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Formative Research on Perceptions of Biobanking: What Community Members Think

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Abstract

Preparing healthy community members with timely communications prior to engaging them in a request to donate biospecimens promises to improve the experience of biobanking participation. To this end, a qualitative study was conducted to assess community member knowledge, attitudes, beliefs, and informational needs about cancer-related biospecimen collection in a large metropolitan area in southwest Florida. The study utilized purposive sampling techniques to recruit a total of 95 participants to participate in 12 focus groups, segmented by race/ethnicity and language preference (mixed race, African American only, and Spanish speaking) and age (18–29, 30–54, and 55 and older). Focus group interviews were analyzed using content analysis to identify emergent themes. Overall, participants in the 30 years and older groups were favorable toward participating in biobanking if their concerns were addressed, such as confidentiality and consent issues, in contrast to participants aged 18–29 who were more skeptical. For all participants, the desire to participate in research that seeks new cancer treatments outweighed mistrust. Moreover, many cited the potential scientific benefit for future generations as a primary motivator. Finally, in

some groups a therapeutic misconception was expressed, where participants expressed a willingness to forego confidentiality of their health status in exchange for therapeutic benefit. This study contributes to the literature on community perceptions of the benefits and barriers of biobanking and adds to the development of meaningful education communication priming tools to advance understandings about biobanking.

Keywords

Biobanking; Biospecimens; Tissue Donor; Focus Group; Informed Consent; Ethics

Introduction

Biobanks are repositories of human tissue (e.g., blood, urine, etc.), often connected to electronic databases containing medical and personal health information, for the purposes of diagnostic procedures, surgical treatment, and education or research [1, 2]. Biobanks are envisioned as essential for effective basic, epidemiologic, and translational research. They allow researchers to discover genetic associations of complex diseases and develop new therapies and prevention strategies [3, 4]. To move closer to achieving goals related to personalized medicine and individualized cancer care, participation in biobanking from large numbers of diverse, multi-ethnic patients, in addition to healthy volunteers, is essential.

With the growth of biobanking, there is public concern over privacy issues, genetic discrimination from employers and insurance providers, regulation of scientific research, and compensation or other benefit from donated tissues [5, 6]. The National Cancer Institute's (NCI) Office of Biorepositories and Biospecimen Research identified the development of educational communication priming tools and resources related to biobanking as one of its strategic priorities [7]. To assuage the public's concerns, the use of community engagement methods to improve communications and understandings on biobanking has been suggested by major health care institutions, such as the Mayo Clinic, as one way to bring constituents' voices into discussions and influence the way biobanks are implemented [8–11]. In addition, accountability, transparency, and proper monitoring of biobanking procedures are found to engender and maintain the public's trust in biobanking [12, 13].

The theme of “therapeutic misconception” has emerged as an explanatory category for possible egoistic motives for volunteering in clinical trials. In other words, some people believe that participation in research might directly lead to a medical cure for either themselves or their relatives [14, 15]. One study found that the type of tissue requested for donation may affect the donor's willingness to participate [5]. In qualitative research on tumor tissue donation, responses from participants indicated that such tissue was “useless” and better to be “thrown away,” or would just “go to waste” [16]. In a Swedish study, varying rates of biobanking participation were shown to be a function of trust in one's health care provider, study investigator, or institution [17]. One recent study found that a multipronged communication “strategy” with participants after receiving consent for biobanking participation is a promising approach to enhance ‘trust’ in research, but that each communication tool needs to be evaluated independently for effectiveness [18]. Other motives might include a “gift exchange” or altruistic motives, wherein social ties are reinforced between the giver and receiver of tissue, with the notion of future benefit for either patients or science in general through the act of tissue donation [19]. An obvious reason why healthy individuals may not participate in biobanking is lack of awareness or knowledge of donation opportunities. Simply put, they may not have been aware that donation is possible in certain clinical settings or even know what questions to ask about this

topic. Additionally, some community members might initially refuse to participate in biobanking because they have never considered the benefits of contributing to future scientific research.

After donation, some participants may want assurances that their samples will be handled responsibly. One study found that individuals are more likely to participate in biobanking if they could maintain some control and monitoring over their biospecimens, preferring categorical versus blanket informed consent for use of their samples [20]. This position however is problematic for researchers since future technological advances cannot always be predicted, and consequently, donors may be unable to meaningfully engage in an informed consent process which requires future decisions about the use of their tissue samples [21]. Other studies suggest that many individuals have found participants do not feel the need to understand all the study details to participate in biobanking. Rather, they feel relatively confident in the merits of scientific research [5, 22]. A systematic review reported that participants who refused consent were often more concerned with the method for obtaining the tissue (e.g., blood draw, biopsy) than with the possible use of their samples for research [23].

Preparing healthy community members with timely communications prior to engaging them in a request promises to improve the experience of biobanking participation, as people will have an opportunity to understand the topic and make an informed decision. Attention to health literacy and specific cultural and linguistic needs of multi-ethnic populations when creating biobanking communications are integral to meaningfully address proximal decisional determinants [24]. Moreover, from a researcher's perspective, there is a strong need for donors as healthy controls for epidemiological studies.

Thus, a qualitative study was undertaken to assess community member knowledge, attitudes, beliefs, and informational needs about biobanking, in response to the establishment of a biobank in Tampa Bay, Florida. This study was conducted as part of the NCI-funded Tampa Bay Community Cancer Network (TBCCN), which is one of the Community Network Program sites composed of 22 partner organizations and tasked with the goal of reducing cancer health disparities among racial/ethnic minority and medically underserved populations. This study gauges how to best frame information in advance of opportunities for community donation to a local biobank, such as with Moffitt's Cancer Center's Total Cancer Care plan, which combines information technology, science, and clinical treatment [25]. Findings may also have implications for other regional and national biobanking initiatives seeking to include participation of community members as healthy controls.

Methods

Design

Twelve focus groups were conducted to explore knowledge, attitudes, beliefs, and informational needs regarding biobanking with healthy community members.

Community Advisory Group

The study was conducted with the guidance of a biobanking community advisory group (CAG). Members from the CAG were identified from the TBCCN partner organizations. The advisory group members guided study efforts by ensuring the study design and instruments had relevance and meaning for community members. The CAG met quarterly to review study instruments, examine focus group questions, evaluate the promotional materials, and provide important community insights and perspectives. Interactive activities to engage advisory group members included educational presentations and a tour of biobanking facilities. The study was conducted under the auspices of the TBCCN cancer

health disparities initiative with full support of a diverse group of community partner organizations.

Sampling and Recruitment

The number of groups was determined by three preidentified age and sociodemographic segments, based on the principle of thematic saturation [26]. The groups were segmented by: (1) race/ethnicity and language (mixed race; African American only and Spanish speaking) and (2) age group (18–29, 30–54, and 55 and older). Groups were segmented based on potential differences that were previously found from studies on cancer-related knowledge with diverse populations in Tampa Bay [27, 28]. The sample included six mixed race, three African American, and three Spanish-speaking focus groups, and the focus groups ranged in size from four to 11 people (Table 1).

The study utilized purposive sampling techniques to recruit a total of 95 participants. Eligibility criteria for participation in the focus groups included individuals who were: (1) able to speak English or Spanish; (2) 18 years of age; and (3) not previously diagnosed with cancer other than non-melanoma skin cancer. Recruitment was facilitated through collaborations with existing community networks and the CAG. Recruitment flyers were disseminated at community partner sites and through word of mouth using outreach workers, community leaders, and health educators. Research personnel screened interested individuals for eligibility over the phone. Eligible individuals were then invited to participate in one of the focus groups, which lasted approximately 2 h.

Instrumentation and Data Collection

A semi-structured focus group guide was developed through a review of existing literature and with feedback from the CAG members and lead investigators who helped shape the following domains for exploration: (1) general health and research knowledge and attitudes; (2) knowledge, attitudes, and beliefs towards biospecimen collection; (3) motivations toward research and biospecimen collection and informational needs; (4) ethical concerns regarding biospecimen collection; and (5) learning preferences [5, 29, 30]. A brief sociodemographic survey was used to collect participant's age, race/ethnicity, gender, marital status, highest educational level attainment, occupation, and employment status. All instruments were professionally translated by a certified translator for the Spanish language focus groups. The general purpose of the focus groups was to explore community members' knowledge, attitudes, and beliefs toward cancer-related biospecimen collection/biobanking [31].

Focus groups were conducted at various community sites by pairs of trained focus group moderators, in either English or Spanish depending on the language preference of the group. All participants provided informed consent prior to the focus group. Light refreshments were served. At the beginning of each focus group, the moderator provided a definition of the term “biobank” and explained its function. After each focus group, participants completed a brief demographic questionnaire. In our study, we discovered that no new themes were identified after five focus groups; however, based on our sampling strategy of having three groups per demographic composition (to identify possible differences), we continued to conduct the groups until we had completed our original sampling strategy. This study was approved by the university institutional review board, and participants received a \$30 cash stipend.

Qualitative Data Coding and Analysis

Focus groups were digitally recorded, transcribed verbatim, manually coded, and reviewed by members of the research team. Grounded Theory, a content analysis technique, was used to identify emergent themes, or trends from the focus group transcripts [32]. The coding

procedures followed a series of steps which included: (1) developing a preliminary set of codes (themes) corresponding to each item in the interview protocol, (2) creating additional codes that emerged and were of special interest to the research goals, (3) developing non-substantive codes, and (4) producing detailed codes to use for analyses of specific topics. MAXQDA [33], a computer-assisted qualitative data analysis software was used to facilitate the coding process. The software package enabled pairs of coders to work collaboratively across transcripts on each theme. Each theme was assessed in terms of its implications for developing educational communication priming tools on biobanking. Sociodemographic information of focus group participants was summarized using descriptive statistics, including means, standard deviations, and frequencies.

Results

Knowledge of Genetics, Biobanks, and Terminology

Focus group participants reported their sources of health information primarily came from the internet (e.g., WebMD and Wikipedia), television, or personal contact with health professionals. There was limited prior genetic knowledge among all participants. Participants most frequently mentioned genetic research in relation to stem cells and Alzheimer's disease. In one of the African American focus groups, participants expressed mistrust of research because of the perception that scientific recommendations were constantly changing, and the ethical issues raised with animal testing. Tied to this idea of how research was typically conducted was the perception that research depersonalized disease processes. Using cancer as an example, one participant said, "When we are talking about this research, and any human being ... to donate for research. To me, it should be more PERSONALIZED in the sense of some cancers affect some people, and the same circumstances don't affect other people. So, in my opinion ... I kind of feel like the research is time wasted." (30–54 years, female).

Another common association elicited in the groups was the relationship between genetics and DNA with paternity testing, criminal investigations, and hereditary diseases. Six of the 12 groups mentioned the role of genetics as a determinant of cancer (i.e., *BRCA 1 or 2*), and the unrelated recent controversy about changing breast cancer screening guidelines by the US Preventive Services Task Force for increasing the initial recommended screening age from 40 to 50 years [34].

After a brief definition of biobanking, the focus group moderators asked participants to share their knowledge and suggest alternative terms to describe the term biobanking. In four of the 12 groups, there was limited knowledge or awareness of biobanking. For example in one of the groups, participants asked, "How do they store it? Do they freeze it?" (18–29 years, male). Participants in another group believed that biospecimen collection was already being conducted with de-identified leftover tissue. Other participants in the same group suspected that this tissue might be shipped to other countries without "strict laws" governing research, as in the USA. Another group also expressed mistrust of donated tissue for possible deceptive research purposes. In two of the groups, there was the association of sperm, blood, and umbilical cord banking with biobanking. Of the four groups with biobanking knowledge, possible alternative terms for biobanks included, biolibrary, biostorage, and biodatabase. The three Spanish language groups used possible alternative terms such as *biblioteca* (library), *bodega* (storage warehouse), and *banco de células* (cell bank), as described by one participant, "I would call it storage because we will have everything [in it], and because we will have everything [in it] we will discover everything [from it]." (30–54 years, female). In general, the word biobank was an acceptable term despite its obvious association with financial institutions.

Perceived Benefits

Perceived benefits to participation in biobanking included having a family history of chronic disease (e.g., family member with cancer and perceived future therapeutic benefit of contributing to research), convenience (e.g., already having a procedure done and donating tissue), immediate benefits to someone else (e.g., donating blood or bone marrow), receiving cash incentives, and a general sense of helping society and future generations (Table 2). One sentiment of benefiting future generations was described: “So for all those millions out there that got all those children, they are sitting there watching them die... that purpose alone would make me, because they deserve a fair chance, just for the children.” (30–54 years, female).

Having positive relationships with a healthcare provider was reported as increasing one’s motivation to donate. In one African American group, there was mention that one would donate in exchange for payment for urine and saliva samples, but not for blood. In one of the mixed race groups, a participant stated, “as long as the doctors performing it give you an explanation why, and what it’s going to do, how it’s going to be a benefit to maybe yourself or another individual, then I’d have no problem.” (55+ years, male). Finally, some participants did not feel strongly about the topic, explaining that they did not need to know all the specifics of studies as explained in informed consent documents, and that leftover tissue from medical procedures was disposable and not of profound importance, as one participant expressed, “It’s already out, they’ll throw it out anyway.” (18–29 years, male).

Perceived Barriers

Perceived barriers for biobanking participation included fear of biospecimen extraction procedures (e.g., needles or repetitive blood draws), cloning concerns (e.g., research misconduct or bioweapons development), and lack of information about how biobanks functioned (e.g., biospecimen extraction and storage procedures or access to the data). Moreover, there was mistrust of researchers (e.g., lack of transparency or potential exploitation of research subjects for profit), as well as privacy concerns (e.g., insurance companies using information in determining coverage, disclosure of personal health history, or vulnerable computer database systems). For example, one participant said, “I wonder about the security of the actual physical storage place. I don’t want people breaking in the place.” (18–29 years, male).

Media coverage on the Henrietta Lacks story and HeLa cells, prompted by the publication of a popular book, was directly mentioned in one focus group, and alluded to in two other focus groups, thus contributing to negative perceptions toward the use of biospecimens [35]. In two of the African American groups, there was the view that research was conducted for the benefit of white populations, while minority groups have been unjustly used as “lab rats” or “guinea pigs.” In one of these groups, participants felt that doctors were more concerned with research than caring for their patients. Moreover, questions were raised relating to the direct benefits stemming from biomedical research participation, as one participant stated: “if your cells DO become useful, whose are they, and do you benefit from them? So, I think that would be my concern ... there’s a collection of cells from us ... okay, this could be beneficial to generations after us, but we won’t actually ever see it. Maybe in the future we’ll see it, and so there’s not really a DIRECT BENEFIT to it; but I think there are still a lot of questions.” (18–29 years, female).

Similarities and Differences by Age Group in Biobanking Perceptions

Across all age groups, those who had a family member diagnosed with cancer were more willing to consider participation and to donate to help others to advance scientific research. This theme was expressed by one participant in one of the African American groups, “I have

had members of my family die of cancer, and so anything I can do to be of assistance as far as education and research.” (30–54 years, female). However, participants in the youngest age group expressed more concerns about privacy, confidentiality, and mistrust of the use for their biospecimens: “In order to [donate], I would have to REALLY research that company. I would want to know where ... what they are doing, how they are going to do it, everything!” (18–29 years, female). Participants in the two other groups (30–54 and 55+) voiced some mistrust in medical research, the validity of consent forms, and the ability to withdraw consent; however, they were more willing to donate than the youngest age group for the benefit of science, as stated by one participant, “I will give you anything you want—blood, whatever you want—if you find a cure.” (30–54 years, male).

Promotion Types and Content of Messages

There was a wide variation of traditional and nontraditional promotion channels, content, and messengers discussed in the focus groups. In particular, the 18–29-year group mentioned social media while the other groups suggested television news programs and talk shows. Across all age groups, participants referred to the use of health fairs, workshops, and physician’s offices as appropriate places for dissemination of pamphlets and exposure to video content. In one of the Spanish-speaking groups, the suggestion was made to involve community members in the dissemination of biobanking information and to use a workshop format so potential participants could have their questions answered. Two of the focus groups, one Spanish-speaking group and one group composed of predominately women 55+, mentioned the use of photo-novellas. For messengers, doctors and sports celebrities were identified as the most common spokespersons. In one example, a conversation between a doctor and a patient was discussed, wherein the doctor would explain in a serious tone the importance of obtaining biospecimens for research purposes to a well-known celebrity acting as a patient. In sum, most participants wanted to learn about biospecimen donation from a credible (physician) or familiar (sports celebrity) source, and in an easy-to-understand, entertaining, and engaging manner.

Regarding message content, a number of groups expressed concerns about blanket consent for the use of their tissue because they would not benefit financially if new cures or discoveries were to result. Also, participants wanted information related to the steps involved with biobanking and an explanation of the commitment required for participants. Moreover, participants felt consent issues should be addressed sufficiently in terms of ethics, ownership, access to their biospecimens, and specific tests to be undertaken.

Discussion

The development of novel cancer therapies tailored to an individual’s genetic profile is the promise of personalized medicine [36]. Biobanks provide the resources for a robust database for future scientific advances in biomolecular and bioinformatics technology. Yet, to realize these scientific activities, it is necessary to earn the public’s trust to ensure donation of biospecimens from willing and well-informed participants. Formative research can aid in this endeavor by identifying beliefs and attitudes toward cancer-related biobanking and inform the production of educational communication priming tools to address the learning needs and concerns of diverse audiences. A key finding was that participants wanted to learn about biospecimen donation from a credible source, and in an easy-to-understand, entertaining, and engaging manner.

We chose an exploratory, qualitative methodological approach since there is little known about the opinions of healthy volunteers in the USA toward participation in biobanking. We stratified groups by age, race/ethnicity, and language preference to allow us to discern differences by these sociodemographic characteristics. Generational differences were most

pronounced. Among focus group participants in the youngest age group (18–29 years), mistrust was expressed toward biomedical research and the government in general terms. In two of these focus groups (one mixed race, one Hispanic), the topics of the Tuskegee and Guatemala syphilis experiments and the HeLa cell line were discussed as examples of mistrust in research and why more education was needed to convince potential biobanking donors to participate [37, 38]. Moreover, in the 18–29-year age groups, monetary incentives in exchange for biobanking participation were indicated as a necessary tradeoff for participation, despite elevated privacy concerns and worries about exploitation. Comparison of focus group themes did not reveal obvious differences based on group stratification by race/ethnicity or language preference.

One salient theme from our results is that most people choose to donate based on their life histories, experiences, and perceptions of the costs and benefits [5]. Less important perhaps are the specific details of how their information will be kept or used in future research studies if they make the determination that donating will provide a benefit which is greater than the limited cost of imaginary negative outcomes (e.g., cloning). More important barriers might be related to actual fears people have of needles or other intrusive methods which could cause them discomfort in the process of tissue donation. Results showed people will be more motivated to donate tissue if they have had a personal experience of a family member affected by cancer or hold a favorable view toward the intrinsic merits of scientific or medical research.

Issues concerning privacy and mistrust of research reported in US biobanking studies appear to be less salient issues in European biobanking studies [39, 40]. In a US study, the researchers found that privacy concerns were paramount for many prospective participants, and could be a primary reason for withdrawing from a research study [41]. On the other hand, a large survey of biobank donors in Sweden found that fewer than two thirds recalled consenting to donate a blood sample and less than 6% felt unsatisfied with the study information they had received in the process [22]. The study found that donors may be overloaded with written information in the informed consent document that they do not necessarily need to read or fully understand to make a decision. The decision to donate tissue may actually be a low-risk decision for many in terms of privacy concerns or other worries, such as not receiving research results, having future studies conducted with their tissues, or not sharing in future profits from scientific discoveries [41].

Once people decide to donate biospecimens—either for altruistic reasons, to save someone else’s loved one, or to benefit science—they can become subsequently detached from the donated tissue, thinking of it as “disposable,” or perhaps recyclable, as expressed by the participant who said the “thrown out” tissue might as well be used for something. Donors of healthy tissue may become disassociated from the tissue, and consequently, the expectation of a personal benefit from the exchange relationship is diminished. This stands in sharp contrast to the experience of organ donors who have sacrificed tissue imbued with “sacredness” and a higher intrinsic value; therefore, organ donor recipients often feel emotionally motivated to reciprocate the gift in some fashion [19].

This qualitative study has certain limitations. While we were successful in recruiting a diverse sample for the focus group discussions, our research participants lived in a large metropolitan area in southwest Florida. Particular sociodemographic characteristics of the participants from this region may have influenced responses to our questions, so similar research conducted in other parts of the USA near academic medical centers may produce different results.

This study contributes to the literature on community opinions of knowledge, attitudes, and beliefs toward biobanking and offers direction for researchers seeking to engage community members in biospecimen collection for disease-focused protocols and for recruitment of healthy controls. The focus group results contributed to the design of a creative brief and communication strategies to effectively frame biobanking educational content for print and visual media, with attention to health literacy and cultural competency [24]. Our next steps entail developing educational communication priming tools (English and Spanish versions) customized to community member's learning preferences, expectations, and literacy levels. These tools will be designed to primarily reach the 30+ age groups since they are most similar in their perceptions and attitudes about biobanking participation, and in their communication preferences (e.g., DVD/booklet). We feel that separate educational tools that address the concerns of the younger group (age 18–29) and delivered in a social media format may be warranted. In addition, focus group data contribute to the development of scales designed to measure attitudes toward biospecimen donation and biobanking, knowledge regarding biospecimen donation and biobanking, self-efficacy for making the decision to donate specimens to a biobank, and intention to donate specimens to a biobank. Taken together, findings and tools from these studies will inform education efforts, recruitment and participation of community members in behavioral, epidemiologic, and other biomedical research involving biobanking. Future studies are expected to test the efficacy of these tools for decision priming.

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References

1. Bauer K, Taub S, Parsi K. Ethical issues in tissue banking for research: a brief review of existing organizational policies. *Theor Med Bioeth.* 2004; 25(2):113–142. [PubMed: 15368750]
2. Hewitt RE. Biobanking: the foundation of personalized medicine. *Curr Opin Oncol.* 2011; 23(1): 112–119. [PubMed: 21076300]
3. Khoury MJ, Millikan R, Little J, Gwinn M. The emergence of epidemiology in the genomics age. *Int J Epidemiol.* 2004; 33(5):936–944. [PubMed: 15319400]
4. Morente MM, Fernández PL, Alava E. Biobanking: old activity or young discipline? *Semin Diagn Pathol.* 2008; 25(4):317–322. [PubMed: 19013897]
5. Barr M. I'm not really read up on genetics: biobanks and the social context of informed consent. *BioSocieties.* 2006; 1(02):251–262.
6. Jack AL, Womack C. Why surgical patients do not donate tissue for commercial research: review of records. *BMJ.* 2003; 327(7409):262. [PubMed: 12896938]
7. Compton C. Cancer biobanking: the American perspective. *Eur J Cancer Suppl.* 2007; 5(8):5–6.
8. O'Doherty K, Hawkins A. Structuring public engagement for effective input in policy development on human tissue biobanking. *Public Health Genomics.* 2010; 13(4):197–206. [PubMed: 20395688]
9. Goldman RE, Kingdon C, Wasser J, et al. Rhode Islanders' attitudes towards the development of a statewide genetic biobank. *Per Med.* 2008; 5(4):339–359.
10. Secko DM, Preto N, Niemeyer S, Burgess MM. Informed consent in Biobank research: a deliberative approach to the debate. *Soc Sci Med.* 2009; 68:781–789. [PubMed: 19095337]
11. Mayo Clinic. [Accessed 13 May 2009] DNA Biobanking in Olmstead County, a deliberative community engagement. Available from: <http://biobank.mayo.edu>
12. Deschênes M, Sallée C. Accountability in population biobanking: comparative approaches. *J Law Med Ethics.* 2005; 33:41–53.

13. Chalmers D. Genetic research and biobanks. *Methods Mol Biol.* 2011; 675:1–37. [PubMed: 20949382]
14. Appelbaum PS, Roth LH, Lidz CW, Benson P, Winslade W. False hopes and best data: consent to research and the therapeutic misconception. *Hastings Cent Rep.* 1987; 17(2):20–24. [PubMed: 3294743]
15. Lidz C, Appelbaum P, Grisso T, Renaud M. Therapeutic misconception and the appreciation of risks in clinical trials. *Soc Sci Med.* 2004; 58:1689–1697. [PubMed: 14990370]
16. Morrell B, Lipworth W, Axler R, Kerridge I, Little M. Cancer as rubbish: donation of tumor tissue for research. *Qual Health Res.* 2011; 21:(X1).
17. Johnsson L, Hansson MG, Eriksson S, Helgesson G. Patients' refusal to consent to storage and use of samples in Swedish biobanks: cross sectional study. *BMJ.* 2008; 337:a345. [PubMed: 18617496]
18. Watanabe M, Inoue Y, Chang C, et al. For what am I participating? The need for communication after receiving consent from biobanking project participants: experience in Japan. *J Hum Genet.* 2011; 56(5):358–363. [PubMed: 21390038]
19. Axler RE, Irvine R, Lipworth W, Morrell B, Kerridge IH. Why might people donate tissue for cancer research? Insights from organ/tissue/blood donation and clinical research. *Pathobiology.* 2008; 75(6):323–329. [PubMed: 19096227]
20. Murphy J, Scott J, Kaufman D, Geller G, LeRoy L, Hudson K. Public perspectives on informed consent for biobanking. *Am J Public Health.* 2009; 99(12):2128–2134. [PubMed: 19833988]
21. Hede K. New biorepository guidelines raise concerns. *J Natl Cancer Inst.* 2006; 98(14):952–954. [PubMed: 16849672]
22. Hoeyer K, Olofsson B-O, Mjörndal T, Lynöe N. The ethics of research using biobanks: reason to question the importance attributed to informed consent. *Arch Intern Med.* 2005; 165:97–100. [PubMed: 15642883]
23. Wendler D. One-time general consent for research on biological samples. *BMJ.* 2006; 332:544–547. [PubMed: 16513715]
24. Meade C, Menard J, Martinez D, Calvo A. Impacting health disparities through community outreach: utilizing the CLEAN look (culture, literacy, education, assessment, networking). *Cancer Control.* 2007; 14(1):70–77. [PubMed: 17242673]
25. Yeatman TJ, Mule J, Dalton WS, Sullivan D. On the eve of personalized medicine in oncology. *Cancer Res.* 2008; 68(18):7250–7252. [PubMed: 18794109]
26. Morgan DL. Focus groups. *Annu Rev Sociol.* 1996; 33:129–152.
27. Meade CD. Cancer care for diverse populations: relevant communications and research. *Cancer Control.* 2003; 10(5 Suppl):1–2. [PubMed: 14581898]
28. Quinn GP, Thomas KB, Hauser K, Rodriguez NY, Rodriguez-Snapp N. Evaluation of educational materials from a social marketing campaign to promote folic acid use among Hispanic women: insight from Cuban and Puerto Rican ethnic subgroups. *J Immigr Minor Health.* 2008; 11(5):406–414. [PubMed: 18561023]
29. Goodson ML, Vernon BG. A study of public opinion on the use of tissue samples from living subjects for clinical research. *J Clin Pathol.* 2004; 57(2):135–138. [PubMed: 14747435]
30. Wendler D, Emanuel E. The debate over research on stored biological samples: what do sources think? *Arch Intern Med.* 2002; 162(13):1457–1462. [PubMed: 12090881]
31. Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. *Qual Saf Health Care.* 2003; 12(2):93–99. [PubMed: 12679504]
32. Charmaz, K. *Constructing grounded theory: a practical guide through qualitative analysis.* Sage Publications; Thousand Oaks: 2006.
33. VERBI Software. MAXQDA; Marburg, Germany: 2010.
34. U.S. Preventive Services Taskforce. Screening for breast cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med.* 2009; 151(10):716–726. W-236. [PubMed: 19920272]
35. Skloot, R. *The Immortal Life of Henrietta Lacks.* Random House; New York: 2010.

36. Hawkins AK. Biobanks: importance, implications and opportunities for genetic counselors. *J Genet Couns.* 2010; 19(5):423–429. [PubMed: 20680423]
37. Tanne JH. President Obama apologises to Guatemala over 1940s syphilis study. *BMJ.* 2010; 341:c5494. [PubMed: 20921075]
38. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved.* 2010; 21(3): 879–897. [PubMed: 20693733]
39. Goebel JW, Pickardt T, Bedau M, et al. Legal and ethical consequences of international biobanking from a national perspective: the German BMB-EU Coop project. *Eur J Hum Genet.* 2010; 18(5): 522–525. [PubMed: 19953124]
40. Forsberg JS, Eriksson S, Hansson MG. Changing defaults in biobank research could save lives too. *Eur J Epidemiol.* 2010; 25(2):65–68. [PubMed: 19957020]
41. Beskow LM, Dean E. Informed consent for biorepositories: assessing prospective participants' understanding and opinions. *Cancer Epidemiol Biomarkers Prev.* 2008; 17(6):1440–1451. [PubMed: 18559560]

Table 1Characteristics of focus group participants ($N=95$)

Characteristics	<i>n</i> (%)
Age group (years)	
18–29	31 (32.6)
30–54	34 (35.8)
55+	30 (31.6)
Sex	
Female	65 (68.4)
Male	30 (31.6)
Race	
American Indian/Alaska native	3 (3.2)
Asian	1 (1.0)
Black/African American	33 (34.7)
White	36 (37.9)
Other	17 (17.9)
No answer	5 (5.3)
Spanish speaking	
Yes	37 (38.9)
No	56 (59.0)
No answer	2 (2.1)

Table 2

Representative responses grouped by thematic and topical categories

Theme/topic	Illustrative quotes
Barriers Fear of needles	<p>“I think like, as far as like the blood ... if they ask me right when I’m giving it, and it’s not going to endanger me, I don’t care. But, if they are going to poke me again, I don’t know about that.” (18–29-year female; mixed race, mixed gender group)</p> <p>“Or ‘needle friendly.’ It just, you know, you think of what type of specimen do they need? If it’s blood, if it’s needles, if you need to cut something out, you know.” (30–54-year female, mixed race; mixed gender group)</p> <p>“It conjures up images of giving blood, and not all of us are needle worthy.” (55+-year female; mixed race, mixed gender group)</p>
Privacy concerns	<p>“I wonder about the security of the actual physical storage place. I don’t want people breaking in the place.” (18–29-year male; mixed race, mixed gender group)</p>
Lack of information	<p>In reference to informed consent protocols, “It doesn’t matter. Like, if you want to be really specific and you want to tell me, then that’s fine. But I don’t really need to know.” (18–29-year male; African American, mixed gender group)</p>
Mistrust of researchers	<p>“They ask me for samples then, and they explain everything to me. And then, let’s say that I go to another, like another hospital or somewhere else, and I happen to know that they sell their, you know, their samples for a ridiculous price to other people. I think it matters on the situation. Or whether they want, like, two tubes of blood to like a whole pint of blood. Like you were saying, we want to know pros and cons for every situation.” (18–29-year female; mixed race, mixed gender group)</p>
Generational or religious factors	<p>“Me, personally, I had looked into like um, a donation because I think it would be a beneficial thing for a family or something, and my mom was against me going for it. And to her, you know, it’s kind of like a cultural religious shock, but I didn’t personally have that kind of, um, that personal view. Yeah, it didn’t really like factor into my thought process behind making that decision. But for her it did. I think it kind of just depends on how you perceive, know where your donation is going and what benefit it will have.” (18–29-year female; African American, mixed gender group)</p>
Lack of cash remuneration	<p>“You know, like oh, well, this person you gave her the donation, but we are charging them \$3,000, \$4,000, X amount of dollars so that they can have it, and I wouldn’t really want to agree with that.” (18–29-year female; mixed race, mixed gender group)</p>
Benefits Family history as motivator	<p>“My sister just died from cancer ... I’d give up a finger right now if it would help.”</p> <p>“I have had members of my family die of cancer, and so anything I can do to be of assistance as far as education and research.” (18–29-year female; African American, mixed gender group)</p>
Convenience	<p>“It’s already out; they’ll throw it out anyway.” (18–29-year; mixed race, mixed gender)</p>
Immediate benefits to someone else	<p>“I will give you anything you want—blood, whatever you want—if you find a cure.” (30–54-year male; mixed race, mixed gender group)</p>
Helping science or society	<p>“So for all those millions out there that got all those children, they are sitting there watching them die... that purpose ALONE would make me, because THEY DESERVE a fair chance, just for the children.” (30–54-year female; mixed race, mixed gender group)</p>
Positive relationships with a healthcare provider	<p>“As long as the doctors performing it give you an explanation why, and what it’s going to do, how it’s going to be a benefit to maybe yourself or another individual, then I’d have no problem.” (55+-year male; mixed race, mixed gender group)</p>
Message content Informed consent information	<p>“In the consent form that I sign saying hey yeah, I give you authorization to do this, it should be stated maybe in the consent form that do you give us permission to test for other things in the future with this current sample.” (30–54-year male; mixed race, mixed gender group)</p> <p>“I might question though—even if I do have an informed consent and I do agree to it, and my specimens are used somewhere else—I have no way to, I maybe will have no way to track how my samples were being used. And so this contract—this legal contract—doesn’t really mean anything because I have no way to track how it’s being used anyhow.” (18–29-year female; mixed race, mixed gender group)</p>