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Impact of Non-Welfare Interests on Willingness to Donate to Biobanks: An Experimental Survey

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Abstract

The ethical debate surrounding biobanks has focused on protecting donors' welfare and privacy. However, little attention has been given to the ethical significance of donor interests that go beyond privacy and welfare (non-welfare interests [NWIs]), such as their concerns about the moral or religious implications of researchers using their donated samples. Using an experimental survey design with 1,276 participants recruited via Amazon Mechanical Turk (MTurk), we studied the potential impact of eight NWI scenarios on people's attitudes toward research studies being performed on samples donated to biobanks by assessing willingness to donate, attitudes toward disclosure of NWIs, impact of timing and format of disclosure (number of NWIs disclosed on a page), and participant factors associated with willingness to donate. Baseline willingness to donate to biobanks prior to any mention of NWIs was comparable with previous studies, at 85% to 89%. Most participants wanted NWI disclosures prior to donation to biobanks, but far fewer favored specific consent. Overall pattern of responses showed that as participants receive more information about NWIs, willingness to donate decreases in a scenario dependent manner. Specifically, NWI concerns about profit seeking research and insurance risk assessment had the strongest impact, even greater than controversial issues such as reproductive research, regardless of political, religious, and most other characteristics of respondents. Based on the results, a schema of NWI types is proposed that could be used for further research and policy discussions.

Keywords

informed consent; non-welfare interests; blanket consent; public attitudes; biobank donation

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Authors' Note

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By linking biospecimens and related health data, biobanks enable researchers to study the multifactorial nature of disease. It is hoped that this will ultimately lead to improved health care outcomes (Watson et al., 2009). However, complex ethical, legal, and social issues accompany the scientific promise of biobanks and most of the ethical concerns have primarily focused on the risk of harm related to the privacy interests of donors (Cambon-Thomsen, 2004; Greely, 2007; Hansson, 2009; Wolf et al., 2012). Risk of physical harm in donating to biobanks is low. And although absolute protection of privacy may not be possible, steps can be taken to provide a high degree of privacy. Because of this, the majority of the policy recommendations have focused on blanket consent or obtaining generic consent when biosamples are first donated (National Bioethics Advisory Commission, 1999). Yet little discussion has been devoted to consent issues surrounding *future* uses of biobanked samples. Some suggest that the blanket consent acquired at the initial time of donation is sufficient for all possible future studies (Wendler, 2006b) or that additional consent should be collected by investigators whenever possible (Wolf et al., 2012).

Individuals willing to donate to biobank that allow research studies to be performed on banked tissues might not only be concerned with risks to their welfare and privacy but also have an interest in the *types* of research in which their samples are to be used. These are “non-welfare interests” (NWIs; Tomlinson, 2013) and are often thought of as moral objections (e.g., research affecting philosophical, religious, or cultural values), group-identity violations (e.g., research related to racial or ethnic distribution of traits that reinforce stereotypes about groups), or the concern over the distribution of benefits beyond one’s own personal interests (e.g., commercial exploitation of a public resource; Buchanan, 2000; National Bioethics Advisory Commission, 1999; Tomlinson, 2009). Because previous reports on willingness to provide blanket consent for archived biosamples were obtained without any disclosures about NWI issues (Wendler, 2006a; Wendler & Emanuel, 2002), they do not provide guidance on the potential impact of NWIs.

We currently lack systematic data about the impact of NWIs on potential donors, and thus lack important information about whether and how to develop policy for addressing NWIs in biobank donation. To begin to characterize the potential impact of NWIs on potential donors, we conducted an experimental survey using a convenience sample obtained through Amazon Mechanical Turk (MTurk; Buhrmester, Kwang, & Gosling, 2011). We examined the comparative effects of eight different NWI scenarios on potential donors’ attitudes, including whether they feel they should be told of NWIs and whether they would donate samples given the NWI information. We also tested whether the mode of disclosure of NWI scenarios (presenting a single NWI scenario vs. multiple NWI scenarios) and the timing of NWI disclosure (i.e., impact of soliciting a donation and being informed after the fact that there are NWI implications) affect participant willingness to donate. Finally, we examined potential participant characteristics (e.g., role of being in a minority group, religious and political orientation, etc.) associated with participant willingness to donate to biobanks.

Method

Participant Recruitment

We recruited a sample of Internet users from MTurk volunteers which consists of more than 500,000 U.S. adults aged 18 years and older (Buhrmester et al., 2011). MTurk uses a method referred to as “crowdsourcing,” in which survey participants or “workers” complete online jobs (Human Intelligence Tasks [HITs]) posted by “requesters” (e.g., companies or researchers). After a worker completes a HIT, the requester instructs Amazon.com to credit the worker’s account. Amazon.com handles all transactions so that workers remain effectively anonymous to the requesters. The institutional review board of the University of Michigan reviewed this study and deemed it exempt from U.S. federal regulations.

Study Design

To test the effect of various NWI scenarios on biobank donation, we used a randomized design, assigning respondents to 1 of 12 arms.

Arms 1 to 8 consisted of eight different NWI scenarios selected from a survey of the literature. The eight NWI scenarios included the following: (a) Abortion (research to make abortion more safe and effective), (b) Mixed With Non-Human Cells (research involving the mixture of human and animal tissues; National Research Council, 2005), (c) For-Profit Research (research resulting in the commercialization and corporate profits from biobank resources; Goodson & Vernon, 2004; Schiller et al., 1992), (d) Stem Cell Research (the development of immortal induced stem cells; Pfeffer, 2008; Selgelid, 2009), (e) Bioweapon Development (development of biological weapons to develop defenses; Haddow, Laurie, Cunningham-Burley, & Hunter, 2007; National Research Council, 2011), (f) Evolutionary Origins of Humans (research into evolutionary origins of ethnic and racial groups; Mello & Wolf, 2010), (g) Insurance Risk Assessment (development of diagnostic tests that could be used by insurance companies for differential premium charges; Bombard et al., 2012), and (h) Race-Based Traits (research into the genetic basis for ethnic and racial differences of human traits; Greely, 2007; Mello & Wolf, 2010; Schwartz, Rothenberg, Joseph, Benkendorf, & Lerman, 2001). Arm 9 combined four scenarios (Abortion, Bioweapon Development, Evolutionary Origins, and Race-Based Traits). Arms 10, 11, and 12 consisted of the Abortion, Evolutionary Origins, and four combined scenarios, respectively, except that we obtained a pre-scenario willingness to donate response, as explained below (see the online appendix for the survey).

Survey Procedures

The participants were randomly assigned to 1 of 12 arms (Figure 1). All participants first received a brief introduction to biobanks and the process of biobank donation. This included information on privacy protection through sample de-identification, the general consent process, and what it means to provide blanket consent (the survey is available at <http://bit.ly/IntQ6oe> and at jre.sagepub.com/supplemental).

Individuals randomized to experimental Arms 10, 11, and 12 were first asked whether they would give blanket consent (“Would you be willing to donate your de-identified tissue

samples and medical records to a biobank to be used for any type of future research?”) *prior* to the introduction of the NWI scenarios (these arms are thus labeled with a “P” appended to their scenario label to indicate this, for example, Abortion-P in Tables 2, 3, and 5).

Next, participants in all arms were given their respective NWI scenarios. For example, the Abortion NWI scenario read, “Researchers may use your tissues to develop safer and effective abortion methods” (refer to the online appendix for other NWI scenario texts). Participants were then told, “The above type of research is one of the possible types of studies that could be conducted using biobank samples you donate. Keeping this possibility in mind, consider the following questions.” They were then asked, “Would you be willing to donate your de-identified tissue samples and medical records to a biobank to be used for any type of future research?” Responses were made on a 4-point scale: 1 (*definitely not*) to 4 (*definitely yes*). Those individuals randomized to Arms 10 to 12 (who had already answered a willingness to give blanket consent *prior* to being given their scenario) were again asked about their willingness to donate to biobanks, after seeing their NWI scenario. The question read, “Considering this new information, would you be willing to donate your de-identified tissue samples and medical records to a biobank to be used for any type of future research?”

All participants (Arms 1–12) were then asked a series of questions to assess their preferences for disclosure and reactions to being told about the various NWI scenarios after giving consent (refer to the online appendix for all survey questions).

We again presented the eight different NWI scenarios, but this time all eight scenarios were presented together on a single page (soliciting a response for each NWI scenario) to all participants (Arms 1–12). We asked them to “Please indicate if you would give blanket consent to biobank research, if you knew that the following research studies might use your tissue samples” for each of the eight NWI scenarios. Responses were again made on a 4-point scale ranging from 1 (*definitely not*) to 4 (*definitely yes*).

Finally, participants were given the Research Attitudes Questionnaire (RAQ; Rubright, Cary, Karlawish, & Kim, 2011) to assess their general attitudes toward biomedical research. The RAQ uses 11 items with response options on a 5-point scale ranging from 1 (*strongly agree*) to 5 (*strongly disagree*), with a total score range of 0 to 55. All participants were asked a series of general socio-demographic questions (age, gender, education, household income) as well as key participant characteristics that might be associated with NWIs (religion, political views, race, and ethnicity). We also invited written comments regarding any other specific NWIs.

Analyses

We tabulated the proportion of participants willing to donate for each NWI scenario and evaluated whether certain NWI scenarios were of more concern than others and to avoid excessive multiple comparisons, we performed pairwise comparisons of specific NWI scenarios using chi-square tests. We also summarized participant’s preferences for disclosure and reactions to being told about the various NWI scenarios after giving consent (i.e., percentage of participants who responded “yes” if answered *definitely yes* or *probably yes*; “no” if answered *definitely not* or *probably not*).

We analyzed the effect of disclosing a single NWI versus multiple NWIs on willingness to donate in two different ways. Using a within-subjects approach, we examined the change in an individual's willingness to donate (dichotomized as "yes" if respondent answered *definitely yes* or *probably yes*; "no" if respondent answered *definitely not* or *probably not*) given a single NWI scenario (Arms 1–8) compared with their response for the same NWI presented jointly (i.e., with the other NWIs on the same page) using McNemar's test (with continuity correction). Using a between-subjects approach, to take into account the different sample sizes within each scenarios respondent group, we compared the weighted mean difference in the single NWIs (Arm 1—Abortion; Arm 5—Bioweapon Development; Arm 6—Evolutionary Origins of Humans; Arm 8—Race-Based Traits) to group responses on the same NWI scenario in the four scenario presentation (Arm 9—Abortion, Bioweapon Development, Evolutionary Origins of Humans, and Race-Based Traits) using a weighted *t* test.

To address the impact of timing of NWI disclosure (i.e., comparing responses before and after disclosing NWIs using experimental Arms 10, 11, and 12), we used a within-subjects analysis to assess whether there was a difference in the paired proportion of participants willing to donate (dichotomized as previously described) using McNemar's test.

To assess whether certain participant characteristics are associated with their willingness to donate to a biobank, we performed a series of logistic regression analyses with each of the eight NWI scenarios with the participants' "willingness to donate" response for each NWI scenario (dichotomized into "yes" or "no" as previously described for ease of interpretation) as the dependent variable. Each model included the following independent variables: age (<20 years old, 20–30, 30–40, 40–50, >50), gender, race, education (HS, BA, >BA), household income, political orientation (conservative, moderate, liberal), religiosity (if respondent selected Protestant, Roman Catholic, Mormon, Orthodox, Jewish, Muslim, Buddhist, Hindu, or Something else, then their response was coded as "yes"; if respondent selected: Atheist, Agnostic, Nothing in particular or Don't know, then their response was coded as "no"), evangelical affiliation, and trust in medical research (total RAQ score).

All analyses were computed with the R v2.15.0 statistical programming language.

Results

Participant Characteristics

A total of 1,276 people completed the survey. The average age of participants was 31.9 years old (*SD* = 12.4), 46.3% were female, and the majority reporting being White (80.4%; Table 1).

Nearly half (49%) identified themselves as atheist, agnostic, or nothing in particular in terms of religious beliefs; 49% had a BA or higher and 17% of the participants self-identified as politically conservative or very politically conservative.

Participant willingness to donate and preferences for disclosure—In general, even with specific NWI disclosures, participants are willing to donate to biobanks (*mean*

percent willing across all NWI scenarios 77.7%). The highest willingness rates were found for the Race-Based Traits (83.5%), Abortion (82.4%), and the development of immortalized Stem Cells scenario (81.3%). The lowest willingness rates were for the Bioweapon Development scenario (67.9%), Insurance Risk Assessment scenario (71.3%), and For-Profit scenario (75.9%). The Bioweapon Development, Insurance Risk Assessment, and For-Profit scenarios elicited lower willingness to donate rates than controversial topics such as abortion (82.4%): $\chi^2(3, n = 208) = 16.43, p < .01$; $\chi^2(3, n = 210) = 20.35, p < .01$; and $\chi^2(3, n = 206) = 29.62, p < .01$, respectively. Compared with the NWIs with the lowest rates for willingness to donate, the NWIs with highest willingness rates were associated with a decreased desire for a disclosure law, lack of wanting to know before donating, and the opinion that there need not be a requirement of specific consent. In the Abortion scenario, for example, 82.4% of participants were willing to donate, 66.7% thought there should be a law requiring disclosure of this NWI, 71.6% wanted to know the NWI before donating, and only 37.3% thought this NWI required specific consent. In the For-Profit scenario, 82.7% thought there should be a law requiring disclosure of this NWI, and 87.5% wanted to know about this NWI before donating. For the Insurance Risk Assessment scenario, 50.9% of respondents thought specific consent should be required (Table 2).

Most respondents wanted to be told about potential NWIs before donating (*weighted average across all NWI scenarios* = 78.2%) and a slightly smaller proportion (*weighted average across all NWI scenarios* = 72.0%) wanted disclosure even if there were only a very small chance that this type of research will be performed. Most also answered yes to the question “Should there be a law that requires biobanks to inform people about this type of possible future research?” referring to the NWI disclosed (*weighted average across all NWI scenarios* = 72.5%). However, far fewer participants felt specific consent was necessary if such a procedure would inhibit research progress (*weighted average across all NWI scenarios* = 40.8%).

In assessing the respondents’ potential reactions to finding out that their tissues had been used in NWI relevant research after donating without having been told, their self-report of possible emotional reactions to the news generally tracked their willingness to donate responses. However, for the Bioweapon Development and the Insurance Risk Assessment scenarios, the negative emotional reactions and the desire to withdraw samples were markedly higher than for other scenarios. Furthermore, when people said they would be displeased to learn that research was being done using their tissues for these two NWI scenarios, they said they would also be more angry and would be more likely to withdraw permission. For the Bioweapon Development scenario, 40.6% would be displeased, 30.2% would be angry, and 30.2% would withdraw their permission. For Insurance Risk Assessment, 46.7% would be displeased to hear that such research was being conducted using their tissue, 39.8% would be angry, and 32.4% would withdraw their permission (Table 3).

Impact of Disclosing Additional NWI Scenarios on a Single Page

Disclosing seven scenarios, in addition to the initial single scenario (i.e., all eight NWI scenarios together on a single page), had an effect that depended on the scenario. For three

scenarios (Mixed Cells, Stem Cells, Evolutionary Origins scenarios), there was no significant decrease in willingness to donate. For the Abortion, Race-Based Traits, and Bioweapon Development scenarios, the decrease in willingness ranged from 10% to 14%. However, the decrease in willingness was much more substantial in two scenarios, with 30% decrease for the For-Profit scenario and 29% decrease for the Insurance Risk Assessment scenario (Table 4).

When we examined effect of disclosing four NWI scenarios (refer to Table 2, column 1, comparing Arm 9 vs. average of Arms 1, 5, 6, 8) at once (but compared *between-subjects* rather than within-subjects as in the eight scenarios disclosure above), we found that participants who were given four scenarios together (Arm 9 which included Abortion, Bioweapon Development, Evolutionary Origins of Humans, Race-Based Traits scenarios; $M = 3.21$, $SD = 0.92$) were *more* willing to donate ($t = 3.35$, $p = .05$) than weighted average willingness of those given each of those scenarios separately ($M = 2.99$, $SD = 0.86$).

Effect of Timing of NWI Disclosure

Table 5 shows the change in willingness to donate from *before* being given a NWI scenario to *after* seeing a NWI scenario.

For Abortion (Arm 10) and the four NWI scenarios grouping (Arm 12—Abortion, Bioweapon Development, Evolutionary Origins of Humans, and Race-Based Traits), the paired difference in proportion of those willing to donate was significantly lower when given the scenario after consenting, $\chi^2(1, n = 106) = 6.86$, $p < .01$ and $\chi^2(1, n = 107) = 13.47$, $p < .01$, respectively. There was no change in willingness to donate for the Evolutionary Origins of Humans (Arm 11) scenario.

Participant Characteristics Associated With Willingness to Donate to Biobanks

The willingness to donate for the Insurance Risk Assessment and For-Profit Research scenarios were generally not associated with participant characteristics such as religion, political orientation, or education. The only associations for the For-Profit scenario was that White respondents were more willing to donate compared with Black respondents (odds ratio [OR] = 1.76, 98% confidence interval (CI) = [1.06, 2.92]), and for the Insurance Risk Assessment scenario, there was an effect of age only for the oldest age group compared with the youngest (OR = 0.49, 98% CI = [0.33, 0.89]; Table 6).

The only participant characteristics that predicted willingness to donate for the Bioweapon Development NWI scenario was political orientation, with moderates and liberals *less* willing than conservatives to donate (OR = 0.67, 98% CI = [0.46, 0.99]; OR = 0.58, 98% CI = [0.39, 0.86]).

The willingness to donate to the remaining scenarios had several associated participant characteristics. For Mixed With Non-Human Cells and Stem Cell research, White participant were more willing (compared with Black participant) to donate (OR = 2.07, 98% CI = [1.22, 3.52]; OR = 2.12, 98% CI = [1.22, 3.70]), women were less willing to donate than men (OR = 0.73, 98% CI = [0.55, 0.97]; OR = 0.60, 98% CI = [0.43, 0.86]), and those in a religious

group were less willing to donate (OR = 0.72, 98% CI = [0.53, 0.98]; OR = 0.69, 98% CI = [0.47, 1.00]).

In the NWI scenarios concerning Abortion and Evolutionary Origins of Humans, religious individuals as well as self-reported evangelical Christians were less willing to donate. Having a moderate or liberal political orientation was associated with greater willingness to donate in the Abortion scenario (OR = 2.50, 98% CI = [1.61, 3.75]; OR = 6.20, 98% CI = [4.06, 9.48]) and women were less willing to donate to research studies where evolutionary origins were being investigated (OR = 0.63, 98% CI = [0.42, 0.96]).

Notably, the only NWI scenario with consistent race effects was the Race-Based Traits scenario. Both being White and “Other” racial affiliation were associated with an increased willingness to donate compared with being Black (OR = 1.62, 98% CI = [1.01, 2.68]; OR = 1.93, 98% CI = [1.02, 3.67]). Being liberal or moderate, more educated, and older than 50 were associated with lower willingness to donate.

In all eight NWI scenarios, an increase in total RAQ score was significantly associated with willingness to donate.

Discussion

NWIs have complex religious, philosophical, political, and socio-demographic dimensions that pose a unique potential to affect public trust in medical research. Yet there is a paucity of data on the potential impact of NWIs on the public’s willingness to donate to biobanks, their preferences for disclosure of NWI issues, and the factors that are associated with their preferences regarding NWIs. Our sample was not a representative sample of the U.S. public, and the generalizability of our findings are limited. However, as an early exploration of the topic using an experimental method (to increase the internal validity of our findings), the results reveal important patterns showing that NWIs could have significant impact on potential donors to biobanks.

Preferences for NWI Disclosure and Willingness to Donate

Although ours was not a population sample, the overall willingness to donate to biobanks among our participants when no NWI information is disclosed (Arms 10–12) was approximately 85% to 89%. This is consistent with previous findings on donation for future research when NWIs are not mentioned (Wendler, 2006b). Even after disclosure of NWIs, the average willingness to donate was 78%, reflecting a very positive view of their donated samples being used for research studies. However, we also found that participants generally want disclosure of NWIs, even if only a minority would want specific consent. This pattern of response in which trust in the system is combined with desire to be informed is seen in other spheres as well, as when patients trust their doctor’s decisions but still want to be informed and be part of the discussion (Jenkins, Fallowfield, & Saul, 2001; Quill & Brody, 1996; Wright, Holcombe, & Salmon, 2004).

NWI Scenario Dependent Effect of Timing and Format of Disclosure

The synthesis of the results from the format and timing experiments provide an intriguing set of hypotheses that could inform policy making. In general, our findings can be summarized as follows: As the respondents are given more information about potential NWIs, their willingness to donate tends to decrease but that decrease is highly dependent on the nature of the NWI scenario. The number of scenarios presented in itself does not seem to matter: When participants are compared between-subjects (i.e., randomized to different arms), the number of scenarios do not matter. What seems to matter is the change over time in the participant's awareness of the implications of NWIs, that is, perhaps there is more to the issue than one had initially realized. Thus, participants' willingness to donate after being given a single or multiple NWI scenarios is lower than their willingness prior to seeing any NWI scenarios (but in a scenario dependent manner, that is, participants were significantly less willing to donate after seeing the Abortion scenario, but not after seeing the Evolutionary Origins of Humans scenario). And those shown a single scenario are less willing to donate after seeing additional seven scenarios presented on a single page (again, depending on the scenario). Thus, it appears that being told more and more information about potential NWIs tends to decrease willingness—but only for certain scenarios.

The pattern of the interaction between increasing the number of NWI scenarios and the nature of scenarios suggests the following potential explanation for this effect, by categorizing the eight scenarios into three groups. First, the magnitude of the impact of the For-Profit and Insurance Risk Assessment scenarios was quite large. These two scenarios have the common theme of distributive justice; it may be that people object to what they see as private gain from what should be a publicly shared resource. Unlike the polarizing topics that receive much more media attention, this concern over fairness is shared much more widely (cutting across ideological and religious lines according to our multivariate analysis) leading to a large effect.

The remaining set of six scenarios can be grouped into two types of NWIs. First, although the Mixed Cell, Stem Cell, and Evolutionary Origins scenarios may be controversial for people with opposing philosophical views, those scenarios share the characteristic of being “expectedly” scientific, in the sense that laypeople may be familiar with these types of studies as “what scientists do.” The concern that some people have about these studies is more along the lines of “should *science* go there?” rather than about an existing social policy controversy or dispute. But the other three scenarios (Abortion, Race-Based Traits, Bioweapon Development) are about the social *uses and implications of science* and thus may create more reservations in a wider group of people. We emphasize, however, that our interpretation is highly speculative and other interpretations may be possible. For example, the Evolutionary Origins scenario may be experienced by some as an application to a social policy issue more than a “what scientists do” scenario.

These results reinforce the dilemma for policy making. If the potential donors are not informed about NWIs, or only cursorily informed, then there may be high donation rates and cooperation. As long as the relatively superficial interaction is maintained, there may not be any controversy. However, as the public becomes more and more aware of the potential NWI

implications of biobank donation, there is a tremendous potential for loss of trust in the system.

Participant Characteristics Affecting Donation for Specific NWI Scenarios

For each NWI scenario, we examined participant characteristics that were significantly associated with their willingness to donate. The results have some important potential implications. First, for the two scenarios that engendered the greatest amount of concern from our respondents—the Insurance Risk Assessment and For-Profit NWI—participants’ characteristics were generally not associated with their willingness to donate, suggesting a concern that cuts across ideological, religious, and other socio-demographic lines. Such a nonpartisan and widely shared concern will likely need special attention in policy making.

Second, the only NWI that was consistently associated with the race variable (i.e., significant effect for all race comparisons) was the Race-Based Traits scenario. Participants, who self-identified as Black, even after controlling for other factors were less willing to donate when that scenario was given compared with Whites and to Other races. This suggests that if policy development relies only on the majority group’s views, it will not be sensitive enough to accommodate the concerns of minority groups who have historically been victims of abuse in research and are specially sensitized to issues that the majority may not see.

Third, for some NWI scenarios, the associations were not surprising. Identification with a religious group, evangelical Christian affiliation, and being politically conservative were all predictors of being less willing to donate to biobanks for the Abortion scenario (as well as with Mixed With Non-Human Cells, Stem Cells, and Evolutionary Origins of Humans; Kitzinger & Williams, 2005; Polak & Bishop, 2006). But there were also associations that we cannot explain. For example, women were less willing to donate to the NWI scenarios of Mixed With Non-Human Cells, Stem Cells, and Evolutionary Origins of Humans.

Limitations

There are significant limitations to our study and it is important to recognize them to put the results in perspective. First, our sample was based on volunteers to our experimental survey rather than a random sample, limiting generalizability. However, we note that the overall baseline attitudes toward biobanks were quite similar to those in other studies. Also, our use of a randomized design supports internal validity for relative effects of NWI scenarios, which was our main concern in this experimental study. Second, our disclosures were single sentence descriptions of NWIs and do not comprise a “fully informed” elicitation of responses. Given that the role of NWIs in biobank donation is not a widely discussed topic, other methods of disclosure could have different effects. Finally, because our goal was to test potentially controversial uses of stored biobank samples, rather than to explore public’s views on the most common uses of such samples, our scenarios were not designed to reflect actual or even likely uses of stored sample.

Most discussions of the ethics of biobanks assume that because there is relatively little welfare risk, the main issue is one of privacy. However, long-term use of biobanked materials for scientific study may involve uses that were unanticipated and yet are important

to the donors (Tomlinson, 2009, 2013). Despite its limitations, because there is a paucity of data to inform the potential impact of such NWIs on willingness to donate, our study provides early indications that this is a participant that needs more attention.

Best Practices

Given that our study is an initial exploration of the potential impact of NWIs on biobank donation, it would be premature to make any firm recommendations on policy or practice. However, it may not be premature for institutional review boards (IRBs) and investigators to begin to discuss how these findings might relate to the informed consent process in biobank donation. This might build on the approach to informed consent already suggested for collecting induced pluripotent stem (iPS) cells in which future researchers could potentially carry out a wide range of experiments on donated sample (Aalto-Setälä, Conklin, & Lo, 2009; Cambon-Thomsen, Rial-Sebbag, & Knoppers, 2007).

Research Agenda

This study provides some preliminary, yet important empirical data to support the idea that the NWI implications of research on biobanked samples may have increasingly important effects on people's decision to contribute to bio-banks. However, several significant normative and policy questions remain unanswered.

First, more theoretical analysis of the typology of NWIs proposed in this study is needed. It may be that the pattern of responses shown by our respondents tap into an intuitive typology that might prove useful in policy discussions. Second, a deeper understanding of the scope and potential impact of specific NWIs is needed. For example, follow-up is needed on our findings that suggest disclosure of certain NWIs pertaining to issues of trust and fairness (i.e., commercial profits and insurance risk assessment) are of more concern to donors than other historically controversial issues (e.g., reproductive research). One way this could be accomplished is through engaging the public in a democratic deliberation to ascertain their preferences (Kim et al., 2011; Kim et al., 2010; Kim, Wall, Stanczyk, & De Vries, 2009) regarding policy options to determine how to best address the NWIs of biobank donors. Finally, a more representative national survey to assess public attitudes and preferences about NWIs is needed.

Educational Implications

The concept of NWIs is still not a widely discussed topic, but our results show that it could have a strong impact on people's decisions as they become more and more aware of the NWI implications of biobanks. It would seem then that educational opportunities should focus on raising awareness of potential donors' NWIs and its impact on decisions to donate. Raising such awareness among the public, researchers, and human participant protections professionals will promote much-needed discussion to better characterize the likely impact of NWIs on contributions to biobank and the use of donated samples in research studies. Such discussion will help enable the development of transparent yet effective measures to prevent the potential loss of public's trust in biobank donation.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Biographies

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Figure 1.
Study design to test the effect of NWI scenarios on donation to biobanks.
Note. NWI = non-welfare interest; RAQ = Research Attitudes Questionnaire.

Table 1Socio-Demographics of Participants ($N = 1,276$).

Age (years)	$M = 31.9, SD = 12.4$
Gender	
Female	591 (46.3%)
Race	
White	1,026 (80.4%)
Black	89 (7.0%)
Asian	106 (8.3%)
Other	55 (4.3%)
Ethnicity	
Hispanic	89 (7.0%)
Non-Hispanic	1,187 (93.0%)
Education	
High school	155 (12.2%)
<Bachelor's degree	498 (39.0%)
Bachelor's degree	452 (35.5%)
>Bachelor's degree	170 (13.3%)
Household income	
<20,000	274 (21.5%)
20,000–40,000	322 (25.2%)
40,000–60,000	275 (21.6%)
60,000–80,000	171 (13.4%)
80,000–100,000	102 (8.0%)
>100,000	132 (10.3%)
Religion	
Protestant	298 (23.4%)
Roman Catholic	167 (13.1%)
Mormon	17 (1.3%)
Orthodox	12 (0.9%)
Jewish	32 (2.5%)
Muslim	12 (0.9%)
Buddhist	26 (2.0%)
Hindu	14 (1.1%)
Atheist	257 (20.1%)
Agnostic	194 (15.2%)
Something else	73 (5.7%)
Nothing in particular	174 (13.8%)
Evangelical	147 (11.5%)
Political view	
Very liberal	176 (13.5%)
Liberal	455 (35.7%)

Moderate	425 (33.3%)
Conservative	173 (13.6%)
Very conservative	47 (3.7%)

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Table 2

Participant Willingness to Donate and Views on NWI Disclosures.

Arm	Scenario	<i>n</i>	Willing to donate (after NWI disclosure)? ^a	Require NWI disclosure law? ^b	Want to know NWI before donating? ^c	Want to know even if NWI only a very small chance? ^d	Require specific consent? ^e
			% yes ^f	% yes ^f	% yes ^f	% yes ^f	% yes ^f
1	Abortion	102	82.4	66.7	71.6	62.0	37.3
2	Mixed With Non-Human Cells	107	79.4	69.2	75.0	63.6	34.6
3	For-Profit	104	75.9	82.7	87.5	79.8	40.4
4	Stem Cells	107	81.3	77.6	79.4	72.0	36.5
5	Bioweapon Development	106	67.9	72.0	78.3	76.4	41.5
6	Evolutionary Origins of Humans	107	76.6	75.0	80.4	75.7	43.9
7	Insurance Risk Assessment	108	71.3	68.5	77.8	73.1	50.9
8	Race-Based Traits	109	83.5	68.9	75.2	74.3	43.1
9	Four scenarios ^g	110	80.4	71.9	78.5	69.1	38.3

Note. NWI = non-welfare interest.

^a“Would you give blanket consent (general consent) to biobank research, if you knew that the following research studies might use your tissue sample?”

^b“Should there be a law that requires biobanks to inform people about this type of possible future research?”

^c“Would you want to know that your biobank samples could be used for such a research project before donating your tissue sample to the biobank?”

^d“Would you want to know about such a research project before making a decision, even if there is only a very small chance that tissues could be used in such studies?”

^e“Do you think donors should be asked for their specific consent in studies like this each time, even if it meant it might slow research progress?”

^fCombining *definitely* or *probably* “yes” responses (valid %).

^gFour scenario grouping includes Abortion, Bioweapon Development, Evolutionary Origins of Humans, and Race-Based Traits.

Table 3

Potential Reactions if Donor Finds Out, *After* Donating, About NWI Scenario.^a

Arm	Scenario	n	Overall reaction ^b		Angry ^c		Withdraw my permission ^d	
			% displeased ^e	% agreed ^f	% angry ^c	% agreed ^f	% agreed ^f	% agreed ^f
1	Abortion	102	23.5	18.9	18.9	20.6		
2	Mixed With Non-Human Cells	107	16.8	13.0	13.0	10.3		
3	For-Profit	104	22.1	24.0	24.0	15.4		
4	Stem Cells	107	13.1	13.1	13.1	14.0		
5	Bioweapon Development	106	40.6	30.2	30.2	30.2		
6	Evolutionary Origins of Humans	107	14.0	12.3	12.3	10.3		
7	Insurance Risk Assessment	108	46.7	39.8	39.8	32.4		
8	Race-Based Traits	109	18.2	19.3	19.3	22.0		
9	Four scenarios ^g	110	14.9	11.2	11.2	16.7		

Note. NWI = non-welfare interest.

^a“Suppose you gave blanket consent to all future research when you donated your tissue. Later, you find out that the research described above was conducted using your tissue. What would your reaction be?”

^b“Would you be pleased or displeased to hear that such research was conducted using your tissue?”

^c“I would be angry that they had conducted such research using my tissues.”

^d“I would try to withdraw my permission so they could not do any more research with my tissue.”

^eCombining *displeased* and *very displeased* (valid %).

^fCombining *agree* and *strongly agree* (valid %).

^gFour scenario grouping includes Abortion, Bioweapon Development, Evolutionary Origins of Humans, and Race-Based Traits.

Table 4

Change in Willingness to Donate for Each NWI Scenario by Presentation Format (Within-Subject).

Arm	Scenario description	n	Single scenario presentation		Eight scenario presentation		p value ^d
			% yes ^b		% yes ^b		
1	Abortion	102	82.4		68.6		<.01
2	Mixed With Non-Human Cells	107	79.4		75.7		.45
3	For-Profit	104	75.9		47.1		<.01
4	Stem Cells	107	81.3		80.4		1.00
5	Bioweapon Development	106	67.9		57.6		.04
6	Evolutionary Origins of Humans	107	76.6		83.2		.17
7	Insurance Risk Assessment	108	71.3		42.6		<.01
8	Race-Based Traits	109	83.5		70.6		<.01

Note. NWI = non-welfare interest.

^aMcNemar's test with continuity correction, including responses: *definitely not* versus *probably yes definitely yes*.

^bCombining *definitely yes/probably yes* responses (valid %).

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Table 5

Effect of NWI Scenario Disclosure *After* Participants Are Asked Whether They Would Give Blanket Consent Without NWI Disclosure.

Arm	Scenario description	n	Willingness to donate prior to NWI information		Willingness to donate after being given NWI information		p value ^a
			% yes ^b	% yes ^b	% yes ^b	% yes ^b	
10	Abortion-P	106	89.6	77.4		<.01	
11	Evolutionary Origins of Humans-P	106	84.9	84.8		1.0	
12	4 Scenarios-P ^c	107	85.0	69.2		<.01	

Note. NWI = non-welfare interest.

^a McNemar's test with continuity correction.

^b Definitely yes/probably yes.

^c Four scenario grouping includes Abortion, Bioweapon Development, Evolutionary Origins of Humans, and Race-Based Traits.

Table 6

Factors Related to Willingness to Donate, for Each NWI Scenario.^a

	NWI scenario					
	Abortion	Mixed With Non-Human Cells	For-Profit Research	Stem Cells	Bioweapon Development	Evolutionary Origins of Humans
Age (years old) ^b						
20–30	0.50 [0.32, 1.79]	0.76 [0.52, 1.13]	0.67 [0.48, 1.00]	1.68 [1.00, 2.79]	1.19 [0.84, 1.80]	1.00 [0.55, 1.83]
30–40	0.36 [0.22, 1.59]	0.67 [0.44, 1.03]	0.90 [0.63, 1.30]	1.00 [0.59, 1.69]	1.22 [0.76, 1.91]	1.35 [0.69, 2.63]
40–50	0.53 [0.28, 1.00]	0.98 [0.56, 1.73]	0.77 [0.48, 1.27]	1.32 [0.67, 2.61]	1.59 [0.95, 2.69]	1.89 [0.80, 4.46]
>50	0.54 [0.31, 0.99]	0.50 [0.30, 0.82]	0.64 [0.41, 1.00]	1.05 [0.58, 1.92]	1.21 [0.76, 1.91]	1.37 [0.66, 2.83]
Education ^c						
BA	1.23 [0.78, 1.96]	1.10 [0.73, 1.68]	0.90 [0.63, 1.30]	0.75 [0.44, 1.30]	0.70 [0.47, 1.03]	1.16 [0.64, 2.12]
>BA	1.20 [0.66, 2.17]	1.59 [0.91, 2.77]	1.32 [0.82, 2.13]	0.74 [0.37, 1.47]	0.66 [0.39, 1.09]	1.22 [0.66, 2.70]
Race ^d						
White	1.21 [0.69, 2.12]	2.07 [1.22, 3.51]	1.76 [1.06, 2.92]	2.12 [1.22, 3.70]	1.57 [0.96, 2.56]	1.86 [0.75, 4.60]
Other	1.31 [0.65, 2.67]	1.30 [0.68, 2.47]	1.31 [0.71, 2.42]	1.80 [0.88, 3.69]	1.36 [0.75, 2.48]	1.05 [0.54, 2.04]
Gender ^e						
Female	0.79 [0.58, 1.07]	0.73 [0.55, 0.97]	1.02 [0.80, 1.30]	0.60 [0.43, 0.86]	0.84 [0.65, 1.08]	0.63 [0.42, 0.96]
Religious ^f						
Yes	0.55 [0.37, 0.73]	0.72 [0.53, 0.98]	1.25 [0.96, 1.63]	0.69 [0.47, 1.00]	1.16 [0.88, 1.54]	0.57 [0.34, 0.94]
Evangelical Christian ^g						
Yes	0.25 [0.16, 0.41]	0.67 [0.42, 1.02]	0.86 [0.57, 1.30]	0.62 [0.38, 1.01]	0.67 [0.44, 1.02]	0.21 [0.12, 0.36]
Political orientation ^h						
Moderate	2.50 [1.67, 3.75]	1.13 [0.76, 1.68]	0.83 [0.58, 1.20]	0.92 [0.58, 1.48]	0.67 [0.46, 0.99]	1.13 [0.67, 1.93]
Liberal	6.20 [4.06, 9.48]	1.38 [0.92, 2.07]	0.75 [0.52, 1.07]	1.32 [0.80, 2.18]	0.58 [0.39, 0.86]	1.39 [0.79, 2.47]

Note. NWI = non-welfare interest; HS = high school.

^aOdds ratios and 98% confidence intervals; significant findings in bold.^bReferent group defined as 20 years old.

^cReferent group defined as HS. If respondent selected “Did not graduate high school” or “High school graduate or General Education Development (GED),” then coded as “HS”; if respondent selected “Some schooling past high school” or “College graduate” then coded as “BA”; if respondent selected “Some schooling past college” or “Advanced degree,” then coded as “>BA.”

^dReferent group defined as Black. Race variable category “Other” includes self-reported American Indian, Asian, Pacific Islander, or indicated “Other” race.

^eReferent group defined as male.

^fReferent group defined as non-religious. If respondent selected Protestant, Roman Catholic, Mormon, Orthodox, Jewish, Muslim, Buddhist, Hindu, or “Something else,” then response was coded as “yes”; if respondent selected Atheist, Agnostic, “Nothing in particular” or “Don’t know,” then response was coded as “no.”

^gReferent group defined as Not Evangelical Christian. Responded “yes” to the question “Would you consider yourself a born again or evangelical Christian, or not?”

^hReferent group defined as conservative. Conservative = “Very conservative” and “Conservative”; Moderate = “Moderate,” Liberal = “Very liberal” and “Liberal.”