

The Effects of Physician Trust on Preferences for and Beliefs about Genetic Testing

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Abstract

Americans have been promised the unimaginable with regards to genetic testing. However, when making personal decisions about health care, Americans are not overzealous consumers of genetic testing. Instead, Americans' preferences are nuanced, reflecting a sophisticated decision-making calculus rather than blind medical credulity. In this thesis, I use survey data from United States Public Knowledge and Attitudes about Genetic Testing, 2000 to analyze the effects of physician trust on respondent preference for adult and prenatal genetic testing. I find that respondents' preferences for prenatal and adult genetic testing are shaped more by physician trust than by confidence in the government, the makers of genetic tests, and the leaders of science. Physician trust is also predictive of lesser concern about the possible interpersonal and social misuses of genetic testing. Furthermore, when asked about the most controversial topics in genetics, the most knowledgeable and educated respondents express the greatest concern over the possible misuses of genetic testing. My results suggest that decisions about preferences for genetic testing are influenced by interpersonal beliefs about medical professionals rather than by global beliefs about the institution of medicine.

Introduction

It is perhaps not surprising that many Americans are dissatisfied with the state of health care in the United States. Inequalities are inherent in America's private healthcare system. Research in medical sociology often concentrates on the views of specific disadvantaged social groups with regard to physicians and the medical profession in general. Much of this research centers on the concept of trust. In the context of medicine trust manifests in two distinct forms—

social and interpersonal. In the institution of medicine as in other institutions, the public often has high levels of interpersonal trust and paradoxically low levels of social trust. For example, a respondent may report a great deal of trust in his or her primary care physician while reporting great skepticism, and correspondingly low levels of trust, in health maintenance organizations. Although trust is widely discussed in medical sociology, my thesis will extend the existing literature to the field of genetics.

The American public's degree of trust in the medical profession is interesting in its own right. However, the highly contentious nature of genetic testing heightens the importance of trust in this setting. Social concerns over the potential misuses of genetic testing abound. Issues of privacy, eugenics, and discrimination are just a few of the central controversies. The dataset used for the analysis that follows assesses at least ten separate measures of respondent concern over the uses of genetic testing. Furthermore, genetic testing is often accompanied by a substantial degree of uncertainty and risk. The results of genetic tests are often inconclusive or probabilistic, exposing damaging conditions for which there may be no available treatments or cures. The controversial nature of genetic testing, coupled with the uncertainty and risk that the testing arouses, undoubtedly increases the importance of American's trust in physicians when forming their preferences about the hypothetical utilization of prenatal or adult genetic testing.

My thesis will explore both the relationship between physician trust and preferences for adult and prenatal genetic testing and the relationship between confidence in medicine and preferences for genetic testing. I will utilize a nationally representative survey containing questions that adequately assess respondents' degree of physician trust, respondents' confidence in medicine, respondents' knowledge of genetics, and respondents' preferences for utilization of prenatal and adult genetic testing. I will address and attempt to answer the following questions:

1. Is respondent preference for prenatal and adult genetic testing linked to trust in his or her physician? 2. Is respondent confidence in the institutions involved in genetic testing associated with respondent preference for genetic testing? 3. Which sociodemographic factors mitigate this linkage? 4. Are differences in respondent preference for genetic testing contingent on the respondent's knowledge about genetic testing?

Hypotheses

- 1) Physician trust will be positively associated with respondent preference for prenatal and adult genetic testing.
 - a) Increased physician trust will be more predictive of preference for genetic testing in situations of heightened risk and uncertainty.
 - b) Whites, the well-educated, and those of high socioeconomic status will score highest on trust indices. These groups will also show greater preferences for both adult and prenatal genetic testing.
- 2) Respondent confidence in the leaders of government, the leaders of science, and in the makers of genetic tests will be positively associated with preferences for genetic testing.
- 3) Knowledge of genetic testing (measured by summing the correct answers to the knowledge questions) will be positively associated with preferences for genetic testing.

Methods

I plan to undertake a quantitative analysis using the dataset United States Public Knowledge and Attitudes about Genetic Testing, 2000 (see Appendix A). This is a large dataset containing 2,239 cases from the contiguous United States. Telephone interviews were conducted from the Survey Research Center Telephone Facility on the College Park campus of the University of Maryland. Adults age 18 or over residing in households with telephones were

interviewed. The sample design consisted of a list-assisted Plus One Random Digit Dial (RDD) scheme. Once the households were identified, respondents were randomly chosen using a household roster (Singer 2000). The dataset also contains independent Hispanic and black oversamples.

The survey asked questions regarding the public's attitudes towards both prenatal and adult genetic testing, personal experiences involving prenatal and adult genetic testing and knowledge about the uses of genetic testing and the causes and cures of genetic diseases. Questions also assessed the public's level of trust in doctors, confidence in the government and companies that make and sell genetic tests, uses of genetic tests by employers and health insurers and interest in science and technology. Background variables include sex, age, education, income, race, employment, religious affiliation, religiosity, disability status, health insurance coverage and geographic region.

I undertake a hypothesis-driven statistical analysis of the determinants of respondent preference for genetic testing and respondent concern for the misuses of genetic testing. My analysis of the dataset will primarily consist of five distinct linear regression models designed to address five different components of genetic testing: prenatal genetic testing, adult genetic testing for treatable and non treatable genetic diseases, genetic testing for behavioral traits, social concerns about the possible misuses of genetic testing and interpersonal concerns about the possible misuses of genetic testing. The key independent variables analyzed in the models are physician trust, confidence and knowledge. Race, income, age, education and sex are also included in the models.

The formation of the knowledge, confidence and trust measures used in the analysis deserve special consideration. First, the knowledge outcome variable is the result of the sum of

each respondent's correct responses to the five true or false survey questions about genetic testing.¹ The average knowledge score was 1.88 (1.06 std. dev.) correct answers out of 5. The confidence variable is defined as the mean of the response scores on three measures of confidence—confidence in the people running the government in Washington, confidence in the leaders of science and confidence in the corporations that make and see genetic tests. The mean confidence score was 2.65 (0.45 std. dev.) out of 4, where 1 is “hardly any confidence” and 4 is “a great deal of confidence”. The measure for physician trust is taken from responses to the survey question “How much do you trust your doctor to keep medical information about you private?” The mean trust score was 3.39 (0.8 std. dev.) out of 4, where 4 signifies a response of “a great deal”. This particular dimension of physician trust is the most relevant to genetic testing as the results of genetic tests often expose potentially damaging information that many patients would want to keep private. The results of genetic tests could impact interpersonal relationships, employment status, and/or health insurance coverage. Thus, a patient's degree of trust in his or her physician to keep the results of these tests private is incredibly relevant to his or her decision to undergo a genetic test. Furthermore, according to Hall, et al. (2001), measures of physician trust are unidimensional and intercorrelated, with positive scores on one dimension predicting positive scores on all other dimensions. Responses to the privacy dimension of physician trust are therefore indicative of physician trust generally. Consequently, for the purposes of this analysis, the privacy dimension of physician trust has been extrapolated to represent physician trust more generally.

¹ The following true or false questions were used to tabulate the knowledge outcome variable used in the linear regression models. Correct answers are in parentheses. Genetic testing can be used in adults to find out if they have a greater than average chance of developing certain kinds of cancer (True). Genetic testing can be used in adults to find out if they have a greater than average chance of developing depression (False). Genetic testing can be used in adults to predict whether a person will have a heart attack (False). Genetic testing can be used during pregnancy to find out whether the baby will develop sickle cell disease or cystic fibrosis (True). Gene therapy is currently being used to correct many of the defects found through gene testing (False). These are the correct answers as of year 2000.

Results

Physician trust

Table 1 suggests that physician trust is positively associated with respondent desire to have both a prenatal genetic test and a test for cystic fibrosis ($b=0.032, p<0.05$; $b=0.042, p<0.05$). Respondents who express a great deal of trust in their physician's ability to keep medical information private are more likely to desire a prenatal test for a serious genetic defect should they or their partner become pregnant than are respondents who are less trusting of their physician's ability to keep medical information private. Respondents who are more trusting of their physicians are also more likely to prefer a test for cystic fibrosis. These findings fully support the hypothesis that respondents who are more trusting of their physicians are more likely to express a preference for genetic testing.²

INSERT TABLE 1 ABOUT HERE

The models in Table 2 suggest that physician trust is also positively associated with a desire to be tested for both a treatable genetic condition and a non treatable genetic condition ($b=0.053, p<0.01$; $b=0.044, p<0.01$). This finding confirms the hypothesis that trust measures will be positively associated with respondent preferences for genetic testing. Those respondents who report a great degree of trust in their physician's ability to keep their medical information private are more likely to want a genetic test to tell whether or not they are likely to get a treatable genetic disease later in life and a genetic test to tell whether or not they will develop a serious, disabling disease later in life for which there is no treatment or cure at present. Thus, physician trust and respondent preference for adult genetic testing are associated, regardless of the test's

² The functional form of the relationships between the trust and the outcomes was explored by including a squared term in the regression models. This term was not significant in any of the analyses, suggesting that the relationships between trust and the outcome variables are linear.

potential outcomes or the available treatment options. Essentially, physician trust in this setting is predictive of a desire for information and knowledge about one's health status. Mechanic asserts that physician trust is especially salient in situations marked by risk, uncertainty, and vulnerability. Adult genetic testing predicts and exposes future health risks. Thus, patients who trust their physician should be and are more likely to want the knowledge and information that a genetic test brings, even though the test may be coupled with a degree of risk and uncertainty.

INSERT TABLE 2 ABOUT HERE

Tables 4 and 5 suggest that physician trust is negatively associated with concerns about genetic testing leading to discrimination ($b=-0.093, p<0.01$), concerns about genetic testing benefiting people who already have a lot of advantages ($b=-0.097, p<0.01$), concerns about information from genetic testing being misused ($b=-0.130, p<0.01$), concerns about genetic testing being the first step to getting rid of the people the government considers undesirable ($b=-0.166, p<0.01$) and concerns about scientists creating unrealistic hopes about how soon cures will be found for genetic diseases ($b=-0.101, p<0.01$). Those respondents who trust their physician to keep medical information private are less concerned about the possible social and interpersonal misuses of genetic testing. Thus, high levels of physician trust are associated with high levels of social trust. This finding substantiates Hall, et al's (2001) claim that trust measures are unidimensional.

INSERT TABLES 4 and 5 ABOUT HERE

Confidence

Confidence is far less predictive of respondent preference for genetic testing than is physician trust. Although physician trust is positively associated with a desire to be tested for a

non treatable genetic condition, respondent confidence is not. Rather, table 2 suggests that confidence is negatively associated with a respondent's desire to be tested for a genetic condition for which there is no cure at present ($b=-0.077, p<0.05$). Those respondents who express a great deal of confidence in the people running the government, the leaders of science and the corporations that make and sell genetic tests are less likely to express a preference to be tested for a non treatable genetic condition. This finding is indicative of the difference between measures of trust and confidence related to interpersonal settings versus those measures related to institutional settings. Lipset and Schneider assert that respondents can express high levels of confidence in physicians and paradoxically low levels of confidence in medical institutions—confidence, unlike trust, is not unidimensional.

Knowledge Matters

Throughout the survey, higher educational attainment is consistently linked to increased concern over the potential misuses of genetic testing and the possible eugenic consequences of genetic testing. Specifically, education is negatively associated with the belief that prenatal genetic testing for height, weight, and hair color will do more good than harm (see Table 1). Those who are more highly educated seem particularly averse to such “novelty” prenatal genetic tests. Table 3 suggests that college education is also positively associated with the belief that genetic tests for homosexuality, criminal behavior, and shyness would do more harm than good ($b=0.238, p<0.01$; $b=0.190, p<0.01$; $b=0.249, p<0.01$). Higher educational attainment is also linked to an increased concern about genetic testing allowing people to choose to have the children they really want—a question that surely conjures up images of the eugenic possibilities of the technology (see Table 4).

INSERT TABLE 3 ABOUT HERE

Knowledge of genetic testing is positively associated with a respondent's belief that genetic tests for criminal behavior would do more harm than good ($b=0.042, p<0.05$). The average knowledge score was 1.88 (1.06 std. dev.) correct answers out of 5. On the whole, Americans are not incredibly knowledgeable about genetic testing—most survey respondents answered less than half of the questions correctly. However, those respondents who scored higher on the questions gauging knowledge of genetic testing are more concerned about the potential harms of genetic tests for criminal behavior than those respondents with lower knowledge scores. Table 5 suggests that knowledge is also positively associated with a strong concern that genetic testing is the first step to getting rid of the people the government considers undesirable ($b=0.055, p<0.05$). This finding is congruent with earlier findings that greater educational attainment and higher knowledge scores are associated with increased concern about the possible misuses of genetic testing. Respondents who are most knowledgeable about genetic testing are especially concerned with the eugenic possibilities of the technologies. This finding again reveals that knowledge matters more when looking at the most controversial topics in genetics. In the context of this study, knowledge of genetic testing signals an awareness of the controversies surrounding genetic testing.

Education is also negatively associated with a desire to be tested for a not treatable genetic disease (see Table 2). The more educated the respondent, the less likely he or she will want to be tested for a genetic disease for which no current treatment exists. This may be due to the fact that those respondents who are more highly educated are also more knowledgeable about genetic testing.³ Thus, they may be more cognizant of the devastating nature of the conditions for which no treatment is available. This knowledge may heighten their awareness of the burden of

³ Knowledge and education are positively correlated in the sample.

knowing you have a serious, disabling condition for which there is currently no cure or treatment, swaying them towards the rejection of such a test.

Determinants of Preferences for Genetic Testing

Interestingly, females express a greater preference than males to be tested for a non treatable genetic condition ($b=-0.074, p<0.05$). Conversely, females are less likely than males to prefer a prenatal test for cystic fibrosis ($b= -0.078, p<0.01$). In fact, being female is negatively associated with a desire to have a test for cystic fibrosis (see Table 1). This finding is most likely explained by females' better understanding of the risks involved in the current prenatal tests for cystic fibrosis. Many prenatal tests for genetic conditions can be obtained through a simple blood test. To test a fetus for cystic fibrosis, amniocentesis or chorionic villus sampling (CVS) must be preformed⁴. Both of these procedures pose a risk to the fetus. One in 200 to one in 400 women who undergo amniocenteses have a miscarriage. This risk increases slightly with CVS (March of Dimes 2006).

Blacks and Hispanics are more likely than whites to want to avail themselves of prenatal genetic testing ($b=0.100, p<0.01$; $b=0.086, p<0.05$) and adult genetic testing for a non treatable genetic disease ($b=0.136, p<0.01$; $b=0.154, p<0.01$). Hispanics are also more likely than whites or blacks to want to be tested for a treatable genetic disease ($b=0.105, p<0.05$). Blacks and Hispanics are less likely to believe that genetic tests for homosexuality would do more harm than good ($b=-0.110, p<0.01$; $b=-0.180, p<0.01$). Hispanics are also less likely to believe that tests for criminal behavior would do more harm than good ($b=-0.143, p<0.05$). Blacks and Hispanics are also more likely to believe that genetic tests for height, weight and hair color will do more good than harm ($b=0.065, p<0.01, b=0.106, p<0.01$). These findings demonstrate that blacks and

⁴ A CVS test involves taking a small tissue sample from outside the sac containing the fetus. Amniocentesis involves taking a small sample of the woman's amniotic fluid. CVS can be performed slightly earlier in the pregnancy than amniocentesis and poses a slightly greater risk to the fetus (March of Dimes 2006).

Hispanics are less concerned than whites about the possible misuses of genetic testing and more inclined to prefer both adult and prenatal genetic testing. Thus, the above findings that black and Hispanics are more supportive than whites of genetic testing for behavioral traits (homosexuality, shyness and criminality) and designer traits (height, weight and hair color) may be a reflection of their general support and enthusiasm for all forms of genetic testing. These results reflect the findings of Schnittker, et al. (2005) that blacks are more disposed than whites to desire medical care for the treatment of hypothetical symptoms and that blacks are more optimistic than whites about the outcomes of medical treatment.

That said, blacks are more likely than whites to be concerned about genetic testing leading to discrimination against people, information from genetic tests being misused, genetic testing being the first step towards getting rid of people the government considers undesirable, scientists creating unrealistic hopes about how soon cures will be found for genetic diseases and research on genes taking away money that should be used for other health problems (see Tables 4 and 5). Thus, although blacks are more likely to express a personal preference for genetic testing and less likely to be concerned about the “novelty” and behavioral possibilities of genetic testing, they do have concerns about the social and interpersonal misuses of genetic testing.

Hispanics also express significant concerns about the possible misuses of genetic testing. They are especially concerned about the possibility that genetic testing will benefit people who already have a lot of advantages and that scientists are creating unrealistic hopes about how soon cures will be found for genetic diseases (see Tables 4 and 5).

Discussion

Key Findings

Regression analysis of survey data from United States Public Knowledge and Attitudes about Genetic Testing, 2000 reveals that physician trust is positively associated with respondent preference for prenatal testing. Physician trust is also positively associated with preferences for adult genetic testing for both treatable and not treatable genetic diseases. Regardless of the treatment options, physician trust is linked to greater preferences for genetic testing. These findings support my original hypothesis that greater physician trust will be associated with increased preferences for prenatal and adult genetic testing. Genetic testing exposes the potential for medical risk. Patients who trust their physicians are more likely to desire to undergo these sorts of tests. This is likely tied to their belief that their personal physician will help them to navigate important decisions regarding these health risks in a competent and considerate manner. A patient who does not trust his or her personal physician would be more likely to shy away from undergoing a test that could expose medical uncertainties and vulnerabilities. If a patient does not trust his or her physician, he or she is unlikely to want the physician to assume the responsibility of making important medical decisions regarding the information uncovered by genetic testing.

Higher levels of physician trust are also associated with decreased social and interpersonal concerns about the potential misuses of genetic testing. Those respondents who trust their physician more are less concerned about genetic testing leading to discrimination, information from genetic tests being misused, genetic testing serving eugenic purposes, genetic testing creating false hopes about cures for genetic diseases and genetic testing preferentially benefiting people who already have many advantages. In the realm of genetic testing, physician trust seems to have a pervasive quality that is associated with less skepticism and concern about the potential evils of genetic testing. These findings are reflective of the unidimensional nature of physician

trust. These findings also suggest that the dichotomy between social and interpersonal trust may be less pronounced than previously thought. Interpersonal measures such as physician trust are linked to social trust too, as high levels of physician trust are negatively associated with the social concerns surrounding genetic testing.

My second hypothesis, that respondent confidence in the leaders of government, the leaders of science and in the makers of genetic tests will be positively associated with preferences for genetic testing, was not supported. Confidence was not statistically linked to respondent preference for prenatal or genetic testing in most analyses. Nor was confidence linked to increased or diminished concerns about the possible social or interpersonal misuses of genetic testing. The discrepancy between trust and confidence in respondents' preferences for and concerns about genetic testing may be illustrative of differences between respondent beliefs that are shaped by interpersonal experiences versus respondent preferences that are shaped by global beliefs about social institutions. The difference may lie in the level of sociological analysis, micro or macro. The findings of this analysis reveal that conceptions such as physician trust, which are likely shaped by micro-level, doctor-patient interactions are more influential in shaping respondent preferences for genetic testing than are global beliefs about social institutions, which may be influenced less by personal experience and more by the media or other macro-level social processes.

It is important to note that respondent confidence was associated with one component of preference for genetic testing. Respondents with high levels of confidence in science and the government are less likely to prefer an adult genetic test that can expose the likelihood of developing a serious, disabling disease later in life for which there is no treatment or cure at present. This finding is perhaps better explained by cognitive-level analyses than by macro-level

sociological accounts. Respondents who have a great deal of confidence in government and science may also hold positive beliefs about medicine and health more generally. These positive beliefs are satisfactory and do not provoke anxiety. Thus, the holders of these positive beliefs may not want to receive the potentially devastating results of an adult genetic test that could uncover a serious, disabling genetic disease for which there is currently no available treatment or cure. Besides provoking personal worry and anxiety, these results could potentially call into question the respondents' current positive beliefs about medicine. Furthermore, respondents who have a great deal of confidence in science and the makers of genetic tests do not have the option of attributing undesirable test results to a "faulty test" or "bogus technology". Essentially, "confident" respondents are reluctant to seek out information that would violate their current positive beliefs about the medical profession.

Contrary to my third hypothesis, increased knowledge scores are not indicative of greater preferences for genetic testing. This does not imply that the public's decisions about genetic testing are uniformed. Rather, respondents' rationales for utilizing genetic testing are based on factors other than their knowledge of genetic testing. The knowledge variable was statistically linked to other dependent variables in the analyses; specifically, to the belief that genetic tests for criminal behavior would do more harm than good and to increased concern that genetic testing is the first step to getting rid of people the government considers undesirable. These findings mirror the linkages between educational attainment and increased concern over the potential eugenic misuses of genetic testing. This is perhaps not surprising as measures of knowledge and education are positively correlated in the sample.

The associations between educational attainment, knowledge of genetic testing and concerns about the possible misuses of genetic testing are most likely related to respondents' awareness of

the historical legacy of eugenics. Those with more education have most likely studied the consequences of the Holocaust and other historical events that called into question the sinister nature of discrimination based on appearance and other biological determinants. This knowledge may be mediating these respondents' particularly strong aversions to the most controversial uses of genetic testing.

Gender and race are two particularly significant determinants of respondents' beliefs and attitudes about genetic testing. Firstly, females are less likely than males to express a preference for prenatal genetic testing for cystic fibrosis. This finding is in line with the Parsons' notion of clinical impotence. Pregnant women know that there is no cure for cystic fibrosis.⁵ Thus, a prenatal test for cystic fibrosis reveals devastating information with no accompanying power or insight regarding the next best course of action. Genetics professionals and doctors can merely present the new information; they are unable to offer solutions to any problems that the new information may present. Women's relatively lower preference for testing for cystic fibrosis than men may also reflect a desire on the part of women to let chance determine the fate of their pregnancies. Rothman writes that the increasing medical management of pregnancy has eliminated the choice to let chance determine pregnancy outcomes. Perhaps increasing cognizance of the clinical impotence of genetics professionals is leading women to reject the medical management of pregnancy.

Women's relatively greater preference than men to be tested for a genetic disease for which there is no cure at present may be related to the fact that women are more susceptible to medicalization (Riska 2003). Women may be more prone to worry about future medical conditions such as genetic diseases. They may also be more knowledgeable about their families'

⁵ The majority of women in the sample answered correctly a question about whether or not there is a cure for cystic fibrosis.

medical histories and therefore more likely to want to have their genetic predispositions for heritable diseases tested. Women may also be disproportionately targeted by marketing campaigns for genetic tests. These advertising tactics may unduly influence women's decisions to undergo genetic testing.

My findings with regard to respondent race are in line with previous research which suggests that blacks are more optimistic and disposed to seek treatment for hypothetical symptoms than are whites (Schnittker et al. 2005). In this sample, both blacks and Hispanics were more likely than whites to prefer a prenatal test and an adult genetic test for a non treatable disease. The fact that they do not seek treatment as often as whites is therefore not reflective of a lesser desire for treatment. Rather, this discrepancy between 'real and ideal' care is likely indicative of the greater barriers that black and Hispanics face when accessing care or the dissuasive power of unsatisfactory doctor-patient interactions. Finally, blacks and Hispanics do demonstrate greater concern than whites for several of the social and interpersonal concern measures in the study, specifically those concerns relating to issues of eugenics and discrimination. Minority groups may be more acutely aware of the harms of genetic testing than whites given the devastating historical legacy of scientific experimentation on minority groups such as the Tuskegee syphilis study.

Policy Implications: Does Public Opinion Really Matter?

In the short text *Public Opinion*, Vincent Price discusses the connection between public opinion research and democracy. The founding fathers of public opinion research and polling, George Gallup and Elmo Roper, "were strong on democratic principles and pleased to provide a means that the voice of the people might be more clearly heard" (1992:36). Despite the initially

idealistic intentions of public opinion researchers, the efficacy of survey research as a measure of public opinion has recently been contended.

Methodological issues such as acquiescence⁶, the prevalence of nonattitudes⁷, and question wording surely confound the results of public opinion research. However, empirical studies demonstrate a persistent link between public opinion and policy outcomes. Jeff Manza and Fay Lomax Cook (2002) outline three prevailing ideas pertaining to the opinion-policy link. Firstly, much evidence suggests that the effects of public opinion have a significant and enduring effect on public policy. Quantitative time-series analyses have demonstrated a correlation between public opinion and policy responsiveness over time. In one quantitative study, Monroe analyzed 500 cases of policy adoptions (Monroe 1979 in Manza & Cook 2002: 20). “He found that in 63% of the cases, policy moved in the direction preferred by majority opinion” (Manza and Cook 2002: 20). In a related study, Stimson, Erikson, and MacKuen found that “effects of public opinion produce an exceptionally large coefficient for the impact of policy mood on policy, estimated in the full analysis to be 1.094 (or as they put it, “there exists about a one-to-one translation of preferences into policy” [1995: 557]) (Stimson et al. 1995 in Manza and Cook 2002: 20). Essentially, this evidence suggests that “policy reflects public opinion” (Manza and Cook 2002: 21).

The prevailing counterargument to the alleged opinion-policy link suggests that there are limited connections between opinion and policy. This theory relies on two central criticisms: the prevalence of nonattitudes in public opinion research and the ability of elites to manipulate public opinion. Converse (1964) demonstrated that the public often forms inconsistent “responses to repeated survey questions” (Manza and Cook 2002: 24). Critics of the opinion-

⁶ Acquiescence is the respondent’s “tendency to agree irrespective of item content” (Schaeffer and Presser 2003:80).

⁷ “Answers from respondents with no opinion that are arrived at through a process akin to mentally flipping coins” are considered nonattitudes (Schaeffer and Presser 2003:79).

policy link argue that the prevalence of nonattitudes diminishes the significance of this linkage and subjects public opinion to manipulation by elites. However, more recent studies (Paige and Shapiro 1992) suggest that public opinion is “‘rational’ as it is associated with, and moves in a meaningful way with, events, crises, or economic fluctuations, even if individual survey respondents are poorly informed or ideologically inconsistent” (Manza and Cook 2002: 25). The nonattitudes literature presents an overly cynical view of the American public, however. Although a respondent may not have accurate knowledge of the specific issues being targeted by a research question, he or she will most likely rely on a combination of his or her existing opinions about related topics and information from his or her existing value systems.

Finally, a third view suggests that if the opinion-policy link does exist, it is certainly mediated by contingent “institutional and comparative-historical variation” (Manza and Cook 2002: 27). Supporters of this view see the opinion-policy link as plastic, subject to fluctuations over time and variations between different policy realms. However, if the recent inundation of literature regarding the ethical, legal and social implications of genetic testing is any indicator, policymakers are indeed responding to the public’s worries about the potential misuses of genetic testing. Public opinion anticipates future policies.

Areas for Future Research

The findings of this research begin to elucidate Americans’ varying preferences for genetic testing. However, this research, like the results of genetic tests, brings about more questions than answers. Future research should delve deeper into the decision-making processes of patients with regard to genetic testing. Our current medical sociology theories do not anticipate this data. Qualitative research, such as in-depth interviews, would surely complement the existing empirical research in that it would give respondents the opportunity to explain the

rationales behind their various preferences for genetic testing. Given that the findings of this research suggest that Americans are often rational actors—employing means-ends calculations when making decisions about the hypothetical utilization of genetic testing—I would surmise that Americans would be able to clearly articulate the rationales for their preferences for genetic testing. Specifically, a study similar to that of Markens, et al. (1999) which asks respondents to explain their preferences for adult genetic testing for treatable and not treatable genetic diseases would surely enhance and further explicate this study’s findings.

The positive associations between physician trust and preferences for genetic testing found in this study should also be explored further. It is possible that these associations are contingent upon or mediated by other factors, such as patients’ feelings about recent physician encounters. Perhaps micro-sociological studies of doctor-patient interactions would shed light on how physician trust is established. Analysis of video footage of clinical encounters might illuminate the components of doctor-patient interactions that enhance or diminish a patient’s trust in his or her physician—high solidarity doctor-patient interactions versus low-solidarity doctor-patient interactions, if you will. This research could be a key component in explaining why macro-level measures, such as confidence in the makers of genetic tests, are poor predictors of patient preference for genetic testing while more interpersonal measures, such as physician trust, are significant predictors of preferences for genetic testing. Future research should explore trust as it relates to the doctor-patient interaction.

Conclusions

The promises of the Human Genome Project abound and Americans continue to be flooded with media pronouncements of successful ‘gene-finding’ missions. Gene stories do not always have happy endings, however (Lewontin 1991). They are often accompanied by

unanswered questions and a substantial degree of clinical impotence (Bosk 1992). Americans are cognizant of these genetic “false starts”. Their personal preferences for genetic testing reflect a significant degree of skepticism. Americans’ preferences for prenatal and adult genetic testing are nuanced, reflecting a sophisticated decision-making calculus rather than blind medical credulity. These decisions are influenced by physician trust, a trust undoubtedly formed by perceptions of previous doctor-patient interactions. Personal interactions with the medical profession are more influential in shaping decisions about the utilization of genetic testing than are global beliefs about the institution of medicine. Despite the commanding presence of university, government, and corporate institutions involved in the genetics industry, Americans’ look to experiences with their personal physician to guide their decisions about genetic testing. Trust has consequences.

Tables:

Table 1. Linear Regression of Prenatal Genetic Testing: United States Public Knowledge and Attitudes about Genetic Testing, 2000

	Prenatal	Cystic fibrosis	Sickle Cell Anemia	Novelty testing
Knowledge	.014 (.010)	-.001 (.012)	.016 (.016)	-.003 (.008)
Physician Trust	.032* (.013)	.042* (.018)	.009 (.019)	-.009 (.011)
Confidence	-.023 (.023)	-.027 (.029)	-.031 (.037)	-.034 (.020)
Female	-.036 (.021)	-.078** (.027)	-.026 (.034)	-.091** (.018)
Race (vs. Non Hispanic white)				
Black	.100** (.026)	--	.094 (.128)	.065** (.022)
Hispanic	.086* (.031)	.011 (.049)	.013 (.129)	.106** (.026)
Age	.000 (.001)	.001 (.001)	-.001 (.001)	-.001 (.001)
Income *10 000	0.0050 (0.0038)	0.0013 (0.0046)	0.00038 (0.0069)	-0.0072* (0.0032)
Education (vs. < High School)				
High school	.004 (.034)	-.064 (.047)	-.052 (.048)	-.147** (.029)
Some College	-.035 (.035)	-.104* (.048)	-.114* (.051)	-.168** (.030)
College	-.033 (.037)	-.088 (.050)	-.196** (.057)	-.211** (.032)
R ²	.017	.018	.037	.080
Number of Observations	1777	1173	603	1777

* $p < .05$ ** $p < .01$ (standard errors are in parenthesis)

Note: Respondent preference for a prenatal genetic test, a test for cystic fibrosis or a test for Sickle Cell Anemia. Respondent belief that prenatal genetic tests for height, weight and hair color would do more good than harm. Black respondents were not asked about cystic fibrosis. Only black respondents were asked about Sickle Cell Anemia.

Table 2. Linear Regression of Adult Genetic Testing: United States Public Knowledge and Attitudes about Genetic Testing, 2000

	Treatable	Not treatable
Knowledge	-.006 (.014)	.015 (.015)
Physician Trust	.053** (.019)	.044* (.021)
Confidence	.025 (.033)	-.077* (.037)
Female	-.017 (.031)	-.074* (.033)
Race (vs. non Hispanic white)		
Black	-.007 (.038)	.136** (.040)
Hispanic	.105* (.045)	.154** (.048)
Age	-.002* (.001)	-.001 (.001)
Income * 10 000	0.0026 (0.0055)	0.002 (0.0060)
Education (vs. < High School)		
High school	-.113* (.045)	-.197** (.053)
Some College	-.063 (.051)	-.152** (.055)
College	-.093 (.054)	-.191** (.058)
R ²	.032	.056
Number of Observations	877	910

* $p < .05$ ** $p < .01$ (standard errors are in parenthesis)

Note: Respondent preference for genetic tests for treatable and not treatable genetic diseases.

Table 3. Linear Regression of Genetic Testing for Behavioral Traits: United States Public Knowledge and Attitudes about Genetic Testing, 2000

	Homosexuality	Criminal Behavior	Shyness
Knowledge	.003 (.017)	.042* (.017)	-.005 (.018)
Physician Trust	-.016 (.023)	-.016 (.023)	.063* (.026)
Confidence	-.039 (.038)	.049 (.042)	-.022 (.046)
Female	-.060 (.035)	-.033 (.040)	-.001 (.040)
Race (vs. < non Hispanic white)			
Black	-.110** (.043)	-.078 (.048)	-.086 (.048)
Hispanic	-.180** (.053)	-.143* (.056)	-.016 (.057)
Age	-.001 (.001)	-.002 (.001)	-.001 (.001)
Income *10 000	0.0060 (0.0064)	0.015* (0.0072)	0.0084 (0.0071)
Education (vs. < High School)			
High school	.205** (.057)	.044 (.063)	.113 (.064)
Some College	.243** (.060)	.092 (.066)	.169** (.064)
College	.238** (.063)	.190** (.070)	.249** (.069)
R ²	.093	.082	.063
Number of Observations	590	588	599

* $p < .05$ ** $p < .01$ (standard errors are in parenthesis)

Notes: Respondent belief that genetic tests for homosexuality, criminal behavior or shyness would do more harm than good.

Table 4. Linear Regression of Interpersonal Concerns about the Uses of Genetic Testing: United States Public Knowledge and Attitudes about Genetic Testing, 2000.

	Choose the children they really want	Anonymous genetic testing should be available	Benefit people who already have advantages	Information from tests will be misused
Knowledge	-.006 (.026)	-.012 (.028)	.031 (.025)	.018 (.024)
Physician Trust	-.001 (.035)	-.013 (.038)	-.097** (.033)	-.130** (.032)
Confidence	.049 (.062)	-.019 (.066)	.020 (.059)	-.026 (.058)
Female	.114* (.056)	.068 (.060)	.023 (.053)	.015 (.052)
Race (vs. non Hispanic white)				
Black	-.094 (.068)	.153* (.073)	.039 (.064)	.188** (.063)
Hispanic	-.348** (.081)	.119 (.087)	.266** (.077)	.062 (.075)
Age	-.004* (.002)	-.001 (.002)	.001 (.002)	.001 (.002)
Income *10 000	-0.0049 (0.010)	-0.026* (0.011)	-0.021* (0.0095)	-0.019* (0.0092)
Education (vs. < High School)				
High school	.584** (.091)	.069 (.097)	-.009 (.086)	.157 (.084)
Some College	.637** (.094)	.098 (.101)	-.039 (.089)	.223* (.086)
College	.545** (.100)	.057 (.107)	-.112 (.094)	.253** (.091)
R ²	.055	.011	.025	.023
Number of Observations	1722	1729	1671	1703

* $p < .05$ ** $p < .01$ (standard errors are in parenthesis)

Notes: Respondent degree of concern about the uses and potential misuses of genetic testing. Dependent variables from left to right correspond to respondent agreement with the following statements: Genetic testing during pregnancy is a good thing because it allows people to choose to have the children they really want; Anonymous genetic testing, where no record is kept of the person's name, should be available to people who want it; Genetic testing will mostly benefit people who already have a lot of advantages; Information from genetic testing is most likely to be misused.

Table 5. Linear Regression of Social Concerns about the Uses of Genetic Testing: United States Public Knowledge and Attitudes about Genetic Testing, 2000.

	Testing will lead to discrimination	Testing will get rid of undesirables	Scientists are creating unrealistic hopes	Tests will take away money for other health problems
Knowledge	.006 (.026)	.055* (.025)	-.005 (.024)	-.020 (.024)
Physician Trust	-.093** (.034)	-.166** (.034)	-.101** (.032)	-.054 (.032)
Confidence	.002 (.062)	-.104 (.060)	.089 (.058)	-.070 (.057)
Female	.079 (.056)	.016 (.054)	.049 (.051)	.118* (.052)
Race (vs. non Hispanic white)				
Black	-.053 (.068)	.310** (.067)	.164** (.063)	.252** (.063)
Hispanic	-.187* (.081)	.124 (.079)	.303** (.074)	-.007 (.077)
Age	.000 (.002)	-.002 (.002)	.000 (.002)	-.003* (.002)
Income *10 000	0.0048 (0.010)	-0.021* (0.0098)	-0.042** (0.0091)	-0.026** (0.0093)
Education (vs. < High School)				
High school	-.056 (.091)	.039 (.089)	-.196* (.083)	.055 (.084)
Some College	.080 (.095)	.064 (.092)	-.342** (.086)	-.156 (.087)
College	.182 (.010)	-.048 (.097)	-.450** (.091)	-.339** (.092)
R ²	.016	.047	.083	.066
Number of Observations	1699	1703	1651	1669

* $p < .05$ ** $p < .01$ (standard errors are in parenthesis)

Notes: Respondent degree of concern about the uses and potential misuses of genetic testing. Dependent variables from left to right correspond to respondent agreement with the following statements: Genetic testing will lead to discrimination against people; Genetic testing is the first step to getting rid of the people the government considers undesirable; Scientists are creating unrealistic hopes about how soon cures will be found for genetic diseases; Research on genes is taking away money that should be used for other health problems.

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