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Two Large-Scale Surveys on Community Attitudes Toward an Opt-Out Biobank

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Abstract

Although US research regulations allow for de-identified biorepositories to be developed without formal informed consent from the patients whose samples are included, it is unknown whether this model will be well-received by community members. Based on early evidence that such a biobank could be successful if patients who object have the opportunity to opt-out, Vanderbilt University developed a biorepository named BioVU that follows this model. This study reports the findings from two large-scale surveys among communities important to this biorepository. In the first, a population-based phone survey of Nashville residents, we found that approval for BioVU is high (93.9%) and that this approval is similar among all population groups. A hypothetical biobank that does not obtain some form of written permission is much less well received. In the second, an online survey of Vanderbilt University faculty and staff, we found a higher level of support for BioVU (94.5%) among faculty and staff working throughout the university. In this survey, employees least likely to approve of BioVU are those employees who prefer not to receive medical care at Vanderbilt University. These surveys demonstrate the highest level of approval for a genomic biobank ever reported in the literature, even among groups traditionally cautious about such research. This high level of approval may reflect increasing comfort with genomic research over time combined with the effect that trust in a specific institution can have on approval for an operating biobank compared with approval of a hypothetical biobank.

Keywords

biorepository research; patient perspectives; research ethics

INTRODUCTION

Vanderbilt University Medical Center broke new ground in creating BioVU, its biobank combining a de-identified version of its electronic medical record with DNA derived from residual blood samples [Roden et al., 2008]. Although this biobank is exempt from the requirements of the federal regulations for the protection of human research subjects [OHRP, 2008], Vanderbilt decided early on to offer patients the opportunity to choose not to have their DNA included in the biobank, an option that to date has been exercised by approximately 5% of patients [Pulley et al., 2010]. Research on patients' and the public's opinions of BioVU has been an important element of this model for a number of reasons. First, we are interested in assessing whether the opt-out form is an effective tool for enabling

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patients who do not want their samples to be included in research to exercise this preference. Second, we wish to identify whether the opinions of patients vary across demographic groups, including racial and ethnic groups, in order to assess community engagement and oversight needs. Third, we want to provide the evidence base required for investigators at other institutions to develop biorepositories using the opt-out model.

The institution has examined patient perceptions through a variety of methods over time, including focus groups and exit interviews with patients [Brothers et al., 2010; Pulley et al., 2008]. We report here the results of two large surveys. The first was part of a larger, population based survey of Nashville citizens, designed to sample the diversity of the population here. Because the opt-out rate has been low, we hypothesized that approval for the opt-out model among members of the community would be high. Studies, however, have shown repeatedly that minority groups tend to be more cautious of medical research, including genetic biorepositories, so we hypothesized that minority respondents would be less supportive of the opt-out model. The second survey was an online survey of Vanderbilt faculty and staff. There has been only limited research on approval of genomic biobanking among employees of research institutions, but we were interested in this group because Vanderbilt employee health insurance incentivizes the use of Vanderbilt healthcare services and because employment within the institution could sharpen concerns related to privacy and voluntariness. We hypothesized that non-Medical Center faculty would have especially strong concerns regarding privacy, and would therefore be more critical of BioVU.

MATERIALS AND METHODS

Study Design - Nashville Community Health Survey

The Nashville Community Health Survey (NCHS) is a population-based survey of adults living in the Nashville, Tennessee area conducted from August 2008 to March 2009. The topic of the survey was health, broadly construed to include sections on general health and mental health, health behaviors and injury, neighborhood and crime, discrimination, religion, social support, labor force participation, attitudes and experiences related to racial discrimination, and general demographics. The sample was drawn from lists of pre-screened random-digit dial (RDD) phone numbers supplemented by targeted lists of cell phone numbers and phone numbers listed to persons with Hispanic surnames and was conducted by the University of Chicago Survey Lab. This survey was designed to generate a sample representative of the population of Nashville, with the exception of African Americans, who were intentionally oversampled to facilitate analysis within these groups.

In order to attain the target sample mix, a rigorous selection process was followed. In the first stage of the survey, households were called using the RDD and cell phone lists. A single adult was selected from each household using the “next-birthday” method. Any adult resident of Davidson County, Tennessee was eligible to participate. In the second stage of the survey, callers oversampled Hispanic households by calling phone number listed to persons with Hispanic surnames. Respondents were eligible to participate in this stage if they were adult residents of Davidson County who self-identified as Hispanic. In the third stage, callers oversampled African American households by calling RDD numbers and screening for race. Respondents were eligible to participate in this stage if they were adult residents of Davidson County and self-identified as African American. Researchers attempted to contact participants on average five times (mean=4.99, SD=4.149). Over 50 percent of respondents were reached by the third attempt. 7649 households were contacted to generate the initial sample of 786 completed surveys. An additional 3539 households were contacted in stages 2 and 3. These oversampling stages generated an additional 157 completed surveys from Hispanic respondents and 79 surveys from African American respondents. In all, 11,188 households were contacted to complete a total of 1022 completed

surveys and 34 partial surveys (Table I). A subset of 677 respondents was selected to respond to questions on genome-based biorepository research. The resulting sample was weighted by race and analyzed using PASW 18.0 (IBM Corporation, Somers, New York), with partial respondents included in our analysis.

The sections of the survey analyzed and reported here contain two types of questions. Collaborators in the Department of Sociology developed and adapted basic demographic questions, including age, race, gender, and religious affiliation. Questions related to genomic biorepository research were developed by two physicians working in biorepository research ethics and a sociologist with experience in survey design. The content validity and feasibility were ensured by employing an iterative process. We elicited feedback on an initial draft from a collaborator in the Department of Sociology and with an expert at another institution who investigates perceptions of genomics from a medical sociology perspective. The draft was revised based on this input and then re-circulated for additional feedback. The final survey included 11 questions designed to elicit respondents' perspectives on biorepository research along with questions generated by other groups of investigators covering a wide range of topics mentioned above. The complete survey contained approximately 100 questions, but only findings related to demographics and the 11 questions related to biorepository research are reported here.

Study Design - Vanderbilt Faculty and Staff Survey

The Vanderbilt Faculty and Staff Survey (VFSS) is a cross-sectional study of perceptions of biorepository research among faculty and staff employed by Vanderbilt University. All employees were solicited by e-mail to participate in an online survey. Responses were collected during November of 2008. In order to increase response rates, respondents were entered into a drawing for one of twenty digital music players. Out of 25,450 employees who were invited to participate, 4050 completed the survey, for a response rate of 16%.

This questionnaire was developed based on the questions asked in the NCHS, retaining wording and question order wherever possible. A few questions required significant revision based on the field experience of the NCHS, and several questions were omitted to minimize respondent fatigue. Drafts of this second questionnaire were also shared with an expert at another institution who investigates perceptions of genomics from a medical sociology perspective and revised based on her input.

Both surveys were determined by the Vanderbilt Institutional Review Board to meet criteria for non-human subjects research.

Outcome Variables

The primary outcome variable for these two surveys was the approval of a genomic biorepository that utilizes an opt-out procedure. This perspective was clarified by additional questions intended to assess the importance of ethics panel oversight and deidentification procedures. In order to assess the importance of providing an opportunity for patients to opt out, we asked respondents about their approval of a biorepository that does not seek written permission from patients whose samples could be included.

Background Variables

Comprehensive sociodemographic factors were included in the NCHS, including age, gender, race, ethnicity, education, and income. For the VFSS, demographic factors were abbreviated in order to keep the survey brief and to ensure anonymity. The demographics included in this survey were age, gender, campus location (medical center vs. central campus) and Faculty/Staff classification.

Questions about attitudinal factors were largely shared between the two surveys and included past participation in research, attitudes toward research, experience with genetic testing, and trust in Vanderbilt or other research institutions.

Data Analysis

All data were coded and analyzed with the PASW 18.0 software program (IBM Corporation, Somers, New York). Sociodemographic data for the NCHS were compared between the study sample and the entire Nashville population, while sociodemographic data for the Faculty and Staff Survey were compared between the study sample and Vanderbilt employee data. Comparisons of the study samples with the associated populations are listed in Table II. Descriptive and univariate analyses for the NCHS such as means, frequencies, and other basic statistics were performed using data weighted to mirror the Nashville population at the time the survey was conducted. Analyses for the VFSS were not weighted, since the faculty and staff members were not sampled through randomized or stratified methods. Despite this, proportions of respondents closely reflected actual faculty and staff levels.

RESULTS

Sample Characteristics

The mean age of respondents in the NCHS was 49 years old (SD=17.9), and most considered their health either good (32.7%), very good (29.9%), or excellent (20.8%). More than half of respondents in the Faculty and Staff Survey reported that they were between 30 and 49 years of age (51.5%). Compared with the population of all Vanderbilt employees, women and employees aged 18–29 were overrepresented in the sample that completed the survey (Table I).

Experience with and Views on Genetic Testing and Research

Although respondents to the VFSS were significantly more likely to have participated in research (13.7% in NCHS, 48.8% in VFSS, $p<0.0001$ by χ^2 test), the overwhelming majority of the respondents in both surveys reported that they considered research to be somewhat or very important in improving health care (99.1% in NCHS, 99.7% in VFSS). Vanderbilt employees were twice as likely to report that they had been offered a genetic test for their clinical care (2.7% in NCHS, 7.0% in VFSS, $p<0.001$). There was also a trend toward more employees' reporting that they had donated blood or tissue for genetic research compared with the general population.

Trust in Medical Research Institutions

The majority of respondents in both surveys reported that they were somewhat or very confident that research hospitals such as Vanderbilt do a good job of protecting patients' medical information. In the NCHS, respondents were also asked about their confidence in the privacy of genetic information generated for research; responses to this question demonstrated slightly lower confidence compared with the privacy of medical record information (Table III).

Approval of Opt-Out Biobank

Respondents were presented with a brief description of a DNA biorepository and then asked several questions about biorepositories. The majority of respondents in the NCHS responded that they somewhat or strongly agreed that “DNA biobank research is fine as long as people can choose not to have their DNA included.” Similarly, the majority of respondents in the VFSS responded that they somewhat or strongly agreed that “DNA databanks with all

identifying information removed are fine as long as people can choose to opt out of having their DNA included" (Table IV). We noted very little variation in approval of an opt-out biobank among all groups of respondents across both surveys. Due to this low amount of variation, we do not report multivariate logistic regression on this question.

Importance of Deidentification, Oversight, and Data Sharing

Participants were asked in both surveys about their agreement with statements highlighting different elements of this biobanking model, although these questions were worded differently. In the NCHS, 88.5% of respondents approved of a biorepository in which investigator access depends on ethics committee review, while 87.3% approved of a biorepository in which identifying information is removed. In contrast, just 45.5% of respondents agreed that researchers should be allowed to use de-identified genetic information without getting written permission from patients (Table V).

By comparison, among VFSS respondents 93.3% approved of a biorepository in which identifying information is removed. 91.6% approved of the use of deidentified information as long as research conducted using samples is approved by an ethics committee. 88.9% of respondents agreed that deidentified information could be used as long as written permission from patients is required (Table V). We also asked faculty and staff respondents whether depositing deidentified information into a national database would make them more or less likely to allow their sample to be included. 18.5% said more likely, while 12.1% said less likely, and 69.5% said it would make no difference.

DISCUSSION

Approval of Opt-Out Biobanking

We found that the approval of the opt-out biobank model adopted in Vanderbilt's genomic biobank BioVU is high among faculty and staff as well as among members of the community at large. In both groups, more than 90% of respondents approved of the biobank. This finding indicates that support for the opt-out model adopted for BioVU is strong. Even though a very large proportion of potential patients in the Nashville community and among Vanderbilt employees support this model, we want to ensure that the small proportion of patients who disapprove of the use of their sample are afforded an opportunity to exercise that preference. If the opt-out procedures are successful, the percentage of patients who disapprove of the biorepository should correlate closely with the percentage of patients who opt-out of the inclusion of their sample in the biobank. Although neither of these surveys provides a perfectly representative sample of patients, the NCHS should fairly represent the perspective of potential patients living in Vanderbilt's catchment area. The approval of this model within this population is 93.9%, which correlates closely with the observed opt-out rate in adult patients of about 5% [Pulley et al., 2010].

While approval for this opt-out biorepository is high, it is possible that patients would prefer a brief opt-in approach. We were interested in examining, therefore, whether a similar biobank that only included samples from patients who had given affirmative signed permission would receive stronger support compared with an opt-out model biobank. In our survey of faculty and staff, 2.1% of respondents do not approve of a genetic biobank regardless of the consent method. Three and three-tenths precent of respondents object to a biobank when only an opt-out is available, but agree that DNA biobanks are fine as long as formal written permission is required. These respondents seem cautious of genetic biorepositories, and would likely object to the opt-out model adopted by BioVU. Nine percent accept a biobank that makes an opt-out available but do not also believe that written consent needs to be required. Eighty-five and six-tenths percent approve of genetic

biobanking as long as patients can choose to opt out of having their DNA included but also agree that written permission should be required for the DNA of a patient to be included in a biorepository. At least two interpretations of this last finding are possible. It may be that over 80% of respondents agree with biobanking as long as there is some opportunity for patients to make a choice. Alternatively, it may be that respondents did not understand that these consent procedures are mutually exclusive—that is, a biobank cannot operate using an opt-out *and* require written permission from patients. Respondents may have considered each question, and each consent procedure, independently and therefore express a perspective that seems contradictory. This hypothesis is supported by the fact that the questions related to these consent procedures were not adjacent in the survey form.

Factors Associated with Approval of an Opt-Out Biorepository

The findings of these surveys are also significant because they represent one of the highest levels of approval ever reported for a genetic biorepository although other investigators have also found high levels of support for biobanks. Goldman et al [2008] found that 80% of Rhode Islanders were willing to have their sample included in a biobank. Hoeyer et al [2004] found that 71% of Swedish respondents approved of genetic research using a biobank, and in a separate study Kettis-Lindblad *et al* demonstrated that 89.0% of Swedes would allow for their de-identified sample to be included in a biobank [2006]. A similar number (89%) of participants in a Baltimore epidemiological study agreed to have their DNA stored for research [Mezuk et al., 2008]. The level of support for Vanderbilt's biobank among African Americans (89.8%) and Hispanics (96.5%) was particularly striking. This finding demonstrates higher support for Vanderbilt's biobank among Hispanics than among non-Hispanics, and support among African Americans that is only slightly lower than among Whites. Although this findings is consistent with those reported by Pentz and her colleagues [2006], most previous studies have reported lower interest in biobank participation among respondents who are not White [Henderson et al., 2008; Neidich et al., 2008; Sanner and Frazier, 2007].

We hypothesize that this high level of approval can be attributed to two factors. First, it is possible that as time passes, members of the general public are becoming more familiar with genetic research and their level of caution related to this research is decreasing. This could explain why our recent results show a higher level of support than studies conducted in the past. However, studies that have looked at this question over recent years have not shown a clear trend. Second, respondents were not being asked about a hypothetical biobank, but rather about a biobank already in operation at an institution about which respondents were likely to have an impression. Therefore, responses may have been affected by the level of trust placed in this institution. Among members of the Nashville community at large, 94.4% reported that they were somewhat or very confident that research hospitals like Vanderbilt adequately protects patients' medical information, which is strongly correlated with approval of the opt-out model (bivariate correlation of .978, $p<.0001$). Eighty-eight and eight-tenths percent were confident that researchers would protect the identity of those whose samples are used in genetic research, which is also strongly correlated with approval of the opt-out model (bivariate correlation of .972, $p<.0001$). This trend is also evident in the VFSS, where employees who prefer not to receive medical care at Vanderbilt were among those least likely to approve of BioVU. Because approval of the opt-out biorepository model is closely correlated with trust in research hospitals, and this institution in particular, the exportability of this biobank model to other healthcare institutions may be affected by the relationship these institutions have with the communities they serve.

Methodological Considerations

The Nashville Community Health Survey was conducted using well-established methods for population-based social surveys, in this case a phone survey. The study design required callers to field a very large number of phone numbers. Two factors contributed to this large number. First, cell phone numbers were only considered eligible if the respondent reported that he or she did not also have a residential landline, leading to a low eligibility rate. Second, 3000 additional phone numbers were called in order to oversample for African American respondents. This large number was required because only 10.0% of those contacted at random self-identified as African American.

Eligibility, therefore, was a major driver of the requirement to field a large number of phone numbers. However, participation bias remains a consideration. The response for the rate entire survey was moderate at 31.8%, with slightly higher response rates during the portion of the study focused on oversampling Hispanic and African American residents (Table I) [AAPOR, 2011]. Because this survey sample used both random-digit dial and cell phone number lists, bias common in surveys that utilize land-line numbers only was mitigated. Underrepresented in this sample were native-born men, persons below age 35, persons with less than a college degree, and those living alone.

Sampling for the Vanderbilt Faculty and Staff Survey was less structured. All employees were sent an e-mail invitation and needed access to a computer to complete the survey. Computer literacy and access were thus prerequisites for participation in the survey. The response rate was 16%, which may contribute to non-response bias in this study. Despite this low response rate, those who responded to the survey were reasonably representative of employees of Vanderbilt University (Table II).

It is unclear how informed the views expressed by respondents were. Both surveys included a brief description of the biorepository, but understanding of this description and knowledge of genomic research were not assessed. In the VFSS, 62.7% of respondents reported that they had prior knowledge or awareness of the biorepository. Although we did not ask this question to respondents of the NCHS, we would expect that awareness of the biorepository is much lower in the general population compared with Vanderbilt faculty and staff who have had the opportunity to read numerous stories in university media. There would be a great deal of value in ascertaining perceptions of the biorepository in settings where more information could be provided and understanding could be assessed; we have already performed some of this work with parents of pediatric patients who might be included in the biobank [Brothers et al., 2010]. In the present surveys, however, we were interested in evaluating the reactions patients, employees, and community members would have to the idea of such a biorepository as they would be more likely to learn about in the real world. That is, we were interested in understanding how patients and members of the public are likely to respond when they are provided with only brief information about the biorepository, such as the information they might receive from clinic staff or through pamphlets or educational posters.

These studies are also limited by differences in the wording of similar questions. The NCHS was designed and fielded first. Feedback from this process was used to modify similar questions in the VFSS. This process led to significant differences in wording between questions targeting similar topics in the two surveys. These wording differences make drawing comparisons between the two studies difficult. For this reason, we have refrained from emphasizing quantitative similarities or differences between the samples.

CONCLUSIONS

In two large-scale surveys, we found that support for a genomic biorepository that utilizes an optout model is very high. In our population-based survey of Nashville community members, we found that support for Vanderbilt's biobank is high across all demographic groups. In our online survey of Vanderbilt employees, we found that support for this biobanking model is high among faculty and staff working throughout the university. These survey findings confirm earlier qualitative work we have conducted demonstrating that a biorepository operating on an opt-out model has the potential to be well-received by community members, particularly if trust in the institution is high.

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Table I

NCHS Sample Selection Process

Survey Stage:	**Stage 1**		**Stage 2**	**Stage 3**	**Total**
Phone Number Source:	**RDD**[a]	**Cell Phone List**	**Hispanic surnames**[b]	**RDD**[a]	
Targeted Eligibility Criteria:[c]	**None**	**None**	**Self-Identified Hispanic**	**Self-Identified African American**	
A. Total number fielded	4,649	2,748	791	3,000	11,188
B. Not Eligible[d]	2,124	1,526	319	1,709	5,678
C. Unknown Eligibility[e]	744	1,096	170	1,101	3,111
D. Known Eligible	1,781	126	302	190	2,399
E. Completed Surveys	666	79	157	120	1,022
F. Partially Completed Surveys	13	2	13	6	34
G. Eligibility Rate[f]	45.6%	7.6%	48.6%	10.0%	29.7%
H. Response Rate[g]	32.0%	38.7%	44.2%	42.0%	31.8%

[a] RDD = Random Digit Dial. Numbers were pre-screened to be working, non-business phone numbers. All phone number lists were purchased from a vendor, Marketing Systems Group (M-S-G), Genesys Division.

[b] Phone numbers listed to persons with Hispanic surnames

[c] Respondents were eligible for participation in all three stages if they were an adult resident of Davidson County, Tennessee. In stages 2 and 3, participants were additionally screened for race and ethnicity in order to identity eligibility for the oversampled groups.

[d] Phone numbers were classified as not eligible if the number was disconnected, the caller could confirm that the number was not associated with a housing unit (i.e. a business or institution), or if the caller could confirm that the number was associated with a housing unit where no adult residents of Davidson County resided. Cell phone numbers were considered ineligible if the answering respondent indicated that he or she also had a residential landline. Phone numbers were ineligible in stages 2 and 3 if the answering adult did not self-identify as Hispanic or African American.

[e] The eligibility of a phone number was classified as unknown if the caller could not confirm that a number was associated with a housing unit (as opposed to a business) or if the caller was unable to determine whether the respondent was eligible because the respondent did not complete screening procedures, including refusals, breakoffs, and hang-ups [AAPOR 2011].

[f] Eligibility rate is used to estimate the proportion of unknown eligibility cases that are actually eligible. We have calculated this value as: D/(B+D)

[g] Response rate is based on Response Rate 4 as defined by the American Association of Public Opinion Research [AAPOR 2011]. This definition assumes that a proportion of respondents whose eligibility could not be determined would have been eligible to participate (see Eligibility Rate). Response Rate 4 is calculated as: (E + F)/(D+G*C).

Table II

Sociodemographic Factors

	Nashville Community Health Survey[a] N(%)	All Nashville Residents[b] N(%)		Vanderbilt Faculty and Staff Survey N(%)	All Vanderbilt Employees[c] N(%)
Gender			**Gender**		
Male	263 (39.5)	302,173 (48.7)	Male	962 (23.9)	8,606 (33.8)
Female	402 (60.5)	313,031 (51.3)	Female	3069 (76.1)	16,844 (66.2)
Age[d]			**Age**[e]		
18–29yo	100 (15.4)	99,814 (21.1)	18–29yo	914 (22.7)	3,845 (15.1)
30–49yo	253 (38.9)	195,061 (41.2)	30–49yo	2080 (51.7)	13,379 (52.6)
50–65yo	144 (22.2)	110,741 (23.4)	50–65yo	993 (24.7)	7,363 (28.9)
>65yo	152 (23.4)	67,932 (14.3)	>65yo	38 (0.9)	860 (3.8)
Race			**Employee Classification**		
White	311 (46.8)	414,846 (66.9)	VUMC Faculty	354 (8.9)	2,672 (10.5)
African American	184 (27.7)	171,516 (27.7)	VUMC Staff	2761 (69.2)	16,726 (65.7)
Asian or PI	8 (1.2)	21,590 (3.5)	VU Faculty	181 (4.5)	1,482 (5.8)
American Indian	7 (1.1)	4363 (0.7)	VU Staff	695 (17.4)	4,570 (18.0)
Other	154 (23.2)	15,425 (2.5)[f]			
			Duration of Employment		
Ethnicity			Less than 5 years	2199 (55.0)	
Hispanic	182 (27.4)	46,618 (7.5)	More than 5 years	1802 (45.0)	
Not Hispanic	482 (72.6)	573,586 (92.5)			
Education					
Less than High School	126 (19.7)	63,053 (15.1)			
High School or GED	137 (21.4)	108,925 (26.2)			
Some College	125 (19.5)	82,976 (20.0)			
2-year degree	37 (5.8)	24,503 (5.9)			
4-year degree	143 (22.3)	87,817 (21.1)			
Graduate Degree	73 (11.4)	48,485 (11.7)			

	Nashville Community Health Survey[a] N(%)	All Nashville Residents[b] N(%)		Vanderbilt Faculty and Staff Survey N(%)	All Vanderbilt Employees[c] N(%)
Income[g]					
<$40,000	267 (40.8)	108,779 (43.1)			
$40–75,000	197 (30.1)	73,314 (29.1)			
$75–100,000	77 (11.8)	26,019 (10.3)			
>$ 100,000	66 (10.1)	44,214 (17.5)			
Refused/Missing	47 (7.2)				
Self-Reported Health					
Excellent	127 (18.8)				
Very Good	205 (30.3)				
Good	212 (31.3)				
Fair	95 (14.0)				
Poor	38 (5.6)				

[a] Data have been weighted by race and ethnicity, so values do not add up to 677.

[b] Source: U.S. Census Bureau, American Community Survey, 3-year running average from 2006–2008

[c] Source: Vanderbilt University Human Resources Employment Data

[d] American Community Survey provides data in age groups of 18–29yo, 30–49yo, 50–64yo, and ≥65. Differences in age categories therefore preclude direct comparison around age 65.

[e] Percentages do not total 100% because multiracial persons may be listed in more than category

[f] Survey income is reported as total household income in 2007. Population income is reported as total household income in inflation-adjusted 2008 dollars.

[g] Due to privacy concerns, respondents were asked to select the appropriate age range. Thus, statistics such as standard deviation are not reported.

TABLE III

Respondents' Perceptions about Protection of Information

Nashville Community Health Survey N(%)		**Vanderbilt Faculty and Staff Survey N (%)**	
How confident are you that research hospitals such as Vanderbilt Medical Center do a good job of protecting patients 'medical information?		*How confident are you that Vanderbilt Medical Center adequately protects patients' medical information?*	
Responses:	*639*	*Responses*	4,026
Somewhat or Very Confident:	603 (94.4)	Somewhat or Very Confident	3,713 (92.2)
Only a Little or Not at All Confident:	36 (5.6)	Not very or not at all confident	217 (5.4)
		Don't Know	96 (2.4)
How confident are you that your identity is protected when genetic information is used for research?			
Responses:	*614*		
Somewhat or Very Confident:	546 (88.8)		
Only a Little or Not at All Confident:	69 (11.2)		

Table IV

Cross-Tabulations Summarizing the Association Between Approval of the Opt-Out Biobanking Model with Sociodemographic and Background Characteristics

Nashville Community Health Survey			Vanderbilt Faculty and Staff		
	Strongly and Somewhat Agree N (%)	**Strongly and Somewhat Disagree N (%)**		**Strongly and Somewhat Agree N (%)**	**Strongly and Somewhat Disagree N (%)**
Gender			**Gender**		
Male	255 (97.3)	7 (2.7)	Male	901 (94.1)	66 (5.9)
Female	355 (92)	31 (8)	Female	2904 (94.8)	160 (5.2)
Age			**Age**		
18–29yo	98 (99)	1 (1.0)	18–29yo	865 (94.4)	52 (5.6)
30–49yo	228 (90.5)	24 (9.5)	30–49yo	1975 (94.9)	105 (5)
50–65yo	124 (91.2)	12 (8.8)	50–65yo	938 (94.4)	55 (5.5)
>65yo	143 (98.6)	2 (1.4)	>65yo	34 (89.5)	4 (10.5)
Race			**Employee Classification**		
White	291 (95.1)	15 (4.9)	VUMC Faculty	334 (94.9)	18 (5.1)
African American	155 (90.1)	17 (9.9)	VUMC Staff	2,615 (94.9)	141 (5.1)
Asian or PI	8 (100)	0	VU Faculty	167 (92.3)	14 (7.7)
American Indian	7 (100)	0	VU Staff	654 (94.1)	41 (5.9)
Other	147 (96.1)	6 (3.9)			
			Duration of Employment		
Ethnicity			Less than 5 years	2,077 (94.5)	119 (5.4)
Hispanic	175 (96.7)	6 (3.3)	More than 5 years	1,702 (94.6)	96 (5.3)
Not Hispanic	434 (93.1)	32 (6.9)			
			Received Medical Care at VUMC		
Education			Yes	2,781 (94.5)	164 (5.5)
Less than High School	107 (93.9)	7 (6.1)	No	1010 (95.4)	49 (4.6)
High School or GED	127 (94.8)	7 (5.2)			
Some College	109 (87.2)	16 (12.8)	**Prefer to Receive Care at VUMC**		
2-year degree	32 (86.5%)	5 (13.5)	Yes	3143 (95.4)	152 (4.6)

Nashville Community Health Survey			Vanderbilt Faculty and Staff		
	Strongly and Somewhat Agree N (%)	**Strongly and Somewhat Disagree N (%)**		**Strongly and Somewhat Agree N (%)**	**Strongly and Somewhat Disagree N (%)**
4-year degree	139 (98.6)	2 (1.4)	No	621 (91.2)	60 (8.8)
Postgraduate, no degree	17 (100)	0			
Master's Degree	48 (96)	2 (4.0)			
PhD, M.D. or other advanced degree	23 (100%)				
Income [a]					
<$40,000	231 (91.3)	22 (8.7)			
$40–75,000	187 (94.9)	10 (5.1)			
$75–100,000	75 (98.6)	1 (1.4)			
>$100,000	65 (98.5)	1 (1.5)			

[a] Survey income is reported as total household income in 2007

Table V

Respondents' Views on Biobank Models

Nashville Community Health Survey N(%)		**Vanderbilt Faculty and Staff Survey N (%)**	
DNA biobank research is fine as long as people can choose not to have their DNA included.		*DNA databanks with all identifying information removed are fine as long as people can choose to opt out of having their DNA included.*	
Responses	*629*	*Responses*	*4033*
Somewhat or Strongly Agree	590 (93.9)	Strongly or Somewhat Agree	3816 (94.6)
Somewhat or Strongly Disagree	38 (6.1)	Somewhat or Strongly Disagree	217 (5.4)
You are comfortable with your DNA being used for research as long as personal information that can identify you is not included		*DNA databanks are fine as long as all identifying information is removed.*	
Responses	*639*	*Responses*	*4037*
Somewhat or Strongly Agree	557 (87.3)	Strongly or Somewhat Agree	3766 (93.3)
Somewhat or Strongly Disagree	81 (12.7)	Somewhat or Strongly Disagree	271 (6.7)
If all personal information is removed, researchers should be able to use leftover blood for research that has been approved by an ethics review board.		*DNA databanks with all identifying information removed are fine as long as an ethics review panel approved research with DNA in the databank*	
Responses	*630*	*Responses*	*4020*
Somewhat or Strongly Agree	557 (88.5)	Strongly or Somewhat Agree	3682 (91.6)
Somewhat or Strongly Disagree	73 (11.5)	Somewhat or Strongly Disagree	338 (8.4)
Researchers should be allowed to use de-identified genetic information without getting written permission from patients.		*DNA databanks with all identifying information removed are fine as long as written permission from patients is required for their DNA to be included.*	
Responses	*639*	*Responses*	*4017*
Somewhat or Strongly Agree	291 (45.5)	Strongly or Somewhat Agree	3573 (88.9)
Somewhat or Strongly Disagree	348 (54.5)	Somewhat or Strongly Disagree	444 (11.1)