

Factors Associated with Willingness to Participate in Biospecimen Research Among Chinese Americans

Wanzhen Gao,¹ Grace X. Ma,^{1,2} Yin Tan,¹ Carolyn Fang,³
JoEllen Weaver,⁴ Ming Jin,⁵ and Philip Lai⁶

A paucity of information exists on the recruitment of Asian Americans for biospecimen research. Although studies show that Chinese Americans are at high risk for hepatitis B virus (HBV) infection, little is known about their willingness to participate in HBV-related biospecimen research and how knowledge, attitudes, and cultural factors impact their willingness to participate. The study was guided by Community-Based Participatory Research principles. Data were derived from an assessment study on HBV-related biospecimen research participation among Chinese Americans in the Philadelphia region. The assessment was conducted with 415 Chinese Americans recruited from eight Chinese community-based organizations. Cultural beliefs, knowledge, and attitudes toward biospecimen research were examined for associations with their willingness to participate in biospecimen banking research. Overall, 192 (46.3%) of 415 participants who completed the assessment indicated they were willing to participate if they were invited to donate blood to be frozen and stored for future HBV biospecimen studies. Cultural variables significant in bivariate analysis included collectivism, knowledge about biospecimen research, and Yin-Yang beliefs. Fatalism and individualism were not associated with participation willingness. In multivariate analysis, age, health care attitudes, and trust were significantly associated with willingness to participate in biospecimen banking research. Asian American communities have little knowledge of biospecimen banking and will benefit from educational campaigns that emphasize collective benefits and attitudes towards and trust in the health care system. Understanding cultural factors is important for improving Chinese Americans' knowledge, awareness, and intentions of participation in biospecimen research. Similar efforts need to be undertaken to develop culturally appropriate educational intervention programs to increase participation in biospecimen research among other Asian American groups.

Introduction

BIOSPECIMEN RESEARCH USING SAMPLES of blood, tissue, and proteins from body fluids is integral for studies that examine variations in disease risk or characteristics,¹ including variations by race/ethnicity or Ancestry Informative Markers.²⁻⁴ Low rates of racial/ethnic minority participation in biospecimen research may negatively impact advances in medical research pertinent to these groups.⁵

A paucity of data exists on Asian cultural beliefs and attitudes regarding biospecimen donation and storage for medical research. A Singapore-based study examining individual willingness to donate blood specifically for genetic research found that fear of personal injury and hurt was an over-riding factor against blood donation. The Singapore study participants also reported concerns such as no self-

benefits, fear of discovery of disease, fear of discrimination, and weakness and shame.⁶ A focus group study with Chinese community members and an in-depth interview study with Chinese community leaders in the Philadelphia area revealed some concerns that blood donation may be harmful to one's health. Participants in these two studies stated that they might consider testing if there was a direct health benefit to themselves or a family member.^{7,8} Other cultural factors such as a respect for authority or Yin-Yang are less understood as they influence health related behaviors.⁹⁻¹² Cultural research suggests that these values may keep Chinese individuals from seeking Western medicine for help, and they influence conceptions of illness and cancer.¹²⁻¹⁸

To improve Chinese American participation in biospecimen research, the current study builds on a needs assessment of Philadelphia Chinese Americans using Community-

¹Center for Asian Health, and ²Department of Public Health, College of Health Professions, Temple University, Philadelphia, Pennsylvania.

³Cancer Prevention and Control, and ⁴Biosample Repository, Fox Chase Cancer Center, Philadelphia, Pennsylvania.

⁵Department of Pathology and Laboratory Medicine, Temple University Hospital and School of Medicine, Philadelphia, Pennsylvania.

⁶Philadelphia Senior Center, Philadelphia, Pennsylvania.

Based Participatory Research (CBPR) approaches. The purpose of this article is to determine how demographics, health care access, knowledge, and cultural beliefs are associated with willingness to participate in biospecimen research among Chinese Americans.

Materials and Methods

This research program was approved by Temple University's Institutional Review Board (protocol #3515) and participating partner organization review groups for the Protection of Human Subjects.

Study sites and participant recruitment

Using CBPR approaches, long-term partnerships were established with more than 100 Chinese Community organizations in targeted geographic areas. Community leaders in eight areas agreed to partner with the Center for Asian Health to recruit participants for this study. A formal partnership agreement was signed to develop, implement, and deliver the education intervention and to disseminate study findings. Protocols for involving partners in this phase of the study included planning meetings involving participating site leaders, Community Advisory Boards, and project staff to: 1) review study aims, design, recruitment strategies, and protocols; 2) discuss on-site training for community health workers and partner roles and responsibilities; 3) clarify community leaders' roles in announcing and facilitating the study; and 4) assess participant eligibility screening and confidentiality processes (e.g., keeping local sign-in sheet contact information in local, locked facilities).

A total of 449 Chinese Americans were recruited from the eight community-based organizations (CBOs). Among recruits, 415 completed the assessment. The inclusion criteria included: 1) self-identified Chinese ethnicity; 2) aged 18 or older; and 3) available by telephone or email.

Measures

All English measures were translated, back-translated, and pretested in Chinese to ensure the scientific and cultural appropriateness for Chinese participants. The 20–30-minute survey was conducted in Chinese and English. Bilingual assistance was available at all sites. Questionnaires were checked for completeness to ensure the quality of data.

Demographics included participants' age, marital status, educational level, and household income. Acculturation measures were the number of years living in the US, English proficiency, and healthcare access. Developed by our research team, these measures explore how immigrant Asian Americans' adaption to a new culture and environment could influence health and health-related behaviors.^{7,8,19}

Knowledge about biospecimen research. Participants were asked: 1) "How much do you know about biospecimen research?" Responses were "Nothing," "Only heard the name," "Know some," and "Know a lot."; 2) To identify possible biospecimen samples from a list of multiple choices such as: urine, blood, tissue, cells, DNA/RNA, protein; and 3) To recognize possible uses of biospecimen samples from a list of multiple choices including: a) identify and validate ways to deliver drugs or agents to specific cells, b) identify how diseases progress and vary, c) group patients as more or less likely to respond to specific drugs, d) group patients to

determine which treatment is appropriate, and e) develop screening tests to detect biomarkers that are associated with certain stages or subtypes of a disease. Correct answers were summed to obtain a total score for knowledge about biospecimen research.

Cultural beliefs and attitudes toward health and blood donation for biospecimen research. In order to better understand how Chinese Americans' general life philosophy and health beliefs potentially influence their attitudes and willingness to participate in biospecimen research, information on fatalism, collectivism/individualism, and Yin-Yang beliefs were collected. Fatalist beliefs held by many Asian Americans have lowered participation in health behaviors.^{13,20,22} Our hypothesis was that fatalistic beliefs would reduce willingness to participate in biospecimen research. Fatalism was measured using a 7-item FATE scale developed by Straughan and Seow.²³ Items included: 1) Life and death are all predestined; there is nothing we can do to change our destiny; 2) Serious diseases like cancer are all fated; we cannot prevent them from happening; 3) If you are fated to get cancer, you will get cancer; there is nothing you can do to change fate; 4) If you don't die from this, you'll die from that. So there's no point taking medical screening tests; 5) If we feel well, we should not go looking for trouble by having medical screening tests; 6) Many types of diseases can be prevented; it's up to us to do something about it; and 7) Whether I enjoy good health or not depends a lot on how well I take care of myself. Item responses ranged from "strongly disagree" (coded 1) to "strongly agree" (coded 10). The scale Cronbach's alpha was 0.72, indicating moderate reliability, slightly lower than found in other studies (0.77 to 0.82).^{13,20}

Compared to European and American values of individualism, Asian Americans more often believe in considering and valuing the group above oneself or individual needs.^{24,28} Our hypothesis was that those with collectivist beliefs would be more willing to participate in biospecimen research than those with individualist beliefs. The horizontal and vertical individualism and collectivism scale²⁹ was adapted by Singelis³⁰ and used in the current study. The scale included 14 statements: 1) My happiness depends very much on the happiness of those around me; 2) I would do what would please my family, even if I detested that activity; 3) I usually sacrifice my self-interest for the benefit of my group; 4) I enjoy working in situations involving competition with others; 5) The well-being of my co-workers is important to me; 6) I enjoy being unique and different from others in many ways; 7) Children should feel honored if their parents receive a distinguished award; 8) I often "do my own thing"; 9) Competition is the law of nature; 10) If a co-worker gets a prize, I would feel proud; 11) I am a unique individual; 12) I would sacrifice an activity that I enjoy very much if my family did not approve of it; 13) Without competition it is not possible to have a good society; and 14) I feel good when I cooperate with others.²⁹ Responses ranged from "strongly disagree" (coded 1) to "strongly agree" (coded 10). Items 4, 6, 8, 9, 11, and 13 were summed to measure individualism, and the remaining items summed to measure collectivism. Corresponding reliability coefficients were 0.67 and 0.76, respectively, similar to those reported elsewhere.²⁹

The concept of Yin-Yang is widely used to examine Chinese cultural beliefs^{31–33} and health behaviors. Yin-Yang philosophy places value on maintaining a balance in life to promote health, good nutrition, and righteousness.

Those with strong Yin-Yang beliefs may embrace traditional over western beliefs about health. Our hypothesis was that those with high Yin-Yang beliefs would be less willing to participate in biospecimen research. Because no standard measure exists, based on existing literature and advice from the Community Advisory Board, our research group developed 8 items to capture Chinese beliefs about Yin-Yang, traditional medicine versus western medicine, and medical care.¹³ Questions included: 1) Cancer can be caused by an imbalance of Yin and Yang; 2) Cancer can be caused by poor qi and blood circulation; 3) We should not take “western” medicine too often, because its chemical ingredients will hurt our bodies; 4) Herbs are a better remedy for illness than western medicine; 5) As long as I take good care of myself and keep myself healthy, I don’t need to see a doctor; 6) A lot of medical tests are too invasive (e.g., by incision or by insertion of an instrument or chemical into the body) and make me uncomfortable; 7) Medical doctors usually do unnecessary tests; and 8) Blood is precious as the source of life and giving blood would make people feel faint. All responses were rated on a scale of 1 to 10, ranging from “strongly disagree” to “strongly agree.” The reliability coefficient was 0.74.

Healthcare attitudes and trust. Six items assessed participants’ attitudes toward health care (either as a patient or relative), trust in healthcare personnel, experience ever having been a blood donor, attitudes towards genetic research, and trust in the ability of different authorities to evaluate the risks and benefits of genetic research. Responses were rated from “strongly disagree” (coded 1) to “strongly agree” (coded 5). The scale Cronbach’s alpha was 0.88, a high reliability score.

Willingness to participate in biospecimen research. Participants were asked “Have you ever donated blood for scientific research?”; “If you are invited to participate in a project that includes donating blood to be processed and stored for future HBV biospecimen studies, what would you feel?” Responses ranged from “Willing to participate” (coded 1) to “Not willing to participate” (coded 10). Responses of 4 or lower were coded as indicating willingness to participate in biospecimen research with “1” being willing to participate and “0” not willing to participate.

Statistical approach

Descriptive statistics included percentages, means, and standard deviations. Bivariate analyses include Chi-square, Fisher’s exact, and a Student’s *t*-test. Summed scores for variables measuring cultural beliefs, knowledge, and attitudes were further grouped into tertile categories. Univariable logistic regression was used to examine the association between willingness to participate in biospecimen research and each tertile group reporting odds ratios (OR) and 95% confidence intervals (CI). Only variables identified as significant in univariate analyses were included in multivariate analyses. Forward selection multivariate logistic regression modeling was performed using tertile variables and age groups.

Results

Overall, 46.3% (192/415) reported a willingness to participate by donating blood to be frozen and stored for future HBV biospecimen studies. Table 1 includes sample characteristics for those unwilling and willing to participate in

TABLE 1. DEMOGRAPHICS, HEALTH CARE ACCESS, AND WILLINGNESS TO PARTICIPATE IN BIOSPECIMEN RESEARCH

	Unwilling		Willing		P value
	N	%	N	%	
Age					0.02
18–40 years old	40	65.6	21	34.4	
41–50 years old	29	67.4	14	32.6	
51–60 years old	16	43.2	21	56.8	
>60 years old	136	50.0	136	50.0	
Gender					0.36
Male	77	50.7	75	49.3	
Female	145	55.3	117	44.7	
Born in the U.S.					0.88
No	211	53.0	187	47.0	
Yes	5	55.6	4	44.4	
Years lived in U.S.					0.14
1–10 years	107	55.2	87	44.8	
11–20 years	58	46.8	66	53.2	
>20 years	50	60.2	33	39.8	
Current marital status					0.76
Married	165	54.3	139	45.7	
Never married	14	58.3	10	41.7	
Other	40	50.6	39	49.4	
Level of education					0.09
Less than high school	109	59.9	73	40.1	
High school	43	51.8	40	48.2	
University/graduate	64	47.8	70	52.2	
Employment					0.54
Employed	39	54.2	33	45.8	
Unemployed	16	44.4	20	55.6	
Other	158	54.1	134	45.9	
Annual household income					0.35
<\$10,000	122	51.3	116	48.7	
\$10,000–20,000	39	59.1	27	40.9	
\$20,001–30,000	13	61.9	8	38.1	
>\$30,000	17	65.4	9	34.6	
Health insurance					0.19
No	80	57.1	60	42.9	
Yes	128	50.2	127	49.8	
Have regular physician					0.07
No	73	59.8	49	40.2	
Yes	131	49.8	132	50.1	
Speak English well					0.13
Not at all/not well	192	52.2	176	47.8	
Well/Very well	23	65.7	12	34.3	

biospecimen research. Older people were more willing to participate compared to younger (34.4% for those aged 18–40, 32.6% for 41–50, 56.8% for 51–60, and 50% for 61 or older, respectively; *p*<0.05). Education (*p*=0.09) and having a physician (*p*=0.06) were marginally significant.

Mean differences between those willing and not willing to participate in biospecimen research and cultural beliefs, knowledge about biospecimen research, and health care attitudes and trust are presented in Table 2. Chinese Americans with higher total scores on the collectivism scale reported higher levels of willingness to participate in biospecimen research (62.0 vs. 58.6, *p*=0.02). Those with higher scores on the Yin-Yang scale were less willing to participate in biospecimen research (*p*=0.05).

TABLE 2. MEAN SCALE DIFFERENCES AND WILLINGNESS TO PARTICIPATE IN BIOSPECIMEN RESEARCH

	<i>Unwilling</i>		<i>Willing</i>		<i>P value</i>
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	
Cultural beliefs					
Fatalism	25.0	13.1	23.8	13.5	0.3830
Collectivism	58.6	13.5	62.0	12.2	0.0157
Individualism	38.1	11.2	37.3	11.2	0.5350
Yin-Yang beliefs	43.5	14.3	40.4	15.2	0.0546
Knowledge of biospecimen research	3.1	2.8	4.0	3.2	0.0029
Health care attitudes and trust	23.1	4.2	25.2	3.5	<0.0001

Higher levels of knowledge about biospecimen research were associated with willingness to participate in biospecimen research ($p < 0.01$). Those reporting higher scores for health care attitudes and trust had higher mean scores for willingness to participate in biospecimen research (25.2) compared to those with lower scores (23.1) ($p < 0.01$).

Univariable logistic regression results suggested age, collectivism, knowledge of biospecimen research, and health care attitudes and trust were significantly associated with the willingness to participate in biospecimen research (Table 3). In multivariate logistic regression, only age and health care attitudes and trust were independently associated with willingness

to participate in biospecimen research. Those aged 51–60 years had the highest likelihood to participate (OR = 2.43, 95% CI = 1.02–5.76) compared with the reference age group (18–40 years). For the variable health care attitudes and trust, those in the second and third tertiles were two and three times more likely to participate compared with the first, lowest tertile (OR = 2.21, 95% CI = 1.27–3.83 and OR = 3.08, 95% CI = 1.82–5.23).

Discussion

This study breaks new ground in uncovering cultural factors, knowledge, and attitudes associated with Chinese American

TABLE 3. UNIVARIATE AND MULTIVARIATE ASSOCIATIONS OF WILLINGNESS TO PARTICIPATE IN BIOSPECIMEN RESEARCH

<i>Independent Variables</i>	<i>Unadjusted OR</i>	<i>95%CI</i>	<i>P value</i>	<i>Adjusted OR</i>	<i>95%CI</i>	<i>P value</i>
Age			0.02			0.05
18–40 years	reference			reference		
41–50 years	0.92	0.40–2.11		0.83	0.36–1.95	
51–60 years	2.50	1.09–5.78		2.43	1.02–5.76	
>60 years	1.91	1.07–3.40		1.69	0.92–3.08	
Fatalism tertiles			0.17			
Tertile 1 (<16)	reference					
Tertile 2 (16–30)	0.56	0.34–0.94				
Tertile 3 (≥31)	0.79	0.48–1.31				
Missing values	0.81	0.40–1.62				
Collectivism tertiles			0.03			
Tertile 1 (<56)	reference					
Tertile 2 (56–66)	1.24	0.73–2.11				
Tertile 3 (≥67)	1.81	1.07–3.08				
Missing values	0.80	0.44–1.46				
Individualism tertiles			0.85			
Tertile 1 (<33)	reference					
Tertile 2 (33–41)	0.86	0.49–1.49				
Tertile 3 (≥42)	0.81	0.48–1.37				
Missing values	0.80	0.45–1.42				
Yin Yang tertiles			0.11			
Tertile 1 (<36)	reference					
Tertile 2 (36–47)	0.70	0.41–1.20				
Tertile 3 (≥48)	0.64	0.37–1.10				
Missing values	0.49	0.27–0.88				
Knowledge tertiles			0.02			
Tertile 1 (<2)	reference					
Tertile 2 (2–3)	1.52	0.91–2.54				
Tertile 3 (≥4)	2.05	1.24–3.39				
Attitude tertile group			0.00			0.00
Tertile 1 (<23)	reference			reference		
Tertile 2 (23–24)	2.13	1.24–3.66		2.21	1.27–3.83	
Tertile 3 (≥25)	3.18	1.89–5.34		3.08	1.82–5.23	
Missing values	1.83	0.90–3.72		1.62	0.78–3.33	

willingness to participate in biospecimen research. About half (46.3%) of the Chinese Americans in our study reported a willingness to donate blood for future studies of HBV. US studies of willingness to participate in biospecimen banking vary in study design and population limiting direct comparison of results.^{1,34-41} These studies grouped results so that specific information for Asian American subpopulations remains unknown. Overall reported rates from general and patient populations indicated between 60.0% and 98.4% of participants were willing to donate some kind of specimen for genetics or medical research. Other studies that report rates for Chinese or Asian populations range from 33.0 to 49.5%.^{5,6,42}

Participants aged 50 and older were more likely to be willing to participate in biospecimen research compared to their younger counterparts, as in other studies.^{37,43} This finding might be explained by Erikson's theory of generativity where caring for the next generation increases with age,⁴⁴ or generational differences.⁴³

Our study suggests that positive attitudes toward and greater trust in the health care system are critical facilitators for participating in biospecimen research among Chinese Americans. Many other studies indicate that trust in health care is linked to better health screening, adherence to medication, and satisfaction with health care.^{7,8,45-51} CBPR best practices suggest that including scientists and clinicians from respected health institutions in community partnerships builds community trust and may help to increase community involvement in biobanking.⁵²

Knowledge about biospecimen research plays an important role in Chinese American willingness to participate in biospecimen research as indicated by our bivariate results. Only 50% of study participants had heard about biospecimen research and the majority could not correctly identify the use of biospecimens in medical research. Much research has been done documenting similarly low levels of knowledge,⁷ especially compared to U.S. populations.⁵³ Knowledge of specific and general medical information has been linked to health behaviors such as screening.^{50,51,54-57}

Findings from the present study suggest that Chinese Americans with higher collectivism views were more willing to participate in biospecimen research compared with those with less collectivism views, although this did not remain significant in multivariate analyses. Collectivists value actions with benefits to society and social life²³⁻²⁸ and so support medical research by being willing to donate blood. Collectivist views may reflect Chinese traditional values and may be a promising health communications strategy to increase Chinese Americans' participation in biospecimen research. Indeed, Chinese American participants in other focus groups and key informant studies conducted by our Center expressed their desire to participate in health screenings and biospecimen banking to help their community and the next generation.^{7,8,54,55,57}

The measure of Yin-Yang used in this study reflects both the importance of maintaining a balance but also beliefs about western medicine and traditional health practices.^{13,31-33} In bivariate analyses, those with higher Yin-Yang beliefs were more unwilling to participate in biospecimen research (mean scores of 43.5 vs. 40.4, $p=0.05$). Although this relationship did not hold in multivariate analyses, this finding indicates that this message resonates with a subsection of Chinese Americans. Future health promotion campaigns for biospecimen banking recruitment should explore how Yin-Yang

beliefs may be in parallel with research goals. Similarly, although fatalism was not a factor distinguishing those willing or unwilling to participate, health communication strategies may want to explore this belief because it has been shown to be a factor in other areas such as medical screenings.^{20-23,58}

An emerging body of research on biospecimen participation among ethnic groups revealed various concerns, such as stigmatization, loss of confidentiality, and a lack of trust in health care organizations.^{6,34-39,42} For example, Native Americans are often reluctant to consent to future unspecified research for fear that research results would stigmatize their community.⁵⁹ In addition, Native Americans are sensitive to the use of their specimens for the development of treatments by commercial entities because they perceive such treatments are often too expensive and, therefore, would be less available to them because of their economic status.⁵⁹ Some Jewish leaders have discouraged their community members from participating in genetics research because they fear the possible discrimination or stigmatization of Jews as a consequence of research to identify their populations as being at higher risk for particular diseases.⁶⁰

Innovations in medicine such as stem cell research or biospecimen banking challenge beliefs and values of many cultures including Chinese Americans.⁶¹⁻⁶³ A summary report of eight studies of public attitudes toward stem cell research in 34 countries found little consensus.⁶² Such a lack of consensus reflects differences in uncertainty over safety, informed consent and unknown future benefits, risks and consequences, as well as cultural values of respect for life, "ownership" over biospecimens, and religious beliefs.⁶¹ Efforts to engage the public in discussions of new technologies and scientific advances had the goal to identify belief systems and address concerns, but some had mixed results including public backlash.⁶⁴⁻⁶⁶ Positive engagement leading to enhanced participation depends on a thorough understanding of cultural beliefs and proactive messaging to reach diverse communities.^{64, 67}

Limitations

Partnering with various community organization settings such as community service and action, community support groups, church groups, and educational groups, we endeavored to recruit a diverse sample. In general, our sample was older, female, not born in the US, married, low income, and connected to health care by having a physician and insurance, not as diverse as anticipated. Also, Chinese residents who are not engaged with partner community groups may have different views and patterns of participating in biospecimen research, limiting the generalization of this study.

Fatalism, collectivism/individualism, and Yin-Yang beliefs were used to explore how Chinese American general life philosophy and health beliefs could potentially influence or were associated with their attitude and willingness toward participating in biospecimen research. The measures used in this study had a moderate reliability similar to those used in other studies.^{20-22,24-28,32,33} Some measures, such as collectivism/individualism, were very abstract. These measures may perform better if modified or tailored to be more specific to biospecimen research.

In this study, the outcome variable is self-reported willingness to participate in biospecimen banking for HBV, which may or may not translate into actual behavior. One study of women attending a clinic for breast cancer screening found that, although 66.0% said they were willing to donate for biospecimen research, only 56.4% actually donated, with Asian Americans having the lowest willingness and participation rates.⁶⁸ Based on this study, our findings may overestimate the percentage of Chinese Americans willing to be part of biospecimen banking research. Future studies will need to estimate the “social desirability” gap⁶⁹ in order to better predict participation rates.

Conclusions

Improving outreach and education to Chinese Americans about possibilities to advance science by participating in biospecimen banking research is important for this growing US population. Trust and positive attitudes toward health care were the most important modifiable variables in our model, which underscores the importance of building relationships between health care providers and communities, especially those who speak languages other than English and may be unfamiliar with Chinese cultural practices and ideas. CBPR methods demonstrated in projects like this hold promise for both identifying and developing health interventions to improve participation of Chinese Americans and other Asian American groups.

This pilot study explored cultural values related to willingness to participate in biospecimen research. Specifically, promoting recruitment by emphasizing collectivist messages should enhance Asian American participation. Fatalism and Yin-Yang beliefs may be more difficult to address. Additional studies are needed to better understand cultural values of Chinese, other Asian Americans, and other minority populations to guide biospecimen collection protocols and procedures and to enhance diverse recruitment.

Acknowledgments

This research is a pilot study project supported by NIH-NCI funded ACCHDC (1U54CA153513, PI: Grace Ma; Pilot Study Leader, Wanzhen Gao). The authors wish to thank Asian Community Health Coalition for collaboration and the community members who participated in this study.

Author Disclosure Statement

The authors declare no conflict of interest.

References

1. National Cancer Institute: NCI Dictionary of Cancer Terms. Available from: <http://www.cancer.gov/dictionary?cdrid=561324>. Accessed 25 March 2014.
2. Carey LA, Perou CM, Livasy CA, et al. Race, breast cancer subtypes, and survival in the Carolina Breast Cancer Study. *JAMA* 2006;295:2492–2502.
3. Morris GJ, Naidu S, Topham AK, et al. Differences in breast carcinoma characteristics in newly diagnosed African-American and Caucasian patients: A single institution compilation compared with the National Cancer Institute’s Surveillance, Epidemiology, and End Results database. *Cancer* 2007;110:876–884.
4. Albain KS, Unger JM, Crowley JJ, Coltman CA Jr, Hershman DL. Racial disparities in cancer survival among randomized clinical trials patients of the Southwest Oncology Group. *J Nat Cancer Inst* 2009;101:984–992.
5. Crider KS, Reefhuis J, Woomert A, Honein MA. Racial and ethnic disparity in participation in DNA collection at the Atlanta site of the National Birth Defects Prevention Study. *Am J Epidemiol* 2006;164:805–812.
6. Wong ML, Chia KS, Yam WM, Teodoro GR, Lau KW. Willingness to donate blood samples for genetic research: A survey from a community in Singapore. *Clin Genet* 2004;65:45–51.
7. Ma GX, Seals B, Tan Y, Lee R, Fang C. Increasing Asian American participation in clinical trials by addressing community concerns. *Clin Trials* 2014, in press.
8. Ma GX, Seals B, Tan Y, Lee R, Toubbeh J: (under review) Using mixed methods to examine perceptions and willingness to participate in biospecimen banking in diverse Asian Americans. *Community Med Health Edw*.
9. Ngo PYL, Malz TA. Cross-cultural and cross generational differences in Asian Americans’ cultural and familial systems and their impact on academic striving. In: *Resiliency in Native American and Immigrant Families*, McCubbin HI, (ed.). Thousand Oaks, CA: Sage Publications, 1998, pp.265–274.
10. Oyserman D, Sakamoto I. Being Asian American: Identity, cultural constructs, and stereotype perception. *J Appl Behav Sci* 1997;3:435–453.
11. Fang T, Faure GO. Chinese communication characteristics: A Yin Yang perspective. *Int J Intercult Relat* 2011;35:320–333.
12. Liang W, Yuan EH, Mandelblatt JS, Pasick RJ. How Chinese women view health and cancer screening? Results from focus groups and implications for intervention. *Ethn Health* 2004;9:283–304.
13. Liang W, Wang JH, Chen M, et al. Developing and validating a measure of Chinese cultural views of health and cancer. *Health Educ Behav* 2008;35:361–375.
14. Hoeman SP, Ku YL, Ohl DR. Health beliefs and early detection among Chinese women. *West J Nurs Res* 1996;18:518–533.
15. Ma GX. Between two worlds: The use of traditional and Western health services by Chinese immigrants. *J Community Health* 1999;24:421–437.
16. Mo B. Modesty, sexuality, and breast health in Chinese-American women. *West J Med* 1992;157:260–264.
17. Vu HH. Cultural barriers between obstetrician-gynecologists and Vietnamese/Chinese immigrant women. *Tex Med* 1996;92:47–52.
18. Yamashiro G, Matsuoka JK. Help-seeking among Asian and Pacific Americans: A multiperspective analysis. *Soc Work* 1997;42:176–186.
19. Ma GX, Tan Y, Blakeney NC, et al. The impact of a community-based clinical trial educational intervention among underrepresented Chinese Americans. *Cancer Epidemiol Biomarkers Prevent* 2014;23:424–432.
20. Straughan PT, Seow A. (2000). Attitudes as barriers in breast screening: A prospective study among Singapore women. *Social Sci Med* 2000;51:1695–1703.
21. Seow A, Huang J, Straughan PT. Effects of social support, regular physician and health-related attitudes on cervical cancer screening in an Asian population. *Cancer Causes Control* 1000;11:223–230.
22. Kang Y, Crogan NL. Social and cultural construction of urinary incontinence among Korean American elderly women. *Geriatric Nursing* 2008;29:105–111.

23. Straughan PT, Seow A. Fatalism reconceptualized: A concept to predict health screening behavior. *J Gend Cult Health* 1998;3:85–100.
24. Kuo BC. Collectivism and coping: Current theories, evidence, and measurements of collective coping. *Intl J Psychol* 2013;48:374–388.
25. Wang M, Kviz FJ, Miller AM. The mediating role of parent-child bonding to prevent adolescent alcohol abuse among Asian American families. *J Immigrant Minority Health* 2014;14:831–840.
26. Le TN, Goebert D, Wallen J. Acculturation factors and substance use among Asian American youth. *J Primary Prevent* 2009;30:453–473.
27. Li Y, Costanzo PR, Putallaz M. Maternal socialization goals, parenting styles, and social-emotional adjustment among Chinese and European American young adults: Testing a mediation model. *J Genetic Psychol* 2010;171:330–362.
28. Le TN, Stockdale GD. Individualism, collectivism, and delinquency in Asian American adolescents. *J Clin Child Adolesc Psychol* 2005;34:681–691.
29. Sivadas E, Bruvold NT, Nelson MR. A reduced version of the horizontal and vertical individualism and collectivism scale: A four-country assessment. *J Bus Res* 2008;61:201–210.
30. Singelis TM, Triandis Harry C, Bhawuk D, Gelfand MJ. Horizontal and vertical dimensions of individualism and collectivism: A theoretical and measurement refinement. *Cross-Cult Res* 1995;29:240–275.
31. Fang T, Yin Yang. A new perspective on culture. *Manage Organ Rev* 2012;8:25–50.
32. Ma-Kellams C, Blascovich J. Enjoying life in the face of death: East-West differences in responses to mortality salience. *J Personality Soc Psychol* 2012;103:773.
33. Smith CS, Hung LC. The influence of Eastern philosophy on elder care by Chinese Americans attitudes toward long-term care. *J Transcult Nursing* 2012;23:100–105.
34. Wang SS, Fridinger F, Sheedy KM, Khoury MJ. Public attitudes regarding the donation and storage of blood specimens for genetic research. *Community Genet* 2001;4:18–26.
35. McQuillan GM, Porter KS, Agelli M, Kington R. Consent for genetic research in a general population: The NHANES experience. *Genet Med* 2003;5:35–40.
36. Schwartz MD, Rothenberg K, Joseph L, Benkendorf J, Lerman C. Consent to the use of stored DNA for genetics research: A survey of attitudes in the Jewish population. *Am J Med Genet* 2001;98:336–342.
37. Malone T, Catalano PJ, O'Dwyer PJ, Giantonio B. High rate of consent to bank biologic samples for future research: The Eastern Cooperative Oncology Group experience. *J Natl Cancer Inst* 2002;94:769–771.
38. Treweek S, Doney A, Leiman D. Public attitudes to the storage of blood left over from routine general practice tests and its use in research. *J Health Serv Res Policy* 2009;14:13–19.
39. Pulley JM, Brace MM, Bernard GR, Masys DR. Attitudes and perceptions of patients towards methods of establishing a DNA biobank. *Cell Tissue Bank* 2008;9:55–65.
40. Kaufman D, Murphy J, Scott J, Hudson K. Subjects matter: A survey of public opinions about a large genetic cohort study. *Genet Med* 2008;10:831–839.
41. McQuillan GM, Pan Q, Porter KS. Consent for genetic research in a general population: An update on the National Health and Nutrition Examination Survey experience. *Genet Med* 2006;8:354–360.
42. Gao W, Ma GX, Tan Y, et al. Culturally appropriate education intervention on biospecimen research participation among Chinese Americans. *Cancer Epidemiol Biomarkers Prev* 2014;23:383–391.
43. Kettis-Lindblad A, Ring L, Viberth E, Hansson MG. Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think? *Eur J Publ Health* 2005;16:433–440.
44. Erikson JM, Kivnick HQ. *Vital Involvement in Old Age*. NY: Norton, 1986.
45. Cobb TG. Strategies for providing cultural competent health care for Hmong Americans. *J Cult Divers* 2010;17:79.
46. Thorburn S, Kue J, Keon KL, Lo P. Medical mistrust and discrimination in health care: A qualitative study of Hmong women and men. *J Community Health* 2012;37:822–829.
47. Shiao R, Bove F, Henne J, Zola J, Fang T, Fernyak S. Using survey results regarding hepatitis B knowledge, community awareness and testing behavior among Asians to improve the San Francisco Hep B Free Campaign. *J Community Health* 2012;37:350–364.
48. Jang Y, Kim G, Chiriboga DA. Health, healthcare utilization, and satisfaction with service: Barriers and facilitators for older Korean Americans. *J Am Geriatr Soc* 2005;53:1613–1617.
49. Hunt KA, Gaba A, Lavizzo-Mourey R. Racial and ethnic disparities and perceptions of health care: Does health plan type matter?. *Health Serv Res* 2005;40:551–576.
50. Nguyen TUN, Tran JH, Kagawa-Singer M, Foo MA. A qualitative assessment of community-based breast health navigation services for Southeast Asian women in Southern California: Recommendations for developing a navigator training curriculum. *J Inf* 2011;101:87–93.
51. Nguyen GT, Bellamy SL. Cancer information seeking preferences and experiences: disparities between Asian Americans and Whites in the Health Information National Trends Survey (HINTS). *J Health Commun* 2006;11:173–180.
52. Erwin DO, Moysich K, Kiviniemi MT, et al. Community-based partnership to identify keys to biospecimen research participation. *J Cancer Educ* 2013;28:43–51.
53. Ulrich CM, Kristal AR, White E, Hunt JR, Durfy SJ, Ptter JD. Genetic testing for cancer risk: A population survey on attitudes and intention. *Community Genet* 1998;1:213–222.
54. Ma GX, Shive SE, Toubbeh JI, Tan Y, Wu D. Knowledge, attitudes, and behaviors of Chinese hepatitis B screening and vaccination. *Am J Health Behav* 2008;32:178–187.
55. Ma GX, Gao W, Tan Y, Chae W, Rhee J. A community-based participatory approach to a hepatitis B intervention for Korean Americans. *Prog Community Health Partnersh* 2012;6:7–16.
56. Han HR, Kang J, Kim KB, Ryu JP, Kim MT. Barriers to and strategies for recruiting Korean Americans for community-partnered health promotion research. *J Immigr Minor Health* 2007;9:137–146.
57. Ma GX, Shive SE, Fang CY, et al. Knowledge, attitudes, and behaviors of hepatitis B screening and vaccination and liver cancer risks among Vietnamese Americans. *J Health Care Poor Underserved* 2007;18:62–73.
58. Liang W, Wang J, Chen MY, Feng S, Yi B, Mandelblatt JS. Cultural views, language ability, and mammography use in Chinese American women. *Health Educ Behav* 2009;36:1012–1025.
59. Vaught JB, Lockhart N, Thiel KS, Schneider JA. Ethical, legal, and policy issues: Dominating the biospecimen discussion. *Cancer Epidemiol Biomarkers Prev* 2007;16:2521–2523.

60. Rothenberg K, Rutkin AB. Toward a framework of mutualism: The Jewish community in genetics research. *Commun Genet* 1998;1:148–153.
61. Koeller K. *Science and the Lay Perspective: Lay People's Involvement in Assessing Tissue Engineering*. *Tissue Eng Part A*. 2013 Nov 26. [Epub ahead of print]
62. Blendon RJ, Kim MK, Benson JM. The public, political parties, and stem-cell research. *New Engl J Med* 2011;365:1853–1856.
63. MacLean S, Burgess MM. In the public interest: Assessing expert and stakeholder influence in public deliberation about biobanks. *Public Underst Sci* 2010;19:486–496.
64. Gottweis H, Gaskell G, Starkbaum J. Connecting the public with biobank research: Reciprocity matters. *Nature* 2011;12:738–739.
65. Besley JC, Kramer VL, Yao Q, Tourney C. Interpersonal discussion following citizen engagement about nanotechnology: What, if anything, do they say? *Science Commun* 2008;30:209–235.
66. Knight T, Barnett J. Perceived efficacy and attitudes towards genetic science and science governance. *Public Underst Sci* 2010;19:386–402.
67. Burgess J, Stirling A, Clark J, Davies G, Eames M, Staley K, Williamson S. Deliberative mapping: A novel analytic-deliberative methodology to support contested science-policy decisions. *Public Understanding Sci* 2007;16:299–322.
68. Lee CI, Bassett LW, Leng M, et al. Patients' willingness to participate in a breast cancer biobank at screening mammogram. *Breast Cancer Res Treat* 2012;136:899–906.
69. Mossavar-Rahmani Y, Tinker LF, Huang Y, et al. Factors relating to eating style, social desirability, body image and eating meals at home increase the precision of calibration equations correcting self-report measures of diet using recovery biomarkers: Findings from the Women's Health Initiative. *Nutr J* 2013;12:63.

Address correspondence to:
Grace X. Ma, PhD
Department of Public Health
Center for Asian Health
Temple University
1301 Cecil B Moore Avenue
913 Ritter Annex
Philadelphia, PA 19122

E-mail: grace.ma@temple.edu