Willingness to Participate in Biomarker Research among African Americans

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Overview

• VOICES HEARD project
• Background
• Objective
• Methods
• Research Question
• Demographics of Key Informants
• Findings
• Conclusion
Acknowledgements

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Project: Increasing Participation of Underrepresented Minorities in Biomarker Research

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VOICES HEARD Project

Phase I:
Key Informant Interviews

Phase II:
Survey Development and Testing
  • Cognitive Interviews

Phase III:
Telephone Survey
Background

• What are Biomarkers?

• Racial and ethnic minorities are underrepresented

• Literature suggests low participation rates among African Americans are due to key factors such as mistrust and lack of information.

• Population-based surveillance studies incorporate biomarkers
Objective

Examine the responses of African American Key Informants to:

• Determine willingness to participate in studies that request a saliva and/or blood sample

• Evaluate whether willingness differed based on type of sample

• Identify the barriers and facilitators to participation in biomarker research
Methods

- Conducted face-to-face interviews with respondents (n=26), stratified by:
  - Age
  - Education attainment
  - Gender
- All interviews were audio-taped and transcribed.
- Two researchers used direct content analysis to identify emergent themes
Research Questions

Participants were asked the following question:

“Would you be willing to participate in a research project that asks you for a sample of your saliva?”

-and-

“Would you be willing to participate in a research project that asks you for a sample of blood?”
### Demographics of Key Informants

<table>
<thead>
<tr>
<th>Variable</th>
<th>N ( %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Range (yrs)</td>
<td>22-77 (Mean: 53)</td>
</tr>
<tr>
<td>25-45</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>46-65</td>
<td>11 (42.3)</td>
</tr>
<tr>
<td>66 &amp; older</td>
<td>7 (26.9)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>14 (53.8)</td>
</tr>
<tr>
<td>Male</td>
<td>12 (46.2)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>Associate &amp; Bachelors</td>
<td>9 (34.6)</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>9 (34.6)</td>
</tr>
</tbody>
</table>
Findings: Barriers to Providing Saliva Sample

Misuse (n=2)

I wouldn't want to get caught in some kind of crime of like your sample, it would be used against me.

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.

Lack of Information (n=4)

I don't know what they're doing with this information

Risk to health (n=2)
Findings: Barriers to Providing Blood Sample

**Fear of Needles (n=2)**

I got a thing about needles. Always have. And taking my blood

**Discomfort (n=2)**

Well, just the process involved, it could involved some pain... it can hurt.

**Risk to Health (n=1)**

Testing for Alzheimer’s Disease (n=1)

**Distrust (n=4)**

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.

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. But like the bottom line or if it can help someone, sure.
### Findings: Motivating Factors to Providing Saliva Sample

<table>
<thead>
<tr>
<th>Benefits to the individual, a family member, or others (n=14)</th>
<th>Simple procedure (n=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relevance to Research (n=6)</td>
<td><em>It's not hard spitting into a tube</em></td>
</tr>
<tr>
<td><em>I would give a sample if it was explained to me exactly why they're taking the test.</em></td>
<td>Less invasive (n=4)</td>
</tr>
<tr>
<td><em>I mean, the more information that you give me, the more I'm subject to say okay</em></td>
<td>Not harmful or Risky (n=5)</td>
</tr>
<tr>
<td></td>
<td>Non- incriminating (n=2)</td>
</tr>
</tbody>
</table>
Findings: Motivating Factors to Providing Blood Sample

Altruism (n=15)

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

Positive prior experience (n=4)

Appreciation or interest in research (n=2)

Sterile procedures and low risk of infection (n=2)

Need Information about use and storage (n=4)
Summary of the Findings

Respondents reported differences based on the type of sample:

Blood Sample – few facilitators and more barriers
Saliva Sample – more facilitators and few barriers

Over half of participants were favorable toward participating in biomarker research if it would benefit themselves, a family member, or others.
Conclusion

• For better recruitment of minorities in biomarker studies, more research is needed to develop **culturally appropriate, effective evidence-based strategies** to reduce obstacles that impede enrollment.

• Implications for researchers:
  • Cultural competence training
  • Clarify the research agendas and address potential benefits
  • Provide informational workshops and educational materials
  • Report research findings back to communities
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