

Public Attitudes regarding the Donation and Storage of Blood Specimens for Genetic Research

Sophia S. Wang^{a,b} Fred Fridinger^c Kris M. Sheedy^b Muin J. Khoury^b

^aEpidemic Intelligence Service, Division of Applied Public Health Training, Epidemiology Program Office, ^bOffice of Genetics and Disease Prevention, National Center for Environmental Health, ^cDivision of Nutrition and Physical Activity, National Centre for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Ga., USA

Key Words

Genetic research · Blood donation · Blood storage · Public attitudes

Abstract

Objective: As sequencing of the human genome is completed, there is a need for population-based research to assess frequencies of genetic variants and their associations with human diseases. The authors therefore assessed the current climate regarding the donation and storage of blood for genetic research. **Methods:** Data from the American Healthstyles Survey of health attitudes and behavior were examined. In the 1998 survey, four questions regarding blood donation and storage for genetic research were posed to the participants. **Results:** Of 3,130 participants, 2,621 (84%) completed these questions. Of the respondents, 42% were in favor of both blood donation and long-term storage for genetic research, 37% were in favor of either blood donation or storage but not both and 21% were not willing to donate blood or have it stored for genetic research under any circumstances. Loglinear analysis demonstrated that the characteristics of respondents who favored both blood donation and long-term storage for genetic research

were attitudinal; specifically, those believing that genetic research will prevent disease [odds ratio (OR) 2.9; $p < 0.001$]; those believing in genetic determinism (OR 1.5; $p = 0.004$) and those agreeing they would participate in government research (OR 2.9; $p < 0.001$). The model also demonstrated that characteristics indirectly associated with attitudes towards blood donation/storage for genetic research were demographic and included higher education, white race, living in the Mountain/Pacific or mid-Atlantic regions of the United States and positive family history of a genetic disorder ($p < 0.05$). **Conclusion:** Understanding the various factors contributing to knowledge, attitudes and behavior regarding the donation and storage of blood specimens for genetic research will contribute to future actions in communicating genetic research goals to the public and recruitment for population-based genetic studies.

Copyright © 2001 S. Karger AG, Basel

Introduction

There is a current and ongoing need to determine the public health implications of each gene discovery. Understanding these implications will require population-based

KARGER

Fax +41 61 306 12 34
E-Mail karger@karger.ch
www.karger.com

© 2001 S. Karger AG, Basel
1422-2795/01/0041-0018\$17.50/0

Accessible online at:
www.karger.com/journals/cm

Muin J. Khoury, MD, PhD
Office of Genetics and Disease Prevention, Centers for Disease Control and Prevention
4770 Buford Highway, NE, Mailstop K-28
Atlanta, GA 30341 (USA)
Tel. +1 770 488 3235, Fax +1 770 488 3236, E-Mail mukl@cdc.gov

studies to determine frequencies of gene variants across different populations and ethnic groups and their associations with human diseases. Generation of these data will originate from large population-based cross-sectional, cohort and case-control studies that collect and store blood specimens for DNA analyses. Epidemiologic studies have therefore steadily moved toward collecting and storing biological specimens for genetic analysis [1-5]. These studies can be designed to assess already discovered genes or store specimens for future use when genes that have yet to be discovered are finally identified.

There is much consensus among the scientific community with regard to the value of collecting and storing blood specimens for genetic research [6-8]. A recent report by the National Bioethics Advisory Commission (NBAC) entitled 'Research Involving Human Biological Materials: Ethical Issues and Policy Guidance' [8] emphasized the value and importance for research investigators of both collecting human biological materials prospectively as well as accessing the more than 282 million specimens already in storage. Genetic and epidemiologic research will rely equally on the increasing use of biological specimens and the willingness of individuals to participate in such studies by donating and allowing storage of their biological specimens.

In addition to the NBAC's report and recommendations, policy statements and recommendations by scientific organizations such as the American College of Medical Genetics and the American Society of Human Genetics have addressed issues concerning the storage and use of genetic material [6, 7, 9]. Both organizations have issued guidelines for storing and using genetic materials for both prospective collection of samples and future genetic analysis, as well as for retrospective studies on existing and previously collected materials.

While scientific organizations have issued statements regarding the importance of collecting and using biological specimens for research, little information exists on the public's attitudes regarding the donation and storage of biological materials, such as blood, for such purposes. As part of their report, the NBAC contracted with the Center for Health Policy Studies to qualitatively assess public knowledge, beliefs and feelings about issues regarding human biological materials [10]. Discussions in distinct ethnic and sociodemographic groups in seven geographic locales were conducted. Results include finding participants comfortable with the confidential use of stored tissue and willing to relinquish ownership of their biological specimen with consent. However, because this study was not designed to draw conclusions about the

general public, these findings are limited in their generalizability.

The present study is intended to quantitatively assess current public opinion and attitudes regarding the donation and storage of blood for genetic research by analyzing a series of questions on genetics included in the 1998 Healthstyles survey. The assessment of the public's attitudes is crucial; the generalizability of and implications from population-based genetic studies will depend on the willingness of the public to participate.

Subjects and Methods

The study population originated from the 1998 Healthstyles survey, a yearly population-based cross-sectional market research survey of health attitudes and behaviors. The Healthstyles survey is a subsample of the annual DDB Needham Lifestyles survey, commissioned by DDB Needham Worldwide. The Lifestyles survey is conducted annually, and consists of 300-400 questions on demographics, perceived personality traits, media habits, shopping habits, political beliefs, religiosity, civic involvement, sensation-seeking scales, general life satisfaction, psychographics and additional lifestyle questions. Supplemental mailing of the Lifestyles survey is conducted to compensate for low response rates among low-income persons and minorities, therapy employing quota sampling to generate a list of participants representative of all US adults. The final sample of Lifestyles participants is balanced with regard to age, sex, marital status, race/ethnicity, income, region, household size and population density [11].

The Healthstyles survey is conducted annually, on a representative subset of the Lifestyles participants. The Healthstyles survey assesses relevant health data and health attitudes/behaviors; data analyzed in this study therefore included demographic, media use and questions that pertain to the participants' health knowledge, practices, attitudes and perceptions. Sampling and data collection was conducted for Porter Novelli, a Washington social marketing and health communication firm, with technical assistance and question development from several public health agencies, including the Centers for Disease Control and Prevention.

Seven questions regarding genetics were included in the 1998 Healthstyles survey. Four of the questions pertained to the donation and storage of blood specimens for genetic research.

On the basis of these questions, respondents were categorized in terms of their attitudes toward the collection and storage of blood specimens for genetic research. Participants were asked to answer the statements below on a scale from 1 to 5, with the scale defined as follows: 1, strongly disagree; 2, disagree; 3, neither disagree nor agree; 4 agree, and 5, strongly agree.

(1) I would be willing to donate blood for research to find genes that affect people's health.

(2) If I donated blood for a specific health research project, I would not mind if the blood was stored and used later for health research in genetics.

(3) I would donate my blood for health research in genetics but want a guarantee that researchers would not provide the test results to anybody except me.

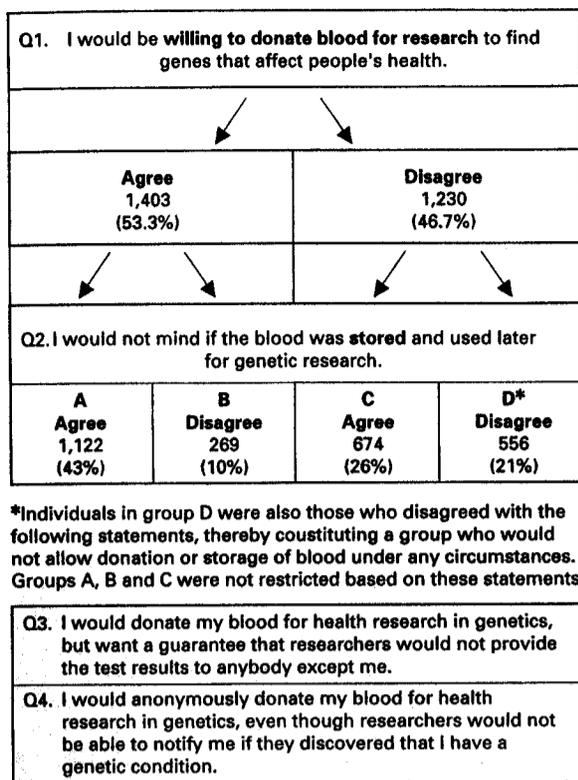


Fig. 1. Schematic diagram of population categorization for attitudes regarding the donation and storage of blood specimens for genetic research (n = 2,621).

(4) I would anonymously donate my blood for health research in genetics, even though researchers would not be able to notify me if they discovered that I have a genetic condition.

In the analysis, only those responding 4 or 5 were categorized as agreeing with the statement. Question 1 was used to dichotomize respondents into persons willing to donate blood for genetic research and persons unwilling to donate blood for genetic research. Upon this dichotomization, question 2 was used to dichotomize the two subgroups further. Respondents who agreed to both questions 1 and 2 were categorized as persons willing to both donate and store blood for genetic research purposes. Respondents who did not agree with all four statements were categorized as persons unwilling to have blood stored or donate blood, despite guarantees for confidentiality or anonymity. Final categories consisted of persons (A) willing to donate and store blood for genetic research without specification of confidentiality or anonymity, (B) willing to donate blood but not to have it stored for genetic research, (C) unwilling to donate blood for genetic research, but supposing that they did, would consider allowing storage of blood, and (D) unwilling to donate blood or have blood stored under any circumstances (fig. 1).

Univariate, stratified and multivariate analyses were conducted. Statistical significance was set at $p < 0.05$, two sided. Associations between demographic and behavioral factors regarding attitudes

toward the donation and storage of blood for genetic research were assessed. Adjusted odds ratios (ORs) for positive attitudes towards donating and storing blood for genetic research were calculated by multivariate logistic regression comparing the two extreme groups (A versus D). Demographic characteristics assessed included gender, race, age, population density, household income, education, geography, marital status and family history. Behavioral characteristics assessed included smoking habits, alcohol intake, body mass index and thrill-seeking behavior (defined as those seeking frightening experiences). Beliefs and attitudes assessed included beliefs on whether genetics will prevent disease in the future, if genes determine a person's health more than behavior or environment and attitudes toward participation in government studies. General knowledge on health issues was assessed by whether respondents were a source of health information for their families and friends. All covariates were dichotomized in the model except for geography, which was categorized into mid-Atlantic, Central, Mountain/Pacific and Northeast regions of the United States.

A loglinear model was subsequently constructed to simultaneously account for the indirect (demographic characteristics) as well as the direct (behavioral/attitudinal characteristics) pathways involved in attitude development towards the donation and storage of blood specimens for genetic research. Indirect and direct pathways were determined on the basis of results from the previous multivariate logistic regression. The use of the loglinear analysis allowed for a robust model to be constructed accounting for all characteristics directly and indirectly associated with our outcome. In this analysis, geography was dichotomized into mid-Atlantic or Mountain/Pacific and Central/Northeast regions of the United States. This geographical dichotomization was based on univariate analysis that demonstrated that those in the mid-Atlantic and Mountain/Pacific regions were statistically significantly associated with a favorable attitude towards blood storage while those in the Central/Northeast regions were not. ORs for the associations were calculated; the statistical significance of each interaction was determined using the likelihood ratio test. All analyses were performed with SAS 6.12 for Windows.

Results

Of the 3,130 Healthstyle participants, 84% (n = 2,621) responded to the genetics questions. Based on dichotomization of the first question, 53% (n = 1,391) of the respondents were willing and 47% (n = 1,230) were not willing to donate blood for genetic research. Upon dichotomization by the second question and qualifications with the third and fourth questions, 43% (n = 1,122) of the respondents were both willing to donate blood and in favor of blood storage for genetic research (group A), 10% (n = 269) of the respondents were willing to donate blood but not to have it stored for genetic research (group B), 26% (n = 674) were not willing to donate blood, but if they did, would allow storage (group C), and 21% (n = 556) of the respondents were neither willing to donate nor store blood for genetic research under any circumstances (group D) (fig. 1).

Table 1. Univariate analysis of demographic characteristics with regard to attitude toward blood donation and storage for genetic research (n = 2,621)

Demographics		Willing to donate blood		Not willing to donate blood		p value	A vs. D	
		A in favor of blood storage (n = 1,122)	B not in favor of blood storage (n = 269)	C may donate or allow storage under certain conditions (n = 674)	D no storage, no donation under any circumstances (n = 556)		OR	95% CI
Gender	male	461 (43%)	102 (10%)	280 (26%)	230 (21%)	0.760	1.0	0.8-1.2
	female	661 (43%)	167 (11%)	394 (25%)	326 (21%)		1.0	
Race	white	927 (44%)	205 (10%)	533 (25%)	433 (21%)	0.017	1.4	1.1-1.9
	black/Hispanic	158 (36%)	52 (12%)	124 (28%)	105 (24%)		1.0	
Age, years	≥65	226 (38%)	66 (11%)	187 (31%)	116 (20%)	0.011	1.2	0.9-1.8
	45-64	407 (47%)	82 (9%)	210 (24%)	177 (20%)		1.5	1.0-2.0
	30-44	371 (44%)	89 (10%)	205 (24%)	188 (22%)		1.2	0.9-1.8
	18-29	118 (40%)	32 (11%)	72 (24%)	75 (25%)		1.0	
Population density	urban	370 (44%)	83 (10%)	226 (27%)	162 (19%)	0.323	1.2	1.0-1.5
	rural	227 (43%)	45 (9%)	140 (27%)	113 (21%)		1.1	0.8-1.4
	suburban	525 (42%)	141 (11%)	308 (25%)	281 (22%)		1.0	
Household income, USD	≥50,000	479 (49%)	94 (10%)	210 (22%)	185 (19%)	0.001	1.5	1.2-1.8
	<50,000	643 (40%)	175 (11%)	464 (28%)	371 (22%)		1.0	
Education	college or more	729 (47%)	162 (10%)	372 (24%)	305 (19%)	0.001	1.5	1.2-1.9
	high school or less	393 (37%)	107 (10%)	302 (29%)	251 (24%)		1.0	
Geography	Central	456 (41%)	107 (10%)	293 (27%)	242 (22%)	0.174	1.4	0.9-2.2
	mid-Atlantic	377 (43%)	92 (11%)	226 (26%)	176 (20%)		1.6	1.0-2.5
	Mountain/Pacific	234 (46%)	53 (10%)	128 (25%)	96 (19%)		1.9	1.2-2.9
	Northeast	55 (39%)	17 (12%)	27 (19%)	42 (30%)		1.0	
Marital status	divorced	131 (49%)	24 (9%)	62 (23%)	49 (18%)	0.017	1.4	0.8-2.3
	married	763 (44%)	173 (10%)	426 (24%)	391 (22%)		1.0	0.7-1.3
	never married	134 (39%)	44 (13%)	97 (28%)	68 (20%)		1.0	0.6-1.6
	widowed	80 (36%)	25 (11%)	76 (34%)	42 (19%)		1.0	
Family history	yes	162 (52%)	33 (11%)	60 (19%)	57 (18%)	0.003	1.5	1.1-2.0
	no	724 (41%)	176 (10%)	468 (27%)	376 (22%)		1.0	

Differences in demographic characteristics were assessed between the four groups (table 1). Significant differences were observed for race, age, household income, education, marital status and family history of a genetic disorder. Comparing groups A and D, however, significant associations were limited to white race [OR 1.4, 95% confidence interval (CI) 1.1-1.9], household income of USD 50,000 and higher (OR 1.5, 95% CI 1.2-1.8), those living in the Mountain/Pacific region (OR 1.9, 95% CI 1.2-2.9) and positive family history of a genetic disorder (OR 1.5, 95% CI 1.1-2.0). Respondents believing genetic research will help prevent disease in the future or believing that genes are more determinant of a person's health than behavior or environment, and those who said they would participate in government research studies in general were also significantly different between the four

groups. Behaviors that were significantly different between the four groups were alcohol intake, body mass index levels and thrill-seeking (liking or seeking frightening activities). Lastly, those who said they were a source of health information for their family and friends were also more likely to possess positive attitudes (table 2). Comparing A to D, significant differences were maintained for smoking (>21 cigarettes/day) (OR 1.9, 95% CI 1.1-3.4), moderate/high alcohol intake (OR 1.6, 95% CI 1.2-2.0), participation in government studies (OR 6.2, 95% CI 4.9-7.7), thrill-seeking behavior (OR 2.1, 95% CI 1.5-2.8), belief in genetic research preventing disease (OR 4.6, 95% CI 3.7-5.8) and belief in genetic determinism (OR 2.1, 95% CI 1.6-2.6).

Assessing these characteristics in a multivariate logistic regression model adjusting for covariates, we found

Table 2. Univariate analysis of behavioral and attitudinal characteristics with regard to attitude towards donation and storage of blood for genetic research (n = 2,621)

Behavior/attitudes		Willing to donate blood		Not willing to donate blood		p value	A vs. D	
		A in favor of blood storage (n = 1,122)	B not in favor of blood storage (n = 269)	C may donate or allow storage under certain conditions (n = 674)	D no storage, no donation under any circumstances (n = 556)		OR	95% CI
Smoking, cigarettes/day	>21	57 (53%)	13 (12%)	23 (21%)	15 (14%)	0.083	1.9	1.1-3.4
	≤21	1,065 (42%)	256 (10%)	651 (26%)	541 (22%)		1.0	
Alcohol ¹	moderate/high	561 (46%)	118 (10%)	309 (25%)	225 (19%)	0.001	1.6	1.2-2.0
	never/low	546 (39%)	149 (11%)	363 (26%)	328 (24%)		1.0	
BMI, kg/m ²	≥25	698 (45%)	153 (10%)	373 (24%)	321 (21%)	0.025	1.2	1.0-1.5
	<25	424 (39%)	116 (11%)	301 (28%)	235 (22%)		1.0	
Source of health information	agree	245 (52%)	65 (14%)	96 (20%)	69 (14%)	0.001	2.0	1.5-2.6
	disagree	872 (41%)	198 (9%)	563 (27%)	487 (23%)		1.0	
Would participate in government studies	agree	780 (59%)	168 (13%)	214 (16%)	150 (11%)	0.001	6.2	4.9-7.7
	disagree	334 (26%)	97 (8%)	440 (35%)	397 (31%)		1.0	
Like frightening activities	agree	365 (53%)	76 (11%)	139 (20%)	111 (16%)	0.001	1.9	1.5-2.5
	disagree	740 (30%)	189 (10%)	511 (27%)	434 (23%)		1.0	
Seek frightening experiences	agree	221 (52%)	50 (12%)	93 (22%)	59 (14%)	0.001	2.1	1.5-2.8
	disagree	896 (41%)	216 (10%)	564 (26%)	493 (23%)		1.0	
Believe genetics prevents disease	agree	923 (51%)	182 (10%)	424 (23%)	279 (15%)	0.001	4.6	3.7-5.8
	disagree	199 (24%)	87 (11%)	250 (31%)	277 (34%)		1.0	
Believe in genetic determinism	agree	460 (48%)	108 (11%)	243 (26%)	140 (15%)	0.001	2.1	1.6-2.6
	disagree	662 (40%)	161 (10%)	431 (26%)	416 (25%)		1.0	

BMI = Body mass index.

¹ Moderate/high alcohol intake defined as daily alcoholic beverage intake or a few times a week.

that the demographic characteristics significantly associated with positive attitudes toward both the donation and storage of blood specimens for genetic research (group A compared with group D) were higher education (OR 1.6, 95% CI 1.2-2.0), white race (OR 1.6, 95% CI 1.1-2.1), geographic locale, namely mid-Atlantic (OR 1.9, 95% CI 1.1-3.2) or Mountain/Pacific region (OR 2.0, 95% CI 1.1-3.5), and positive family history of a genetic disorder (OR 1.6, 95% CI 1.1-2.2). However, the addition of behavioral and attitudinal characteristics into the model rendered these associated demographic characteristics insignificant, namely, those agreeing that they would participate in government research (OR 5.4, 95% CI 4.2-6.9), those believing genetic research will prevent disease in the future (OR 3.9, 95% CI 3.0-5.0), those believing in genetic determinism (OR 1.9, 95% CI 1.5-2.5), thrill-seekers (OR 1.5, 95% CI 1.0-2.1) and those with moderate/high alcohol intake (OR 1.5, 95% CI 1.1-2.0).

Based on results from the multivariate logistic regression, a loglinear model was constructed with the a priori hypothesis that characteristics with a direct pathway to attitudes towards blood donation/storage for genetic research were behavior and attitudes, and characteristics with an indirect pathway toward our outcome were demographic characteristics. The loglinear model allows for the inclusion of all characteristics and the assessment of interactions between all characteristics to measure both pathways, yielding the following results. Significant associations for the direct causal pathway towards a positive attitude towards donation/storage for genetic research were observed for those willing to participate in government research (OR 2.9; $p < 0.001$), those believing that genetic research will prevent disease (OR 2.9; $p < 0.001$) and those believing that genes are more determinant of health than behavior or environment (OR 1.5; $p = 0.004$) (table 3).

Table 3. Results of the loglinear model: direct relationship with outcome (attitude toward donation/storage of blood specimens for genetic research)

Characteristic	OR	p value
Believe genetics determine a person's health more than environment or behavior	1.5	0.004
Believe genetic research will help prevent disease in the future	2.9	<0.001
Would participate in government research (referent: disagree)	2.9	<0.001

Table 4. Results of the loglinear model: relationship between demographics and intermediate attitudinal outcomes

Characteristic	OR	p value
<i>Believe genetics determine a person's health more than environment or behavior</i>		
College+ (referent: high school)	0.7	0.0050
Family history of genetic disorder	1.4	0.0312
<i>Believe genetic research will help prevent disease in the future</i>		
White race (referent: other)	1.5	0.0144
<i>Would participate in government research (referent: disagree)</i>		
College+ (referent: high school)	1.4	0.0059
White race (referent: other)	1.6	0.0073
Mountain/Pacific and mid-Atlantic geography (referent: Northeast, South, Midwest)	1.4	0.0263

Significant associations with the three directly associated characteristics, and therefore indicative of indirect pathways, were as follows. Characteristics of respondents willing to participate in government research were higher education (OR 1.4; $p = 0.0059$), white race (OR 1.4; $p = 0.0073$) and living in the Mountain/Pacific or mid-Atlantic region of the US (OR 1.4; $p = 0.0263$). Characteristics of those believing that genetic research will help prevent disease in the future were white race (OR 1.5; $p = 0.0144$). Lastly, characteristics associated with the belief that genes are more determinant of health than environment or behavior were higher education (OR 0.7; $p = 0.003$) and family history of genetic disorder (OR 1.4; $p = 0.0312$) (table 4). A schematic diagram of the loglinear results is shown in figure 2.

Discussion

Multiple characteristics were associated with the likelihood of having a positive attitude towards the storage and donation of blood specimens for genetic research. The association between demographic characteristics and these attitudes was as expected. The association with education is expected as a general surrogate for knowledge;

the association between positive family history and positive attitude is also expected due to a possible increase in awareness and knowledge of genetics, and the association between white race and positive attitude was possibly due to the high correlation of race with education and income (data not shown) as well as other cultural factors which were not measured. The association with geography cannot readily be explained; however, geography is also associated with a variety of factors, including education, income and race. These demographic characteristics associated with positive attitudes towards genetic research are important for audience segmentation and developing communication messages for the public.

The inclusion of attitudes and behavior into the final multivariate regression model resulted in exclusion of the demographic characteristics, suggesting that although demographic characteristics are appropriate for audience segmentation purposes, attitudes and behaviors are the most significant contributors and the direct pathway toward a person's attitudes towards blood storage/donation for genetic research. Persons who favor participation in government research in general, those who believe genetic research would prevent disease and those who believe in genetic determinism were significantly associated with positive attitudes toward donation and storage

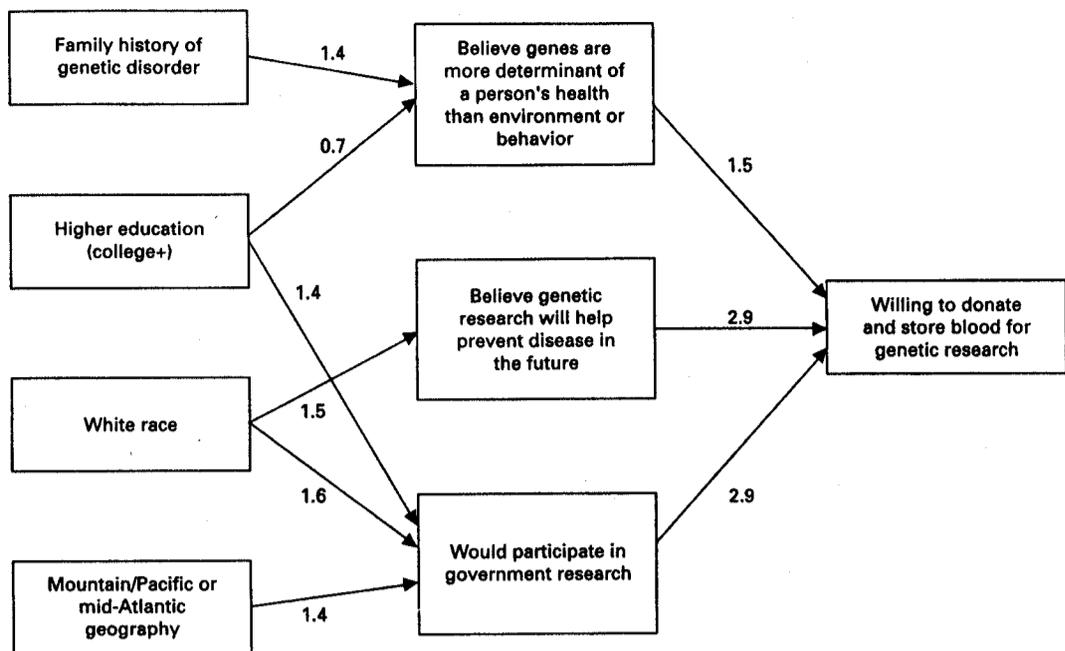


Fig. 2. Schematic diagram of pathways and contributors towards attitudes regarding the donation and storage of blood samples for genetic research – results from the loglinear model (all variables significant at $p < 0.05$). Numbers are odds ratio values among different variables.

of blood for genetic research. Furthermore, behaviors significantly associated with the likelihood of having a positive attitude towards blood storage/donation for genetic research included thrill-seeking and higher alcohol consumption. These findings are consistent with one another, as our data indicate that persons who believe in a role for genetics in disease prevention and genetic determinism are also those whose behavioral characteristics are riskier and who have a stronger belief in the role of genetics in their health outcomes. Our data further demonstrate that those with a stronger belief in the role of genetics are most likely to agree to donate/store blood for research in genetics.

The loglinear model was employed to provide a more robust model to detect the direct and indirect pathways involved in the development of attitudes toward donation/storage of blood specimens for genetic research. Rather than discounting demographic variables as in the final multivariate model, the loglinear methodology measures both the direct and indirect pathways while similarly adjusting for all factors included in the model. Therefore, not only are associations between variables associat-

ed with the outcome assessed, but variables associated with these intermediate outcomes can also be identified. The results of this model are as expected and are consistent with results from the multivariate logistic regression model. The variables associated with outcome were again those willing to participate in government research, those believing that genetic research would prevent disease in the future and those believing that genes are more determinant of person's health than behavior or environment. These characteristics were also the three strongest associations demonstrated in the multivariate model. The demographic characteristics associated with these intermediate outcomes were higher education, white race, geography and family history of a genetic disorder, which were also the same demographic characteristics whose association with the outcome was the strongest, prior to the inclusion of the behavioral/attitudinal characteristics in the multivariate model. The loglinear analysis is most useful when there are multiple variables to assess interactions, as is the case here [12, 13].

As indicated previously, the basis of the loglinear model was the results from the multivariate model. Although

demographic characteristics were significantly associated with our outcome of interest, their associations were negated by behavioral and attitudinal characteristics. The loglinear model allowed the elucidation of the pathway of involvement with regard to these various factors. It demonstrates that while the attitudinal and behavioral characteristics are directly associated with the likelihood of donating/storing blood for genetic research, the demographic characteristics are also associated with the outcome, but through an indirect pathway and through interaction with the intermediate attitudinal and behavioral characteristics. In the final loglinear model, only the characteristics with the strongest associations in the multivariate model were significant in the loglinear model.

Limitations of the study include the use of an uninformed population and the fact that storage and donation of blood specimens were not defined for the participants. Furthermore, due to the nature of the survey, the questions were not asked in tandem, but were dispersed throughout the questionnaire, leaving little context with regard to the genetics questions. Further issues of concern include the effect of knowledge, time and a combination of these and other measures on attitude (e.g. education with time) [14–17]. For the present study, although attitudinal measurement refinement techniques such as excluding items that show statistical or conceptual weakness (e.g. wording of questions and question development) and techniques for reducing random measurement error were not employed for this study, the basic information required for attitudinal studies, such as gender, age, education and thrill-seeking/fearfulness, were addressed in this study.

Strengths of the study include the use of a population that was representative of US adults. Furthermore, there are very little data regarding the public's opinion on the donation and storage of blood specimens for genetic research purposes. While the NBAC report conducted focus groups to assess attitudes, these types of study do not provide quantitative results, are limited to small groups and numbers of persons and are not representative of the general public. This study therefore provides a quantitative assessment of the US public's attitudes towards donation/storage of blood specimens for genetic research.

Future studies in this area will need to address the role that knowledge plays in individual attitudes and the role that knowledge and attitudes play in actual behavior. A study targeted at understanding the development of attitudes will need to include specific definitions for the donation and storage of blood specimens and further define

the intended use of these specimens for study participants. Educational knowledge about genetics as well as personal/family history of genetic diseases will also need to be determined. Lastly, assessing differences between individuals who indicate their willingness to participate in such studies compared to individuals who actually do or have participated in such research studies will be of enormous value.

While there is scientific agreement on the value of collecting and storing blood specimens for DNA studies, there is a need to understand the public's attitudes towards genetic research. Understanding of these attitudes has far-reaching implications for future population-based studies. According to our findings, only 40% of the population was willing to both donate blood and have it stored for genetic research. This 40% was associated with various demographic and behavioral characteristics. Genetic studies that recruit participants at the population level to assess frequencies of different genetic variations may therefore involve a biased 40% of the population and possibly an even more biased sample when we determine who from this 40% actually do participate in such studies. Understanding the factors contributing to attitudes and behavior regarding participation in genetic research studies will be beneficial for developing ways to communicate research goals to the public and in recruiting persons to donate blood for genetic research.

References

- 1 Khoury MJ: Genetic epidemiology and the future of disease prevention and public health. *Epidemiol Rev* 1997;19:175-180.
- 2 Plan and operation of the Third National Health and Nutrition Examination Survey, 1988-94. Series 1: Programs and collection procedures. *Vital Health Stat* 1, 1994;32:1-407.
- 3 Schulte P, Hunter D, Rothman N: Ethical and social issues in the use of biomarkers in epidemiological research. *IARC Sci Publ* 1997;142:313-318.
- 4 Schulte PA, Lomax GP, Ward EM, Colligan MJ: Ethical issues in the use of genetic markers in occupational epidemiologic research. *J Occup Environ Med* 1999;41:639-646.
- 5 Steinberg KK, Sanderlin KC, Ou CY, Hannon WH, McQuillan GM, Sampson EJ: DNA banking in epidemiologic studies. *Epidemiol Rev* 1997;19:156-162.
- 6 ACMG statement. Statement on storage and use of genetic materials. American College of Medical Genetics Storage of Genetics Materials Committee. *Am J Hum Genet* 1995;57:1499-1500.
- 7 DNA banking and DNA analysis: Points to consider. Ad Hoc Committee on DNA Technology, American Society of Human Genetics. *Am J Hum Genet* 1988;42:781-783.
- 8 National Bioethics Advisory Commission: Research Involving Human Biological Materials: Ethical Issues and Policy Guidance. Rockville, National Bioethics Advisory Commission, 1999, vol 1.
- 9 ASHG report. Statement on informed consent for genetic research. The American Society of Human Genetics. *Am J Hum Genet* 1996;59:471-474.
- 10 National Bioethics Advisory Commission: Research Involving Human Biological Materials: Ethical Issues and Policy Guidance. Rockville, National Bioethics Advisory Commission, 2000, vol 2, commissioned papers.
- 11 Maibach EW, Maxfield A, Ladin K, Slater M: Translating health psychology into effective health communication: The American Health-styles audience segmentation project. *J Health Psychol* 1996;1:261-277.
- 12 Khoury MJ, Beaty TH, Tockman MS, Self SG, Cohen BH: Familial aggregation in chronic obstructive pulmonary disease: Use of the loglinear model to analyze intermediate environmental and genetic risk factors. *Genet Epidemiol* 1985;2:155-166.
- 13 Stokes ME, David CS, Koch GG: Categorical Data Analysis Using the SAS System; chapter 14: Loglinear Models. Cary, SAS Institute, 1995.
- 14 International Social Science Survey: Public Perceptions of Genetic Engineering: Australia. Final report to the Department of Industry, Science and Technology, 1994 (<http://www.dist.gov.au/pubs/reports/genengin/>).
- 15 Singer E: Public attitudes towards genetic testing. *Popul Res Policy Rev* 1991;10:235-255.
- 16 Singer E, Corning AD, Antonucci T: Attitudes towards genetic testing and fetal diagnosis, 1990-1996. *J Health Soc Behav* 1999;40:429-445.
- 17 Singer E, Corning A, Lamias M: Trends: Genetic testing, engineering and therapy - awareness and attitudes. *Public Opin Q* 1998;62:633-664.