Beliefs about Biospecimen Collection and Use in Research

Understanding Older, Underserved Urban African American Adults’ Beliefs about Biospecimen Collection and Use for Cancer Research

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Research Team

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- Carie Francis
- Lauren Ramsey, MPH

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Community Based Participatory Research

- Research Advisory Committee:
  - Ron Beford
  - Gloria Hicks Long
  - Margaret Williamson

- Research Partners/Sites:
  - Healthier Black Elders
  - Interfaith Health and Hope Coalition
  - KCI Community Based Research Registry
  - Pro Literacy Detroit
  - SEER Registry
Two Major Research Questions

• Why are racial minorities under-represented in biospecimen collection and banking?

• How can we help racial minorities understand the importance of biospecimens in medical research, and encourage them to donate their biospecimens?
Background

- Biospecimens can be used to further our understanding of many serious diseases, including cancer.

- Research using biospecimens has been conducted to discover and advance treatment and prevention of disease.

- Hospitals and clinics in the US are working to increase the number of people who volunteer to donate biospecimen.
However, racial minority populations are severely underrepresented in biospecimen collection.

Older, underserved African Americans living in the metropolitan Detroit area are no exception.

We know very little about why this is the case.
Why study causes of racial minority under-representation in biospecimen collection?

- Lack of representation may significantly contribute to the creation and maintenance of disparities in health outcomes, including cancer survival.

- In order to reduce health disparities and improve health status among African Americans, we must understand causes of underrepresentation of racial minority populations in biospecimen collection.
Why study older underserved African Americans living in SE Michigan?

• They are underrepresented in research.

• Cancer disparities disproportionally affect this particular population.

• We propose that one factor among many contributing these disparities may be the lack of representation of this population in biospecimen collection.
Components of the Study

Part 1: Focus Groups & Survey Development

• Investigate the causes of lower biospecimen donations among older African Americans.

• Explore how demographic characteristics, health status, and factors discussed in focus groups relate to attitudes toward and willingness to donate biospecimens through the development of a standardized survey.
Components of the Study

Part 2: Workshop & Survey Administration

• Develop an educational intervention aimed at:
  1) Improving knowledge and attitudes toward biospecimen collection among older African Americans in metropolitan Detroit.
  2) Encouraging older African Americans in metropolitan Detroit to participate in biospecimen collection and biobanking.

• Assess the effectiveness of the workshop.
Study Part 1: Focus Groups

• HBEC Participant Registry:
  – $N = 9$ (Women 75%, $Mage = 65.5$, $SD = 9.9$, Mode Ed = attended college)

• IHHC:
  – $N = 3$ (Women 33%, $Mage = 57.7$, $SD = 5.9$, Mode Ed = completed associate, bachelors or graduate degree)

• Pro-Literacy Detroit:
  – $N = 11$ (Women 100%, $Mage = 65.2$, $SD = 10.2$, Mode Ed = completed associate, bachelor’s or graduate degree)

• KCI BFRC Participant Registry:
  – $N = 6$ (Women 17%, $Mage = 57.2$, $SD = 1.9$, Mode Ed = completed associate, bachelor’s or graduate degree)
Study Part 1: Personal Interviews

• Sought participants who had actually donated biospecimens through SEER database.

• Conducted 4 interviews (women 75%, $M_{age} = 61.8$, $SD = 12.5$, Education varied from junior high to completed associate, bachelor’s or graduate degree)
Data Analysis

- Focus group discussions were transcribed.
- Carefully reviewed audio recordings to determine data saturation.
- Three independent coders identified barriers and motivators for biospecimen donation.
- Coders met to come to consensus and establish themes.
- Themes were structured hierarchically.
Identified Themes

**Barriers**

- Fear
- Lack of understanding
- Lack of transparency
- Lack of trust
- Complex information
- Religious beliefs

**Motivators**

- Transparency
- Effective communication
- Altruism
- Individual compensation
- Self-motivation
- Trust
- Other (unspecific)
Barriers: Fear

- History of abuse (e.g., Tuskegee)
- Invasive/painful procedures
- Being used as a guinea pig
Barriers: Lack of Understanding

• Not enough knowledge about what is available

• General lack of available health education about biobanking and medical research

• Potential multiple and unknown uses of biospecimens
Barriers: Lack of Transparency

- Researchers’ failure to communicate study’s purpose
- Not knowing the results of the study, or the uses of the biospecimens once they are donated
- Specifics of potential future studies
- Financial gain (for researchers)
Barriers: Lack of Trust

- Government
- Healthcare
- White researchers
- Biobanking system
- Profit motives
Barriers: Complex Information

- Literacy rates
- Complex issue
- Complicated forms - long, often rushed
Motivators: Transparency

- Information about researchers
- Research results
- Full disclosure/clear explanation of use
Motivators: Effective Communication

- Appropriate literacy level
- Appeal and interest of format of materials
- Face to face recruitment
- Trusted local source
Motivators: Altruism

• Benefits to future generations

• Helping process of scientific discovery

• Sense of “giving back” to the community
Motivators: Compensation

• Monetary

• Health care services (e.g., health check-up, dental appointments)

• Material benefits to specific community
Motivators: Self-Motivation

• Threats to one’s own health (e.g., age, environment)
• Family history
• Prevention/screening
• Social participation (ability to interact with social group)
• Satisfaction of curiosity
• Previous positive experience with biospecimen donation
Motivators: Trust

- Confidentiality assurance
- Familiarity with research organization
- Familiarity with research liaison
- Someone from research team same racial background as participants
Motivators: Others

- Being asked to participate
- Ease of participation (e.g., time, proximity, availability, lack of invasiveness)
- Knowing cancer survivors/Being a cancer survivor
- Ability to opt-out
Part 2: Survey Development

• Participant Pool
  – Goal was 100 surveys, N=73
  – Recruitment from HBEC Participant Research Pool (PRP)
  – 55 years or older
  – Living in the metropolitan Detroit area

• Procedures
  – Phone interviews
  – Web based survey system
## Participant characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>M ± SD or No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (Missing = 1)</strong></td>
<td>71.82 ± 8.34</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>42 (57.5)</td>
</tr>
<tr>
<td>Male</td>
<td>31 (42.5)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>≤ High School</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>Completed High School</td>
<td>15 (20.5)</td>
</tr>
<tr>
<td>Attended some college</td>
<td>21 (28.8)</td>
</tr>
<tr>
<td>Completed college</td>
<td>21 (28.8)</td>
</tr>
<tr>
<td>Completed a post graduate degree</td>
<td>13 (17.8)</td>
</tr>
<tr>
<td><strong>Income (Missing = 13)</strong></td>
<td></td>
</tr>
<tr>
<td>≤ $20,000</td>
<td>14 (19.2)</td>
</tr>
<tr>
<td>$20,000 - $39,999</td>
<td>24 (32.9)</td>
</tr>
<tr>
<td>$40,000 - $59,999</td>
<td>13 (17.8)</td>
</tr>
<tr>
<td>≥ $60,000</td>
<td>9 (12.2)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4 (5.5)</td>
</tr>
<tr>
<td>Married</td>
<td>31 (42.5)</td>
</tr>
<tr>
<td>Separated</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Divorced</td>
<td>14 (19.2)</td>
</tr>
</tbody>
</table>

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## Items used to assess willingness, experience with biospecimen donation and fear of research exploitation

<table>
<thead>
<tr>
<th>Willingness</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Based on what you know about biospecimen collection, banking, and use in medical research, how willing are you to donate your biospecimens for medical research?</td>
</tr>
<tr>
<td>• (If “yes”) What type of biospecimen are you willing to donate?</td>
</tr>
<tr>
<td>• (If “yes”) What personal information are you willing to provide along with your biospecimen?</td>
</tr>
</tbody>
</table>

### Experience with biospecimen donation

<table>
<thead>
<tr>
<th>Experience with biospecimen donation</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Have you ever been asked to donate biospecimens for medical research?</td>
</tr>
<tr>
<td>• (If “yes”) Did you decide to donate the requested biospecimen?</td>
</tr>
</tbody>
</table>

### Fear of research exploitation

<table>
<thead>
<tr>
<th>Fear of research exploitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I am concerned that I will be treated as a guinea pig in medical research.</td>
</tr>
<tr>
<td>• I am concerned that medical researchers will use contaminated equipment to collect biospecimens from me.</td>
</tr>
<tr>
<td>• I am concerned that something like the Tuskegee Trial can happen again.</td>
</tr>
</tbody>
</table>

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### Items used to assess trust

<table>
<thead>
<tr>
<th>Trust in medical researchers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Sometimes medical researchers care more about what is convenient for them than about people’s medical needs.</td>
<td></td>
</tr>
<tr>
<td>• Most medical researchers are extremely thorough and careful in their work.</td>
<td></td>
</tr>
<tr>
<td>• I completely trust medical researchers’ decisions about how my biospecimens are best used.</td>
<td></td>
</tr>
<tr>
<td>• Medical researchers would never mislead people about anything.</td>
<td></td>
</tr>
<tr>
<td>• All in all, I trust medical researchers completely.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Trust in biobanks</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Sometimes biobanks care more about what is convenient for them than about keeping people’s personal information private.</td>
<td></td>
</tr>
<tr>
<td>• Biobanks are extremely thorough and careful in their work.</td>
<td></td>
</tr>
<tr>
<td>• I completely trust biobanks’ procedures on how biospecimens are stored.</td>
<td></td>
</tr>
</tbody>
</table>
# Items used to assess willingness

## Willingness after barriers are addressed

- How likely would you be to donate your biospecimen if you learn about the researchers who will be using your biospecimens (e.g., educational background, medical training, research expertise, research records)?

- How likely would you be to donate your biospecimen if you know why you are asked to donate biospecimens?

- How likely would you be to donate your biospecimen if you learn how your biospecimens will be used in medical research step-by-step?

- How likely would you be to donate your biospecimen if you learn step-by-step procedures that biobanks will follow to keep the personal information associated with your biospecimens (e.g., age, gender, health status) private?

- I would donate my biospecimens if I received monetary compensation in return.

- I would donate my biospecimens if I received a health service in return (e.g., check for diabetes, cholesterol, blood pressure, dental work).
Willingness after barriers are addressed

<table>
<thead>
<tr>
<th>Lack of Transparency</th>
<th>M</th>
<th>SD</th>
<th>Reference Point</th>
<th>t</th>
<th>df</th>
<th>SEM</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who medical researchers are</td>
<td>3.21</td>
<td>.86</td>
<td>2.5</td>
<td>6.73</td>
<td>66</td>
<td>.11</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Why being asked to donate</td>
<td>3.42</td>
<td>.78</td>
<td>2.5</td>
<td>9.94</td>
<td>71</td>
<td>.09</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>How biospecimens are used</td>
<td>3.34</td>
<td>.91</td>
<td>2.5</td>
<td>7.77</td>
<td>70</td>
<td>.11</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>How personal information is protected</td>
<td>3.34</td>
<td>.84</td>
<td>2.5</td>
<td>8.37</td>
<td>70</td>
<td>.10</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>What the research results are</td>
<td>4.14</td>
<td>1.38</td>
<td>3.0</td>
<td>7.05</td>
<td>72</td>
<td>.16</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

Incentives

<table>
<thead>
<tr>
<th>Incentives</th>
<th>M</th>
<th>SD</th>
<th>Reference Point</th>
<th>t</th>
<th>df</th>
<th>SEM</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Money</td>
<td>3.32</td>
<td>1.52</td>
<td>3.0</td>
<td>1.79</td>
<td>71</td>
<td>.18</td>
<td>.078</td>
</tr>
<tr>
<td>Health service</td>
<td>3.93</td>
<td>1.54</td>
<td>3.0</td>
<td>5.06</td>
<td>69</td>
<td>.18</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>
Type of biospecimens older African Americans are willing to donate

![Bar graph showing the willingness of older African Americans to donate different types of biospecimens. The graph compares the frequency of willingness versus unwillingness for blood, hair, nails, saliva, skin, tumors, and urine.](image)

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Type of personal information older African Americans are willing to provide along with their biospecimen

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On average, older African Americans are willing to donate biospecimens: M=3.94, SD=1.22

The majority (84%) have not been asked to donate biospecimens

How information is conveyed was more important than prior knowledge of, beliefs about, or attitudes toward these processes when predicting willingness to donate biospecimens

Interventions targeting researchers communication may be more effective than those targeting changing older African Americans’ knowledge and attitudes

Limitations
- Study assessed willingness but did not test whether participants actually would donate a biospecimen
- Participants recruited through a community based research registry, potential for self-selection bias
Currently
• Implementing a community education program developed based on what we learned from focus groups and survey.

Future
• Educational intervention for clinical settings.

Dissemination
• 1 manuscript, Journal of Cancer Education, in press.
• Ongoing presentations
• University of Kentucky, UC Berkeley, UC San Francisco, California State University Fullerton, and Washington University utilizing our moderator guide and survey with their populations.
Questions?