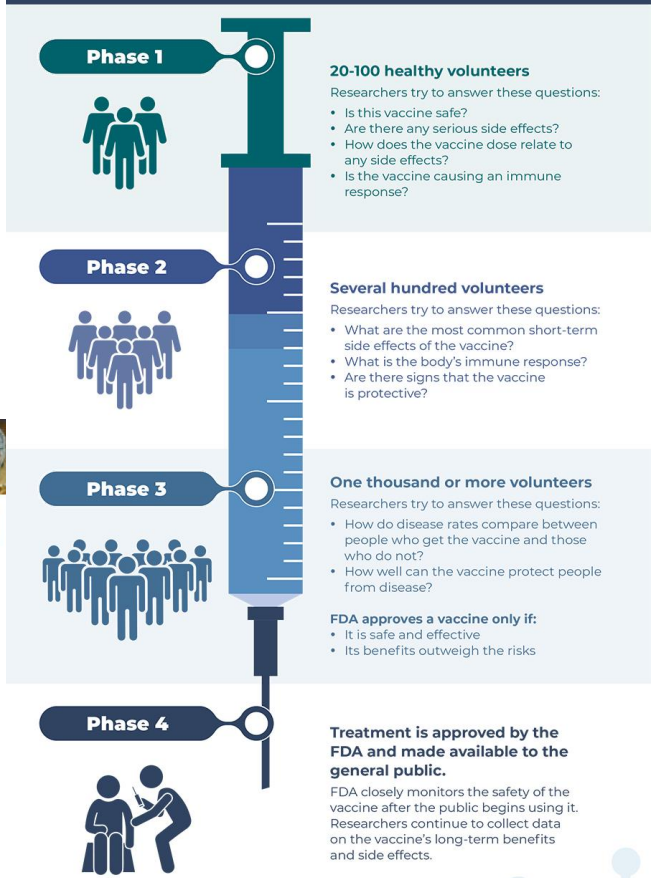


The U.S. Food and Drug Administration (FDA) sets rules for the four phases of clinical research so that researchers can learn about the effects of new therapies while keeping volunteers safe. This includes trials of new vaccines to protect against infection; researchers always test vaccines with adults first.



Vaccine Adverse Event Reporting System (VAERS)

VAERS, a national monitoring program run by the FDA and the Centers for Disease Control and Prevention, collects and reviews reports of any health problems that develop after a person gets a vaccine. Anyone can submit a report, including patients and healthcare professionals.

Medical recommendations for taking the vaccine may change if safety monitoring reveals new information about its risks. **vaers.hhs.gov**

For more information, visit
cdc.gov/vaccinesafety

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Source: **https://www.cdc.gov/vaccines/parents/infographics/journey-of-child-vaccine.html**

Takeaway Message

Vaccine hesitancy can change, but it requires community engagement, building trust, understanding the vaccine process, and sharing truthful information

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Thank You!
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