Published in final edited form as:

Transfusion. 2010 September ; 50(9): 1943–1950. doi:10.1111/j.1537-2995.2010.02667.x.

Biospecimen repositories: Are blood donors willing to participate?

Erik A. Scott¹, Karen S. Schlumpf², Sunitha M. Mathew², Alan E. Mast^{1,3}, Michael P. Busch⁴, and Jerome L. Gottschall¹ for the National Heart, Lung, and Blood Institute Retrovirus Epidemiology Donor Study-II (REDS-II)

¹ BloodCenter of Wisconsin, Milwaukee, WI

² Westat Corporation, Rockville, MD

³ Department of Cell Biology, Neurobiology and Anatomy, Medical College of Wisconsin, Milwaukee, WI

⁴ Blood Systems Research Institute, San Francisco, CA

Abstract

Background—Sponsored by the National Heart, Lung and Blood Institutes (NHLBI), the Retrovirus Epidemiology Donor Studies (REDS-I and -II) have conducted epidemiological, laboratory and survey research on volunteer blood donors. Some studies request additional permission to store biospecimens in a repository for future studies. Even if minority enrollment goals are achieved, minority participants may decline to participate in biospecimen repositories, potentially reducing the representativeness and applicability of studies performed using repositories.

Study Design and Methods—Demographics of donors consenting to “study only” or “study and repository” participation in the 2007 REDS-II Leukocyte Antibodies Prevalence Study (LAPS) were compared to data from a 1998 REDS-I survey of donor opinion regarding storage and use of biospecimens.

Results—Overall, 91% of LAPS subjects agreed to participate in the repository. Odds of repository participation were lower for subjects who were African American or Hispanic, 35 to 43 years old or had not completed high school. Odds of repository participation were lowest at one geographic location, regardless of other demographics. The 1998 survey of 50,000 blood donors revealed that 97% would approve of long-term storage of biospecimens for blood safety monitoring. Many donors would want notification or permission prior to repository participation.

Conclusion—Minority blood donors are less likely to participate in biospecimen repositories than Caucasians, though other variables also influence participation. The reluctance of minority donors to participate in repositories may result in a reduced number of biospecimens available for study and a decreased ability to definitely answer specific research questions in these populations.

Keywords

Repository; Participation; Minority

Corresponding Author: Erik Scott, BloodCenter of Wisconsin, 638 N. 18th Street, Milwaukee, WI 53233, Tel: 414-937-6023, Fax: 414-933-6803, erik.scott@bcw.edu.

The authors have no conflicts of interest or other financial involvement to declare.

A number of recent reports have described the utility of biospecimen repositories in transfusion medicine, both donor only repositories and matched donor-recipient repositories.^{1–5} Busch and Glynn recently editorialized on the usefulness of biospecimen repositories to blood-safety and infectious disease research alongside a study by Cannon et al. that utilized repository biospecimens to determine the transmission rate of human herpesvirus-8 through blood transfusion.^{6,7} Reesink and colleagues recently described the results of an international survey of repository practices, which indicated that many countries have a national policy requiring storage of biospecimens from blood donors.⁸ Although biospecimens are used mainly for infectious disease look-back investigations, testing new or more sensitive tests for products still in inventory, or for investigation of suspected TRALI cases, many countries also allow archived biospecimens to be used for research applications. Allain and Busch provide an extensive list of donor-only, recipient-only and linked donor-recipient repositories and cite over 200 original articles that use these repositories, emphasizing the high utility of biospecimen repositories.⁹

In the United States, there is no policy requiring storage of routine biospecimens from blood donors. Existing donor biospecimen repositories have been created through multi-center collaborative efforts such as the Transfusion-Transmitted Viruses Study, the Transfusion Safety Study, and the Retrovirus Epidemiology Donor Studies (REDS-I and II). The REDS-I group created four large repositories: the General Serum Repository (GSR), the General Leukocyte and Plasma Repository (GLPR), the REDS Allogeneic Donor and Recipient Repository (RADAR) and the HTLV Outcomes Study (HOST) repository, formerly known as the REDS HTLV Cohort.⁹ In most cases institutional review boards require that consent be obtained from participants before biospecimens are stored in repositories and allow patients/donors to refuse to participate. A potential limitation of volunteer-based biospecimen repositories is the representativeness of the participants to the population at large. More specifically, the well-documented limited participation of minorities in medical research studies may lead to under representation of some groups in studies performed using biospecimens obtained through volunteer repositories.^{10–12}

In 1998, REDS-I conducted a comprehensive mail survey of volunteer allogeneic donors. The survey was designed to measure donor demographics and donation patterns as well as attitudes regarding a diverse range of topics, such as motivation to donate, blood donation incentives, knowledge of infectious disease screening and transmission and unreported deferrable risks, and the influence of computer assisted self-interviewing on the likelihood of disclosing sensitive information during donor screening.^{13–17} In addition to those and other topics, five questions designed to determine donor opinion regarding storage of residual biospecimens from blood donations as well as potential uses of those biospecimens were included in the survey.

As part of the second REDS (REDS-II) program, the Leukocyte Antibody Prevalence Study (LAPS), which was designed to determine the prevalence and characteristics of antibodies to human leukocyte antigens (HLA) in the allogeneic donor population of the United States, included a secondary objective to create a repository of plasma and DNA biospecimens collected from well-characterized donor-subjects who were also willing to allow residual biospecimens to be preserved and used for future transfusion medicine research. The rationale, design and implementation of LAPS has previously been described.^{18,19}

The impetus for this analysis arose from an anecdotal observation by recruitment staff that minority donors, though willing to participate in the antibody screening arm of the LAPS protocol, were less likely to agree to also participate in the LAPS repository. This report describes subject participation rates in the LAPS biospecimen repository by race/ethnicity and other demographic parameters (e.g., gender, geographic region) and then compares them

to donor opinions regarding the collection, storage and use of biospecimens for research collected through the 1998 REDS-I survey.

MATERIALS AND METHODS

The Leukocyte Antibodies Prevalence Study (LAPS)

LAPS was conducted between December 2006 and May 2007 as a prospective cross-sectional multicenter study by the National Heart, Lung, and Blood Institute's (NHLBI) Retrovirus Epidemiology Donor Study-II (REDS-II) program. All six REDS-II blood centers participated in the study: American Red Cross New England Region (Dedham, MA); American Red Cross Southern Region (Douglasville, GA); BloodCenter of Wisconsin (Milwaukee, WI); Blood Centers of the Pacific (San Francisco, CA); Hoxworth Blood Center/University of Cincinnati Academic Health Center (Cincinnati, OH); and the Institute for Transfusion Medicine (Pittsburgh, PA). Westat (Rockville, MD) and Blood Systems Research Institute (San Francisco, CA) functioned as the REDS-II coordinating center and central laboratory, respectively.

The LAPS protocol was approved by institutional review boards of each participating REDS-II institution. The recruitment goal was 7,900 allogeneic donors, distributed evenly among the six REDS-II blood centers and comprised of 1,100 male donors who had previously received an allogeneic blood transfusion, 1,100 male donors who had never been transfused and 5,700 female blood donors. Potential subjects were required to be at least 18 years old and eligible to donate an allogeneic blood product. No other recruitment criteria were specified.

All subjects consented to allogeneic blood donation and completed the LAPS Informed Consent (IC) prior to participation in the study. The majority of subjects were approached by dedicated research staff subsequent to successful donor qualification, though two centers obtained consent from a small percentage of female and transfused male donors by mail prior or subsequent to a successful donation. Biospecimens from donors recruited by mail were sequestered until a completed IC was received. Donors recruited in person received a verbal description of the study; interested donors read the IC and were given an opportunity to have their questions answered prior to completing the two-part IC. The first section indicated the subject's "consent to participate in white blood cell antibody testing and characterization." The second section concerned the biospecimen repository, indicating the subject's "consent to participate in storage of my sample and consent for future studies that may be performed with my sample that are designed to improve our understanding of transfusion biology and transfusion safety."

1998 REDS-I Survey

In 1998, REDS-I mailed an anonymous survey to 92,581 volunteer allogeneic (community whole blood, apheresis, directed) donors to better understand the factors that influence blood donation behavior, the presence of risk factors for deferral, and demographic distributions of the donor population. Respondents were also asked their opinion regarding the collection of biospecimens for long-term storage and future research. Five survey questions addressed this area and were preceded by the following statements:

Collection and Storage of Blood. Sometimes blood (1–2 tablespoons) may be saved from donations for long-term storage and future research. This blood is linked to the donor's records and may be used to monitor the safety of the blood supply as new infectious disease tests become available. This blood may also be used for other research studies. Any medically important test results are given to the donor. Please give your opinion about each of the following items.

Sample selection and survey procedures have been described in detail in a previous publication.²⁰

Statistical Analysis

A logistic regression model was developed to determine the predictive factors for participation in the LAPS repository. The final model included race/ethnicity, geographic location (i.e. enrolling blood center), gender, age, donor status (i.e. first-time versus repeat), transfusion recipient, number of pregnancies and level of education as independent variables. Frequency distributions of the 1998 REDS survey data were generated using weighted estimates.

RESULTS

LAPS Recruitment and Repository Participation

A total of 8,171 subjects were enrolled in LAPS, 7,452 (91%) of whom also agreed to participate in the biospecimen repository. Caucasians accounted for 90% of LAPS subjects. Almost 97% of subjects had donated allogeneic blood at least one time prior to the donation at which they were enrolled. Subjects agreeing to participate in the repository were classified as “Study and Repository” and subjects declining to participate in the repository are classified as “Study Only.” Among Caucasians, 92% were willing to participate in both arms. Lower repository participation rates were seen within minority groups: approximately 88% of Asians, 84% of Hispanics and 70% of African Americans agreed to participate in both the study and the repository. Repository participation rates by blood center ranged from 68% to 99% of enrolled LAPS subjects, though participation at all but one blood center was over 90%. Repository participation rates were similar for male (90.5%) and female (91.5%) subjects. Adjusted odds ratios (OR) and 95% Confidence Intervals (CI) for repository participation are presented in Table 1. Repository participation was not influenced by gender, donor status, prior transfusions or number of pregnancies. Race/ethnicity and geographic location exerted the largest effect on the likelihood of repository participation. Both Hispanic and African American donors had lower odds of participating in the repository than their Caucasian counterparts. Compared to donors at site 1, site 2 donors had somewhat reduced odds of repository participation while donors at site 3 had much lower odds of participating in the repository. In contrast, donors at sites 4 and 5 had much higher odds of repository participation. Donors aged 35 to 44 had significantly lower odds of participating in the repository than donors between the ages of 45 and 54. In addition, the odds of repository participation were lower for donors with less than a high school education compared to donors with a college or graduate degree.

1998 REDS Survey

Of the 92,581 donors sampled, 52,650 returned the 1998 opinion survey (56.9% response rate). Respondents were more likely to be older, repeat, and female donors. Among the 66 years and older donors, 73% responded compared to 39% of the 26 years and younger donors. Response rates for repeat and first-time donors were 61% and 41%, respectively. Sixty-one percent of females and fifty-two percent of males responded.

Tables 2 and 3 present survey results by question and race/ethnicity. Approximately 85.5% of responding donors were Caucasian; race/ethnicity data was unavailable for 2.3% of respondents. Overall, 3.3% of respondents felt that a small amount of blood from all donors should not be stored for long-term blood safety monitoring. Of the respondents who indicated that a biospecimen should be stored, opinions regarding informing the donor or obtaining the donor's permission varied among different ethnicities. Twenty-six percent of respondents indicated that donor permission should be obtained before storing a

biospecimen, ranging from 25.9% of Caucasians to 33.0% of African American respondents. The opinion that a donor should be notified prior to biospecimen storage varied less, ranging from 17.2% of others to 22.5% of Asian respondents with an average response rate of 18.9%. Eighty-seven percent of respondents indicated they would allow a biospecimen of their blood to be stored if they were asked. Only 2.0% of respondents indicated that, if asked, they would refuse to allow a biospecimen of their blood to be stored; the highest rate of refusal was observed among African Americans (3.8%) and the lowest among Caucasians (1.8%). The remaining 10.6% of respondents were not sure if they would allow a biospecimen of their own blood to be stored, ranging from 10.0% of Caucasians to 18.3% African Americans.

Over 95% of respondents indicated it would be “OK” to test stored blood for any research, though two thirds of respondents would require the donor’s permission to do so. The requirement to obtain permission ranged from 60.3% of Caucasians to 73.3% of Asian donors. Of the 4.6% that did not think it was acceptable to test stored blood for any research, the highest rate was observed among other race/ethnicities (7.5%) and the lowest among Caucasians (4.3%). Ninety-nine percent of respondents indicated it would be acceptable to test stored blood for research on blood supply safety, with 56.5% of respondents indicating it would be ok to do so without donor permission. The requirement to obtain permission for this type of activity ranged from 53.5% of African Americans to 41.2% of Caucasians. Two percent of African American respondents indicated this type of activity would not be acceptable, as did almost one percent of Caucasian and Asian respondents.

If asked, 87.3% of respondents would give permission for their stored blood to be tested; this opinion ranged from 88.0% of Caucasians to 77.2% of African Americans. Only 1.4% of respondents said they would not give such permission; 1.2% of Caucasians indicated they would refuse such a request, as would 2.9% of African Americans. Overall, 11.3% of respondents were not sure if they would give permission; Caucasians expressed the lowest rate of uncertainty (10.8%) and African Americans expressed the highest (19.9%).

DISCUSSION

We have described allogeneic blood donors’ participation in a recent research-study-associated biospecimen repository alongside historical survey data regarding donors’ self-reported attitudes on long-term storage and use of biospecimens. In 1998, 96.7% of respondents indicated storing biospecimens in a repository for future use was acceptable with donor permission or notification, while only 87.4% of respondents indicated they themselves would give their permission for such an activity. Almost a decade later, 91.2% of LAPS subjects agreed to participate in the study-associated biospecimen repository, a repository specifically intended for research designed to improve blood safety and transfusion medicine knowledge. Participation rates in the LAPS repository along with results from the 1998 REDS survey suggest U.S. blood donors generally support the creation of biospecimen repositories. The degree of support in LAPS repository participation rates varies by ethnicity and surprisingly, an apparent strong regional affect.

Our analysis indicates that donors enrolling in LAPS at sites 2 and 3 had significantly lower odds of participating in the repository than donors enrolled at other sites. The regional effect for site 2 was relatively minor compared to site 3. Enrolling at site 3 exerted a greater effect than being of Hispanic or African American descent, as site 3 experienced relatively low participation rates across all ethnic groups. While this may be simply attributable to lack of effort on the part of recruitment staff, there are likely additional factors at play because all sites achieved their recruitment goal for antibody testing and the coordinating center provided a Manual of Procedures (MOP) which allowed staff to recruit subjects using

similar procedures. However, whereas recruiters at all sites were aware that the primary goal of LAPS was to consent donors for antibody testing, they may not have consistently emphasized the secondary objective, i.e., that of repository participation. Inclusion of a recruitment script in the MOP would have helped standardize the recruitment process for both goals of the study and may have increased repository participation.

Other factors known to influence participation in research include access to research, race, gender, socio-economic status, education level, age, marital status, culture and trust.²¹ The possibility of genetic research may also be a deterrent to participation, particularly among non-Caucasians.²² Other variables, such as age, education level, donor status and gender characteristics exerted little to no effect in this analysis. While specific ethnic characteristics may play some part in the low rate of repository participation at site 3, a general sense of distrust of research among donors in this region may also have played a role. These data suggest that researchers in certain geographic areas may need to engage in trust-building activities and train recruitment staff to explain research studies and privacy safeguards to potential subjects in greater detail in order to achieve higher participation rates. Such activities may be particularly important if recruitment staff is also distrustful of repository participation.

It is well-documented that the majority of volunteer blood donors are Caucasian, although efforts to increase minorities to donate blood have been productive.^{23,24} Various reports also suggest that minorities are less likely to participate in research because of either distrust arising from knowledge of previous research studies that took advantage of minority subjects, particularly the Tuskegee study, or a lack of interest in research.²⁵ There are also reports that attribute the low level of minority participation in research to the fact that minorities are less likely to be given the opportunity to participate in research.²⁶ Data from LAPS and the 1998 REDS survey suggest that minorities are willing to participate in research studies when the opportunity is provided. Participation in the LAPS repository was over 50% at all REDS-II blood centers but did vary somewhat by race/ethnicity and even more by geographic region, with two sites experiencing lower repository participation rates regardless of race/ethnicity. Sites 2 and 3 enrolled the highest number of minority subjects and only one of those sites experienced what would be considered a low rate of repository participation; the overall participation rate at site 2 was similar to the average participation rate for all six blood centers. The survey data, while indicating general support for the storage of biospecimens for research related to the safety of the blood supply (99.0%) as well as research in general (95.4%), indicates differences in level of support among ethnic groups. In both cases a higher yet still relatively small percent of African American donors indicated they would not agree to provide stored donated biospecimens for blood safety research (2.2%) or general research (6.7%).

It has been suggested that minority subjects may be more likely to participate in a study when the recruiter was of similar ethnic background.²⁷ LAPS recruitment staff consisted of non-Hispanic Caucasians at four of the six blood centers. Recruiters at site 3 were of African American heritage; Caucasian and Asian recruiters consented subjects at site 2. Sites 2 and 3 enrolled a similar number of subjects as other centers but together recruited 69% of all minority subjects. These two centers also experienced the lowest overall repository participation rates, although as previously noted site 3 experienced repository participation rates of only 55–70% across all ethnicities while the lowest participation rate at site 2 was 85%. These enrollment figures are representative of the ethnic makeup of the respective donor populations and the relative consistency of repository participation rates across ethnicities at each center suggests that the race/ethnicity of the recruiter may not exert much influence on willingness to participate in a study. However, the lack of documentation

regarding the number and race/ethnicity of donors who completely refused to participate in LAPS allows the possibility that recruiter race/ethnicity could influence participation rates.

Among the limitations of this data analysis, the relatively low rate of blood donation among minority populations should be considered. This is reflected in the race/ethnicity of LAPS subjects (90.1% Caucasian) as well as participants in the 1998 REDS survey (85.5% Caucasian). Such low numbers of minority participants and confounding characteristics such as age, education and geographic location make it difficult to draw definitive conclusions about specific groups. Additionally, LAPS subjects were predominately repeat donors. It is unclear how first-time donors may consider participation in a biospecimen repository. Also, it is unfortunate that LAPS recruitment staff did not document refusals to participate in the antibody screening component of the study and hence we are unable to report the rate at which blood donors refused to participate in the study at all. Anecdotally, staff reported infrequent occurrences of complete refusal. It is quite likely that the nature of the research study itself influences the decision to participate, suggested by the fact that a preponderance of approached blood donors agreed to participate in the well-defined and finite antibody testing arm of the study while only a subset of study participants allowed a biospecimen of their blood to be stored for future research related to the safety of the blood supply. Lastly, as only allogeneic blood donors were included in this study, these findings may not reflect attitudes and practices of non-donors.

This data analysis and review of relevant research suggest methods that could be employed to increase the participation of donors, particularly among minorities, in transfusion medicine research repositories. Defining enrollment goals by race/ethnicity may increase the number of minority participants, although recruitment time may need to be extended if the minority population remains small. Targeted recruitment of minority donors may be necessary to ensure that minorities are well represented in repositories. Clearly specifying the aim and methodology of the research protocol, including characterizing the study as relating to transfusion medicine and blood safety instead of general research, may also encourage higher participation rates. Future studies should also document the race/ethnicity of recruiters and overall rates of refusal along with the race/ethnicity of those potential subjects, to determine if recruiter race/ethnicity does play a role in the decision to participate in a study.

While the development and maintenance of transfusion medicine biospecimen repositories involve significant costs, such repositories have the capacity to be highly useful to a variety of research programs. Blood donors, particularly dedicated repeat donors, represent a well-characterized population that is generally supportive of research related to transfusion medicine and blood safety, as well as broader biomedical research. This study reveals that although minority blood donors are more reluctant to participate in a biospecimen repository, most would agree to do so. Given regional and ethnic differences in research participation, it remains important to attempt to ensure that research protocols, especially those including biospecimen repositories, enroll a significant number of minority participants.

Acknowledgments

The authors thank the staff at all six participating blood centers. Without their help, this study would not have been possible.

This work was supported by NHLBI contracts N01-HB-47168, -47174, -47175 and -57181.

References

1. Franklin IM, Dow BC, Jordan AD. Benefits of a blood donation archive repository: international survey of donor repository procedures and Scottish experiences. *Transfusion* 2007;47:1172–1179. [PubMed: 17581151]
2. Yoshikawa A, Gotanda Y, Minegishi K, Taira R, Hino S, Tadokoro K, Ohnuma H, Miyakawa K, Tachibana K, Mizoguchi H. Lengths of hepatitis B viremia and antigenemia in blood donors: preliminary evidence of occult (hepatitis B surface antigen-negative) infection in the acute stage. *Transfusion* 2007;47:1162–1171. [PubMed: 17581150]
3. Satake M, Taira R, Yugi H, Hino S, Kanemitsu K, Ikeda H, Tadokoro K. Infectivity of blood components with low hepatitis B virus DNA levels identified in a lookback program. *Transfusion* 2007;47:1197–1205. [PubMed: 17581154]
4. Matsumoto C, Tadokoro K, Fujimura K, Hirakawa S, Mitsunaga S, Juji T. Analysis of HBV infection after blood transfusion in Japan through investigation of a comprehensive donor specimen repository. *Transfusion* 2001;41:878–884. [PubMed: 11452155]
5. Kleinman SH, Glynn SA, Higgins MJ, Triulzi DJ, Smith JW, Nass CC, Garratty G, Murphy EL, LeParc GF, Schreiber GB, King MR, Chamberland ME, Nemo GJ. The RADAR repository: a resource for studies of infectious agents and their transmissibility by transfusion. *Transfusion* 2005;45:1073–1083. [PubMed: 15987350]
6. Busch MP, Glynn SA. Use of blood-donor and transfusion-recipient biospecimen repositories to address emerging blood-safety concerns and advance infectious disease research: the national heart, lung, and blood institute biologic specimen repository. *Journal of Infectious Disease* 2009;199:1564–1566.
7. Cannon MJ, Operskalski EA, Mosley JW, Radford K, Dollard SC. Lack of evidence for human herpesvirus-8 transmission via blood transfusion in a historical US cohort. *Journal of Infectious Disease* 2009;199:1592–1598.
8. Reesink HW, Engelfriet CP, Hyland CA, Coghlan P, Tait B, Wsolak M, Keller AJ, Henn G, Mayr WR, Thomas I, Osselaer J-C, Lambermont M, Beaten M, Wendel S, Qiu Y, Georgsen J, Krusiu T, Mäki T, Andreu G, Morel P, Lefrère J-J, Rebullà, Giovanelli S, Butti B, Lecchi L, Mozzi F, van Hilten JA, Zwaginga JJ, Flanagan P, Flesland Ø, Brojer E, Łętowska M, Åkerblom O, Norda R, Prowse C, Dow B, Jarvis L, Davidson F, Kleinman S, Bianco C, Stramer SL, Dodd RY, Busch MP. Biobanks of blood from donors and recipients of blood products. *Vox Sang* 2008;94:242–260. [PubMed: 18225990]
9. Allain JP, Busch MP. Donation archives and prospective donor-recipient repositories: indispensable tools for monitoring blood safety. *Transfusion* 2007;47:1110–1114. [PubMed: 17581143]
10. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA* 2004;291(22):2720–6. [PubMed: 15187053]
11. Gavaghan H. Clinical trials face lack of minority group volunteers. *Nature* 1995;373:178. [PubMed: 7816116]
12. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology* 2002;12:248–256. [PubMed: 11988413]
13. Glynn SA, Kleinman SH, Schreiber GB, Zuck T, McCombs S, Bethel J, Garratty G, Williams AE. Motivations to donate blood: demographic comparisons. *Transfusion* 2002;42:216–225. [PubMed: 11896338]
14. Glynn SA, Williams AE, Nass CC, Bethel J, Kessler D, Scott EP, Fridey J, Kleinman SH, Schreiber GB. Attitudes toward blood donation incentives in the United States: implications for donor recruitment. *Transfusion* 2003;43:7–16. [PubMed: 12519425]
15. Sharma UK, Schreiber GB, Glynn SA, Nass CC, Higgins MJ, Tu Y, Bethel J, Williams AE. Knowledge of HIV/AIDS transmission and screening in United States blood donors. *Transfusion* 2001;41:1341–1350. [PubMed: 11724976]
16. Schreiber GM, Sanchez AM, Garratty G, Nass CC, Tu Y, Busch MP. Mammalian brain consumption in blood donors in the United States: brains today, deferred tomorrow? *Transfusion* 2004;44:667–674. [PubMed: 15104646]

17. Sanchez AM, Schreiber GB, Glynn SA, Bethel J, Kessler D, Chang D, Zuck TF. Blood-donor perceptions of health history screening with a computer-assisted self-administered interview. *Transfusion* 2003;43:165–172. [PubMed: 12559011]
18. Triulzi DJ, Kakaiya R, Schreiber G. Donor risk factors for white blood cell antibodies associated with transfusion-associated acute lung injury: REDS-II Leukocyte Antibody Prevalence Study (LAPS). *Transfusion* 2007;47:563–564. [PubMed: 17381611]
19. Triulzi DJ, Kleinman S, Kakaiya RM, Busch MP, Norris PJ, Steele WR, Glynn SA, Hillyer CD, Carey P, Gottschall JG, Murphy EL, Rios JA, Ness PM, Wright DJ, Carrick D, Schreiber GB. The effect of previous pregnancy and transfusion on HLA alloimmunization in blood donors: implications for a transfusion-related acute lung injury risk reduction strategy. *Transfusion* 2009;49:1825–1835. [PubMed: 19453983]
20. Glynn SA, Smith JW, Schreiber GB, Kleinman SH, Nass CC, Bethel J, Biswas B, Thomson RA, Williams AE. Repeat whole-blood and plateletpheresis donors: unreported deferrable risks, reactive screening tests, and response to incentive programs. *Transfusion* 2001;41:736–743. [PubMed: 11399812]
21. Corbie-Smith GM. Minority recruitment and participation in health research. *North Carolina Medical Journal* 2004;65(6):385–387. [PubMed: 15714732]
22. Rice MS, Custer BS, Hindes DA, Hirschler N, Nguyen KA, Busch MP, Murphy EL. Genetic Research in the blood bank: Acceptability to donors. Abstract P-671). *Vox Sang* 2008;95(suppl 1): 304–305.
23. McNeal C. BloodCenter of Wisconsin: Diversifying the Blood Supply One Donor at a Time. *AABB News* 2009;11(3):8–9.
24. Price CL, Johnson MT, Lindsay T, Dalton D, DeBaun MR. The Sickle Cell Sabbath: a community program increases first-time blood donors in the African-American faith community. *Transfusion* 2009;49:515–523.
25. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology* 2002;12:248–256. [PubMed: 11988413]
26. Wendler D, Kington R, Madans J, Van Wye G, Christ-Schmidt H, Pratt LA, Brawley OW, Gross CP, Emanuel E. Are racial and ethnic minorities less willing to participate in health research? *Proceedings of the Library of Science Medicine* 2006;3(2):e19.
27. Ballen KK, Hicks J, Dharan B, Ambruso D, Anderson K, Bianco C, Bemiller L, Dickey W, Lottenberg R, O'Neill M, Popovsky M, Skerrett D, Sniecinski I, Wingard JR. Racial and ethnic composition of volunteer cord blood donors: comparison with volunteer unrelated marrow donors. *Transfusion* 2002;42:1279–1284. [PubMed: 12423511]

Appendix

The Retrovirus Epidemiology Donor Study - II (REDS-II Study Group) is the responsibility of the following persons:

Blood Centers

American Red Cross Blood Services, New England Region

R. Cable, J. Rios and R. Benjamin

American Red Cross Blood Services, Southern Region/Department of Pathology and Laboratory Medicine, Emory University School of Medicine

J.D. Roback

Hoxworth Blood Center, University of Cincinnati Academic Health Center

R.A. Sacher, S.L. Wilkinson and P.M. Carey

Blood Centers of the Pacific, University of California San Francisco, Blood Systems Research Institute

E.L. Murphy, B. Custer and N. Hirschler

The Institute for Transfusion Medicine

D. Triulzi, R. Kakaiya and J. Kiss

Blood Center of Wisconsin

J. Gottschall and A. Mast

Coordinating Center: Westat, Inc

J. Schulman and M. King

National Heart, Lung, and Blood Institute, NIH

G.J. Nemo and T. Mondoro

Central Laboratory: Blood Systems Research Institute

M.P. Busch and P. Norris

Table 1

Adjusted odds ratios for LAPS repository participation by demographic and other factors

	Adjusted OR (95% CI)
<u>Race/Ethnicity</u>	
Caucasian	1.00
Asian	0.71 (0.44 – 1.16)
African American	0.48 (0.34 – 0.68)
Hispanic	0.46 (0.31 – 0.68)
Other	1.08 (0.55 – 2.08)
<u>Geographic location</u>	
Site 1	1.00
Site 2	0.67 (0.48 – 0.92)
Site 3	0.13 (0.10 – 0.17)
Site 4	5.08 (2.86 – 9.09)
Site 5	7.41 (3.85 – 12.50)
Site 6	1.09 (0.77 – 1.56)
<u>Gender</u>	
Female	1.00
Male	0.92 (0.70 – 1.22)
<u>Age</u>	
18 ≤ 24 yrs old	0.97 (0.67 – 1.41)
25 ≤ 34 yrs old	0.96 (0.71 – 1.30)
35 ≤ 44 yrs old	0.72 (0.57 – 0.92)
45 ≤ 54 yrs old	1.00
55 ≤ 64 yrs old	1.12 (0.88 – 1.45)
65+ yrs old	0.78 (0.57 – 1.08)
<u>Donor Status</u>	
First-Time	1.00
Repeat	1.08 (0.67 – 1.72)
<u>Transfused?</u>	
Yes	0.82 (0.64 – 1.06)
No	1.00
<u>Number of Pregnancies</u>	
None	1.00
One	0.78 (0.55 – 1.11)
Two	0.90 (0.67 – 1.22)
Three	0.90 (0.65 – 1.25)
Four or more	1.03 (0.72 – 1.45)
<u>Education</u>	
< High School	0.52 (0.28 – 0.99)

	Adjusted OR (95% CI)
High School/GED	1.16 (0.85 – 1.61)
Some College	0.72 (0.44 – 1.20)
≥ College	1.00

Table 2
REDS 1998 Survey responses regarding long-term storage of donor biospecimens for blood safety monitoring

	White	Asian	Black	Hispanic	Other	Total N
Question 1: "Opinion about long-term storage for blood safety monitoring: A small amount of blood from all donors..."						
Total Respondents	41,898 (85.5%)	1,560 (3.2%)	1,981 (4.0%)	2,896 (5.9%)	658 (1.3%)	48,993
should be stored	52.2 %	46.5 %	43.3 %	50.4 %	49.5 %	25,241 (51.5%)
should be stored <u>only</u> if donors are notified that it is being saved.	18.8 %	22.5 %	20.4 %	19.4 %	17.2 %	9,239 (18.9%)
should be stored <u>only</u> if donors provide specific permission for their blood to be stored.	25.9 %	27.8 %	33.0 %	26.9 %	29.2 %	12,906 (26.3%)
should <u>not</u> be stored.	3.1 %	3.1 %	3.3 %	3.3 %	4.1 %	1,607 (3.3%)
Question 2 "If asked, would you give permission for a small amount of your blood to be stored?"						
Total Respondents	43,498 (85.6%)	1,611 (3.2%)	2,049 (4.0%)	2,995 (5.9%)	688 (1.4%)	50,841
Yes	88.2 %	85.2 %	77.9 %	84.5 %	81.1 %	44,426 (87.4%)
No	1.8 %	2.7 %	3.8 %	2.8 %	3.7 %	1,015 (2.0%)
Not Sure	10.0 %	12.1 %	18.3 %	12.7 %	15.2 %	5,400 (10.6%)

Table 3

REDS 1998 Survey responses regarding use of stored donor biospecimens for general research or blood supply safety

	White	Asian	Black	Hispanic	Other	Total N
Question 3: "Please indicate your opinion of testing stored blood for <i>any</i> research"						
Total Respondents	42,626 (85.5%)	1,578 (3.2%)	1,992 (4.0%)	2,908 (5.8%)	671 (1.3%)	49,775
OK with Donor's permission	60.3 %	73.3 %	69.1 %	67.2 %	66.6 %	30,529 (61.3%)
OK without Donor's permission	35.5 %	22.0 %	24.2 %	28.1 %	25.9 %	16,952 (34.0%)
Not OK	4.3 %	4.7 %	6.7 %	4.7 %	7.5 %	2,294 (4.6%)
Question 4: "Please indicate your opinion of testing stored blood for research on blood supply safety"						
Total Respondents	41,600 (85.5%)	1,559 (3.2%)	1,953 (4.0%)	2,883 (5.9%)	659 (1.3%)	48,654
OK with Donor's permission	41.2 %	50.9 %	53.5 %	49.5 %	49.8 %	20,760 (42.7%)
OK without Donor's permission	57.9 %	48.2 %	44.2 %	49.0 %	47.9 %	27,380 (56.3%)
Not OK	0.9 %	0.9 %	2.2 %	1.5 %	2.2 %	514 (1.1%)
Question 5: "If asked, would you give permission for a small amount of your stored blood to be tested?"						
Total Respondents	43,428	1,604	2,041	2,999	685	50,757
Yes	88.0 %	85.7 %	77.2 %	85.8 %	81.0 %	44,302 (87.3%)
No	1.2 %	2.0 %	2.9 %	2.1 %	2.8 %	718 (1.4%)
Not Sure	10.8 %	12.4 %	19.9 %	12.1 %	16.2 %	5,737 (11.3%)