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Factors Associated with Biomedical Research Participation within Community-Based Samples across three NCI-designated Cancer Centers

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Abstract

Background: Engaging diverse populations in biomedical research including biospecimen donation remains a national challenge. This study examined factors associated with 1) invitation to participate in biomedical research, 2) intent to participate in biomedical research in the future, and 3) participation in biomedical research and biospecimen donation, among a diverse, multilingual community-based sample, across three distinct geographic areas.

Methods: Three NCI-designated cancer centers engaged in community partnerships to develop and implement population health assessments reaching a convenience sample of 4343 participants spanning their respective catchment areas. Data harmonization, multiple imputation, and multivariable logistic modeling were utilized.

Results: African Americans, Hispanic/Latinos, and other racial minority groups were more likely offered opportunities to participate in biomedical research compared to whites. Access to care, history of cancer, education, survey language, nativity, and rural residence also influence opportunity, intent, and actual participation in biomedical research.

Conclusions: Traditionally underserved race and ethnic groups report heightened opportunity and interest in participating in biomedical research. Well established community partnerships and long-standing community engagement around biomedical research led to reaching a diverse sample at each site and may, in part, explain findings. However, study findings illustrate an ongoing need to establish trust and diversify biomedical research participation through innovative and tailored approaches.

Impact: NCI-designated cancer centers have the potential to increase opportunity for diverse participation in biomedical research through community partnerships and engagement. Additional work remains to identify and address system and individual level barriers to participation in both clinical trials and biospecimen donation for research.

Condensed Abstract

Engaging diverse populations in biomedical research and biospecimen donation remains a national challenge. This study examined factors associated with biomedical research participation in diverse, multilingual community-based samples across three distinct geographic areas.

Keywords

Prevention; Clinical Trials; Diversity in Research Participation; Community Engagement; Biospecimen Donation; Disparities

Introduction

Despite National Institutes for Health requirements to diversify and include minority populations in biomedical research, low enrollment rates among racial and ethnic minorities in research remains a national challenge (1–6). Lack of diverse representation in biomedical research, including studies of causation and prevention, limits generalizability of studies and contributes to increased but preventable disparities in cancer incidence, outcomes, and survival. In the era of precision medicine, lack of diverse representation in clinical trials and/or biospecimen donation has significant consequences in limiting our understanding of individual and population level differences in disease aggressiveness and response to therapy as a function of differential ancestry- related genetics, epigenetic and genomic research (3,5). These gaps in knowledge worsen disparities for those who are not represented in biomedical research, and directly impacts population level cancer disparities.

The literature highlights numerous factors that play a role in the underrepresentation of diverse groups in biomedical research particularly among underserved populations (7). Medical distrust, fear of research motives, lack of awareness regarding the value of research, and clinician/researchers attitudes and perceptions are examples of individual level barriers to research participation (1, 6, 8–11). System and institutional level barriers such as lack of a comprehensive platform to increase awareness and engagement among patients, restrictive eligibility criteria, lack of access to medical care, and cost all impact familiarity, exposure, and participation in biomedical research, particularly for vulnerable populations. Likewise, underrepresentation in cancer clinical trials also extends to residents of rural areas, and individuals with low socioeconomic status (7). Several studies found having a cancer diagnosis increases the likelihood of participating in clinical trials, however, disparities in participation even among cancer patients remain across race, income, and gender (12).

The paucity of diversity in biospecimen science and cancer genomic studies are potentially more tied to a lack of communication and engagement of diverse and underserved populations as opposed to their willingness/ unwillingness to participate, and /or reasons related to medical distrust (13–16). Formative research efforts inclusive of diverse and underserved populations regarding biospecimen science have shed some light on the following areas: awareness and interest in biospecimen donation for research, reasons for non-participation, collaborative study designs that include community-based approaches to engage and integrate community research partners, and underserved populations in this type of research, in addition to data on cultural perspectives and requirements for research specific to biospecimen science (14–18). In fact, exploratory studies examining motivational factors and barriers to participation in biospecimen donation from diverse racial and ethnic minorities suggests that the majority of African Americans and Hispanics [Latinos] are willing to donate different types of biospecimens and that they do donate when asked (19).

The purpose of this study is to examine factors associated with opportunity, actual participation, and willingness to participate in biomedical research broadly, and specifically related to clinical trials and biospecimen donation among a diverse, multilingual sample across three distinct geographic areas. It is important to understand factors related to opportunities and willingness to participate in biomedical research including access to care,

personal or family history of having cancer, and other social demographic characteristics including, race, ethnicity, within a social and geographically diverse sample of research participants. Such findings will have significant implications for next level interventions, strategic outreach and engagement that can facilitate linkages to biomedical research for traditionally underrepresented groups. Our analysis is guided by the following research questions:

1. What demographic and health care factors (e.g. access to care, cancer history, cancer diagnosis), are associated with having been invited to participate in biomedical research?
2. What demographic and health care factors are associated with having been invited to donate biospecimens for biomedical research?
3. What demographic and health care factors are associated with one's perceived likelihood to participate in biomedical research in the future?
4. What demographic and health care factors are associated with deciding to participate in biomedical research?
5. What demographic and health care factors are associated with having decided to donate biospecimens for biomedical research?

We examine the association of these types of research participation with factors such as health care access, sociodemographics characteristics including race and ethnicity, and cancer history.

Materials and Methods

Study Settings – NCI-designated Comprehensive Cancer Center Catchment Areas

Study sites described in this paper include survey data from populations residing near NCI-designated comprehensive cancer centers located in Buffalo, New York, Durham, North Carolina, and San Francisco, California. Each site defined their respective catchment area which represents the geographic area and population the cancer center serves (20). Sites administered a population health assessment within the cancer center's catchment area, as part of a National Cancer Institute P30 Supplement. Utilizing data from population health assessments across the catchment areas of three NCI-designated comprehensive cancer centers affords unique opportunity to have a large sample in which to assess aspects of research engagement in diverse geographic areas of the United States: West Coast, South, and Northeast. The survey data collection was overseen by the Institutional Review Board at each cancer center, and site-specific procedures for human subjects' protections were approved by the Institutional Review Boards at Roswell Park Comprehensive Cancer Center, Duke Cancer Institute, and UCSF Helen Diller Family Comprehensive Cancer Center.

Roswell Park Comprehensive Cancer Center (RP) is located in western New York State (WNY), serving both dense urban centers and remote rural areas. The primary catchment area served by RP cancer center consists of eight counties with about 1.5 million people, and approximately 60% of that base resides in Erie County, where RP is located. Buffalo is the largest city in the region and is the 4th poorest city in the United States of its size, with over

30% of the population at or below the poverty level and a poverty rate of 48% for racial/ethnic minority groups. African Americans represent the largest minority group in the area at 10% of the overall population (148,745), and Hispanics are the second largest minority representing 4% of the population (61,616).

The DCI principle patient catchment area is the 85th percentile of its total patient distribution, encompassing central North Carolina, southern Virginia and northern South Carolina. Overall this region is over 25% African American (compared to the national average of 12.4%), with some counties having over 50% African American representation. Although the Hispanic (~10%) and Asian (~3–5%) population is relatively small, the North Carolina State census bureau reports that these populations are expanding rapidly. Approximately 25% of this region reports earning less than \$25,000 per year compared to the national average of 21%. Of the counties in DCI's catchment area 47% are rural, and 20% of these rural counties exhibit increased rurality (RUCC 7). A large percentage of residents in these counties live in poverty, and are disproportionately African American, ranging from 32–52% (21).

The catchment area of UCSF Helen Diller Family Comprehensive Cancer Center (HDFCCC) is defined as 48 counties of Northern California, based on the residences of approximately 98% of HDFCCC cancer cases (20). For the purposes of this study, we focused on the city and county of San Francisco, at the center of the catchment area, in order to map survey results to city and county-wide cancer prevention and screening initiatives, the San Francisco Cancer Initiative (22). The total population of San Francisco in 2017 was 884,363 (U.S. Census Bureau, 2018). The largest minority group in San Francisco are Asians (35%), followed by Hispanics (15%) and Black/African Americans (6%)(23).

Measures

Survey items were replicated from existing surveys, and the survey development has been previously described (24). *Sociodemographic Characteristics.* Education was identified as the highest grade or level of schooling completed, and was coded as less than high school degree, high school degree or some college, and college graduate or more. Self-reported race and ethnicity was coded as non-Hispanic white, non-Hispanic Black/African Americans, Hispanic, Asian, and other. Age was coded as three categories 18–34, 35–54, and 55 and over. Gender was coded as male, female, or does not identify as male or female. Income adequacy was captured with the question “Which one of these phrases comes closest to your own feelings about your household’s income these days: living comfortably on present income; Getting by on present income; Finding it difficult on present income; or, Finding it very difficult on present income?” Income adequacy was coded as comfortable or getting by on present income versus finding it difficult or very difficult on present income. Cancer history was measured with two variables, “Have you ever been diagnosed with cancer?” [yes/no] and “Have any of your family members ever had cancer?” [Yes/no]. Having a usual place of care when sick or need advice about health was coded as yes, no, and more than one place. Self-reported home-ownership was coded as owns home and does not own home. Metro vs. non-metro place of residence was captured with participant-reported zip code that was coded using Rural-Urban Continuum Codes (RUCC) codes where RUCC codes 1–3

were coded as metro, and RUCC codes 4–9 were coded as non-metro. Nativity was coded as a dichotomous variable, born in the United States and not born in the United States.

Participation in Biomedical Research.

Having been asked to participate in biomedical research was measured with the question, “Have you ever been asked to participate in a clinical trial or medical research [yes, no, don’t know]?” Don’t know and no responses were collapsed to one category. Participation in biomedical research was measured with the question, “Did you decide to participate in the clinical trial or medical research [yes, no]?” Having been asked to donate biospecimens was measured with the question “Have you ever been asked to donate bio specimens (blood, saliva, or other tissue) for the purpose of medical research? [Yes, No, Don’t know]. Don’t know and no responses were collapsed to one category. Having donated biospecimens was measured with the question “Did you decide to donate the biospecimen [Yes, No]?” Finally, perceptions of future likelihood to participate in medical research was measured with the question “How likely would you be to participate in medical research in the future?” Responses were on a 7-point Likert scale where 1 = would not participate and 7 = definitely participate. Responses were coded as three categories: likely to participate, unsure, and not likely to participate.

Data Collection

Site-specific methods—The RP site used two approaches to reach a diverse sample of survey participants from the eight WNY counties in the cancer center catchment area to recruit a total of 1001 adult participants. Data collection began in June 2017 and ended in September 2017. The survey included a total of 67 items that were either self or interviewer administered. A web-based opt-in panel survey was distributed by a contracted provider (Lightspeed GMI) to reach a non-probability sample of adults over 18 years old that reside within the defined geographic catchment area. Demographic-based quotas were used at the county level to manage selection biases. Panel members meeting the selection criteria for the study received an invitation to participate in the web-based survey, and a link to the survey. The second mode of participant recruitment was through in-person invitations at community events to increase the participation of several underserved groups in the RP catchment area: African American, Hispanic, rural, recent immigrant and refugee, and Native American. Survey materials for all non-English speaking groups were administered in participant’s native language as required. Seventeen community partners serving the identified target populations collaborated with RP study staff on recruitment efforts to distribute surveys at community partner sites or during events. The response rate for the community recruitment was 96%. Individuals who completed the survey received a \$5 incentive. Erie County represents approximately 60% of the Roswell Park catchment area. Forty-two percent of the Roswell Park sample have a college degree or more, compared to 32.2% of residents of Erie County. In Erie county 75.3% of the population is white, 14% African American, and 5.5% is Hispanic or Latino. The Roswell Park sample is 65.4% white, 11.6% Black, and 13% Hispanic.

The DCI site used a multimodal approach to reach a targeted sample of diverse populations across selected areas of the catchment area. Data collection duration spanned from April

2017 to December 2017. A total of 2315 surveys were completed. The majority were recruited from community organizations primarily located in Durham, Wake, Vance, Alamance, and Johnston counties in Central NC. The self-administered survey included 91 items and was available in English, Spanish and Chinese. Surveys were administered via paper questionnaire and online. Long term DCI community partners were subcontracted to co-lead recruitment efforts. Several approaches were used to collect survey data. First, DCI Community Navigators (CNs) worked with 24 community partners to distribute the surveys to their constituents at 47 events. The network of community partners is comprised of community organizations, diverse faith organizations, community outreach programs, and a health clinic in the catchment area. Community partner organizations received stipends (\$10 per survey up to \$2000) to meet their specific programmatic needs, and to collaborate with the DCI to co-develop a community engaged research strategy. Second, an online version of the survey was disseminated by community partners through emails to their constituents containing a brief letter describing the assessment (Project PLACE), and a link to the survey.

The UCSF site used a snowball sampling approach among community contacts to determine best locations for survey recruitment to reach their populations of interest and applied quota sampling to ensure that the sample was gender-balanced. Populations of interest included representation from equal proportions of non-English and English-speaking participants, African American participants, and a proportionate sample of individuals who identified as sexual and gender minority (SGM). The non-English participation was equally divided between Spanish and the Chinese languages. Culturally appropriate translations were produced in Spanish, Cantonese and Mandarin and validated by community members. Data collection was restricted to adult residents in the City and County of San Francisco between the ages of 18 and 79. In total 1027 participants completed the survey. Data collection took place May and September 2017. The final survey included 79 items. Bilingual staff administered and supervised the field survey using computer tablets. Participants were recruited from popular community establishments (e.g., restaurants, churches, salons, and community centers) and community events (health and wellness fairs, street fairs, and support groups.) Individuals who completed the survey received a \$25 incentive. Data were captured and stored using REDCap.

Data Analysis

Data harmonization was completed across the three survey sites, including renaming and recoding of discordant variables. Missing data were imputed using Proc MI in SAS which utilizes regression-based approaches to impute plausible values for missing data. Multiple imputation methods are used to incorporate the uncertainty induced by the imputation process in estimating the variability and allowing more accurate significance in statistical testing (Rubin, 1987; Little and Rubin, 2002). For all analyses, we utilized 5 imputations. All analyses used a subset of the questions asked on the surveys, those that were determined by the research team to be of interest as outcome variables and potential predictors. The outcome measures of interest are described in detail above. Potential predictors include socio-demographics such as age, gender, education level, race/ethnicity, location of residence (metropolitan or not), family history of cancer, personal history of cancer, born in the US, and survey language (English, Spanish, Chinese).

After imputation, we conducted bivariate analysis to identify variables important for multivariable modeling. Additionally, several covariates were selected by the study team for multivariable model inclusion, based on theoretical importance, regardless of statistical significance. It was determined that one potential covariate, general health status, was not asked at all sites, and was removed from further consideration for this study.

Multivariable logistic regression models were then run utilizing the 5 imputed datasets, with the selected variables used in all models, regardless of statistical significance. Logistic models also controlled for center effects, to control for the potential differences in underlying populations, based on different sampling and outreach strategies at each center. The sets of parameters for each model were then summarized using SAS Proc MIANALYZE, providing an overall estimated adjusted odds ratio, standard error, confidence intervals, and p values. All analyses were completed using SAS v9.4. Multivariable model results are displayed as forest plots, generated using the forest plot function in R v3.3.2 for the MAC OS.

Results

Descriptive Statistics

In the pooled sample, nearly two thirds of participants were under 55 (23% 18–34 yrs. old and 35% 35–54 yrs. old) and the majority were female (63%). Racial and ethnic distribution was 34% White 28% Black or African American 19% Latino or Hispanic 14% Asian, and 5% Other. In comparison to their underlying catchment area demographics, Duke's sample was 1.5 times higher in the black/AA and Hispanic/Latino populations, and 3.4 times in the Asian population. Roswell's sample was 3.3 times higher in Hispanic/Latino population, and UCSF's sample was 2.4 times higher in Hispanic and 4 times higher in the AA population.

Forty percent were college graduates and 74% reported getting by or living comfortable on their current income. Sixty-seven percent were born in the United States and 80% reported that they had one usual place to access health care. The majority were from metro counties (80%). Overall, 21% of participants had been asked to participate in a clinical trial or biomedical research and 17% had been asked to donate biospecimen for research. As seen in Table 1, many of the demographic characteristics varied across the DCI, RP, and the UCSF. Notably, factors such as gender, race/ethnicity, education, and financial security reflected the unique demographic characteristics of each individual site. Greater percentage of participants at Duke and UCSF reported being asked to participate in clinical trials/ biomedical research and biospecimen collection than at Roswell Park.

Multivariable Analysis

Having been asked to participate in biomedical research was significantly and positively associated with Black/African Americans, Hispanic and Other Race/ethnicity, college graduate or higher, High School (HS) and some college, metropolitan residence, and born in the US. Being asked to participate was significantly and negatively associated with no cancer diagnosis, no usual place for healthcare, no family history of cancer, respondents

aged 18–34, and Chinese as survey language (see Figure 1 for adjusted OR (AOR), confidence intervals (CI), and p-values).

Being asked to donate biospecimens for research was significantly and positively associated with college degree or higher, HS and some college, ages 18–34, not owning your own home, living in a metropolitan area. Conversely, biospecimen donation requests were significantly and negatively associated with no diagnosis of cancer, no family history of cancer, having more than one place for usual healthcare, having no place of usual healthcare, and Chinese survey language (see Figure 2 for AOR, CI, and p-values).

Likelihood to participate in biomedical research in the future was significantly and positively associated with Black/African Americans, and Other Race, being comfortable with your income, a cancer diagnosis, and a family history of cancer. Likelihood of participation was significantly and negatively associated with college graduate or higher, HS and some college, aged 18–34, aged 35–54, born in the US, and having more than one place for usual healthcare (see Figure 3 for AOR, CI, and p-values).

The decision to participate and the decision to donate biospecimens were only asked at Duke and Roswell Park, and only to those who said Yes to the biomedical research participation or the asked to donate biospecimens questions, using a skip pattern in the survey. Deciding to participate in biomedical research was significantly negatively associated with being aged 18–34. There were no other significant findings for this measure in the final multivariable model (see Figure 4 for AOR, CI, and p-values). Likewise, deciding to donate biospecimens for research was significantly and positively associated with college graduate or higher. The decision to donate biospecimens for research was significantly and negatively associated with Black/African Americans Race/Ethnicity, and not having a family history of cancer (see Figure 5 for AOR, CI, and p-values).

Discussion

In a pooled analysis of survey data obtained from three geographic sites within NCI-designated Cancer Centers' catchment areas, we found that healthcare factors which are measured by access to care, sociodemographic factors, and history of cancer were associated with several aspects of participation in biomedical research including clinical trials and biospecimen donation. Specifically we focus on the following outcome variables 1) being invited to participate in clinical trials or biomedical research (opportunity), 2) participation in clinical trial/biomedical research and bio-specimen donation (participation), and 3) intent to participate in biomedical research in the future (willingness). Overall, our findings are consistent with previous research showing relationships between access to care and opportunity to participate in clinical trials or biomedical research and biospecimen donation. However, we also discovered some interesting findings particularly around race and ethnicity.

Access to Care

In our study, access to care played a key role in the opportunity to participate in biomedical research studies. Participants who report no usual place for care had less opportunity to

participate in clinical trials or biomedical research and biospecimen donation. Likewise, living in a metropolitan region compared to a rural region increased opportunity for clinical trials or biomedical research participation and biospecimen donation compared to living in a rural region. Moreover, low-income populations are disproportionately cared for in safety-net health systems which have varying capacity and opportunities for biomedical research participation (8,9). To achieve diversity in biomedical research participation, health systems including safety-nets serving diverse populations need to have the capacity and willingness to engage with research at the institutional level. As noted in prior studies, lack of access to research-intensive academic-medical centers limits access to cutting-edge research that could potentially reduce health disparities (8, 9, 11, 17, 25).

Race and Ethnicity

Interestingly, we found that African Americans, Hispanic/Latinos and racial groups other than Asian were more likely to be asked to participate in clinical trials or biomedical research. In addition, African Americans and individuals in the Other race category were also more willing to participate in biomedical research in the future. This is in contrast to previous studies that suggest racially and ethnically underserved groups, and particularly African Americans are not invited to participate in clinical trials and biomedical research, and are not interested in participating due to past medical research atrocities, lack of quality care, and mistrust in the health system and research (15). Recent studies suggest that underrepresented populations are interested in learning more and potentially participating in clinical trials and biomedical research, specifically biospecimen donation. For example, a qualitative study of Latino participants found they were willing to participate in biospecimen donation, despite not being aware of biobanks (26). In a study collaborating with local partners in California, Florida, and New York to recruit a diverse sample of participants, Dang et al. found that the majority of participants expressed interest and willingness to donate specimens for research (14). One explanation for our findings is that all three sites worked with existing community partners to collect data. It is possible that our findings reflect positive effects of a well-established and long standing community engagement and outreach program where communication is bidirectional and heightens awareness, benefits, and participation in clinical trials and biomedical research, including its potential impact on reducing racial and ethnic health disparities. Our well established and diverse community partners coupled with our longstanding outreach and engagement programs may, in part, explain our findings-although we clearly have more work to do in this area. Many of the same factors involved in partnership building that focus on bidirectional communication, health equity, and social justice contributes to improving medical trust within diverse communities. While we did not focus on assessing what factors contribute to medical trust in our study, this may be an important next step for future research efforts using both quantitative and qualitative approaches that captures the perspective of our community partners and how they define medical trust.

It is notable that African American participants responding to this survey indicated less willingness to donate biospecimens. This finding differs from recent studies showing that African Americans are willing to donate biospecimens when offered the opportunity. Rodriguez et al. found that community engagement efforts and initiatives that provide

investigation to better understand age and biomedical research invitation and actual participation. We found that adults aged 18–34 reported being less likely to be invited to participate in biomedical research, and less likely to actually participate when invited. Adults aged 18–34 reported being more likely to be invited to donate biospecimens (29). We found that participants who spoke Chinese were much less likely to have the opportunity to participate in research and biospecimen donation, which is consistent with previous research (30). Likewise, in terms of nativity we found that being born in the US was significantly associated with being asked to participate in biomedical research. This finding may in part be due to eligibility criteria for research studies, which are often limited to English speakers. It may also be indicative of the need for academic health and cancer centers to enhance and deepen community engagement efforts in Chinese and the broader Asian communities.

Collectively these findings indicate the need for more research, both quantitative and qualitative, to better understand these relationships. It also highlights the importance of outreach and engagement activities at the community and systems level around biomedical research participation are tailored to reach all communities, while targeting information, communication, and resources to meet the diverse populations we serve. This is crucial as we strive to increase access to, and diversity in, biomedical research participation (28).

Limitations and Caveat

There are limitations and caveats to this study. Each study site (RP, UCSF, and Duke) used non-random community-based sampling strategies to ensure over-representation of some demographic groups compared to their respective catchment areas (see Methods and Results Sections). Using community engagement strategies may limit generalizability of the findings. All three sites relied upon existing community partnerships, and may have surveyed participants who were more likely to be invited to participate in clinical trials or biomedical research studies and biospecimen donation opportunities. Similarly, participant recruitment strategies across the three study sites differed. Social-contextual, demographic, and socioeconomic differences should be noted when interpreting findings. Our study was cross sectional, and responses may be subject to errors in participant recall or differences in defining biomedical research. Also, given our sampling strategy, it should be noted that our data do not provide institutional, system, or provider level data. However, our findings do have implications for each of these areas and should be considered within these contexts. Diversity across race and ethnic sub-groups is important to examine within the context of research participation and health communication, however, given our focus across three diverse geographic regions, we examine broader race and ethnic categories. More research is needed to understand research participation among race and ethnic subgroups. Finally, due to small sample sizes Native Americans were included in the “other” racial categories. This analytical decision limits the ability to understand the experiences of diverse groups within this category. An important future direction is to examine health communication and research participation among Native Americans.

Conclusion

Engaging diverse populations in clinical/ biomedical research and biospecimen donation is a critical step in the path towards health equity. Our results suggest that diverse populations

including those with limited educational aspect express willingness to participate in biomedical research, but may lack sufficient opportunities to do so. The findings contribute to a recent but growing body of literature that suggests expressed willingness to participate in medical research among traditionally under represented race and ethnic groups.

However, there is still an immense opportunity and need to improve diversity among biomedical research participants. Prior studies on diversity in research participation emphasize raising awareness and education, building community relationships, and implementing community-based research to increase awareness, access, and ultimately participation in biomedical research(17, 29–31) The diversity of our research participants, and the increased likelihood of participation in biomedical research among underrepresented race and ethnic groups, may in part, be due to each site's collaborations with local, well-established and long-standing community partners and our ongoing and outreach, engagement, and research programs (13, 32–34).

This study also highlights opportunities for NCI-designated cancer centers to build upon and leverage community and institutional relationships to better understand and enhance health communication and behavior around biomedical research participation. Such studies will have a meaningful impact on actual enrollment thereby increasing diversity in research participation, and improving population health. Additional work needs to be done to build trust and increase diversity in biomedical research participation, authentic and transparent community engagement and partnerships are paramount to achieving this goal.

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Asked to Participate in Biomedical Research

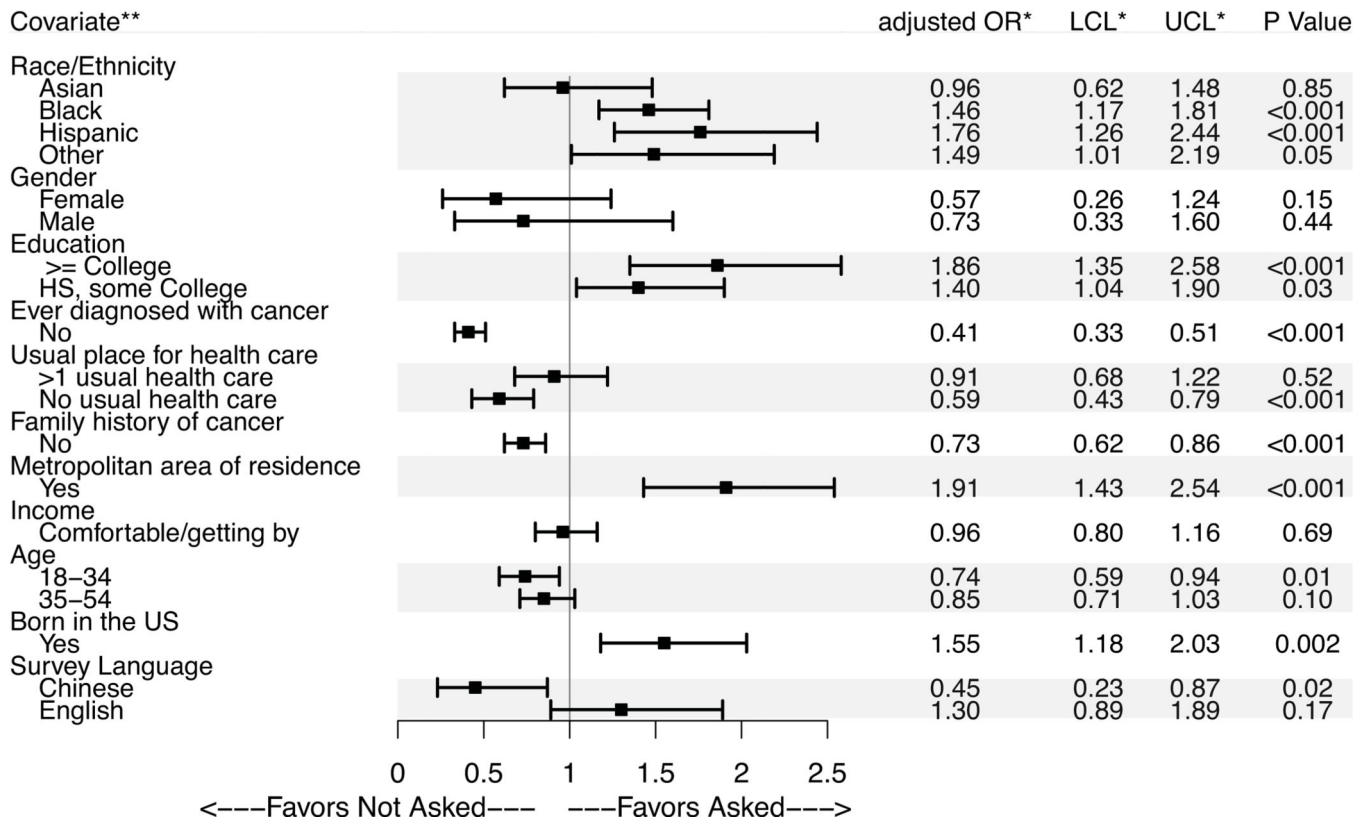


Figure 1. Forest plot of multivariable logistic model of “Asked to participate in medical research or clinical trials” (denoted biomedical research), based on summary of 5 multiply imputed datasets. Model also controls for survey site (Duke, UCSF, RP), and whether the respondent owns their own home.

Asked to Donate Biospecimens

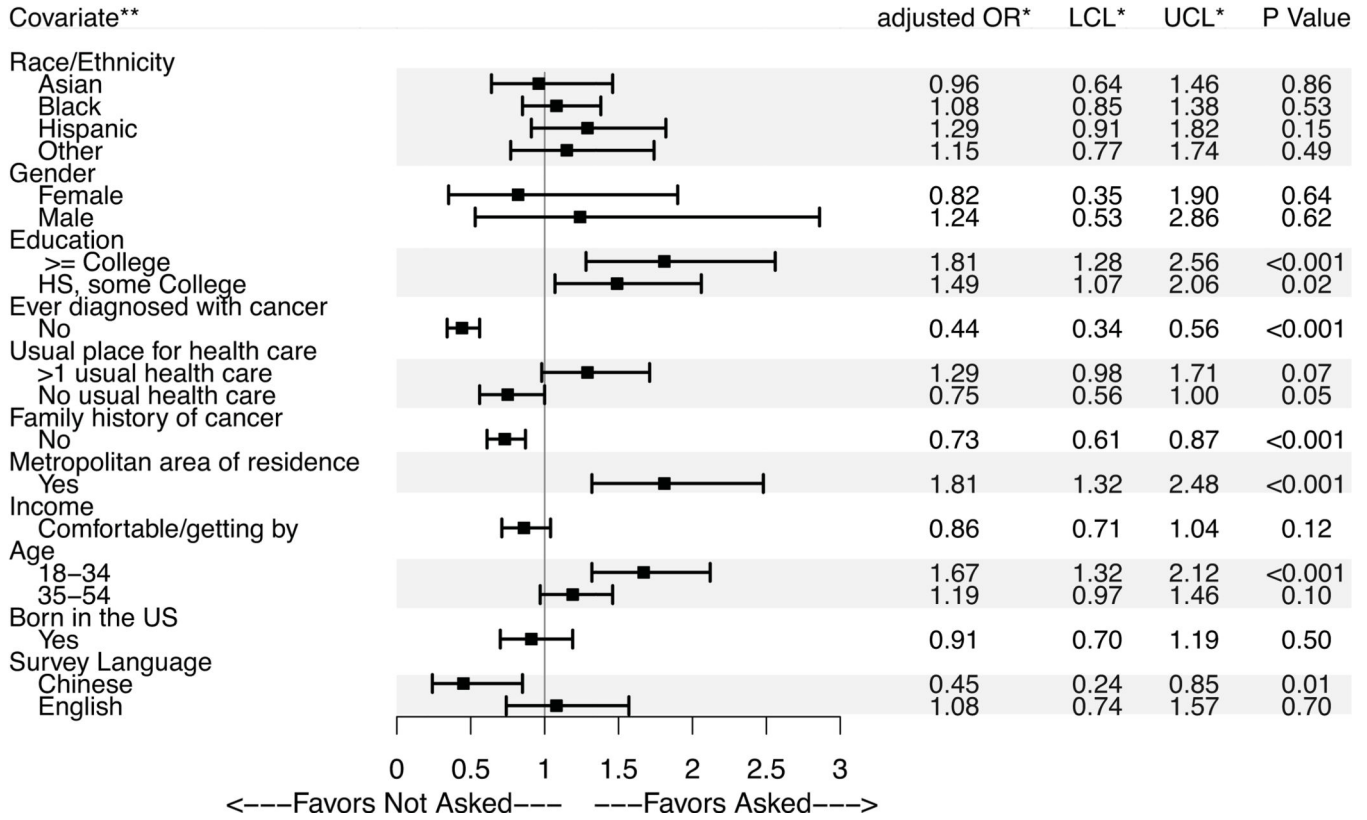


Figure 2. Forest plot of multivariable logistic model of “Asked to donate biospecimens”, based on summary of 5 multiply imputed data sets. Model also controls for survey site (Duke, UCSF, RP), and whether the respondent owns their own home.

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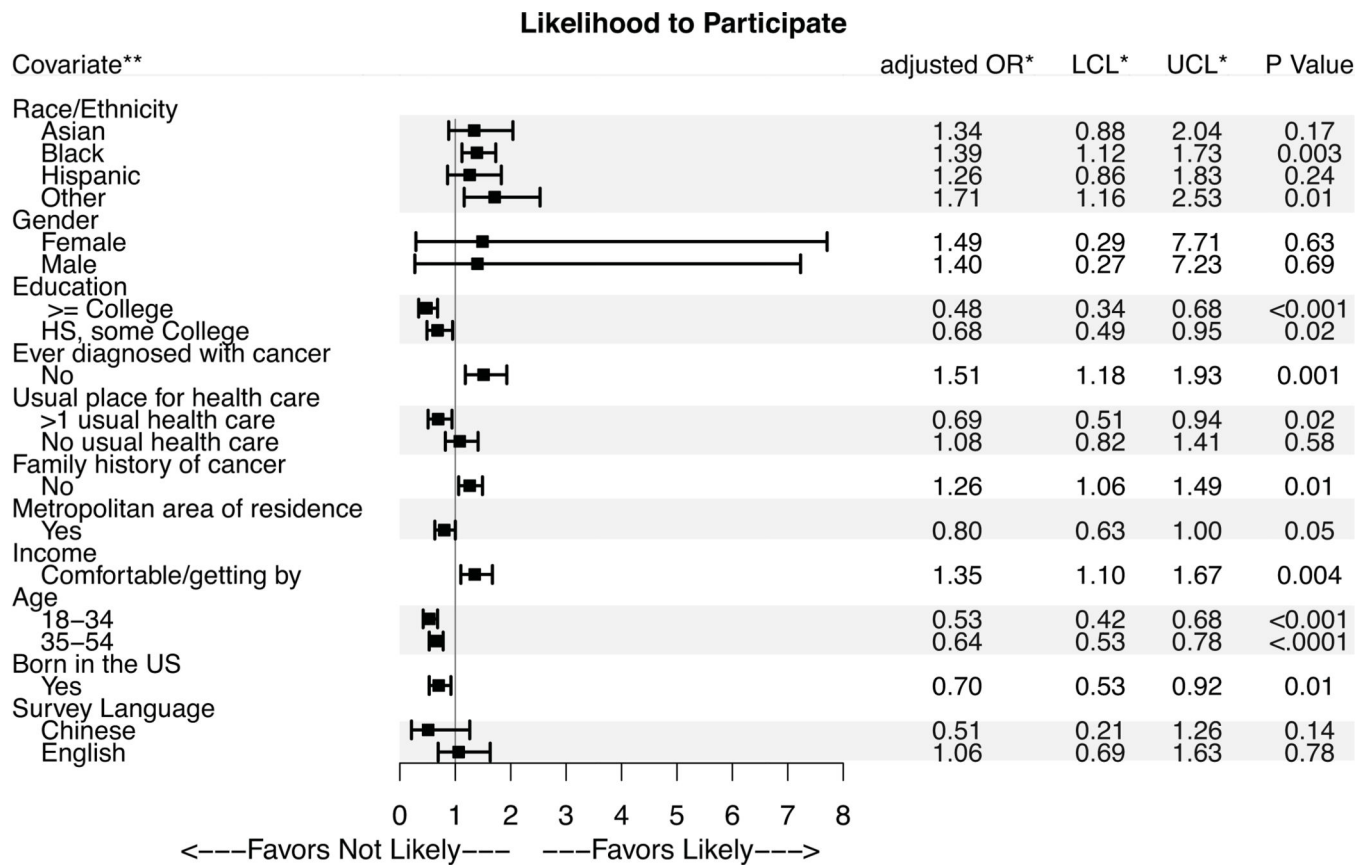


Figure 3. Forest plot of multivariable logistic model of “Likely to participate in medical research in the future”, based on summary of 5 multiply imputed data sets. Model also controls for survey site (Duke, UCSF, RP), and whether the respondent owns their own home.

Decided to Participate in Biomedical Research

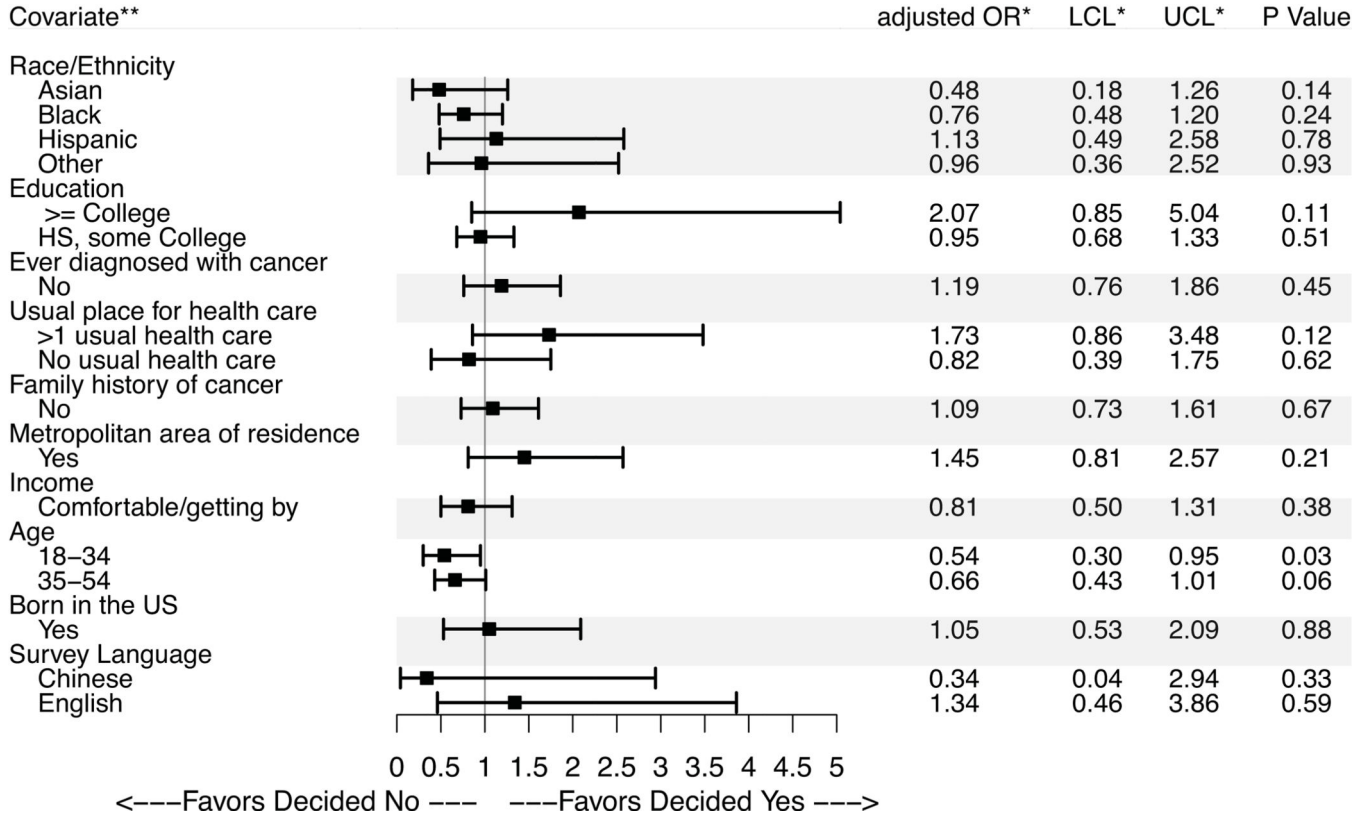


Figure 4. Forest plot of multivariable logistic model of “Decided to participate in medical research”, based on summary of 5 multiply imputed data sets. Model also controls for survey site (Duke, RP), gender, and whether the respondent owns their own home.

Decided to Donate Biospecimens

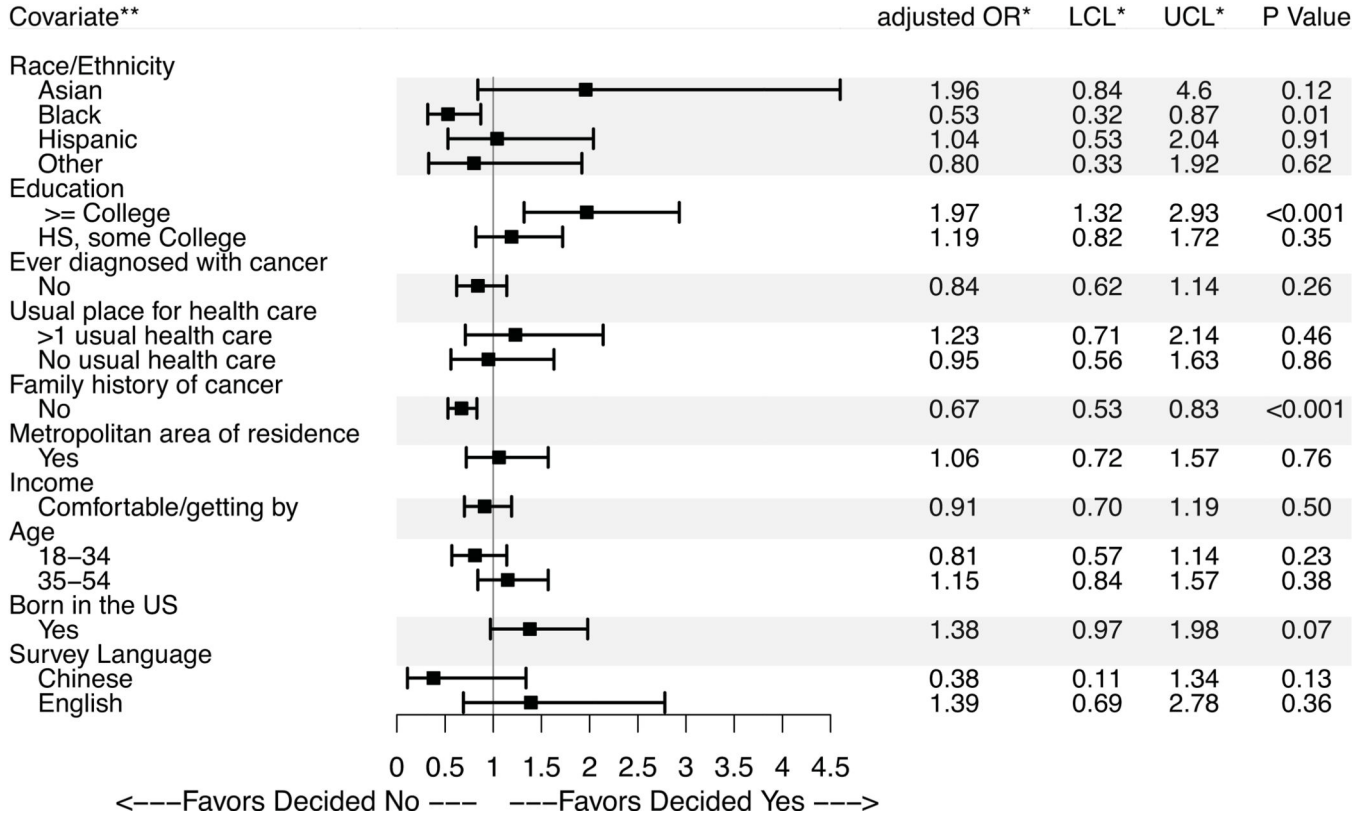


Figure 5. Forest plot of multivariable logistic model of “Decided to donate biospecimens”, based on summary of 5 multiply imputed data sets. Model also controls for survey site (Duke, RP), gender, and whether the respondent owns their own home.

Table 1.

Description Characteristics for Pooled Sample and Individual Site Sample

Sociodemographic Characteristics and Outcome Variables	Pooled Sample N= 4,343		Duke N=2,315		RPCI N=1,001		UCSF N=1,027	
	N	%	N	%	N	%	N	%
Age (%)								
18–34	962	23.0	409	19.0	272	27.2	281	27.4
35–54	1475	35.3	800	37.2	329	32.9	346	33.7
55+	1741	41.7	942	43.8	399	39.9	400	39.0
Gender (%)								
Male	1513	35.9	783	35.7	267	26.7	463	45.2
Female	2673	63.4	1402	63.9	734	73.3	537	52.4
Does not identify as male or female	32	0.8	8	0.4	0	0.00	24	2.3
Race/Ethnicity (%)								
White	1421	34.0	724	33.6	653	65.4	44	4.3
Black	1174	28.1	815	37.8	116	11.6	243	23.7
Hispanic	800	19.1	305	14.2	130	13.0	365	35.5
Asian	577	13.8	244	11.3	16	1.6	317	30.9
Other	207	5.0	66	3.1	83	8.3	58	5.7
Educational Level (%)								
Less than high school education	475	11.4	162	7.5	77	7.7	236	23.3
High school diploma or some college education	2019	48.4	933	43.1	497	49.9	589	58.3
College graduate or higher	1681	40.3	1072	49.5	423	42.4	186	18.4
Financial Security (%)								
Getting by or living comfortably on present income	3065	74.0	1724	81.4	717	71.8	624	60.8
Finding it difficult or finding it very difficult on present income	1077	26.0	393	18.6	281	28.2	403	39.2
Respondent owns home (%)	1987	45.8	1352	58.4	559	55.8	76	7.4
Respondent born in the United States (%)	2918	67.2	1574	68.0	862	86.1	482	46.9
Respondent has been diagnosed as having cancer (%)	534	12.6	369	16.6	108	10.78	57	5.6
Respondent has family history of cancer (%)	2130	50.1	1113	50.0	506	50.5	512	49.9
Usual Place for Healthcare (%)								
Respondent has usual place for health care	3299	79.8	1773	81.5	757	75.8	769	80.1
There is more than one place I usually go	377	9.1	180	8.3	118	11.8	79	8.2
There is no place I usually go	458	11.1	222	10.2	124	12.4	112	11.7
Measure of Rurality (RUCC codes; %)								
Metro: RUCC 1–3	3575	86.1	1736	81.7	814	81.4	1025	100.0
Nonmetro: RUCC 4–9	576	13.9	390	18.3	186	18.6	0	0.0
Survey Language (%)								
English	3484	80.2	2042	88.2	928	92.7	514	50.5
Spanish	554	12.8	225	9.7	73	7.3	256	24.9

Sociodemographic Characteristics and Outcome Variables	Pooled Sample N= 4,343		Duke N=2,315		RPCI N=1,001		UCSF N=1,027	
	N	%	N	%	N	%	N	%
Chinese	305	7.0	48	2.1	0	0.0	257	25.0
Respondent has been asked to participate in a clinical trial or medical research? (%)	901	21.3	534	24.0	101	10.2	266	26.1
Respondent has been asked to donate bio specimens (blood, saliva, or other tissue) for the purpose of medical research? (%)	723	17.0	400	17.9	117	11.7	206	20.4
How likely would you be to participate in medical research in the future? (%)								
Unlikely to participate	1083	33.9	811	36.9	272	27.3		*
Neither likely nor unlikely	448	14.0	286	13.0	162	16.2		*
Likely to participate	1667	52.1	1103	50.1	564	56.5		*
Respondent decided to participate in medical research? (NOTE: Subject to respondent answering YES to whether they had been asked to participate in medical research) (%)	428	68.9	363	69.8	65	64.4		*
Respondent decided to donate the biospecimen? (NOTE: Subject to respondent answering YES to whether they had been asked to donate a biospecimen) (%)	360	68.7	271	70.2	89	64.5		*

* Questions were asked only to Duke Cancer Institute and Roswell Park Comprehensive Cancer Center respondents.