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Survey of U.S. Public Attitudes Towards Pharmacogenetic Testing

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Abstract

To assess public attitudes and interest in pharmacogenetic (PGx) testing, we conducted a random-digit-dial telephone survey of U.S. adults, achieving a response rate of 42% (n=1139). Most respondents expressed interest in PGx testing to predict mild or serious side effects (73% ±3.29% and 85% ±2.91%, respectively), guide dosing (91%) and assist with drug selection (92%). Younger individuals (ages 18–34) were more likely to be interested in PGx testing to predict serious side effects (vs. ages 55+), as well as Whites, those with a college degree, and who had experienced side effects from medications. However, most respondents (78% ±3.14%) were not likely to have a PGx test if there was a risk that their DNA sample or test result could be shared without their permission. Given differences in interest among some groups, providers should clearly discuss the purpose of testing, alternative testing options (if available), and policies to protect patient privacy and confidentiality.

Pharmacogenetic (PGx) testing can potentially reduce adverse drug responses and improve efficacy of drug treatment. PGx testing may measure either inherited or acquired genetic variation and inform drug selection and/or dosage. For example, testing for polymorphisms in two genes, VKORC1 and CYP2C9, can inform initial dosage of warfarin, one of the most commonly prescribed drugs in the world and one with a narrow therapeutic window.1 While it is estimated that about one-fourth of outpatients are taking medications with PGx information in their labels,2 only a few require or recommend testing prior to drug use.2, 3

Several studies have assessed general public interest in disease susceptibility genetic testing, 4–9 though only a handful of studies have assessed the public's perspectives of PGx testing, most of which have been on European populations. For example, studies from Germany and

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the U.K. report that the public are generally supportive of PGx testing but expressed concerns regarding patient sovereignty, the unavailability of suitable drugs based on genetic make-up, and privacy.10, 11 Participants of an Iceland study were concerned that genetically tailored drugs would be more costly and result in greater health disparities.12 It is uncertain whether differences in the healthcare systems and coverage and reimbursement as well as concerns about genetic discrimination between the U.S. and Europe would yield differences in public support for PGx testing in the U.S.

The saliency of these issues were partially confirmed in three focus group studies conducted in the U.S. explored public attitudes toward PGx testing within the framework of drugs targeted to a patient's race.13–15 One study found that participants preferred individualized genetic testing versus race-based medications, but raised concerns about cost, privacy, and discrimination.14 In the other two, participants were likely to be highly suspicious of the safety and efficacy of race-based drugs.13, 15 A phone survey of 1,796 Americans reported that the public was generally supportive and interested in participating in genetics research, including PGx research, but had conflicting views regarding affordability of targeted drugs.16

Due to the limited understanding of interest in PGx testing among Americans, we conducted an anonymous, random-digit-dial telephone survey of a sample of the U.S. public. This survey ascertained the public's views about PGx testing (e.g., knowledge of risks and specific uses of PGx tests and how demographics influence their interest in PGx testing). In particular, we examined the public's interest in PGx testing given three potential risks (DNA sample could be accessed without patient permission, test result could be accessed without patient permission, testing requires a blood draw) and five distinct uses (to predict risk of mild side effects, to predict risk of serious side effects, to understand side effects in self or family members, to select most effective drug to treat illness, or to select appropriate dose or strength) of PGx testing. Past studies have not distinguished between different purposes of PGx testing; we believed it would be informative to learn whether interest varied by the purposes of testing and if such interest was influenced by personal characteristics, familiarity with genetic testing or history of medication side effects as previously demonstrated.17 Furthermore, we were interested in identifying subpopulations of respondents with lower interest in PGx testing which may warrant further study to understand their concerns, to limit disparities in the use of testing with demonstrated benefits, and maximize benefits of testing. These data can help identify potential challenges of translating PGx testing based on the public's overall interest as well as interest in specific uses of testing.

METHODS

Survey Development

Development of the survey involved a collaborative effort between investigators at Duke University's Institute for Genome Sciences & Policy (IGSP) and the Survey Research Unit (SRU) at the University of North Carolina, Chapel Hill. The content was based on data collected from a series of focus groups, a literature review, and a legal analysis of managing incidental findings from PGx testing. IGSP investigators convened four focus groups of the

general public to ascertain perceptions and attitudes about PGx testing, and specifically about ancillary information resulting from PGx testing. Forty-five individuals recruited from Durham, North Carolina participated in the focus groups; members were predominantly African-American females, median age range 40–49 years, with a Bachelor's or graduate degree. A hypothetical vignette was used to illustrate potential clinical and ethical issues that may arise with PGx testing, particularly regarding ancillary information. The discussion was structured so as to guide participants toward formulation of informed opinions and to elicit the reasons underlying their opinions. Although not nationally representative, the focus groups served to increase our understanding of public attitudes toward PGx testing and inform the creation of the survey to incorporate issues important to the public along with other issues identified in the published literature.

Survey Pilot

The SRU conducted a pretest between the 9th and 16th of August 2009 with 52 North Carolina residents. The purpose of the pretest was to evaluate the quality of the computer-assisted telephone interviewing (CATI) programming; ii) appropriateness of the survey content for telephone administration; and iii) quality of the survey data. The sampling frame consisted of 500 randomly selected telephone numbers in North Carolina purchased from GENESYS Sampling Systems (Fort Washington, PA). Adults 18 years of age or older were eligible to participate in the survey. Behavioral coding18 was conducted during the pilot survey to identify potential problems with survey items as well as documenting other administration barriers. Revisions to the survey were made to minimize redundancy, clarify intention of questions, and reduce length. The resulting survey was comprised of five major parts, totaling 52 questions: 1) demographics; 2) experience with prescription medications; 3) experience with and awareness of genetic testing; 4) interest in PGx testing given certain risks and benefits of testing; and 5) interest in learning of ancillary information revealed by PGx testing. Responses to questions regarding management of ancillary findings will be published separately.

Sampling methods

A stratified random-digit-dial sample of 20,848 telephone numbers was selected for this survey. Stratification was based on the U.S. census regions (West, Mid-West, Northeast, South) and included all households with telephone-line access. We achieved an overall response rate of 42% (n=1139)19 where telephone numbers were finalized as either non-response (eligible but no interview; n=1,010), ineligible (non-residential numbers, non-English speaking households, or emancipated youth households; n=14,335), or unknown (eligibility never verified; n=4,364). To be considered eligible, a telephone number needed to reach a household with an English-speaking adult resident 18 years of age or older. If more than one eligible adult resided in the household, one was selected at random via a computer-generated algorithm.

Data Collection

The national survey was conducted from September 17 to November 20, 2009. Calls were made every day of the week except Friday between the hours of 9:30am to 12:00am (EST). A CATI software package (Blaise 4.6)20 was used to assist interviewers in the

administration of the survey and to manage all call attempts. No telephone numbers were removed from calling until a minimum of 12 unsuccessful call attempts were made and at least one weekend, evening, and daytime call was made. Interviewers completed general and project-specific training before conducting the surveys. Interviews lasted approximately 13 minutes. For quality control, all interviewers were monitored periodically and written feedback was provided to them biweekly. This study was approved by the Institutional Review Boards at Duke University Medical Center and the University of North Carolina, Chapel Hill.

Data Analysis

Though random selection procedures were used within households, the respondents who completed the survey (n=1,139) tended to be older, White, and female, to a greater extent than would be expected by chance alone (see Table 1). To correct for such sample imbalances and reduce the potential effects of bias, the survey data were adjusted by age (18–34, 35–54, 55 years and older), race (White, non-White), and gender (male, female) according to normative data from the American Community Survey.21 The majority of questions had answer options based on a 4-point Likert scale that measured respondent's levels of either likelihood, interest or, comfort relative to certain scenarios. For the purposes of statistical analysis, the answer choices were dichotomized into "likely", which included "most likely" and "somewhat likely", and "unlikely", which included "most unlikely" and "somewhat unlikely". Analysis primarily consisted of logistic regressions by which model building was based on hypothetically related covariates with adjustment for demographic characteristics; final variable selection was conducted using the backward selection approach. Odds ratios and corresponding 95% confidence intervals were then computed, using a significance level of 5% for all statistical tests. Cochran-Mantel-Haenszel (CMH) tests adjusted for four control variables (sex, age group, level of education, race) and were applied when comparing two groups on a binary response. All analyses were conducted in SAS (Version 9.1.3 using Proc Frequency, Proc Logistic & Proc Regression).

RESULTS

Respondent Characteristics

Respondents were 51% female, between 34–55 years (38%), and predominantly White (78%) (Table 1). Almost all respondents had some type of health insurance (86%), mostly provided through their employer (74%), and 62% were employed. Seventy-nine percent of respondents characterized their health status as excellent or good, which is comparable to national reports of self-rated health status.22 Forty-seven percent of respondents had experienced a side effect from a prescription drug; of those, 80% had stopped taking the drug. Overall, 36% had stopped taking a drug due to ineffectiveness, of their own accord or based on physician orders.

Awareness/Experience with Genetic Testing

Eighty percent of respondents heard of genetic testing. Overall, 14% (±2.80%) of respondents indicated they or a family member had had a disease-related genetic test performed. A few respondents indicated their physician had ordered a PGx test for them (1%

±0.76%) or a family member (4% ±1.70%) to predict drug response. As shown in Table 2, awareness of genetic testing was associated with several factors including gender (women), race (White), a college degree, and good or excellent self-rated health status. Those over the age of 54 were less likely to have heard of genetic testing as compared to those between the ages of 18–34.

Of those that had heard of genetic testing, 54% (±4.30%) reported that they understood its healthcare application ‘very well’ or ‘somewhat well.’ In contrast to the positive associations observed with awareness of genetic testing, women (OR=0.71, p= 0.01, 95% CI [0.54, 0.93]) as well as Whites (OR=0.71, p= 0.049, 95% CI [0.50, 0.999]) were less likely to report having a good understanding about the use of genetic testing in healthcare. However, those with at least a college degree compared to those with less than a college degree (OR=1.85, p <0.0001, 95% CI [1.40, 2.46]), as well as those who have a health-related job versus those who do not (OR=1.50, p=0.03, 95% CI [1.05, 2.15]) were more likely to report a good understanding of the uses of genetic testing in healthcare.

Interest in PGx Testing Given Potential Risks and Uses

As information order may influence interest in testing,23–26 we presented general information about PGx testing first, followed by three potential risks, and lastly, five different uses of PGx testing (i.e., benefits). Respondents were asked their likelihood to have testing after learning of each risk or specific use, and then overall, after each set of potential risks and test uses were presented. Most respondents were ‘not very’ or ‘not at all’ likely to have PGx testing if there was a chance their DNA sample or test result could be shared with others without their permission (78% ±3.14% each). A minority would be “not very’ or ‘not at all’ likely to have testing if a blood sample was required (23% ±3.25%). In contrast, most respondents (70%–92%) expressed interest in PGx testing for the various purposes presented (see Figure 1). Using the CMH test, adjusting for sex, age group, level of education, and race, the differences between the levels of interest for these questions were found to be statistically significant.

Impact of Personal Factors on Interest in PGx Testing

Four factors were found to be significantly associated with interest in testing for two of the three risks and intended uses presented: awareness of genetic testing (intended uses only), race (risks and intended uses), education (risks only), and personal history of side effects (risks only) (see Tables 3 and 4). No independent variables were found to be significantly associated with strong interest in PGx tests for two of the uses presented (guiding drug selection to optimize effectiveness and dosing) (Table 4).

Respondents who self-identified as White were more likely to have a strong interest in PGx testing (“strong” referring to extremely or somewhat likely to have testing) to understand why they or a family member experienced side effects or failed to respond to certain drugs or despite the risk that the DNA sample could be accessed without the patient’s permission. Similarly, Whites were more likely to have a stronger interest in PGx testing to understand why they or a family member experienced side effects or failed to respond to certain drugs or despite the risk that the DNA sample could be accessed without the patient’s permission.

Whites were more likely to have a strong interest in testing to predict risk of *serious* side effects.

Those who had experienced a side effect from a prescribed drug were more likely to have a strong interest despite the risk that the DNA sample could be accessed without the patient's permission or the need for a blood test. In addition, respondents who had experienced a side effect from a prescribed drug in PGx testing were more likely to have a strong interest in testing to understand why they or a family member experienced side effects or failed to respond to certain drugs.

Respondents with a college degree had a higher likelihood of having a strong interest in testing to predict risk of *serious* side effects (such as heart failure or seizures) and a lower likelihood of having a strong interest in testing to predict risk of *mild* side effects (such as drowsiness, dizziness, or upset stomach). However, respondents familiar with genetic testing were more likely to have a strong interest in testing to predict risk of either serious or mild side effects.

Overall Interest in PGx Testing

After being informed about the risks, 65% (±3.69%) indicated they would be extremely or somewhat likely to have a PGx test. After learning of the uses of PGx testing, interest in PGx testing significantly increased to 82% ±3.02% (CMH statistic of general association: 263.74, $p<0.0001$).

After learning of some of the risks, the likelihood of having an overall strong interest in PGx testing was greater for those with a college degree (OR=1.45, p=0.0145, 95% CI [1.08, 1.94]) and for respondents who had experienced a side effect with a prescribed drug (OR=1.55, p=0.0022, 95% CI [1.17, 2.05]). Women (OR=0.63, p=0.0008, 95% CI [0.476, 0.822]) were less likely to have PGx testing. However, after learning about the different uses of PGx testing, the associations between likelihood of testing and gender and education were no longer significant, leaving experience of a side effect as the only factor significantly associated with likelihood of testing (OR=1.56, p=0.042, 95% CI [1.02, 2.40]). No significance was found between strong interest in PGx testing and age, race, health status, or awareness of genetic testing.

For the subset of respondents who indicated they were not very or not at all likely to have a PGx test after learning of some risks (35% ±3.69%), we assessed interest in having a non-genetic test (did not involve analysis of genes) that would provide similar information about drug response. Half of the respondents (±6.67%) indicated that they would still be unlikely to have a non-genetic test. Compared to respondents aged 18–34 years though, 35–54 year olds were more likely to have a non-genetic test in this scenario (OR=1.25, p=0.012, 95% CI [0.73, 2.15]) and those aged 55+ were less likely (OR=0.48, p=0.0005, 95% CI [0.278, 0.841]). In addition, the likelihood of interest in a non-genetic test was greater for those with a college degree (OR=2.12, p=0.0023, 95% CI [1.307, 3.424]) and Whites (OR=2.79, p=0.0001, 95% CI [1.644, 4.724]). After learning of the uses of PGx testing, 18% were still not very or not at likely to have PGx testing; 62% of this indicated that they were not likely to have a non-genetic PGx test.

DISCUSSION

As PGx testing expands across medical specialties and into primary care, a larger proportion of the public will begin to encounter these tests. In addition to demonstrating the clinical utility and ensuring coverage of testing, the translation of PGx tests will be influenced by patient attitudes and interest. Past surveys have reported favorable support for PGx testing and our findings are consistent with these results in a national U.S. sample.

Level of interest in PGx testing is comparable to the generally high interest reported for genetic testing for colon cancer5 or hereditary cancers in general4, 6–8 and heart disease.6, 8, 9 There are conflicting data on the relationship between level of education and attitudes toward genetic testing.9, 27–30 Some studies have found an inverse relationship between education level and positive attitudes toward genetic testing.9, 28 Others have found that individuals knowledgeable about genetic testing have more positive attitudes towards testing29 but also may express skepticism.27 Yet other surveys find no evidence to support a correlation between knowledge about biotechnology in general and attitudes towards it.31 Although 20% of respondents in our survey had not heard of genetic testing, we did not observe a relationship between overall interest in PGx testing and awareness. However, we found that those with less than a college degree had a lower interest in PGx testing after being informed of the risks; this association disappeared after they learned about the specific uses of testing. Similar to other studies,32 we found greater awareness of genetic testing in Whites compared to non-Whites, but race was not associated with overall interest in PGx testing.

The order of information presented about genetic testing can affect attitudes toward testing with the information presented first being more influential.24 After assessing overall interest, we did not find presentation of the risks first as most influential, perhaps due to high general interest in genetic testing or familiarity and/or experience with drug side effects or non-response. However, when presented with individual risks such as loss of confidentiality, only a minority indicated they would be interested in PGx testing. Despite the nearly 10-year gap between the two surveys, our findings were comparable to Rothstein & Hornung (2003) with respect to interest in PGx testing given concerns about confidentiality (78% in our survey vs. 70% in their survey would be less likely to undergo PGx testing). As we did not disclose the fact that federal law now prohibits discriminatory actions by health insurers or employers (regulations were still pending at the time the survey was administered), it is not certain whether knowledge of federal protections would have increased interest following presentation of individual risks. Given ongoing concerns, disclosure of these policies should be a required element of the discussion about PGx testing with patients.

As anticipated, presentation of the different uses of PGx testing boosted interest. We had hypothesized that the public would vary in their level of interest of different uses of a PGx test as some uses may be considered more important than others, but found little difference. Commonalities existed between factors predictive of interest in PGx testing given certain risks or intended uses, though no single characteristic was predictive of likelihood, suggesting that a combination of personal factors, awareness of genetics, and health and

medication history influence interest in PGx testing. The absence of significant differences could also be attributed to lack of understanding of the different specific test uses (e.g., effectiveness vs. safety). The lack of context or details of a specific treatment scenario may have also resulted in generally high interest in all uses. Four factors were significantly associated with interest in testing for two of the three risks and intended uses presented: awareness of genetic testing, race, education, and personal history of side effects. The lower interest in PGx testing by non-Whites given some risks and intended uses may indicate differences in perceived harms (higher) and value of the information (lower), potentially attributed to mistrust of genetic testing33, 34 or the health system in general, but not strong enough to influence overall interest in testing. Interestingly though, race and education were not associated with likelihood of testing given risk of loss of confidentiality as reported by Rothstein & Hornung (2003). Our finding that history of side effects was linked to overall interest confirm previous findings with respect to PGx testing,17, 35 analogous to the higher interest in genetic testing in at-risk individuals (i.e., those with a family history).36, 37

Of the minority of respondents that indicated they were initially not very or not at all likely to have a PGx test, about half indicated they would be interested in a non-genetic test that provided similar information about drug response, suggesting that development of non-DNA-based PGx tests may help increase uptake. Interest in a non-genetic test was associated with higher education status, possibly suggesting greater awareness of potential risks of testing. Shields et al.38, 39 reported that primary care physicians would be more likely to order a non-genetic test compared to a genetic test to predict response to smoking cessation therapy, suggesting some reluctance, either on the part of physicians or their belief that their patients would be reluctant to consent to a genetic test. Of our respondents who were unlikely to have any testing for drug response, genetic or otherwise, we speculate that other concerns not related to ‘genetic testing’ account for their lack of interest in testing. Given the long-term benefits of PGx testing over a patient’s lifetime, declining testing could have multiple adverse consequences including access to best available therapies if testing is required prior to use. Thus, careful consideration must be given to weighing the benefits and risks of use of a given treatment if testing is not performed, coverage policies of treatments without testing, and alternative approaches to monitoring adverse responses.

Given the sometimes different allele prevalence between populations, it will be essential to include as diverse study populations as possible to ascertain PGx associations as well as potential physiologic functional differences. Groups with lower interest in PGx testing may be less inclined to participate in such studies, creating a significant knowledge gap. On the other hand, groups with higher interest in PGx testing, such as individuals with prior experience of side effects, may be more interested in participating in PGx research. Careful attention should be given to assessing outcomes based on patient self-reporting to minimize confounding.

As the clinical evidence basis increases and PGx testing is routinely ordered in the clinic, it is critical to ascertain the public’s interest and perceived barriers to this new application. The public is strongly supportive of PGx testing, however, their interest is influenced by a combination of factors, most notably prior experience with side effects. Although informed consent is not usually obtained for PGx tests currently40–42 given the different levels of

interest among some groups, providers should discuss the exact purpose of testing, alterative testing options (if available), and the protections in place to protect their privacy and confidentiality. While the high level of interest in PGx testing is encouraging, public interest in genetic testing may not translate to high uptake.43, 44 Patients recommended PGx testing in an actual clinical situation may respond differently depending on the circumstances of the situation or potential other factors not raised in this study. Thus, clinical studies will be needed to assess actual uptake of testing, with a particular focus on patients who are declining testing, such as assessing factors that impact patient decisions regarding testing such as patient expectations and/or concerns about testing . Based on these data gathered from a real-world setting, we will gain a better understanding of the barriers to actual uptake or refusal that may inform changes in the delivery of PGx testing, patient communication, and application of PGx testing to therapeutic decision-making.

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REFERENCES

1. Kamali F, Wynne H. Pharmacogenetics of warfarin. Annu Rev Med. 2010; 61:63–75. [PubMed: 19686083]
2. Frueh FW, Amur S, Mummaneni P, Epstein RS, Aubert RE, DeLuca TM, et al. Pharmacogenomic biomarker information in drug labels approved by the United States food and drug administration: prevalence of related drug use. Pharmacotherapy. 2008; 28(8):992–998. [PubMed: 18657016]
3. Zineh I, Gerhard T, Aquilante CL, Beitelshees AL, Beasley BN, Hartzema AG. Availability of pharmacogenomics-based prescribing information in drug package inserts for currently approved drugs. Pharmacogenomics J. 2004; 4(6):354–358. [PubMed: 15483659]
4. Andrykowski MA, Munn RK, Studts JL. Interest in learning of personal genetic risk for cancer: a general population survey. Prev Med. 1996; 25(5):527–536. [PubMed: 8888320]
5. Petersen GM, Larkin E, Codori AM, Wang CY, Booker SV, Bacon J, et al. Attitudes toward colon cancer gene testing: survey of relatives of colon cancer patients. Cancer Epidemiol Biomarkers Prev. 1999; 8(4 Pt 2):337–344. [PubMed: 10207638]
6. Hietala M, Hakonen A, Aro AR, Niemela P, Peltonen L, Aula P. Attitudes toward genetic testing among the general population and relatives of patients with a severe genetic disease: a survey from Finland. Am J Hum Genet. 1995; 56(6):1493–1500. [PubMed: 7762573]
7. Andrykowski MA, Lightner R, Studts JL, Munn RK. Hereditary cancer risk notification and testing: how interested is the general population? J Clin Oncol. 1997; 15(5):2139–2148. [PubMed: 9164229]
8. Sanderson SC, Wardle J. Associations between anticipated reactions to genetic test results and interest in genetic testing: will self-selection reduce the potential for harm? Genet Test. 2008; 12(1): 59–66. [PubMed: 18318647]
9. Sanderson SC, Wardle J, Jarvis MJ, Humphries SE. Public interest in genetic testing for susceptibility to heart disease and cancer: a population-based survey in the UK. Prev Med. 2004; 39(3):458–464. [PubMed: 15313084]
10. Rogausch A, Prause D, Schallenberg A, Brockmoller J, Himmel W. Patients' and physicians' perspectives on pharmacogenetic testing. Pharmacogenomics. 2006; 7(1):49–59. [PubMed: 16354124]
11. The Royal Society. Pharmacogenetics dialogue. 2005
12. Almarsdottir AB, Bjornsdottir I, Traulsen JM. A lay prescription for tailor-made drugs--focus group reflections on pharmacogenomics. Health Policy. 2005; 71(2):233–241. [PubMed: 15607385]

13. Bates BR, Poirot K, Harris TM, Condit CM, Achter PJ. Evaluating direct-to-consumer marketing of race-based pharmacogenomics: a focus group study of public understandings of applied genomic medication. J Health Commun. 2004; 9(6):541–559. [PubMed: 15764452]
14. Bevan JL, Lynch JA, Dubriwny TN, Harris TM, Achter PJ, Reeder AL, et al. Informed lay preferences for delivery of racially varied pharmacogenomics. Genet Med. 2003; 5(5):393–399. [PubMed: 14501835]
15. Condit C, Templeton A, Bates BR, Bevan JL, Harris TM. Attitudinal barriers to delivery of race-targeted pharmacogenomics among informed lay persons. Genet Med. 2003; 5(5):385–392. [PubMed: 14501834]
16. Rothstein, MA.; Hornung, CA. Public attitudes about Pharmacogenomics. In: Rothstein, MA., editor. Pharmacogenomics: Social, Ethical, and Clinical Dimensions. New Jersey: Wiley-Liss; 2003. p. 3-27.
17. O'Daniel J, Lucas J, Deverka P, Ermentrout D, Silvey G, Lobach DF, et al. Factors Influencing Uptake of Pharmacogenetic Testing in a Diverse Patient Population. Public Health Genomics. 2009
18. Lessler J, Forsyth B. A coding system for appraising questionnaires. Answering questions. 1996:259–291.
19. Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. 5th edn. Lenexa, Kansas: AAPOR; 2008. The American Association for Public Opinion Research.
20. Statistics Netherlands. Blaise 4.6 computer software. 2003
21. US Census Bureau. American Community Survey 2008. 2008
22. Zahran HS, Kobau R, Moriarty DG, Zack MM, Holt J, Donehoo R. Health-related quality of life surveillance--United States, 1993–2002. MMWR Surveill Summ. 2005; 54(4):1–35. [PubMed: 16251867]
23. Bergus GR, Levin IP, Elstein AS. Presenting risks and benefits to patients. J Gen Intern Med. 2002; 17(8):612–617. [PubMed: 12213142]
24. Morrison V, Henderson BJ, Taylor C, A'Ch Dafydd N, Unwin A. The impact of information order on intentions to undergo predictive genetic testing: An experimental study. J Health Psychol. 2010
25. Adelman L, Bresnick T, Black P, Marvin F, Sak S. Research with Patriot air defense officers: Examining information order effects. Human Factors. 1996; 38(2):250–261.
26. Wroe AL, Salkovskis PM. Factors influencing anticipated decisions about genetic testing: Experimental studies. British Journal of Health Psychology. 1999; 4:19–40.
27. Jallinoja P, Aro AR. Does knowledge make a difference? The association between knowledge about genes and attitudes toward gene tests. J Health Commun. 2000; 5(1):29–39. [PubMed: 10848030]
28. Catz DS, Green NS, Tobin JN, Lloyd-Puryear MA, Kyler P, Umemoto A, et al. Attitudes about genetics in underserved, culturally diverse populations. Community Genet. 2005; 8(3):161–172. [PubMed: 16113533]
29. Rose A, Peters N, Shea JA, Armstrong K. The association between knowledge and attitudes about genetic testing for cancer risk in the United States. J Health Commun. 2005; 10(4):309–321. [PubMed: 16036738]
30. Tan EK, Lee J, Hunter C, Shinawi L, Fook-Chong S, Jankovic J. Comparing knowledge and attitudes towards genetic testing in Parkinson's disease in an American and Asian population. J Neurol Sci. 2007; 252(2):113–120. [PubMed: 17174340]
31. Gottweis H. Gene therapy and the public: a matter of trust. Gene Ther. 2002; 9(11):667–669. [PubMed: 12032683]
32. Pagan JA, Su D, Li L, Armstrong K, Asch DA. Racial and ethnic disparities in awareness of genetic testing for cancer risk. Am J Prev Med. 2009; 37(6):524–530. [PubMed: 19944919]
33. Thompson HS, Valdimarsdottir HB, Jandorf L, Redd W. Perceived disadvantages and concerns about abuses of genetic testing for cancer risk: differences across African American, Latina and Caucasian women. Patient Educ Couns. 2003; 51(3):217–227. [PubMed: 14630378]
34. Satia JA, McRitchie S, Kupper LL, Halbert CH. Genetic testing for colon cancer among African-Americans in North Carolina. Prev Med. 2006; 42(1):51–59. [PubMed: 16297974]

35. Fargher EA, Eddy C, Newman W, Qasim F, Tricker K, Elliott RA, et al. Patients' and healthcare professionals' views on pharmacogenetic testing and its future delivery in the NHS. Pharmacogenomics. 2007; 8(11):1511–1519. [PubMed: 18034616]

36. Kinney AY, Croyle RT, Dudley WN, Bailey CA, Pelias MK, Neuhausen SL. Knowledge, attitudes, and interest in breast-ovarian cancer gene testing: a survey of a large African-American kindred with a BRCA1 mutation. Prev Med. 2001; 33(6):543–551. [PubMed: 11716649]

37. Cowan R, Meiser B, Giles GG, Lindeman GJ, Gaff CL. The beliefs, and reported and intended behaviors of unaffected men in response to their family history of prostate cancer. Genet Med. 2008; 10(6):430–438. [PubMed: 18496220]

38. Shields AE, Blumenthal D, Weiss KB, Comstock CB, Currivan D, Lerman C. Barriers to translating emerging genetic research on smoking into clinical practice. Perspectives of primary care physicians. J Gen Intern Med. 2005; 20(2):131–138. [PubMed: 15836545]

39. Shields AE, Levy DE, Blumenthal D, Currivan D, McGinn-Shapiro M, Weiss KB, et al. Primary care physicians' willingness to offer a new genetic test to tailor smoking treatment, according to test characteristics. Nicotine Tob Res. 2008; 10(6):1037–1045. [PubMed: 18584467]

40. Woelderink A, Ibarreta D, Hopkins MM, Rodriguez-Cerezo E. The current clinical practice of pharmacogenetic testing in Europe: TPMT and HER2 as case studies. Pharmacogenomics J. 2006; 6(1):3–7. [PubMed: 16314885]

41. Hedgecoe A. 'At the point at which you can do something about it, then it becomes more relevant': informed consent in the pharmacogenetic clinic. Soc Sci Med. 2005; 61(6):1201–1210. [PubMed: 15970231]

42. Hedgecoe AM. Context, ethics and pharmacogenetics. Stud Hist Philos Biol Biomed Sci. 2006; 37(3):566–582. [PubMed: 16980195]

43. Ropka ME, Wenzel J, Phillips EK, Siadaty M, Philbrick JT. Uptake rates for breast cancer genetic testing: a systematic review. Cancer Epidemiol Biomarkers Prev. 2006; 15(5):840–855. [PubMed: 16702359]

44. Persky S, Kaphingst KA, Condit CM, McBride CM. Assessing hypothetical scenario methodology in genetic susceptibility testing analog studies: a quantitative review. Genet Med. 2007; 9(11): 727–738. [PubMed: 18007141]

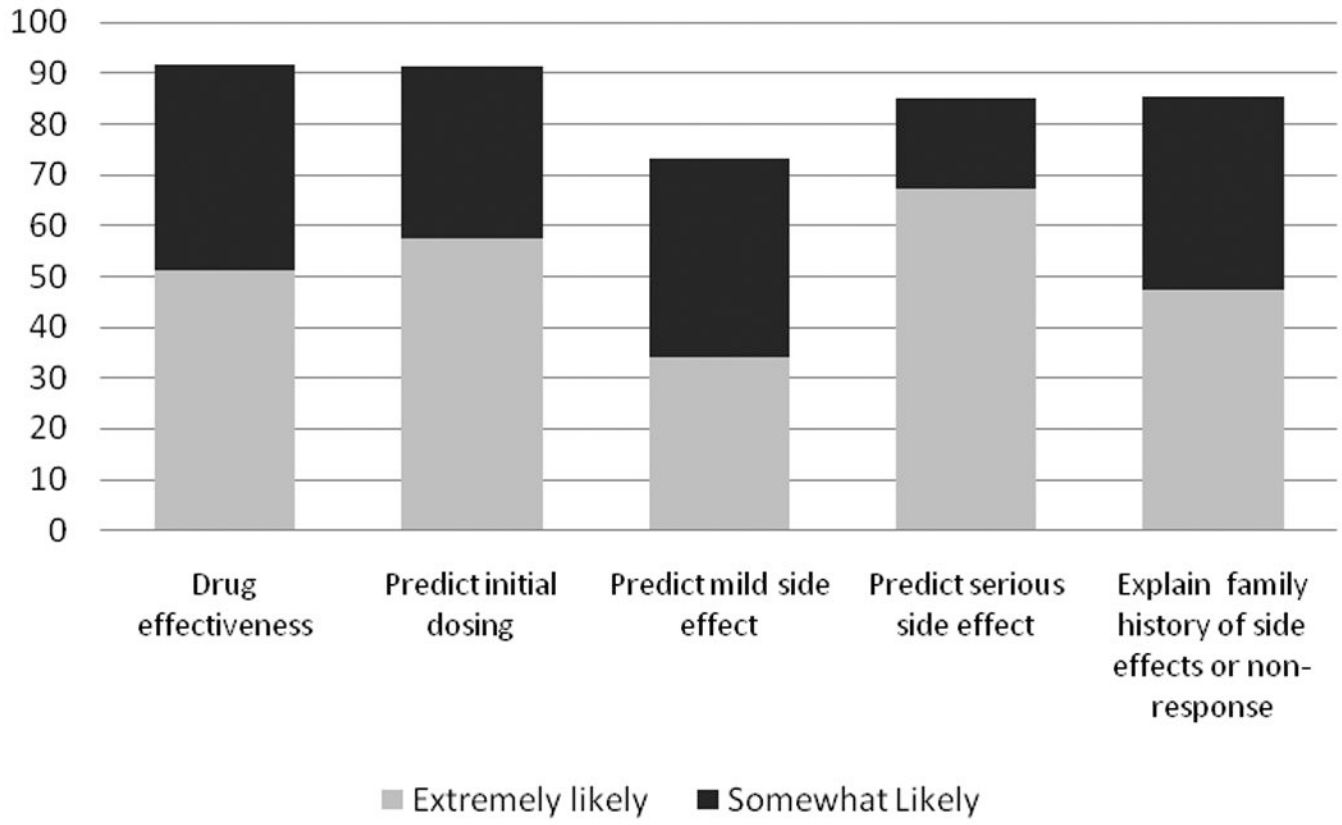

Figure 1.
Likelihood to have PGx testing for certain uses. Using the CMH test, adjusting for sex, age group, level of education, and race, the differences between the levels of interest for these questions were found to be statistically significant.

Table 1

Demographic characteristics of survey respondents (n=1139).

Demographic			Number	Unadjusted %[§]	Adjusted %[*]
Female			695	61.0	51.3
Race[†]					
•	**White**		965	85.8	77.8
•	**Non-White**		159	14.2	22.2
	○	**Black/African-American**	123	10.9	15.8
	○	**Asian**	22	2.0	4.1
	○	**American Indian/Alaskan Native**	10	0.9	1.9
	○	**Native Hawaiian/Pacific Islander**	3	0.3	0.4
	○	**Other**	1	0.1	0.1
Hispanic			53	4.6	Not adjusted
Age					
•	**18–34**		139	12.2	31.1
•	**35–54**		418	36.7	37.5
•	**55+**		582	51.1	31.4
Educational Status					
•	**Some College or Less**		652	58.1	Not adjusted
	○	**Less than 9th grade**	17	1.5	Not adjusted
	○	**9th–12th grade (no diploma)**	59	5.3	Not adjusted
	○	**High school graduate/GED**	221	19.7	Not adjusted
	○	**Some college (no degree)**	231	20.6	Not adjusted
	○	**Associate's degree**	124	11.0	Not adjusted
•	**College Degree**		471	41.9	Not adjusted
	○	**Bachelor's degree**	266	23.7	Not adjusted
	○	**Graduate/Professional degree**	205	18.2	Not adjusted

[*] Unadjusted percentages are weighted to the U.S. population based on data reported by the American Community Survey (2008).21

[§] Percentage based on total responses per question;

† Total number of responses may not equal 1139 as respondents could select more than response or could choose not to respond.

Table 2

Respondent characteristics associated with awareness of genetic testing in general based on multivariate logistic regression modeling. The odds ratio (OR) was calculated to reflect the likelihood of awareness of genetic testing given respondent characteristics.

	Odds Ratio	95% CI	p-value
Age Group 2 vs. 1 (35–54 years vs. 18–34 years)	0.81	[0.53, 1.23]	0.07
Age Group 3 vs. 1 (+55 years vs. 18–34 years)	0.35	[0.23, 0.54]	<0.0001
Sex (F vs. M)	1.51	[1.10, 2.07]	0.01
Education (At least a college degree vs. Less than a college degree)	1.69	[1.18, 2.42]	0.004
Health Insurance (Insured vs. Not insured)	1.38	[0.88, 2.16]	0.16
Race (White vs. Non-White)	1.74	[1.22, 2.49]	0.002
History of Side Effects (Yes vs. No)	1.81	[1.31, 2.51]	0.0004

* Unadjusted percentages are weighted to the U.S. population based on data reported by the American Community Survey (2008). This table reflects the weighted data.

Table 3

Multivariate logistic regression model with three potential risks of PGx testing as dependent variables. The odds ratio (OR) was calculated to reflect the likelihood of having a PGx test given each potential risk.

	DNA sample could be accessed without patient permission	Test result could be accessed without patient permission	PGx testing may require a blood draw
Awareness of Genetic testing (Aware vs. Not aware)	OR=0.93, p=0.69, 95% CI [0.63, 1.35]	OR=0.72, p=0.07, 95% CI [0.50, 1.03]	OR=1.51, p=0.02, 95% CI [1.06, 2.15]
Age Group 2 vs. 1 (35–54 years vs. 18–34 years)	OR=0.84, p=0.92, 95% CI [0.59, 1.20]	OR=1.00, p=0.91, 95% CI [0.70, 1.43]	OR=0.63, p=0.86, 95% CI [0.43, 0.92]
Age Group 3 vs. 1 (+55 years vs. 18–34 years)	OR=0.73, p=0.18, 95% CI [0.50, 1.07]	OR=1.03, p=0.84, 95% CI [0.71, 1.51]	OR=0.37, p<0.0001, 95% CI [0.25, 0.56]
Sex (F vs. M)	OR=0.75, p=0.06, 95% CI [0.56, 1.01]	OR=0.65, p=0.004, 95% CI [0.49, 0.87]	OR=0.76, p=0.07, 95% CI [0.56, 1.02]
Education (At least a college degree vs. Less than a college degree)	OR=0.92, p=0.60, 95% CI [0.67, 1.26]	OR=1.17, p=0.32, 95% CI [0.86, 1.61]	OR= 2.30, p<0.0001, 95%CI [1.64, 3.24]
Race (White vs. Non-White)	OR=1.53, p=0.03, 95% CI [1.04, 2.24]	OR=1.31, p=0.16, 95% CI [0.90, 1.90]	OR=2.03, p<0.0001, 95% CI [1.45, 2.85]
Self-Rated Health Status (Excellent/ Good vs. Fair/Poor)	OR=1.19, p=0.38, 95% CI [0.81, 1.75]	OR=0.62, p=0.01, 95% CI [0.44, 0.89]	OR=0.82, p=0.31, 95% CI [0.56, 1.20]
Personal History of Side Effects (Yes vs. No)	OR=1.37, p=.04, 95% CI [1.02, 1.85]	OR=1.13, p=0.43, 95% CI [0.84, 1.52]	OR=1.55, p=0.005, 95% CI [1.14, 2.11]

Table 4

Multivariate logistic regression model with three of the five potential benefits of PGx testing presented in the survey as dependent variables. No significant associations were observed for use of PGx testing to select most effective drug to treat illness or to select appropriate dose or strength. The odds ratio (OR) was calculated to reflect the likelihood of having a PGx test given a specific use.

	PGx testing used to predict risk of mild side effects	PGx testing used to predict risk of serious side effects	PGx testing used to understand side effects in self or family members
Awareness of Genetic testing (Aware vs. Not aware)	OR=1.53, p=0.02, 95% CI [1.09, 2.16]	OR=1.80, p=0.004, 95% CI [1.21, 2.67]	OR=1.42, p=0.10, 95% CI [0.94, 2.16]
Age Group 2 vs. 1 (35–54 years vs. 18–34 years)	OR=0.97, p=0.98, 95% CI [0.69, 1.36]	OR=0.98, p=0.26, 95% CI [0.63, 1.53]	OR=1.01, p=0.49, 95% CI [0.65, 1.56]
Age Group 3 vs. 1 (+55 years vs. 18–34 years)	OR=0.93, p=0.71, 95% CI [0.65, 1.33]	OR=0.627, p=0.02, 95% CI [0.40, 0.98]	OR=0.78, p=0.20, 95% CI [0.50, 1.22]
Sex (F vs. M)	OR=0.77, p=0.06, 95% CI [0.58, 1.01]	OR=0.91, p=0.60, 95% CI [0.64, 1.29]	OR=0.55, p=0.001, 95% CI [0.38, 0.78]
Education (College degree vs. Less than a college degree)	OR=0.68, p=0.01, 95% CI [0.51, 0.91]	OR=2.10, p<0.001, 95% CI [1.38, 3.20]	OR=1.04, p=0.85, 95% CI [0.71, 1.52]
Race (White vs. Non-White)	OR=0.84, p=0.33, 95% CI [0.59, 1.19]	OR=2.54, p<0.0001, 95% CI [1.74, 3.70]	OR=1.57, p=0.03, 95% CI [1.05, 2.34]
Self-Rated Health Status (Excellent/ Good vs. Fair/Poor)	OR=0.65, p=0.03, 95% CI [0.45, 0.95]	OR=1.35, p=0.15, 95% CI [0.89, 2.04]	OR=1.07, p=0.77, 95% CI [0.69, 1.67]
Personal History of Side Effects (Yes vs. No)	OR=0.83, p=0.19, 95% CI [0.63, 1.10]	OR=1.28, p=0.18, 95% CI [0.89, 1.85]	OR=1.58, p=0.02, 95% CI [1.10, 2.28]