

# Black People Like Me



## Asthma and COVID-19: Is Research Really that Important To Me?

Sharon D. Allison-Ottoy

Courtney Clyatt

Mary White



# Black People Like Me

## Welcome

### Welcome

- Short COVID-19 update
- Real world research study – outcomes
- Participating in research beyond being "just a subject"
- How to get engaged in PCOR research
- Q & A

### Closing Remarks

### What we will cover:

What perspectives Black patients shared with researchers regarding COVID-19 and getting the vaccine. Hear what they have to say!

How Black Asthma patients and caregivers can engage in this new approach to research, called patient centered outcomes research (PCOR), and how it can make a positive difference in the African American community.

How including patient perspective in research helps people and their caregivers communicate and make informed health care decisions



LeRoy Graham, MD



Tonya Winders

Hosts



## Speakers



Sharon D. Allison-Otney, MD  
Executive Director of The  
COSHAR Healthy Communities  
Foundation



Courtney Clyatt, MA, is a Senior  
Program Officer for  
Engagement at the Patient-  
Centered Outcomes Research  
Institute (PCORI).



Mary White  
Patient advocate and research  
advisor



## Polling Question #1

Do you participate in research? (Choose only one)

1. Yes
2. No



# COVID -19 Update

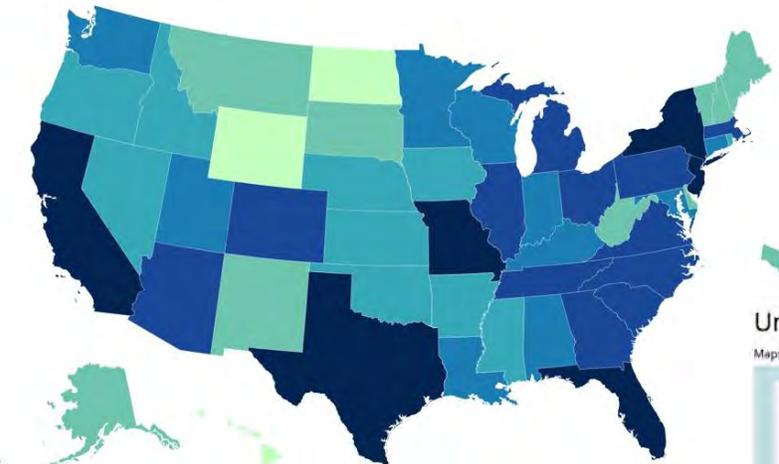
- Some States opening 100% - No Masks
- New Vaccine approved by FDA – Feb 2021  
**Johnson & Johnson**  
Ensemble / Ensemble 2
- Even those who have been vaccinated need to practice being safe!
- One of “our own” recovering from COVID-19



Dr. LeRoy  
Graham



## US Data Report - CDC



### United States COVID-19 Cases and Deaths by State

Maps, charts, and data provided by the CDC, updated daily by 8 pm ET<sup>†</sup>

TOTAL CASES <b>28,992,598</b> +52,815 New Cases	CASES IN LAST 7 DAYS <b>476,646</b>	TOTAL DEATHS <b>526,213</b> +1,503 New Deaths
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CDC | Updated: Mar 10 2021 12:26PM

#### Territories

AS	FSM	GU	MP	PR	PW	RMI	VI
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#### Cases in Last 7 days



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**Not for General Release**



## **Synopsis of Survey of African Americans and Covid-19**

The COSHAR Healthy Communities Foundation

**S. Allison-Otley, MD Exec. Director**



### About The COSHAR Foundation

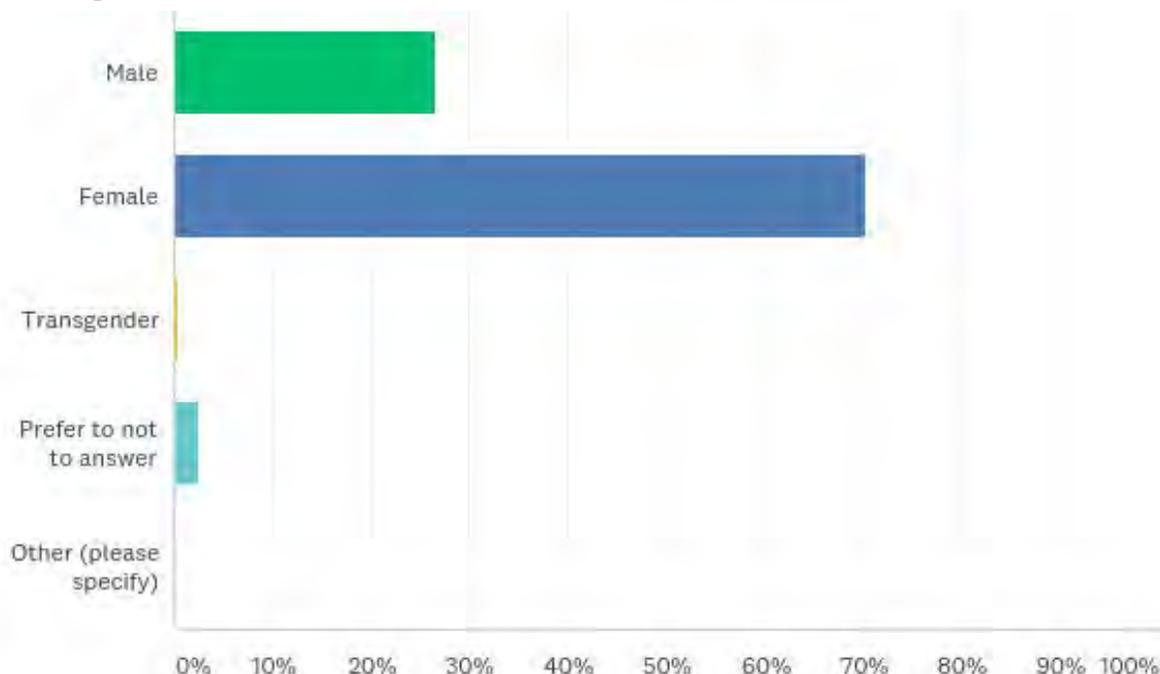
- The COSHAR Foundation is a non-profit organization dedicated to improving minority health in the U.S. through advocacy, information, education and training
  - The foundation is NOT a faith based organization but utilizes the faith based community in our outreach models.
  - The foundation has developed the **National Health Ministry Network (NHMN)** which consists of over 78,040 places of worship and 2,600 community organizations and is continuing to grow. *(NHMN is non denominational, no exclusions, no doctrine promoted and we are a resource for health/wellness and educational programs)*
  - The foundation has an extensive network of volunteers, health professionals and a guiding health advisory board which supports its national and international objectives.



- Large scientific surveys of African Americans/Blacks (over 96.1% AA/Blacks respondents ) on Covid19 perceptions and specifically potential vaccine engagement
  - Oversampled to this population
  - Used prior survey models and our NHMN to reach respondents
  - Electronic surveys were the major method for data collection thru private, secure servers of our NHMN members and in <7% of respondents---printed oral surveys.
  - Consistent with previous surveys development to final data collection: 31 days
  - Independent analysis and tabulation
- 1<sup>st</sup> survey 3,109 validated respondents; the majority were online with subset of printed surveys received. P value .03 therefore statistically significance. Confidence interval 96.8%
- **FOCUS AREAS**
  - Covid-19
    - Current impact on direct family/friends
    - Perceptions on vaccines
    - Trust and other questions
    - Vaccinations



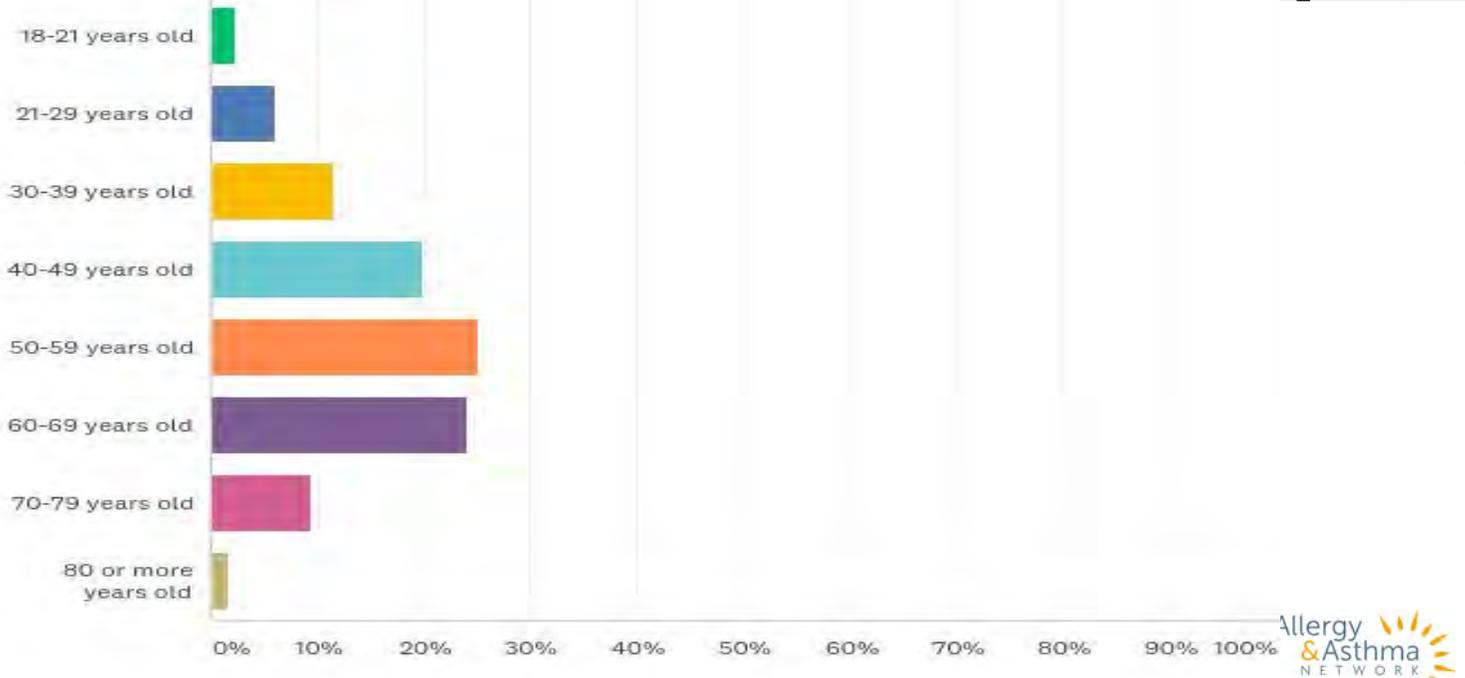
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# Black People Like Me

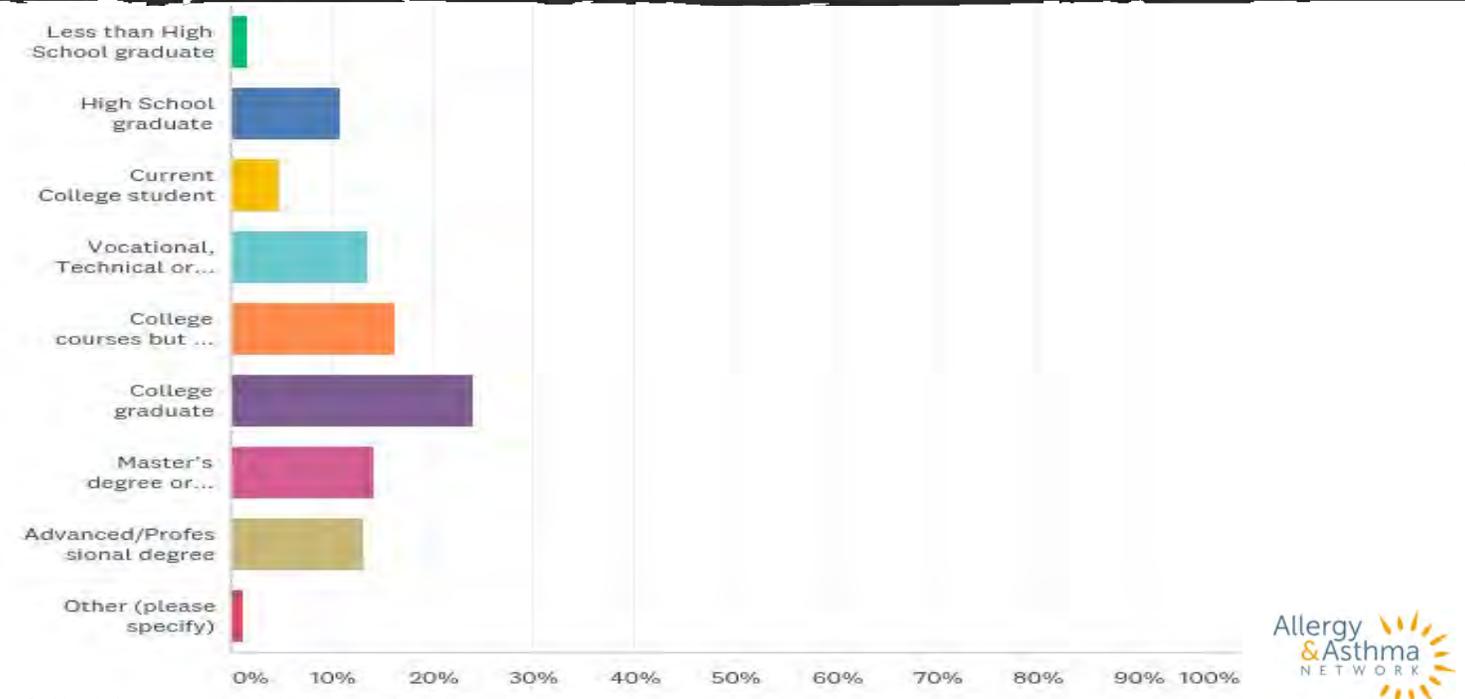
## Age Distribution - Majority are 40-69 yo



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# Black People Like Me

## Education Levels



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# Black People Like Me

# Geographic Distribution

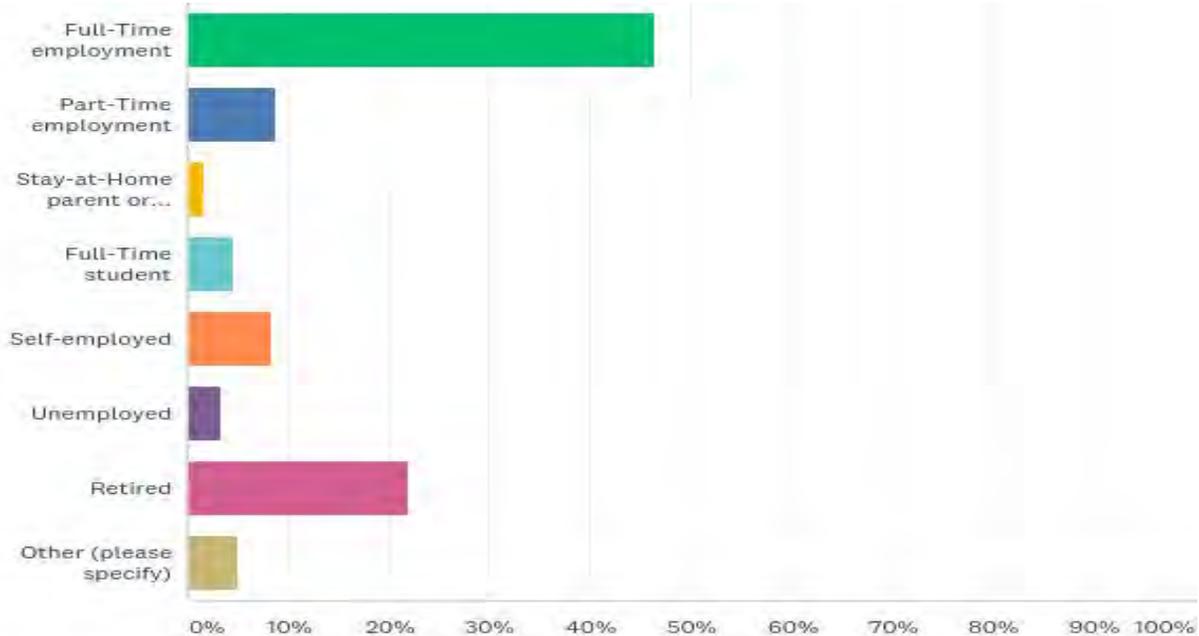
\*note the "bubbles" indicate areas of >15 respondents; nationwide participation with respondents from all states except for validated surveys from Wyoming, Idaho or Montana.



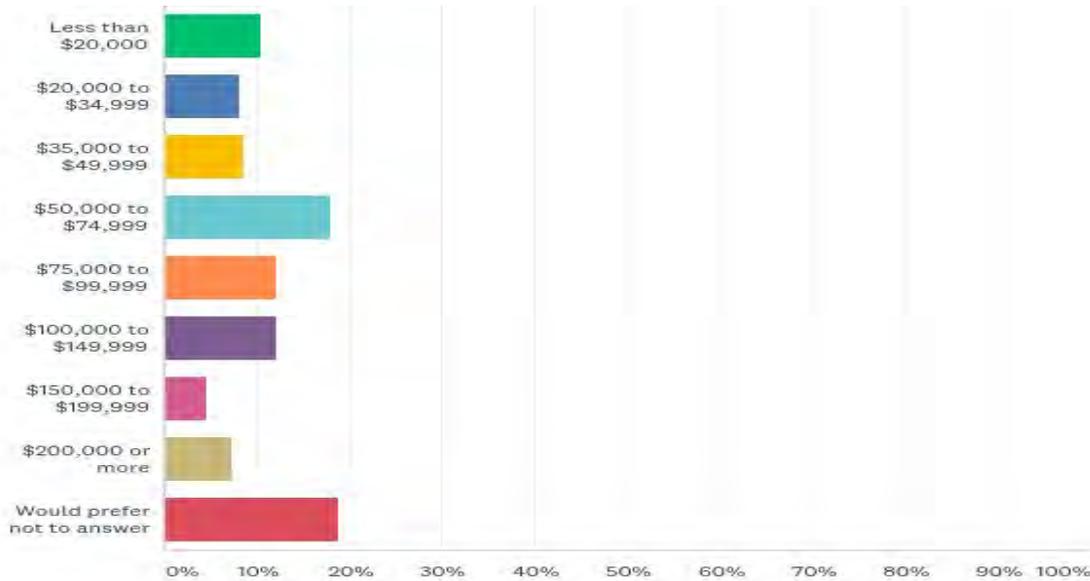
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# Black People Like Me

# Employment Status



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- 100% of respondents were familiar with the term Coronavirus or Covid-19
  - 2 respondents were eliminated because of no indicated knowledge of terms and other missing data
- **April 2020 Survey (>3,109 surveys)**
  - Do you believe that the Covid-19 is Real Disease vs. a Hoax/Made Up?
    - 96.3% Real 1.91% Hoax 1.79% I don't know
  - Have you been diagnosed with Covid-19?
    - Yes: 7.1% No: 92.9%
  - Are you afraid of you or someone in your family contracting Covid-19?
    - YES: 93.4% NO: 6.6%
  - Do you know anyone (family/friend/work associate) who was hospitalized with COVID-19?
    - YES: 28.4 % NO: 71.6 %
  - Do you know anyone who (family/friend/work associate) died from COVID-19?
    - YES: 19.3% NO: 80.7%
  - Do you know anyone (family/friend/work associate) who tested positive for COVID-19 that was not hospitalized?
    - Yes: 61%. No: 39%

### Survey Sept 16, 2020 (>2, 994)

- Do you believe that the Covid-19 is Real Disease vs. a Hoax/Made Up?
  - Real: 96.9% Hoax: 1.4 % Unsure: 1.7%
- Have you been diagnosed with Covid-19?
  - Yes: 13.4% No: 86.6%
- Are you afraid of you or someone in your family contracting Covid-19?
  - YES: 97.7% NO: 2.3%
- Do you know anyone (family/friend/work associate) who was hospitalized with COVID-19?
  - YES: 41.2% NO: 58.8%
- Do you know anyone who (family/friend/work associate) died from COVID-19?
  - YES: 26.8% NO: 73.2%
- Do you know anyone (family/friend/work associate) who has tested positive for COVID-19 that was not hospitalized?
  - Yes: 78.3%. No: 21.7%

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- If the COVID-19 vaccine were available today would you get vaccinated?
  - Yes: 14.3% No: 69.1% Unsure: 16.6%
- Would you recommend that your family be vaccinated?
  - Yes: 9.8% No: 73.8% Unsure: 16.4%
- Do you believe that the development process of COVID-19 vaccine is safe for the public?
  - Yes: 6.2% No: 64.1% Unsure: 29.7%
- Do you believe that more AA/Blacks are affected by and die from COVID-19?
  - Yes: 71.3% No: .9% Unsure: 27.8%
- Do you believe that the vaccine should be targeted to AA/Blacks first because of risk factors and death rates with COVID-19?
  - Yes: 1.7% No: 91.9% Unsure: 6.4%
- Would you trust your physician/primary care provider's recommendation on the COVID-19 vaccine?
  - Yes: 19.1% No: 3.8% Unsure: 77.1%
- Would you participate in a COVID-19 vaccine clinical trial?
  - Yes: 2.3% No: 60.6% Unsure: 37.1%
- Would you participate in a COVID-19 medication/treatment clinical trial?
  - Yes: 18.5% No: 33.9% Unsure: 47.6%

- Do you trust the information given by Dr. Anthony Fauci and the National Institute of Allergy and Infectious Diseases on COVID-19?
  - Yes: 83.6% No: 1.2% Unsure: 15.2%
- Do you trust the information given by President Donald Trump and the White House Officials on COVID-19?
  - Yes: 1.4% No: 78.9% Unsure: 19.7%
- Do you trust the information given by other government officials like the US Surgeon General, Centers for Disease Control and Food and Drug Administration and state governments on COVID-19?
  - Yes: 8.5% No: 51.8% Unsure: 39.7%
- Do you trust the information given by the pharmaceutical industry/drug makers on Covid-19?
  - Yes: 8.1% No: 59.4% Unsure: 32.5%
- Do you trust the information shared by your Pastor or Faith Leader or member of your church or community org's health ministry on COVID-19?
  - Yes: 71.4% No: 0% Unsure: 28.6%
- Did you get the flu vaccine in the last 3 years?
  - Yes: 28.1% No: 49.4% Unsure: 22.5%
- Will you get the flu vaccine this year?
  - Yes: 13.1% No: 52.7% Unsure: 34.2%

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- 100% of respondents were familiar with the term Coronavirus or Covid-19
- **Jan. 2021 Survey (>2,918 surveys)**
  - Do you believe that the Covid-19 is Real Disease vs. a Hoax/Made Up?
    - 96.1% Real 1.8 % Hoax 2.1 % I don't know
  - Have you been diagnosed with Covid-19?
    - Yes: 19.4% No: 80.6%
  - Are you afraid of you or someone in your family contracting Covid-19?
    - YES: 86.6 % NO: 13.4%
  - Do you know anyone (family/friend/work associate) who was hospitalized with COVID-19?
    - YES: 59.2 % NO: 40.8%
  - Do you know anyone who (family/friend/work associate) died from COVID-19?
    - YES: 8.1 % NO: 72.6%
  - Do you know anyone (family/friend/work associate) who tested positive for COVID-19 that was not hospitalized?
    - Yes: 69.3%. No: 30.7%

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- If the COVID-19 vaccine were available today would you get vaccinated?
  - Yes: 28.6% No: 39.5% Unsure: 31.9%
- Would you recommend that your family be vaccinated?
  - Yes: 21.4% No: 45.8% Unsure: 32.8%
- Do you believe that the development process of COVID-19 vaccine is safe for the public?
  - Yes: 19.2% No: 57.2% Unsure: 23.6%
- Do you believe that more AA/Blacks are affected by and die from COVID-19?
  - Yes: 93.7% No: 2.1% Unsure: 4.2%
- Do you believe that the vaccine should be targeted to AA/Blacks first because of risk factors and death rates with COVID-19?
  - Yes: 18.3% No: 60.8% Unsure: 20.9%
- Would you trust your physician/primary care provider's recommendation on the COVID-19 vaccine?
  - Yes: 39.1% No: 16.6% Unsure: 44.3%
- Would you participate in a COVID-19 vaccine clinical trial?
  - Yes: 8.7% No: 32.9% Unsure: 58.4%
- Would you participate in a COVID-19 medication/treatment clinical trial?
  - Yes: 6.5% No: 21.7% Unsure: 71.8%

- Do you trust the information given by Dr. Anthony Fauci and the National Institute of Allergy and Infectious Diseases on COVID-19?
  - Yes: 92.4% No: .4% Unsure: 7.2%
- Do you trust the information given by President Donald Trump and the White House Officials on COVID-19?
  - Yes: .6% No: 93.9% Unsure: 5.5%
- Do you trust the information given by other government officials like the US Surgeon General, Centers for Disease Control and Food and Drug Administration and state governments on COVID-19?
  - Yes: 18.9% No: 30.3% Unsure: 50.8%
- Do you trust the information given by the pharmaceutical industry/drug makers on Covid-19?
  - Yes: 4.7% No: 52.8% Unsure: 42.5%
- Do you trust the information shared by your Pastor or Faith Leader or member of your church or community org's health ministry on COVID-19?
  - Yes: 78.3% No: .9% Unsure: 20.8%
- Did you get the flu vaccine in the last 3 years?
  - Yes: 27.2% No: 44.9% Unsure: 27.2%
- Will you get the flu vaccine this year?
  - Yes: 9.9% No: 57.6% Unsure: 32.5%

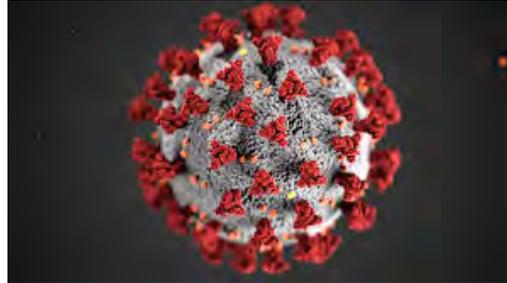
## Key Points Black People Like Me

- The comparison for education level/socioeconomics is negligible on questions of trust, vaccine trial participation
- Women were slightly more willing to participate in vaccine clinical trials than men (>6% variation)
- Majority of respondents would be open to receiving more information from "trusted" national, state and local resources.
- We also surveyed physicians and healthcare professionals (>750) on 3 of the questions as well as others specific to their area of expertise and found the following:
  - Hesitancy in participating in clinical trials similar to general population
  - Distrust at the pace of vaccine development, safety measures and more importantly hesitancy in recommending COVID-19 vaccine in 2020 for themselves, family members or patients without extensive peer reviewed studies.

## Key Points

- **General comments** were allowed at the end of the survey and major top line info follows:
  - The current political climate is contributing to the distrust of information and individual actions around COVID-19.
    - This improved in the 2<sup>nd</sup> survey.
  - Distrust of the President drives the reticence of getting a vaccine or participating in clinical trials.
    - This decreased in the 2<sup>nd</sup> survey
  - SIGNIFICANT references to being "guinea pigs", "test tubes", being taken advantage of in the initial trials and distribution of the vaccine were prevalent. More than 100 plus references to genocide and sacrificing black lives in the rush to develop a vaccine mentioned with some conspiracy theories.
    - Hesitancy remains and past history or company is a factor (talcum powder JnJ)
  - MAJOR emphasis and written comments on the politics of the vaccine, rush to development and safety are barriers
    - This has not significantly changed
  - Other surveys and feedback from around the country is now demonstrating an impact on willingness to participate in clinical trials and other awareness campaigns.
  - Other findings to be discussed. We conducted focus groups of subset of respondents as well as 4 focus groups with clergy, community leaders and have developed an action plan.

## Synopsis of AA Engagement and Discussion



- Current programs and outreach
- Vaccination tactics
- Fact, Fiction, FEAR
- What Works/ Next Steps

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## **Synopsis of Survey of African Americans and Covid-19**

**The COSHAR Healthy Communities Foundation  
S. Allison-Ottey, MD Exec. Director**

## Black People Like Me

### Polling Question #2

Have you ever participated in one of the following roles in research:  
(choose all that apply)

1. None
2. Patient/subject
3. Study Advisor
4. Member of advisory board
5. Study Focus group member
6. Co – investigator
7. Other



## Black People Like Me

### Polling Question #3

Why do you not participate in research?

1. Don't want to be treated like a guinea pig
2. Don't trust researchers
3. Don't know how to get involved or where to find information
4. I do participate in research
5. Other





Mary White  
Research Study Patient  
Patient Advisor

My Journey and Why I Got  
Involved in Research



## What Is PCOR? And How Can You Get Involved?

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Courtney Clyatt  
Senior Program Officer

*Asthma and COVID-19: Is Research Really  
that Important To Me*

March 11, 2021



# Who PCORI Is and What We Do

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## Patient-Centered Outcomes Research Institute (PCORI)



- An independent research institute authorized by Congress in 2010 and governed by a 21-member Board
- Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns
- Helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information



- We focus on answering questions most important to patients and those who care for them.
- We aim to produce evidence that can be easily applied in real-world settings.
- We engage patients, caregivers, clinicians, insurers, employers, and other stakeholders throughout the research process.
- This makes it more likely we'll get the research questions right and the study results will be useful and taken up in practice.



## PCORI's Work Answers Patients' Questions

**Given my personal characteristics, conditions and preferences...**

“What should I expect will happen to me?”

“What are my options and what are the potential benefits and harms of those options?”

“What can I do to improve the outcomes that are most important to me?”

“How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?”

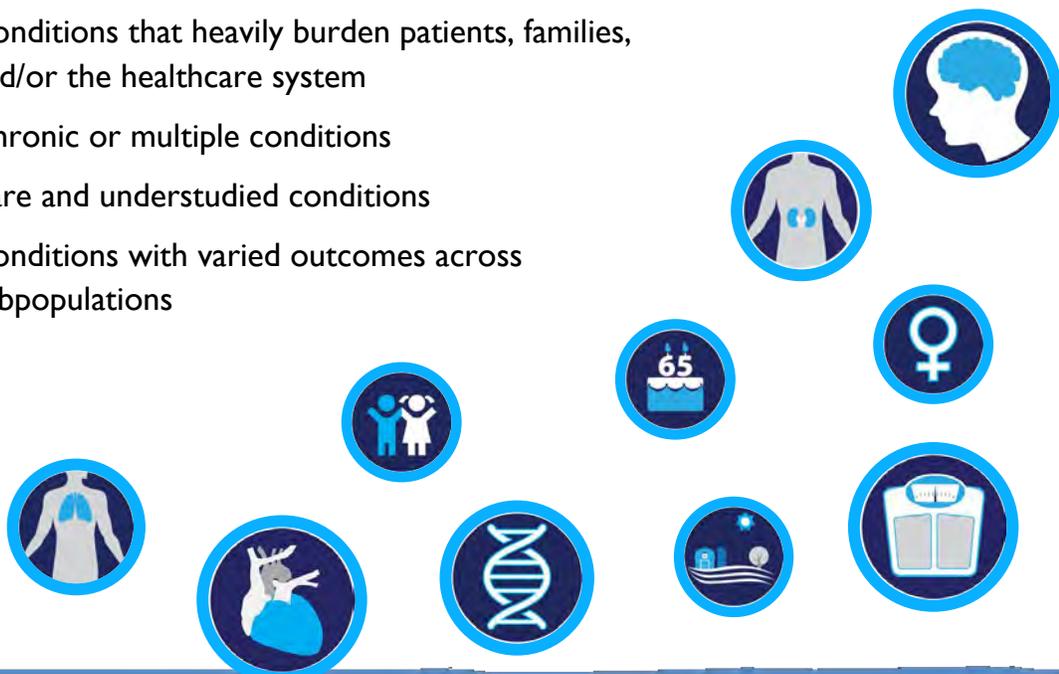
PCOR is a relatively new form of CER that....

- Considers patients' needs and preferences, and the outcomes most important to them
- Investigates what works, for whom, under what circumstances
- Helps patients and other healthcare stakeholders make better-informed decisions about health and healthcare options



## Pays Particular Attention to

- Conditions that heavily burden patients, families, and/or the healthcare system
- Chronic or multiple conditions
- Rare and understudied conditions
- Conditions with varied outcomes across subpopulations



# PCORI Funds Research on High-Cost, High-Impact Health Conditions



National Per Capita Expenditure	Condition	Number of PCORI Studies	PCORI Investment
\$33,485	Stroke	15	\$63 M
	Heart Failure	17	\$79 M
	Chronic Obstructive Pulmonary Disease	18	\$91 M
	Hepatitis (Chronic Viral B and C)	9	\$60 M
	Atrial Fibrillation	5	\$8 M
	Alzheimer's Disease/Dementia	13	\$78 M
	Chronic Kidney Disease	19	\$75 M
	Schizophrenia/Other Psychotic Disorders	12	\$26 M
	Asthma	14	\$49 M
	Depression	48	\$200 M
	Cancer	90	\$360 M
	Ischemic Heart Disease	24	\$111 M
	HIV/AIDS	11	\$34 M
	Osteoporosis	1	\$14 M
	Diabetes	38	\$88 M
	Arthritis	15	\$50 M
	Hyperlipidemia	7	\$27 M
	Hypertension	12	\$54 M
	Autism Spectrum Disorders	2	\$4 M

PCORI has **281 CER studies** examining what works best in care for the **19 highest cost conditions** in the United States<sup>^</sup>

<sup>^</sup>High-cost clinical conditions identified by the Centers for Medicare and Medicaid Services for 2015.

A study may be counted across more than one condition category. The PCORI CER portfolio includes 494 active/completed CER studies as of June 2020.

## Better Research Through Engagement

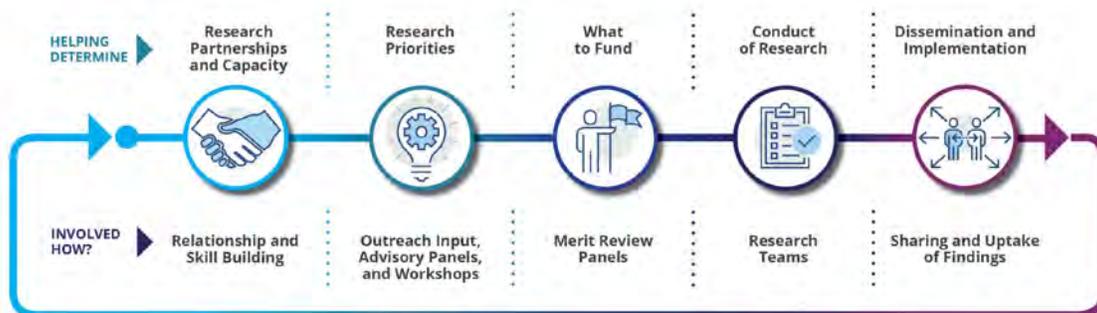


- By "engagement in research," we refer to the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from **topic selection through design and conduct of research to dissemination of results**.
- Patients and other stakeholders as **partners**, not "subjects", throughout the entire research process
- We believe that such engagement can
  - influence research to be more patient centered,
  - establish trust and a sense of legitimacy in research findings
  - encourage successful uptake of research results by the patient and broader healthcare community



## This is What Makes PCOR Different

### Patient and Stakeholder Engagement





## *Black People Like Me*

# Opportunities to Get Involved

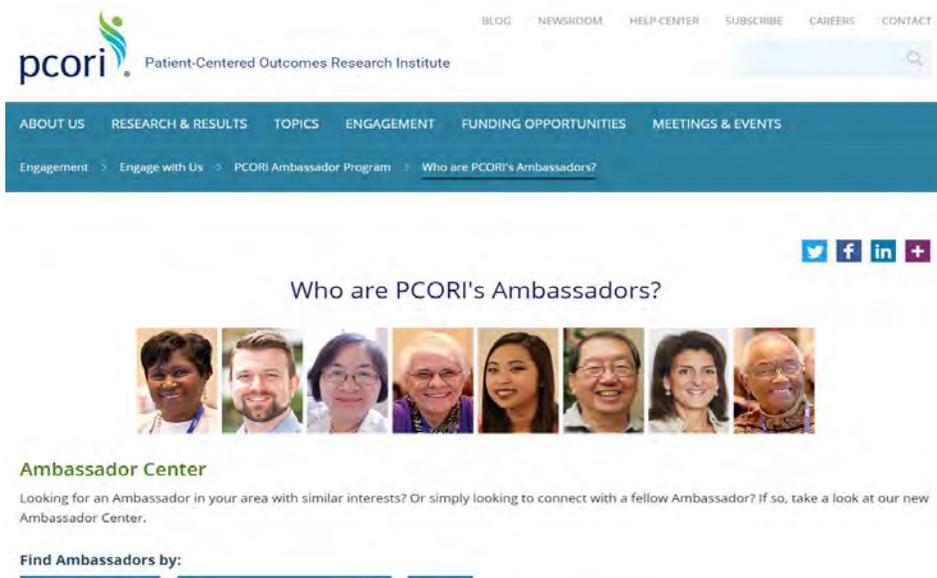
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# How We Engage Stakeholders



# PCORI Ambassador Center



pcori Patient-Centered Outcomes Research Institute

BLOG NEWSROOM HELP-CENTER SUBSCRIBE CAREERS CONTACT

ABOUT US RESEARCH & RESULTS TOPICS ENGAGEMENT FUNDING OPPORTUNITIES MEETINGS & EVENTS

Engagement > Engage with Us > PCORI Ambassador Program > Who are PCORI's Ambassadors?

Twitter Facebook LinkedIn Plus

### Who are PCORI's Ambassadors?



**Ambassador Center**

Looking for an Ambassador in your area with similar interests? Or simply looking to connect with a fellow Ambassador? If so, take a look at our new Ambassador Center.

Find Ambassadors by:

## Key goals:



1 Identify applications that have the strongest potential to help patients, caregivers, clinicians, policy makers and other healthcare system stakeholders make informed decisions to improve patient outcomes.



2 Implement a transparent, fair, objective, and consistent process to identify these applications.



3 Elicit high-quality feedback that reflects a diversity of perspectives to ensure that the PCORI-funded research reflects the interests and views of patients and other stakeholders and those who care for them, and that it meets the criteria for scientific rigor.



4 Fund projects that fill important evidence gaps and have strong implementation potential.



5 Regularly evaluate and continually improve the merit review process and policies in support of PCORI's mission.

# Resources for Engagement Practice

1. Provide **foundational knowledge in PCOR/CER to non-scientist participants** on research and other projects, and to patient and stakeholder merit reviewers, peer reviewers, and PCORI Ambassadors.
2. Provide **training and resources to support multi-stakeholder teams** in both the engagement of patient and stakeholder partners and effectively working together (i.e., team science).

**Self-paced** and focused on **just-in-time needs** throughout the PCOR process.



Patients



Researchers



Caregivers



Providers



Insurers

# Intended Outcomes

Enable diverse teams of researchers, patients, and stakeholders to participate effectively in PCOR

Increase stakeholder understanding of PCOR, CER, and basic research principles

Enable all team members to understand their respective roles, contributions, and assets

Enable all team members to obtain skills and learn behaviors to work successfully in a multi-stakeholder team environment

# Research Fundamentals Structure

## Learning Need Navigation Tool



The PCORI Approach to Patient-Centered Outcomes Research

pcori Patient-Centered Outcomes Research Institute

**Interactive PDF**



Engaging in Stakeholder-Driven Research

pcori

**Video-Based Module**

Developing Research Questions

Designing the Research Study

Planning Patient-Centered Consent and Study Protocols

Sampling, Recruiting, and Retaining Study Participants

Understanding and Sharing Research Findings



## Five Interactive Learning Modules

# Find Out About Other Ways to Get Involved

- PCORI Advisory Panel Openings – <https://www.pcori.org/engagement/engage-us/pcoris-advisory-panels/advisory-panel-openings>
- *Health Disparities and Delivery Research*
- *Patient Engagement*
- *Clinical Trials*
- *Rare Disease*
- *Clinical Effectiveness and Decision Science*
- PCORI Peer Review Process
  - <https://www.pcori.org/research-results/peer-review/peer-review-process>
- PCORI Engagement Tools and Resources Repository
  - <https://www.pcori.org/engagement/engagement-resources/Engagement-Tool-Resource-Repository>
- Subscribe to PCORI's Newsletter
  - <https://www.pcori.org/webform/subscribe>

# Contact Information

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PCORI



/pcori

## Questions and Answers



Sharon D. Allison-Ottoy, MD  
Executive Director of The  
COSHAR Healthy Communities  
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Courtney Clyatt, MA, is a Senior  
Program Officer for  
Engagement at the Patient-  
Centered Outcomes Research  
Institute (PCORI).



Mary White  
Patient advocate and research  
advisor



LeRoy Graham, MD  
Not One More Life  
Founder



## Polling Question #4

Has this session changed your mind about participating in research?

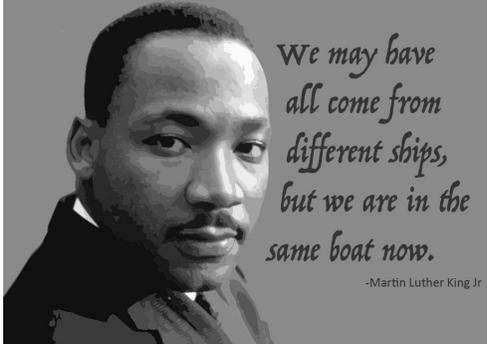
1. Yes
2. No
3. Already participate in research



# Black People Like Me

## Integrating Inspirational Imagery and Quotes

- Over the past month we have been collecting quotes that you find inspirational. From these we have developed the below artwork.



This quote was provided by our moderator Laonis Quinn.



The quotes above were provided by Charnette Darrington Zaskoda and our moderator Laonis Quinn.



# Black People Like Me

## We request that you stay creative, social, and engaged

- Continue to post drawings, photos, and/or quotes to our Facebook page that give you inspiration. We will use these posts to create more artwork as a way to celebrate our progress.



# Black People Like Me

## Closing Remarks – Thank you!

- Asthma360 Registry
- COVID-19 Registry
- #BlackPeopleLikeMe Facebook page
- Allergy & Asthma Network Education/Materials
- Visit our website: [www.allergyasthmanetwork.org](http://www.allergyasthmanetwork.org)
  
- Join us next month, April 8, 2021 at 5pm EDT for  
Session 5 – “Black People Like Me”

