Biobank Recruitment: Motivations for Nonparticipation

Katrina A.B. Goddard, K. Sabina Smith, Chuhe Chen, Carmit McMullen, and Cheryl Johnson

Molecular data, essential for genomics research, can be captured more efficiently in large-scale, population-based biobanks of genetic material rather than by individual studies. Biobanks also offer improved quality and reliability of genetic samples and access through automated sample retrieval. However, it is challenging to adequately inform participants of the broad nature of the research and participation risks and benefits. In addition, recent studies suggest concerns about data sharing and return of research results, or future research topics (eg, stereotypical or potentially stigmatizing traits). We evaluated the interest in participating in a biobank and reasons for nonparticipation.

Brief Report

MOLECULAR DATA, ESSENTIAL FOR genomics research, can be captured more efficiently in large-scale, population-based biobanks of genetic material rather than by individual studies. Biobanks also offer improved quality and reliability of genetic samples, and access through automated sample retrieval. However, it is challenging to adequately inform participants of the broad nature of the research and participation risks and benefits. In addition, recent studies suggest concerns about data sharing¹ and return of research results,^{2,3} or future research topics (eg, stereotypical or potentially stigmatizing traits).⁴ We evaluated the interest in participating in a biobank and reasons for nonparticipation.

This research was part of the development of a biobank at Kaiser Permanente Northwest (KPNW), an integrated healthcare delivery system in Oregon and Washington. Eventually, we plan to invite all adult members to contribute blood samples that are left-over after routine clinical visits. We developed written recruitment materials at an eighth grade reading level that were vetted by a communications team, focus groups of KPNW members, KPNW's Institutional Review Board (IRB), and external advisory boards. We then surveyed 500 KPNW members to assess response to the materials. Research staff approached KPNW members in waiting rooms, and asked them to review the materials then complete a brief survey on demographics, willingness to participate, reasons for nonparticipation, and knowledge of the written materials. Most questions were categorical, although 2 open-ended questions asked about reasons for nonparticipation and concerns or questions about the biobank. The overall response rate was 62%. SAS

Release 9 (SAS Institute, Cary, NC) was used for all statistical analysis including descriptive statistics, χ^2 -tests, and logistic regression for multivariate modeling. Qualitative responses were summarized using theme analysis to identify the most salient concerns regarding participation in the biobank.⁵ KPNW's IRB approved this study.

KPNW serves >485,000 members, which is about 17% of the area's population. Medicare members represent about 12% of KPNW's membership. Members over 65 represent 11.5% of total membership, 2% are below 200% of the federal poverty level, and 13% are minorities. Survey respondents were broadly representative of the overall adult membership including 39% male, 20% with a high school education or less, 16% minorities, and 50% over 49 years old.

Overall, 69% agreed to contribute to the biobank, 20% were not sure, and 11% did not agree (Table 1). Respondents who were more likely to agree to contribute were males (75% males vs. 64% females, $P = 0.02$), older (75% highest age group vs. 62% lowest age group, $P = 0.12$), more affluent (77% highest income group vs. 58% lowest income group, $P = 0.02$), and white (71% vs. 56% of minorities, $P = 0.002$). However, in a multivariate model to adjust for confounding factors, only gender remained in the model after backward variable selection.

In consideration of the NIH data sharing policy for genome-wide association studies (NIH Guide Notice: NOT-OD-07-008), we asked respondents if they would agree to allow researchers to post [their] information in a US government database that can be broadly shared with researchers worldwide to maximize the chances of new discoveries. Of those who would contribute to the biobank, 82% would

also agree to have their information posted in a US government database.

The primary reason for nonparticipation was concern about confidentiality of health-related and genetic information. Respondents who said they were not sure or would not agree to the biobank were asked "what is the main reason you would not give your left-over blood." The reasons for not agreeing to contribute to the biobank included concerns about confidentiality/privacy, lack of interest, confusion with a blood bank (eg, "I already give blood to the red cross"), concerns about sample use (eg, "I don't agree with all research, so I wouldn't agree to blindly participate in research"), lack of trust (eg, "I do not trust HMOs to protect my information and if you found something wrong, I would be afraid you would withhold care because of a known pre-existing condition"), and religious or philosophical reasons. Respondents who said they were not sure cited all of the same concerns listed above. However, many respondents in this category also said they would like more information (eg, "feel that I need a little more info[rmation] before deciding," "Need to think over what I read").

In addition to the qualitative responses, we asked whether 5 specific concerns affected the decision not to give their residual blood: (1) security and confidentiality of their *health* information, (2) security and confidentiality of their *genetic* information, (3) results for their sample will not be shared or returned to them, (4) the potential to develop commercial products, and (5) disapproval of future research studies

that could be conducted (respondents could select more than one). The most frequent issues were concern about security and confidentiality of *health* (73%) and *genetic* (61%) information, followed by disapproval of future research studies (40%). Concerns about commercialization and returning research results were not frequently selected (26% and 28%, respectively) as primary reasons for nonparticipation in this biobank.

Overall, 74% of respondents correctly answered ≥ 6 of 9 questions about the information presented in the recruitment materials, indicating a high level of comprehension. Respondents who were white (77% vs. 58% of minorities, $P = 0.004$), college graduates (83% vs. 52% of high school education or less, $P \leq 0.0001$), and more affluent (86% highest income group vs. 58% lowest income group, $P \leq 0.0001$) answered more questions correctly. Respondents who agreed to contribute to the biobank were more likely to correctly answer the knowledge questions (71% vs. 51% who did not agree or 56% who were not sure).

Biobanks will benefit genomic research most if they broadly represent the underlying population. Our findings indicate that in a healthcare setting, data security and confidentiality are the primary reasons for nonparticipation. Our findings that women and minorities are less willing to participate in genetic research are consistent with studies on similar topics,⁶⁻⁹ some of which have investigated possible solutions.¹⁰ Overall, many people will provide broad consent for population-based research.^{9,11-13} Although our

TABLE 1. CHARACTERISTICS OF SURVEY RESPONDENTS BY AGREEMENT TO CONTRIBUTE TO BIOBANK

Characteristic	Agree	Not sure	Not agree	P value ^a
N	301	90	47	
Gender, % male	43%	29%	36%	0.02
Race, % minority ^b	11%	23%	11%	0.02
Age				0.75
Under 31 years	12%	15%	22%	
31–40 years	19%	21%	20%	
41–50 years	19%	22%	16%	
51–60 years	24%	21%	22%	
61–70 years	15%	15%	11%	
Over 69 years	10%	7%	9%	
Education				0.16
High school graduate or less	18%	20%	30%	
Some college or technical school	34%	41%	32%	
College graduate	48%	39%	38%	
Employment				0.17
Employed for wages	53%	57%	67%	
Self-employed	10%	8%	7%	
Not working ^c	15%	20%	13%	
Retired	22%	15%	13%	
Income				0.05
Less than \$25,000	14%	22%	24%	
\$25,000–\$34,999	16%	12%	15%	
\$35,000–\$49,999	16%	21%	22%	
\$50,000–\$74,999	20%	17%	26%	
\$75,000 or more	34%	28%	13%	

^aWald χ^2 -test for dichotomous outcome, agree vs. no or not sure.

^bMinority includes: Black or African American (53%), Asian (14%), Native Hawaiian or other Pacific Islander (2%), American Indian or Alaska Native (7%), Other (23%).

^cNot working includes: unemployed (34%), homemakers (20%), students (24%), and unable to work (22%).

contact method is necessarily brief given the magnitude and broad scope of potential participation, recruitment could be improved by providing additional opportunities^{14,15} to learn about the biobank beyond the written materials presented in this survey.

Acknowledgments

This publication was made possible with support from the Oregon Clinical and Translational Research Institute (OCTRI), grant number UL1 RR024140 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research.

Author Disclosure Statement

The authors have no conflicts of interest to disclose.

References

- McGuire AL, Hamilton JA, Lunstroth R, et al. DNA data sharing: research participants' perspectives. *Genet Med* 2008;10:46–53.
- Murphy J, Scott J, Kaufman D, et al. Public expectations for return of results from large-cohort genetic research. *Am J Bioeth* 2008;8:36–43.
- Kaufman D, Murphy J, Scott J, et al. Subjects matter: a survey of public opinions about a large genetic cohort study. *Genet Med* 2008;10:831–839.
- Schwartz MD, Rothenberg K, Joseph L, et al. Consent to the use of stored DNA for genetics research: a survey of attitudes in the Jewish population. *Am J Med Genet* 2001;98:336–342.
- Ryan GW, Bernard HR. Techniques to identify themes. *Field Methods* 2003;15:85–109.
- Henderson G, Garrett J, Bussey-Jones J, et al. Great expectations: views of genetic research participants regarding current and future genetic studies. *Genet Med* 2008;10:193–200.
- McQuillan GM, Porter KS, Agelli M, et al. Consent for genetic research in a general population: the NHANES experience. *Genet Med* 2003;5:35–42.
- Bussey-Jones J, Henderson G, Garrett J, et al. Asking the right questions: views on genetic variation research among black and white research participants. *J Gen Intern Med* 2009;24:299–304.
- Sterling R, Henderson GE, Corbie-Smith G. Public willingness to participate in and public opinions about genetic variation research: a review of the literature. *Am J Public Health* 2006;96:1971–1978.
- Green BL, Partridge EE, Fouad MN, et al. African-American attitudes regarding cancer clinical trials and research studies: results from focus group methodology. *Ethn Dis* 2000;10:76–86.
- 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.
- Chen DT, Rosenstein DL, Muthappan P, et al. Research with stored biological samples: what do research participants want? *Arch Intern Med* 2005;165:652–655.
- Trauth JM, Musa D, Siminoff L, et al. Public attitudes regarding willingness to participate in medical research studies. *J Health Soc Policy* 2000;12:23–43.
- Godard B, Marshall J, Laberge C, et al. Strategies for consulting with the community: the cases of four large-scale genetic databases. *Sci Eng Ethics* 2004;10:457–477.
- Corbie-Smith G, Williams IC, Blumenthal C, et al. Relationships and communication in minority participation in research: multidimensional and multidirectional. *J Natl Med Assoc* 2007;99:489–498.

Address correspondence to:
Dr. Katrina A.B. Goddard
Center for Health Research
Kaiser Permanente Northwest
3800 N. Interstate Avenue
Portland, OR 97227

E-mail: katrina.goddard@kpchr.org

Received 22 September, 2009/Accepted 7 October, 2009