Public opinion on policy issues in genetics and genomics

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Purpose: The aim of this study was to examine public opinion on major policy issues in genetics and genomics, including federal spending on genetic research, the perceived significance of the Genetic Information Nondiscrimination Act of 2008, and whether clinicians should be involved in direct-to-consumer genetic testing.

Methods: This is a survey with a nationally representative sample of 2,100 American adults administered by the nonpartisan research firm YouGov in January 2011.

Results: The majority of the respondents (57%) believe that the federal government should spend more on genetic research, 82% rank the 2008 antidiscrimination law as “important,” and 65% say that clinicians should be involved in explaining genetic test results (contra the practice of some direct-to-consumer companies). On all three policy issues, sex and political party affiliation are statistically significantly associated with respondents’ views, whereas race/ethnicity and education are less consistently associated with policy opinions.

Conclusion: Americans demonstrate widespread support for scientific research on genetics, laws protecting citizens against genetic discrimination, and the need to involve medical professionals in the process of genetic testing. These results are useful for scientists designing research projects, clinicians interacting with patients, professional organizations lobbying for resources, federal agencies setting budget priorities, and legislators designing regulation.

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Public opinion is the basis of representative democracy.1 It informs decisions made by political leaders, and it can also be useful for scientists designing research projects, clinicians interacting with patients, and professional organizations lobbying for resources. Even as genetics and genomics play an increasingly important role in science and medicine, little is known about what the general public think of major policy issues in this arena. As a result, scientists and clinicians have called for high-quality, public opinion data.2

Previous research suggests that demographic factors, such as racial or ethnic background and educational level, are important in shaping individuals’ views.3 However, many studies are limited by samples that are unrepresentative of the general population and so, it is difficult to assess the generalizability of the results.4–6 When national polls are conducted, the focus is usually limited to a single condition, such as cancer or depression.7,8 Additionally, more attention has been given to how individuals respond to genetic risk9–11 rather than assessing their policy opinions. What is the view of the general public when it comes to policy issues in genetics and genomics? What produces variation in these views?

MATERIALS AND METHODS

To examine public opinion on major policy issues in genetics and genomics, we conducted a nationally representative survey of American adults. The survey involved an experimental design in which we randomly assigned respondents to imagine that they were at increased genetic risk for one of the following three conditions: heart disease, colon cancer, or Alzheimer disease. We provided a brief description of each disease and asked 55 questions about what the respondent would do in this hypothetical situation, ranging from consulting one’s family to engaging in genetics-related community events (results from the hypothetical questions are being published elsewhere). Following the hypothetical questions, we asked for general views on major policy issues, including federal spending on genetic research, the Genetic Information Nondiscrimination Act of 2008 (GINA), and direct-to-consumer (DTC) genetic testing. With a nationally representative sample, we can systematically assess whether variation in policy views is associated with particular demographic factors. Additionally, because we primed respondents to be thinking about genetic risk for a particular disease, we can examine whether specifying particular diseases produces variation in public opinion.

The survey was administered by the nonpartisan research firm YouGov to 2,100 respondents on their home computers in January 2011. A random sample was drawn from YouGov’s opt-in Internet panel using sample matching to constitute a nationally representative sample (see Supplementary Note S1 online). Scholars across the social sciences are increasingly utilizing YouGov because “survey experiments that integrate representative samples with the experimental control of questions represent the most valuable tool for gaining access.
to the processes that underlie opinion formation. Using the American Association of Public Opinion Researchers’ Response Rate Calculator (category 3), our response rate is 39.2%, which is standard for public opinion research with nationally representative samples. The American Association of Public Opinion Researchers’ Response Cooperation Rate (category 3) is 76.3%, which reveals that once people began the survey, they were likely to finish.

The sample is largely representative of the American public. It includes 53% women; 75% self-identified as white, 10% as African American, and 8% as Latino; 38% had a college or postgraduate degree; 75% self-rated their health as “good” or “excellent” and 4% as “poor”; and 36% self-identified as democrats, 30% as republicans, and 35% as independents. As a further adjustment for nonresponse or exclusion from the sample, significance tests are χ-squared tests weighted with weights provided by YouGov. The study received institutional review board approval at the University of California–Berkeley.

RESULTS
Analyzing Americans’ policy views reveals that most people support increased federal spending on genetic research, believe that genetic antidiscrimination law is important, and think that clinicians should be involved in explaining genetic test results. Yet, there are ongoing divides in public opinion based on sex and political party affiliation, and to a lesser extent, race/ethnicity and education. In contrast, we find no evidence of differences among respondents asked to consider different kinds of diseases. Below, we provide detailed results for the three policy questions.

Federal spending on genetic research
Americans consistently demonstrate strong support for federal spending on scientific research, and our results show this remains true when asked specifically about research on genetic causes of disease. The survey question reminded respondents of the condition they were to imagine facing: “As mentioned above, (heart disease, colon cancer, or Alzheimer disease) can be caused by genetic, environmental, and/or lifestyle factors. Do you think that the federal government should spend more, less, or the same amount on research on genetic causes of disease?” Respondents indicated their answer using a 10-point horizontal slider with the end points “less” and “more.” Scores of 1–5 are categorized as “spending the same or less” and scores of 6–10 as “spending more.”

More than half of the respondents (57%) believe that the federal government should spend more researching genetic causes of disease, whereas 27% thought spending levels should stay the same, and 15% thought that they should be lower. There are statistically significant differences by sex, race, and political party at P < 0.05. As shown in Table 1, women (more than men), nonwhites (more than whites), and democrats (more than independents and republicans) support greater federal spending. Neither the respondent’s education nor the experimental treatment (being asked to consider genetic risk for a specific disease) is statistically associated with views on federal spending.

Genetic Information Nondiscrimination Act
The passage of GINA in 2008 followed more than a decade of legislative efforts to secure protection against genetic discrimination by health insurers and employers. Opinion polls have consistently revealed concerns about genetic discrimination, both among the general public and particular patient populations; however, most of the research was conducted prior to GINA. How do Americans respond to the new protections offered by this law? The question stated: “In 2008, the federal government passed a law to prohibit health insurers and employers from discriminating on the basis of genetic information. How important do you think this law is?” Respondents had five answer choices, which we combined into the following two categories: unimportant (answers included “not at all important,” “unimportant,” and “neither important nor unimportant”) and important (answers included “important” and “very important”).

The vast majority of respondents (82%) rate GINA as “important.” As with federal spending, women and democrats are aligned in marking this antidiscrimination law as significant. There are also differences by race/ethnicity, but it is Latinos who ranked the law as slightly less important than did whites, African Americans, and others. This is the only policy question in which education is statistically significant, with the more highly educated more likely to rank GINA as important. As above, the experimental treatment is not statistically associated with respondents’ views.

DTC genetic testing
Scientists and clinicians have expressed as much hope for the future of personalized medicine as dismay about its commercialization. Editorials published over the past decade reveal deep concerns about the emergence of for-profit companies offering DTC genetic testing. Much discussion has centered on what role should be played by medical professionals, but on the assumption that clinicians should be the ones to provide genetic results, researchers have not directly asked about the public about this matter. To what extent are Americans familiar with DTC companies, and do they believe that genetic testing should involve a clinician?

About a fifth of the respondents had heard of companies marketing genetic tests directly to consumers. Women and men are equally likely to be aware of such companies, but there are differences by race and education. Whites are more likely to report awareness than nonwhites (23 vs. 18%, F(1, 2099) = 5.15; P = 0.02), as are people with more education; 33% of college graduates had heard of DTC companies compared to 17% of those without a college degree (F(1, 2099) = 58.2; P = 0.00). However, awareness does not translate into consumption. Less than 1% of the respondents had purchased a testing kit, with 9 of the 14 consumers being white men (these results are similar to a three-state survey of nutrigenomic DTC testing in 2006.
that found 14% of people were aware of companies and 0.6% had purchased tests. In an Oregon-only sample for the CDC’s Behavioral Risk Factor Surveillance System in 2008, 33% of the people were aware of DTC genetic testing, and 2.5% had purchased a testing kit.

Next, we asked about the role of clinicians. The survey explained: “Right now, people who purchase genetic tests from companies do not have to discuss their results with a medical professional.” This was followed by the question: “How much would you agree with the following statement: medical professionals should be involved in explaining genetic test results.” A strong majority of respondents (65%) agreed, whereas just 9% disagreed (26% neither agreed nor disagreed). As discussed above, although there are demographic differences, women and democrats are more likely to support clinician involvement in genetic testing. There is some attitudinal variation by race/ethnicity, with respondents falling into the “other” category least likely to agree. Neither education nor the experimental treatment is significantly associated with respondents’ views on this issue.

**DISCUSSION**

The American public demonstrates widespread support for research on the genetic causes of disease, laws protecting citizens against genetic discrimination, and the need to involve medical professionals in the process of genetic testing. Like other studies, demographic differences punctuate the survey results, but this nationally representative poll allows for the examination of variation in respondents’ views across different policy issues. In all three areas, women and democrats were consistently aligned in favor of scientific research, antidiscrimination law, and clinician involvement (there is, of course, substantial overlap in these categories: 40% of women in the sample are democrats and 8% are independents who “lean” toward the democratic party. In addition, 60% of the democrats are women). These results cohere with the robust finding that women are more likely than men to seek medical care and the general attitudes of democrats and republicans toward regulation. Educational attainment was also associated with support for GINA but not with attitudes toward federal spending or clinician involvement.

The results for race/ethnicity are more difficult to explain and require future research. Why are whites less likely than nonwhites to favor federal spending? Why, of all the racial/ethnic groups, are Latinos less likely to view antidiscrimination law as important? And given the longstanding history of mistrust toward the medical system among minorities, why are African Americans and Latinos just as inclined as whites to support clinician involvement? It is the case that nonwhites are more likely to identify as democrats than whites, so this may partly explain their support for federal funding and clinician involvement, but further research may reveal additional nuances.

This study is not without limitations. The policy questions are part of a larger survey that began with an experimental treatment in which people were asked to imagine facing genetic risk for a disease, and this may have influenced their answers to the later policy questions. However, we do find

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**Table 1 Public opinion on policy issues in genetics and genomics, by sex, race/ethnicity, education, and political party**

<table>
<thead>
<tr>
<th></th>
<th>Federal spending</th>
<th>Genetic Information Nondiscrimination Act’s importance</th>
<th>Clinician involvement</th>
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<tbody>
<tr>
<td></td>
<td>Spend less or same (%)</td>
<td>Spend more (%)</td>
<td>Unimportant (%)</td>
</tr>
<tr>
<td>Male (n = 972)</td>
<td>45</td>
<td>55</td>
<td>21</td>
</tr>
<tr>
<td>Female (n = 1,128)</td>
<td>40</td>
<td>60</td>
<td>16</td>
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<tr>
<td></td>
<td>5.01</td>
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<td>7.79</td>
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<tr>
<td>White (n = 1,584)</td>
<td>45</td>
<td>55</td>
<td>17</td>
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<tr>
<td>African American (n = 206)</td>
<td>37</td>
<td>63</td>
<td>19</td>
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<tr>
<td>Latino (n = 172)</td>
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<td>64</td>
<td>27</td>
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<tr>
<td>Other (n = 138)</td>
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<td>3.05</td>
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<td>High school degree and less (n = 819)</td>
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<tr>
<td>Some college and 2-year degree (n = 685)</td>
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<td>57</td>
<td>18</td>
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<td>Four-year degree and more (n = 596)</td>
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<td>0.14</td>
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<td>Democrats (n = 748)</td>
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<td>Republicans (n = 615)</td>
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<td>0.01</td>
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[Q5]
CONSISTENCIES BETWEEN OUR SURVEY RESULTS AND THOSE OF PREVIOUS OPINION POLLS ON GENETIC POLICY. MOREOVER, WE DID NOT FIND ANY SIGNIFICANT ASSOCIATION BETWEEN THE EXPERIMENTAL TREATMENT AND POLICY RESPONSES, WHILE WE DID FIND MANY OF THE EXPECTED DEMOGRAPHIC DIFFERENCES, WHICH AUGUR WELL FOR THE RELIABILITY OF OUR RESULTS.

IN THE ONGOING DEBATES OVER POLICY ISSUES IN GENETICS AND GENOMICS, IT IS IMPORTANT TO KEEP IN MIND THE VIEWS OF THOSE MOST AFFECTED BY SUCH DEBATES: THE PUBLIC. AMERICANS EVINCE STRONG SUPPORT FOR FEDERAL FUNDING OF GENETIC RESEARCH, RESULTS WHICH SHOULD BE USEFUL FOR PROFESSIONAL ORGANIZATIONS LOBBYING FOR RESOURCES AND FEDERAL AGENCIES SETTING BUDGET PRIORITIES. THE OVERWHELMINGLY POSITIVE RESPONSE TO GINA SUGGESTS THAT CLINICIANS SHOULD BE SURE TO MENTION ITS EXISTENCE TO PATIENTS, MANY OF WHOM REMAIN FEARFUL ABOUT GENETIC DISCRIMINATION AND UNAWARE OF THE LAW.20 PERHAPS THE STRONG SUPPORT FOR THIS LAW WILL ALSO EMBOLDEN LEGISLATORS TO TAKE ADDITIONAL STEPS IN ERADICATING GENETIC DISCRIMINATION.

FINALLY, AS CLINICIANS AND PROFESSIONAL ORGANIZATIONS ATTEMPT TO PERSUADE FEDERAL AGENCIES THAT DTC GENETIC TESTING SHOULD BE MORE TIGHTLY REGULATED, IT IS ESSENTIAL TO KNOW THAT THE PUBLIC SUPPORTS EFFORTS TO ENSURE THAT CLINICIANS ARE INVOLVED IN EXPLAINING GENETIC TEST RESULTS.

SUPPLEMENTARY MATERIAL
Supplementary material is linked to the online version of the paper at http://www.nature.com/gim

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DISCLOSURE
The authors declare no conflict of interest.

REFERENCES

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