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Moral Concerns and the Willingness to Donate to a Research Biobank

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Research biobanks are increasing in number and importance, with great potential for advancing knowledge of human health, disease, and treatment.[1] Recruitment of donors is vital to their success and relies largely on blanket consent, in which donors give one-time permission for any future research uses of their coded specimen. This approach to consent has been endorsed recently in proposed changes to federal regulations.[2]

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Previous studies suggest that donors may have moral, religious, and cultural concerns about the use to which their specimens are put, which may affect their willingness to give blanket consent.[3,4] These earlier studies, however, used convenience samples unrepresentative of the US population.

Methods

The institutional review boards at the University of Michigan and Michigan State University approved this study as exempt. Between June 18, 2014, and June 30, 2014, we used the GfK KnowledgePanel (a probability-based online panel of adults aged 18 years or older, designed to represent the civilian, noninstitutionalized US population) to field a survey examining associations between moral concerns and the willingness to donate to a biobank.

Respondents read an introductory description of a fictional biobank and then used a 6-point scale—from strongly agree to strongly disagree—to indicate their willingness to donate, first using blanket consent and then "even if" their samples might be used in each of 7 potential research scenarios presenting moral concerns. We then gave respondents short descriptions of the benefits and consequences of 5 methods of gaining consent and asked them to indicate which were the acceptable, best, and worst options.

All analyses were weighted to correct for the stratified sampling designs and other sources of survey errors including nonresponse and noncoverage. We used conditional logistic regression to compare willingness to consent with blanket consent vs other scenarios. Analyses were done using Stata version 13.1 (StataCorp); all tests were 2-sided, with a threshold of $P = .05$.

Results

After excluding 39 surveys with nonresponses to at least half of the substantive survey questions, our final analysis included 1599 participants, resulting in a response rate of 60.2% (1599 of 2654 participants). Respondents were older (51 years vs 45 years for nonrespondents), were more commonly white (82% vs 75%), and had higher levels of education and household income (eTable in the Supplement). Using blanket consent, 68.0% (95% CI, 65.5%–70.5%) were willing to donate. In all but 1 scenario, moral concerns were associated with a significant reduction in willingness to donate (Table 1).

When asked about different approaches to gaining consent, 43.6% (95% CI, 41.1%–46.0%) of respondents found the blanket consent method to be unacceptable, and 37.8% (95% CI, 35.3%–40.4%) said blanket consent was the worst among 5 policy options. Specific consent, in which donors are asked to consent to each study using their specimen, was considered the worst option by 45.0% (95% CI, 42.4%–47.6%) (Table 2).

Discussion

As shown in previous studies,[5] this survey documented that members of the general population are willing to donate to biobank research. Most respondents were willing to donate using a blanket consent. However, willingness to donate waned when they were

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informed of possible uses of their specimens that raised moral concerns. As recruitment of donors becomes more widespread, such concerns may need to be addressed to moderate possible effects on donation rates.

Respondents' preferences toward biobank consent options are also noteworthy. Specific consent, the option that gives donors the most control over potentially concerning uses, was the least preferred option. But blanket consent, the option currently in widespread use, was not far behind. This suggests that an adequate approach for dealing with donors' moral concerns may lie between these 2 extremes.

Limitations include a response rate of 60%, with respondents and nonrespondents differing on some characteristics that may introduce bias. Because respondents may be more in favor of research, the association between moral concerns and decreased willingness to donate may be a conservative estimate. Also, respondents' views were based on brief scenarios rather than on detailed understanding of the issues. Deliberative engagement with citizens may deepen understanding of public opinion regarding biobank policy.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Willingness to Give Blanket Consent at Baseline and for 7 Potential Research Scenarios Raising Moral Concerns

Blanket Consent	Total[a]	Agreed[b]	% (95% CI)[c]	*P* Value[d]
At baseline: "I would donate tissue samples and medical information to the biobank, so that it can use them for any research study that it allows, without further consent from me."	1593	1122	68.0 (65.5–70.5)	
Under research scenario: "I would donate tissue samples and medical information to the biobank, so that the biobank can use them for any research study that it allows, without further consent from me even if researchers might use donations to…"[e]				
…develop more safe and effective abortion methods.	1588	790	49.5 (46.9–52.1)	<.001
…develop kidney stem cells. They would then try to grow these cells in a pig embryo that would grow into an adult pig with human kidneys. The goal would be to grow kidneys or other organs that could be transplanted into people.	1592	1066	64.2 (61.6–66.8)	.007
…develop patents and earn profits for commercial companies. Most new drugs used to treat or prevent disease come from commercial companies.	1591	912	55.2 (52.6–57.8)	<.001
…develop stem cells that have the donor's genetic code. These could be kept alive for many years. Scientists might use those stem cells to create many different kinds of tissues and organs for use in medical research.	1591	1151	70.1 (67.6–72.6)	.17
…create vaccines against new biological weapons. The government might need to develop biological weapons of its own when it does this research.	1590	918	56.6 (53.9–59.2)	<.001
…understand the evolution of different ethnic groups, and where they come from. What they learn might conflict with some religious or cultural beliefs.	1591	1042	64.0 (61.5–66.6)	.005
…discover genes that make some people more violent. This could lead to ways to reduce violent behavior. But if these genes are found to be more common among some racial and ethnic groups, this might increase prejudice.	1591	946	58.1 (55.5–60.7)	<.001

[a] Excluded those who refused to respond to each question.

[b] Selected 4, 5, or 6 on a 6-point scale (1 = strongly disagree and 6 = strongly agree).

[c] Percentages accounted for poststratification weights.

[d] From comparisons between willingness to consent under each scenario vs willingness to first give blanket consent, using conditional logistic regression with survey weights. Each conditional logistic regression model used paired binary willingness responses (under each scenario and under blanket consent) from each participant as the dependent variable, and the *P* value was from testing for the significance of the parameter estimate of the indicator for the scenario (vs blanket consent).

[e] Descriptions of scenarios as presented to respondents.

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Table 2

Public Opinions on 5 Different Biobank Consent Options

Consent Options	Description[a]	Respondents, % (95% CI)[b]		
		Acceptable Option (n=1587)[c]	Best Option (n=1555)	Worst Option (n=1548)
Blanket	This means that donors have control over whether to donate but not over how the samples are used in any future research. It gives the biobank and researchers a lot of freedom in deciding how to use samples.	56.4 (53.8–59.0)	21.1 (19.1–23.4)	37.8 (35.3–40.4)
Blanket combined with a caution	Donors are alerted in advance with the following statement: “Some people may have moral, religious, or cultural concerns about some kinds of research.” Donors can then decide whether they are still willing to donate. Some donors may decide not to donate, resulting in fewer samples for research.	71.9 (69.5–74.4)	19.7 (17.7–21.9)	4.2 (3.1–5.5)
Blanket combined with an option to withdraw	Donors first give their blanket consent. The biobank then gives them easy access to information about current research projects being done with donated samples. If donors see research projects that worry them, they can decide to withdraw their tissues. If too many people withdraw their donation, researchers may have trouble finding enough samples to do their research.	70.8 (68.4–73.3)	25.5 (23.2–27.8)	6.2 (5.0–7.8)
Blanket combined with limits	Donors are given a short list of types of research projects that might worry some people. The donors then decide which types of research can’t use their donation. Research not on the list would still be covered by a blanket consent. This system may cost more, leaving less money for research.	65.1 (62.5–67.6)	14.3 (12.6–16.2)	6.8 (5.5–8.3)
Real-time specific for each use of the donated samples	Donors don’t give blanket consent. Instead, the biobank contacts them and asks for their consent for each specific project. Donors are given maximum control, but some might get tired of being contacted repeatedly. The cost of recontacting every donor for consent will be high. If too many people refuse to give their consent, many research studies will not be possible.	57.0 (54.3–59.6)	19.4 (17.3–21.6)	45.0 (42.4–47.6)

[a] Description as presented to respondents.

[b] Percentages were calculated after those who refused to respond to each question were excluded and accounted for poststratification weights.

[c] Respondents could select more than 1 option as acceptable.