BIOPRESERVATION AND BIOBANKING
Volume 11, Number 3, 2013

DOI: 10.1089/bio.2013.0001

Public Perspectives on Biospecimen Procurement: What Biorepositories Should Consider

Jamie L'Heureux,[1] Jeffrey C. Murray,[1] Elizabeth Newbury,[2] Laura Shinkunas,[3] and Christian M. Simon[3,4]

Purpose: Human biospecimens are central to biobanking efforts, yet how members of the public think about biobank procurement strategies is not well understood. This study aimed to explore public perspectives toward the procurement of residual clinical material versus "direct" procurement strategies such as the drawing of blood.
Methods: Members of the public residing in and beyond the biobank catchment area of the University of Iowa Hospitals and Clinics were randomly selected to participate in focus groups and a telephone survey.
Results: The majority of survey participants (75%, $n = 559$) found both residual and direct procurement strategies equally workable. Small proportions preferred either residual (15%; $n = 117$) or direct (5%; $n = 40$) procurement. Focus group participants ($n = 48$) could identify benefits to both procurement strategies, but raised concerns about possible donor inconvenience/discomfort and reduced biospecimen accrual in the case of direct procurement. Residual procurement raised concerns about lower-quality samples being procured without full donor awareness.
Conclusion: Biobanks should consider that members of the public in their research programs may be willing to make specimen donations regardless of whether a residual or direct procurement strategy is employed. Limiting patient discomfort and inconvenience may make direct procurement strategies more acceptable to some members of the public. Ensuring donor awareness through effective informed consent may allay public concerns about the indirectness of donating clinical biospecimens.

Introduction

The value of biobanks to translational medical science is widely recognized, including by the public.[1–5] Biobanks collect different types of biological materials from which DNA and RNA are often extracted, and are used to spur research into the genetic basis of a broad range of diseases. Currently, biobanks face numerous challenges, including insecure long-term funding, operational and quality control issues, ethical and legal challenges (such as how to obtain informed consent, whether and how to return research results, confidentiality, and commercialization and industry/government access), lack of standardization, and slow recruitment.[3,6–8] Published rates of participation for individual biobanks range from 15% to 95% of individuals approached with the option of participating.[9–11]

Many of the factors associated with the decision to participate in research are complex and cannot be easily changed, such as people's educational, sociodemographic and cultural backgrounds and health/genetic literacy.[5,12–16] Public attitudes, perceptions, and trust can also impact participation.[16,17] While many members of the public consider biobank-supported research valuable and important, they are also concerned about the adequacy of biobank informed consent practices, biospecimen ownership issues, data sharing and confidentiality, and the possible intersection of biobank research and industry.[2,18–21] At a physical level, people are concerned about the prospect of pain or discomfort associated with blood draws, one strategy for directly procuring samples, and a common reason why people prefer not to donate blood samples for research.[16,22,23]

Biobanks can opt for specific biospecimen procurement strategies and manage these strategies with the public interest and concern in mind. In this respect, hospital-integrated biobanks are faced with two options: 1) procuring discarded clinical specimens; and/or 2) procuring specimens specifically for the purpose of conducting research through procedures such as a dedicated blood draw. A recent survey of U.S. biobanks suggests that the two largest sources of banked specimens are direct contribution by individuals (75%), and residual specimens from hospitals and other clinical settings (57%).[24] Many biobanks (41%) include specimens from both these sources, and only 8% do *not* report either individuals or clinical settings as sources of specimens.

Public support is important to biobank success.[17,25] Two important factors deserving consideration when determining

[1]Departments of [1]Pediatrics and [4]Internal Medicine, [3]Program in Bioethics and Humanities, Carver College of Medicine, and [2]Department of Anthropology, College of Liberal Arts and Sciences, The University of Iowa, Iowa City, Iowa.

which sample procurement strategy should be adopted and how it is managed are public perception and preference. A number of studies have examined participant willingness to participate in research studies that either utilized residual specimens or requested a blood draw.[5,15,16,26–30] However, studies that examine whether members of the public prefer a specific biospecimen procurement strategy over another, or whether different strategies are viewed as equally workable, are lacking. The aim of this study was to explore public attitudes and preferences with respect to residual and direct procurement of biospecimens in the context of a comprehensive DNA and tissue biobank at the University of Iowa Hospitals and Clinics (UIHC), which currently employs both strategies of sample procurement. The findings reported here add to the understanding of potential participant preferences and perspectives for two common strategies of procuring human biospecimens for research biobanks.

Materials and Methods

The findings of this study are a subset of data generated from a larger study reported elsewhere.[2] The larger study focused more broadly on a number of biobank features such as informed consent models, biospecimen procurement, the possibility of recontact, and return of results. Focus groups and a telephone survey were conducted, both with randomly selected members of the public. Support for the research design and implementation was contracted with the Center of Social and Behavioral Research (CSBR) at the University of Northern Iowa (UNI) which has particular expertise in public opinion research in the state of Iowa. The UNI institutional review board approved both the focus group and the survey. The strategies described below have been previously reported.[2]

Both the surveys and focus groups began with the following introduction to biobanks:

> Biobanks are typically managed by a medical center and do the following:
>
> - Store biological samples such as blood or tissue. These samples could be left over from either inpatient or outpatient medical procedures such as blood draws, surgeries, or biopsies, or they could come from procedures such as blood draws done to get samples specifically for the biobank.
> - Store a patient's medical records along with their samples.
> - Provide samples and medical records to scientists to conduct medical research.
> - Keep people's samples and information for many years, so research can be done on them well into the future.

To aid understanding, focus group participants were also told that "biobanks are a little like libraries. But instead of books, they contain biological samples and medical records. And instead of just anybody being able to access these samples and records, only researchers with special approval can get at them and use them for research." Survey participants were given more specific information about the proposed biobank at the University of Iowa Hospitals and Clinics (UIHC): "The University of Iowa Hospitals and Clinics is considering developing a biobank. Samples that are left over from a standard procedure during a routine visit at the University of Iowa Hospitals and Clinics, such as a blood draw, biopsy, or surgery, that would otherwise be discarded, would instead be collected for the biobank. With the exception of those too ill to participate, all patients at the University of Iowa Hospitals and Clinics will be invited to participate. The collected samples would be linked to each patient's medical records. Both the sample and the medical record information could be used for medical research, aimed at development of possible new treatments and better understanding the causes and courses of diseases."

Survey

Table 1 shows how survey participants were introduced to, and asked about, the two biospecimen procurement strategies, and the categories into which their responses were coded. Participants were also asked to report selected demographic information as well as whether they had previously participated in medical research, whether they had heard the term "biobank" before, their likelihood of participating in medical research in the next year if asked, their current health status, and their perceived value of biobanks. Survey data collection began on June 17, 2010 and ended on July 25, 2010. Sampling, which targeted residents both across the entire state of Iowa, and those specifically within the UIHC catchment area, resulted in 751 completed interviews;

Table 1. Study Descriptions and Questions on Biobank Procurement Methods

Survey	*Focus groups*
Many biobanks obtain blood or tissue samples from patients by using samples that are left over from routine procedures, such as a blood draw or surgery. Some biobanks also obtain samples by asking patients to come to the medical center specifically to undergo a blood draw or donate a small amount of tissue to the biobank for a specific research study. Thinking about the two means of collecting samples, do you have a preference for one over the other or do you view them as equally workable options? 1. I would prefer that biobanks collect leftover material from routine medical procedures 2. I would prefer that biobanks ask for specific donations. 3. Both methods are equally workable. 4. Don't know/not sure. Declined to answer.	Biobanks can get samples in two main ways. One way is to use samples that are left over from a routine procedure such as a blood draw or surgery. These samples would only be used with your consent. If these left-over samples don't go into a biobank, they would be destroyed. • What are some of the advantages to this approach? • What are some of the disadvantages to this approach? Another approach would be to draw blood from patients solely for the purpose of the biobank. In this case, the samples are not left over from a procedure, but instead, patients are asked for their permission to do a blood draw specifically for the biobank. • What are some of the advantages to this approach? • What are some of the disadvantages to this approach?

the majority ($n=700$; 86%) resided in the state of Iowa and the remainder resided in Illinois (48; 13%) and Wisconsin (3; 1%). The UIHC catchment area includes several counties in Illinois and Wisconsin, accounting for the small proportion of samples from these states. Both types of samples were provided by Genesys Sampling Systems.[31] The response rate for the statewide sample was 30% with a cooperation rate of 64%, and the response rate for the catchment area oversample was 28% with a cooperation rate of 60%. The response rate is the ratio of interviews to eligible numbers dialed, and the cooperation rate is the ratio of interviews to all eligible participants contacted.[32] All data were collected via the Computer Assisted Telephone Interviewing (CATI) system at UNI's CSBR. Survey data were organized and analyzed in SAS using basic descriptive statistics, cross tabulations, and Pearson chi-squares. Data from both populations were weighted to U.S. census demographic benchmarks and combined. To determine whether we needed to report results separately for those participants within the state of Iowa but outside the 90-mile catchment area (noncatchment) and those within the catchment area, we used the Pearson chi-square statistic to compare the two samples for possible differences in responses to key survey items. No significant differences were found between the two groups in any variables of interest reported in this paper. Hence, results from the participants in the catchment and noncatchment areas were combined (denominator of 751 participants) and analyzed. Available 2010 U.S. Census data for the state of Iowa[33] were also compared to the 95% confidence intervals of the combined survey data to determine whether survey participants differed from the general Iowa population. Because income data were recorded in $5000 ranges for the survey, we were unable to directly compare the median income in the survey to the Census data.

Focus groups

Seven focus groups with a total of 48 participants were conducted in April 2010, in three communities (two cities and one rural town) in the UIHC primary, 90-mile catchment area. Eligible participants were contacted by telephone using random digit dialing (RDD) in order to ensure representation of both listed and unlisted numbers. A screening tool was developed and used to promote variability in participant age, gender, education, and ethnicity, as well as identify and exclude from the study any non-English speakers and individuals who had not utilized a formal health care service in the last 10 years. Focus groups were held in convenient, neutral locations in each community (e.g., public libraries). Each group interview lasted between 80 and 90 minutes. Standard focus group procedures were followed,[34] with a trained moderator and research assistant conducting and audio-taping the focus groups. The manner and sequence in which focus group participants were introduced to the two possible biospecimen procurement strategies is shown in Table 1.

All focus group audiotapes were transcribed and transcriptions validated. Once uploaded into a qualitative management software package, Nvivo 8.0 (QSR International Pty Ltd, 2008), conventional content analysis was used to analyze the transcribed data. Conventional content analysis is one of three distinct approaches to content analysis.[35] The conventional approach was selected for this focus group study because the approach aims to identify attitudinal categories evident in the text data, which was considered appropriate to the study's goal of identifying participant attitudes toward specimen procurement strategies. The text data were independently analyzed by two coders, who grouped relevant discussion on procurement strategies into categories derived directly from the data. The coders and the study PI met regularly to refine the coding categories and reconcile independent coding discrepancies.

Results

Survey

Survey respondents ($n=751$) had a mean of 58 years of age (range: 18–94 years), and were predominantly female ($n=488$; 63%) and Caucasian ($n=725$; 97%). They had a median annual household income ranging from $55,001 to $60,000, and had a high school degree or higher ($n=714$; 95%). Most participants reported their general health to be either very good or good (40%, $n=291$ and 31%, $n=235$, respectively). Compared to Iowa 2010 census data,[33] survey participants included a larger proportion of females, Caucasians, and more highly educated individuals. Survey participants also reported a slightly higher income than the general population in Iowa. See Table 2 for additional demographic information.

The majority of survey participants (86%, $n=645$) reported that they had never before participated in a medical research study. When asked how likely they would be to take part in a medical research study in the next year, 53% ($n=400$) said they definitely or probably would participate. Most participants (74%, $n=562$) had not heard of the term "biobank," but after hearing the description of a biobank, most participants felt it would be very or extremely valuable (84%, $n=632$).

The majority of survey participants ($n=559$, 75%) said that both direct and residual procurement of biospecimens were equally workable options. Twenty percent ($n=157$) preferred

Table 2. Demographic Information of Focus Group Respondents and Survey Participants[2]

Characteristic	*Focus group*	*Survey (95% CI)*	*Iowa 2010 Census data*
Gender (%)			
Female	58	63 (59–67)	51
Age (years)			
Mean	52	58	—
Range	18–92	18–94	—
Ethnicity (%)			
Caucasian	88	97 (95–98)	89
Annual household income (%)			
$25,000 or less	—	20 (16–23)	—
$25,001 to $50,000	—	22 (18–26)	—
$50,001 to $80,001	—	29 (24–33)	—
$80,001 or more	—	30 (25–34)	—
Median	—	$55,001–$60,000	$48,065
Education (%)			
High school graduate or more	98	95 (93–97)	90
4-year college graduate or more	60	37 (33–41)	24

one strategy over the other, with 15% ($n=117$) preferring use of residual clinical specimens and 5% ($n=40$) preferring direct biospecimen collection. Five percent ($n=35$) of participants did not answer, said they did not know, or were not sure which strategy, if any, they preferred. Participants' age, gender, race/ethnicity, income, education, and self-reported likelihood of participating in medical studies were not associated with their sample collection preferences.

Collecting residual material, health status and recontact acceptability

Survey participants who preferred the collection of residual clinical specimens were less likely to: 1) report their health as very good or good ($p=0.014$), and 2) consider as acceptable the need to recontact donors for additional samples ($p<0.0001$), when compared to participants who considered both strategies equally workable, or who preferred direct biospecimen collection.

Direct biospecimen collection and perceived value of biobanks

Participants were asked both at the outset and at the end of the survey to rate how valuable they thought a biobank was on a scale of 1–5, with 1 being not at all valuable and 5 being extremely valuable. When responses were grouped into less valuable (1–3) and more valuable (4–5), those who preferred direct collection strategies considered biobanks to be less valuable than those who preferred residual procurement, or who thought that both were equally workable options, both at the beginning ($p=0.0013$) and end ($p=0.0003$) of the survey.

Focus groups

Focus group participants ($n=48$) were predominantly female ($n=28$, 58%) and Caucasian ($n=42$, 88%), with an average age of 52 years (range: 18–92), and most had a 4-year college degree or more ($n=29$, 60%) (Table 2). Focus group discussions were centered on the perceived advantages and disadvantages of the two sample collection strategies. Results are summarized in Table 3 and below.

Collecting residual clinical material: perceived advantages and disadvantages. Participants identified several advantages to the procurement of residual biospecimens, notably that this strategy minimized inconvenience and physical discomfort to participants. Participants also liked the concept of "recycling" or "not wasting" samples, with one stating "I see no value in throwing human tissue in the trash when something good could come of it." Collection of residual material was also seen as cost effective and expedient. "You don't have any costs in securing the tissue and you don't have some costs of destroying the tissue." However, focus group participants were concerned that residual biospecimen collection may be susceptible to gaps in donor awareness, comprehension, and consent. Participants wondered whether patients would be appropriately consented prior to or following the procurement of residual material. One stated that "If you consciously opt out, then you know it would be seen as you know kind of behind the back—you go in for a glucose monitoring and all of a sudden your medical information's free for anybody." Participants also questioned whether this strategy might encourage material to be withdrawn from patients "just because of the biobank."

Direct biospecimen procurement: perceived advantages and disadvantages. Participants said that while direct sample collection strategies may not directly benefit biobank participants, they were likely to provide biobanks with sufficient sample amounts and quality. One participant said, "I don't think there's any advantages for us, but there might [be an] advantage for [the biobank] to have a whole vial." Participants felt that direct collection strategies such as a dedicated blood draw would ensure awareness of, and voluntary participation in, research. One participant said, "Clearly if they came there, they're consenting." Participants felt that donor inconvenience and discomfort were disadvantages of direct procurement strategies, particularly blood draws. They predicted that the inconvenience of "the commute" and "the time that you would have to wait," and the discomfort from "the needle" might deter participation. As one participant stated, "I'm wondering if you would get less participants because it's another blood draw." They felt that this strategy would be particularly troubling to parents who might be approached for permission to draw blood samples from their children.

Coordinating direct biospecimen collection with clinical appointments. Focus group participants were not prompted to consider the possibility of coordinating direct specimen collection with clinical appointments, yet several individuals suggested this as an option. For example: "Just make it a part of that process. Just throw in another tube or something—that would be fine. But I wouldn't want to have—I certainly would not want to…go in and donate for that purpose."

Discussion

Human biospecimens such as tissue or blood have been called "the foundation of personalized medicine and the fuel

Table 3. Summary of Perceived Advantages and Disadvantages of Biospecimen Collection Strategies from Focus Group Discussions

Residual clinical biospecimens	*Direct biospecimen procurement*
Advantages	Advantages
Convenience, less subject burden	More desirable/higher quality samples
Not wasting samples—like recycling	Participants are aware of sample collection
Cost effective and expedient for the biobank	
Disadvantages/Concerns	Disadvantages/Concerns
Less desirable samples	Inconvenience, subject burden
Participants may not be aware of sample collection	Lower specimen accrual
Unnecessary sample collection	

that drives the basic and translational research needed to achieve this vision."[36] Sample collection strategies are a critical element of this foundation. Whether biobanks should adopt either strategy or both is a complex question requiring evaluation of organizational, logistic, financial, research-related, and legal, social and ethical considerations.[6,37] Public perceptions of these strategies are one of many factors warranting consideration.

Equally workable strategies

Effective genetics and genomics research needs continual, broad, and representative public participation.[25] Given this context, it will be encouraging to biobank centers and researchers to learn that many of the participants in this study view residual clinical and direct biospecimen procurement as equally workable strategies. Members of the public are generally supportive of biobank research,[2,5,19] and this support may underlie the view that these strategies of biospecimen collection are equally workable. The focus group findings suggest that there is public appreciation for the research-oriented and public health benefits of each strategy, including the concept of not wasting biological material when there are opportunities to use it in research, and of obtaining quality samples by using direct collection procedures.

Patient-centered considerations

1) Informed consent: Recent studies and legal cases suggest that many people do not sufficiently understand the information presented during the informed consent process for biospecimen and biobank research.[9,38–41] These studies underscore the importance of appropriately informing and obtaining consent from individuals, where relevant. This study found that members of the public are concerned about the possibility of residual clinical material being used by biobanks without adequate knowledge of participation. While this concern is not likely to translate directly into participant willingness to participate at the time of recruitment (since those who were unaware of participation would inherently not be able to decline participation), the informed consent process is important to participants and should be a key consideration when implementing either sample collection strategy. Appropriate, easy-to-understand language on procurement strategies should be included in biobank consent information, where applicable.
2) Participant burden: Focus group participants were concerned about inconveniencing or causing donors discomfort or pain by requiring biobank donations through direct procedures. In a review of studies that examine willingness to consent for research involving human biospecimens, Wendler reports that members of the public who are unwilling to donate genetic samples to research tend to be concerned with the method of obtaining samples.[30] Others report fear of pain, needles, injections, and blood as the most common reason given by those unwilling to donate blood for research.[16,23]

These concerns stress the importance of appropriate scheduling and pain management when using direct procurement strategies. Coordinating a research-specific blood draw with an already scheduled clinical appointment may be a middle ground option that limits patient-centered burdens while maximizing biobank benefits.

Other considerations

Health status. In this study, participants who preferred the collection of residual clinical material had a poorer self-reported health status than other participants. Other studies have found that willingness to donate blood samples for research increased with better self-reported health status.[16,17] Preference variations among participants with differing health status may be another reason for biobanks to consider utilization of a combination of collection strategies. Healthy participants who are not having blood drawn for clinical reasons may be more willing to undergo direct procurement procedures, while those who are less healthy may be reluctant to have yet another blood draw and prefer to have residual specimens collected.

Value of biobanks and preference for direct collection strategies. Survey participants who preferred direct collection strategies, such as a blood draw, also reported a lower perceived value of biobanks. This may seem contradictory given that direct procurement strategies entail more participant burden, and therefore could lead one to conclude that only members of the public who see significant value in a biobank would be willing to donate. For example, Wong et al.,[16] find people more willing to donate samples for research if they also believe that genetic research prevents future disease—a clear indication of perceived value. One possible explanation for our seemingly contradictory finding is that direct collection strategies are associated with a more active opportunity to decline research participation, when compared to procurement of residual material. People reporting a lower perceived value of biobanks may find direct collection strategies preferable because they would not want their biospecimens used in research without their explicit knowledge and permission. Public perceptions of biobank value and informed consent are widely considered important in efforts to improve transparency and trust in biobank research, and need further empirical study.

Study limitations

While members of the public are among those being approached to participate in biobanks, their views are not necessarily representative of actual biobank donors. The experience of being approached in a health care setting with a request to donate residual or newly acquired biological material may change how individuals view these strategies. Our study demographics also did not allow for an exploration of differences in perspective based on ethnicity, urban/rural residence, and race.

Our study focused on a blood draw as the only method for direct biospecimen procurement. Many biobanks may utilize less invasive alternative methods for direct procurement such as buccal swabs, saliva collection, or mouthwash specimens. While these methods may have some of the same time/inconvenience burdens as a blood draw, they eliminate the burden of pain and may be more acceptable to potential biobank participants. Future studies are needed to explore further public perceptions and preferences with regards to alternative direct biospecimen collection methods.

Conclusion

Members of the public are hypothetically willing to make specimen donations regardless of whether a biobank employs a direct or residual procurement procedure. Limiting patient discomfort and inconvenience may make direct procurement procedures more acceptable to some members of the public. Ensuring donor awareness through effective informed consent may allay public concerns about the indirectness of donating residual biospecimens. Biobanks should be cognizant of organizational, logistical, financial, research-related, and legal, social, and ethical considerations, along with any known preferences of the potential biobank participants in determining which strategy to employ and should consider implementing a combination of collection strategies, where feasible.

Author Disclosure Statement

The authors declare no conflict of interest.

This publication was made possible by The National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health Grant UL1RR024979; UI Carver College of Medicine (CCOM); and UI/CCOM Vice President for Medical Affairs (VPMA).

References

1. Maschke KJ. Biobanks: DNA and research. In: Crowley M, ed. *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns.* Garrison, NY: The Hastings Center; 2008. p. 11–14.
2. Simon CM, L'Heureux J, Murray JC, et al. Active choice but not too active: Public perspectives on biobank consent models. *Genet Med* 2011;13:821–831.
3. Watson PH, Wilson-McManus JE, Barnes RO, et al. Evolutionary concepts in biobanking—The BC BioLibrary. *J Transl Med* 2009;7:95.
4. Ginsburg GS, Burke TW, Febbo P. Centralized biorepositories for genetic and genomic research. *JAMA* 2008;299:1359–1361.
5. Pulley JM, Brace MM, Bernard GR, et al. Attitudes and perceptions of patients towards methods of establishing a DNA biobank. *Cell Tissue Bank* 2008;9:55–65.
6. Ahmed FE. Biobanking perspective on challenges in sample handling, collection, processing, storage, analysis and retrieval for genomics, transcriptomics and proteomics data. *Anal Methods* 2011;3:1029–1038.
7. Vaught J, Rogers J, Carolin T, et al. Biobankonomics: Developing a sustainable business model approach for the formation of a human tissue biobank. *J Natl Cancer Inst Monogr* 2011;2011:24–31.
8. Scott CT, Caulfield T, Borgelt E, et al. Personal medicine-the new banking crisis. *Nat Biotechnol* 2012;30:141–147.
9. Ormond KE, Cirino AL, Helenowski IB, et al. Assessing the understanding of biobank participants. *Am J Med Genet A* 2009;149A:188–198.
10. McCarty CA, Wilke RA, Giampietro PF, et al. Marshfield Clinic Personalized Medicine Research Project (PMRP): Design, methods and recruitment for a large population-based biobank. *Person Med* 2005;2:49–79.
11. Pulley J, Clayton E, Bernard GR, et al. Principles of human subjects protections applied in an opt-out, de-identified biobank. *Clin Transl Sci* 2010;3:42–48.
12. Ma Y, Kong X, Dai H, et al. Attitudes towards biosample donation in andrology patients. *Int J Androl* 2012;35:170–175.
13. McQuillan GM, Pan Q, Porter KS. Consent for genetic research in a general population: An update on the National Health and Nutrition Examination Survey experience. *Genet Med* 2006;8:354–360.
14. Meisel SF, Shankar A, Kivimaki M, et al. Consent to DNA collection in epidemiological studies: Findings from the Whitehall II cohort and the English Longitudinal Study of Ageing. *Genet Med* 2011 Sep 26 [Epub ahead of print].
15. Tupasela A, Sihvo S, Snell K, et al. Attitudes towards biomedical use of tissue sample collections, consent, and biobanks among Finns. *Scand J Public Health* 2010;38:46–52.
16. Wong ML, Chia KS, Yam WM, et al. Willingness to donate blood samples for genetic research: A survey from a community in Singapore. *Clin Genet* 2004;65:45–51.
17. Kettis-Lindblad A, Ring L, Viberth E, et al. Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think? *Eur J Public Health* 2006;16:433–440.
18. Cambon-Thomsen A, Rial-Sebbag E, Knoppers BM. Trends in ethical and legal frameworks for the use of human biobanks. *Eur Respir J* 2007;30:373–382.
19. Murphy J, Scott J, Kaufman D, et al. Public perspectives on informed consent for biobanking. *Am J Public Health* 2009;99:2128–2134.
20. Simon CM, Newbury E, L'Heureux JL. Protecting participants, promoting progress: Public perspectives on community advisory boards (CABs) in biobanking. *J Empir Res Hum Res Ethics* 2011;6:19–30.
21. Goddard KA, Smith KS, Chen C, et al. Biobank recruitment: Motivations for nonparticipation. *Biopreserv Biobank* 2009;7:119–121.
22. Brothers KB, Clayton EW. Parental perspectives on a pediatric human non-subjects biobank. *AJOB Prim Res* 2012;3:21–29.
23. Sanner JE, Frazier L. Factors that influence characteristics of genetic biobanks. *J Nurs Scholarsh* 2007;39:25–29.
24. Henderson GE, Cadigan RJ, Edwards TP, et al. Characterizing biobank organizations in the U.S.: Results from a national survey. *Genome Med* 2013;5:3.
25. Green ED, Guyer MS. Charting a course for genomic medicine from base pairs to bedside. *Nature* 2011;470:204–213.
26. Stegmayr B, Asplund K. Informed consent for genetic research on blood stored for more than a decade: A population based study. *BMJ* 2002;325:634–635.
27. Jack AL, Womack C. Why surgical patients do not donate tissue for commercial research: Review of records. *BMJ* 2003;327:262.
28. Treweek S, Doney A, Leiman D. Public attitudes to the storage of blood left over from routine general practice tests and its use in research. *J Health Serv Res Policy* 2009;14:13–19.
29. Gillespie TW, Hillyer CD. Blood donors and factors impacting the blood donation decision. *Transfus Med Rev* 2002;16:115–130.
30. Wendler D. One-time general consent for research on biological samples. *BMJ* 2006;332:544–547.
31. Genesys Sampling Systems. 1987–2011. Available from: http://www.m-s-g.com/web/genesys/index.aspx. Accessed July 14, 2011.
32. The American Association for Public Opinion Research. *Standard definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys.* 4th ed. Ann Arbor, MI: AAPOR; 2006.
33. U.S. Census Bureau. State and county quick facts. Available from: http://quickfacts.census.gov/qfd/states/19000.html. Accessed January 20, 2012.
34. Krueger R. Focus groups: *A Practical Guide for Applied Research.* 2nd ed. Thousand Oaks, CA: Sage Publications; 1994.
35. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–1288.
36. Vaught J, Rogers J, Myers K, et al. An NCI perspective on creating sustainable biospecimen resources. *J Natl Cancer Inst Monogr* 2011;2011:1–7.
37. Riegman PH, Morente MM, Betsou F, et al. Biobanking for better healthcare. *Mol Oncol* 2008;2:213–222.

38. Neidich AB, Joseph JW, Ober C, et al. Empirical data about women's attitudes towards a hypothetical pediatric biobank. *Am J Med Genet A* 2008;146:297–304.
39. *Havasupai Tribe v. Arizona Board of Regents* (2008) 220 Ariz. 214, 204 P.3d 1063.
40. Allen J, McNamara B. Reconsidering the value of consent in biobank research. *Bioethics* 2011;25:155–166.
41. McCarty CA, Nair A, Austin DM, et al. Informed consent and subject motivation to participate in a large, population-based genomics study: The Marshfield Clinic Personalized Medicine Research Project. *Commun Genet* 2007;10:2–9.

Address correspondence to:
Christian M. Simon, PhD
Program in Bioethics and Humanities
University of Iowa Carver College of Medicine
500 Newton Road, 1-106 MEB
Iowa City, IA 52242-1190

E-mail: christian-simon@uiowa.edu