

# **Barriers and Facilitators to Participate in Biomarker Research Among African Americans**

Christa Fields<sup>1</sup>, Tracy Schroepfer PhD<sup>2</sup>, Diane Michalski Turner PhD<sup>3</sup>, Wade Gunn MS<sup>3</sup>, Jesus Renteria MA<sup>4</sup>, Jennifer Dykema PhD<sup>5</sup> & Dorothy F. Edwards PhD<sup>3</sup> <sup>1</sup>Department of Population Health Sciences, University of Wisconsin School of Medicine and Public Health, <sup>2</sup>School of Social Work, University of Wisconsin-Madison, of Wisconsin-Madison, <sup>4</sup> School of Education, University of Wisconsin-Madison, <sup>5</sup> University of Wisconsin Survey Center

Background

There is a growth in the number of population-based research studies linking biomarkers to other measures of health. These findings illuminate the individual- and community-level variables (social, behavioral, psychosocial, and genetic) associated with the distribution of disease.

Racial and ethnic minorities bear a disproportionate burden of chronic disease; yet, they are underrepresented in virtually all aspects of studies collecting biomarker information. The literature suggests that low African American participation in biomarker research is due, in part, to factors such as mistrust of medical and clinical research investigators and lack of information specific to study procedures. Currently, however, researchers have not studied barriers to participation with regard to specific biomarker collection procedures.

This study sought to understand the barriers and facilitators related to African Americans' participation in saliva and blood sample collection. These procedures were chosen for this study since they are the most frequently used biomarkers to assess health status, genetic risk, and diseases characteristics. Saliva collection uses non-invasive drool collection, while blood requires more invasive venous access.

## Purpose of the Study

To understand the barriers and facilitators associated with African American participation in saliva and blood data collection procedures.

## **Research Questions**

What are the barriers and facilitators to African Americans' participation in saliva and blood data collection procedures?

Do these barriers and facilitators differ between the noninvasive saliva procedure and the more invasive blood procedure?

Variable	N (%)
Age (yrs)	
25-45	8 (30.8)
46-65	11 (42.3)
66 & older	7 (26.9)
Gender	
Female	14 (53.8)
Male	12 (46.2)
Education	· · ·
High School	8 (30.8)
Associate & Bachelors	9 (34.6)
Master & Doctorate	9 (34.6)

Ο Ο Ο Ο

• "Well, there has been a history of African Americans getting caught up into some messy situations, because they have been used to, for studies, some, mostly without their permission, and that sticks in the back of my mind. And I'm not willing to do, participate in any of those, in the studies that where my information may be used, and I can't see where it's going." **Barriers Specific to Biomarker** Studies that require a Saliva Sample



- they're taking the test.
- to say okay."

#### Methods

- Face-to-face interviews were conducted with 26 African American respondents, who were evenly stratified by age (25-45, 46-64, and 65 and older), education level (high school or less, some college, and master's or above), and gender.
- All interviews were preformed by an African American graduate student.
- The interviewer first provided respondents with a definition of each data collection procedure and then asked the following questions:
  - "Would you be willing to participate in a research project that asks you for a sample of your saliva? Why or Why not?"
  - "Would you be willing to participate in a research project that asks you for a sample of your blood? Why or Why not?"

-and-

- All interviews were audio-taped and transcribed.
- Content analysis was used to identify and categorize the main themes and patterns found in the data. These themes and patterns were not predetermined: rather, they were allowed to emerge from repeated readings of the transcripts. Two researchers independently performed the coding to insure reliable.

Lack of information Misuse of African Americans for research

**Facilitators Specific to Biomarker Studies that** require a Saliva Sample

Simple procedure Less invasive Not harmful or Risky Relevance of the research project

Benefits to the individual, a family member, or others facilitate participation

• "I would give a sample if it was explained to me exactly why

• "I mean, the more information that you give me, the more I'm subject



• "I don't know if I trust. because I don't know you, I don't have a relationship with you. And I think some people would be very hesitant.<sup>\*</sup>

**Barriers Specific to Biomarker** Studies that require a Blood

• "I'm not too sure until I know all the specifics, until I know exactly what's going, what the bottom line, exactly what's going on.'

Sample

Fear of needles

Discomfort

Altruism

research

of Infection

Risk to health Testing for Alzheimer's disease. Distrust of medical researchers and healthcare professionals

Facilitators Specific to Biomarker Studies that require a Blood Sample

Positive prior experience Appreciation or interest in

Sterile procedures and low risk

"I would have no problem doing a sample of blood in light of the uses that you just indicated. I'd be happy to help in trying to discover biomarkers in dealing with the various diseases.'

# Major Findings

Similarities and differences with regard to barriers and facilitators were found for both saliva and blood procedures.

**Barrier Themes:** 

- researchers as a barrier.
- O Invasiveness: Invasiveness served as a barrier for

Facilitator Themes:

- blood
- themselves and others.
- only emerged for the saliva collection procedure.

## **Research Implications**

- collection
- risk (i.e., sterilization of items).

## Acknowledgements

This study was funded by NIMHD grant 5P60MD003428 (PD: A. Adams). Project: Increasing Participation of Underrepresented Minorities in Biomarker Research (PI: D. Farrar-Edwards). Additional support was provided by NCATS grant UL1TR000427 (CTSA) and resources and use of facilities at the University of Wisconsin School of Medicine and Public Health

A special thank you to Dr. Diane Michalski Turner for recruiting participants and assisting with interview preparation.

### Correspondence

Christa Fields: fields.christa@gmail.com Tracy Schroepfer: tschroepfer@wisc.edu Dorothy Farrar Edwards: dfedwards@wisc.edu





O <u>Distrust</u>: For both saliva and blood samples, African American respondents reported distrust of medical research and

respondents when considering providing a blood sample O Lack of Information: Respondents reported that not receiving information from the researcher about the study and its purpose would serve as a barrier for providing a saliva sample

O <u>Minimal risk</u>: was reported as a facilitator for both saliva and

O Beneficial: Respondents reported that they would provide a saliva or blood sample if the research would have benefits to

O <u>Procedure's simplicity and lack of invasiveness</u>: This theme

O Time and effort must be given by researchers to establishing relationships and trust with a community prior to biomarker

O Information must be provided on the study' purpose and its potential benefits for respondents and their community O Discussions must be had with the community on the risk of a procedure and the actions that will be taken to reducing that

