


Amplifying Their Voices: Advice, Guidance, and Perceived Value of Cancer Biobanking Research Among an Older, Diverse Cohort

Altovise T. Ewing¹  · Arlener D. Turner² · Kwame S. Sakyi³ · Ahmed Elmi⁴ · Michele Towson⁵ · Jimmie L. Slade⁶ · Adrian S. Dobs⁷ · Jean G. Ford⁸ · Lori H. Erby⁹

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Abstract

The use of biobanks may accelerate scientists' chances of developing cures and treatments that are tailored to individuals' biological makeup—a function of the precision medicine movement. However, given the underrepresentation of certain populations in biobanks, the benefits of these resources may not be equitable for all groups, including older, multi-ethnic populations. The objective of this study was to better understand older, multi-ethnic populations' (1) perceptions of the value of cancer biobanking research, (2) study design preferences, and (3) guidance on ways to promote and increase participation. This study was designed using a community-based participatory research (CBPR) approach and involved eight FGDs with 67 older (65–74 years old) black and white residents from Baltimore City and Prince George's County, MD. FGDs lasted between 90 and 120 min, and participants received a \$25 Target gift card for their participation. Analysis involved an inductive approach in which we went through a series of open and axial coding techniques to generate themes and subthemes. Multiple themes emerged from the FGDs for the development of future cancer-related biobanking research including (1) expectations/anticipated benefits, (2) biobanking design preferences, and (3) ways to optimize participation. Overall, most participants were willing to provide biospecimens and favored cancer-related biobank. To increase participation of older, diverse participants in biobanking protocols, researchers need to engage older, diverse persons as consultants in order to better understand the value of biobanking research to individuals from the various populations. Scientists should also incorporate suggestions from the community on garnering trust and increasing comfort with study design.

Keywords Biobanking · Cancer research · Community-based participatory research (CBPR) · Diverse population

Introduction

There are striking differences in representation of various populations in cancer biospecimen research, with many minority populations being scarcely represented [1]. Recent studies have highlighted consequential implications across the cancer

research continuum ranging from inaccuracies in the labelling of commonly used commercial cell lines to the disproportionate number of genomic studies that consistently perform analyses on samples predominantly from people of European descent. Hooker et al. discovered that cell lines with 97% of European ancestry, on average, were correctly labeled as

✉ Altovise T. Ewing
ewinga2@gene.com

¹ Global Health Equity and Population Science, Roche Genentech, 1 DNA Way, South San Francisco, CA 94404, USA

² Department of Psychiatry, Center for Sleep and Brain Health, New York University School of Medicine, New York, NY, USA

³ Public and Environment Wellness Department, School of Health Sciences, Oakland University, Rochester, MI, USA

⁴ All of Us Research Program, National Institutes of Health (NIH), Rockville, MD, USA

⁵ Maxwell Enterprises, 211 East Lombard Street, Baltimore, MD #300, USA

⁶ Community Ministry of Prince George's County, P.O. Box 250, Upper Marlboro, MD, USA

⁷ Division of Endocrinology, Diabetes and Metabolism, The Johns Hopkins University School of Medicine, Baltimore, MD, USA

⁸ Ardmore, USA

⁹ Department of Health Behavior, The Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

White/Caucasian, whereas many of the cell lines labeled as Black/African American were actually comprised of greater than 90% European ancestry and therefore incorrectly classified [2]. To date, more than 85% of genetic- and genomic-based studies primarily involve European participants, and only 4% of cancer-related genome-wide association studies (GWAS) were conducted on samples from underrepresented groups [3–5]. Despite modest improvements, a pervasive disconnect persists between the goal of ensuring genomic health equity or justice for underrepresented populations and the access to biospecimens from underrepresented populations.

Recently, there has been a growing emphasis on a national level in inclusion of underrepresented groups in biomedical research, including biospecimen collection, through the National Institute of Health's Precision Medicine Program, *All of Us* (<https://allofus.nih.gov>). Biospecimen or biobanking research is defined as the collection and storage of biological specimens in biobanks for large-scale studies to identify the basis of disease and the development of future therapies [1, 3]. Usage of biobanks has the potential to foster equity in scientific advancements by accelerating our ability to develop population- and biological-based treatments, improve access to samples from diverse populations, and facilitate our ability to conduct research on multiple disease types concurrently. However, in some cases, the ability to discover differences in genetic underpinnings of disease, such as cancer, in various populations may be highly dependent upon access to sufficient numbers of accurately labeled samples from diverse populations [2]. *All of Us* attempts to address this representation conundrum with a focused emphasis on inclusion of underrepresented communities and recruitment and retention of more than one million people who reflect the rich diversity of the USA.

While knowledge of population-specific engagement has increased and intentions and attitudes in biospecimen research are reported as favorable in some cases, our understanding of these concepts among older members of multi-ethnic populations remains limited [6–13]. In addition, older multi-ethnic populations are underrepresented in biobanking efforts [1, 14]. The latter limitation may hinder understanding of disease prevention and progression in these groups and may exacerbate disparities in health outcomes between underrepresented and majority populations.

While some studies reveal increases in cancer survivorship rates, quality of life, and life expectancy, these advancements are less likely to apply to older, culturally diverse individuals [15, 16]. Most cancers are associated with older age and disproportionately impact medically underserved and underrepresented populations [17, 18]. As a nation that is increasingly aging and becoming more diverse, it is imperative that researchers understand the needs and characteristics of older, diverse populations. Innovative efforts to engage older, diverse groups may ensure genomic resources and benefit older and culturally diverse populations.

In an effort to amplify the voice of a community that has been historically suppressed in medical research, this qualitative analysis focuses on advice and guidance from a sample of older, diverse individuals from Baltimore City and Prince George's County, MD. Two community–academic advisory groups (CAGs) in Baltimore City and Prince George's County made valuable contributions to the cancer program. In a recent study, the CAG's contributions and partnership were demonstrated to be highly impactful in multiple domains [19]. The purpose of this study was to obtain guidance and information regarding research design and participation in cancer-related biobanking research from a medically underserved and underrepresented sample of older, diverse individuals.

Materials and Methods

Study Design

Following extensive discussions with CAGs members in Baltimore, MD, and Prince George's County, MD, the stakeholders strongly recommended that the Johns Hopkins Center to Reduce Cancer Disparities team conduct focus group discussions (FGD) to document the target populations' attitudes, beliefs, and behavioral intentions regarding biospecimen collection before the team developed a tailored strategy for outreach and biospecimen collection among the target population.

Participants were recruited from Baltimore City and Prince George's County, MD. We selected these jurisdictions for reasons including (1) our existing relationship with stakeholders, including local organizations and health departments; (2) differences in cancer mortality rates; and (3) socioeconomic factors. Although African Americans are the largest ethnic group in both areas, the regions differ significantly. At the time of this project, the average household income in Baltimore City was \$40,800 relative to \$73,500 in Prince George's County. The poverty rate in Baltimore City was 23% compared with 8.7% in Prince George's County. Despite these differences, these two localities had some of the highest breast, colorectal, and prostate cancer mortalities in Maryland. In 2010, the mortality rates per 100,000 for Baltimore City and Prince George's County were 22 vs 28 for breast cancer, 24 vs 22 for colorectal cancer, and 50 vs 53 for prostate cancer, respectively. The high cancer mortality rates coupled with the stark socioeconomic differences between the jurisdictions provided a unique opportunity to explore diverse attitudes, knowledge, and beliefs about cancer-related biobanking research among older, diverse individuals in these two communities [20, 21].

Eligible participants met the following criteria: (1) reside in Baltimore or Prince George's County, (2) be between 65 and 74 years of age, and (3) not have a personal history of breast, cervical, or colon cancer. The eligibility criteria aligned with a

parallel screening study occurring within the JHCRC [22]. Participants were recruited into the FGDs to explore through purposive sampling principles. This study protocol was approved by the Johns Hopkins University Bloomberg School of Public Health's Institutional Review Board (IRB). The study received a waiver of documentation of consent, but all individuals provided verbal consent after an extensive consent discussion.

Initially, this study was to precede the actual collection of samples for a biobank. The samples were to be collected from participants in a supplemental study funded as part of the Center to Reduce Cancer Disparities (CRCDC) entitled "Evaluating Coaches of Older Adults for Cancer Care and Healthy Behaviors (COACH)". The COACH study excluded individuals with prior diagnoses of breast, cervical, and/or colon cancers because it was a cancer screening study and because literature indicates cancer patients consent to biospecimen donation at significantly high rates. Because we wanted our FGD to inform the collection of samples in the COACH study, we wanted the populations to be similar. Although we ultimately separated our biobank study from the COACH study, we kept the historical eligibility criteria.

Focus Group Procedure

The FGD guide consisted of three broad sections (knowledge and prior beliefs, community attitudes toward participation, and attitudes toward specific design features) about cancer-related biobanks (see Table 1). Drawing on community-based participatory research (CBPR) principles, the guide's content was created based on a literature search and deliberations with the CAG. A sub-group of CAG members was formed for intensive involvement in conceptualization and development of study design and training in qualitative analytic techniques during the piloting phase.

Eight focus group discussions (FGDs) were conducted from June 2012 to February 2013 with 67 Maryland residents between the ages of 65 and 74. Four FGDs were conducted in each jurisdiction. Initially, we intended to recruit two groups of Caucasian participants only, but we had difficulty recruiting such participant; thus, we focused on individuals who met the age requirements and adequate gender representation. Six groups included only African American participants, and two included African American and Caucasian participants. While most groups included men and women, there was one group comprised of only female participants and one that included only male participants. CAG members hosted most of the FGD at their centers and churches. FGDs lasted between 90 and 120 min. Participants were compensated with a \$25 Target gift card. Individuals were recruited via active outreach efforts facilitated by the JHCRC staff, CAG members, or other individuals working in formal leadership positions throughout the community.

Prior to each FGD, participants provided verbal consent; responded to a questionnaire on general physical and emotional health, functional status, sources of care, and demographic information; and completed a genetic literacy assessment [23]. Each FGD began with the moderator providing a brief introduction and explanation about the purpose of the FGD. Then, with the use of a semi-structured moderator guide and the diagram in Fig. 1, the moderator began with a 5-min description of biobanks and led participants in a discussion about biobanking research. This led into a series of open-ended questions about participants' understanding of the purpose and procedures involved in biobanks as well as their attitudes toward future participation.

In the second section, participants were asked to discuss reasons that community members may or may not choose to participate, along with perceived benefits and harms and barriers and facilitators to participation. In the final section, participants discussed a variety of possible design features of a cancer-related biobanks. Additionally, the groups discussed six specific sets of a priori design options related to recruitment, consent, and return of results. For each set, FGD participants chose one from a list of three or four options and then discussed their preferences.

All FGDs were audio-recorded and transcribed verbatim by a professional transcription service. Prior to transcription, the research team members exchanged notes about each FGD used to supplement interpretation of the transcripts.

Data Analysis

Transcripts absent of identifying information were imported into ATLAS-ti.v7 and Microsoft Word for data management and descriptive or structural thematic coding. The study team developed an initial codebook based on the primary interview questions and responses and refined the initial draft with input from the CAG members. Coding and analysis occurred in several stages. Initially, a three-person team independently reviewed and coded half of the FGD transcripts based on the initial codebook, added additional emerging codes as the process unfolded, and then met to discuss the coding process. Transcripts were also shared with two CAG members who shared thoughts on the coding process. The codebook was refined throughout the process. A single coder analyzed all eight transcripts, with 50% of transcripts coded by a second analyst for quality control and consistency. Emergent themes were compared and discussed until consensus was reached. The coding team engaged in discussions to resolve discrepancies in the thematic analysis process. As new themes emerged, the single coder added codes to the codebook and identified prevalent themes that could be supported by quotes. The team used exemplar quotes and descriptions to convey the breadth and strength of agreement with a statement.

Table 1 Focus group discussion guide

Factor	Questions
Knowledge and beliefs about biobanks and cancer research	<p>What have you heard about cancer research that takes blood samples or other samples from people and study those along with other sorts of health information about those same participants (for example, information about diet, environmental exposures, and health conditions)?</p> <p>There are some cancer research studies that rely on biobanks. What do you think the word ‘biobank’ means? Have you heard anything about keeping tissues/blood for researchers to use to study disease?</p> <p>What are your initial thoughts about a cancer biobank being started in this community? Would people be interested in participating? Why or why not?</p>
Community attitudes toward participating in biobanking research	<p>What would you see as the benefits of participating in a cancer biobank? For you? For others? For society? For researchers? What might others see as the benefits? What might be some good things that would come from cancer research using these sorts of biobanks?</p> <p>What would you see as the possible harms of participating in a cancer biobank? What concerns would you have? For you? For others? For society? What concerns might others have? What might be some bad things that would come from cancer research using these sorts of biobanks?</p> <p>What makes people in your community trust any researcher? A hospital? A research institution or university? What makes people distrustful?</p> <p>How could a research team that wanted to create a biobank for research build trust in your community? What would they need to do?</p> <p>What sorts of people or organizations should be involved in the decision about whether or not to create a biobank in your community? Who should be involved in decisions about how to recruit community members into a biobank?</p>
Attitudes toward implementation	<p>What kinds of biological samples would people be willing to provide? Blood (how much?), urine, skin, other? Why?</p>

Results

Demographics

Characteristic information of participants is provided in Table 2. Participant ages ranged from 65 to 74 years. The majority of participants self-identified as African American/Black, 53 (79%), and 10 (15%) self-identified as non-Hispanic, White. More than 75% (51) of participants were female, and more than half (51%) of the sample reported earning \$49,999 or less annually. Approximately one-half (48%) comprehended genetics information at an eighth-grade-level or lower.

Themes

Multiple themes emerged from the FGDs, but for the purposes of this study, the following three themes/categories relating to the development of future cancer-related biobanking research studies inclusive of older, diverse participants are presented:

(1) expectations/anticipated benefits, (2) biobanking design preferences, and (3) ways to optimize participation. Overall, most participants were willing to provide biospecimens and favored cancer-related biobank. Illustrative quotes representative of the emergent themes are *italicized* in text.

Theme 1: Expectations/Anticipated Benefits

Participants described multiple potential benefits and advantages to establishing a cancer biobank. Participants mentioned that some entities such as science/medicine, self, the African American community, family/future generations, and pharmaceutical companies could potentially benefit from a cancer-related biobank. The sentiment that cancer-related biobanking research would be advantageous for the scientific and medical fields was pervasive in all discussions. One participant commented: “*They’ll get a faster cure and maybe different medicines for different diseases through the bank.*” Some participants noted the role that the FGDs played in raising

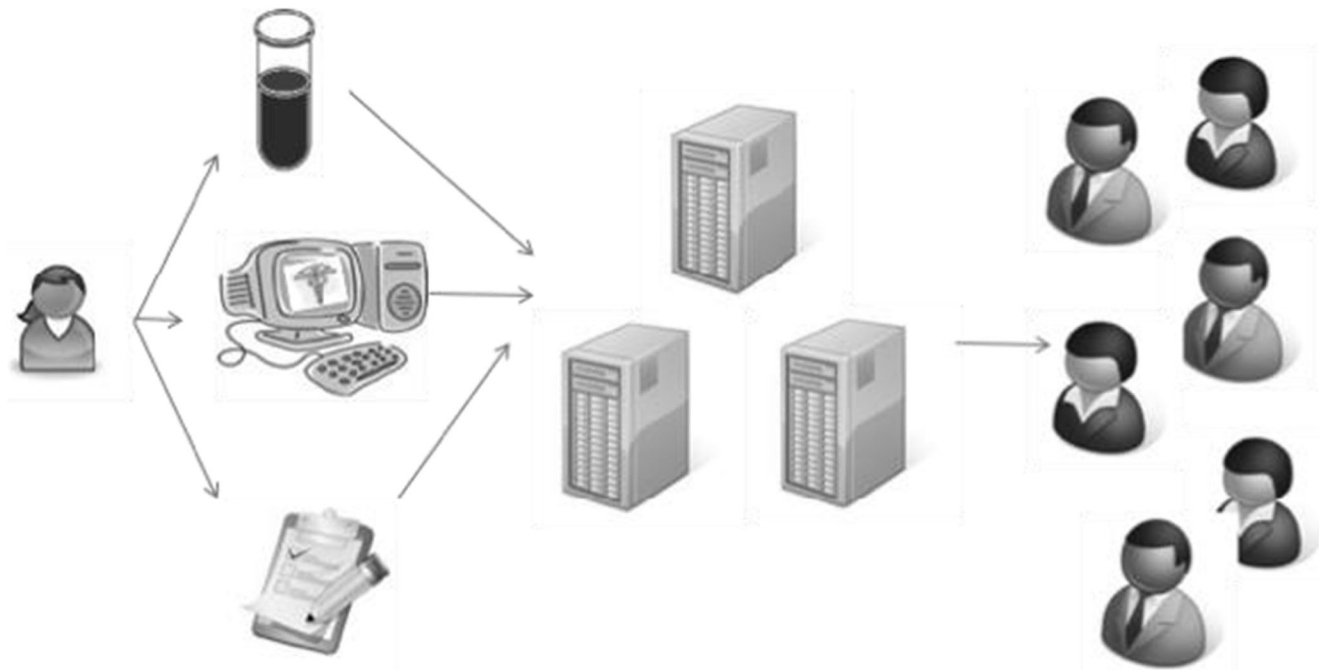


Fig. 1 Biobank diagram. Diagram used to explain the concept of biobanking in cancer research and to spark discussions about understanding and beliefs about biobanks among 65–75-year-old multi-ethnic participants

awareness about cancer outcomes, health disparities, and inequities in health care experienced by African Americans. For instance, one African American female participant commented:

“Because we are concentrating on the African American community in particular, I think groups like

this, I think we are finding out more about the fact that our health care may not be as good as some other groups. And I think that awareness in itself is a very good thing so that we know, you know, it helps us with our knowledge. We become more knowledgeable.”

Participants agreed that biobanking efforts could address health disparities for underserved and underrepresented populations. Several participants felt that communities that participate in a biobanking effort should benefit first, and throughout the research process. One male participant voiced:

“Let’s say if you had a biobank in this community, I would like to make sure that this community will get to benefit in this community first before you go out and resource... I would hope that wherever the location you have that this community that it’s in, that we are the number one.”

Table 2 Sociodemographic characteristics of participants

		Number (%)
Gender	Male	16 (24%)
	Female	51 (76%)
Race	African American	53 (79%)
	Caucasian	10 (15%)
	Not identified	4 (6%)
Annual household income	Less than \$20,000	14 (21%)
	\$20,000-49,999	24 (36%)
	\$50,000-79,999	11 (16%)
	\$80,000+	9 (13%)
	No response	9 (13%)
Education	High school graduate or less	31 (47%)
	Some college	13 (20%)
	Bachelor’s degree	10 (15%)
	Technical degree	2 (3%)
	Graduate degree	10 (15%)
Literacy level	8 th grade or less	32 (48%)
	Greater than 8 th grade	34 (52%)

While participants acknowledged that this biobanking endeavor could benefit multiple parties, some also had reservations that pharmaceutical companies would disproportionately benefit and have a potential conflict of interest. For example, an African American gentleman stated: *“I have a concern regarding research in that if they—if researchers did find a cure—say for cancer—it would affect the pharmaceutical companies.”* And a female participant specified: *“Well, people whom I know who have cancer, the medicine is terribly expensive, and if they found the cure, the pharmaceutical companies wouldn’t make as much money.”*

Participants expected that they should be able to reap the benefits of the biobanks in real-time as opposed to waiting for futuristic promises. An African American male participant articulated: “[I]’m trying to figure out how it’s gonna help others by the research. But I still want to know how it will help me. I want to know how it will help me.” In that same sentiment another participant said “If I’m gonna help somebody else, I want to help myself, too.” Additionally, participants had strong opinions about how their engagement should be used to benefit their family. Some participants envisioned potential benefits as a transaction that could take place to assist their family members’ health outcomes:

“Well, I would think that though the people—well, I would do it because you never know what’s going to happen down the road to you or your family, and a perk would be because I have given blood a—part of the research—that I would be—me or my family would be benefit as a result of what I’ve done or someone who is [in] need that I know. That because I did it, someone else would benefit, and we’re living in a world of advanced medicines, which I think the more advanced and the more information that we have in that area, the better off we are.”

Theme 2: Study Design Preferences

We asked participants to elaborate on study design practices that may successfully engage older, diverse populations. Participants talked in detail about biospecimen preferences, follow-up communication, confidentiality/privacy, autonomy, and accountability.

Biospecimen Preferences

Biospecimen preferences focused on the type of specimen, invasiveness of procedures, and timing of specimen collection. Most participants had similar preferences for biospecimen collection. Overall, convenience and noninvasive measures were favored as factors that were conducive to draw older, diverse participants in cancer-related biobanking efforts. Generally, participants were accepting of saliva and urine as options; although, some were reluctant to discuss and endorse the provision of urine. Additionally, people were more divided about giving blood. One participant indicated: “I would do anything to contribute, except if it’s invasive.” While another stated: “You mentioned tissue. That might hurt.”

Participants also voiced the importance of having multiple biospecimen collection options. For instance, one participant remarked: “I think some people are going to donate urine or,

like you said, saliva and other things—something that’s not painful—.” The majority of participants believed that timing of sample collection would impact their willingness and ability to provide a biospecimen, with time convenience playing a major role. Several mentioned the option of tacking it onto an existing doctor’s appointment or scheduled blood draw. Some participants mentioned, “Convenience is more important to me at least than money.” and “If they do it when they’re taking your blood or they’re taking your urine here and they decide that they need some for the biobank, so that’s all right—.”

Focus group members also discussed expectations of biobanks to communicate findings. While opinions were mixed about desires for personal or general information, the majority favored receipt of personal information. They believed this information could help them in their current state. An example of content preference: “Yes. I would like to know if I’m at risk. And like she said, find my own doctor, my own counseling, and I have that paper in hand. I know what’s going on.” General research status updates and the importance of timely communication were also favored. Even though participants understood that research studies could ensue for an extended period, they still expected to receive an update within the first two years of engaging in the study. For instance, a participant expressed, “I think we should hear back about individual results in a timely manner. In other words, Hopkins or whatever hospital is doing it, gets their results back in a year, two years, then tell us at that time. Don’t wait five years down the road, even if you’re still continuing to do that research.”

Participant’s preferences were mixed on the frequency of researcher communication with participants, especially about additional permissions for individual-level studies involving donated specimens. Some individuals favored frequent contact and engagement from researchers, while others desired limited contact once initial consent was provided. A participant who was interested in being re-contacted and providing narrow consent shared: “I’m donating this one and if you want to use it this one time, yes. But then if you need it—if you want to use it again, if you still have some left, they should ask for my approval.” Contrastingly, another participant indicated that she was not interested in being re-contacted for consent but would prefer some sort of ongoing communication: “I might not necessarily want to be contacted every time but I would like to know at some point if my tissues had benefited someone.”

Follow-up Communication

Participants deliberated on preferences about follow-up communications from the biobank. Most participants desired easily understandable information and an appreciation for their participation, which some thought could be as simple as follow-up communications that indicated gratitude: “It could

be a letter saying we used your tissue. We appreciate it. We thank you so much. As a result of that, this is what happened. And be truthful about what happened.”

Confidentiality/Privacy

Participants also expressed the desire for their information to remain confidential and private. Most participants understood the collaborative nature of the cancer-related biobank and the benefit of multiple scientists being engaged, but concerns from participants about having their information broadly shared were reflected in the following: *“That everybody doesn’t have access to everything. You have a team or a unit and they have a policy and procedure to follow to first of all initially to be part of that team and then second of all to complete the survey or the research that they’re doing”*. Many participants vocalized a strong desire for privacy and provided suggestions on how this could be maintained and balanced, for instance, *“As long as the database is really secure. Again, the confidentiality they’ve got and the reputation of the institution and it’s really, the locked box is really a locked box, where this linkage is only to verified–.”*

Autonomy

Participants also voiced the importance of autonomy or having a say in the use of their samples, the duration of specimen retention, and the study type. Preferences for autonomy were conveyed in the following quotes: *“Mine would be the length of time. I wouldn’t want it to go on indefinitely. There should be a cut off period, and this particular one, you’re just giving your whole body, your whole life over to someone, and wouldn’t want to do that, I would want to have some kind of control.”* and *“But I want to be sure that I at least said what I would like to have done with that sample.”*

Theme 3: Optimizing Participation

Participants were forthcoming in providing guidance on facilitators that could potentially increase participation in cancer-related research among older, diverse participants. In particular, focus group members emphasized the importance transparency and involving key stakeholders to incentivize broad participation. Individual-level elements underscored the importance of researchers being physically present in the community, disseminating helpful strategies and results and helping the community understand the benefits of research in order to get buy-in. *“I don’t need no paper. I need somebody coming to the community saying this will help, let’s try this.”* They strongly echoed that there should be the same urgency in returning results and meaningful information as there is in recruiting the community into research studies. One participant stated the following: *“Don’t*

just take advantage of the neighborhood, get all your samples, and don’t do nothing in return, coming back. ‘Cause if I give my blood, and then I go to my doctor and he tells me I’m sick, then why didn’t you tell me I was sick?’”

Participants recounted and encouraged multiple strategies at the researcher-level in order to facilitate participation from older, diverse participants in cancer-related biobanking research. Participants expressed the importance of having credible scientists involved in the research process that is filled with checks and balances. Per participants, researchers should take the time to educate and fully understand the unethical research injustices that the African American community has experienced when it comes to research. This quote from an African American female participant captures the belief:

“If you educate yourself to the studies that I was talking about, things that have happened to black-to African Americans from the beginning, and be able to go in and say, we are not going to do this, like the syphilis study in, I think it was Alabama, or the ladies that were–women that were sterilized in Virginia, and Virginia is just getting ready to pay them for that, that’s an ongoing case. And study those things and say to people, especially seniors and middle-aged people, you know, this is not what we are doing. You know, you have to know the history and let us know that you’re not going to do the same thing to us, that you are not just being used, and I say that, when I say you, you–well you know, minorities coming in and being used by the man, and I’m talking you from an old person that’s been there. And that’s what they will say, oh you just using her and him to get in, and you have to–.”

Participants identified that expertise and buy-in would be needed from several different groups in order to optimize participation from older, diverse individuals. The notion that researchers should be reflective in appearance and experience of the community they are serving was salient in multiple FGDs. This strategy was mentioned as a way for researchers to better understand the target communities, as expressed by the following: *“You would have people from the community as part of the board so they would be able to let you know what the community thinks or not thinks.”* Some participants also noted the importance of receiving information from the biobank or from a familiar or similar individual: *“And then also say, if you would go to communities and citizens associations, and into African American communities, you want someone to look like you, to tell you that, you know, so...”*

The data show that participants encouraged the younger generation to be involved, as they are more skilled and adept in understanding technology than they are. Individuals expressed that involvement of younger generations would help to serve in educating multiple generations, for example, *“And technology has improved, science has improved, the*

younger generation is getting a little more information earlier than we got it. Therefore, I think they would listen to you if you talk to them in that manner, because you're trying to help them live longer, you're trying to share your information because of your learning and your study."

Participants highlighted the value of including healthcare professionals (HCPs) in cultural sensitivity training as an emergent theme. HCPs or trainees' involvement in cancer-related biobanking efforts were cited as a way to effectively engage older, diverse populations. One participant summed this up by saying: *"Go to the hospitals and start with the students in the hospitals that's taking chemistry and science. To be honest with you, start with the young people."* The transcripts showed that participants preferred to have representation of key stakeholders to enhance the overall research experience, including legitimizing the effort or helping to educate and inform participants. While participants agreed that institutional stakeholders could play an important role, they were divided about which institutions would add trustworthiness to a biobank. Some mentioned NIH as a trusted partner: *"I think NIH is crucial, both in terms of the legitimacy and of course for the peer review and that sort of."* Interestingly, others mentioned Johns Hopkins as a trusted partner, but others also saw the institution in a different light.

Accountability

Participants passionately indicated that the researchers with whom they have contact should be the ones to convey information back to them. One individual mentioned: *"I still would like to have if I were working with this research group I would like for them to give me the information. I would rather have it from them than to go to a third party."* There was also the sentiment that researchers have a certain level of accountability to that participants' samples and data are not carelessly distributed. Additionally, participants were not comfortable with the idea that someone outside of the research team might have their information or contact them. One participant commented, *"...but I wouldn't want them to give out my information, but I would like to find out what's going on with me, maybe I can live a little longer."*

There was also the recommendation that researchers be truthful in conveying information back to the African American community. Several participants made comments with the importance of truth and transparency as an obligation: *"And disperse the information or the data that's been gathered fairly and honestly. If this is what it is, then let us know this is what it is, not what you want it to be."*

Discussion

This qualitative study demonstrated an overwhelming willingness and favorable regard for cancer-related biobanking

research among an older and predominantly African-American sample of residents from Baltimore City and Prince George's County. Central cancer-related biobanking research themes that emerged from the FGDs included (1) expectations/anticipated benefits, (2) biobanking design preferences, and (3) optimizing participation. Participants highlighted these themes as critical in the success of constructing cancer-related biobanks that are inclusive of populations that are often underrepresented in research, underserved in medicine, understudied in science, but disproportionately impacted by the burden of disease.

There were several participants who indicated expectations or anticipated benefits that could result from their involvement in cancer-related biobanking research. Many participants specified that they would be willing to participate in cancer biobanking research to optimize their ability to obtain personal risk information, but also for the benefit of others including family members, the African American community, society, and pharma. While the anticipated community and societal benefits may be reasonable long-term outcomes, some of these comments reflect the pervasive belief of "therapeutic misconception"—the idea that participation in research yields the same type of information and benefit one would expect to receive when seeking personal medical care. Several studies involving underrepresented populations suggest therapeutic misconception as a robust motivator for interest in and participation in biobanking research [6, 7, 24]. Therefore, it is important to develop materials that clearly elucidate the intended purpose of these studies during the recruitment and consent stages.

If twenty-first century research aims to be more inclusive of populations that have historically been underrepresented in research, then biobanks should consider establishing protocols that offer immediate benefits to research participants and use ethical and equitable approaches. While recognizing therapeutic misconception highlights an opportunity for researchers and healthcare professionals to clarify the difference between research and medical care, it also presents opportunities for researchers to establish nontraditional protocols in which participants actually receive medical information they are seeking and deem useful for health management and disease prevention. Recent works suggest the need to reconsider the concept of therapeutic misconception, especially within the context of biobanking research [25]. The authors suggest that it is difficult to optimize biobanking research and truly keep the research separate from treatment options that could be offered to participants. This challenge is even more critical when it involves populations that have been historically marginalized, excluded, and underserved and also disproportionately experience poorer health outcomes. In some instances, it is possible that treatment options within the research context could be the "lifeline" that an individual or community needs to make favorable health outcomes a reality. It is also important to consider that therapeutic misconception may be widespread

among diverse populations, in particular if members are cognizant of the health disparities that impact their communities. As a result, individuals from diverse populations may anticipate that any focus on diseases resulting in higher morbidity and mortality rates in their community may automatically translate into interventions and strategies to ameliorate disparity.

Our findings offer rich descriptions of biobanking design preferences. Many of the emergent themes focused on older participants' desires to engage in noninvasive, convenient studies characterized by the opportunity to exercise autonomy in making ongoing choices about receiving results or exercising the option to withdraw from the study at any time. These findings do not deviate from prior work that demonstrated that older individuals are not discouraged, maintain an optimistic mindset about cancer genetics research, and have a willingness to donate biospecimens and health information for biobanking purposes [6, 26]. The study design recommendations offered by participants in this project highlight the importance of researchers in taking the time to understand the preferences and history of the communities that they want to better engage. Participants voiced suggestions that they envisioned could optimize both participation and engagement. This study adds to the body of work that engages diverse CAGs in various aspects of biobanking research [19, 27–30].

Participants were very vocal about the importance of racial concordance between individuals leading the research and engaging the community and the participating population. This recommendation aligns with recent work that highlights the importance of diversity within the healthcare workforce and its impact on the delivery of quality care to underrepresented populations [31]. A concerted effort to diversify the research staff and clinical professions to ensure that those who engage underrepresented and underserved populations look like or have similar experiences as the communities they serve may also influence participation rates of diverse groups. Additionally, diversification of the genetics professions may also lead to an increase in cultural competency among researchers and improve their ability to address the needs and concerns of diverse individuals in a sensitive and compassionate manner. Given the central role of genetics and genomics in research conducted using biobank specimens, Halbert and Harrison outline several strategies that must be considered to ensure the provision of ethically sound genetic counseling to minority populations in this era of precision medicine ranging from addressing gaps in genetics knowledge and language barriers, improving health literacy, and being attentive to cultural differences [32]. A culturally competent and sensitive and diverse research workforce could be paramount in obtaining and maintaining the trust and buy-in from underrepresented populations in cancer-related biobanking research.

The suggestion to engage the younger generation may potentially be an effective way to increase participation among

older and multi-ethnic individuals in cancer-related biobanking research efforts. Similar to a prior study, several remarks among participants reflected a sense of reluctance to use technology or doubt in their ability to understand the material covered in medical research [33]. Soliciting support and buy-in from younger generations may serve as a vehicle to help educate, encourage, and motivate older participants to become more comfortable with technology and the context of information discussed in medical research efforts. A recent study conducted by a subset of coauthors included on this manuscript demonstrated the effectiveness of an intervention that includes a trusted family member as an integral cancer screening care coordinator for a loved one [22]. It is possible that a similar strategy may be effective in increasing engagement rates of older and diverse participants in cancer-related biobanking efforts in the future. Future studies should evaluate the success of incorporating younger generations in a randomized controlled trial to evaluate the potential impact on recruitment of older and multi-ethnic participants into cancer-related biobanking studies.

The central theme of transparency was pervasive throughout the FGDs. Participants voiced the importance of disclosing details of research protocols and providing updates in real time throughout the duration of the study. Additionally, they highlighted the importance of acknowledging the lingering effects of historical, egregious medical mistreatment of vulnerable and underrepresented populations. It is possible that contextualizing the historical and unethical experiences that many minority populations encountered in medical research or acknowledging the past may help in reconciliation efforts and engagement. This may lead to increased mutual respect and rapport between the research community and diverse populations as well as lead to increased relevance of research findings and efficacy of treatment for all populations involved in biobanking research. These sentiments may highlight diverse populations' desires to hold the research community accountable to meeting their reasonable expectations that may be driven by the concerns involving unethical practices of the past. Recent works still highlight the lack of knowledge around biobanking design preferences, but an interest in participating among African Americans [7, 13]. This study helps to fill that gap by providing suggestions and strategies for biobanking research and study design from an underrepresented population of diverse individuals 65–74 years of age.

This study is not without limitations; however, it should be evaluated within the context of its strengths. It is important to interpret data from our FGDs through the lens of a voice that may be unique to a predominantly African American sample in an urban area. While focus group research is designed to highlight preferences and opinions that exist within one or more target groups, it is possible that nonparticipants may have had differing opinions, concerns, and attitudes about designing and participating in cancer-related biobanking

research. Additionally, it is worth noting that the preponderance of participants was female and unaffected with a personal history of breast, cervical, or colon cancer. It is possible that had more men been involved in the FGDs and we sampled individuals with a personal history of breast, cervical, or colon cancers, the emergent themes may have differed. We did not collect exhaustive demographic information from participants, so we are unable to provide more refined details about this sample. Additionally, considering that all participants were, by design, Maryland residents in order to inform subsequent biobanking efforts specific to that state, it is possible that the content generated during these FGDs may be unique to Maryland and not generalizable to other states.

We are no longer on the brink of biobanking research being used to aid in the development of genetic and genomic technologies that shift the way medicine is practiced today. In some health systems, the resource is standard in the provision of medical care [33–35]. Since these efforts are being implemented in real time, it is critically important that intentional measures are taken to ensure equity for all populations. Advancements in research will only be equitable if we ensure that historically underrepresented groups are provided a seat at the table and the opportunity to tell their respective stories. Findings from this study could inform future studies to better assess engagement rates of older, multi-ethnic individuals in biobanking research, particularly in this rapidly advancing era of precision medicine. Without adequate representation of multi-ethnic and underserved populations in biomedical research, scientific advances and medical breakthroughs may not reach and benefit some communities and inadvertently increase health disparities. It is a worthy investment for scientists to design protocols that prioritize partnerships between researchers and participants and active engagement of diverse populations.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Statement of Ethics This research complies with the guidelines for human studies and was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. This study protocol was approved by the Johns Hopkins University Bloomberg School of Public Health’s Institutional Review Board (IRB). The study received a waiver of documentation of consent, but all individuals provided verbal consent after an extensive consent discussion.

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