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Demographic Differences in Willingness to Provide Broad and Narrow Consent for Biobank Research

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Purpose: This study examined acceptability of two biobank consent models and evaluated the impact of beliefs about privacy and genetic safeguards on acceptance.
Methods: U.S. adults surveyed online in English and Spanish were randomly assigned to one of two scenarios examining acceptance of broad consent ($n=1528$), or narrow consent ($n=1533$).
Results: Overall, willingness to provide broad (76%) and narrow (74%) consents were similar. African Americans were as likely as white non-Hispanics to accept narrow consent (72% vs. 77%, $p=0.35$) but significantly less likely to accept broad consent (69% vs. 81%, $p=0.004$). Education, insurance, and blood donation history were also related to acceptance. Adjusting for beliefs about privacy and policy protections (Genetic Information Nondiscrimination Act, GINA), the effects of the variables were reduced. Respondents who drew comfort from GINA were more likely to support both consent (both $p<0.001$); those who believed it is impossible to maintain privacy were less likely to find both broad ($p=0.04$) and narrow models acceptable ($p=0.02$).
Conclusions: Choice of consent model matters when engaging diverse populations in biobank research. Beliefs underlying concerns about privacy and genetic protections should be considered when constructing biobank protocols.

Introduction

Biobanks are invaluable sources of large amounts of genetic data linked to clinical records. Most hospitals and disease registries contain samples and data that could be used to represent diverse populations in genetic research.[1,2] The United States (US) Census Bureau reports that the demographic profile of the US population is shifting and is expected to become a majority–minority nation in less than five decades.[3,4] To date, much of the biospecimen research conducted in the US has been performed with samples that are inadequately representative of ethnically diverse populations.[5] This under-representation of diverse groups in research jeopardizes the scientific validity and generalizability of results, as well as the utility and public health value of genomics in the US. Biobanks have been proposed as one way to address the longstanding quandary of under-representation of diverse populations in research because they facilitate rapid and efficient access to biological samples from multicultural communities for population-based studies.

Minority populations engage in biomedical research less often than white non-Hispanic populations due to factors such as historical encounters with the medical field, previous research experiences, disease risk perceptions, mistrust, and incomplete understanding of research requirements or informed consent.[6–9] To achieve parity in the benefits anticipated from biobanks and population-based genomics research, it is essential to improve the representation, recruitment, and retention of individuals from various demographic backgrounds.

The informed consent process is one of the most salient components for biobank collection. Biobanks are employing a variety of consent models in their recruitment; some use consent waivers. Others employ tiered models where participants can agree to participate in a specific study and choose separately whether to share data and samples more broadly. Two commonly considered consent models for biospecimen research are broad and study-by-study (''narrow'') models. Broad consent (which may also be referred to in the literature as blanket consent or one-time consent) refers to the one time approval of one's biospecimen to be used for multiple research purposes, some of which may not be foreseen or described at the time consent is obtained. In contrast, narrow or study-by-study consent requires that individuals be re-contacted each time their sample or information is used for a new research project.[10–15]

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Despite the benefits and limitations of each approach, opinions remain divided on the appropriateness of the different consent models in biobank efforts.[16] However, few studies have explored if there are racial and ethnic, or other demographic differences in acceptance of a given consent model.[17]

Acceptance of informed consent models for biobank research has received significant international attention,[18–21] but limited focus in the US. Additionally, the results of studies on the public's acceptance of the various consent models used and proposed for biobank research has been conflicting and variably received.[17,20,22–24] Understanding participants' preferences and concerns regarding consent for research may help researchers address issues specific to their populations as they design and administer consent; this may be critical to achieving adequate minority representation in biobanks. Previous studies have identified the need to demystify and simplify the informed consent process in order to yield greater participation from diverse populations.[8,25–27] These studies highlight the need to ensure that culturally sensitive and approachable language is used in addition to providing a variety of consent models. Therefore, analysis of informed consent acceptance in diverse populations may be informative in increasing participation from diverse participants in biobank efforts.

The general populations' understanding of the federal Genetic Information Nondiscrimination Act, GINA, has yet to be assessed. GINA is a health care protection that prohibits most employment and insurance discrimination based on one's genetic information.[28] Previous literature indicates that failure to thoroughly understand the legal language of consent forms and implemented health care protections reduces hypothetical and actual biobank participation.[29] Therefore, it may be useful to evaluate the impact of GINA as a deterrent or motivator on demographic groups' willingness to provide broad or narrow consent for biobank research.

To our knowledge, this is the first study to evaluate the impact of beliefs about privacy and genetic safeguards on acceptance of broad and narrow biobank consent among diverse populations. The purpose of this study was to examine differences that exist among various racial and ethnic groups and demographics in regards to acceptability of broad and narrow consent.

Methods

Building on previous research, an online survey was developed to measure public attitudes about disclosing, receiving, and using information collected or discovered during a national cohort study proposed by the National Human Genome Research Institute (NHGRI).[17,30–32] The proposed NHGRI study would follow 500,000 Americans for more than one decade to assess the effects of genes, environment, and lifestyle on disease and health, and would therefore involve biobank specimens for future study.[33] The current study captured attitudes about two modes of consent from a population representative of current US adults, in order to inform scientists working to create biobanks inclusive of diverse groups within the US population.

The survey was conducted online in English and Spanish, according to respondent preference. Sample selection and online survey administration was managed by Knowledge Networks (KN), which is now known as GfK.[34] The survey was administered from April 29–May 12, 2011 to 5412 respondents 18 years and older. Respondents were randomly selected from KN's web-enabled master panel of approximately 35,000 US residents. For households without Internet access, KN provides a laptop computer and an Internet connection to complete the surveys. Hispanics were sampled from KN's KnowledgePanel Latino, which comprises a representative sample of U.S. adults who identify with Hispanic culture and values.[35] This panel tracks the distributions of age, education level, geographic region, Spanish and English proficiency among the U.S. Latino population as measured in a 2011 Current Population Survey (KN Latino). In this study, the Hispanic sample was stratified to include equal numbers of individuals who chose to take the survey in English and in Spanish. KN knows the survey language preference of each KnowledgePanel Latino member ahead of time. The study sample was designed to oversample Black non-Hispanics and Hispanics in order to facilitate comparisons between groups and provide adequate statistical power to compare opinions in these groups to those of white non-Hispanics.

Survey respondents initially viewed a 3-minute video in English or Spanish,[32] describing the goals and design of the proposed large study. Respondents who could not view the video ($n = 1012$) saw a written script of the video, accompanied by a diagram of study components. Definitions of several terms were provided. Hyperlinks to the study description and to each definition were available throughout the survey. Following the video, participants were asked about their support and willingness to participate in the study about privacy concerns and about aspects of study design including the use of broad and narrow consent models, and the return of individual research results. The survey was qualified as exempt by the Johns Hopkins University Institutional Review Board (Application # NA_00040539).

A total of $n = 1528$ individuals were randomized to view a scenario asking about their acceptance of broad consent, and $n = 1533$ were randomized to view a scenario asking about their acceptance of narrow consent. The full text of both scenarios and the follow-up question are found in the Appendix.

The study was piloted in two phases. Phase I evaluated survey length, logic, skip patterns wording and participant comprehension. Phase II determined if there was any order effect depending on whether a conjoint experiment preceded or followed other questions about study design and the return of results; no ordering effect was observed. Results from the pilot studies are not included in these analyses.

Analyses

All analyses were conducted using Statistical Package for Social Sciences (SPSS) version 22.0 statistical software. The analyses in this article that represented the entire US population in aggregate (that is, where we report the total samples' opinion) were weighted to U. S. 2010 Census demographic benchmarks. Analyses to examine differences between (or within) races and ethnic groups were performed using unweighted data, as reliable weights within these groups were not available. Logistic regressions were used to determine between- and within-group differences for broad and narrow consent. Differences were considered significant at $p \leq 0.05$. Additionally, logistic regression was used to model the effects of GINA beliefs, privacy concerns, current health status, blood donor status, and genetic testing history on willingness to provide broad or narrow

Table 1. Demographic Profile and Overall Opinions of Surveyed Population ($N=3061$)

	Survey respondents actual N *(%)*	*Survey respondents weighted* N *(%)*	*US Census, 2010 (%)*
Demographic groups			
Men	1,480 (48%)	1,482 (48%)	49%
Women	1581 (52)	1579 (52)	51%
White, non-Hispanic	1529 (50)	2077 (68)	68%
Black, non-Hispanic	675 (22)	350 (11)	12%
Hispanic (all races)	708 (23)	431 (14)	14%
Other non-Hispanic	149 (5)	203 (7)	6%
Age 18–44	1551 (51)	1464 (48)	48%
45–64	1080 (35)	1110 (36)	35%
65 +	429 (15)	487 (16)	17%
Household income ≤ $25K	721 (24)	719 (24)	26%
$26K–$50K	759 (25)	750 (25)	25%
$51K–$85K	735 (24)	757 (25)	23%
> $85K	846 (28)	836 (27)	27%
Education < high school	489 (16)	400 (13)	19%
High school	972 (32)	953 (31)	27%
Some college	851 (28)	860 (28)	27%
Bachelor's degree or higher	748 (25)	848 (28)	28%
Has health insurance	2465 (80)	2515 (82)	–
No health insurance	595 (20)	546 (18)	
Donated blood past 5 years	572 (19)	619 (20)	–
Did not donate blood	2038 (68)	1988 (65)	
Cannot donate blood	410 (14)	402 (13)	
Opinions			
GINA makes me feel more comfortable that genetic information collected in the study could not be used against me (% Agree)	2363 (79%)	2368 (79%)	
It is not possible to maintain my privacy these days (% Agree)	1770 (60)	1778 (60)	
I limit my Internet use because of privacy concerns (% Agree)	1527 (51)	1480 (50)	
Breaches of my privacy are inevitable. (% Agree)	1865 (63)	1880 (64)	
How concerned are you about the privacy of your medical information?			
Concerned	1127 (37)	1081 (36)	
Neutral	920 (31)	948 (32)	
Not Concerned	959 (32)	965 (32)	
Ever had a genetic test	192 (6)	191 (6)	
Current perceived health status			
Excellent	292 (10)	286(10)	
Very good	1014 (34)	1014 (34)	
Good	1463 (49)	1461 (49)	
Poor	223 (7)	219 (7)	
Very Poor	24 (1)	26 (1)	

consent for biobank research, adjusting for the demographic factors listed above. Ability to view the video was analyzed and did not influence responses to the consent or opinion items analyzed here.

Dependent variables

To examine willingness to provide broad or narrow consent for a hypothetical biobank study, respondents were randomized to view one of two questions about consent models. Half of participants saw the following description: ''Researchers who get official approval from the study would be allowed to use your samples and information to study a wide range of diseases.'' The other half saw a second description: ''Each time a researcher gets official approval to do research using the biobank, you would be asked for your permission to use your samples and information for that specific project.'' All respondents were then asked ''Would you agree to share your samples and information with researchers in this manner?'' Yes and no responses were provided.

Independent variables

Independent variables included items that assessed participants' perceptions of GINA, privacy concerns for medical information, genetic testing history, internet use, perceived health status, blood donor status, and demographics.

Prior to providing an opinion about GINA, respondents were given a brief description detailing the provisions of the law. The GINA question read as follows: ''The law GINA makes me feel more comfortable that genetics information collected in the study could not be used against me.'' Original responses were collected on a four-point Likert scale as: strongly agree, agree, disagree, and strongly disagree.

Concerns about privacy were evaluated with four items. Original responses to the question: ''How concerned are you

about the privacy of your medical information?'' were collected on a five-point Likert scale; responses ranged from ''very concerned'' to ''not concerned at all concerned.'' For analysis purposes, three categories were created: concerned, neutral, and not concerned. Other privacy questions included: ''I limit my Internet use because of privacy concerns''; ''It is not possible to maintain my privacy these days.'' and ''Breaches of my privacy are inevitable.'' Responses were provided in a four-point Likert scale format as strongly agree, agree, disagree, and strongly disagree.

A proxy measure for altruism was also included. Individuals were asked if they had donated blood within the past 5 years and could respond ''yes'', ''no,'' or ''I cannot give blood.''

Individuals were also asked: ''Have you ever had a genetic test?'' and given options of ''yes'', ''no,'' or ''don't know'' answers.

Health status and information was captured in an item that asked: ''In general, how would you describe your current health?'' Initial responses included: ''excellent,'' ''very good,'' ''good,'' ''poor,'' and ''very poor.''

Demographic items, including: age, race and ethnicity, gender, marital status, education, household income, and health insurance status, were collected.

Results

Survey sample characteristics

Overall, 5371 individuals were asked to participate in this study, and a total of 3061 people responded to the survey. This yielded an 57% overall response rate. Response rates were 51% and 52% among Hispanics and Black non-Hispanics, respectively. Response rates of Hispanics taking the survey in English and Spanish were both 51%. Median time to complete the survey was 32 minutes. Table 1 compares the weighted (using 2010 census weights) and unweighted demographic data of the sample to the 2010 US Census figures. Unweighted data correspond to the 2010 U.S. population for age, gender, education, and income. Race and ethnicity of the sample did not correspond with national figures because Black non-Hispanics and Hispanics were oversampled in the survey.

Acceptability of broad versus narrow consent

Table 2 indicates the acceptability of biobank participation by demographic characteristics of the sample stratified by broad and narrow consent. Rates for willingness to provide broad (76%) and narrow (74%) consent did not differ significantly in this sample. However, when evaluating willingness within each demographic stratum, there were trends towards differences in willingness to consent under the two models. Higher, but not significantly larger, percentages of white non-Hispanics ($p=0.07$), males ($p=0.13$), those who had not completed a bachelors degree ($p=0.12$) and respondents who donated blood within the last 5 years ($p=0.14$) found the broad consent model acceptable, compared to acceptance of the narrow consent model in these groups (Table 2).

Demographic predictors of broad and narrow consent models

Table 3 presents two sets of multiple logistic regressions, one for each consent model, that were used to evaluate the relationships between acceptability of the consent model and age, race and ethnicity, gender, education, income, insurance, and blood donor status. It is important to remember that each survey participant saw only one of the two models and no participant directly compared the two models; therefore findings for the two models are completely independent of one another. Looking at broad consent, individuals who had a bachelor's degree or greater (83% vs. 73%, $p=0.05$) and those who had donated blood within the last 5 years (84% vs. 73%, $p=0.002$) were significantly more likely to find the broad consent model acceptable. Additionally, African Americans were significantly less likely than white non-Hispanics (69% vs. 81%, $p=0.004$) to accept the broad consent model.

Examining demographic differences for the acceptability of narrow consent, women (76%, vs. 71%, $p=0.01$), individuals with a bachelor's degree or greater (82% vs. 70%, $p=0.002$), and those with insurance coverage (77 vs. 59%, $p=0.001$) were significantly more likely to find the narrow consent model acceptable. We also noted a marginal trend in blood donors' acceptance of narrow consent ($p=0.06$). Although fewer African Americans (72%) than white non-Hispanics (77%) found the narrow consent acceptable, this difference was not statistically significant ($p=0.35$).

Table 2. Willingness to Provide Broad and Narrow Consent by Selected Demographic Characteristics

Independent variable	*Broad consent (n=1528) % Finding this model acceptable*	*Narrow consent (n=1533) % Finding this model acceptable*	*Odds Ratio*	P *value*
Total	76	74	1.5	0.14
Race and ethnic group				
White non-Hispanics	81	77	1.29	0.07
Black non-Hispanics	69	72	0.86	0.42
Hispanics	71	67	1.19	0.36
2+ Races	72	67	1.53	0.39
Gender				
Male	74	71	1.22	0.13
Female	77	76	1.08	0.56
Education				
<Bachelor's degree	73	70	1.18	0.12
Bachelor's degree+	83	82	1.02	0.91
Income				
≤$25,000	71	70	0.89	0.54
$26,000–$50,000	73	70	1.32	0.12
$51,000–$85,000	77	74	1.26	0.23
≥$86,000	82	79	1.21	0.34
Insurance				
No insurance coverage	66	59	1.25	0.24
Insurance coverage	78	77	1.21	0.34
Blood donation in past 5 years				
No	73	72	1.10	0.33
Yes	84	80	1.41	0.14

We controlled for age as a continuous variable in all p value calculations. Within Hispanics, chosen survey language was not a significant predictor of broador narrow consent.

Table 3. Multivariate Logistic Regression Model of Demographics Predictors on Acceptability of Broad and Narrow Consent

	Broad consent (n = 1528)			*Narrow consent (n = 1533)*		
Independent variable	*% Finding this model acceptable*	*Odds Ratio*	P *value*	*% Finding this model acceptable*	*Odds Ratio*	P *value*
Age (continuous)	–	1.02	0.51	–	1.01	0.21
Race and ethnic group						
White non-Hispanics (reference)	81			77		
Black non-Hispanics	69	0.62	0.004	72	0.85	0.35
Hispanics	71	0.76	0.12	67	0.76	0.11
2 + Races	72	0.72	0.37	67	0.70	0.27
Gender						
Male (reference)	74			71		
Female	77	1.22	0.15	76	1.38	0.01
Education						
< Bachelor's degree (reference)	73			70		
Bachelor's degree +	83	1.42	0.05	82	1.71	0.002
Income						
≤ $25,000	71	0.78	0.25	70	1.10	0.66
$26,000–$50,000	73	0.88	0.54	70	0.83	0.35
$51,000–$85,000	77	0.91	0.64	74	0.89	0.53
≥ $86,000 (reference)	82			79		
Insurance						
No insurance coverage (reference)	66			59		
Insurance coverage	78	1.34	0.09	77	1.81	0.001
Blood donation in past 5 years						
No (reference)	73			72		
Yes	84	1.76	0.002	80	1.39	0.06

Demographic and belief predictors of broad and narrow consent models

Two additional series of models, summarized in Table 4, evaluated the relationship between beliefs (described above in the methods section) including confidence in GINA, privacy concerns, current health status, and genetic testing history and the acceptability of broad and narrow consent for biobank research. Again, each participant only saw one of these models. These regressions also adjusted for demographic variables in Table 3. Recent blood donors ($p = 0.04$), participants with a history of genetic testing ($p = 0.05$), those who were comfortable with GINA ($p < 0.001$), and individuals who had no privacy concerns about medical information ($p = 0.03$) or were neutral ($p = 0.05$) were all significantly more likely to agree to broad consent. In contrast, respondents who believed that it is not possible to maintain their privacy ($p = 0.04$) and those who did not limit their Internet use because of privacy concerns ($p = 0.05$) were significantly less likely to agree to broad consent. After adjusting for other sociodemographic variables, and including beliefs about GINA, concerns about privacy, genetic testing history, blood donor practice, and health status in this model, the relationship between race and broad consent preferences diminished. African Americans were slightly, but not significantly less likely favor broad consent, compared to white non-Hispanics ($p = 0.08$).

Table 4 also models the relationships between beliefs and the acceptability of narrow consent. Individuals who completed college ($p = 0.03$), those who had insurance ($p < 0.001$), those who were comfortable with the protections of GINA ($p < 0.001$), and those who disagreed that it was not possible to maintain privacy ($p = 0.02$) were more likely to say they would agree to narrow consent. In both broad and narrow consent models, the largest difference in opinion existed between those who did and did not draw comfort in the protections offered by GINA (83% vs. 43% and 80% vs. 50%, respectively).

Discussion

In this study, we assessed variation in demographic groups' acceptance of two consent models for biobank research: narrow and broad consent; half of the sample was asked about a broad consent model and half was asked about narrow consent. We also evaluated the influence of beliefs about privacy and genetic safeguards, genetic testing history, as well as blood donor and health status on acceptance of the consent models while controlling for demographics. When asked about their willingness to engage in biobank research, more than three-quarters of the sample expressed acceptance of both models. Although not statistically significant, in most demographic groups acceptance of broad consent was slightly higher than acceptance of narrow consent. Among African Americans the narrow consent model was more widely accepted.

Racial and ethnic differences in acceptance of broad and narrow consent models were observed in this study. African Americans were significantly less likely than white non-Hispanics to find broad consent acceptable (69% vs. 81%, respectively), while the same was not true of the narrow consent model. These findings are consistent with previous studies that found African Americans to be more reluctant to consent to storage of their biospecimens for future use,[5,17,36]

Table 4. Multivariate Logistic Regression Model of Demographics and Beliefs on Preference for Broad and Narrow Consent

	Broad consent (n = 1528)			*Narrow consent (n = 1533)*		
Independent variable	*% Finding this model acceptable*	*Odds Ratio*	P *value*	*% Finding this Model Acceptable*	*Odds Ratio*	P *value*
Age (continuous)		1.00	0.27		1.00	0.65
Race and ethnic group						
White non-Hispanics (reference)	81			77		
Black non-Hispanics	69	0.70	0.08	72	0.92	0.66
Hispanics	71	0.75	0.20	67	0.86	0.45
2 + Races	72	0.93	0.86	67	0.67	0.33
Gender						
Male (reference)	74			71		
Female	77	1.10	0.56	76	1.21	0.21
Education						
< Bachelor's degree (reference)	73			70		
Bachelor's degree +	83	1.27	0.24	82	1.79	0.003
Income						
≤ $25,000	71	0.72	0.20	70	1.29	0.32
$26,000–$50,000	73	0.74	0.22	70	0.88	0.58
$51,000–$85,000	77	0.88	0.58	74	0.96	0.85
≥ $86,000 (reference)	82			79		
Insurance						
No insurance coverage (reference)	66			59		
Insurance coverage	78	1.10	0.64	77	2.14	< 0.001
Blood donation in past 5 years						
No (reference)	73			72		
Yes	84	1.55	0.04	80	1.28	0.22
Genetic testing history						
No (reference)	77			74		
Yes	85	2.21	0.05	80	1.39	0.32
Comfort from GINA						
Disagree (reference)	48			50		
Agree	83	5.50	< 0.001	80	3.51	< 0.001
It is not possible to maintain privacy these days						
Agree (reference)	73			70		
Disagree	81	1.52	0.04	79	1.49	0.02
I limit my Internet use because of privacy concerns						
Agree (reference)	70			69		
Disagree	82	0.67	0.05	78	1.27	0.15
Breaches in privacy are inevitable						
Disagree (reference)	79			78		
Agree	75	1.26	0.28	71	1.02	0.93
Privacy concerns about medical information						
Concerned (reference)	68			67		
Neutral	79	1.46	0.05	77	0.70	0.06
Not concerned	83	1.56	0.03	79	0.94	0.75
Current health status						
Poor/Very poor (reference)	76			74		
Good/Very Good/Excellent	76	0.67	0.22	74	0.64	0.17

less willing to participate in biobanks,[36] and to highly prefer a study-by-study-consent process.[17] In spite of previous reports of reticence towards and reluctance to participate in biobank research, recent community-based participatory studies in various racial and ethnic groups have found an overwhelming degree of willingness to provide biospecimens.[37–39] Based on findings from our study, researchers designing biobank protocols, especially studies that involve a broad consent model, should actively explore and address diverse populations' concerns about biobank research and perceptions about providing broad consent for unspecified future uses of samples and data.

Individuals who completed college were more likely than those with less education to find both models acceptable. This finding has been echoed in few biobank- related studies. It is possible that individuals with more formal education are more knowledgeable about biobanks,[40] the associated conventions,[41] and discourse around consent models.

Individuals with health insurance were significantly more likely than persons without insurance to find both consent models acceptable, although the difference was only statistically significant in the narrow consent model. While additional research would need to be conducted to understand the reason for this finding, it is possible that those without heath insurance are less trusting of medical research or have other non-research-related health priorities.

Many studies have shown that privacy concerns significantly influence individuals' decisions to use genetic testing and engage in genetic research.[42–44] In this study, acceptance of both models was significantly higher among individuals who believed in the ability of the proposed study to secure participants' privacy, and the ability of GINA to safeguard this information. Since GINA is relatively new and is the initial form of legislation that protects people against the misuse of their genetic information, it is possible that individuals' lack of understanding of the strengths and limitations of the law influence acceptance of both consent models. Studies conducted since GINA was enacted indicate that individuals have lingering fears of insurance discrimination related to genetic testing.[45] We did not assess individuals' prior knowledge of and concerns about GINA or the depth of their understanding of the statute. Despite previous data revealing pervasive misunderstanding of this law,[45,46] a solid majority of persons believe it to be an important law.[47] In this study, a majority indicated that they were confident with GINA's ability to confer protections. Therefore, it will be important for biobank resources to clarify misperceptions about GINA and its strengths and limitations in order to guarantee understanding of consent models associated with biobanks.

Other findings in this study associated with acceptance of broad and narrow consent were reflections of previous attitudes, behaviors and familiarity with providing biospecimens. Persons who donated blood within the past 5 years, those with a history of genetic testing, and those who were neutral or not concerned about the privacy of their medical information were more likely to agree to broad consent. It is possible that individuals with previous personal experience with genetic research or genetic testing liken consent for biobank research to their prior experiences in providing biospecimens for blood banks and genetic testing or place relatively higher value on the role of medicine and medical science.

High rates of acceptability of both types of consent were observed. In practice, it is unlikely that three-quarters of people solicited would actually participate. One possible explanation for high interest in the proposed study is that participants were asked several questions about their interest in receiving individual research results prior to questions about consent. The order of the questions could have artificially increased interest and led to increased reported acceptability of consent. As developing biobanks consider the consequences and benefits of returning individual results and incidental results,[48–50] there is a possibility that the public perceives the return of results to be common practice. The absolute levels of acceptability of consent should not be construed as precise measures of the percentages that would find broad and narrow consent acceptable in an actual nationwide biobank. However the comparisons between broad and narrow consent, across demographic groups, and the relationships of acceptability to personal beliefs are likely to be valid. Although interest in individual results might have increased overall responses, previous work has demonstrated that interest in the return of results is quite uniform across demographic groups.[32]

Another limitation of the study is the wording used to describe the narrow consent model, which reads as follows: ''Each time a researcher gets official approval to do research using the biobank, you would be asked for your permission to use your samples and information for that specific project.'' This description might overly emphasize the burden of giving one's permission each time a new study arises, which might have lowered enthusiasm for the narrow consent model. Additionally, we did not specify the frequency or form of re-contact that would be utilized. Inclusion of information that accurately describes and details the re-contact practices could have influenced participants' decisions to opt into narrow consent. A single, narrow consent that does not re-contact individuals to seek additional permission might be more strongly preferred to repeated narrow study-by study consents.[51] In our previous work,[17] a large majority said that being asked repeatedly for consent would be burdensome or unnecessary, suggesting that this aspect of study-by-study consent is one that should be further explored.

Traditionally, diverse populations have remained absent from biomedical research, and this has inadvertently contributed to the exacerbation of health disparities. There is a critical need to educate diverse groups about the importance of biobank research and provide opportunities for them to engage while also taking into consideration the respective concerns and preferences of each group. We did not collect data on ethnic decent, aside from Hispanic ethnicity. We recognize that all racial and ethnic groups are heterogeneous populations and consent acceptance may vary with ancestral lineage. Additional studies should explore intra-racial and intra-ethnic differences. If implemented correctly, biobanks may serve as a mechanism to enrich representation of historically underserved and underrepresented populations in research.

Author Disclosure Statement

No competing financial interests exist.

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APPENDIX

Consent Scenarios

Survey participants were randomized to view only one of the two following scenarios about consent, and subsequently asked if they would agree to share samples and information under this model. Scenario 1 represented a model of broad or blanket consent, while scenario 2 represents a narrow model where participants would be re-contacted each time a new study using the biobanks was proposed.

Scenario 1

Imagine you were a participant in the study. You would be asked to sign a consent form explaining how your samples and information would be shared with researchers. Please read the following section of the consent: ''Researchers who get official approval from the study would be allowed to use your samples and information to study a wide range of diseases.''

Would you agree to share your samples and information with researchers in this manner?

- Yes
- No

Scenario 2

Imagine you were a participant in the study. You would be asked to sign a consent form explaining how your samples and information would be shared with researchers. Please read the following section of the consent: ''Each time a researcher gets official approval to do research using the biobank, you would be asked for your permission to use your samples and information for that specific project.''

Would you agree to share your samples and information with researchers in this manner?

- Yes
- No