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Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing

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Abstract

Purpose—To measure changes to genetics knowledge and self-efficacy following personal genomic testing (PGT).

Methods—New customers of 23andMe and Pathway Genomics completed a series of online surveys. Prior to receipt of results, and 6 months post-results, we measured genetics knowledge (9 true/false items) and genetics self-efficacy (5 Likert-scale items) and used paired methods to evaluate change over time. Correlates of change (e.g., decision regret) were identified using linear regression.

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Results—998 PGT customers (59.9% female; 85.8% White; mean age 46.9±15.5 years) were included in our analyses. Mean genetics knowledge score out of 9 was 8.15±0.95 at baseline and 8.25±0.92 at 6 months (p = .0024). Mean self-efficacy score out of 35 was 29.06±5.59 at baseline and 27.7±5.46 at 6 months (p < .0001); on each item, 30–45% of participants reported lower self-efficacy following PGT. Change in self-efficacy was positively associated with health care provider consultation (p = .0042), impact of PGT on perceived control over one's health (p < .0001), and perceived value of PGT (p < .0001), and negatively associated with decision regret (p < .0001).

Conclusion—Lowered genetics self-efficacy following PGT may reflect an appropriate reevaluation by consumers in response to receiving complex genetic information.

Keywords

direct-to-consumer genetic testing; personal genomic testing; genetic literacy; genomic literacy; self-efficacy; knowledge; commercial genetic testing

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Health literacy has been defined as "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[1] Inadequate health literacy is most common among elderly, minority, and low socioeconomic status populations,[2] and has consistently[3] been associated with increased hospitalization,[4] less regular use of preventive medicine,[5] reduced adherence to medical recommendations,[6] and poorer health status.[7] A sub-type of health literacy is *genetic literacy*, which refers to "the capacity to obtain, process, understand, and use genomic information for health-related decision making."[8] No systematic national assessments of genetic literacy have been performed; however, there is evidence to suggest considerable confusion about genetics in the general population,[9] and that low genetic literacy is associated with low health literacy.[10]

The clinical genetics encounter provides an opportunity to promote genetic literacy, and studies have shown improvements in basic genetics knowledge[11,12] and comprehension of genetic testing concepts,[13] more accurate risk perception,[14] and greater perceived personal control[15] following clinical genetic counseling. Direct-to-consumer (DTC) personal genomic testing (PGT), through which individuals purchase commercial analysis and interpretation of a wide range of genetic variants, has been called a "novel milieu for health education,"[16] with the potential to educate and empower consumers, increase health autonomy, and motivate self-guided education in genetics.[17] Whether or not PGT actually impacts consumer genetic literacy, however, remains unknown.

Among DTC-PGT customers in the Impact of Personal Genomics (PGen) Study, we measured two components of genetic literacy: health-related genetics knowledge, and perceived self-efficacy with genetics knowledge (defined as confidence in one's ability to use genetic information[18]). We sought to investigate two questions within this sample of customers: (1) is there is a significant change in health-related genetics knowledge following PGT?; and (2) is there a significant change in customer confidence with health-related genetics knowledge following PGT?

METHODS

Study Design and Procedures

The PGen Study was approved by the Partners Human Research Committee and the University of Michigan School of Public Health Institutional Review Board. Informed consent was obtained electronically from each participant prior to enrollment. Complete details of the study design and data collection procedures have been reported previously.[19,20]

New customers of 23andMe, Inc.[21] (23andMe) and Pathway Genomics Corp.[22] (Pathway) were recruited online after placing an order for DTC-PGT between March and July 2012. Participants were invited to three web-based surveys administered by Survey Sciences Group, LLC (Ann Arbor, Michigan): the first at baseline, after testing was ordered but prior to receipt of results; the second approximately 2 weeks after results were viewed; and the third approximately 6 months after results were viewed. In total, 1,464 participants completed the baseline survey and were eligible for follow-up; of these, 1,046 (71.4%) and 1,042 (71.2%) submitted the 2-week and 6-month surveys, respectively. PGT results were returned to customers per standard company practice, and then linked to survey data at the end of survey administration.

Instruments

At baseline, we measured age, race/ethnicity,[23] gender, income, education, PGT company, self-reported health (a single item from the SF-36 Health Survey[24]), consultation with a health care provider when deciding whether or not to order PGT (yes/no, and type of health care provider), prior use of PGT services (yes/no), current anxiety, health-related genetics knowledge (*Knowledge*), and self-efficacy with health-related genetics knowledge (*Self-Efficacy*).

Current anxiety was measured with the 2-item Generalized Anxiety Disorder (GAD-2) scale.[25] Frequency of each item (e.g., “Over the past two weeks, how often have you felt nervous, anxious, or on edge”) was answered on a 4-category scale (0 – 3 points), for a total possible score of 6, and a score ≥3 is considered a positive screen for Anxiety Disorder or Panic Disorder on the GAD-2 scale.

Few validated measures of genetic literacy exist; moreover, those that do have been developed for use in specific groups (including undergraduate students[26] and the general population of the late 1990s[27]) or were designed to be administered verbally.[28] Because none of these was deemed appropriate for online surveying of a highly educated, generally healthy population seeking commercial PGT in 2012, no pre-existing, validated genetic literacy instruments were available for use in the PGen Study.

We therefore evaluated *Knowledge* using 9 true/false statements, selected from existing measures of genetic literacy/knowledge[26,27,29,30] to reflect the type of genetic information provided by PGT. A *Knowledge* score was computed by summing the number of correct responses (maximum = 9). *Self-Efficacy* was measured with a 5-item scale based on one previously used by Kaphingst et al. in a study of PGT users,[31] and adapted from a scale first developed and employed by Parrott et al.[32] Participants rated their agreement with each item

(e.g., “I am confident in my ability to understand information about genetics”) on a 7-point Likert scale ranging from “strongly disagree” (1) to “strongly agree” (7). A *Self-Efficacy* score was computed by summing the ratings for each item (maximum = 35).

At 6 month follow-up, we asked whether or not the consumers had discussed their PGT results with a health care provider (yes/no, and type of health care provider). We also measured decision regret related to PGT, current anxiety, the impact of PGT on perceived control over one’s health, and perceived financial value of PGT. Decision regret was measured with a validated, 5-item scale.[33] Agreement with each item (e.g., “The decision did me a lot of harm”) was answered on a 5-category Likert scale from “strongly disagree” (1) to “strongly agree” (5), and the mean score across items was then computed and converted to a total score out of 100. Current anxiety at 6 month follow-up was measured with the GAD-2 scale, as described above. Single survey items were used to measure change in perceived control over one’s health (“Having personal genomic testing made me feel like I have more control over my health”), and perceived commercial value of PGT (“I feel that I got what I paid for”), with agreement measured on a 5-point Likert scale from “strongly disagree” (1) to “strongly agree” (5).

Statistical Analyses

Data for this analysis were obtained from PGen Study participants who submitted both baseline and 6-month surveys, and who had complete data for age, gender, race/ethnicity, education, *Knowledge*, and *Self-Efficacy*. Descriptive statistics were computed to characterize baseline demographic characteristics of the study sample, and to describe *Knowledge* and *Self-Efficacy* performance. Cronbach’s alpha statistics were computed as a measure of internal consistency of the 5 *Self-Efficacy* scale items.

Multivariate linear regression models were used to evaluate associations between demographic characteristics and baseline *Knowledge* and *Self-Efficacy* scores. In these and all further analyses, age was modeled as a continuous variable; Hispanic/Latino ethnicity was modeled as a dichotomous variable; and race and education were modeled as 4-category variables, as presented in Table 1.

McNemar exact tests were used to test the hypothesis that participants’ performance would change, from baseline to 6 month follow-up, on each *Knowledge* item. Similarly, paired *t*-tests were used on a per-item basis to test the hypothesis that participants’ reported *Self-Efficacy* would change following PGT. Paired *t*-tests were also used to evaluate change in total *Knowledge* and *Self-Efficacy* scores from baseline to 6 month follow-up.

Due to modest observed variability in *Knowledge* over time, the remaining analyses were performed for *Self-Efficacy* only. We used multivariate linear regression models for change in *Self-Efficacy* score to evaluate, in turn, associations between change in *Self-Efficacy* score and each of: post-PGT health care provider consultation; decision regret; anxiety at 6 month follow-up; reported change in perceived control over health; and perceived value of PGT. All models were adjusted for baseline *Self-Efficacy* score, age, gender, race/ethnicity, education, and PGT company; the model for the association between *Self-Efficacy* score and anxiety at 6 month follow-up was additionally adjusted for baseline GAD-2 score.

Because post-PGT health care provider consultation measured an action temporally placed between baseline *Self-Efficacy* and 6-month *Self-Efficacy*, and because of a particular interest in the role of health care providers in DTC-PGT, we further examined the association between health care provider consultation and change in performance on each *Self-Efficacy* item using multivariate linear regression.

All analyses were conducted using SAS software (version 9.3; SAS Institute, Cary, NC), and linear regression models were fitted using PROC GLM. Statistical significance for all analyses was set at $p < .05$.

RESULTS

A total of 1,042 PGen Study participants submitted baseline and 6 month follow-up surveys, of which 44 were excluded from analysis due to missing *Knowledge* or *Self-Efficacy* data at 6 month follow-up. Demographic characteristics of the 998 participants included in our analyses are presented in Table 1.

Genetics Knowledge

At baseline, *Knowledge* scores ranged from 4 (44% correct) to 9 (100% correct), with a mean score of 8.15 (standard deviation = 0.95). In a multivariate model for baseline *Knowledge* score, including age, gender, education, race/ethnicity, and PGT company, male gender ($\beta = 0.13$, $p = 0.03$) and higher levels of education ($\beta_{college} = 0.31$, $p = .0003$; $\beta_{graduate} = 0.32$, $p < .0001$; $\beta_{doctorate} = 0.57$, $p < .0001$; Global F-test $p < .0001$) were associated with higher baseline scores, while Hispanic/Latino ethnicity ($\beta = -0.69$, $p < .0001$) and older age ($\beta = -0.008$ per year, $p < .0001$) were associated with lower baseline scores.

At 6 month follow-up, scores again ranged from 4 to 9, but the mean *Knowledge* score showed a significant increase of 0.10 units to 8.25 (standard deviation = 0.92; paired *t*-test $p = .0024$). Approximately half of the participants (n = 509, 51%) showed no change in *Knowledge* score, while 191 participants (19.1%) improved by 1 point, and 81 participants (8.1%) improved by 2 or more points. Most participants (79.6% at baseline; 83.6% at 6 month follow-up) received a score ≥ 8 at both time points, and a plurality received perfect scores at both time points (44.2% at baseline; 49.0% at 6 month follow-up).

Item-specific performance over time is presented in Table 2. Performance was poorest on Item 4 (“Most genetic disorders are caused by only a single gene”), with 63.8% and 68.1% of participants answering correctly at baseline and 6 month follow-up, respectively. The proportion of correct responses surpassed 85% on all other items, at both time points. On a per-item basis, a significant improvement in performance was observed only for Items 4 (paired *t*-test $p = .0134$) and 8 (“A healthy lifestyle can prevent or lessen the negative consequences of having genetic predispositions to some disease”; 95.5% correct at baseline versus 97.9% correct at 6 month follow-up, $p = .0022$).

Genetics Self-Efficacy

At baseline, *Self-Efficacy* scores ranged from 5 (“Strongly Disagree” with all 5 statements) to 35 (“Strongly Agree” with all 5 statements), with a mean score of 29.06 (standard deviation = 5.59). In a multivariate model for baseline *Self-Efficacy* score, including age, gender, education, race/ethnicity, and PGT company, only education was positively associated with baseline score: $\beta_{college} = 0.34$, p = .50; $\beta_{graduate} = 1.01$, p = .0404; $\beta_{doctorate} = 2.49$, p <.0001; Global F-test p = .0004.

At 6 month follow-up, scores again ranged from 5 to 35, but mean *Self-Efficacy* score showed a significant decrease of 1.35 units to 27.71 (standard deviation = 5.46; paired *t*-test p < .0001). Approximately one-fifth of the participants (n = 189, 18.9%) showed no change in *Self-Efficacy* score, while 385 participants (38.6%) indicated a decrease of 1–5 points, and 153 (15.3%) indicated a decrease of more than 5 points. At baseline, 43.7% of participants agreed or strongly agreed with all 5 *Self-Efficacy* statements; whereas 6 months following PGT, 34.7% of participants did so. Cronbach’s alphas for the 5 self-efficacy items at baseline and 6 month follow-up were 0.94 and 0.95, respectively, suggesting excellent internal consistency across items.

Item-specific performance over time is presented in Table 3. The proportion of participants reporting that they “agreed” or “strongly agreed” with each item varied by item and survey time point, with items 1, 2, 3, and 5 showing significant decreases (p < .0001) of 9.7 – 18.0 percentage points from baseline to 6 month follow-up. There was a small, non-significant decrease in agreement with Item 4 (64.3% at BL versus 61.7% at 6M, p = .1536). On each item, 30–50% of participants reported lower self-efficacy after PGT compared to baseline.

Correlates of Change in Genetics Self-Efficacy Following PGT

Six months after receiving their PGT results, 348 (34.9%) of participants had shared their results with a health care provider; of these, 272 (27.3%) had shared with a primary care provider, 30 (3.0%) with a genetics specialist (e.g., genetic counselor, medical geneticist), and 159 (15.9%) with some other medical specialist. In a multivariate model, health care provider consultation was positively associated with change in *Self-Efficacy* score from baseline to 6 month follow-up (Table 4): among participants who did not share their results with a health care provider, the least squares-adjusted mean change in *Self-Efficacy* score was −1.88 (standard deviation = 0.38), compared to a mean change of −0.93 (standard deviation = 0.44) among those who did share their results with a health care provider ($p_{difference} = .0042$). Health care provider consultation was also significantly associated with change on each *Self-Efficacy* item, with the exception of Item 3 (“I have a good idea about how genetics may influence risk for disease generally”), although this item showed a similar trend (Figure 1).

There was no significant difference in the proportion of participants with a positive screen for anxiety at 6 month follow-up (14.5%) compared to baseline (15.8%, McNemar’s test exact p-value = 0.33), and no significant association between a positive screen for anxiety at 6 month follow-up and change in *Self-Efficacy* score. After adjustment for baseline *Self-Efficacy* score, age, gender, race/ethnicity, education, and PGT company, an increase in

perceived control of one's health ($p < .0001$), and perceived financial value of PGT ($p < .0001$), were each positively associated with change in *Self-Efficacy* score following PGT, while greater decision regret was negatively associated with change in *Self-Efficacy* score following PGT ($p < .0001$) (Table 4). Decision regret following PGT was, however, quite rare: 583 participants (58.4%) received a score of 0/100 (no decision regret), and 972 (97.4%) received a score of 40/100 or less.

DISCUSSION

Direct-to-consumer personal genomic testing customers who enrolled in the PGen Study demonstrated high levels of genetics knowledge both prior to and following testing. Consistent with prior studies of health literacy[2] and genetic literacy,[10] genetics knowledge was positively associated with higher levels of education, younger age, and non-Hispanic/Latino ethnicity. In contrast to prior studies of both health literacy[2] and genetic literacy,[29] in which female gender was associated with higher levels of literacy, we found here a significant association between male gender and higher genetics knowedge. The reason for this discrepancy is not immediately obvious, however, it should be noted that male gender was associated with only a small increase in performance (0.13 points on a 9 point scale). Moreover, genetics knowledge was universally high in the PGen Study cohort (particularly in comparison to the general population[9]), suggesting that individuals with high levels of genetics knowledge are more likely to seek out PGT services.

Unlike genetics knowledge, greater genetics self-efficacy was associated only with education level, and not with other baseline demographic characteristics. As this is the first study to identify predictors of genetics self-efficacy, this finding should be followed-up with further investigation in the general population and other populations undergoing genetic testing.

A statistically significant but small increase in genetics knowledge (0.10 points out of 9) was observed at 6 month follow-up; however, a ceiling effect was expected given strong baseline performance. These results provide modest evidence for an educational effect of the PGT experience; they also highlight the need for more sensitive measures of genetics knowledge that can be employed in highly educated and informed users of new technologies, to both evaluate static genetics knowledge and detect subtle changes to understanding over time.

Performance was poorest at both timepoints on Item 4 ("Most genetic disorders are caused by only a single gene"), with fewer than 70% of participants responding correctly. This particular misconception is notable because the PGT provided to these customers largely focused on non-Mendelian complex traits attributable to multiple genetic variants and non-genetic factors. That improvement on this item was so minimal (and included 123 participants who correctly answered "false" at BL changed their response to "true" at 6M) suggests that, even after receiving a personalized genetic risk assesment, customers may still lack a sophisticated understanding of the genetic etiology of complex disease.

We observed a significant decrease, from baseline to 6 month follow-up, in overall genetics self-efficacy, and in item-specific ratings for Items 1, 2, 3, and 5. On these items, 34–46% of participants reported lower genetics self-efficacy at six month follow-up, while only 11–20%

reported higher genetics self-efficacy post-PGT. Notably, performance on Item 4 ("I have a good idea about how my own genetic make-up might affect my risk for disease") – the item most directly related to the PGT experience – did not significantly decrease following PGT. On the other hand, there was no significant increase in performance on Item 4 either, with slightly more participants reporting a negative change in confidence (32.1%) than a positive change (28.1%) at 6 month follow-up.

One interpretation of our findings is that PGT customers, prior to receiving their PGT results, overestimated their grasp of complex disease genetics and thus had inflated perceptions of self-efficacy. Through the process of PGT – including the provision of dozens of results detailing both environmental and genetic contributions to disease, and lengthy reports highlighting the inherent limitations of genetic risk assessment – participants improved their genetics knowledge, and perhaps became aware of previously unrecognized complexities of genetics, thus becoming *less* confident in their understanding. Arguably, this is an appropriate and even expected response to the experience of PGT among non-expert individuals, with high baseline levels of genetics self-efficacy, engaging with a novel genomic technology.

Other interpretations of our findings are also possible. For example, it may be that PGT *inappropriately* reduced participants' genetics self-efficacy. Perceived self-efficacy predicts an individual's ability to perform a particular action; however, self-efficacy is also shaped by attempts to perform that action.[34] If PGT consumers were to perceive a challenge to their attempts to learn about their genetic risk of disease (for example, due to the use of technical jargon in results reports[35]), then genetics self-efficacy could be negatively impacted by the PGT experience.

Regardless of the mechanism underlying the decrease in genetics self-efficacy, our results hint at a means of supporting and promoting consumer self-efficacy: Both before and after PGT, participants were least confident in their ability to understand how their own genetic make-up affects their risk for disease (Item 4), and to explain to others how genes affect one's health (Item 5). Notably, risk assessment/counseling and facilitation of family sharing fall within the scope of practice of certified genetic counselors (CGCs),[36] and are integral to the clinical genetic counseling encounter,[37] whether performed by a CGC, medical geneticist, or other health professional. These results, together with the finding that post-PGT consultation with a health care provider was positively associated with both overall and item-specific change in genetics self-efficacy, suggest that greater engagement of health care providers (either ones made available by the companies, or customers' own providers) in the testing process may have the potential to positively impact genetics self-efficacy.

Given the small number of participants who reported consulting a genetics specialist or other medical specialist, we were unable to evaluate how changes to self-efficacy might differ depending on the type of health care provider consulted. In the future, should the use of PGT and its incorporation into medical care become more common, studies that compare a range of service delivery models (e.g., genetic counselor-mediated PGT, primary care provider-mediated PGT, and pure DTC PGT) could help elucidate the nature of the relationship between consultation and consumer self-efficacy. In the meantime, and in light of our

findings here, we suggest that all current and future studies of PGT users would benefit from consistent evaluation of longitudinal genetics self-efficacy, in addition to the more commonly measured outcome of genetics knowledge, to permit the comparison of longitudinal trends in self-efficacy across different cohorts.

Even after the observed decrease in genetics self-efficacy following PGT, genetics self-efficacy levels were still moderately high, with mean scores ranging from 5.01 – 5.75 ("somewhat agree") out of 7 at 6 month follow-up. Nonetheless, we noted significant associations between change in genetics self-efficacy and certain measures of the PGT customer experience, including decision regret, perceived financial value of PGT, and reported impact of PGT on perceived control over one's health. Although our study design does not permit investigation of the causal relationship between change in genetics self-efficacy and each of these correlates, we suggest it is at least *plausible* that interventions to improve genetics self-efficacy could also reduce decision regret, and increase perceptions of value and control among PGT customers.

Critics of DTC PGT have suggested that without mediation through a health care provider, exposure to genetic risk information could lead to needless worry and increase the risk for clinical anxiety in customers.[38] One mechanism for increased anxiety is through a reduction in self-efficacy: for example, when anxiety is aroused in an individual who perceives him or herself to be ill-equipped to handle a particular challenge.[39] Here, however, we observed no significant difference in the proportion of customers with a positive screen for anxiety disorder following PGT, and found no association between anxiety at 6 month follow-up and change in *Self-Efficacy* score.

Strengths of the PGen Study include its large sample size, recruitment of actual PGT customers, and longitudinal data collection. This is the first study to measure both genetics knowledge and self-efficacy among PGT users, and to do so longitudinally, thus providing a dynamic picture of customer knowledge and confidence over the course of PGT.

Limitations of this study include the potential for selection bias inherent to voluntary survey data, and the use of non-validated scales for genetics knowledge and self-efficacy. We are also unable to delineate the causal relationship between change in genetics self-efficacy and its correlates, such as health care provider consultation: that is, it may be the case that highly self-efficacious consumers are more likely to engage in discussions of their results with a health care provider, and not that health care provider consultation has a positive impact on genetics self-efficacy. Finally, our findings are generalizable only to consumers obtaining DTC-PGT, and PGen Study participants tended to be well-educated, high-earning, and White; thus, the impact of PGT on genetics knowledge and self-efficacy may differ in groups without these qualities, particularly among those with low baseline health literacy or self-efficacy.

In conclusion, PGT may serve as an educational intervention in genetics for its consumers, but more sensitive measures of genetics knowledge will be needed in order to answer this question among highly educated and informed populations, including PGT customers. While genetics knowledge was modestly improved, there is evidence of a negative effect of PGT on

genetic self-efficacy, which may reflect an appropriate reevaluation of self-efficacy following receipt of complex genetic risk information. Regardless of the reason for the observed decrease in genetics self-efficacy, the association between genetics self-efficacy and each of decision regret, perceived control over health, and perceived value of PGT, suggests that steps to promote genetic self-efficacy could positively impact customer satisfaction with PGT.

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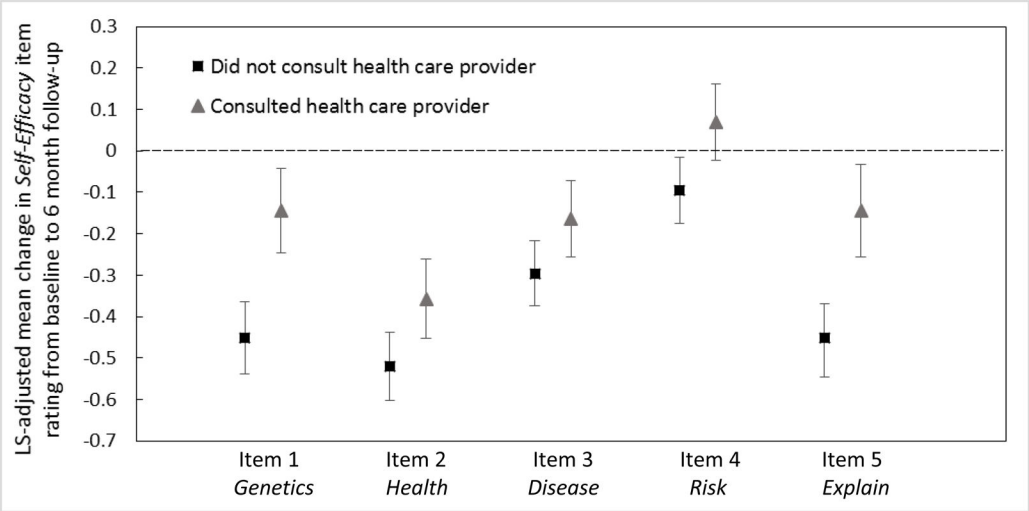

Figure 1.

Least squares (LS)-adjusted mean change in rating of each *Self Efficacy* item from baseline to 6 month follow-up, stratified by post-PGT health care provider consultation status. Adjusted means were obtained from linear regression models for change in rating of each item, with adjustment for baseline item rating, age, gender, race/ethnicity, education, and PGT company. Health care provider consultation was significantly associated change in rating of Item 1 (p = .0041), Item 2 (p = .0253), Item 4 (p = .0208), and Item 5 (p = .0003), but not Item 3 (p = 0.0590).

Table 1

Baseline demographics (n = 998)

	No.	%
Male	400	40.1
Race		
Caucasian	856	85.8
African-American	23	2.3
Asian	32	3.2
More than One Race / Other	87	8.7
Hispanic/Latino Ethnicity	50	5.0
Education		
< College Degree	203	20.3
College Degree	304	30.5
Some Graduate School	359	36.0
Doctoral-level Degree	132	13.2
Income		
< $100,000	559	56.0
$100,000–$199,999	302	30.3
≥ $200,000	126	12.6
Unknown	11	1.1
Self-Reported Health		
Excellent	149	14.9
Very Good	401	40.2
Good	295	29.6
Fair	110	11.0
Poor	41	4.1
Unknown	2	0.2
Positive GAD-2 Screen for Panic/Anxiety Disorder[+]	158	15.8
Pre-PGT Health Care Provider Consultation		
Genetics Specialist	5	0.5
Other Health Care Provider	15	1.5
PGT Company		
23andMe	616	61.7
Pathway	382	38.3
Prior PGT (Different Company)	103	10.3
Age, years		
Mean (range)	46.8 (19, 94)	

	No.	%
Standard Deviation	15.5	

Abbreviations: GAD-2, Generalized Anxiety Disorder Screener, 2-Item; PGT, personal genomic testing

[+]The GAD-2 instrument provides a score between 0 and 6. A score ≥ 3 suggests Panic or Anxiety Disorder.

Table 2

Longitudinal performance on a measure of genetics knowledge among participants in the PGen Study

Genetics Knowledge	Correct Response, n (%)		Changed Response at 6M, n (%)	
	Baseline	6 Months	to incorrect / to correct	p-value*
1. Healthy parents can have a child with an inherited disease (True)	990 (99.2)	990 (99.2)	8 (0.8) / 8 (0.8)	1.00
2. If your close relatives have diabetes or heart disease, you are more likely to develop these conditions (True)	955 (95.7)	961 (96.3)	28 (2.8) / 34 (3.4	0.53
3. Some genetic disorders occur more often within particular ethnic groups (True)	990 (99.2)	992 (99.4)	5 (0.5) / 7 (0.7)	0.77
4. Most genetic disorders are caused by only a single gene (False)	637 (63.8)	680 (68.1)	123 (12.3) / 166 (16.6)	**0.0134**
5. Once a genetic marker for a disorder is identified in a person, the disorder can usually be prevented or cured (False)	867 (86.9)	876 (87.8)	78 (7.8) / 87 (8.7)	0.53
6. A disease is only genetically determined if more than one family member is affected (False)	877 (87.9)	878 (88.0)	78 (7.8) / 79 (7.9)	1.00
7. Some genetic disorders occur later in adult life (True)	930 (93.2)	948 (95.0)	40 (4.0) / 58 (5.8)	0.09
8. A healthy lifestyle can prevent or lessen the negative consequences of having genetic predispositions to some diseases (True)	953 (95.5)	977 (97.9)	17 (1.7) / 41 (4.1)	**0.0022**
9. The environment has little or no effect on how genes contribute to disease (False)	938 (94.0)	935 (93.7)	50 (5.0) / 47 (4.7)	0.84

* p-value obtained from McNemar exact tests

Table 3

Longitudinal self-efficacy with health-related genetics concepts among participants in the PGen Study

Genetic Self-Efficacy	Rating[+], mean (SD)			Agree or Strongly Agree (%)			Changed Response at 6M, n (%)
	BL	6M	p-value[*]	BL	6M	p-value[^]	increase / decrease
1. I am confident in my ability to understand information about genetics. (*Genetics*)	6.06 (1.18)	5.60 (1.25)	<.0001	79.5	62.2	<.0001	126 (12.6) / 457 (45.8)
1. I am able to understand information about how genes can affect my health. (*Health*)	6.15 (1.09)	5.72 (1.12)	<.0001	82.7	64.7	<.0001	118 (11.8) / 448 (44.9)
2. I have a good idea about how genetics may influence risk for disease generally. (*Disease*)	5.91 (1.19)	5.75 (1.10)	<.0001	73.6	63.9	<.0001	180 (18.0) / 343 (34.4)
3. I have a good idea about how my own genetic make-up might affect my risk for disease. (*Risk*)	5.63 (1.36)	5.64 (1.09)	0.63	64.3	61.7	0.15	280 (28.1) / 320 (32.1)
4. I am able to explain to others how genes affect one's health. (*Explain*)	5.31 (1.45)	5.01 (1.45)	<.0001	49.8	38.7	<.0001	202 (20.2) / 409 (41.0)

Abbreviations: SD, standard deviation

[+] Likert rating scale from 1 (strongly disagree) to 7 (strongly agree)

[*] p-value obtained from paired *t*-tests

[^] p-value obtained from McNemar Exact tests

Table 4

Correlates of change in total genetic self-efficacy (GSE) score

	Frequency, n (%)	$B_{adjusted}$ *	p-value
Post-PGT Consultation with Health Care Provider	348 (34.9)	0.96 ± 0.33	**0.0042**
Positive GAD-2 Screen for Anxiety/Panic Disorder at 6 Month Follow-up	145 (14.5)	−0.68 ± 0.48#	0.1580
"Having personal genomic testing made me feel like I have more control over my health."			**<.0001**†
Strongly Disagree	64 (6.4)	Reference	---
Somewhat Disagree	74 (7.4)	0.06 ± 0.82	0.9423
Neither Agree nor Disagree	197 (19.7)	1.88 ± 0.69	**0.0064**
Somewhat Agree	448 (44.9)	2.22 ± 0.64	**0.0005**
Strongly Agree	215 (21.6)	3.61 ±0.68	**<.0001**
"I feel that I got what I paid for."			**<.0001**†
Strongly Disagree	18 (1.8)	Reference	---
Somewhat Disagree	31 (3.1)	1.37 ± 1.41	0.3313
Neither Agree nor Disagree	112 (11.2)	3.90 ± 1.21	**0.0013**
Somewhat Agree	308 (30.9)	4.66 ± 1.15	**<.0001**
Strongly Agree	529 (53.0)	5.97 ± 1.14	**<.0001**
Decision Regret Score, Mean ± SD (Range = 0–100)	7.59 ± 13.7	−0.09 ± 0.44	**<.0001**

Abbreviations: GAD-2, Generalized Anxiety Disorder Screener, 2-Item; SD, standard deviation

*All models adjusted for baseline *Self-Efficacy* score, age, gender, race, ethnicity, education, and PGT company

#Additionally adjusted for result of baseline GAD-2 screen for anxiety/panic disorder

†p-value from global F-test for the categorical variable