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Encouraging Participation And Transparency In Biobank Research

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Abstract

Medical biobanks often struggle to obtain sustainable funding. Commercialization of specimens is one solution, but disclosure of commercial interests to potential contributors can be dissuasive. Recent revisions to the federal human subjects research regulations will soon mandate such commercialization disclosure in some circumstances, which raises questions about implications for practice. In this nationally representative, probability-based survey sample of the US adult population, we found that 67 percent of participants agreed that clear notification of potential commercialization of biospecimens is warranted, but only 23 percent were comfortable with such use. Sixty-two percent believed that profits should be used only to support future research, and 41 percent supported sharing profits with the public. We also considered other factors related to disclosure in our analysis and argue for a “disclosure plus” standard: informing potential contributors that their biospecimens might be accessed by commercial organizations and explaining how profits would be used to both enhance transparency and facilitate contributors altruistic motivations.

Keywords

Business Of Health; Ethical Issues; Legal/Regulatory Issues; Public Opinion; Research And Technology

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Human biospecimen collections—procured with consent or waiver, or deidentified for research use—continue to provide critical material for the advancement of science. However, the acquisition and research use of biospecimens are not without controversy. The now infamous “HeLa” cell line, for example, has fueled generations of cancer research, but the recent telling of the story of the patient behind HeLa, Henrietta Lacks, has turned public attention to the perspective of biospecimen contributors, generating questions about the appropriate role of informed consent, the ethics of commercialization, and the distribution of profits from biomedical research. The public generally does not see participation in research as an ethical obligation,[1,2] despite claims by some that all citizens have a fundamental societal responsibility to contribute to research.[3] Thus, the Lacks story and recent debate about consent for secondary research with deidentified specimens raise important questions about transparency, privacy, and the obligations of researchers that the US court and regulatory systems have yet to resolve satisfactorily.[4,5]

There is widespread support for the use of biospecimens in research generally,[6] but contributors’ altruism may be diminished by the strategy some biobanks use to achieve financial sustainability. While biobanks vary widely in design, institutional support, and funding mechanisms, monetary support is consistently a problem: 71 percent of repositories report that funding is a concern, and 37 percent report that it is their greatest challenge.[7] Although philanthropy is one potential solution,[8] the major sustainable funding model is to sell access to biospecimens.[9,10] But allowing private or for-profit entities (such as pharmaceutical companies) to purchase access to biospecimens is controversial, might not be consistent with public values, and is even prohibited in some European countries (for example, Norway).[9] These concerns have led to the suggestion of other types of models for biobanks—such as a charitable trust—to underscore the altruistic nature of the contribution, allow community engagement, and encourage a joint investment between the patient and scientific communities.[11] The charitable trust model would also allow for a type of profit sharing without the potentially insurmountable logistical complexities of individualized distributions.

Effective methods of disclosing the commercial uses of biospecimens will soon become more important as a result of recent revisions to the Federal Policy for the Protection of Human Subjects (often called the Common Rule) that regulates federally funded human subjects research. These revisions, made public in 2017 and now slated to take effect in January 2019, include new requirements for disclosing the possibility of future commercialization of specimens.[5] Under the current regulations, informed consent or disclosure is not required for the secondary research use of biospecimens, as long as the specimens do not include identifying information.[12] In some cases, whole genomes or other types of large-scale genetic sequencing have been reidentified (for example, by researchers pairing genetic data with readily available identifying information[13])—which was one of the concerns that led to the new regulations.[5] The revised Common Rule requires that contributors who provide informed consent must be told that their biospecimens could be deidentified for secondary research use. But it also requires disclosure of whether contributor biospecimens could be used “for commercial profit” and whether contributors will share in such profit themselves.[5] While the disclosure requirement currently applies

only to identified specimens, the revised Common Rule also stipulates that experts will reconsider what makes a specimen "identifiable" within a year of regulatory implementation, and every four years thereafter. Therefore, the range of specimens for which commercialization must be disclosed could expand rapidly in the near future.[14]

Regulators argued that disclosure of commercial interests should be mandated because investigator profit was a major concern of many members of the public who submitted comments regarding the regulatory revisions. Many commenters also discussed their interest in the sharing of such profit. Thus, the updated regulations will likely lead to increased disclosures of commercial relationships.[5]

While prospective biospecimen contributors may strongly support mandated disclosure requirements regarding future commercial interests, a potential consequence is the "commercialization effect," wherein participants are less likely to contribute their specimens to research if they know that private or for-profit interests are at stake.[15] Research in Australia,[16] Sweden,[17] and Canada[18] reveals public skepticism about commercial interests in biobanks. Patients are more likely to trust doctors (71.3 percent) than the for-profit industry like a drug company (61.7 percent).[18] Reasons for this include beliefs that any benefit derived from for-profit research would be less publicly accessible and that private researchers are generally less benevolent.[15] Many also argue that contributors should share in the profits if their specimens are commercialized.[19] In light of this, scholars have called for more research into the concept of "benefit sharing" in biospecimen work[19]—for example, the charitable trust model discussed above.[11]

To gain further insight into public concerns regarding the commercialization of biospecimens—and to investigate whether those concerns could be alleviated by additional disclosure of the uses of resulting profits—we solicited opinions about the commercialization of biospecimens from a nationally representative sample of the US adult population. We asked people about notification, use, and preferences for the disposition of profits. We also examined the association between the opinions expressed and a number of variables, including demographic characteristics; recent health experiences; attitudes regarding research; and the values of trust, privacy, and altruism.

Study Data And Methods

Respondents were surveyed in December 2016 using KnowledgePanel,[20] GfK's nationally representative, probability-based sample of US adults, for which there was a 64.7 percent survey completion rate. GfK calculated poststratification weights corresponding to the Census Bureau's demographic benchmarks for age, sex, household income, education, and race/ethnicity to reduce bias from random sampling error. We used responses from 886 people with completed data.

Opinions about the commercialization of biospecimens—including use, notification, and preferences for profits—were solicited as part of a larger twenty-minute survey examining trust in health information sharing. (Relevant excerpts, including questions used in this analysis, are in online appendix exhibit 1.)[21] The online survey was pilot-tested and

iteratively designed by expert review[22] The final survey had a Flesch reading-ease score of 66.1 and a Flesch-Kinkaid Grade Level of 5.7—which suggests that it was accessible to people from a wide range of educational levels. The final survey was administered using GfK's online platform. All survey participants viewed a ninety-second animated video that described a health system in broad terms as the network of relationships among health care providers, departments of health, insurance companies, and researchers.[23,24]

Variable Design And Selection

Questions about the commercialization of biospecimens were asked in the context of academic medical centers (referred to as "university hospitals" in the survey) and developed by several of the authors in collaboration with a biorepository based at an academic medical center that was considering developing commercial partnerships.

We asked several policy-relevant questions, including one about use for commercialization (question A), one about contributor notification (question B), and two about preferences for profits (questions C and D). Specifically, we asked participants to rate statements about these issues on a scale from 1 (not true) to 4 (very true).

We then identified variables that captured four factors associated with these opinions. We asked respondents about both their demographic characteristics and whether they had one of two recent health experiences (self or a loved one in the emergency room or hospitalized in the past year). Respondents' support for research was measured using two variables: their views on data sharing ("Given what you know about information sharing among organizations in the health system, do you have a generally favorable or generally unfavorable view?," with the answer on a four-point scale of very favorable to very unfavorable) and whether they were likely to believe that "people have an ethical obligation to participate in health research" (with the answer on a four-point scale of not at all true to very true).

We also looked at three values of interest: trust, privacy, and altruism. We analyzed three specific types of trust: in general, in health systems' information sharing, and in health care providers. Trust in health systems' information sharing was derived from four dimensions: fidelity, integrity, competency, and global trust (the development of this index is described in detail elsewhere).[22] Measures of generalized trust and trust in health care providers were adapted from prior studies, including the Wake Forest Study,[25] the Medical Mistrust Index,[26,27] and the General Social Survey.[28] Privacy in health information was measured using a single index compiled from six questions (Cronbach's $\alpha = 0.88$), adapted from the National Consumer Health Privacy survey.[29] The altruism index consisted of four questions (Cronbach's $\alpha = 0.69$), and measures were adapted from the General Social Survey[28] and the National Election Survey.[30]

Analysis

Using Stata, version 13.1, we generated summary descriptive statistics of respondents' attributes and four variables that measured commercialization opinions. We created a probability tree (to display conditional probabilities graphically [31]) to examine the relationships between how comfortable a person is with commercializing biospecimens,

whether they want to be clearly notified, and whether they believed that profits should be used only for research or shared with the public.

Responses were given on a four-point scale and dichotomized into “yes” (“very true” or “fairly true”) or “no” (“somewhat true” or “not at all true”). Tests of proportions were used to evaluate whether there were significant differences in agreement with commercialization options at each branch in the probability tree. We conducted weighted univariable logistic regression models and report odds ratios to express the relationship of each independent variable to each of the four commercialization opinions. An α level of 0.05 was used to assess significance.

Limitations

Our methods had certain limitations. First, while the GfK probability-based panel is one of the strongest types of survey sampling methods, one can never fully eliminate all bias-related limitations.

Second, we surveyed the general public, instead of patients being recruited for a specific research project or being asked to contribute to a specific institutional biobank, which might limit the generalizability of our data.

Third, several terms we used in questions (such as *charitable trust*) were not specifically defined, and participants may have understood them differently. However, we did not find education to be a significant factor associated with the reported opinions.

Fourth, we might have gotten different results if we had provided information at different points in the survey (for example, regarding disclosing possible uses of profits).

Despite these limitations, we believe that this research represents a novel contribution to the literature in its focus on the newly mandated disclosure requirements, and best practices for institutions implementing those requirements while still encouraging people to contribute biospecimens for research. Future studies should consider protocols that evaluate contributors’ decision making in real-time to assess individual trade-offs and the possible effect of the disclosure of commercialization on informed consent. The use of complementary qualitative methods would further inform understanding of the reasons underlying attitudes toward commercialization, disclosure, and the use of profits from research.

Study Results

Demographic Characteristics

Exhibit 1 presents demographic characteristics of survey respondents—specifically, their sex, age range, race/ethnicity, education, and income. We also found that respondents, on average, rated their health between very good and good (data not shown).

Opinions About Commercialization

Exhibit 2 shows overall percentages of respondents who agreed with our four statements regarding commercialization; conditional probabilities that suggest relationships between these opinions are in appendix exhibit 2.[21] Fewer than one-fourth of our participants stated that they were comfortable with leftover biospecimens being used to generate income, and two-thirds agreed that being notified about such use was important. The desire to be notified was higher among those who were not comfortable with commercialization (appendix exhibit 2, p value for test of equal proportions <0.001).[21]

Regarding preferences for profits, the majority of survey participants agreed that profits should be used only to support future research (exhibit 2). Fewer than half agreed with the previously described policy proposal[11] that profits be shared with the public using a charitable trust model. Participants who both were comfortable with commercializing their biospecimens and wanted to be clearly notified when that happened had a significantly (p = 0.002) greater desire for profits to be used for future research, compared to those who were comfortable with commercialization but did not feel it was important to be notified (appendix exhibit 2).[21]

What was most surprising was that participants who were not comfortable with commercializing their biospecimens and who did not feel that it was important to be notified of such commercialization if it happened, also did not think profits should be used only to support future research: 93.3 percent of these participants supported the public trust model (appendix exhibit 2).[21] This majority is the greatest of all subgroups in this multidimensional analysis.

Factors Associated With Opinions About Commercialization

Only about one-fifth of respondents believed that people have an ethical obligation to participate in research (although survey participants' views toward data sharing were generally favorable) (exhibit 2). Fewer than half agreed that "most people can be trusted." On an index of trust in health care providers, the median value (2.8 on a 1–4 scale) suggested medium or high trust. The median value of the privacy concerns index (1.8 on a 1–4 scale) suggested medium or low levels of concern. The median value of the altruism index was also below the midpoint.

Exhibit 3 presents odds ratios that quantify the magnitude and direction of the relationships between the variables capturing attitudes about commercialization and survey participants' characteristics.

Commercial Use Of Biospecimens (Question A):

Eight variables were associated with being comfortable with an academic medical center using leftover biological specimens to generate income, including: those with a recent health experience, having a favorable view of data sharing, believing that people have an obligation to participate in research, being altruistic, and being trusting (exhibit 3). Participants with greater privacy concerns were less accepting of using leftover samples for generating income.

Notification (Question B):

Trust in health care providers was inversely related to believing that notification about commercialization is important (exhibit 3), which suggests that those who trusted their providers were less likely to feel the need to be notified. Similarly, those with a favorable view of data sharing were less likely to want to be notified. Respondents with greater concerns about privacy and those with higher levels of altruism were more likely to agree that notification is important.

Preferences For Profits (Questions C And D):

Participants who felt that people have an obligation to participate in research were more likely to want profits to be used for future research or shared with the public as a charitable trust. Those with a favorable view of data sharing were more likely to want profits to be used for research. All three trust measures were positively related to the belief that profits from commercial use should be used only to support future research (exhibit 3). Altruism was also associated with a desire for profits to be used for future research as well as with a preference for them being put into a charitable trust.

Discussion

In this research we analyzed survey participants' opinions about the commercialization of biospecimens for research at academic medical centers and how these opinions were related to respondents' demographic characteristics, a recent health experience, support of research, and values (related to trust, privacy, and altruism). Information about disclosure preferences generated by these questions are critical to implementing the revised Common Rule related to the need to tell research participants who provided informed consent that their biospecimens might be used "for commercial profit" and whether the participant will share in such profit.[5] Our data suggest that there may be a need for more transparency—particularly for prospective contributors with privacy and trust concerns—to increase confidence in the research enterprise.

Past research has demonstrated that while people recognize the importance of commercial uses of biospecimens overall,[6] they are skeptical of the role commercialization might play in public research and disapprove of private researchers receiving public funds and public researchers receiving private funds (but not necessarily of researchers using private funds generally).[16] Our data confirm these findings: Fewer than a quarter of our survey participants indicated that they were comfortable with a university hospital's commercializing specimens. Comfort was positively associated with a recent health experience, support for research, altruism, and trust. Privacy concerns were negatively associated with comfort.

Consistent with the results of previous studies,[32] we found that disclosure was important to the majority of our participants. Those with more concern for privacy or who scored higher on the altruism scale were more likely to agree that notification was important, while trust in providers was inversely related to the need for notification.

Our findings suggest that disclosure should be taken as an opportunity—not simply for adding language to already complex consent disclosures, but for enriching the consent process to build "active trust." Such trust is important for cultivating personal connections that are easily obscured in complex systems, such as the research enterprise, and in the context of rapidly developing systems in which governance structures cannot keep pace with social expectations or technological capacity.[33]

Another critical consideration is the actions of secondary researchers who buy or use contributed biospecimens. Contributors might feel differently about unknown secondary researchers than they feel about the team to which they provided consent and shared their initial contribution. Our data suggest that it would behoove researchers, to the best of their ability, to share information regarding the identity and possible research aims of potential secondary researchers, while acknowledging the practical limitations of anticipating future goals and motivations.

Nearly two-thirds of our survey participants also agreed that profits from commercialization of specimens should be used only to support future research—a belief that was positively associated with higher incomes and trust. A substantial minority also thought that profits should be shared with the public. A charitable trust was proposed to our participants as the mechanism for doing this, though other alternatives should be investigated. For example, after our data had been collected, George Church of Harvard University and his colleagues announced a new blockchain-enabled genomic data sharing and analysis platform for individual profit sharing.[34] However, it is still unclear how successful the approach will be, and the Church et al. model focuses on sharing data as opposed to biospecimensl.

In our survey, being altruistic or believing that people have an obligation to participate in research increased support for both options for profit sharing. These data bolster previous findings that people seem to be mainly concerned that private interests will limit access to any advancements that are derived from research.[10] In 2014 Timothy Caulfield and coauthors suggested that a benefit-sharing agreement could encourage participants to donate in the face of commercialization.[10] Our data support this hypothesis.

Given the funding climate and increasing challenges of supporting sustainable biorepositories, our study raises the question of how best to provide appropriate context for people who contribute biospecimens regarding biorepositories' need for generating funding streams. Our data do not imply that contributors will reject such models, or even that they would necessarily prefer profit sharing. But the aversion of the general public to commercialization challenges biorepositories to disclose these complexities in transparent ways designed to cultivate trust.

Our data also support previous findings that people generally do not feel that there is an ethical obligation to participate in research.[1,2] Nearly four-fifths of our survey participants felt the need for something other than ethical obligation to compel them to contribute their specimens. These results may be related to past research that found trust to be the variable that most affects willingness to participate in research.[35] Notably, only about half of the

public thinks that the health system can be trusted to use their health information responsibly.[23]

Our empirical data have distinct policy implications. When updating informed consent practices to adhere to the revised Common Rule, institutions will confront the challenge of how to ensure compliance, enable participants' autonomy, and be transparent while supporting the critical research needed to improve the health of future patients. Of note, the regulatory requirements in the revised Common Rule have much broader application than just for researchers with federal funding. Many institutions require all human subjects research to be conducted in accordance with federal regulation. In addition, federal human subjects research rules often set the standard for private research—for example, via private journal requirements for publication (such as Institutional Review Board [IRB] review for human subjects research that was not federally funded).[36] Finally, regulators have reserved the right to reconsider the currently narrow definition of *identifiable* within a year of implementation—which means that the debate over whether all biospecimen contributions will require informed consent (or an IRB waiver) is far from settled.[14]

Based on our findings, we recommend a "disclosure plus" standard: Researchers should disclose potential commercial interests in contributed specimens (as they will be legally obligated to do in many circumstances) *and also* disclose the intended use of funds that may be received in return. Even though the revised Common Rule does not mandate disclosure and consent for all biobanking, we interpret our data in a way that encourages researchers and clinicians to be as inclusive as possible when notifying potential specimen contributors of how leftover tissue samples might be used. Such transparency would encourage trust—a key component of the research enterprise.

People participate in research to benefit themselves, others, or both. Commercial research focused on getting products to market is an important complement to research done in university hospitals.[37] However, if contributors are told only that commercial entities may have access to their donated biospecimens, they are likely to assume that the general benefit of future research will decrease.[15] If institutions are going to use funds to support the biobank (as many have reported)[7] or other research, they should make that clear to potential contributors. Reassuring contributors that commercial funds will be reinvested might reduce the threat to their altruistic motivations posed by the disclosure of possible commercialization.

Conclusion

The general public remains averse to the routine commercialization of biospecimens and suspicious of how the financial gains from those arrangements might be used. Changes to the federal regulations governing human subjects research will require many institutions to revise their informed consent process. In so doing, they should disclose not only who will be given access to specimens, but also how profits generated from contributed biospecimens will be used. Such disclosure will both enable participant autonomy via increased transparency, which will allow prospective contributors the most informed decision for

themselves. Assuming commercial funds are invested in supporting the research enterprise, this may reinforce the altruistic motivations of potential contributors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Exhibit 1:

Demographic characteristics of survey respondents

Characteristic	Percent
Sex	
Female	50.0
Male	50.0
Age range (years)	
18–29	12.0
30–44	21.3
45–59	26.0
60 or more	41.7
Race/ethnicity	
Not white	23.3
White, non-Hispanic	76.7
Education	
High school or less	33.3
Some college	27.5
Bachelor’s degree or more	39.2
Annual income	
More than $50,000	64.0

SOURCE Authors’ analysis of data from the 2016 trust in health information sharing survey. NOTE Median self-reported health was 2.6, on a scale of 1 (excellent) to 5 (poor).

Exhibit 2:

Survey respondents' attitudes about commercialization, recent health experience, support for research, and values

	Percent very or fairly true, or median
Commercialization of biospecimens	
I would be comfortable with my university hospital using my leftover biological samples to generate income (question A)	22.6%
It is important to be clearly notified about my biological samples being used for commercial use (question B)	66.6
Profits from commercial use should only be used to support future research (question C)	62.1
Profits should be shared with the public in the form of a charitable trust fund (question D)	40.5
Recent health experience (past year)	
Self or loved one in ER	40.4%
Self or loved one hospitalized	31.5
Support for research	
Favorable view of data sharing	74.2
People have an obligation to participate in research.	21.8
Values[a]	
Index of privacy concerns[d]	1.8
Index of altruism[e]	2.8
Whether most people can be trusted	39.4
Index of trust in the health system[b]	10.8
Index of trust in health care providers[c]	2.8

SOURCE Authors' analysis of data from the 2016 trust in health information sharing survey. NOTE ER is emergency room.

[a]Median.

[b]Range: 4 (low trust) to 16 (high trust).

[c]Range: 1 (low trust) to 4 (high trust).

[d]Range: 1 (low privacy concerns) to 4 (high privacy concerns).

[e]Range: 1 (low altruism) to 4 (high altruism).

Exhibit 3:

Factors associated with respondents' opinions about commercialization of biospecimens

	Use	Notification	Preferences for use of profits	
	Comfortable with commercial use (question A)	**Prefer to be notified about commercial use (question B)**	**Profits used for research only (question C)**	**Profits shared with public (charitable trust) (question D)**
Recent health experience (past year)				
Self or loved one in ER	1.54**	1.32	1.14	1.07
Self or loved one hospitalized	1.24	1.36	1.05	1.18
Support for research				
Favorable view of data sharing	2.07****	0.78**	1.50****	1.08
Obligation to participate in research	1.68****	1.05	1.29***	1.24**
Values				
Index of privacy concerns	0.74**	2.11****	0.99	1.07
Index of altruism	1.45***	2.28****	2.65****	2.53****
Whether most people can be trusted	1.94****	0.84	1.23**	1.12
Index of trust in the health system	1.28****	0.98	1.16****	1.05
Index of trust in health care providers	2.04****	0.76**	1.60****	1.05

SOURCE Authors' analysis of data from the 2016 trust in health information sharing survey. NOTES The exhibit shows odds ratios. The full text of each respondent opinion is in exhibit 2. ER is emergency room.

** $p < 0.05$

*** $p \leq 0.01$

**** $p \leq 0.001$