

Appendix A. Healthy Churches 2020 National Conference pre-conference Institute Agenda



Mayo Clinic Office of Health Disparities Research presents:

Recruiting African Americans to Participate in Medical Research:

Methods, Models and Experiences

Balm in Gilead, Inc., Healthy Churches 2020 Conference, Hilton Head, SC

Tuesday, November 14, 2017, 2-5pm

INSTITUTE AGENDA (updated 9/19/2017)

2:00-2:15 pm WELCOME AND INTRODUCTION

Current state of underrepresentation of African-Americans in medical research

LaPrincess Brewer, MD, MPH, Mayo Clinic Rochester

Christopher Pullins, MD, Mayo Clinic Arizona

2:15-3:15 pm SESSION 1: Part 1

The Researcher Experience: Recruitment strategies to increase enrollment of African-Americans into medical research

Monica Albertie, Mayo Clinic Florida

Richard White, MD, Mayo Clinic Florida

Floyd Willis, MD, Mayo Clinic Florida

3:15-3:25 pm SESSION 1: Q & A

3:25-3:40 pm Break (15 minutes)

3:40-4:10 pm SESSION 1: Part 2

The Researcher Experience: Recruitment strategies to increase enrollment of African-Americans into medical research

LaPrincess Brewer, MD, MPH, Mayo Clinic Rochester

Christopher Pullins, MD, Mayo Clinic Arizona

4:10-4:20 pm SESSION 2: Q & A

4:20-4:50 pm SESSION 3: PANEL DISCUSSION

The Participant Experience: Best practices to foster enrollment of African-Americans in medical research

Mayo Clinic Rochester (Jacqueline Johnson, MSW; Clarence Jones, MEd)

Mayo Clinic Florida (Bishop Rudolph McKissick, Sr.)

Mayo Clinic Arizona (Angela M. Allen, PhD)

4:50-5pm CLOSING REMARKS

LaPrincess Brewer, MD, MPH, Mayo Clinic Rochester

Christopher Pullins, MD, Mayo Clinic Arizona

Appendix B. Healthy Churches 2020 National Conference pre-conference Institute flyer

MAYO CLINIC

Recruiting African Americans to Participate in Medical Research: Methods, Models and Experiences

Healthy Churches 2020 National Conference

SPEAKERS

- LA PRINCESS BREWER, MD, MPH
- CHRISTOPHER PULLINS, MD
- FLOYD WILLIS, MD
- RICHARD WHITE, MD
- MONICA ALBERTIE

REGISTER NOW
»» CLICK HERE

THE INSTITUTE
Session Date: Tuesday, November 14

BxM GLEAD

HealthyChurches2020Conference.org
Nov. 14-17, 2017

Appendix C. Semi-structured interview guide

JOB M-221

Mayo Clinic HC2020 Follow-up Research

ID#: _____

In-Depth Interview Discussion Guide

November, 2018

INT: _____

ASK TO SPEAK WITH THE CONTACT LISTED. IF UNAVAILABLE, SCHEDULE CALLBACK.

Contact Name: _____

Interview Date: _____ Interview Start Time: _____ Interview End Time: _____

INTRODUCTION: Good morning/afternoon. This is [insert interviewer's name] calling from Mayo Clinic.

READ IF ALREADY AGREED TO PARTICIPATE:

Recently, you responded to an email from [insert principal investigator's name], principal investigator for a research project titled: Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences. As a participant in the Healthy Churches 2020 National Conference Pre-conference Institute in November of 2017, she invited you to participate in this research project and you replied back indicating your interest in participating. Is now a good time to conduct the interview or would you like to schedule it for another time?

READ IF HAS NOT ALREADY AGREED TO PARTICIPATE:

Recently, you should have received an email from [insert principal investigator's name], principal investigator for a research project titled: Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences. As a participant in the Healthy Churches 2020 National Conference Pre-conference Institute in November of 2017, she invited you to participate in this research project. Is now a good time to conduct the interview or would you like to schedule it for another time?

INTRODUCTION, CONTINUED: The Mayo Clinic Office of Health Disparities Research is following up with attendees of the Mayo Clinic-led 3-hour pre-conference workshop titled Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences Co-chaired by [insert co-chairs' names] held on November 14th, 2017.

Just to check, did you attend the 3-hour pre-conference workshop titled Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences Co-chaired by [insert co-chairs' names] on November 14th, 2017?

(INTERVIEWER: CHECK ONE RESPONSE.)

Yes --> CONTINUE.

No --> THANK AND END INTERVIEW.

We thank you for your attendance of our session and would like to ask a few questions about your experience during and after it. Our goal is to use this information to improve future sessions. This research study is led by physicians and researchers, [insert names] of the Mayo Clinic. The interview

is entirely voluntary and will be recorded to ensure an accurate summary report is developed of what was said, not of who said what. All answers given are entirely confidential; only the study team will review this information. You will receive a \$25 gift card for your time, either in person if you are attending this year's Healthy Churches 2020 National Conference or a check by mail if not attending. If you agree to participate, we will move forward with the interview, which will take approximately 15 minutes of your time.

Are you willing to continue with this interview? (**INTERVIEWER: CHECK ONE RESPONSE.**)

- Yes --> **CONTINUE.** No --> **THANK AND END INTERVIEW.**

INTERVIEWER: START RECORDING!

1. Prior to attending the 3-hour pre-conference workshop titled Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences Co-chaired by [insert co-chairs' names] on November 14th, 2017, had you ever participated in any of the following types of medical research?

(INTERVIEWER: READ LIST. CHECK 'YES' RESPONSES.)

- Biobank
 Blood or tissue collection as a healthy volunteer
 Clinical trial
 Focus group
 Genetic testing
 Survey or questionnaire
 Any other type of medical research?

(SPECIFY: _____)

INTERVIEWER: DO NOT READ BUT VERIFY IF NONE CHECKED ABOVE—So, none of these?

2. Prior to attending the 3-hour pre-conference workshop titled Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences Co-chaired by [insert co-chairs' names] on November 14th, 2017, had you ever initiated or been a part of a research team for any projects that included African-American research participants? (**INTERVIEWER: CHECK ONE RESPONSE.**)

- Yes No Don't Know

3. After attending the 3-hour pre-conference workshop titled Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences Co-chaired by [insert co-chairs' names] on November 14th, 2017, have you participated in any of the following types of medical research?

(INTERVIEWER: READ LIST. CHECK 'YES' RESPONSES.)

- Biobank
 Blood or tissue collection as a healthy volunteer
 Clinical trial
 Focus group
 Genetic testing
 Survey or questionnaire

Any other type of medical research?
(SPECIFY: _____)

INTERVIEWER: DO NOT READ BUT VERIFY IF NONE CHECKED ABOVE—So, none of these?

4. After attending the 3-hour pre-conference workshop titled Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences Co-chaired by [insert co-chairs' names] on November 14th, 2017, have you initiated or been a part of a research team for any projects that included African-American research participants? **(INTERVIEWER: CHECK ONE RESPONSE.)**

Yes No Don't Know

INTERVIEWER: ONLY ASK IF 'YES' IN Q4

5. Will you please describe the research project(s) you initiated or were a part of that included African-American research participants?

(INTERVIEWER: MAKE SURE THE RESPONSE ANSWERS THE QUESTION. IF IT DOES NOT, RE-ASK. BE SURE TO PROBE FOR A COMPLETE RESPONSE AND THEN CLARIFY FOR UNDERSTANDING.)

INTERVIEWER: ONLY ASK IF 'NO' IN Q4

6. Why haven't you initiated or been a part of a research team for any projects that included African-American research participants in the past year?

(INTERVIEWER: MAKE SURE THE RESPONSE ANSWERS THE QUESTION. IF IT DOES NOT, RE-ASK. BE SURE TO PROBE FOR A COMPLETE RESPONSE AND THEN CLARIFY FOR UNDERSTANDING.)

7. Please tell me one or two things you learned from attending the 'Recruiting African-Americans to Participate in Medical Research: Methods, Models, and Experiences' workshop.

(INTERVIEWER: MAKE SURE THE RESPONSE ANSWERS THE QUESTION. IF IT DOES NOT, RE-ASK. BE SURE TO PROBE FOR A COMPLETE RESPONSE AND THEN CLARIFY FOR UNDERSTANDING.)

8. To the best of your knowledge, is the following statement true or false:
African-Americans are underrepresented in medical research?

(INTERVIEWER: CHECK ONE RESPONSE.)

- True False Don't Know

9. To the best of your knowledge, is the following statement true or false:
Medical research receiving support from the National Institutes of Health requires the inclusion of racial and ethnic minorities and women?

(INTERVIEWER: CHECK ONE RESPONSE.)

- True False Don't Know

10. To the best of your knowledge, what percentage of medical research participants in the United States are African American?

(INTERVIEWER: CHECK ONE RESPONSE.)

- 5% 10% 15% 20%

11. What are two or three barriers (things getting in the way or preventing) that prevent African Americans from participating in medical research?

(INTERVIEWER: MAKE SURE THE RESPONSE ANSWERS THE QUESTION. IF IT DOES NOT, RE-ASK. BE SURE TO PROBE FOR A C/OMplete RESPONSE AND THEN CLARIFY FOR UNDERSTANDING.)

12. What are two or three facilitators (things making it easier or helping) that help African Americans participate in medical research?

(INTERVIEWER: MAKE SURE THE RESPONSE ANSWERS THE QUESTION. IF IT DOES NOT, RE-ASK. BE SURE TO PROBE FOR A COMPLETE RESPONSE AND THEN CLARIFY FOR UNDERSTANDING.)

13. Do you agree or disagree with the following statement: *If I wanted to, I could easily participate in a medical research study?*

(INTERVIEWER: AFTER INITIAL RESPONSE, ASK WHETHER STRONGLY OR NOT, THEN CHECK ONE RESPONSE.)

Other: please specify _____

19. What is your current age? **(INTERVIEWER: RECORD NUMBER.)** _____ year(s)

20. What gender do you identify yourself as?
(INTERVIEWER: READ LIST. CHECK ONE RESPONSE.)

Female Male Other

21. Would you describe your ethnic origin as:
(INTERVIEWER: READ LIST. CHECK ONE RESPONSE.)

Hispanic or Latino Not Hispanic or Latino

22. Which of the following describe your race?
(INTERVIEWER: READ LIST. CHECK ALL RESPONSES THAT APPLY.)

African-American
 American Indian/American Native
 Asian-American
 Native Hawaiian/Pacific Islander
 White
 Other: please specify _____

23. Which of the following best describes your current marital status:
(INTERVIEWER: READ LIST. CHECK ONE RESPONSE.)

Never married Widowed Living with significant
other
 Separated/Divorced Married Other: please specify _____

24. What is the highest level of formal education you have completed?
(INTERVIEWER: READ LIST. CHECK ONE RESPONSE.)

Less than 8th grade
 Completed 8th grade
 Some high school
 Graduated high school
 GED or ABE certificate
 Some college, technical, vocational school (AA, LPN, etc.) but not a 4-
year degree
 Graduated with a 4-year college degree (BS, BA, etc.)
 Graduate or professional degree: please specify _____
 Other: please specify _____

25. Are you planning to attend this year's Healthy Churches 2020 National
Conference being held in Point Clear, Alabama November 13th through the
16th? **(INTERVIEWER: CHECK ONE RESPONSE.)**

Yes --> Great! **(INTERVIEWER: EXPLAIN TO RESPONDENT HOW TO CLAIM THEIR
GIFT CARD, THEN SKIP TO CLOSE.)**

No --> Can I please get your mailing address so I can send you a check?
(INTERVIEWER: RECORD ADDRESS BELOW.)

STREET ADDRESS: _____

CITY: _____

STATE AND ZIP CODE: _____

CLOSE: Those are all the questions I have for you today. On behalf of the investigators of this research: [insert co-chairs' names], thank you very much for your time and participation!

INTERVIEWER: STOP RECORDING!

Interview End Time: _____

Definitions:

Biobank- A place that stores biological samples for use in research.

Blood or tissue collection as a healthy volunteer- Blood or tissue collected for research purposes.

Clinical trial- Researchers learn if a new test or treatment works and is safe, examples (new drugs, new surgical procedures or devices, or new ways to use existing treatments).

Focus group- Small number of people brought together with a moderator to focus on a specific topic. Focus groups also known as round table discussions or listening sessions aim at a discussion instead of on individual responses to formal questions.

Genetic testing- Involves looking for changes in DNA, genes, or proteins. The results of a genetic test can confirm or rule out a suspected genetic or hereditary condition or help determine a person's chance of developing or passing on a genetic disorder.

Survey or questionnaire- An instrument used to collect a set of answers from participants.

Appendix D. Salient themes and selected attendee commentary on Institute message retention and barriers/facilitators to participation in medical research

Themes	Illustrative quotes
Message Retention	
Underrepresentation of African-Americans in medical research	“I must say I did feel like I learned a lot overall from the workshop. This was at the time - and still is - a rather new area for me in terms of work, so I did feel very well-informed when I left the workshop just about overall roadblocks or barriers to clinical trial participation, particularly in the African-American community.” [Female, age 35]
Recruitment strategies	“Well I think one of the things that has always been important has really been the need to have African-Americans to participate in research. The other thing, too, is learning some of the key techniques for that, and then to see how other people have used it, you know, in terms of their own experiences working with various demographics and in various places. Because, you know, the way that you recruit or work with folks in one community doesn’t actually work in another community, so it’s just kind of good to hear the differences in other communities.” [Male, age 66]
Community engagement	“What I remember is talking a lot about building community through relationships, and I think there was even a mention of an advisory board. Um, and so there was a lot of talk and interest about how to engage the community in those types of ways and keeping them informed throughout the process. So from what I can recall, I believe that was the premise of the discussion.” [Female, age 35]
Key Barriers	
Lack of information/not being approached	“Well, knowledge is power, and I think whenever someone is asked to be selected, you’re taking the time to speak with me one-on-one and I think that’s very important that there’s more exposure about, you know, about how the information is going to be used to put people at ease so they can understand exactly

	what’s going to happen with that information and how it will impact the African-American community.” [Female, age 66]
Fear/lack of trust	“Yeah, I think first of all we’re not invited so we don’t know. And then those who do know, they’re fearful. Fear is a tremendous factor and I don’t think we understand. If we know, we may understand that the outcomes could be positive to the next generation of people. So we don’t know, there’s fear, and we don’t understand what the outcomes could be of participating in a study that will make a difference in somebody’s life after us. You know, we have to think about the next generation, you know, because they’re going to get sick, they’re going to have the cancers, they’re going to have the illnesses and you can’t say that African-American women at a certain group do well on this study, on these drugs when they’ve never been studied.” [Female, age 72]
Historical trauma	“...it’s historical facts, you know, like I said, The Tuskegee experiment. There was an experiment in Ohio where pregnant black women, where they would sterilize them without their knowledge once they gave birth” [(Female, age >65)]
Key Facilitators	
Understanding the benefits to research	“I think many times is your approach in regards to actually educating people about the importance of participating in research studies, how it benefits our society. But also how many times because African-Americans can really suffer from a lot of comorbid diseases, how that’s actually going to impact them and impact the community as a whole. So those things I think are very critical. And also being able to... So, educating people in regards to the importance of participating in research is very critical, and then also making sure that you’re able to reach those, actually reach the people who you are trying to recruit, too. So making the additional effort of going into those communities. And then also making sure that even after you get the information, that you will go back and share the results of the individual’s participation in the research is really critical, too.” [Sex, age not given]

<p>Information/being informed</p>	<p>“I think being fully or adequately informed about the research. I think the other part, too, is the facilitator themselves being able to create a connection with people. And, the third thing is for people to feel like what they’re saying is going to be heard, and also they will be informed about the outcomes or the results of the questionnaires or the focus groups”. –[Male, age 66]</p> <p>“I think one thing is educating people. Being transparent when doing research because a lot of the times people go into communities, they do research, and they take the valuable research. They don’t give anything back, they don’t tell them what the end results were. So being transparent, informing people, truly informing them from the beginning to the end of the process. Reaching out to the African-American community in different ways to let them know about the different projects that may be... different research that may be going on that they could be involved in. And informing them on how that could affect their health or their well-being by being a part of the solution to whatever problem it is.” –[Female, age 34]</p>
<p>Trust</p>	<p>“Well, I think one of the most important things is trust. You know, having someone from some organization that they have trust in that’s going to be very fair and attentive to the individual needs if they agreed to participate in the research. Just being... knowing that it’s going to be used for good, for the right purpose.” [Male, age 72]</p>