Published in final edited form as:
*Am J Bioeth*. 2009 ; 9(6-7): 3–10. doi:10.1080/15265160902928209.

# Social Networkers' Attitudes Toward Direct-to-Consumer Personal Genome Testing

**Amy L. McGuire**,
Center for Medial Ethics and Health Policy, Baylor College of Medicine

**Christina M. Diaz**,
Center for Medial Ethics and Health Policy, Baylor College of Medicine

**Tao Wang**, and
Lester & Sue Smith Breast Center, Baylor College of Medicine

**Susan G. Hilsenbeck**
Lester & Sue Smith Breast Center, Baylor College of Medicine

## Abstract

**Purpose—**This study explores social networkers' interest in and attitudes toward personal genome testing (PGT), focusing on expectations related to the clinical integration of PGT results.

**Methods—**An online survey of 1,087 social networking users was conducted to assess 1) use and interest in PGT; 2) attitudes toward PGT companies and test results; and 3) expectations for the clinical integration of PGT. Descriptive statistics were calculated to summarize respondents' characteristics and responses.

**Results—**Six percent of respondents have used PGT, 64% would consider using PGT, and 30% would not use PGT. Of those who would consider using PGT, 74% would use it to gain knowledge about disease in their family. Of all respondents, 34% consider the information obtained from PGT to be a medical diagnosis. Of all respondents, 78% of those who would consider PGT would ask their physician for help interpreting test results, and 61% of all respondents believe that physicians have a professional obligation to help individuals interpret PGT results.

**Conclusion—**Respondents express interest in using PGT services, primarily for purposes related to their medical care and expect physicians to help interpret PGT results. Physicians should therefore be prepared for patient demands for information and counsel on the basis of PGT results.

### Keywords

personal genome testing; patient expectations; genetics; ethics; policy

Direct-to-consumer personal genome testing (PGT) companies such as 23 and Me (available at: https://www.23andme.com/), Navigenics (available at: http://www.navigenics.com/), and deCODEme (available at: http://decodediagnostics.com/) hope to usher in a new era of personalized genomic medicine by "empowering individuals to access and understand their own genetic information" (23andMe 2007,). Yet, some are concerned that PGT is being offered prematurely and without appropriate regulatory and professional oversight (Offit



Address correspondence to Amy L. McGuire, Assistant Professor of Medicine and Medical Ethics, Center for Medical Ethics and Health Policy, Baylor College of Medicine, One Baylor Plaza, Suite 310D Houston, Texas 77030. amcguire@bcm.edu.

2008; Feero et al. 2008; Burke and Psaty 2007). At least two states (New York and California) have formally investigated whether some PGT companies are in violation of state law by engaging in the unlicensed practice of medicine (Langreth 2008; Langreth and Herper 2008). The United States Federal Trade Commission (US FTC) and the US Food and Drug Administration (US FDA) have warned consumers to approach these genomic profiles and other direct-to-consumer genetic tests with "A Healthy Dose of Skepticism" (US FTC 2006), and scholars have advised those who are interested in PGT to "save your money, and spare your health" (Welch and Burke 2008). But will the public heed this advice? And if they do not, what role will they expect physicians to play in helping to interpret their personal genome information?

There is wide variation in the services offered and medical support provided by PGT companies (Offit 2008). Some staff a physician to order tests and offer genetic counseling to consumers (Navigenics. 2009; DNA Direct 2008), while others claim that the information they provide is for informational and educational purposes only and direct consumers who have questions to their own health care provider (23andMe 2009). This raises important questions about how patients view PGT information and whether they will seek help from physicians in interpreting their results. Hunter and colleagues caution physicians against counseling patients on the basis of this information, citing concerns about the analytic validity, clinical validity, and clinical utility of the tests (Hunter et al. 2008). They also worry about physicians' ability to interpret PGT results, suggesting that "a detailed consumer report may be beyond most physicians' skill sets". Instead, they recommend that physicians provide only "a general statement about the poor sensitivity and positive predictive value of such results". We have argued that physicians may be in the best position to counsel patients about test results, but follow-up testing and treatment on the basis of PGT results of unproven clinical significance is an unjustified use of healthcare resources and constitutes a raid on the medical commons (McGuire and Burke 2008).

This survey seeks to explore potential consumers' interest in and attitudes toward PGT, focusing on their expectations of physicians and the clinical integration of PGT results. Because PGT is new, it is difficult to identify the small number of people who have already used these services. It is also challenging to predict who will be among the early adopters of PGT. However, because PGT services are primarily offered through the Internet, and because some of the major PGT companies include an optional social networking component based on an individual's genetic profile, social networkers are likely to be aware of PGT and to be early adopters of PGT services. We therefore conducted an exploratory survey of users of Facebook.com, a popular social networking website. Although this is not a representative sample and the results of this study cannot be generalized, the attitudes and expectations of this cohort can help generate hypotheses for future study and identify potential challenges to the clinical integration of PGT.

## METHODS

### Design

A survey consisting of 40 questions was distributed through an online market research firm in April 2008. The survey was voluntary, anonymous, and confidential; it was approved by the Baylor College of Medicine (Houston, TX) institutional review board.

The survey contained four sections: 1) knowledge and awareness of personal genome testing companies; 2) opinions and attitudes toward personal genome testing companies; 3) opinions and attitudes toward personal genome test results; and 4) demographic information (age, gender, race, education level, occupation, and access to health care). Responses from sections two or three of the survey were rated on a 5-point Likert scale from *strongly*

*disagree* to *strongly agree*. After agreement to participate was obtained, respondents were provided the following information:

> Recently, several 'personal genome' companies have been launched. For a fee, they will analyze your DNA and help you to read and understand your genetic information. Some of the more well-known companies, which you may have heard of, are: 23andMe, deCODEme, and Navigenics.

The survey took approximately 10 to 15 minutes to complete.

### Participants and Data Collection

A total of 1,087 surveys were completed through Zoomerang.com. An invitation to take the survey was distributed to approximately 4,700 members of True-Sample, from Zoomerang's parent company, Market-Tools (available at: http://www.zoomerang.com/online-panel/index.htm). TrueSample provides a quality-assured sample of survey respondents by validating prospective panelists to ensure that they are providing accurate data, de-duplicating survey responders by using digital fingerprinting to eliminate duplicate or professional survey-takers, and correlating survey-taking time and response patterns to identify and eliminate fraudulent responders (Market-Tools.). Only validated panelists who are registered users of Facebook.com were invited to take the survey. Because the survey was pre-set to automatically close once 1,080 respondents had completed it and because 1,080 respondents completed the survey within 36 hours of its launching, the true response rate is unknown.

### Analysis

Respondents were grouped into "did use", "would use", and "would not use" based on their answers to usage and opinions of PGT. Descriptive statistics were calculated to summarize respondents' characteristics and responses by all and by user status. A chi-square test was performed to examine the relationship between answers to different questions. P-values of 5% or less were considered significant. Data on chi-square analyses are not shown.

## RESULTS

### Respondent Demographics

Respondent ages ranged from 18 to 81 years (mean, 35 [SD, 12.0] years). The majority (59%) reported having a bachelor's degree or higher, 85% reported having either government or private healthcare insurance, and 78% reported having a regular physician. Of all respondents, 83% self-identified as Caucasian, 34% reported having children under the age of 18 years, and 98% reported being a citizen or resident of the United States (Table 1).

### Potential Use

Of respondents 47% reported having heard of PGT companies, such as such as 23andMe (available at: https://www.23andme.com/), Navigenics (available at: http://www.navigenics.com/), and deCODEme (available at: http://decodediagnostics.com/) prior to taking the survey. While only 6% reported having used the services of a PGT company, 64% indicated that they would consider using them in the future.

We asked respondents who have used PGT services and those who would consider using these services (n = 756) to select reasons they were interested in PGT (respondents could choose more than one reason) (Table 2). The most common reasons included: "general curiosity about my genetic make-up," (81%) and "to see if a specific disease runs in my family or is in my DNA" (74%). The idea of direct-to-consumer testing appealed to a large

number of participants: 40% reported they would use PGT to learn about their genetic make-up without having to go through a physician.

Of those who reported they would not consider using PGT, 53% "do not think the information would be useful." This group of non-potential users was also deterred by the cost of the service (40%) and has concerns about their privacy (39%), the reliability of the results (21%), and the potential return of unwanted information (21%) (Table 2).

Of those respondents who reported having used PGT or being interested in PGT, 74% would consider testing someone other than themselves. Of those, 54% said they would consider testing their child, and 67% would consider testing their spouse/significant other. Also, 43% expressed interest in using PGT for other family members and 18% would consider using PGT for friends. Those who would test their child were most likely to do so in order to find out if the child has a genetic predisposition to an illness ($p = 0.0015$). Participants were also interested in testing someone other than self because they hoped that it would encourage them to change their lifestyle (28%) and to seek medical help (27%) (Table 2).

## ATTITUDES TOWARD PERSONAL GENOME TESTING

Respondents see a benefit to PGT that extends beyond mere acquisition of genetic information. Of all respondents, 53% reported that PGT will increase individuals' control over their health, whereas 58% said it will stimulate discussion about personal health within families. Of those who would consider using PGT, 65% reported that the results of PGT would influence their future healthcare decisions. The majority (84%) of these respondents reported that if they were to receive PGT information that indicated an increased risk of cardiovascular disease they would consult a physician and the majority (78%) would modify their lifestyle by dieting and exercising more (Table 3).

Less than 50% (42%) of all respondents were confident that they understood the risks and benefits of PGT and knew enough about genetics to understand the results (46%). Only 17% believed that others could accurately interpret their own test results. When asked if PGT companies provide enough information for consumers to make informed decisions about using their services, only 30% of all respondents agreed. Those who reported that PGT companies provide sufficient information were more likely to report personal understanding of the risks and benefits of PGT than those that did not ($p < .0001$). The majority (76%) of all respondents agreed that PGT companies should provide a medical expert to help interpret results, and 51% supported federal regulation of PGT companies (Table 4).

### Expectations of Physicians

Despite the fact that many PGT companies claim only to provide information for educational purposes and not medical diagnoses, 38% of respondents who would consider using PGT and 23% of those who would not consider using PGT considered the information obtained from PGT to be a diagnosis of a medical condition or disease. Of those, 60% who have used these services considered their results as a medical diagnosis (Table 3). Those who thought of the results as a medical diagnosis were more likely to anticipate PGT results influencing their future healthcare decisions than those who did not ($p < .0001$). Most (70%) of respondents who would consider using PGT services reported they would ask for help interpreting their results from the company that conducted the analysis, but even more respondents (78%) would also ask their physician to help interpret the results. Of those who have had PGT, 53% reported they discussed their results with their physician and 10% reported that they plan to. There is a statistically significant association between believing that the test result is a medical diagnosis and having discussed test results with one's physician (for those who have had PGT, $p = .0158$) or intention to seek help interpreting

results from a physician (all respondents, p = .0430). Not only did respondents expect physicians to help them interpret PGT results, 61% of all respondents agreed that physicians have a professional obligation to help individuals understand the results they receive from a PGT. However, there was some concern that physicians may not be capable of fulfilling this obligation. Only 47% of participants agreed that physicians have enough knowledge to help patients interpret PGT results (Table 3). Those who considered a PGT result to be a medical diagnosis were more likely to report that physicians have a professional obligation to help interpret the results ($p < .0001$) and that they have enough knowledge to do so than those who did not ($p < .0001$).

## DISCUSSION

Direct-to-consumer personal genome testing is relatively new, but the results of this research suggest use of these services may be on the rise, at least among individuals from the same demographics as our cohort: 6% of our respondents have already used these services, 47% had heard of PGT companies such as 23andMe, Navigenics, and deCODEme prior to taking the survey, and 64% would consider purchasing a PGT in the future.

Despite claims that PGT companies are not providing medical diagnostic information, many respondents (34%) consider the information obtained from a PGT to be a medical diagnosis and anticipate that it will influence their future healthcare decisions. PGT companies typically provide information to consumers based on validated reports of genetic associations from the scientific literature (23andMe 2009). However, genetic testing for most of these associations has not been incorporated into routine clinical care because of the nascent stage of research, lack of available evidence, and concerns about the validity of research findings, the complexity of gene-environment interactions, and the uncertain or weak penetrance of genetic variants for common and complex disorders (Feero et al. 2008; McGuire et al. 2007). Most PGT companies inform consumers that their services are “for informational and educational purposes only” and should not be used “for health ascertainment or disease purposes” (23andMe 2009,). These disclaimers reinforce the limited clinical utility of PGT results and attempt to mitigate potential misconceptions about their therapeutic significance. However, one hypothesis that can be generated from this survey is that regardless of how PGT is marketed, potential consumers may still consider the information to be diagnostic and material to their healthcare decisions. That this cohort of social networkers overestimates the clinical significance of PGT results may be cause for concern but should not be surprising. Studies suggest that individuals tend to understand risk information categorically, resulting in perceptions that conflict with standard scientific measures and leading to decisions that may not be in the individual’s best interest (Redelmeier et al. 1993).

To comply with state laws, some PGT companies, such as Navigenics, employ a physician who orders the test and provides post-test genetic counseling (Navigenics 2009). This is consistent with the preferences of 76% of our survey respondents who agreed that PGT companies should employ a medical expert to help consumers interpret their test results. Involving healthcare professionals may help to ensure that consumers understand their test results and the implications of those results for their present and future health. It could also relieve primary care physicians and genetic counselors, who often have limited time and knowledge of genomics, from serving as the primary educator and counselor of consumers. Physicians who are knowledgeable about the services offered by the PGT company could also help determine which results are valid and clinically relevant. In another regard, involving health care professionals may legitimize PGT and could reinforce false assumptions about the predictive power of information with unknown relevance or results with low penetrance for the future health of individuals and their offspring.

The majority of social networkers who completed this survey reported that they would also seek help interpreting PGT results from their own primary care physician. At first, physicians may only be able to educate patients about the limitations of PGT results for medical treatment and preventive care. As research advances, however, the hope is that more will be understood about the functional and clinical significance of genetic associations, increasing the likelihood that this information will eventually inform therapeutic decision making and patient care. Yet respondents worry and studies suggest that most primary care physicians are not adequately trained in genetics to fulfill this obligation (Guttmacher et al. 2007). Widespread physician education about the types of tests that are being offered, the scientific validity of genetic associations that are being tested for, and the clinical utility (or lack thereof) of test results will therefore be needed. As clinical utility of this information increases, clinical practice guidelines should be developed to guide physician decisions about confirmatory testing and follow-up care.

Some PGT companies allow testing for children. Most (63%) of our respondents agreed that parents should be able to have their children tested and 52% reported they would test their own child (62% of those who report they have used and 55% of those who report they would use PGT and would test someone other than themselves). This suggests a general acceptance among this cohort of social networkers of testing children for genetic associations of uncertain clinical significance for complex disorders, many of which do not present until adulthood, if at all. The attitudes of these survey respondents toward pediatric testing are inconsistent with professional guidelines that discourage genetic testing of children for adult onset disorders (American Society of Human Genetics Board of Directors and the American College of Medical Genetics Board of Directors 1995). Wilfond and Ross (2009 [in press]) note that these guidelines are traditionally based on a risk-benefit assessment, and that an exclusive focus on balancing risks and benefits may not be consistent with the general practice of respecting parental authority to make healthcare decisions for their children. Whether or not pediatric personal genome testing is advisable, if the general population are as accepting of pediatric PGT as the social networkers who completed this survey then it may become more widespread than anticipated.

If direct-to-consumer personal genome testing is going to be integrated into clinical care to the degree that these respondents anticipate and expect, then physicians will have to be adequately prepared and fairly compensated for the services they provide. Private and public health insurance systems are not currently designed to compensate physicians for the time it will take to educate patients about PGT results, to provide additional confirmatory diagnostic testing when indicated, and to provide follow-up treatment and care on the basis of information obtained from PGT companies (McGuire et al. 2007). Outcomes-based research is needed to examine whether PGT leads to improved health and to determine whether the cost of integrating PGT into clinical care is justified.

## Limitations

This survey was only distributed to Internet users who had pre-identified themselves as willing to participate in survey research through Zoomerang.com and who were registered users of Facebook.com It is therefore possible that there was a selection bias in the sample surveyed. Respondents were mostly Caucasian (83%), female (73%), and highly educated (59% with at least a bachelor's degree). This is not representative of the general US population, but is consistent with the demographics of Internet and social networking site users. Of respondents, 85% reported having healthcare coverage and 78% reported having a regular physician. This is much higher than expected and may help to explain some of our results, including respondents' views about the clinical integration of PGT. Because most of the respondents have not previously used PGT services, responses are hypothetical rather than based on actual behavior. Also, respondents were not told how much PGT costs and no

information on respondents' income was collected. At the time of the survey the cost of PGT through 23andMe was $999. It has subsequently dropped to $399. Knowledge or assumptions about cost may have influenced reported interest in testing. Of those who said they would not consider testing, 40% were concerned about cost, but there was no difference between those who had heard of PGT (41%) and those who had not (39%).

Expressed intent does not always translate into actions taken. For example, in our survey 78% of respondents who report that they would consider using PGT services express an intent to ask their physician for help interpreting the results, but only 53% of those who report that they have used these services say that they did in fact discuss the results with their physician. Further, 53% of respondents report never having heard of PGT companies prior to taking the survey. The only information they were given was that "for a fee, [these companies] will analyze your DNA and help you to read and understand your genetic information." The attitudes and expectations of respondents who had not heard of these companies may not have been as informed or reflective as those who had. Although our results are not generalizable, they can be used to generate hypotheses. Additional research is needed to determine if this group of Internet social networking users is likely to be among the first wave of PGT users and whether their attitudes and expectations are generalizable to other patient populations.

## CONCLUSION

This study suggests that at least some potential consumers of PGT services would seek help interpreting PGT results from their personal physician and believe that physicians have a professional obligation to provide such assistance. However, individual expectations and assumptions vary. Physicians who are asked for help interpreting PGT results from their patients should therefore assess the individual needs and expectations of each patient, strive to correct false assumptions and misinformation, and elicit and address patient concerns prior to providing specific guidance or follow-up assessment and/or treatment. Additional research is needed to determine if the attitudes and expectations of social networkers from this sample are generalizable and to better understand the ethical, legal, social, and clinical implications of integrating PGT into routine medical care.

## Acknowledgments

Generous support funded by the Gillson Logenbaugh Foundation, the ARCO Foundation Young Teacher-Investigator Award, the Greenwall Foundation Faculty Scholars Program in Bioethics, NIH/NHGRI-ELSI R01 HG004333, and NIH/NCI P30 CA125123. We would like to thank Laurence B. McCullough, PhD, for his thoughtful comments and Melody Slashinski, MA, for her help in editing the final version of this manuscript.

## REFERENCES

Demographics of Internet Users. [accessed July 7, 2008]. Available at: http://www.pewinternet.org/trends/User_Demo_2.15.08.htm

Rapleaf Study of Social Networking Users Vs. Age. [accessed July 7, 2008]. Available at: http://business.rapleaf.com/company_press_2008_06_18.html

23andMe. 2007. [press release November 19, 2007]. Available at https://www.23andme.com/about/press (accessed)

23andMe. 23andMe. 2009 [accessed April 10, 2009]. Available at: https://www.23andme.com/

American Society of Human Genetics Board of Directors and the American College of Medical Genetics Board of Directors. ASHG/ACMG report points to consider: Ethical, legal and psychological implications of genetic testing in children and adolescents. American Journal of Human Genetics 1995;57:1233–1241. [PubMed: 7485175]

Burke W, Psaty BM. Personalized medicine in the era of genomics. Journal of the American Medical Association 2007;298(14):1682–1684. [PubMed: 17925520]

DNA Direct. DNA Direct. 2008 [accessed June 20, 2008]. Available at: http://www.dnadirect.com/

Feero GW, Guttmacher AE, Collins FS. The genome gets personal — almost. Journal of the American Medical Association 2008;299(11):1351. [PubMed: 18349096]

Guttmacher AE, Porteous ME, McInney JD. Educating health care professionals about genetics and genomics. Nature Reviews Genetics 2007;8:151.

Hunter DJ, Khoury MJ, Drazen MJ. Letting the genome out of the bottle — will we get our wish? New England Journal of Medicine 2008;358(2):105–107. [PubMed: 18184955]

Langreth, R. California Orders Stop to Gene Testing. 2008 [accessed June 20, 2008]. Available at: http://www.forbes.com/2008/06/14/stop-gene-testing-biz-healthcare-cz_rl_0614genetest_print.html

Langreth, R.; Herper, M. States Crack Down On Online Gene Tests. 2008 [accessed June 20, 2008]. Available at: http://www.forbes.com/2008/04/17/genes-regulation-testing-biz-cx_mh_bl_0418genes_print.html

MarketTools. Introducing TrueSample: The Market Research Industry's First Quality-Assured Sample. [accessed July 14, 2008]. Available at: http://www.zoomerang.com/online-panel/WP_TrueSample.pdf

McGuire AL, Burke W. An unwelcome side effect of direct-to-consumer personal genome testing: Raiding the medical commons. Journal of the American Medical Association 2008;300(22):2669–2671. [PubMed: 19066388]

McGuire AL, Cho MK, McGuire SE, Caulfield T. Medicine: The future of personal genomics. Science 2007;317(5845):1687. [PubMed: 17885116]

Navigenics. Navigenics. 2009 [accessed April 10, 2009]. Available at: http://www.navigenics.com/

Offit K. Genomic profiles for disease risk: Predictive or premature? Journal of the American Medical Association 2008;299(11):1353–1355. [PubMed: 18349097]

Redelmeier DA, Rozin P, Kahneman D. Understanding patients' decisions: Cognitive and emotional perspectives. Journal of the American Medical Association 1993;270(1):72–76. [PubMed: 8510300]

United States Federal Trade Commission. At-Home Genetic Tests: A Healthy Dose of Skepticism May Be the Best Prescription. 2006 [accessed June 20, 2008]. Available at: http://www.ftc.gov/bcp/edu/pubs/consumer/health/hea02.shtm

Welch, HG.; Burke, W. Genetic Testing: DNA is Not Who You Are. 2008 May 14 [accessed June 20, 2008]. Available at: http://www.newsday.com/news/opinion/ny-opdna145684758may14,0,4441447.story

Wilfond B, Ross LF. From genetics to genomics: Ethics, policy, and parental decision-making. Journal of Pediatric Psychology. 2009 In press.

## Table 1

Respondent Demographics

| | Did use *n* = 63 *n* (%) | Would use *n* = 693 *n* (%) | Would not use *n* = 331 *n* (%) | Total *N* = 1,087 *n* (%) |
|---|---|---|---|---|
| Age | | | | |
| 18–24 | 10 (16) | 122 (18) | 78 (24) | 210 (20) |
| 25–34 | 23 (38) | 245 (36) | 120 (37) | 388 (36) |
| 35–44 | 14 (23) | 132 (19) | 52 (16) | 198 (19) |
| 45–54 | 10 (16) | 133 (19) | 49 (15) | 192 (18) |
| >= 55 | 4 (7) | 52 (8) | 26 (8) | 82 (8) |
| No answer | 2 | 9 | 6 | 17 |
| Race | | | | |
| Caucasian | 46 (77) | 566 (83) | 277 (85) | 889 (83) |
| Black | 3 (5) | 39 (6) | 18 (6) | 60 (6) |
| Asian | 7 (12) | 46 (7) | 20 (6) | 73 (7) |
| Other | 4 (7) | 30 (4) | 9 (3) | 43 (4) |
| No answer | 3 | 12 | 7 | 22 |
| Gender | | | | |
| Male | 25 (41) | 172 (25) | 91 (28) | 288 (27) |
| Female | 36 (59) | 503 (75) | 234 (72) | 773 (73) |
| No answer | 2 | 18 | 6 | 26 |
| Education | | | | |
| <High school | | 5 (1) | 3 (1) | 8 (1) |
| High school or general equivalency degree | 8 (13) | 56 (8) | 27 (8) | 91 (8) |
| Some college or tech. school | 15 (25) | 213 (31) | 109 (33) | 337 (31) |
| Bachelor’s degree | 22 (36) | 271 (39) | 121 (37) | 414 (39) |
| Graduate degree | 16 (26) | 143 (21) | 66 (20) | 225 (21) |
| No answer | 2 | 5 | 5 | 12 |
| Healthcare professional | | | | |
| Yes | 6 (10) | 44 (6) | 29 (9) | 79 (7) |
| No | 57 (90) | 649 (94) | 302 (91) | 1008 (93) |
| Healthcare insurance | | | | |
| Yes | 50 (83) | 593 (87) | 262 (80) | 905 (85) |
| No | 10 (17) | 87 (13) | 58 (18) | 155 (14) |
| Not sure | | 4 (1) | 6 (2) | 10 (1) |
| No answer | 3 | 9 | 5 | 17 |
| Have regular physician | | | | |
| Yes | 45 (74) | 544 (79) | 246 (75) | 835 (78) |
| No | 16 (26) | 132 (19) | 76 (23) | 224 (21) |
| Not sure | | 10 (1) | 5 (2) | 15 (1) |
| No answer | 2 | 7 | 4 | 13 |

| | **Did use** ***n*** **= 63** ***n*** **(%)** | **Would use** ***n*** **= 693** ***n*** **(%)** | **Would not use** ***n*** **= 331** ***n*** **(%)** | **Total** ***N*** **= 1,087** ***n*** **(%)** |
|---|---|---|---|---|
| Have children age < 18 years | | | | |
| Yes | 30 (51) | 234 (34) | 100 (32) | 364 (35) |
| No | 29 (49) | 445 (66) | 217 (68) | 691 (65) |
| No answer | 4 | 14 | 14 | 32 |

## Table 2

Attitudes toward use of Personal Genome Testing

| | Did use *n* = 63 *n*(%)[a] | Would use *n* = 693 *n*(%)[a] | Would not use *n* = 331 *n*(%)[a] | Total *N* = 1087 *n*(%)[a] |
|---|---|---|---|---|
| Reasons for using/would consider using PGT services for self | | | | |
| Total answer | 53 | 692 | | 745 |
| Reasons:[b] | | | | |
| General curiosity about genetic make-up | 43 (81) | 561 (81) | | 604 (81) |
| To see if a specific disease runs in family or is in DNA | 27 (51) | 522 (75) | | 549 (74) |
| To learn about genetic make-up without going through a physician | 11 (21) | 286 (41) | | 297 (40) |
| Would use it for somebody else | 1 (2) | 25 (4) | | 26 (3) |
| Other | | 17 (3) | | 17 (2) |
| Reasons for not using PGT services for self | | | | |
| Total answer | | | 331 | 331 |
| Reasons:[b] | | | | |
| Do not think results are reliable | | | 69 (21) | 69 (21) |
| Concerned about privacy | | | 130 (39) | 130 (39) |
| Do not think information would be useful | | | 175 (53) | 175 (53) |
| Would give unwanted information | | | 69 (21) | 69 (21) |
| Costs too much | | | 133 (40) | 133 (40) |
| Other | | | 26 (8) | 26 (8) |
| Would consider using PGT services for someone other than self | | | | |
| Total answer | 45 | 512 | 53 | 610 |
| For whom:[b] | | | | |
| Child | 28 (62) | 273 (53) | 18 (34) | 319 (52) |
| Spouse/Significant other | 25 (56) | 347 (68) | 9 (17) | 381 (62) |
| Another family member | 20 (44) | 220 (43) | 24 (45) | 264 (43) |
| A friend | 11 (24) | 88 (17) | 11 (21) | 110 (18) |
| Other | | 16 (3) | 4 (8) | 20 (3) |
| Reasons:[b] | | | | |
| Find out if they are related to me | 17 (38) | 93 (18) | 8 (15) | 118 (19) |
| As a gift | 18 (40) | 103 (20) | 5 (9) | 126 (21) |
| Find out if they are sick or have a genetic predisposition to an illness | 18 (40) | 395 (77) | 29 (55) | 442 (73) |
| Encourage them to change their lifestyle | 6 (13) | 150 (29) | 7 (13) | 163 (27) |
| Encourage them to seek medical help | 8 (18) | 140 (27) | 4 (8) | 152 (25) |
| Other | 3 (7) | 39 (8) | 7 (13) | 49 (8) |

[a] % calculated from number of respondents who answered question;

[b] respondents could select more than one choice.

## Table 3

Perceptions of Medical Significance of Personal Genome Testing Results

| | Did use *n* = 63 n/N[c](%) | Would use *n* = 693 n/N[c](%) | Would not use *n* = 331 n/N[c](%) | Total *N* = 1087 n/N[c](%) |
|---|---|---|---|---|
| Consider information obtained from personal genome testing to be diagnosis of medical condition or disease | 38/63 (60) | 261/693 (38) | 75/331 (23) | 374/1087 (34) |
| Have discussed results with physician | 31/58 (53) | | | 31/58 (53) |
| Would ask for help interpreting results from physician | | 528/681 (78) | 204/323 (63) | 732/1004 (73) |
| Results of personal genome testing would influence my future healthcare decisions | | | | |
| Strongly Agree or Agree[d] | 45/60 (75) | 445/687 (65) | 75/326 (23) | 565/1073 (53) |
| If got result that indicated increased risk of cardiovascular disease would consult physician | 49/60 (82) | 588/684 (86) | 212/322 (66) | 849/1066 (80) |
| If got result that indicated increased risk of cardiovascular disease would modify lifestyle (i.e., diet, exercise) | 45/60 (75) | 548/684 (80) | 176/322 (55) | 769/1066 (72) |
| Physicians have a professional responsibility to help individuals understand the results they receive from a personal genome test | | | | |
| Strongly Agree or Agree[d] | 43/61 (70) | 466/689 (68) | 152/327 (46) | 661/1077 (61) |
| Physicians have enough knowledge to help patients interpret results of personal genome test | | | | |
| Strongly Agree or Agree[d] | 38/61 (62) | 372/689 (54) | 101/326 (31) | 511/1076 (47) |

[c] n represents number of respondents who agreed with statement, N represents total number of respondents who answered statement.

[d] Scale: strongly disagree, disagree, neither agree nor disagree, agree, strongly agree.

## Table 4

Attitudes Toward Personal Genome Testing Services

| | Did use *n* = 63 n/N (%) | Would use *n* = 693 n/N (%) | Would not use *n* = 331 n/N (%) | Total *N* = 1087 n/N (%) |
|---|---|---|---|---|
| Most people can accurately interpret their personal genome test results | | | | |
| Strongly Agree/Agree[a] | 26/61 (43) | 129/685 (19) | 25/324 (8) | 180/1070 (17) |
| Personal genome companies tell their customers everything they need to know to make informed decisions about using their services | | | | |
| Strongly Agree/Agree[a] | 28/61 (46) | 249/688 (36) | 43/326 (13) | 320/1076 (30) |
| I know enough about genetics to understand the test results | | | | |
| Strongly Agree/Agree[a] | 37/61 (60) | 365/690 (53) | 90/327 (28) | 492/1078 (46) |
| I understand the risks and benefits of using personal genome services | | | | |
| Strongly Agree/Agree[a] | 40/60 (67) | 315/689 (46) | 91/324 (28) | 446/1073 (42) |
| Personal genome companies should have a medical expert to help customers interpret their results | | | | |
| Strongly Agree/Agree[a] | 44/61 (72) | 566/690 (82) | 202/331 (65) | 823/1078 (76) |
| Personal genome companies should be regulated by the federal government | | | | |
| Strongly Agree/Agree[a] | 31/61 (51) | 370/688 (54) | 149/327 (46) | 550/1076 (51) |

[a] Scale: Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree.