



INDIANA UNIVERSITY
CENTER FOR BIOETHICS

Public Attitudes Regarding Genetic Research

Summary of Methods and Findings

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The Survey Research Center at IUPUI, a unit of the IU School of Liberal Arts, is an interdisciplinary survey research center that provides services to a wide variety of private, non-profit and governmental organizations. The lab also serves the entire IUPUI campus by conducting research for faculty members, students and various university departments.

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Methods

The information presented in this section conforms to the best practices guidelines for full disclosure as promoted by the American Association of Public Opinion Research.¹

The survey described in this report was conducted by the Survey Research Center at IUPUI. The work was conducted under contract with the Indiana University Center for Bioethics. The purpose of the survey was to determine the attitudes and behaviors of adults in Indiana regarding medical research in general as well as genetic research specifically.

The target population for the survey was all adult residents of Indiana. Households were initially contacted by phone using a randomized list of phone numbers purchased from Survey Sampling Incorporated. If there was more than one adult in the home, the interviewer used a random selection process to identify the desired respondent. All telephone interviews were conducted by experienced and supervised interviewers. The average interview lasted for approximately 12 minutes. Data collection began on July 24, 2007 and ended on September 8, 2007. When using the entire sample, the error for this study does not exceed +/- 3%. A total number of completed interviews was 1024. The questionnaire used by interviewers is found in Appendix A.

Data were weighted to compensate for non-response by people of certain age and gender characteristics. The weight (W_{ijk}) for a respondent with a specific age (i), gender (j) and region (k) combination is determined by dividing the proportion of people in the entire population (P) with that specific combination of characteristics (P_{ijk}) by the proportion of the people in the survey sample (p) with that same combination of characteristics (p_{ijk}). Therefore the weight for each respondent is calculated using the

following formula: $W_{ijk} = \frac{P_{ijk}}{p_{ijk}}$.

¹ For details on this and other professional standards visit their website:
<http://www.aapor.org/disclosurestandards/>.

Table 1: Survey Participation Rates

Rate:	Percent	Definition
Response Rate	31.3%	the number of completed interviews divided by the number of eligible respondents in the sample
Cooperation Rate	41.1%	the number of completed interviews divided by the number of eligible respondents ever contacted
Refusal Rate	44.8%	the number of interview refusals or break-offs divided by the number of eligible respondents in the sample
Contact Rate	80.7%	the number of eligible respondents ever contacted divided by the number of eligible respondents in the sample

The response rate for this study (31%) is fairly standard for telephone surveys of the general population in which no financial incentives are offered to complete an interview of this length. A review of the demographic characteristics of the sample reveals that the sample of adults interviewed for this survey reflect the general population.

Findings

The Indiana University School of Medicine Center for Bioethics Program in Predictive Health Ethics Research commissioned the Survey Research Center at IUPUI to conduct a random-digit-dial telephone survey of Indiana residents in an effort to determine the following:

- The Public's perception of its own understanding of medical and genetic research
- Public confidence in medical and genetic research
- The likelihood of participation if asked
- The sense of public control of genetic research

The following report details the main findings from this research.

Demographic Characteristics

Interviews were conducted with 1,024 Indiana adult residents. The data obtained from the interviews and reported in this document were weighted by age and gender to account for the known non-response bias in the sample. A detailed explanation of respondent selection and weighting procedures can be found in the Methods Statement.

Respondents were first asked a series of questions to verify their eligibility for inclusion in the study. In order to be interviewed, respondents were required to verify that they were at least 18 years of age. Table 2 illustrates selected demographic characteristics of these individuals.

The unweighted percentages reflect the actual distribution of the respondents who participated in the survey. Following professional standards, the results are weighted to compensate for the known discrepancies between age and gender distributions in the sample compared to the Census data for Indiana. The result is a dataset that closely reflects the actual responses of the population.

Table 2: Demographic Characteristics

		Unweighted	Weighted
Gender	Male	37.2%	48.6%
	Female	62.8%	51.4%
Age	18-24	6.8%	13.5%
	25-44	25.8%	37.4%
	45-64	43.6%	32.4%
	65 and older	23.8%	16.8%
Race/Ethnicity	White/Caucasian	90.2%	88.1%
	Black/African American	4.5%	4.5%
	Other	5.2%	7.4%
Education	High School or less	38.2%	38.6%
	Some College	32.9%	33.1%
	College Grad.	28.9%	28.3%
Income	<\$20,000	16.5%	16.2%
	\$20-\$40,000	23.5%	24.2%
	\$40-\$60,000	22.2%	21.7%
	\$60-\$80,000	15.8%	16.5%
	\$80-\$100,000	7.8%	7.3%
	\$100-\$120,000	6.0%	5.9%
	>\$120,000	8.2%	8.1%
Political Ideology	Conservative	31.1%	29.5%
	Moderate	19.4%	18.0%
	Liberal	12.3%	12.4%
	Do not identify in those terms	37.2%	40.1%
Sample Size		1024	1024

As Table 2 illustrates, 51.4% of Indiana residents are female. More than one third of the population is between the ages of 25 and 44. Slightly less than one third is between 45 and 64. The smallest age cohort is the youngest. Approximately 14% are between the ages of 18 and 24. Over one quarter have a college degree, one third have some college background and nearly 40% have a high school education or less. Almost 25% of households have a combined household income of \$20,000 to \$40,000/year. The median income is between \$40K and \$60K. More than one quarter self-identify as political conservatives, 18% describe themselves as moderates, 12% state they are liberal and 40% claim they do not identify themselves in those terms.

Table 3: Religious Experiences

Protestant (or other non-Catholic Christian):	55.8%	
Mainline		18.9%
Liberal		13.0%
Evangelical		12.0%
Pentecostal		6.7%
Fundamentalist		4.3%
None of these		45.0%
Catholic	18.3%	
Other	8.9%	
No religious preference	17.0%	

Over half (55.8%) of Indiana residents state they are Protestant or another non-Catholic Christian denomination. Eighteen percent state they are Catholic, 9% claim another denomination and 17% claim no religious preference. Nearly 20% of Protestants described themselves as mainline, 12% claimed to be evangelical, but nearly half of these (45%) said they were none of the religious identities listed.

Public's Perception of Their Own Self-Efficacy

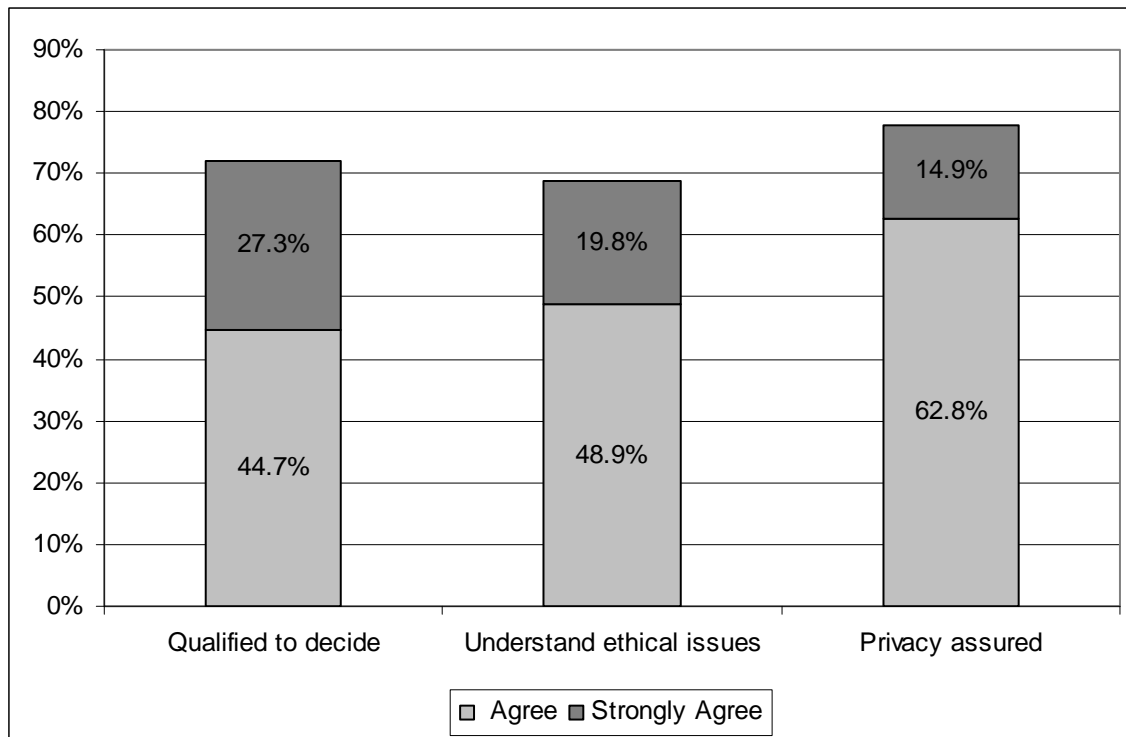
Respondents were read the following three statements regarding their own understanding of genetic research:

- ***“If I were asked by researchers to provide a tissue sample and access to my medical records to carry out genetic research, I would feel qualified to make this decision.”***

- *“I feel I have a good understanding of the ethical issues raised by genetic research.”*
- *“Genetic research is generally carried out in ways that protect the privacy and confidentiality of the research subjects involved.”*

They were then asked to whether they strongly agreed, agreed, disagreed, or strongly disagreed.

Figure 1: Public Perceptions of Self-Efficacy



Forty five percent agreed that they were qualified to decide upon their own participation in genetic research; over one quarter (27.3%) strongly agreed. Almost half agreed that they possessed a good understanding of the ethical issues associated with genetic research; 20% strongly agreed. Nearly two thirds (62.8%) agreed that the privacy of research participants was protected; 15% strongly agreed (*Figure 3*).

Additional analysis by demographic variables revealed no significant differences in these variables when comparing respondents of difference gender or race. People between 25 and 44 years of age are twice as likely as those under 25 or 65 and over to “strongly

agree” that they feel qualified to make a decision to participate in genetic research. One-third of those with college degrees also “strongly agreed” with this statement compared to only one-fifth of those without any college education. Note that these significant differences appear when comparing levels of intensity of agreement. When comparing the dichotomous “agree vs. disagree”, the statistical significance disappears.

The younger (under 25) and less educated (no college) respondents are significantly less likely to “strongly agree” with the statement that they have a good understanding of the ethical issues surrounding genetic research. However, this younger group is more than twice as likely as those 65 and older to “strongly agree” that privacy is adequately protected by those doing genetic research approved by an IRB.

Public Confidence in Medical/Genetic Research

Two general confidence scale questions were asked of respondents:

- ***“On a scale of one to ten, where ten is extremely confident and one is no confidence at all, how confident are you that medical research in the U.S. is being conducted with the best interest of people like you in mind?”***
- ***“...How confident are you that genetic research in the U.S. is being conducted with the best interest of people like you in mind?”***

Responses were grouped into ratings of low (rating of 1-4), moderate (rating of 5-7), or high (rating of 8-10) confidence. Slightly more than half stated moderate confidence in medical research being in the public’s best interest. More than one third (35.5%) expressed high confidence, and approximately 14% of the public expressed low confidence. In contrast, nearly even proportions expressed high (43.8%) and moderate (45.2%) confidence in genetic research. Eleven percent stated low confidence in genetic research being in the public’s best interest, (*Figure 2*).

Figure 2. Public Confidence in Medical and Genetic Research

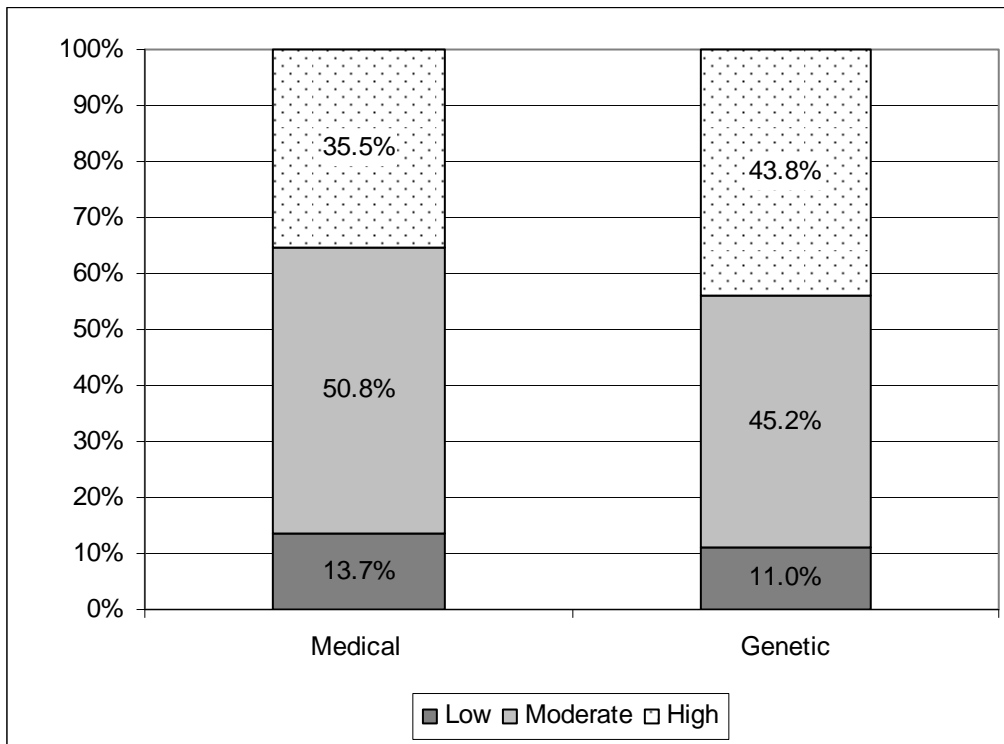


Table 4 shows the average response of those expressing confidence in medical and genetic research by various demographic variables. There were no statistically significant differences by gender or race found when comparing the average confidence scores for general medical research. However, female and white respondents reported significantly higher levels of confidence than men and minority respondents.

There was an unusual, non-linear relationship between age and levels of confidence in medical and genetics research. Those under 25 years old reported the lowest level of confidence in general medical research but reported the highest confidence in genetics research. The average confidence in medical research by age peaks at 25-44 year olds and again with those 65 and older. But the average confidence in genetic research by age peaks at the youngest and then again with the oldest groups of respondents. These results are puzzling, even in light of the analysis of reasons reported for lack of confidence shown in Table 5 below showing no difference by age in reasons given.

Table 4: Confidence in Medical and Genetic Research, by Demographics

	Medical	Genetic
TOTAL	6.54	6.86
Race		
White	6.57	6.93
Minority	6.43	6.46
Gender		
Male	6.52	6.71
Female	6.56	7.00
Age		
18-24	6.29	7.17
25-44	6.71	6.93
45-64	6.33	6.52
65 +	6.87	7.13
Education		
High School or less	6.33	6.84
Some College	6.68	6.88
College Degree	6.65	6.88
Church Attendance		
Rarely/Never	6.23	6.53
Sometimes	6.75	7.14
Regular	6.72	6.97

When asked about genetic research people who stated a confidence level lower than “8” were asked the follow-up question:

- ***“What is the one main reason you are not ‘extremely confident’ in genetic research?”***

The verbatim responses, which are all listed in Appendix C, were clustered into three categories: suspicion that genetic research is all about profit, genetic research is not showing adequate progress, and belief that genetic research is morally wrong.

“Mistrust those involved; all about money” included responses such as:

- *“Because the government has its hand in it and anything that the government has its hand in I am never confident”*
- *“Most doctors are pill happy. Too many pills that the doctors prescribe. ”*
- *“Big businesses tailor the research to fit their needs and what’s going to make them the most money.”*
- *“Well, if it has anything to do with the government that makes me question it.”*
- *“I think that all research is done ultimately for information but ends up being for the companies profits.”*

“Not advancing, not doing enough” included:

- *“Well, in my own family, there’s a situation where I know it’s hereditary and I just don’t think they’ve done enough to cure it or control it better”.*
- *“The government is holding them back. I don’t think they are providing enough funds for the research that needs to be done.”*
- *“They’ve been doing it for a long time and cures should have been found for MS and other diseases.”*
- *“Because there’s so many diseases that man has no cure for such as cancer, it’s been around for many years and yet man can’t cure cancer.”*

“Fear consequences, playing God” included:

- *“Stem cell resource if they use it to only recover a disease. If they start playing God then there is a problem.”*
- *“I have, just when it comes to genetics, when you go into people’s DNA, you’ve got to worry about people copying things they shouldn’t copy. You know, cloning, things like that. ”*
- *“I worry about the consequences.”*
- *“End use of this information how it will be used after researchers are done with the data. I am not concerned about the initial researcher there used of the data. ”*
- *“I feel like it has a tendency to be used in the wrong way and for deceptive purposes.”*

Table 5 contains the three general themes of responses given and their respective proportions. When broken down by demographic variables, the largest percentages cited a level of mistrust perception that genetic research was “all about money” as the reason for their lack of confidence. The only demographic category for which significant differences were found was education. Those with higher levels of education were more likely to have less confidence in genetic research because of mistrust of the process. Those with lower education were more likely to report the lack of progress of genetic research as the source of their lack of confidence.

Table 5: Reasons for Lower Confidence in Genetic Research, by Demographics

	Mistrust those involved, all about money	Not advancing, not doing enough	Fear consequences, playing God
TOTAL	53.0%	31.9%	15.1%
Gender			
Male	53.2%	31.6%	15.2%
Female	47.4%	37.7%	14.9%
Race			
White	50%	35.5%	14.5%
Minority	52.9%	23.5%	23.5%
Age			
18-24	57.1%	28.6%	14.3%
25-44	53.2%	31.9%	14.9%
45-64	47.9%	37.2%	14.9%
65 +	47.2%	36.1%	16.7%
Education			
High School or less	37.2%	48.7%	14.1%
Some College	51.0%	35.3%	13.7%
College Degree	64.4%	16.9%	18.6%

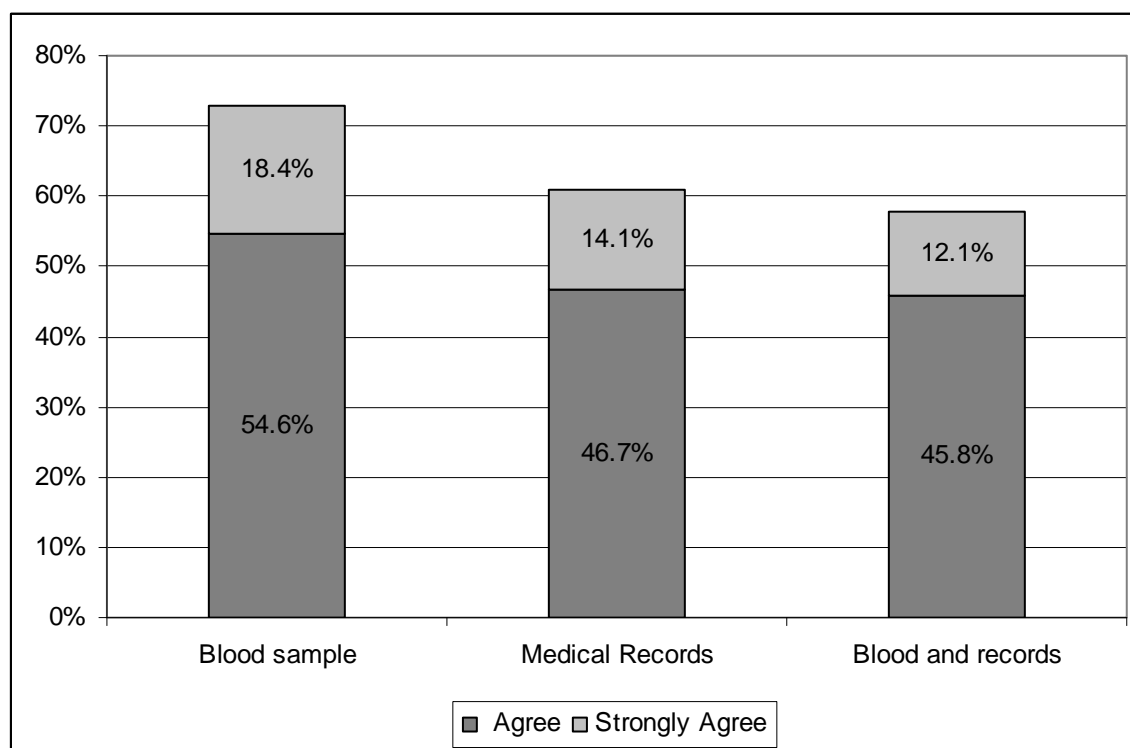
Public Willingness to Participate in Genetic Research

Respondents were asked to state their level of agreement or disagreement with the following three statements:

- *If I were asked to provide a blood sample for genetic research and was given assurance that the research had been properly reviewed and approved by an institutional review board, I would be willing to provide that sample.*
- *If I were asked to provide access to my medical records to obtain information that could be used for genetic research and was given assurance that the research had been properly reviewed and approved by an institutional review board, I would be willing to give permission for use of my records.*
- *If I were asked to provide BOTH a blood sample and access to my medical records for use in genetics research, I would be willing to do so.*

Over 70% agreed that they would be willing to provide a blood sample for genetic research; 18% strongly agreed. Over 60% agreed that they would be willing to provide their medical records for genetic research; 14% strongly agreed. And almost 60% agreed that they would be willing to provide both a blood sample and their medical records with 12% strongly agreeing.

Figure 3: Public Willingness to Participate in Genetic Research



Additional analysis of these participation questions by demographic characteristics revealed no statistically significant differences between subsets of the population regarding use of medical records or agreement to both blood sample and access to records. However, respondents under 25, as well as those with no religious affiliation, were both significantly more likely to “strongly agree” that they would provide blood samples if asked to do so.

Attitudes Regarding Genetic Research

Respondents were asked several questions intended to measure various aspects of their attitudes toward genetic research. For each question they were asked to indicate their level of trust, control, understanding, or concern based on a 1-10 scale. A score of 1 indicated no trust, control, etc. and 10 indicated complete trust, control, etc. The complete questions are as follows:

- ***How much do you think the public trusts genetic researchers to conduct research with the best interests of people like you in mind? (TRUST)***

- *How much control do you feel the public has over the future direction of genetic research in this country? (CONTROL)*
- *How much do you feel the public understands about the kind of genetic research being conducted in the United States? (TYPE)*
- *How much do you think the public understands about the possible effects of genetic research on society? (IMPACT)*

Table 6 shows average score for each. Keeping in mind that the possible range for each score is one through ten, even the highest average (Trust = 6.53 for people over 65) is closer to the middle than either end of the scale. There were significant differences in many of the same areas as shown before regarding confidence in research (see Table 4). Women consistently report a more optimistic view of genetic research. The relationship between age and optimism regarding genetic research shows the same peculiar non-linear relationship as seen earlier.

Minority respondents were much more likely to report a higher sense of public control over genetic research than white respondents. The more education people have, the less they are inclined to feel the public has a high level of understanding of the kinds of genetic research being conducted and its potential effects on society.

Table 6: Attitudes Concerning Genetic Research, by Demographics

	Trust	Control	Type	Impact
TOTAL	6.29	3.97	3.65	4.06
Gender				
Male	6.09	3.69	3.41	3.84
Female	6.47	4.23	3.89	4.27
Race				
White	6.33	3.91	3.64	4.08
Minority	5.97	4.38	3.76	3.89
Age				
18-24	6.67	4.88	3.67	3.92
25-44	6.16	4.05	3.71	3.99
45-64	6.17	3.41	3.45	3.94
65 +	6.53	4.12	3.90	4.56
Education				
High School or less	6.34	4.00	3.83	4.32
Some College	6.26	3.88	3.62	4.03
College Degree	6.24	4.04	3.44	3.72

Privacy and Use of Personal Health Information

There were five questions devoted to understanding the level of concern respondents have about how genetic information is ultimately used.

Now I'd like to ask you some questions about some of the concerns that people have raised about participating in genetic research. On a scale of one to ten, in which ten is very concerned and one is not concerned at all:

- *How concerned are you that genetic research is carried out by pharmaceutical, biotechnology and other for-profit businesses? (BUSINESS)*
- *How concerned are you that information collected in the course of genetic research might be used by people other than the researchers? (NON-SCIENCE)*
- *Specifically, how concerned are you that this information might be used by employers? (EMPLOYERS)*
- *How concerned are you that this information might be used by health insurance companies? (INSURANCE COMPANIES)*
- *And how concerned are you that this information might be used by schools? (SCHOOLS)*

Table 7: Privacy of Genetic Research, by Demographics

	Business	Non-Science	Employers	Insurance Companies	Schools
TOTAL	6.47	6.78	6.47	7.70	5.76
Gender					
Male	6.13	6.73	6.56	7.56	5.55
Female	6.80	6.83	6.39	7.83	5.95
Race					
White	6.44	6.72	6.43	7.71	5.67
Minority	6.55	7.24	6.71	7.61	6.24
Age					
18-24	6.36	6.38	6.05	6.93	5.25
25-44	6.34	6.77	6.31	7.67	5.59
45-64	6.57	7.04	6.85	8.10	6.00
65 +	6.62	6.51	6.40	7.59	6.04
Education					
HS or less	6.65	6.87	6.58	7.59	5.89
Some College	6.48	6.91	6.55	7.76	5.93
4yr Degree	6.21	6.50	6.23	7.75	5.33

In general, the highest level of concern among the public is related to the use of genetic information by insurance companies. The group with the highest level of concern over

this is people who are approaching retirement (45-64 year olds). People in this age group generally report among the highest level of concern over all five of the issues presented.

The issue that was of least concern was use of information from genetic testing in the schools. It should be noted that no additional information was provided to respondents when they inquired as to what this might involve. Anecdotal comments from interviewers indicate that respondents who commented about this issue seemed to assume that schools would only use genetic test results in a benevolent manner.