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

Elliot Israel, MD, Harvard Medical School
Mary White, Patient Partner
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

Agenda:
1. Welcome
2. Impact Asthma has on the Black Community
4. Patient Partner Interview
5. Q & A

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
Dr. Israel, Why are you interested in studying asthma in the African American/Black population?
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
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
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.
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
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
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 the US population, but 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
BLET 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
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, 300 H/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?
Black People Like Me

Q & A

[Images of three individuals]
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
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
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)
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.
And here it is!

"MY MISSION IN LIFE IS NOT MERELY TO SURVIVE, BUT TO THRIVE; AND TO DO SO WITH SOME PASSION, SOME COMPASSION, SOME HUMOR, AND SOME STYLE."

-MAYA ANGELOU

Somewhere over the rainbow the skies are blue and dreams that you dare to dream really do come true...
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 TM Program
- Log on to Facebook Page for BPLM participants – coming soon
- Questions/Answers and Powerpoint will be posted on AAN website