

# Using Mixed Methods to Examine Perceptions and Willingness to Participate in Bio-specimen Banking in Diverse Asian Americans

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## Abstract

**Background:** On a large scale, bio-specimen banking offers researchers the ability to newly understand areas like community genetics and to apply new sampling technologies to housed samples. Understanding cultural differences in knowledge and perceptions of bio-specimen banking allows for addressing community concerns and facilitates dissemination of culturally relevant health education.

**Methods:** Community-based participatory approaches (CBPA) provide opportunities to solicit community input and to build mechanisms for maximizing outcomes of potential interventions. As part of a larger CBPA project, Chinese, Korean, and Vietnamese community members participated in eight focus groups on bio-specimen banking. Demographics and qualitative text were analyzed.

**Results:** The study results indicate that education and English proficiency were the most important predictors of knowledge of bio-specimen banking. Ethnic and age differences also were identified as predictors of knowledge in bivariate analyses. Participants discussed safety in bio-specimen sample collection procedures; processes of tissue removal, including spinal and blood draws; privacy protection; trust in healthcare providers; concerns about genetic research; importance of contributing to science; and family concerns.

**Conclusion:** The diversity of Asian American populations requires that, to increase participation in bio-specimen banking, understanding and addressing community concerns requires health education efforts that improve knowledge of innovations in sampling and cultural tailoring of health education messages. Promotion messages should highlight scientific benefits including possibilities for tailoring medical treatment and new diagnoses. Issues of health information privacy and stigma for communities at risk for certain diseases remain community worries.

**Keywords:** Community based participatory research; Bio-specimen banking; Asian Americans; Tissue donation; Focus group

## Introduction

For some cancers like stomach, liver, colorectal, and cervical, Asian Americans have disproportionately high rates [1]. Of concern, cancer risk factors have escalated among these populations, especially among young Asian Americans and new immigrants. Rising rates of colorectal and breast cancer and cancer co-morbid conditions (e.g., diabetes and heart disease) are linked to lifestyle changes, most notably, diet and activity levels [2,3]. Evidence of the consequences of changes in lifestyle is seen in the correlation between number of years in the US and increased cancer rates and the rise in risk factors that were once rare among those living in their home countries. The ultimate consequence of lifestyle changes [4] coupled with projected increases in the US Asian populations [5], that the cost and hardship of cancer and cancer care may become increasing economic burdens for Asian Americans and the US healthcare system over the next 20 years.

Bio-specimen banking and participation in surveys provide researchers with a means to study genetic and other cancer risk factors as well as to explore new treatment options and to provide tailored treatments to patients. As new technologies and methods arise, banked tissue and blood samples provide both a mechanism for identifying and diagnosing new disorders as well as information for monitoring health status. To make such goals realizable, engaged participation by ethnic and racial communities is ideal. For communities with health disparities to benefit fully from bio-banking and bio-specimen research, awareness of the benefits of and participation in this research are important [6-8].

Previous research on community interest in bio-specimen banking included primarily African American [9] and Caucasian groups [8,10]. The scant information in these studies on Asian Americans indicated

that diverse populations expressed common concerns in regard to bio-specimen collection and banking. These participants feared that bio-samples and information provided to researchers may infringe on their privacy or be used against them [11].

The current study is built on a decade of engagement with Asian American communities in a broad range of cancer and health disparities issues. Over 350 Asian community organizations and clinical partners collaborate with Center for Asian Health (CAH), Temple University, in many research projects. The engagement of these organizations, representing Korean, Chinese, Vietnamese, Cambodian, Asian Indian, Filipino and other underserved Asian communities, is guided by principles of community-based participatory research (CBPR) [12].

The overriding aim of this study is to expand the knowledge base of a critical health-related issue that has far-reaching implications for the future health of populations at risk for certain types of cancer and other chronic illnesses. Because a large subset of Asian Americans today is comprised of new immigrants, the participation and contribution of this population to bio-specimen banking research can have a

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significant impact on the future health of Asians worldwide. Biospecimen banking is a new cultural construct that may have disparate meanings in multi-ethnic/lingual communities. The study's aim is to identify Asian American knowledge, barriers, facilitators, and other cultural influences in regard to biospecimen banking. Concurrently, we sought to identify the mechanisms and messages that would facilitate dissemination of information on biospecimen banking.

## Materials and Methods

### Participants and instrumentation

**Participants:** From November 2011 through February 2012, purposive sampling was used to recruit 103 adults from the New York and Philadelphia metropolitan areas to participate in one of eight focus groups. Recruited participants represented: Chinese (n=55), Vietnamese (n=30), and Korean (n=18). Community leaders from the ethnic groups knowledgeable in CBPR principles assisted in the recruitment of participants. Asian community-based organizations as partners with the Asian Community Health Coalition facilitated the conduct of the study.

**Preliminary meetings:** Prior to the initiation of the focus group sessions, two preparatory events occurred. First, the project staff and an Asian American bilingual moderator, co-moderator, and facilitators participated in a refresher workshop on focus group methodology. Second, the principal investigator and her team held separate meetings with participating community leaders and collaborators to identify issues related to biospecimen banking and to discuss cultural concerns that are unique or common to Chinese, Korean, and Vietnamese communities. The identified issues and recommendations that emanated from these meetings formed the basis for modifying and designing a culturally relevant and sensitive moderator's guide.

**Moderator's guide:** The moderator's guide was divided into three sections that addressed cancer screening, clinical trials, and biospecimen banking. The last section included information on biospecimen banking in general and barriers and facilitators to collecting biospecimens, queries about willingness and cultural beliefs, and suggestions and strategies for increasing community participation in biospecimen collecting programs. The completed guide was reviewed by Asian Community Advisory Board members and expert panel members in draft form and modified by CAH researchers and community collaborators. The final guide includes helpful materials for the moderator and co-moderator, such as brief descriptions of and answers to questions about procedures and innovations in obtaining tissue samples. After finalization the guide, the CAH project staff, the moderator, co-moderator, community facilitators, and a select group of competent note takers attended a training session focused specifically on the finalized guide.

A quantitative questionnaire was developed to include demographics and the individual participant's assessments of his or her knowledge of biospecimen banking. Likert scales or "Yes/No" responses categories were used. The quantitative assessment data enables us to have a better understanding of the qualitative focus group results in a context.

### Implementation procedures

This study was approved by Temple University's Institutional Review Board. Focus groups were conducted at local community-based organizations and churches. The duration of the open-ended and moderator-guided group discussions ranged between 1.5 and 2.5 hours (90-150 minutes). The primary language used in the group discussions

was English. Culturally competent bilingual CAH and community partner translators were on site to assist group discussions in Chinese (Mandarin), Korean, and Vietnamese. Participants were informed and consented in advance that sessions would be recorded electronically as well as by CAH and community-based note takers. Each session of the moderator's guide was preceded by an explanation of the overriding purpose and aims of the study and the role and importance of the focus groups' contributions to study aims. A Q&A session followed the moderator's introductory remarks. All participants signed consent forms prior to completing the quantitative assessment as well as participating in the focus groups.

### Data Analysis

Quantitative survey results were examined using bivariate (chi-square and Pearson correlation) and multivariate analyses. The reduced multivariate model included only significant variables. SPSS v.20 was used to perform the analysis.

Prior to the analysis of qualitative focus group data, recorded focus groups discussion tapes were transcribed verbatim and translated into English by a native speaker. Questions of translation were referred to the native speaker and checked against the original tapes until consensus was achieved [13]. Following this check, data were coded by themes using content analysis, and codes were verified by an independent research assistant.

A senior research associate independently conducted an analysis whose results demonstrated that all participants provided comments and that the percentage of comments made did not differ based on gender. Male participants' comments comprised 40.4% (range 16.67% to 73.33%) of all comments; a percentage that closely matched their representation in groups that included males. The coding was completed using ANSWER.

## Results

Participants were primarily female (59.6%: 40.4%), married, retired, born outside of the US, and had a high school degree or above and a mean age of 64 (Table 1). Most participants reported that they spoke English "not well." Participants had lived in the US an average of 22 years. Most participants had health insurance and a regular doctor (Table 2). Approximately 90% knew nothing or little about biospecimen banking.

To minimize cell sizes under five for chi-square analyses, some categories were combined; these are presented in Tables 1 and 2. Significant differences were identified for ethnicity, with Vietnamese groups' reporting lower levels of knowledge of biospecimen banking (11.1%), compared to Korean (44.4%) and Chinese (51.0%). Age differences in reporting knowledge of biospecimen banking were not linear: 17.4% for those aged 50-64, 37.1% for those aged 71 and above, 50% for those aged 65-70, and 61.5% for those aged 50 and below. Those with higher levels of education and fluency in English reported more knowledge of biospecimen banking. There was no relationship between biospecimen banking and having a physician or health insurance; however, fewer than 15% of respondents answered "No" to these questions.

Multiple regression analyses showed that demographic and health variables predicted knowledge of biospecimen banking. Serial elimination of non-significant variables was performed until a final model with only significant variables was achieved. The final model had an adjusted R<sup>2</sup> of 0.290 (df=88, n=90). Knowledge of biospecimen banking was predicted by education, with a standardized coefficient

Variables	Percent (%), Number (n=)	Percent reporting they knew a little or more about bio-specimen banking
<b>Gender</b>	n=99	Chi-square=.62, p=.43, n=90
Male	40.4 (40)	44.7 (17)
Female	59.6 (59)	36.5 (19)
<b>Born in the US</b>	n=92	Chi-square=.17, p=.68, n=87
No	95.7 (88)	39.8 (33)
Yes	4.3 (4)	50.0 (2)
<b>Ethnic Background</b>	n=103	Chi-square=12.09, p=.00, n=94
Chinese	53.4 (55)	51.0 (25)
Vietnamese	29.1 (30)	11.1 (3)
Korean	17.5 (18)	44.4 (8)
<b>Age</b>	n=102	Chi-square=8.48, p=.04, n=93
Less than 50	12.7 (13)	61.5 (8)
50-64	25.5 (26)	17.4 (4)
65-70	24.5 (25)	50.0 (11)
71 and above	37.3 (38)	37.1 (13)
<i>Mean (Std. Deviation)</i>	64.02 (12.77)	
<b>Marital Status</b>	n=103	Married vs. Not, Chi-Square=1.47, p=.22, n=94
Married	73.8 (76)	41.7 (30)
Never Married	5.8 (6)	Not Married 27.3 (6), category n=22
Divorced/Separated	6.8 (7)	
Widower	13.6 (14)	
<b>Education</b>	n=101	Chi-square=20.56, p=.00, n=92
No Education/Elementary School	11.9 (12)	
Below High School	14.9 (15)	HS and below 4.5 (1), category n=22
High School Graduate	34.7 (35)	34.4 (11)
Some College/Bachelor's Degree	31.7 (32)	Some college and above 63.2 (24), category n=38
Graduate School or Above	6.9 (7)	
<b>Current Employment Status</b>	n=97	Employed vs. Non, Chi-square=1.62, p=.20, n=89
Employed	23.7 (23)	11 (52.4)
Unemployed	5.2 (5)	Not Employed 25 (36.8), category n=69
Retired	46.4 (45)	
Homemaker	24.7 (24)	
<b>English Fluency</b>	n=99	Chi-square=9.37, p=.01, n=93
Not at All	23.2 (23)	20.0 (4)
Not Well	45.5 (45)	32.6 (14)
Well/Very Well	31.3 (31)	60.0 (18)
<b>Years in the US</b>	n=103	Chi-square=4.72, p=.10, n=94
16 years and below	31.1 (32)	16 (53.3)
17 to 26 years	33.3 (34)	8 (26.7)
27 years and above	33.9 (37)	12 (35.3)
<i>Mean (Std. Deviation)</i>	22.35 (10.72)	

Table 1: Sample demographics.

(Beta) of 0.380 (t=3.89, p=0.00,) and English fluency with Beta=0.274 (t=2.81, p=0.01).

For qualitative results, major themes identified in the focus groups are presented in Table 3, with representative quotes for positive (pro) and negative (con) comments. Safety, tissue sampling, drawing blood, privacy issues, trust in health care providers, contribution to science, genetic research, and family were identified as major themes. In general, safety issues were vaguely stated, except for tissue sampling. In regard to tissue sampling, bone marrow sampling was described as very painful, and people were worried about physical consequences of spinal taps.

Variables	Percent (%), Number (n=)	Percent reporting they knew a little or more about bio-specimen banking
<b>Knowledge about Biospecimen Banking</b>		
None	61.7 (58)	--
Know a Little/Heard About It	25.5 (24)	--
Know Some	11.7 (11)	--
Know Well	1.1 (1)	--
<b>Have Health Insurance</b>	n=99	Chi-square=.47, p=.49, n=93
No	14.9 (15)	46.2 (6)
Yes	85.1 (86)	36.2 (29)
<b>Regular Physician Visit</b>	n=99	Chi-square=.04, p=.84, n=87
No	10.5 (10)	4 (44.4)
Yes	89.5 (85)	32 (41.4)

Table 2: Survey health related question responses.

When the moderator explained innovations in sample collection procedures and the small amounts of tissue or blood collected for biospecimen research, many respondents' comments changed to positive. Privacy and trust concerns arose only after a specific query from the moderator. Once the issue was raised, some respondents voiced concerns about how their information would be available to others and how it would affect their families. Participants seemed unaware of legal protections for health information and health care practices in place in the US to protect privacy. In regard to the consequences of genetic testing for families, one respondent mentioned that, for families for which these concerns were found, the possibility of stigmatization might make it difficult for the families to find a spouse for their children or for the children/young adults themselves to find a spouse. Other participants thought that it was important for families to know about genes that increase risks for diseases such as cancer. In this section and in the sections on clinical trials and cancer screening, participants mentioned that trust in their health care providers' advice would be important to their interest in or willingness to provide a biospecimen.

In every group, two themes rallied interest in and willingness to participate in biospecimen banking, with no negative responses: (a) making a contribution to science and (b) developing new treatment options for family members. In focus group discussion, participants stated that such contributions were generally good and could lead to important discoveries and hoped that, eventually, biospecimen research would offer new options for family members and others at risk for cancer and other chronic diseases.

Overall, participants voiced willingness and interest in donating samples for biospecimen banking. Only a few participants in the focus groups showed no interest in or not being willing to participate in biospecimen banking. When the moderator asked participants whether cultural values, religious beliefs, or incentives for participation in the study were factors that influenced interest or willingness to participate in bio-specimen banking, the consensus was that none of these factors had major influence.

Suggestions by focus group participants for increasing participation in bio-specimen banking are summarized in Table 4. The first suggestion was to focus on community awareness by increasing media and other promotions that are convincing and that specifically highlight innovations in sample collection. Of equal importance was participants' suggestion to encourage and perpetuate the one-on-one education of individuals by trusted community representatives or others who have an established relationship within the community and

<p>• <b>Safety:</b> <b>Pro:</b> None; <b>Con:</b> "This may be dangerous for my life."; "This may be dangerous for my life."</p>
<p>• <b>Taking Cells/Tissue Samples:</b> <b>Pro:</b> "If it is helpful to me, it is fine to donate more specimens or do more screenings," "I would like to donate whenever I see it [bone marrow donation] on TV."; <b>Con:</b> ". . . but donating cells or tissues or things like that make me feel that it is going to be a quite big process, and my concern would be if it is safe." "It [bone marrow sampling] is too painful. My body cannot handle it."; "Afraid of spinal tap and worried that afterwards it is harmful to the body."; "I am afraid that [sampling] is harmful . . . the bad side effects."</p>
<p>• <b>Drawing Blood:</b> <b>Pro:</b> "I think drawing a little bit of blood from you is not a big problem." <b>Con:</b> ". . . but we still need to see the amount of blood. One or two tubes of blood are fine, but not too many. Drawing too much blood is bad for the body."</p>
<p>• <b>Privacy:</b> <b>Pro:</b> "The important thing is that the organization that holds the screening must keep all the information confidential, . . ."; <b>Con:</b> "Yes, I do concern about that." [in response to question about protecting personal information.]; "I am afraid if I this [defects are found in your family] happened to me."</p>
<p>• <b>Trust in Health Care Providers:</b> <b>Pro:</b> None; <b>Con:</b> "Sometimes I really don't trust the doctors."</p>
<p>• <b>Genetics:</b> <b>Pro:</b> "It would be a good thing if it [gene in your family that may cause cancers] was discovered."; <b>Con:</b> "It [genetic basis for a cancer] could be hard for people who are just 20 some years old to know because it would be hard for them to find their future spouses."</p>
<p>• <b>Others and Family:</b> <b>Pro:</b> ". . . Generally, people will not do it. But when you learn that the organ you donate could help so many people, and then you may think that at certain point in the future you may be willing to do it."; "I like to do things that can contribute to the society. If we do not make this contribution, it is impossible for people to invent new drugs or other better treatments. Therefore, it needs the participation from every one of us."; "If we have family, I would do it [taking tissue samples] for my family but not for the overall research." <b>Con:</b> none.</p>
<p><b>Overall Willingness to Participate in Biospecimen Banking</b></p>
<p>• <b>Pro:</b> "I would do it. Actually I already did it . . ."; "Majority of the participants are okay with the concept of bio-specimen banking."          • <b>Con:</b> "No because I do not know what it will affect me."; "No, not willing to do so."          • <b>Pro:</b> "As for contributing to science, I will do it because I think it is good for the developing process of the research on the disease."; "It would be a good thing if it [genetic basis for a cancer] was discovered."; <b>Con:</b> None</p>

**Table 3:** Representative focus group statements of perceptions and attitudes toward biospecimen banking.

<p><b>Community Awareness:</b> "I think this topic is very new, and it has not been talked enough, so you need to promote it more."</p>
<p><b>Word of Mouth/Community Representatives:</b> ". . . it is the manpower with the small group spreading the words, . . . that is the best because the relationships have to be built up with all subjects. . ."</p>
<p><b>Media:</b> "With the help of the media, TV and newspapers, it can increase people's sympathetic attitudes, but it has to be pertinence and reasonable."</p>
<p><b>Events/Workshops:</b> "Event like this [small focus group discussion] can helpful. I think this is good information to know, and I like what we talked about today."</p>

**Table 4:** Representative participant quotes suggesting promotion strategies.

are in a good position to explain the purpose and promise of research based on biospecimen banking. Similarly, participants thought that information could be disseminated at community events and at small group workshops similar to the focus group.

## Discussion

Communities of all cultural groups struggle with new medical technologies, trying to figure out how technologies fit or conflict with value systems. Legal case law surrounding genetic research is complex and many wonder how they can take advantage of innovations while protecting themselves from negative consequences. By providing communities with increased knowledge about the purpose of biobanking and the procedures used in collecting blood and tissue samples, biospecimen banking can be achievable for a wide range of Asian American communities. Our findings corroborate those reported by Luque et al. [8] in their focus group study, particularly that community members had low levels of knowledge about biospecimen sampling and misconceptions about the purpose of biospecimen banking. In Luque et al. study [8], concerns of focus group discussants were the fear of pain from sampling techniques, violations of privacy, low levels of trust in health care providers, and unknown risk factors associated with sampling procedures, especially of bone marrow and liver sampling. In our study, community members indicated that most of these barriers could be overcome with increased knowledge about biospecimen banking and the ultimate benefits to families and society. A large majority of participants saw cultural and religious factors as significant, a finding that may suggest the increased participation of church leadership in health education efforts to increase knowledge of the benefits and procedures of bio-specimen sampling. Dissemination of information on innovations in sampling procedures that minimized tissue and fluid extraction and improved safety would further facilitate participation in biospecimen sampling, particularly in easing the fear of pain and problems associated with sample collection. CBPR methods are important to enhance sampling recruitment and improve

community involvement in tailoring bio-specimen banking messages and influencing policies that address health privacy concerns.

By moderators' including in the discussion both pro statements (the importance of scientific benefits, concerns about safety), and con statements (mistrust), community members became willing to consider tradeoffs in the hope that communities would be positioned to receive a therapeutic benefit [8]. In contrast to Luque et al. study [8], no participants mentioned specific fears, e.g., fear of needles. In regard to bio-specimen banking, Asian Americans in this study did not see themselves as "lab rats" and did not bring up cases such as Tuskegee. However, because these concepts were not specifically queried in the Asian American focus groups, it is unknown whether or not these factors are important for this population.

Overall, community members welcomed a forum to discuss new medical technologies and suggested ways to overcome community concerns. The list of communication suggestions was similar to those found in the Luque et al. study [8], except for the use of a media celebrity, which was suggested in this study. Asian American participants emphasized using more one-on-one and small-group methods of communication. Specific concerns about the consent process that came up in the Luque et al. [8], Lemke et al. [10] and Simon et al. studies [14] did not arise in any Asian American groups, although participants did have some concerns about the privacy of health records. The Asian American groups were uniquely concerned about the social consequences of finding genetic problems in families and considered that family members might publicly discuss found genetic concerns, which would make families vulnerable to possible stigma. Patient counseling for recruited families should include a discussion of possible consequences of the public disclosure of results including legal issues.

Based on suggestions from these groups, communities would benefit most from positive messages on contributions to science and helping families and others [8] by participating in bio-specimen

banking. Messaging should clarify existing protections of health care information and privacy and discuss the safety of sampling procedures [6,7]. Further testing of health education messages will benefit from tailoring for diverse ethnic groups within Asian communities. Increasing bio-specimen banking awareness also should include one-on-one education with community representatives, workshops, and events.

Although a wide range of participant education levels were represented in this sample, only about 25% had less than a high school degree, which is unusual for participants in this age group. Educational materials for populations with less than a high school degree need further modification to increase health literacy in both English and their native languages. These materials could include culturally tailored graphics and pictures of many different community members, increasing appeal to a wider range of ethnic groups.

In one community survey [15], minorities, including Asian Americans, seemed less willing to contribute to biospecimen repositories. In our study, only a very small percentage of Asian Americans were unwilling to have their blood stored under any condition, and most (86.2%) were willing to give a small amount of blood for storage but there were more concerns about tissue extraction. Without further study, the differences in regard to willingness to supply tissue and blood sampling, apparent in this study, remain unknown.

### Limitations and Relevant Observations

Our study findings were based on convenience samples of disparate ethnic and cultural/linguistic groups. Therefore, generalizations of the findings to the larger respective ethnic communities should be made with caution. This convenience sample is unique in certain characteristics. Although 95% of the participants were born abroad; the majority had lived a relatively long time in the US, over 17 years. However, over half (53%) of those who lived 16 years or less in the US reported they knew little or nothing about bio-specimen banking, the largest percent for this variable. The awareness of biospecimen banking in this sample of Asian Americans is surprising considering the large majority reported low English fluency limiting their exposure to US media. Community members shared stories about testing procedures indicating that these discussions are ongoing in Asian American groups, albeit without avenues for new information and ways to correct misunderstandings that health education provides.

Our findings indicate needs for expanding this research to include larger, more demographically diverse samples such as younger generations of Koreans, Chinese, Vietnamese, and other Asian American groups, new immigrants who come from countries that lack an infrastructure for health education and bio-specimen research [7,16,17]. Increasing the level of knowledge of innovative biospecimen procedures and the ultimate benefits to the individual participant, his or her family, Asian American communities and society would greatly enhance participation in biospecimen banking campaigns [9,10,15]. Extending studies like for other minority groups with important cancer health disparities such as African Americans is important for biospecimen banks and future research [18].

This study did not ask about testing other family members, such as children, or how to release genetic information about families [10,14] although these concerns surfaced in discussions. Future studies will need to address participant fears about the social and legal consequences of genetic testing [6] and possible community stigma when disease trends are found in families. The survey also did not include a question about religion which may be important for studies of cancer risk because of

diet and lifestyle differences linked to religion. The next step in research would be to test models of information dissemination in different Asian communities to identify methods that maximize participation while successfully protecting community concerns.

### Conclusion

Subsets of the US population are more at risk for certain types of cancers and co-morbid conditions than the general population. Bio-specimen banking offers a way to house samples that with future technology may offer answers to the causes of differential risk and thus has received unusual attention in recent years. Health-disparate populations including Asian Americans, who reportedly have a higher incidence of diseases such as HBV-related liver cancer, cervical cancer (Vietnamese) and colorectal cancer (Koreans) and higher mortality rates from breast cancer (Chinese) will need wider community participation to make such research meaningful [19-23]. Cancers that are genetically related may also benefit from future research that can tailor treatment and maximize health outcomes. Lifestyle factors may also be informed by research on bio-specimens because groups of individuals may be predisposed to certain lifestyles (e.g., smoking, or excessive alcohol consumption) or their genetic makeup may be more vulnerable to such health risks that can ultimately lead to cancer (e.g., laryngeal, lung, or esophageal cancer) [24-27].

Over the past 13 years, our community-based participatory research has shown that the involvement of Asian American communities in all phases of research enterprises yields substantial benefits both to communities and advances in scientific knowledge, particularly by improving the cultural relevance of interventions and health education strategies. Working with more than 280 partners in the eastern region of the US, we find that increased community awareness and knowledge leads to community empowerment and that the process is self-perpetuating. This community study was a unique participatory venture that led to a better understanding of similarities and differences among diverse Asian American groups and could inform dissemination of health education to individuals, families, communities, and society [12,28-30]. Such information is an important mechanism generating community discussion of the benefits and consequences of bio-specimen banking and finding out how new technologies influence cultural values. Korean, Chinese, and Vietnamese community members discussed bio-specimen banking knowledge, barriers, facilitators, and other culturally unique factors and, in the end, supported the idea of promoting bio-specimen banking because of the potential for new treatment and diagnostic options. This study's findings underscore the timeliness and need for a health education campaign that addresses community and cultural concerns about new medical technologies and options.

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The authors declare that they have no conflict of interest.

### References

1. Mc Cracken M, Olsen M, Chen MS Jr, Jemal A, Thun M, et al. (2007) Cancer incidence, mortality, and associated risk factors among Asian Americans of Chinese, Filipino, Vietnamese, Korean, and Japanese ethnicities. *CA Cancer J Clin* 57: 190-205.

2. Anand P, Kunnumakkara AB, Sundaram C, Harikumar KB, Tharakan ST, et al. (2008) Cancer is a preventable disease that requires major lifestyle changes. *Pharm Res* 25: 2097-2116.
3. Lee J, Demissie K, Lu SE, Rhoads GG (2007) Cancer incidence among Korean-American immigrants in the United States and native Koreans in South Korea. *Cancer Control* 14: 78-85.
4. Kolonel LN, Altshuler D, Henderson BE (2004) The multiethnic cohort study: exploring genes, lifestyle and cancer risk. *Nat Rev Cancer* 4: 519-527.
5. Hoeffel EM, Rastogi S, Kim MO, Shahid H (2012) The Asian Population: 2010. U.S. Department of Commerce.
6. Gottweis H, Gaskell G, Starkbaum J (2011) Connecting the public with biobank research: reciprocity matters. *Nat Rev Genet* 12: 738-739.
7. Avar D, Buccini LM, Burgess MM, Kaye J, Heeney C, et al. (2009) Public health genomics (PHG) and public participation: points to consider. *Journal of Public Deliberation* 5(1): 7.
8. Luque JS, Quinn GP, Montel-Ishino FA, Arevalo M, Bynum SA, et al. (2012) Formative research on perceptions of biobanking: what community members think. *J Cancer Educ* 27: 91-99.
9. Halverson CM, Ross LF (2012) Attitudes of African-American parents about biobank participation and return of results for themselves and their children. *J Med Ethics* 38: 561-566.
10. Lemke AA, Halverson C, Ross LF (2012) Biobank participation and returning research results: perspectives from a deliberative engagement in South Side Chicago. *Am J Med Genet A* 158A: 1029-1037.
11. Kaufman DJ, Murphy-Bollinger J, Scott J, Hudson KL (2009) Public opinion about the importance of privacy in biobank research. *Am J Hum Genet* 85: 643-654.
12. Braun KL, Nguyen TT, Tanjasiri SP, Campbell J, Heiney SP, et al. (2012) Operationalization of Community-Based Participatory Research Principles: Assessment of the National Cancer Institute's Community Network Programs. *Am J Public Health* 102(6): 1195-1203.
13. Pope C, Mays N (2006) *Qualitative Research in Health Care*. Malden: Wiley-Blackwell.
14. Simon CM, L'heureux J, Murray JC, Winokur P, Weiner G, et al. (2011) Active choice but not too active: public perspectives on biobank consent models. *Genet Med* 13: 821-831.
15. Scott EA, Schlumpf KS, Mathew SM, Mast AE, Busch MP, et al. (2010) Biospecimen repositories: are blood donors willing to participate? *Transfusion* 50: 1943-1950.
16. Christian KR, Hodgkinson VS, Sitas F (2011) Cancer council NSW biobank: A rich resource for researchers. *Asia Pac J Clin Oncol* 7 (Suppl. 4).
17. Hodgkinson VS, Christian K, Sitas F (2011) Cancer council NSW biobank: Improvements in blood collection protocol compliance. *Asia Pac J Clin Oncol* 7 (Suppl. 4).
18. DeSantis C, Naishadham D, Jemal A (2013) Cancer statistics for African Americans, 2013. *CA Cancer J Clin* 63: 151-166.
19. Hsu CE, Liu LC, Juon HS, Chiu YW, Bawa J, et al. (2007) Reducing liver cancer disparities: a community-based hepatitis-B prevention program for Asian-American communities. *J Natl Med Assoc* 99: 900-907.
20. Lin SY, Chang ET, So SK (2007) Why we should routinely screen Asian American adults for hepatitis B: a cross-sectional study of Asians in California. *Hepatology* 46: 1034-1040.
21. Lee-Lin F, Menon U (2005) Breast and cervical cancer screening practices and intentions among Chinese, Japanese, and Vietnamese Americans. *Oncol Nurs forum* 32(5): 955-1003.
22. Do HH, Taylor VM, Burke N, Yasui Y, Schwartz SM, et al. (2007) Knowledge about cervical cancer risk factors, traditional health beliefs, and Pap testing among Vietnamese American women. *J Immigr Minor Health* 9(2): 109-114.
23. Ma GX, Shive S, Tan Y, Gao W, Rhee J, et al. (2009) Community-based colorectal cancer intervention in underserved Korean Americans. *Cancer Epidemiol* 33: 381-386.
24. Haiman CA, Stram DO, Wilkens LR, Pike MC, Kolonel LN, et al. (2006) Ethnic and racial differences in the smoking-related risk of lung cancer. *N Engl J Med* 354(4): 333-342.
25. Zhang SM, Lee IM, Manson JE, Cook NR, Willett WC, et al. (2007) Alcohol consumption and breast cancer risk in the Women's Health Study. *Am J Epidemiol* 165: 667-676.
26. Altieri A, Garavello W, Bosetti C, Gallus S, La Vecchia C (2005) Alcohol consumption and risk of laryngeal cancer. *Oral Oncol* 41: 956-965.
27. Yang CX, Wang HY, Wang ZM, Du HZ, Tao DM, et al. (2005) Risk factors for esophageal cancer: a case-control study in South-western China. *Asian Pac J Cancer Prev* 6: 48-53.
28. Ma GX, Shive SE, Toubbeh JI, Wu D, Wang P (2006) Risk perceptions, barriers, benefits and self-efficacy of Hepatitis B screening and vaccination among Chinese immigrants. *Int J Health Educ* 9:141-153.
29. Ma GX, Tan Y, Toubbeh JI, Edwards RL, Shive SE, et al. (2006) Asian Tobacco Education and Cancer Awareness Research Special Population Network. A model for reducing Asian American cancer health disparities. *Cancer* 107: 1995-2005.
30. Ma GX, Shive SE, Wang MQ, Tan Y (2009) Cancer screening behaviors and barriers in Asian Americans. *Am J Health Behav* 33: 650-660.