

# Engaging diverse populations about biospecimen donation for cancer research

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**Abstract** Clinical research increasingly relies upon the availability of appropriate genetic materials; however, the proportion of biospecimens from racial/ethnic minority patients and healthy controls are underrepresented, which preclude equitable research across all patient groups for cancer treatment. National Cancer Institute-funded Community Network Program Centers in California, Florida, and New York collaborated with local community partners to conduct three independent formative research studies with diverse (African American, Asian American, Hispanic, and White) participants to explore their knowledge, attitudes, and beliefs about biobanking, and their experiences with the donation of

biospecimens. Our findings demonstrated similarities in overall low knowledge and understanding about the use of biospecimens for research. This was exacerbated for non-English speakers. Racial and ethnic groups differed with regard to a number of factors that are obstacles for participation, e.g., continuing medical mistrust (African Americans), lack of benefit (Hispanics), apprehension about the physical toll of donating (Vietnamese), usage of biospecimen for research (Hmong and Chinese), and suspicion of exploitation by corporate entities (Whites). However, participants uniformly reported general interest and willingness to participate in biobanking for altruistic purposes, particularly to benefit future generations. This interest was framed with a strong admonition that donations should be accompanied by transparency about study sponsorship and ownership, distribution and use of biospecimens, and study information that fit participants' backgrounds and experiences. This cross-cultural regional analysis offers significant insights into the similarities and variations in opinions and perceptions about biobanking and the collection of biospecimens for use in cancer research.

**Keywords** Biobanking · Biospecimens · Asian Americans · African Americans · Hispanics · Medically underserved

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## Introduction

Personalized medicine strives to provide optimal care through targeted drug therapies designed for a specific diagnosis in a specific patient (Suh et al. 2013). Without representation from diverse communities in studies, researchers cannot ensure the generalization/external validity of results (Lee et al. 2012). Inclusion of and participation from racial/ethnic minority populations allows researchers to compare cancer associated genetic variants across populations, measure susceptibility, and determine associated cancer risk (James et al. 2008; Burchard

et al. 2003). Furthermore, this need is also supported by at least three factors. The first factor is the dramatic demographic shift in the US population towards non-White populations such that by 2042, non-White populations will constitute the majority of the population, as has already happened in California, Hawaii, New Mexico, and Texas (US Census Bureau 2010). A second factor is the disproportionate cancer burden faced by many non-White populations as exemplified by the higher rates of cancer incidence in various populations of color (Haynes and Smedley 1999; Smith et al. 2009). Lastly, racial/ethnic minorities are already underrepresented in clinical trials (Chen et al. 2014; Anderson 2004; Bruner et al. 2006; Murthy et al. 2004) that have been the principal conduits to cancer drug development, and unless these trends are reversed, health disparities will be even more magnified as treatments using personalized medicine technologies increase (Hall and Olopade 2006; Rebbeck et al. 2006). To address these needs, institutions with biobank repositories have conducted deliberative engagement with participants to increase the community's knowledge of biobanking and inform institutional policies (Halverson and Ross 2012; Lemke et al. 2012; O'Doherty and Hawkins 2010). The findings from these studies suggest that such practices increase public support for biobanking, engender trust among participants, and translate public input into policy (O'Doherty et al. 2012; Streicher et al. 2011).

Some social scientists describe a perspective on the intentional inclusion of racial/ethnic minority participants into research and how the social and institutional structures shape this inclusion in the USA (e.g., Petryna 2005; Fisher 2009; Timmermans and McKay 2009). As such, Fisher (2009) suggests that efforts to specifically recruit underserved participants could be considered exploitative. Epstein (2008) has termed this focus on the study of inclusion of underrepresented groups as "Recruitmentology," an applied science. He warns scientists that this new science may be reductionistic, emphasizing the biological determinism of race in medicine, while ignoring the sociopolitical determinants of health disparities in minority and lower income populations. This interesting dialectic is an important consideration for researchers' efforts to respond to the National Institutes of Health (NIH 1993) mandates (as well as many other research organization imperatives) for adequate inclusion of underrepresented racial/ethnic minorities to clinical studies (Chen et al. 2014), and biobanking resources (Erwin et al. 2013; Rodriguez et al. 2013; Luque et al. 2012). It is an underlying consideration of the academic investigators and community partners in the studies described herein. There is the argument that the problem of adequate inclusion of all sections of the US population is a direct result of the structural inequalities in the health care system within the USA, which creates disparities by race, class, ethnicity, and migration status and is therefore a political systems issue to be addressed at a policy level (Hasnain-

Wynia et al. 2007; Joseph and Dohan 2012). There is also the question of whether equity can be achieved by enhancing inclusion. Ethnographic research on study recruitment in the clinical context by Joseph and Dohan demonstrates that "the meanings of inclusion in research are multiple, and inclusion by itself does not ensure equity" (Joseph and Dohan 2012, p. 338). Thus, an important approach to address and ease the inclusion and equity tensions is the *engagement* of ethnic and minority community participants in the research and advocacy process. We believe that the use of a Community-Based Participatory Research (CBPR) approach represents an ideal orientation to respectfully and thoughtfully engage diverse members of our community in the research process, thus optimizing the opportunities to address social justice issues within research. Moreover, there needs to be community-level agreement if specific communities are to be approached for consent to participate in biobank research (O'Doherty et al. 2012).

As background, CBPR has developed from both the action research of anthropology and sociology as well as the social justice traditions, which recognize "the unique strengths and perspectives of community partners...to produce tangible benefits for communities participating in research" (Braun et al. 2012, p. 1195; Israel et al. 2003; Minkler 2010; Wallerstein and Duran 2010). This orientation to research, based on principles of community engagement, co-learning, and equitable power and control of studies and resources (Minkler and Wallerstein 2003), is uniquely suited for research to address disparities in topics related to inclusion of diverse populations in clinical and genetic research. This CBPR approach uniquely drives the studies reported here and is the essential core foundation for the Community Network Program Centers (CNPCs) which supported these studies.

In response to a crucial need to eliminate cancer health disparities in specific medically underserved communities, the idea for the Community Network Program Centers (CNPCs) was fueled through the National Cancer Institute (NCI), Center to Reduce Cancer Health Disparities (CRCHD). Based on shared interests, needs, and values, 23 community-academic partnerships were funded across the country to strategically apply CBPR approaches to reduce cancer health disparities through the delivery of culturally appropriate outreach, conduct of high quality research, and training of junior investigators, particularly those from underrepresented backgrounds. As such, the CNPCs represent fertile community laboratories to address important cancer prevention and control needs, engage diverse stakeholders, and combine research with actions aimed at improving health outcomes. This article reports on findings from three CNPCs who have conducted formative research with diverse multi-ethnic populations in their catchment areas to address disparities in biospecimen donation. These CNPCs consist of the Asian American Network for Cancer Awareness Research and Training (AANC-ART): The

National Center for Reducing Asian American Cancer Health Disparities headquartered in Sacramento, California; the Tampa Bay Community Cancer Network (TBCCN) in Tampa Bay, Florida; and the Western New York Cancer Coalition (WNYC2) Center to Reduce Disparities in Buffalo, New York. AANCART serves primarily California and Hawaii focusing on Asian Americans (Chinese, Filipino, Hmong, Korean, and Vietnamese); TBCCN serves the Tampa Bay, Florida region (Pasco, Hillsborough, and Pinellas counties), focusing on medically underserved populations, (Hispanics, African Americans, Haitians, and Whites), which are ethnically and linguistically diverse, at risk for low health literacy, and also which include a growing foreign-born population. WNYC2 serves the Buffalo/Niagara Falls, New York regions, focusing on medically underserved urban Whites, African Americans, and Hispanics. The communities represented in this article reflect racial/ethnic minorities and other medically underserved populations relevant to each site's geographic location and ongoing community-based partnerships. In recognizing the increasing utilization of biospecimens in cancer research, community-based approaches are increasingly important to develop new ways (i.e., biobanking tours, community forums, etc.) to reach communities and generate discussions and shared understandings about this topic (Lemke et al. 2012; Streicher et al. 2011). As such, it became evident that little was known about community members' knowledge, attitudes, beliefs, and informational needs about biospecimen research and biobanking. Thus, the purpose of this article is to report on similarities and variations among diverse communities from three sites and analyze cognitive, communication, and sociocultural factors as the basis for designing educational approaches that are more effective to engage groups regarding their participation in biospecimen donation for cancer research. To our knowledge, this represents the first cross-population analyses of participation in biospecimen donation for research that included medically underserved African Americans, Asian Americans, Hispanics, and Whites.

## Methods

### Bringing the studies together

All studies entailed the use of participatory modes of research, in which communities were actively engaged in the research process (Minkler and Wallerstein 2003; Israel et al. 2003; Minkler 2010). For example, from the onset, community members were involved in various ways to address the research questions (e.g., community advisory boards). We recruited appropriate participants for key informant interviews and focus groups, reviewing focus group data, commenting on design, etc. In accordance with CBPR principles, we considered our community research partners as local gatekeepers and

stakeholders to the population of interest. Participants for the qualitative assessments were recruited through a combined convenience/snowball process, or through purposive sampling in the Tampa study, with a purposeful intent to include participants from specific groups, age cohorts, and gender distribution (Bernard 1998). The studies focused on diverse community members ages 18 to 75. All studies were approved by their respective Institutional Review Boards. Many responses of participants in the focus groups were audio recorded and transcribed and individual interviews were recorded by audio, or responses were documented by the interviewer. Survey data were collected in a pen and paper format, or using electronic keypads with an Audience Response System (ARS). Specific details of methods and measures by ethnic/racial group and study site are presented in Table 1. Interviews and focus groups were conducted in local settings specific to the residents such as community-based organizations, community partner facilities, libraries, faith-based organizations, or the cancer center. All consents, surveys, PowerPoint presentations, brochures, and materials were developed and reviewed with community partners and presented to participants in language specific to their preferences. All transcriptions were translated from the language of the participants into English by research staff from the ethnic group, by trusted community partners with language-specific expertise, or by a certified foreign language transcription service.

These individual CBPR-oriented formative studies resulted in similar, but not identical, methodological approaches, study designs, and similar cognitive and attitudinal questions about the topic, thus providing a rich source of data for an integrative review of our findings. All of the research designs and data collection were completed independently at each site. It was not until preliminary data were shared at presentations at a CNPC annual meeting that the authors recognized the scientific opportunity to compare findings across sites and culture groups. Following individual site analysis and preliminary reporting of these separate outcomes at our annual CNPC meeting, the investigative teams recognized the value of a cross-cultural comparison and began developing ways to discuss and compare our findings as a group. This led to the creation of the CRCHD Biospecimen Affinity Working Group and a subgroup to work on cross-cultural analysis for this article. Working group members met on a monthly basis via conference call to discuss a cross-cultural/cross-community framework for interpreting findings. This helped to identify patterns among community groupings, sources of divergence among our findings by geographic, racial or ethnic group, and other interesting relationships that may not have been seen from a single-site study. Although the goals and specific aims from each site vary slightly, the questions asked in the focus groups and interviews were remarkably similar, and focused on obtaining responses from our specific community members about their understanding, awareness, and interest in

**Table 1** Methods across CNPC sites

Site	Population group	Methods	Sample size	Data collection	Analysis (thematic categories)	Recruitment	Biospecimen information
AANCART	Chinese Hmong Vietnamese	Focus groups (FG) Community questionnaires (CQ)	FG/ <i>n</i> =6 CQ/ <i>n</i> =54	FG: audio recorded and transcribed; CQ: pen and paper; manual data entry	1. Knowledge about biospecimens 2. Degree of willingness to donate 3. Cultural perspectives on biospecimens 4. Preferences in donation 5. Message content	Community partners and contacts at community events/ convenience sample. Incentive: \$30 gift card (retailer)	Official NCI definition of biospecimens Examples of types of biospecimens
TBCCN	Mixed race African American Hispanic/Latino	Focus groups (FG)	FG/ <i>n</i> =12	FG: audio recorded and transcribed	1. Biobanking knowledge 2. Barriers 3. Benefits 4. Message content	Community advisory group and TBCCN partners Incentive: \$30 gift card (retailer)	Official NCI definition of biospecimens Examples of types of biospecimen
WNYC2	African American White Hispanic/Latino Other mix	Key Informant Interviews (KII) Focus groups (FG)	KII/ <i>n</i> =15 FG/ <i>n</i> =7	KII: pen and paper, notes; FG: audience response system/electronic download; notes; audio recorded; CS: pen and paper; manual data entry	1. Biobanking knowledge 2. Barriers 3. Benefits 4. Message content	Community gatekeepers (KII) Incentive: \$15; Community participants from previous cancer education events (FG), incentive: \$10 gift card (retailer) and food; Community events (surveys)	Examples of types of biospecimens (i.e., blood, urine, saliva)

engaging in cancer research around the issue of biospecimen donation and biobanking participation. All sites also collected self-report demographic data from participants at each interview or focus group.

Each of our CNPCs approached the topic of biospecimens in the populations independently of each other; however, we all ended up seeking answers to the following main questions:

1. What do the populations we serve know about “biospecimens and biobanking”?
2. What are the community perceptions of biospecimens and the donation process?

As some sites reported on issues or topics that were not included as variables at all sites, we decided to develop this qualitative narrative review and comparative analysis across sites to discern thematic findings and categories that were addressed by all three sites to describe cross-cultural comparisons. After several months of discussion, revisiting, and categorizing our findings, we came to consensus on four primary domains: (1) terminology/message content as it applies to “biospecimens” or “biobanking”; (2) level of awareness by participants about the concept of donation, biobanking, and biospecimens; (3) perceived impediments to donating biological biospecimens such as blood or saliva for banking; and (4) reported facilitators that enhance the likelihood by participants to donate biospecimens. These domains were selected both because of their significance for our community partners as well as their salience to the issue of biospecimen donation. We report these domains for each site location and each racial/ethnic group as our comparative findings, then discuss the similarities and variations.

All sites designed their studies independently of each other; however, due to the novelty of the topic and low level of community awareness regarding biospecimen donation for cancer research, when we created findings tables by theme to compare across sites, there were noted similarities across the three sites with regard to approach and textual content. A summary of the methods across the sites is provided in Table 1.

### Study sites

These studies were conducted in Sacramento, California; Tampa Bay, Florida; and Buffalo/Niagara Falls, New York. The three CNPCs reported here independently designed formative research in collaboration with community partner sites and individuals to assess the readiness, perceptions, knowledge, and/or attitudes of their respective population groups about biospecimen donations. As there were very little published data on biobanking participation among any racial/ethnic minority groups in 2008 when these studies began, the studies at all three sites required qualitative assessments through focus groups and/or open-ended interviews with

community members to provide understanding of underlying knowledge, attitudes, and beliefs. Engaging community members early in the process reflected our convictions that CBPR operationally means that we investigate these issues with our community partners from the initial stages of the study and value the perspectives they bring to the inquiry (Israel et al. 2003). For example, one needs to consider that the topic biospecimen research is not a widely known subject for most of the general public. When it was first introduced to the TBCCN community partners as a cancer innovation (i.e., personalized medicine) and that it might be helpful in finding better ways to prevent or treat cancer, one community member succinctly stated, “well...if you teach us about this topic, we can help you.” This type of sentiment is what was central to each of our CNPC’s research endeavors that is, exploring through formative research how to best make a community-engaged connection about biobanking in a clear, concise, and salient manner.

Population factors by study site are listed in Table 2 to provide relevant context for the communities each site engaged in for their respective formative research inquiries. AANCART intentionally identified three Asian-American populations for this study because of their long-standing relationships developed through prior collaborative research, and that Asian Americans are characterized by distinct linguistic and cultural factors. TBCCN partnered with a biobanking community advisory group (CAG) formed through their CNPC for the purpose of the biobanking formative research study. Members from the CAG were identified from the diverse TBCCN partner organizations. TBCCN partners include health care, service, and adult education organizations from the counties of Hillsborough (Tampa), Pinellas (St. Petersburg), and Pasco (Dade City). Most of the TBCCN partners are located in Hillsborough County and approximately 24 % of the population are ages 25 years of age or

younger and have not completed high school (US Census Bureau 2010). WNYCC also relied upon existing community advisors to help organize and recruit participants for key informant interviews and focus groups. Partnership groups represented low-income, urban African American, White, and Latino (primarily Puerto Rican) community members. Niagara Falls and Buffalo, NY, both have a high poverty rate and are medically underserved areas. In Niagara Falls, 77 % of the population graduated high school and 12.5 % have a college degree or higher educational attainment. Buffalo is the third poorest city of its size in the USA with almost 30 % of the residents below the poverty level (Thomas 2009).

Site-specific methods

The AANCART center used both focus groups and a self-administered community questionnaire that was completed by participants after the focus group. All focus groups were conducted with experienced bilingual bicultural community facilitators. Participants responded in both English and their native language. Two coders from each ethnicity analyzed the transcripts to identify, reconcile, and summarize themes. Descriptive statistics were used to analyze the participant sociodemographic characteristics. The questionnaires were based on the health behavior framework (Bastani et al. 2010; Maxwell et al. 2010) and assessed sociodemographic information and biospecimen-related attitude, beliefs, behavior, knowledge, and preferences (Bastani et al. 2010; Maxwell et al. 2010). Questionnaires were conducted in English with bilingual staff for participants who required additional language assistance. As the term “biospecimens” originates from the English language, there is not an inherent native term existing in Chinese, Hmong, or Vietnamese. Thus, if the term does not exist, we learned that explaining “biospecimens” in

**Table 2** Community Network Program Centers (CNPCs) population factors by study site

Community Network Program Centers (CNPCs)	The Asian American Network for Cancer Awareness Research and Training (AANCART)	Tampa Bay Community Center Network (TBCCN)	Western New York Cancer Coalition Center to Reduce Disparities (WNYCC)
Study location	Sacramento, CA	Tampa, FL	Buffalo and Niagara Falls, NY
Time of study	November 2009–August 2011	September 2009–December 2012	September 2008–August 2010 October 2010–August 2012
Study site population size	472,178 residents (Sacramento)	1,277,746 residents (Hillsborough County)	259,143 residents (Buffalo) 50,193 residents (Niagara Falls)
Median household income	\$50,661 (Sacramento) <sup>a</sup>	\$43,514 (Tampa) <sup>a</sup>	\$30,502 (Buffalo) <sup>a</sup> \$33,324 (Niagara Falls) <sup>a</sup>
Study sample races and/or national origin	Asian	White, African American, Latino	White, African American, Latino
Study Sample Ethnicities	Chinese, Hmong, Vietnamese	Hispanic: Central America, South American, Mexican, Cuban, Puerto Rican	Puerto Rican

<sup>a</sup> Source US Census Bureau: State and County QuickFacts. Data derived from Population Estimates, American Community Survey, Census of Population and Housing, County Business Patterns, Economic Census, Survey of Business Owners, Building Permits, Census of Governments Last Revised: Tuesday, 07 January 2014 16:01:52 EST

terms of examples was needed. Participants in the focus groups first received the following NCI definition of biospecimens prior to discussion: “Any biological material taken from a person for diagnostic or research purposes. Biospecimens can be cellular molecules (such as DNA or proteins), cells, tissues (such as skin, bone, or muscle), organs (such as liver, heart, or kidney), blood, gametes (sperm and ova), embryos, fetal tissue, or waste (such as urine, feces, or nail clippings).” We next exemplified “biospecimens” as blood, saliva, hair, nail clippings, or tissue, all physical/biological parts of the body that could be extracted and examined in order to contribute to information within the field of cancer research.

The TBCCN study team compiled the 12 focus group transcripts and prepared them for data analysis and coding. Nine of the focus groups were conducted in English and three in Spanish. The study utilized purposive sampling techniques to recruit a total of 95 adult participants. The study team used content analysis to identify emergent themes, or trends from the transcripts. A fuller description of the qualitative research design and coding procedures is described elsewhere (Luque et al. 2012). The groups were segmented by the following: (1) race/ethnicity (African American only and mixed race/ethnicity) and language (Spanish-speaking) and (2) age group (18–29, 30–54, and 55 and older). These categories produced 12 total focus groups composed of six groups of mixed race/ethnicity, three groups of African Americans, and three groups of Spanish-speaking participants.

The WNYCC conducted two separate biobanking pilot studies with nine Key Informant Interviews (KII) and three focus groups conducted in Niagara Falls, NY (Erwin et al. 2013), and six KII and four focus groups with Hispanic participants in Buffalo, NY (Rodriguez et al. 2013). Each of the four focus groups had two sources of data including: (1) ARS polling results and (2) focus group transcripts. The ARS was used during the focus groups to collect demographic data, and incorporated questions in PowerPoint format that were read aloud by the facilitator. Focus group transcripts were analyzed by two coders using an immersion crystallization approach (Borkan 1999). Complete descriptions of the methods and designs of these pilots are published elsewhere (Erwin et al. 2013; Rodriguez et al. 2013), and key details in comparison with the other sites are listed in Table 1.

Participants from all three sites were provided familiar examples of different types of biospecimens, e.g., blood, saliva, and urine (biospecimens), and all three sites related a biobank to a “large library” to contextually help participants understanding. Participants in the AANCART and TBCCN focus groups received short definitions of biobanking and biospecimens drawn from NCI’s Office of Biorepositories and Biospecimens (OBBR) glossary of terms—prior to discussion of the topic (NCI). The term for biospecimen for the Spanish-speaking groups in WNY was described in Spanish

as either *especimen biológico* or *muestra de...*, which translates to biological specimen or sample/specimen of (e.g., saliva or blood).

## Comparative findings across groups on biobanking and biospecimen

### Terminology/message content

Because each body part represents different measures of invasiveness and because cultural beliefs are associated with each of these parts, the willingness of the AANCART populations to contribute biospecimens also varied accordingly. One Vietnamese participant stated, “Blood is not my first choice for contribution but I would do it if the environment is right...In a safe setting with trained professionals.” After learning the definition of biospecimens, one Hmong participant said, “From what I now understand, biospecimen means a lot of different things, not just blood. Everything that is a part of your body, like teeth, saliva, skin, blood, hair, and nails... you can donate different things.” In terms of actual biospecimen donation, participants wanted to be engaged in the process. They wanted to know the quantity of specimen that would be donated (i.e., how many tubes of blood, size of tissue, etc.), where/how the specimens were going to be stored, for how long the specimens would be stored, and what type of research would be conducted with their biospecimens.

In 4 of the 12 focus groups held by TBCCN, there was low knowledge of the definition or purpose of biobanking. In another 4 of the 12 focus groups with some prior knowledge of biobanking, possible suggested alternative terms for biobanking included “biolibrary,” “biostorage,” and “biodatabase.” Findings also showed that there were some concerns expressed about the possible negative connotations of the terms “bank” and “storage.” In the Spanish-speaking groups the term *biblioteca* (library) and *bodega* (warehouse) had the most currency. For example, one male participant stated, “I would call it storage, because we have everything there, and have all classes of specimens.” One group preferred the term “library” to *muestra* (specimen) since they associated urine with specimens. The Spanish language groups were familiar with the concept of biospecimens, but not with the storage aspect. Regarding message content, participants expressed that they wanted thorough and easy explanations of the steps involved with biobanking and what participants needed to commit to in order to participate (e.g., informed consent). Participants also wanted to know how biobanks could benefit future generations and society. Participants expressed interest about how their biospecimens could be useful to people of their own background and heritage (e.g.,

diseases or cancer that might affect certain groups more than others).

The Spanish terms used to discuss biospecimens by the WNYCC were selected by the research team (e.g., *espécimen biológico* or *muestra de saliva/sangre*) and were understood by community participants; however, overall the concept of donating biospecimens for cancer research purposes rather than clinical or diagnostic use was a novel and unfamiliar topic for the majority of participants. Examples rather than a specific definition for biospecimen (e.g., saliva, blood, tissue, etc.) were used to illustrate the meaning of the term during the community presentations. Few White or African-American participants in Niagara Falls understood the concept of biobanking and using genetic material (i.e., biological samples of blood, spit or tumors) for epidemiological research. Upon further explanation and definition (see NCI definition above), participants understood the concepts of using these samples from their bodies for research to discover the causes of cancer, but did not link it to collecting “biospecimens” from cancer patients and healthy controls (Erwin et al. 2013).

#### Level of awareness

There was a low level of awareness regarding the concept of biospecimens in all focus groups conducted by AANCART, TBCCN, and WNYCC. Participants expressed many culturally-specific and cognitive perceptions that differ from current scientific beliefs regarding biospecimens and the donation process. For example, in the Vietnamese focus groups, participants feared that when blood is drawn, the person drawing the blood could inject them with a disease. One Vietnamese participant said, “I would not donate...what if after my blood draw I get sicker because the doctor injected me with some other diseases...you never know...” Another Vietnamese participant stated that he is already in weak health and if he donated he “would be in weaker health, and did not have enough blood as is...” In terms of blood donation, half of the participants felt that blood draws weaken the body (finite number of blood cells in the body, blood does not replenish). All of the focus groups expressed concerns of mistrust of the research being conducted (fear of being cloned). In addition, a majority of the participants felt that if researchers discovered something serious about their health, participants should be informed (issues with anonymous samples).

In addition to low awareness about biobanking, there were some misconceptions about this topic reported by participants. For example, some groups in the Tampa area wondered about the use of biobanking for cloning purposes or believed that biospecimens could be taken without people’s knowledge and used in research in countries without strict laws governing research. For example, one male participant (African American) stated: “So, I think a lot of times a lot of the specimens are sent as close as Canada, because they don’t have the strict laws

in terms of what you can and can’t do in terms of experimentation ... I’ll say I agree with this young lady here that, I think a lot of our stuff is shipped off.” In general, participants in most of the groups acknowledged the value of using biospecimens to make important advances in health research and understanding cancer. Some participants were familiar with sperm banks, blood banks, and umbilical cord banks, but had not heard the term “biobank.” In the Spanish language focus groups, participants thought the moderator was referring to biopsies or to a blood bank with the mention of the term biobank or *banco de muestras*.

Based on WNY participants’ discussion, there was a lack of understanding among Puerto Rican participants, especially, regarding the differences between clinical, prevention, and biobanking research (Rodriguez et al. 2013). Most had never donated any type of biospecimen or ever been asked to participate in a donation for research; therefore, many were unclear on the donation process and had questions with regard to eligibility criteria (i.e., healthy versus ill; having cancer versus having other illnesses; and if being a patient at the cancer center was required). The following quote best represents a recurrent theme in the focus groups with regard to participants’ expectation of receiving individual cancer diagnoses or results upon participating in biospecimen donation: “My baby has cancer, my aunt died of cancer, my sister has cancer, my mother died of cancer, so for example, if I donate, I would like to know the level of development of cancer in me, for example” (Rodriguez et al. 2013). None of the White participants in Niagara Falls had personal experience with biobanking or collection of biospecimens for research, and they were only familiar with blood banks and the process of donating blood or plasma for patient use. Their primary research experiences and perceptions included what they had heard on television and the testing of drugs for profit by the pharmaceutical industry, with no specific references to biobanks (Erwin et al. 2013). Eleven of 14 African-American participants reported being unfamiliar or never having heard of a biobank. Because there was such low awareness and understanding about biospecimen banking for genetic and personalized medical research, there was little discussion by White, Hispanic, and African-American participants regarding the risks or issues of banking genetic materials (Erwin et al. 2013). An African-American participant reported that he would expect biobank participants to be like those of drug-sponsored clinical studies, “...college students and African-Americans who were doing it for the money.” A White male comment demonstrates that the concept of donating specimens was considered like clinical research programs or blood banks, “People [participants] make money off studies, like giving plasma...” (Erwin et al. 2013). Question prompts about the comparison of these donations and blood donations for genetic analysis for biobanking did not promote responses that demonstrated a differentiation between donating

specimens for blood bank purposes and the donation of individual genetic material for long-term banking and research (Erwin et al. 2013).

### Impediments

AANCART participants were asked what their concerns were regarding biospecimen donation. Participants cited numerous factors that may inhibit them from donating, from researchers “selling their specimens to other organizations” to researchers “conducting research on the specimens that they were unaware of.” In terms of contributing blood, several Chinese participants expressed that blood is highly valued in the community and one participant pointed out that the “...Chinese always treasure their blood...” A concern expressed by several Hmong participants was the idea that the leftover stored tissue can be a mechanism for someone to cause them ill will. One Hmong participant stated, “what if someone, my enemy, got their hands on my tissue...they can use the tissue to cast diseases/illnesses upon me...how can the researcher guarantee that won’t happen...” Many Vietnamese participants alluded to their fear of blood and needles as a deterrent for donating. In all focus groups, participants discussed and categorized types of specimens they would be more likely to donate. All participants agreed that the more invasive the specimen was the least likely they would be willing to donate. However, across all groups, participants mentioned that if the specimen was leftover from surgery, they would consent to donate.

TBCCN focus group participants discussed several factors that could deter biobanking participation. Among these included fear of pain involved in donating (e.g., fear of needles, invasive procedures), distrust of research (e.g., cloning, using biospecimens for profit, being used as a “guinea pig”), and privacy concerns (e.g., disclosure of health conditions to insurance companies, HIV status, access to their information). Regarding trust in research and privacy concerns about storing biospecimens, a female focus group member in one of the mixed race focus groups stated: “If you withdraw consent, then that means, you know, you are probably going to be responsible also for paying for that to be destroyed, or making sure that it gets destroyed. And that’s the big question there, you know, do you leave it in circulation, or do you trust the fact that someone actually went ahead and destroyed it?” In one focus group of African-Americans, the theme of “lab rats” and “guinea pigs” was more common when discussing considerations to participating in research than in the mixed race groups or Spanish-speaking groups. One male African-American focus group participant expressed his concern about doctors requesting biospecimens: “By asking for something, like she said, that he don’t have a right to ask you for. You know, why should he be asking for my blood, you know, you already got my blood and this and that, or urine thing, what’s it for?” In a different African-American focus group, a female

participant echoed this concern stating: “I can kind of say that for a lot of African-American Black people, they feel that research uses us as test monkeys and stuff like that.” There was less resistance to the issue of donating tissue in the Spanish-language groups. For example, a participant recalled a situation when a doctor in Mexico asked for some excess tissue that was removed to be used in research. The participant stated that she agreed to donate the tissue for this purpose. In one of the mixed race focus groups, the participants agreed that biobanking was a good idea if it would advance cancer research. However, in the same group, there was some concern that such research would solely be used for commercial gain and not benefit people directly, as well as some concerns about the confidentiality and privacy safeguards.

A lack of direct benefit and the perception that participation in research could pose undue risk to the participant were reported as barriers by Hispanic participants in WNY. An example of undue risk was the perception that participation in the research might cause illness and could then impact their families in terms of caretaking responsibilities, as one Hispanic participant expressed in this statement: “I would not want to get sick and I want to be able to take care of my family.” The majority of participants from the Hispanic community believed that doctors or scientists conducting the research had more to gain from the studies in terms of recognition for finding a cure and receiving profit from their scientific discoveries: “...they are doctors, they are laboratories, and people doing work, and that is money.”

From the African-American and White participants in Niagara Falls, factors that negatively influence participation included convenience of donating, medical mistrust, and fear: “Inconvenient ... not having time or able to leave your job...” (three individuals); “Distrust of doctors...Big Brother aspect of pharmaceuticals” (two White individuals); “Afraid to take something that could put me at more risk...” [fear-related responses] (three African-American individuals); “There’s a power issue—people having power over you” (two African-American individuals); concerns about being a “guinea pig” (three individuals). In addition, several White focus group participants made comments about advertising and issues with drug development and the pharmaceutical industry: “...drug companies—I don’t believe them...” “I wouldn’t want to participate in anything that was done by the drug companies because it’s just going to benefit them” (Erwin et al. 2013). Several White participants reported fears of “needles, keeping my DNA, blood testing/blood draws,” and whether “needles would be clean.”

### Facilitators

Asian-American participants were asked what would make them consider donating their biospecimen for research. Across all three ethnic groups, participants would be more willing to



donate if someone they knew directly benefitted from the biospecimen and to help advance medical discoveries for future generations. One Chinese participant said, “If doctor discover something new, they can help improve people’s health and everyone will become healthy. This can help disabled and cancer patients. If there are enough samples available for research, this can help save people’s life, and it is something good.” Several of the participants reiterated that their community would donate “as long as you give them a good explanation of what a biospecimen is, what it is needed for, and what the intention of collecting the biospecimen is for, it should be ok.” Vietnamese participants were concerned about the donation process and their general health status, one participant said, “depends on the time and how the donation procedure would affect my daily tasks and health.” In terms of what participants thought would be the best way to receive information regarding biospecimens, Chinese participants preferred a brochure introducing the topic that they can take home and read; the Hmong participants preferred an in-language video they can watch prior to their doctor’s appointment; and Vietnamese participants preferred provider referral (Dang and Chen 2011).

Focus group participants in the Tampa Bay area identified multiple facilitators to biobanking participation. These included the following: (1) knowing someone with a chronic disease or personally having a history of a disease such as cancer, (2) perceived immediate benefits of donating (e.g., helping another person), (3) volunteerism, (4) participating in research to help society and future generations, (5) being informed of the benefits of biobanking, and (6) general convenience (e.g., already undergoing a medical procedure and consenting to donate unused or unwanted tissue). A common theme was donating to benefit an immediate family member or to help future generations. An example of this sentiment was illustrated by an African-American male focus group participant who stated: “So, I know if I can, you know, time by everybody lived that ((sigh)) could help the rest of my family with this cancer thing, you know, I’m all for it. Whatever information or data I can get that maybe can help someone in my family, because I had three people die in the last three years from cancer.” Regarding receiving information, most participants suggested either print (e.g., photo-novellas) or video materials (e.g., TV news, internet video, videos in doctor’s offices), as well as workshops and community health fairs. Credible sources included celebrities, medical doctors, and people from the community (Luque et al. 2012).

Puerto Rican participants in WNY stated they would be willing to donate a biospecimen as a way to help advance research, as expressed in the comment made by one participant: “So they are able to do more investigation.” Another Hispanic participant expressed their decision to donate a biospecimen in terms of making a contribution “to better humanity.” Many believed the biobank to be an important community resource

despite their lack of experience with participating in biospecimen donations for cancer research efforts and were not concerned with the existence of a biobank. Receiving a recommendation from their health care provider regarding the biobank was a positive influence since many participants believed their provider would make recommendations that were in their best interest. Although the majority of participants did not expect to receive an incentive for research participation, the majority reported that a monetary incentive would influence their decision to donate to the biobank. Community participants also discussed the importance of providing in-language materials (e.g., Spanish) at relevant community locations and the following quote best illustrates the community perspective on inclusion relative to language as a barrier: “Language is a big barrier, and therefore we do not feel included in these opportunities because we speak Spanish.” Participants also provided insightful suggestions for facilitating the donation process for interested community participants. For example: add this topic to community talks; collect biospecimens at the actual community health event; emphasize the small amount of the biospecimen collected for the donation; and disseminate educational materials on biospecimen donation at local medical offices. Suggestions for outreach in the community to increase awareness on the topic of biospecimen donation included the following: media outlets (e.g., radio, print, ads, and newspaper), community centers and health fairs, Hispanic churches, and businesses that cater to the Hispanic community (e.g., supermarkets, restaurants, bakery, beauty salons/barber shops, and bingo halls).

The White focus group participants knew that this focus group was conducted under the auspices of the regional NCI-designated cancer center. One man stated that “I’d be much more likely to participate in a study sponsored by [cancer center] than a drug company because the drug company is just going to exploit you or the situation to make money.” Upon further discussion, several participants stated personal experiences with the local cancer center that resulted in positive beliefs about the nature of research, particularly research conducted at the cancer center because it was focused on “finding better ways to help people” and “reduce suffering with cancer” (Erwin et al. 2013). One White participant stated that she would expect “[cancer center] to conduct safe research.”

White participants reported several ideas that they thought would increase participation in biobanking including timing, compensation, and involving the scientists: “People who work need to be compensated for their time ... transportation—some people let you take time off from work.” One member in the group suggested having a “lab scientist come talk to people in the community and tell them those stories... [about the uses for the biobanking program].” (Erwin et al. 2013).

All of the participants in the African-American focus group in Niagara Falls agreed that money was a factor in “reasons for

participating” or influencing a person to participate: “People in our community go for extra money.” The discussion and interaction among participants included many comments about the pros and cons of people being paid for donating blood or plasma, or for participating in studies. Questions about the differences in these donations and blood donations for genetic analysis for biobanking did not promote responses that demonstrated a differentiation between donating specimens for blood bank purposes and the donation of individual genetic material for long-term banking and research. Even with prompts about “future research,” there was little discussion regarding the risks or issues of banking genetic materials (Erwin et al. 2013).

#### Findings and research implications across sites

Key implications for conducting biospecimen research, based upon our findings across communities, are summarized in Table 3. Overall, across all our sites, the value of *trust-earning, open, and clear* communications were essential to understandings about the utility of cancer research innovations. In short, findings reinforced that deliberate and thoughtful engagement of local community members was beneficial to defining and refining understandings about a complex scientific topic. As such, the employment of participatory processes that aid in disentangling what people know, think, and believe about biobanks is critical to advancing the development of biobanks that truly represent the diversity within the United States’ demographically changing landscape. Further, our results suggest strong and genuine community support for cancer innovations such as a biobank. With that said, it is recommended that easy-to-understand and language-specific terminology is needed to communicate to the public “what biobanks are all about and how they might help prevent and cure cancer.” These findings are consistent with several IOM reports that reinforce the value of striving for clear patient-centric communications that resonate with people’s needs, values, and preferences (IOM 1999, 2004, 2013).

#### Discussion

To the best of our knowledge, this article is the first to analyze cognitive, communication, and sociocultural factors affecting biospecimen donation as demonstrated through qualitative inquiry concurrently among diverse racial and ethnic populations in three distinct parts of the USA: the northeast (western New York—WNY), southeast (central Florida), and west (inland northern California). Populations studied included African Americans, three Asian-American ethnic groups, diverse Hispanics, and Whites. Existing literature suggests that many populations generally have more negative feelings towards clinical research than their White counterparts (Shavers

et al. 2002); however, this study demonstrated that the feelings and cognitions related to biospecimen banking and research are multifaceted and reflect more about the cultural context, past experiences, and understandings of participants. This was true across all geographic sites and for all ethnic/racial groups. Once participants in our studies understood the meaning, use, and intent of collecting biospecimens for future research, the majority of individuals demonstrated ample willingness to consider participation. A key finding from this study was the fact that the vast majority of participants, regardless of race, ethnicity, or geographic region, had not been exposed to information about genomic and epidemiological types of research programs involving the use of biospecimens from healthy donors. This is not surprising as much of the general public is uninformed about this topic and it represents a relatively new area of cancer research to the general lay audience.

Examining and comparing findings by race and ethnicity, these data suggest that although there are varied expressions of feelings and perceptions about trust, the nature of the concerns across groups are often similar. For example, African-American respondents in WNY and in the Tampa area expressed comments that demonstrated continuing mistrust in the medical system (e.g., “Big Brother,” cleanliness of needles) and concerns of being a “guinea pig.” Likewise, Hmong and Vietnamese participants in California commented regarding concerns that specimens may be used to cause ill will against them or the blood draw would be used to inject something harmful, while White participants in WNY expressed suspicion of exploitation by corporations like large pharmaceutical companies. These correspond to the key implications identified in Table 3, regarding the significant need for building trust.

Responses categorized as “facilitators” for collecting biospecimens also demonstrated congruity across groups. The Puerto Ricans in WNY and other diverse Hispanic participants in Tampa Bay expressed various comments about the importance of the biospecimen donations to “better humanity,” or improve the health of their family members or future generations. Similarly, Chinese participants reported their opinions about the importance of research to help others and save lives, and White participants discussed the role of research at cancer centers to “reduce suffering.” Participants from all racial and ethnic groups and geographic locations agreed that given the appropriate engagement and methods to inform members of their community, biospecimen collections could be successful. Participants from all groups offered specific ideas about improving education, communication, and processes for engaging their community members, overcoming impediments, and providing culturally acceptable methods to collect and use biospecimens. These findings reflect the need for researchers to identify the inherent value of new

**Table 3** Key implications for researchers engaged in biospecimen research

Concept	Key finding	Implications for researchers
Form trust-earning relationships	We found that trust was an essential component of our research for recruiting diverse audiences. Trust allowed us to successfully carry out our work to address the information needs of the community while advancing scientific inquiry in this new field.	Researchers should focus their attention on the development of <i>trust-earning relationships</i> . Researchers need to recognize that: <ul style="list-style-type: none"> <li>• Trust entails placing value on the unique contributions that community and academic members bring to a research situation.</li> <li>• Trust occurs when there is a willingness to be open to others’ ideas, perceptions, and viewpoints.</li> <li>• Transparency on what the objectives and expectations are from all partners engaged in the research process.</li> <li>• Trust is enhanced in relationships with equal power and control.</li> <li>• Trust is gained through multiple efforts that go beyond the research encounter; and which extends to other mutually beneficial and sustained outreach or education partnerships.</li> </ul>
Find the value of research	We found that community members, across geographic sites and cultural groups, saw value in biobanking and biospecimen research, especially for <i>future generations</i> . There were many more similarities than differences.	Researchers need to find out how cancer research can best <i>resonate</i> with community members and is of value to them and their families. This means that the research focus/objective(s) must be understood by community members and match their values and priorities. This knowledge can be beneficial when developing research program messages and interventions that are useful and actionable.
Engage communities through formative research	We found that factors influencing participation negatively or positively are likely to be specific to the local sociopolitical and cultural experiences of a community group. As such, formative research such as focus groups, community discussions, or individual interviews, allows an understanding of community members’ concerns, perceptions, and understandings about a particular topic.	Participatory research approaches require active community engagement efforts in order to form research partnerships. Research partners can employ formative research to gain insights about factors that might influence or hinder receptivity to a new cancer innovation such as biobanking. The use of <i>community-based participatory research</i> (CBPR) can be an especially helpful approach to engage the community and provide co-learning by all partners in the research process.
Utilize clear communications	We found that once the concept of “biobanking,” the requirements for participation, and the sponsorship and organizational/institutional affiliation for such studies were defined clearly, using language-specific terminology, participants showed openness to considering donating biospecimens for research.	Methods that continually verify understanding of research concepts, terms, and phrases pertinent to a particular research topic to ensure <i>shared meaning</i> are essential. Communications (oral and written) must be clear, consumer-friendly, and linguistically, literacy and language-specific. This will help open the door toward an understanding of a research topic which is often laden with unfamiliar and difficult terminology. The messengers and study sponsors must be credible and trustworthy. CBPR approaches support an iterative approach to research that help to clarify meaning and perceptions held by the community that in turn enhance the research process.

innovations by community members regarding research goals (Streicher et al. 2011). As such, one then wonders how researchers can harness this keen public interest in biobanking in a way that supports the participation of diverse groups in biobanking. Others have demonstrated that engaging the community in an institution’s structural and developmental processes informs biobanking policy (O’Doherty and Burgess 2009; O’Doherty et al. 2011). Based on our findings, it is both feasible and advisable for research institutions to employ some form of community-based or community-partnered research to maintain an acceptable level of engagement in biobanking research. Similar to the wide use of community engagement processes in CBPR-oriented studies (e.g., establishment of community advisory panels, conduct of formative research, etc.), this mindset could be incorporated into standard operating processes of

existing or new biobanks. As examples, community members could be part of biobank boards, researchers could host periodic public forums, and results from biospecimen studies can be posted on websites or disseminated in lay publications. This manner of continually engaging the public in various aspects of biobanking may further serve to enhance awareness, inform the costs and benefits of participation, and understanding of the utility of biospecimen research, as others have suggested (Lemke et al. 2012).

Interestingly, one set of beliefs categorized as “impediments” from our findings were expressed only by Chinese, Vietnamese, and Hmong participants, suggesting that these may reflect singularly Eastern cultural values. These participant responses revolved around the value, preciousness, and balance of blood in the body and the nature and special

significance of blood. In these cultures, blood represents life and thus to take blood out implies losing life. These responses, specific to collecting blood and tissue specimens, have no apparent linkage to geographic region, but are reported in other ethnographic and cultural descriptions for these ethnic groups. In traditional Chinese culture, blood is viewed as a nonrenewable vital energy source (Spector 2000). Donating blood is perceived as harmful to your health and can have a negative effect on one's life energy *qi* (Tison et al. 2007). In the study conducted by Zaller et al. (2005), 20 % of Chinese respondents stated they could not contribute blood because they felt it would weaken their body or because they had poor health (i.e., loss of *qi*). In addition, traditionally the action of blood donation can be viewed as being disrespectful to one's ancestors because flesh and blood is inherited from parents (Shan et al. 2002). Similar to the Chinese traditional beliefs, the Hmong believe blood is the source of strength and vitality for the body. Some believe that there is a finite absolute amount of blood in the body and once that blood is drawn it will not be replenished (Cha 2003; EthnoMed 2012a). Among traditional Vietnamese, blood draws are also seen as a practice that will weaken the body, make an individual sicker and some believe blood is nonrenewable (New Hampshire Department of Health and Human Services; EthnoMed 2012b). These may represent culturally-specific methodological and education challenges for researchers collecting biological specimens from Asian ethnic groups.

In presenting our results, we recognize unevenness in the numbers of participants per racial/ethnic group among our three sites and the heterogeneity even within each racial/ethnic population. We recognize that some variations exist between participants who are more "acculturated" (i.e., more English proficient and accustomed to the health care system) versus those who are less "acculturated" (i.e., limited English proficiency and less exposure to the health care system) as well as education and socioeconomic differences. Some differences could be attributed to geography as the three study sites reflect different sociocultural, historical, and political venues in the USA. In addition, the Asian participants only represented California. Moreover, we cannot always determine the relational and representational impact of geographic location of a participant group in comparison to their racial/ethnic identity, leading to some confounding of factors in analysis. For example, many WNY participants have experienced the historical carcinogenic legacy and toxicity of the Love Canal chemical storage fiasco, which is not part of the cultural or historical consciousness of the Hmong or Chinese in California, nor the Hispanic or African-American participants in Florida. Conversely, the historical legacy of Tuskegee (Jones 1981) may impact African-American participants in both New York and Florida. Our purpose was not to seek proportional representation by race/ethnicity or even geographic site, but rather in the qualitative tradition to probe

thoughtfully and respectfully among those we recruited, in order to gain understanding about the scope of their perceptions on this topic of biospecimen research. There was also slight variability in our research procedures, and the findings are limited to the three regions and groups within those regions. We further affirm that others have conducted qualitative research to understand perceptions about biospecimens among Native peoples (Fong et al. 2004; Fong et al. 2006; Santos 2009) and these are not included in our comparisons.

Despite these acknowledged limitations, there are several distinct strengths to this comparative analysis. First, all of the researchers involved (authors) are experienced in working with their respective populations and value the perspectives that community participants have provided to inform the findings of this study. Authors included those who are bilingual and bicultural as well as those who have worked with medically underserved populations and who have the experience and expertise in assessing needs and who are from the communities being served. All of the researchers did not know the methodological approaches that others used until after their respective studies were completed. Hence, it is particularly noteworthy that all independently used similar approaches to understand the phenomenon and explore biospecimen collection within their respective populations adding to the validity of our approaches and demonstrating the seminal nature of this topic. In so doing, all of the researchers employed qualitative approaches, e.g., key informant interviews and focus groups. Likewise, all three studies employed considerable community collaboration using a CBPR approach. As a result, we learned underlying reasons and worldviews of participants, i.e., the "why" and "how" and not just the "what." Another significant strength of this study is the broad and rich array of racial, ethnic, and geographic representation resulting in unique comparative analyses allowing greater insight into understanding the specific issues that may serve as barriers and facilitators to biospecimen donation. The congruence of so many shared perspectives about this topic across groups is especially interesting in light of the significant variations in cultural contexts.

With respect to overarching directions for future interventions, we found most participants knew very little about biospecimens in the aggregate, and the term biospecimens was unfamiliar both to the English-fluent as well as to those who spoke and preferred to speak other languages, such as Chinese, Hmong, Spanish, or Vietnamese. Thus, all populations need clear explanations of the term and meaning of "biospecimen." For those whose primary language was other than English, authors used concrete terms, e.g., blood, tissue, saliva, urine, hair, to denote what biospecimens mean. For the English-speakers, the authors still needed to explain that biospecimens were products from their bodies (e.g., blood, urine, etc.) that could be analyzed for the presence of biological or genetic markers or diseases. As the terms were

explained, responses to questions revealed various racial/ethnic differences with respect to concerns and feelings that may be impediments to donating biospecimens for research. Thus, as new biotechnologies and cancer innovations emerge, we are reminded that easy-to-understand information that is *contextually* situated is basic to the process of good communication and decision-making.

Once study participants understood the nature and definition of the term, biospecimens, and its use and application in science and clinical medicine, individuals reported being very willing to donate blood, saliva, or other biospecimens. A major influencing factor reported to facilitate donation was the altruistic value of having their biospecimen used to benefit others, particularly for future generations (from their racial/ethnic group). In short, they like the idea of knowing someone else might benefit. Understanding sponsorship and ownership of biospecimen collections was also reported as important—particularly affiliations with non-profit and research entities rather than pharmaceutical companies or for-profit corporations.

With regard to the social scientific and ethical dialectic regarding concerns for social justice and equity in the inclusion of racial and ethnic minorities in clinical research, these studies employed community engagement and cultural brokerage through a CBPR orientation in collaboration with local community partners in each site to conduct focus groups and interviews to improve researchers' and participants' understanding of the needs, requirements, and processes that may influence biospecimen donation. These CBPR studies were intentionally created as co-learning opportunities within each focus group and interview. The academic partners were learning to view the issue from the perspective of the lay community, while the lay participants were learning about the science and methods of etiological, epidemiological, and clinical cancer research. In this process, we believe mutual knowledge, understanding, and communication can serve as powerful mechanisms for improving trust and power equity among academic and community partners. In the true spirit of CBPR, the ultimate goal of this research is equitable engagement of the communities we serve and with whom we collaborate to assure appropriate opportunities for treatment, drug development, and prevention as technology and science of personalized medicine advances. Therefore, we support “the crucial need for clinical research that focuses properly on the health concerns of racial and ethnic minority communities while also protecting research participants from undue risk” (Epstein 2008, p. 822). The outcomes from this research can also provide steps to begin to deconstruct the power and trust differentials that have created barriers to access to state-of-the-art clinical sciences, which have contributed to the inequities in cancer incidence and survival since the 1980s for many people of color and poverty in the USA (Elk and Hope 2012).

Findings from these studies have subsequently been used to inform the development of community-specific educational tools and outreach programs (e.g., DVDs, brochures, presentations, lay health worker training modules, etc.) to prime and prompt community members to learn about, decide, and consider biospecimen donation. We view the application of CBPR approaches for creating salient education highly congruent with the new enhanced National CLAS standards (<https://www.thinkculturalhealth.hhs.gov/Content/clas.asp>), from the Office of Minority Health, which recommend program responsiveness to diverse cultural health beliefs, and practices, preferred languages, health literacy, and other communication needs. Moreover, researchers are encouraged to carefully examine how elements of CBPR (i.e., participatory processes) can be incorporated into the fabric of biobank's operating procedures for maintaining trust, transparency, and public engagement. Overall, findings from the research at all sites suggest that if community members become aware and knowledgeable about research technology and practices in ways that are relevant and meaningful, they are likely to be able to make an informed choice about study/biobank participation and donation.

## Conclusions

Engaging diverse communities in biospecimen contribution for cancer research requires *time*, *trust*, and *transparency* (Dang and Chen 2011). In accordance with CBPR principles, researchers should commit to investing the *time* necessary to developing community relationships and earning community *trust* through *transparency*, clear communication, and culturally and contextually appropriate education. The CNPC sites performing this research have benefited from years of collaboration with community-based organizations. Within these sustained and collaborative relationships, for the current and future science of cancer research, collecting biospecimens needs to be viewed as mutually beneficial to all partners. Such collaborations build community capacity to improve understanding about the value of collecting diverse biospecimens for cancer research, and the ultimate potential of biospecimen research for cancer prevention and treatment. Further research and interventions should address the issues of the four primary domains identified in this research: (1) terminology/message; (2) level of awareness by participants; (3) perceived impediments to donating biological biospecimens, such as blood or saliva for biobanking; and (4) reported facilitators/engagement procedures that enhance the likelihood by participants to donate biospecimens.

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