

Black People Like Me



African Americans and
Research:
“Making it work for
folks like us”

Elliot Israel, MD, Harvard Medical School

Mary White, Patient Partner



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Agenda:

1. Welcome
2. Impact Asthma has on the Black Community
3. Patient Centered Research Studies in African American Asthma Patients
4. Patient Partner Interview
5. Q & A

Objectives:

1. Understand the unequal impact of asthma on Black populations in the USA
2. Understand the role that patients can play in advancing the treatment of asthma

Co-Hosts



Tonya Winders
AAN CEO and President
Moderator



Dr. LeRoy Graham
Primary Investigator

Black People Like Me

Guest Speakers



Elliot Israel, MD
Asthma Specialist
Principal Investigator
PREPARE Study



Mary White
Community Asthma Educator
Patient Partner/Advisor
PREPARE Study

Black People Like Me

Dr. Israel, Why are you interested in studying asthma in the African American/Black population?



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If you have **asthma**, how many times have you gone to an emergency room or urgent care for your asthma? (choose only one)

- A. 0
- B. 1
- C. 2
- D. 3
- E. 4
- F. 5 or more

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If you have **asthma**, how many times have you been hospitalized for your asthma in the past year? (choose only one)

- A. 0
- B. 1
- C. 2
- D. 3
- E. 4
- F. 5 or more

Asthma Impact on the Black Community

Question 1

- Asthma happens in African American/Blacks at what rate compared to Caucasians (choose only one)
 - A. The same rate
 - B. 15% higher
 - C. 35% higher
 - D. 50% higher

Asthma Impact on the Black Community

Question 2

- African American/Blacks are how many times more likely to go to the emergency room or be hospitalized for asthma than Caucasians? (choose only one)
 - A. The same number of times
 - B. 2 times
 - C. 5 times

Asthma Impact on the Black Community

Question 3

- The death rate of African Americans/Blacks with asthma compared to Caucasians: (Choose Only One)
 - A. No difference, both the same
 - B. One and a half times
 - C. 2-3 times
 - D. 10 times

BACKGROUND

- Asthma prevalence is 35% higher in African American/Blacks (AA/B) and 100% higher in Hispanic/Latinx (H/L) than Caucasians
- Both AA/Bs and H/Ls have double the rates of asthma related emergency room visits and hospitalizations as Caucasians and 50% higher rates of re-hospitalization
- African Americans/Blacks experience two to three times the death rate due to asthma as Caucasians
- This has been difficult to improve

ASTHMA HEALTH DISPARITIES

Asthma crosses all racial, ethnic and socioeconomic groups. It is more common among African-American, Hispanic and Native American populations, particularly those living in poor urban areas.

RATE OF ASTHMA-RELATED ER VISITS AND DEATHS COMPARED WITH CAUCASIANS

	ER VISITS	DEATHS
African-American children:	4.5X HIGHER	7X HIGHER
African-American adults:	2.8X HIGHER	3X HIGHER
Hispanic children:	2.1X HIGHER	2X HIGHER

Why and how do we do medical research?

- To understand a particular concern about human health such as what can be done to minimize asthma deaths in African American/Blacks
- What does it involve?
 - Deciding on the questions you want to answer
 - Figuring out what information you will need to answer the question
 - Collect the information in a way that it can be analyzed
 - Analyze and figure out what the information means
 - Distribute the findings to those who are impacted:
 - Patients
 - Communities
 - Healthcare providers
 - Healthcare policy makers
 - Payers

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How much do you trust researchers?
(choose only one)

- A. A lot
- B. A little
- C. Not very much
- D. Not at all

Different types of clinical research

- **Observational**
 - Nothing is changed, the researchers observe the effect of something the people have in common such as taking Vitamin E to see if there is an effect on heart disease
- **Experimental – Randomized Control Trial**
 - People are assigned to one or more groups by chance (by the roll of the dice)
 - One group receives an intervention such as Vitamin E and the others get a placebo (looks like a Vitamin E pill, but is not)

Which research type is better?

- Observational studies have biases that may give you the wrong answers

Vitamin E

- Many observational studies suggest that people who took Vitamin E had lower rates of heart disease

BUT

people who take Vitamin E might be different than those who don't

- Maybe they watch their diet more
- Maybe they exercise more
- Maybe they are more conscious about their health
- Maybe there are other differences we don't understand as to why somebody may be a taker of Vitamin E

Randomized trial of Vitamin E

- Patients were assigned to Vitamin E or a fake pill by the flip of a coin
- **NO** benefit on heart disease

That is why it is important to be willing to be in research studies

Without volunteers we can't find out the REAL answers

Different ways to help asthma research

- Being a research subject enrolling into a study
- or
- Becoming a patient partner if you have asthma or care for someone with asthma –
 - advising the researchers, becoming part of the team



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Would you be willing to be a research subject in an asthma study? (Choose only one)

- A. Yes
- B. No
- C. Not sure
- D. Depends on whether my doctor thought it was a good idea or not
- E. Depends on whether my family thought it was a good idea or not

- Diversity in Research means people of different ages, different racial and ethnic groups and different genders who participate in research studies.
- Blacks and Latinos make up 30% of US population – account for **only 6%** of all participants in clinical trials

Why is diversity in research so important?

1. Some groups of people suffer more from certain diseases than other groups
2. Cause of disease may not be the same for all groups
3. Medical treatments may not be equally effective for all groups
4. Individuals within the same racial or ethnic group can respond differently to the same treatment
5. Diversity in genetic samples and databases is needed to guide personalized medicine based on an individual's genetic makeup.



Two asthma studies in African American/Blacks



Blacks and Exacerbations on LABA vs Tiotropium BELT Study

??What is LABA

??What is Tiotropium

BELT Study

- 1,000 AA/B from across the US were enrolled to compare efficacy and safety between 2 different medications that help keep lungs open (LABA, Tiotropium) when added to daily ICS
- Main outcome:
 - Time to exacerbation
- Conclusion:
 - Adding LABA to ICS did not improve time to exacerbation compared to adding tiotropium

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PeRson EmPowered Asthma Relief PREPARE study



Background

- Currently daily inhaled controller medications (inhaled corticosteroids, ICS) are prescribed to be taken twice a day
- Only a quarter of patients seem to do that
- In studies where medication use is monitored and enforced having patients take their controller when they take their reliever (albuterol) decreases exacerbations by almost fifty percent compared to daily use of ICS
- We have called this patient empowering approach *Patient-Activated Reliever-Triggered Inhaled CorticoSteroid (PARTICS)*

PREPARE Research Question

- Does **PARTICS** work in a real life (uncontrolled) research study?

In patient populations that bear increased problems with asthma (**African American/Black (AA/B) and Hispanic/Latinx (H/L) adults**)

can instructing patients to use their daily controller inhaler (ICS) each time they use their rescue (albuterol), **PARTICS**, improve outcomes of importance to patients, providers, and the health care system?

Main outcome of interest

- **Exacerbations:** Asthma event with increased symptoms resulting in need for steroids (pill, shot or intravenous) or an asthma related hospitalization
 - Can a patient empowered strategy (**PARTICS**) decrease the number of exacerbations per year?

PREPARE research patient population

- 20 US sites
 - Primary care and asthma specialty clinics
- 1200 patients, 600 AA/B and 600 H/L
 - Adults 18-75
 - Uncontrolled asthma
- 300 AA/B, 300 H/L – Assigned to **PARTICS**
- 300 AA/B, 300H/L – Assigned to Usual Care

Research Patient follow up

- Patients are seen in person once, then followed for 15 months by monthly survey
- Last patient will finish the study in April 2021 – analysis will begin in the summer to determine if **PARTICS** decreases exacerbations

PREPARE Study research team

- Usually, research is conducted by trained researchers
- PREPARE is different: we include patient partners who work with the team

Why Involve Patients/Caregivers as advisors in Research

- Brings important views from people who will be impacted by the study results
- Patients/caregivers help develop the right question to be answered (what's important to them)
- Connects lived experience together with the research question
- Keeps research staff grounded
- Study results can be distributed to relevant patient populations quickly

PREPARE Patient Partner/advisor population

- AA/B and H/L Patient Partners/Advisors who are asthma patients or caregivers
 - 7 AA/B
 - 9 H/L – 3 Spanish speaking only
- Conference calls weekly at the beginning of the study – then at least once a month – continue 5 years later
 - One in English and one in Spanish
- Involved in every aspect of our work
 - Study question, developing wording and education tools for patients

Changes made because of Patient Partner input

- Wording of instructions
- Shortened monthly survey (7-10 minutes)
- Giving patients a choice of how to answer the monthly survey: online, by phone interview or by mail
- Instructional videos depicting patients like them
- \$20 payment for each survey completed
- Patients who fill out surveys within 6 days of receiving a reminder are entered into a raffle to win one of 3 monthly \$150 prizes
- One click to answer the monthly survey

IMPACT

- Enrolled 603 AA/B and 598 H/L – sometimes difficult populations to enroll
- Consistent 90%+ survey return rate at 15 months – *this is very unusual*
- Low drop out rate – 17/1201
- 84% of the patients assigned to **PARTICS** report adhering to using ICS with reliever all or most of the time over 15 months

Introducing Mary White!



Mary White
Community Asthma Educator
Patient Partner/Advisor
PREPARE Study

Interview with Dr. Graham and Mary White

- Why did you become a patient partner for the PREPARE study?
- Were you involved in other research projects either as a subject or an advisor before?
- What were your concerns about becoming a patient partner?
- Were there times you felt you should not have agreed to be a patient partner?
- Do you feel you have made an impact?

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Q & A



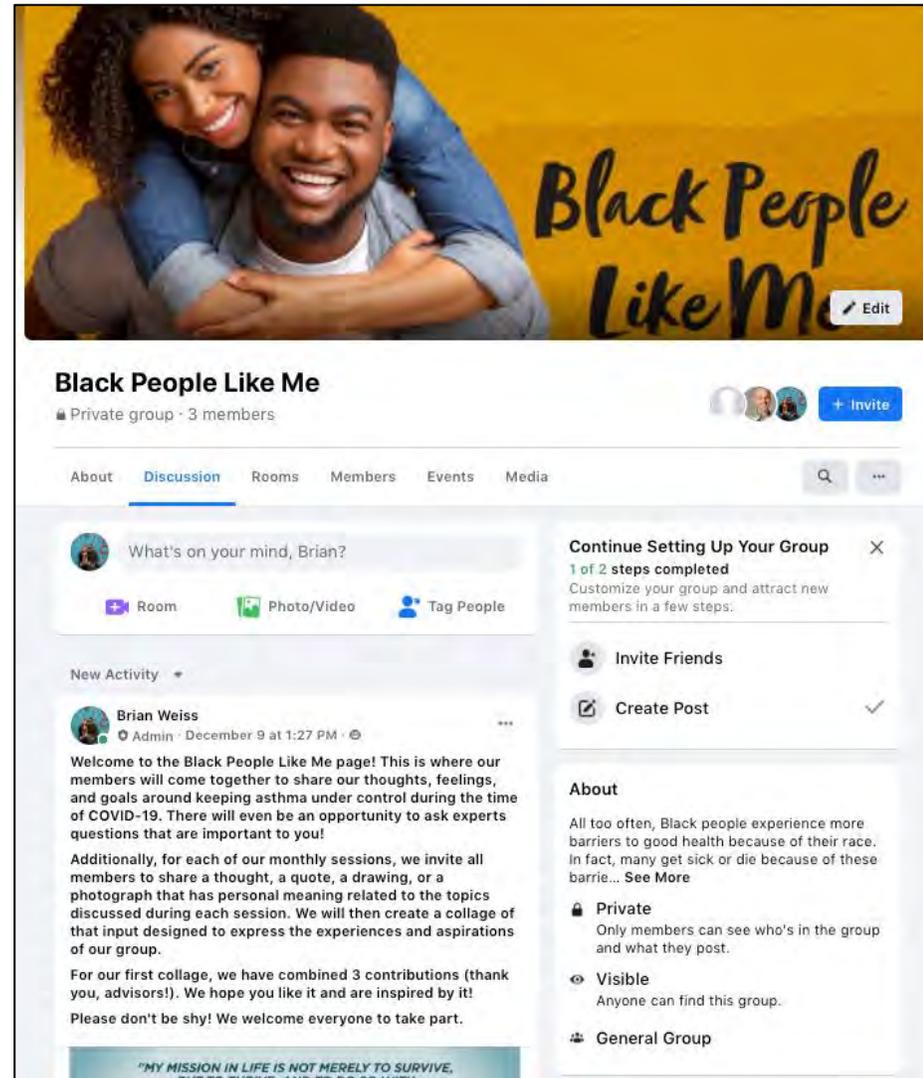
Would you be willing to be a patient partner/advisor for an asthma study?

- A. Yes
- B. No
- C. Not sure
- D. Depends on whether my doctor thought it was a good idea or not
- E. Depends on whether my family thought it was a good idea or not

Black People Like Me

Introducing an online place—just for us

- Our success will come from our ability to act as one team over the next 6 months
- To help support that, we're inviting you to be part of a private Facebook group, called Black People Like Me
- This new online community will let us explore thoughts and feelings about the work that we're doing together
- It can also become a trusted resource, allowing you to ask questions of experts and take part in conversations with others just like you



The screenshot shows a Facebook group page for "Black People Like Me". The cover photo features a smiling Black couple with the text "Black People Like Me" overlaid. The group is a private group with 3 members. The page is currently in the "Discussion" tab. A post by Brian Weiss, the group admin, is visible, dated December 9 at 1:27 PM. The post content reads: "Welcome to the Black People Like Me page! This is where our members will come together to share our thoughts, feelings, and goals around keeping asthma under control during the time of COVID-19. There will even be an opportunity to ask experts questions that are important to you! Additionally, for each of our monthly sessions, we invite all members to share a thought, a quote, a drawing, or a photograph that has personal meaning related to the topics discussed during each session. We will then create a collage of that input designed to express the experiences and aspirations of our group. For our first collage, we have combined 3 contributions (thank you, advisors!). We hope you like it and are inspired by it! Please don't be shy! We welcome everyone to take part." Below the post is a quote: "MY MISSION IN LIFE IS NOT MERELY TO SURVIVE, BUT TO THRIVE, AND TO DO SO WITH...". On the right side of the page, there is a "Continue Setting Up Your Group" notification indicating that 1 of 2 steps is completed. Below this are options to "Invite Friends" and "Create Post". At the bottom right, the "About" section is visible, stating: "All too often, Black people experience more barriers to good health because of their race. In fact, many get sick or die because of these barriers... See More". The group settings are set to "Private", "Visible", and "General Group".

Black People Like Me

Our request of you

- **Be creative:** post a drawing, a photo, or a quote about what we discuss today (and at future meetings)—similar to these examples
- **Be social:** the success of this community is driven by your engagement – ask questions, post your thoughts and feelings, and join the conversation
- **Stay engaged:** we hope that you'll continue to create and communicate with all of us on Facebook during the months ahead

We will use your creative posts to develop artwork, as a way to celebrate our progress—and share it with you at each monthly meeting!

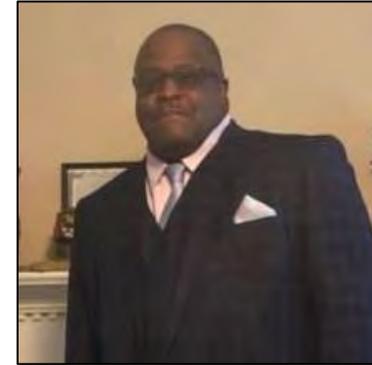
(Just use #BpLMart to tag your creative posts so we can find them more easily)



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**Thanks to our advisors, we have our
first piece of art to share**

Our advisors, pictured here, have given us
photos and quotes about why they decided
to be part of this effort



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And here it is!



Thank you for joining today!

- Please complete the program evaluation survey and the post-test
- Save the date for the next conference Feb. 11, 2021 – Register online
- Join AAN Asthma360Registry today
- Learn about NOML™ Program
- Log on to Facebook Page for BPLM participants – coming soon
- Questions/Answers and Powerpoint will be posted on AAN website