

# Racial minority group interest in direct-to-consumer genetic testing: findings from the PGen study

Latrice Landry<sup>1,2,3</sup> · Daiva Elena Nielsen<sup>4,2,5</sup> · Deanna Alexis Carere<sup>6</sup> · J. Scott Roberts<sup>7</sup> · Robert C. Green<sup>4,2,5,3,8</sup> · the PGen Study Group

Received: 17 May 2017 / Accepted: 21 August 2017  
© Springer-Verlag GmbH Germany 2017

**Abstract** There is little information regarding direct-to-consumer (DTC) personal genetic testing (PGT) in non-White racial minorities. Using a web-based survey, we compared the pretest interests and attitudes toward DTC-PGT of racial minority and White DTC-PGT customers of 23andMe and Pathway Genomics using chi-square tests and multinomial regression. Data were available for 1487 participants (1389 White, 44 Black, and 54 Asian). Survey responses were similar across racial groups, although a greater proportion of Blacks compared to Whites reported being “very interested” in genetic information related to traits (91.9 vs. 70.8%,  $p = 0.009$ ). A greater proportion of Asians compared to Whites reported that a “very important” consideration for pursuing DTC-PGT was limited information about their family health history (58.0 vs. 37.5%,  $p = 0.002$ ). While a number of significant differences between groups were observed in unadjusted analyses, they did not remain significant after adjustment. This study provides a preliminary view of the interests

for purchasing DTC-PGT among customers with racial minority backgrounds.

**Keywords** Direct-to-consumer · Genetic testing · Racial minorities · Interests and attitudes · Blacks · Asians

## Introduction

Advances in knowledge and technology have led to an increased availability and awareness of genetic testing (Roberts and Ostergren 2013). There are two main access points for genetic testing: (1) clinician-facilitated medical testing and (2) direct-to-consumer (DTC) personal genetic testing (PGT). Despite the growing availability of both, research suggests that awareness, use, and interest in medical genetic testing are lower among American racial minority groups (Mai et al. 2014). Factors suggested as possible reasons for lower

---

Latrice Landry and Daiva Elena Nielsen contributed equally to the manuscript.

---

This article is part of the Topical Collection on Inclusion of Diverse Populations In Genomics Research and Health Services: A Scientific and Health Equity Imperative

---

See list of PGen Study members in the Acknowledgements section

✉ Robert C. Green  
rcgreen@bwh.harvard.edu

<sup>1</sup> Department of Pathology, Brigham and Women’s Hospital, Boston, MA, USA

<sup>2</sup> Harvard Medical School, Boston, MA, USA

<sup>3</sup> Partners Personalized Medicine, Boston, MA, USA

<sup>4</sup> Division of Genetics, Department of Medicine, Brigham and Women’s Hospital, Boston, MA, USA

<sup>5</sup> Broad Institute of MIT and Harvard, Cambridge, MA, USA

<sup>6</sup> Department of Pathology and Molecular Medicine, McMaster University, Hamilton, ON, Canada

<sup>7</sup> Department of Health Behavior and Health Education, University of Michigan School of Public Health, Ann Arbor, MI, USA

<sup>8</sup> Partners Personalized Medicine, Brigham and Women’s Hospital and Harvard Medical School, EC Alumnae Building, Suite 301, 41 Avenue Louis Pasteur, Boston, MA 02115, USA

uptake among racial minorities include decreased referral from minority-serving physicians (Shields et al. 2008), lower rates of health insurance (Armstrong et al. 2006), medical distrust (Armstrong et al. 2008), and concerns about potential harm (Catz et al. 2005). Scarce literature exists on racial minorities' engagement with DTC-PGT (Hensley Alford et al. 2011; Bloss et al. 2010); although a number of population surveys have reported lower levels of DTC-PGT awareness among racial minority groups (Ortiz et al. 2011; Kolor et al. 2012; Finney Rutten et al. 2012; Agurs-Collins et al. 2015; Langford et al. 2012). When compared to Whites, however, differences in awareness have not consistently been statistically significant (Finney Rutten et al. 2012; Agurs-Collins et al. 2015). One investigation reported that lower DTC-PGT awareness among Blacks was partially mediated by numeracy levels (Langford et al. 2012), which highlights the need to examine additional factors when considering racial differences in genetic testing participation.

Only two previous studies that offered DTC-PGT as part of study participation evaluated differences in uptake by racial group, and each reported that Whites may be more likely to undergo DTC-PGT than non-Whites (Hensley Alford et al. 2011). In the multiplex study, participants were offered free genetic risk information for eight common complex conditions (Hensley Alford et al. 2011). Blacks were less likely to agree to participate in the study and the authors proposed that this might be due to lesser trust in researchers. Bloss et al. conducted an assessment of behavioral responses to DTC-PGT results among individuals who were offered DTC-PGT for a reduced price (Bloss et al. 2010). When participant demographic variables were compared to non-responders, it was reported that non-White individuals were less likely to participate in the study. The authors concluded that non-White individuals may be less likely to purchase and undergo DTC-PGT. Although these studies suggest non-White groups are less likely to undergo DTC-PGT, no previous study has investigated individuals of racial minority background who have actually purchased DTC-PGT. This study is the first direct investigation of actual DTC-PGT customers with racial minority backgrounds compared with White customers.

Given the increased presence of genetics in health and society, particularly with the rise of DTC-PGT and the promise of precision medicine for Americans (Jaffe 2015), it is important to understand racial minorities' interest in and use of genetic testing. To contribute to this research area, we conducted the first exploration of interest and decision-making factors among Black and Asian individuals who purchased DTC-PGT. Our results suggest that some specific interests for purchasing DTC-PGT may exist for certain racial groups, but overall racial minority DTC-PGT customers seek out the product for largely the same reasons as White customers.

## Materials and methods

### Study design and procedures

The present exploratory analyses utilize baseline data from the Impact of Personal Genomics (PGen) Study, a longitudinal investigation of DTC-PGT customers. Details of the PGen Study design and methodology have been reported previously (Carere et al. 2014). Briefly, new customers of two DTC-PGT companies, 23andMe, Inc. (23andMe) and Pathway Genomics (Pathway) were recruited after ordering PGT. Following online consent, participants were invited to complete a baseline web-based survey that assessed interest and motivations for undergoing PGT. In total, 1838 individuals consented to participate in the PGen Study and 1648 participants (90%) completed the baseline survey prior to viewing their PGT results. The PGen Study was approved by the Partners Human Research Committee and the University of Michigan School of Public Health Institutional Review Board.

### Baseline survey

Participants reported demographic characteristics and were asked to select their race (all that applied) from a list of options: American Indian/Native Alaskan, Asian, Black, Hawaiian or Pacific Islander, White, or Other (please specify). These racial categories are used by the US Census Bureau (<https://www.census.gov/2010census/>) and have enabled comparisons to the US population (Carere et al. 2014). Survey items utilized 3- and 5-point Likert scales (full response items reported in the "Results" section) to assess interest in specific types of genetic information (health and non-health related); factors in the decision-making process; level of trust in the PGT company regarding privacy and use of data; and perceived medical utility of PGT results. Questions related to receiving genetic information about non-health-related "traits" only appeared to 23andMe customers, since Pathway Genomics did not include information about traits in their test results. An explanation of the term "traits" is provided on the 23andMe website where the test is purchased, and the specific traits that are included in the genetic test are also listed on the website. Customers view the same explanation of traits when they receive their test results.

### Data analyses

From the 1648 participants who completed the baseline survey, we excluded from analysis participants who did not report their race ( $n = 1$ ), reported more than one race ( $n = 111$ ), and those who were not Black, Asian, or White ( $n = 49$ ) for a total sample of 1487 participants. Descriptive statistics were used to characterize demographic characteristics. Chi-square tests were used to compare survey responses across the three

racial groups, except in cases where > 20% of cells had expected counts of less than five, in which case Fisher's exact test was used. In addition, we conducted multinomial regression to compare survey responses overall across all racial groups (item-level comparison) as well as between the racial minority and White group (race group comparison e.g., Black vs. White; Asian vs. White), with adjustment for age, sex, education, PGT company, health insurance, and income. These covariates were selected because they could be associated with motivations for pursuing and perceptions of PGT. In the race group comparison models, White was selected as the reference race group (as it was the largest group), and the middle response option was set as the reference for the outcome (e.g., "Somewhat Interested" on a 3-point scale or "Neither Agree nor Disagree" on a 5-point scale) because this provided the most stable and readily interpretable coefficients. An overall  $p$  value for the item-level comparison was computed, followed by odds ratios (OR), 95% confidence intervals (CI), and  $p$  values for the race group comparisons. Analyses were conducted using SAS software (version 9.4; SAS Institute, Cary, NC) and multinomial regression models were fitted using PROC LOGISTIC. Statistical significance for all analyses was set at  $p < 0.05$ .

## Results

Participant characteristics are presented in Table 1. Across racial groups, the PGen population had high levels of education and income, and  $\geq 95\%$  of participants had health insurance. The majority of participants were 23andMe customers (66% of Whites, 84% of Blacks, and 56% of Asians). A larger proportion of Asian participants were male (49 vs. 39% of Whites and 36% of Blacks) and single (35 vs. 17% of Whites and 18% of Blacks) with no children (74 vs. 45% of Whites and 43% of Blacks).

A number of significant differences in survey responses were observed in unadjusted analyses (Table 2). These included interest in pursuing PGT to obtain information related to "risk of disease or health condition" ( $p = 0.025$ ), "carrier status" ( $p = 0.035$ ), "ancestry" ( $p = 0.001$ ), and "traits" ( $p = 0.0001$ ). Among these particular items, Asian participants reported the greatest interest in disease-risk information (77.8% "very interested"), while Blacks reported the greatest interest in information related to ancestry (95.4% "very interested") and traits (91.9% "very interested"). In addition, Blacks reported the least interest in carrier status information (18.2% "very interested"). Related to the potential trend of greater interest in non-health-related information, only 13.5% of Blacks participants (compared to 35.2% of Asians and 31.0% of Whites) indicated that the item "how well the results predict whether I'm going to get a particular disease" was something that they "considered a lot" when deciding to

pursue DTC-PGT ( $p = 0.034$ ). Moreover, fewer Black participants (40.9%) compared to Whites (61.2%) and Asians (74.1%) indicated that "interest in finding out about my personal risk for specific diseases" was a "very important" factor in their decision to seek DTC-PGT ( $p = 0.012$ ), while a much larger proportion (91.0%) indicated that "curiosity about my genetic make-up" was a "very important" factor in their decision compared to Whites (77.3%) and Asians (72.2%) ( $p = 0.038$ ). Asian participants were more likely to indicate that "...limited information about my family health history" was a "very important" factor for seeking DTC-PGT, and least likely to "strongly agree" (31.5%) with the item "I trust (PGT company) to use my genetic information only for the purposes to which I consented." ( $p = 0.0004$ ).

Results from the adjusted multinomial regression models indicated significant differences among item-level comparisons for only two survey items: interest in traits ( $p = 0.0006$ ) and desire to learn about one's genetics due to limited family health history information ( $p = 0.005$ ) (Table 2). In the subsequent race group comparisons, a greater proportion of Black participants compared to Whites reported that they were "very interested" in receiving PGT information related to traits (91.9 vs. 70.8%; OR = 6.86 (95% CI: 1.62–29.1),  $p = 0.009$ ). Conversely, a greater proportion of Asian participants compared to Whites reported they were "not at all interested" in receiving information related to traits (13.3 vs. 2.0%; 20.9 (3.89–112.03),  $p = 0.0004$ ). In addition, a greater proportion of Asian participants reported that a "desire to learn more about my genetics because I have limited information about my family health history" was a "very important" factor for seeking DTC-PGT compared to Whites (58.0 vs. 37.5%; 3.53 (1.62–7.69),  $p = 0.002$ ). Three survey items possessed too few cell counts in some response categories to fit a model appropriately and so we were unable to generate adjusted results for these items ("N/A" in Table 2).

## Discussion

Overall, we found few differences in interests in and motivations for purchasing DTC-PGT between Blacks, Asians, and Whites who were customers of 23andMe or Pathway Genomics. The significant results from our unadjusted tests were, for the most part, no longer significant after multivariable adjustment. However, we have presented them here to fully explore and describe the responses of our unique study population, since racial minority customers of DTC-PGT have not been directly investigated previously. Moreover, the overall narrative from the significant unadjusted results remained present in our significant adjusted findings—namely, an interest in non-health-related information among Black customers and a desire to learn about genetics due to limited family health history among Asian customers.

**Table 1** Demographic characteristics of PGen Study participants

Characteristics	Race		
	White n (%)	Black	Asian
Sample size	1389 (93.4)	44 (3.0)	54 (3.6)
Male	547 (39.4)	16 (36.4)	26 (49.1)
Missing	<i>n</i> = 1	<i>n</i> = 0	<i>n</i> = 1
Age <sup>a</sup>	48.9 ± 15.2 (19–94)	50.0 ± 13.0 (24–74)	34.0 ± 9.6 (20–58)
Hispanic			
Yes	44 (3.2)	0 (0)	1 (1.9)
No	1345 (96.8)	44 (100.0)	53 (98.1)
Education			
< College degree	55 (4.2)	1 (2.3)	0 (0)
College degree	237 (17.9)	12 (27.3)	7 (13.5)
Some graduate school	865 (65.4)	23 (52.3)	38 (73.1)
Doctoral degree	166 (12.5)	8 (18.2)	7 (13.5)
Missing	<i>n</i> = 66	<i>n</i> = 0	<i>n</i> = 2
Income			
< \$40,000	210 (15.4)	6 (13.6)	14 (25.9)
\$40,000–\$99,999	525 (38.4)	17 (38.6)	15 (27.8)
\$100,000–\$199,999	444 (32.5)	16 (36.4)	16 (29.6)
> \$200,000	188 (13.8)	5 (11.4)	9 (16.7)
Missing	<i>n</i> = 22	<i>n</i> = 0	<i>n</i> = 0
Marital status			
Single	240 (17.3)	8 (18.2)	19 (35.1)
Married	797 (57.4)	20 (45.5)	25 (46.3)
Widowed/divorced/separated	177 (12.7)	10 (22.7)	3 (5.6)
Long-term partner	175 (12.7)	6 (13.6)	7 (13.0)
Children			
Yes	763 (54.9)	25 (56.8)	14 (25.9)
No	626 (45.1)	19 (43.2)	40 (74.1)
Health insurance			
Yes	1317 (94.9)	43 (97.7)	52 (96.3)
No	69 (5.0)	1 (2.3)	2 (3.7)
Missing/unknown	<i>n</i> = 3	<i>n</i> = 0	<i>n</i> = 0
Self-reported health status <sup>a</sup>	2.5 ± 1.0 (1–5)	2.3 ± 0.9 (1–5)	2.2 ± 0.9 (1–5)
PGT company			
Pathway Genomics	475 (34.2)	7 (15.9)	24 (44.4)
23andMe	914 (65.8)	37 (84.1)	30 (55.6)

Health status was assessed using an item from the SF-36 Health Survey [20]

<sup>a</sup> Values are mean ± SD (range)

The data presented here represent a detailed evaluation of interest and considerations for participation in DTC-PGT from participants across racial groups who chose to have DTC-PGT testing. The engagement of racial minority groups in DTC-PGT specifically is under-described in the literature and, therefore, our data and reported findings contribute valuable new information to the study of the field of consumer genomics.

Other studies related to this area of investigation have examined how minority groups perceive various types of genetic information. Rahm et al. examined perceptions of DTC-PGT advertising among various demographic groups and reported that individuals from minority groups may not consider genetic knowledge to be as empowering as Whites (Rahm et al. 2012). One vignette-based study found that minority groups

**Table 2** Differences in responses to survey items on interests, considerations, importance, and trust between Whites, Blacks, and Asians in the PGen Study

Survey item	Race			Test	
	White	Black	Asian	$\chi^2$	Adjusted <sup>b</sup>
Interest in types of information					
	<i>n</i> (%)			<i>p</i> value	<i>p</i> value
Risk of disease or health condition ( <i>n</i> = 1487)				0.025 <sup>e</sup>	N/A
Not at all interested	23 (1.7)	1 (2.3)	2 (3.7)		
Somewhat interested	345 (24.8)	19 (43.2)	10 (18.5)		
Very interested	1021 (37.5)	24 (54.5)	42 (77.8)		
Drug response ( <i>n</i> = 1486)				0.241 <sup>e</sup>	0.564
Not at all interested	117 (8.4)	6 (13.6)	5 (9.3)		
Somewhat interested	540 (38.9)	22 (50.0)	22 (40.7)		
Very interested	731 (52.7)	16 (36.4)	27 (50.0)		
Carrier status ( <i>n</i> = 1485)				0.035	0.369
Not at all interested	618 (44.6)	23 (52.3)	16 (29.6)		
Somewhat interested	353 (25.5)	13 (29.5)	13 (24.1)		
Very interested	416 (30.0)	8 (18.2)	25 (46.3)		
Ancestry ( <i>n</i> = 1487)				0.001 <sup>e</sup>	0.191
Not at all interested	59 (4.3)	1 (2.3)	3 (5.6)		
Somewhat interested	325 (23.4)	1 (2.3)	16 (29.6)		
Very interested	1005 (72.3)	42 (95.4)	35 (64.8)		
Traits ( <i>n</i> = 977) <sup>c</sup>				0.0001	0.0006
Not at all interested	18 (2.0)	1 (2.7)	4 (13.3) <sup>f</sup>		
Somewhat interested	248 (27.3)	2 (5.4)	4 (13.3)		
Very interested	644 (70.8)	34 (91.9) <sup>e</sup>	22 (73.3)		
Considerations in the decision to seek testing					
How well the results predict whether I am going to get a particular disease ( <i>n</i> = 1486)				0.034	0.073
Did not consider	260 (18.7)	15 (34.1)	8 (14.8)		
Considered somewhat	698 (50.3)	23 (52.3)	27 (50.0)		
Considered a lot	430 (31.0)	6 (13.5)	19 (35.2)		
Privacy of my genetic information ( <i>n</i> = 1487)				0.953	0.872
Did not consider	289 (20.8)	9 (20.5)	13 (24.1)		
Considered somewhat	558 (40.2)	17 (38.6)	19 (35.2)		
Considered a lot	542 (39.0)	18 (40.9)	22 (40.7)		
Whether or not there are health-related actions I can take as a result of learning my genetic information ( <i>n</i> = 1486)				0.172	0.234
Did not consider	132 (9.5)	6 (13.6)	8 (14.8)		
Considered somewhat	524 (37.8)	22 (50.0)	21 (38.9)		
Considered a lot	732 (52.7)	16 (36.4)	25 (46.3)		
The possibility that I might receive unwanted information ( <i>n</i> = 1486)				0.337	0.179
Did not consider	518 (37.3)	21 (47.7)	20 (37.0)		
Considered somewhat	578 (41.6)	16 (36.4)	27 (50.0)		
Considered a lot	292 (21.0)	7 (15.9)	7 (13.0)		
The education materials made available through the company ( <i>n</i> = 1484)				0.868	0.946
Did not consider	386 (27.8)	11 (25.0)	16 (29.6)		
Considered somewhat	679 (49.0)	20 (45.5)	27 (50.0)		
Considered a lot	321 (23.2)	13 (29.5)	11 (20.4)		
The convenience of being tested at home ( <i>n</i> = 1486)				0.166	0.180
Did not consider	229 (16.5)	3 (6.8)	14 (25.9)		

Table 2 (continued)

		Race		Test	
Considered somewhat	522 (37.6)	19 (43.2)	18 (33.3)		
Considered a lot	637 (45.9)	22 (50.0)	22 (40.7)		
Important factors for seeking testing					
Curiosity about my genetic makeup ( <i>n</i> = 1486)				0.038 <sup>e</sup>	N/A
Not at all important	18 (1.3)	0 (0)	3 (5.6)		
Somewhat important	297 (21.4)	4 (9.0)	12 (22.2)		
Very important	1073 (77.3)	40 (91.0)	39 (72.2)		
Interest in finding out about my personal risk for specific diseases ( <i>n</i> = 1486)				0.012 <sup>e</sup>	0.0687
Not at all important	104 (7.5)	7 (15.9)	3 (5.6)		
Somewhat important	435 (31.3)	19 (43.2)	11 (20.4)		
Very important	849 (61.2)	18 (40.9)	40 (74.1)		
Desire to learn about my genetic makeup without going through a doctor ( <i>n</i> = 1486)				0.358	0.530
Not at all important	547 (39.4)	14 (31.8)	15 (27.8)		
Somewhat important	441 (31.8)	17 (38.6)	22 (40.7)		
Very important	400 (28.8)	13 (29.5)	17 (31.5)		
Desire to improve my health ( <i>n</i> = 1486)				0.206	0.423
Not at all important	202 (14.5)	10 (22.7)	7 (13.0)		
Somewhat important	536 (38.6)	21 (47.7)	20 (37.0)		
Very important	650 (46.8)	13 (29.5)	27 (50.0)		
Interest in finding out about my individual response to different types of medications ( <i>n</i> = 1485)				0.078	0.278
Not at all important	320 (23.1)	16 (36.4)	10 (18.5)		
Somewhat important	516 (37.2)	19 (43.2)	21 (38.9)		
Very important	551 (39.7)	9 (20.5)	23 (42.6)		
Desire to create a better plan for the future ( <i>n</i> = 1485)				0.830	0.770
Not at all important	281 (20.3)	11 (25.0)	12 (22.2)		
Somewhat important	468 (33.7)	16 (36.4)	16 (29.6)		
Very important	638 (46.0)	17 (38.6)	26 (48.2)		
Personal interest in genetics in general ( <i>n</i> = 1486)				0.433 <sup>e</sup>	0.338
Not at all important	113 (8.1)	2 (4.5)	2 (3.7)		
Somewhat important	527 (38.0)	20 (45.5)	26 (48.2)		
Very important	748 (53.4)	22 (50.0)	26 (48.2)		
The service seemed like it would be fun and entertaining ( <i>n</i> = 1485)				0.765	0.878
Not at all important	338 (24.4)	11 (25.0)	11 (20.4)		
Somewhat important	555 (40.0)	18 (40.9)	19 (35.2)		
Very important	494 (35.6)	15 (34.1)	24 (44.4)		
Other members of my family are using personal genomic services <sup>d</sup> ( <i>n</i> = 933)				0.509	0.492
Not at all important	527 (60.6)	18 (75.0)	25 (64.1)		
Somewhat important	172 (19.8)	4 (16.7)	9 (23.1)		
Very important	171 (19.7)	2 (8.3)	5 (12.8)		
Desire to learn more about my genetics because I have limited information about my family health history <sup>d</sup> ( <i>n</i> = 1323)				0.006	0.005
Not at all important	282 (22.9)	4 (9.3)	10 (20.0)		
Somewhat important	487 (39.6)	17 (39.5)	11 (22.0)		
Very important	461 (37.5)	22 (51.2)	29 (58.0) <sup>f</sup>		
Desire to learn more about my genetics because I am adopted <sup>d</sup> ( <i>n</i> = 528)				0.376 <sup>e</sup>	N/A
Not at all important	408 (83.3)	10 (83.3)	20 (76.9)		

**Table 2** (continued)

		Race		Test	
Somewhat important	17 (3.5)	1 (8.3)	0 (0)		
Very important	65 (13.3)	1 (8.3)	6 (23.1)		
Interest in getting information about the risk of health conditions for my current children or future children <sup>d</sup> ( <i>n</i> = 1261)				0.598	0.553
Not at all important	231 (19.5)	7 (21.2)	11 (24.4)		
Somewhat important	361 (30.5)	9 (27.3)	17 (37.8)		
Very important	591 (50.0)	17 (51.5)	17 (37.8)		
Trust and Perceived health utility					
I trust (PGT company) to use my genetic information only for the purpose to which I consented ( <i>n</i> = 1486)				0.0004 <sup>e</sup>	0.054
Strongly disagree	22 (1.6)	2 (4.5)	1 (1.9)		
Somewhat disagree	21 (1.5)	1 (2.3)	1 (1.9)		
Neither agree nor disagree	86 (6.2)	2 (4.5)	10 (18.5)		
Somewhat agree	394 (28.4)	14 (31.8)	25 (46.3)		
Strongly agree	865 (62.3)	25 (56.8)	17 (31.5)		
I trust (PGT company) to keep my genetic information and medical information confidential or private ( <i>n</i> = 1487)				0.125 <sup>e</sup>	0.725
Strongly disagree	22 (1.6)	2 (4.5)	1 (1.9)		
Somewhat disagree	25 (1.8)	0 (0.0)	1 (1.9)		
Neither agree nor disagree	90 (6.5)	4 (9.1)	8 (14.8)		
Somewhat agree	397 (28.6)	13 (29.5)	19 (35.2)		
Strongly agree	855 (61.6)	25 (56.8)	25 (46.3)		
What I learn from my personal genomic testing can help reduce my chances of getting sick. ( <i>n</i> = 1487)				0.870	0.746
Strongly disagree	66 (4.8)	2 (4.5)	1 (1.9)		
Somewhat disagree	170 (12.2)	5 (11.4)	4 (7.4)		
Neither agree nor disagree	401 (28.9)	13 (29.5)	15 (27.8)		
Somewhat agree	619 (44.6)	18 (44.6)	29 (53.7)		
Strongly agree	133 (9.6)	6 (9.6)	5 (9.3)		

<sup>a</sup> Fisher’s exact test used instead of chi-squared test

<sup>b</sup> Results are from multinomial regression models adjusted for age, sex, education, PGT company, health insurance, and income. Reference groups used were “White” and the middle survey response option (i.e., “Somewhat interested”, “Considered somewhat”, “Somewhat important” or “Neither agree nor disagree”)

<sup>c</sup> Item only asked among 23andMe customers, so multinomial regression model is not adjusted for PGT company. Multinomial regression models that had questionable fit are marked with N/A and *p* values are not reported

<sup>d</sup> “Not applicable” response option removed from analyses

<sup>e</sup> Responses of the Black group significantly differed from the White group

<sup>f</sup> Responses of the Asian group significantly differed from the White group

were more likely to report reluctance to adhere to medical prescriptions based on genetics compared to conventional prescriptions (Butrick et al. 2011). While racial differences in knowledge/interest in genetic testing have been reported (Mai et al. 2014; Pagan et al. 2009), contradictory evidence exists. Armstrong et al. reported no statistically significant difference in willingness to undergo medical genetic testing

between Whites and other racial groups (Armstrong et al. 2012) and Catz et al. reported no difference in either knowledge or interest in genetic testing between racial minorities and non-Hispanic Whites (Catz et al. 2005). Therefore, research surrounding interest and knowledge about genetic testing among minorities is conflicting and suggests that additional factors beyond race may contribute to reported differences.

A number of limitations should be noted when considering results from our exploratory analyses. The sample size of our minority racial groups was small, so the responses of these participants may not reflect those of individuals from these racial backgrounds. However, no previous study has directly examined customers of DTC-PGT and so our results provide the first documentation of the interests and decision-making factors of actual DTC-PGT customers with racial minority backgrounds. We also performed several statistical tests on a large number of survey items, so it is possible that the two significant findings reported from our adjusted models arose from chance. However, stringent corrections for multiple testing may not be appropriate to our investigation, as several survey items are related and so item-level responses are unlikely to be independent. Moreover, the magnitude of the difference in the response percentages is notably large between race groups (e.g., 91.9% Blacks vs. 70.8% Whites “very interested” in traits), which suggests that a difference in perceptions was likely present. In addition, we excluded individuals who reported more than one race which contributed to our limited sample size for this investigation. We felt that limiting the analysis to individuals of one racial background would minimize the potential for miscategorization of race, since several diverse combinations of race categories comprised the “multi-racial” group and examination of free text responses illustrated participants’ uncertainty in reporting race. Moreover, we did not account for Hispanic ethnicity in our analyses, but a sensitivity analysis with Hispanic participants omitted did not alter the results (data not shown). Finally, the generalizability of our findings to the US population may be limited because the PGen Study included customers from only two DTC-PGT companies, and these customers tended to be high-earning and highly educated, with high levels of health insurance coverage (Carere et al. 2014). Our findings should assist in generating hypotheses for future studies with a larger non-White sample. Future studies aimed at more rigorously exploring race and engagement with DTC-PGT should target racial minority individuals for recruitment to obtain larger sample sizes. The categorization of race groups may be expanded to more precisely characterize race.

Overall, our findings demonstrate few differences in interests and perceptions of DTC-PGT between racial minority customers and White DTC-PGT customers, although some particular interests may exist for specific groups. Persons who seek out DTC-PGT apparently do so with largely similar perceptions and for largely similar reasons regardless of their racial identity.

**Acknowledgements** We thank the customers of 23andMe and Pathway Genomics who answered a survey and made this work possible. The PGen Study was supported by the National Institutes of Health (NIH) National Human Genome Research Institute (R01-HG005092). LL is supported by the Research Program in the FDA Office of the Chief Scientist and Office of Minority Health. DEN is supported by a

Canadian Institutes of Health Research Fellowship Award. DAC is supported by a Michael G. DeGroot Postdoctoral Fellowship from McMaster University and a Canadian Institutes of Health Research Fellowship Award. RCG is also supported by NIH U01-HG006500, U19-HD077671, U01-HG008685 R01-HG006615 and R01-HG006615. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Center for Research Resources, the National Institutes of Health, the National Cancer Institute, or the Canadian Institutes of Health Research.

Members of the PGen Study at the time of publication are as follows: Robert C Green, Joel B Krier, Sheila Sutti, Daiva E Nielsen, Margaret H Helm, Caroline M Weipert, Sarah S Kalia, Kurt D Christensen, Harvard Medical School and Brigham and Women’s Hospital; Deanna Alexis Carere, Peter Kraft, Harvard School of Public Health; J Scott Roberts, Lan Q Le, Jenny Ostergren, University of Michigan Mack T. Ruffin IV, Penn State Hershey Medical Center; Lisa S. Lehmann, National Center for Ethics in Health Care, US Department of Veterans Affairs; Stacy W. Gray, City of Hope; Joanna L Mountain, Amy K. Kiefer, 23andMe; Glenn Braunstein, Pathway Genomics; Scott D Crawford, SoundRocket; L Adrienne Cupples, Clara A Chen, Catharine Wang, [Na Wang,] Boston University; Barbara A Koenig, University of California San Francisco; Kimberly Kaphingst, University of Utah; Sarah Gollust, University of Minnesota.

**Funding Information** This study was funded by NIH grant R01 HG005092.

#### Compliance with ethical standards

**Conflict of interest** Latrice Landry, J.Scott Roberts, Daiva Elena Nielsen and Deanna Alexis Carere declare they have not conflict of interests.

Dr. Green receives compensation for speaking or consultation from AIA, GenePeeks, Helix, Illumina, Prudential and Veritas, and is co-founder and advisor to Genome Medical, Inc.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants included in the study.

#### References

- Agurs-Collins T, Ferrer R, Ottenbacher A, Waters EA, O’Connell ME, Hamilton JG (2015) Public awareness of direct-to-consumer genetic tests: findings from the 2013 U.S. health information national trends survey. *J Cancer Educ* 30:799–807
- Armstrong K, Hughes-Halbert C, Asch DA (2006) Patient preferences can be misleading as explanations for racial disparities in health care. *Arch Intern Med* 166:950–954
- Armstrong K, McMurphy S, Dean LT, Micco E, Putt M, Halbert CH, Schwartz JS, Sankar P, Pyeritz RE, Bernhardt B, Shea JA (2008) Differences in the patterns of health care system distrust between blacks and whites. *J Gen Intern Med* 23:827–833
- Armstrong K, Putt M, Halbert CH, Grande D, Schwartz JS, Liao K, Marcus N, Demeter MB, Shea J (2012) The influence of health care policies and health care system distrust on willingness to undergo genetic testing. *Med Care* 50:381–387
- Bloss CS, Ornowski L, Silver E, Cargill M, Vanier V, Schork NJ, Topol EJ (2010) Consumer perceptions of direct-to-consumer personalized genomic risk assessments. *Genet Med* 12:556–566



- Butrick M, Roter D, Kaphingst K, Erby LH, Haywood C Jr, Beach MC, Levy HP (2011) Patient reactions to personalized medicine vignettes: an experimental design. *Genet Med* 13:421–428
- Carere DA, Couper MP, Crawford SD, Kalia SS, Duggan JR, Moreno TA, Mountain JL, Roberts JS, Green RC (2014) Design, methods, and participant characteristics of the impact of personal genomics (pigen) study, a prospective cohort study of direct-to-consumer personal genomic testing customers. *Genome Med* 6:96
- Catz DS, Green NS, Tobin JN, Lloyd-Puryear MA, Kyler P, Umemoto A, Cernoch J, Brown R, Wolman F (2005) Attitudes about genetics in underserved, culturally diverse populations. *Community Genet* 8: 161–172
- Finney Rutten LJ, Gollust SE, Naveed S, Moser RP (2012) Increasing public awareness of direct-to-consumer genetic tests: health care access, internet use, and population density correlates. *J Cancer Epidemiol* 2012:309109
- Hensley Alford S, McBride CM, Reid RJ, Larson EB, Baxevanis AD, Brody LC (2011) Participation in genetic testing research varies by social group. *Public Health Genomics* 14:85–93
- Jaffe S (2015) Planning for us precision medicine initiative underway. *Lancet* 385:2448–2449
- Kolor K, Duquette D, Zlot A, Foland J, Anderson B, Giles R, Wrathall J, Khoury MJ (2012) Public awareness and use of direct-to-consumer personal genomic tests from four state population-based surveys, and implications for clinical and public health practice. *Genet Med* 14:860–867
- Langford AT, Resnicow K, Roberts JS, Zikmund-Fisher BJ (2012) Racial and ethnic differences in direct-to-consumer genetic tests awareness in hints 2007: sociodemographic and numeracy correlates. *J Genet Couns* 21:440–447
- Mai PL, Vadaparampil ST, Breen N, McNeel TS, Wideroff L, Graubard BI (2014) Awareness of cancer susceptibility genetic testing: the 2000, 2005, and 2010 national health interview surveys. *Am J Prev Med* 46:440–448
- Ortiz AP, Lopez M, Flores LT, Soto-Salgado M, Finney Rutten LJ, Serrano-Rodriguez RA, Hesse BW, Tortolero-Luna G (2011) Awareness of direct-to-consumer genetic tests and use of genetic tests among Puerto Rican adults, 2009. *Prev Chronic Dis* 8:A110
- Pagan JA, Su D, Li L, Armstrong K, Asch DA (2009) Racial and ethnic disparities in awareness of genetic testing for cancer risk. *Am J Prev Med* 37:524–530
- Rahm AK, Feigelson HS, Wagner N, Le AQ, Halterman E, Cornish N, Dearing JW (2012) Perception of direct-to-consumer genetic testing and direct-to-consumer advertising of genetic tests among members of a large managed care organization. *J Genet Couns* 21:448–461
- Roberts JS, Ostergren J (2013) Direct-to-consumer genetic testing and personal genomics services: a review of recent empirical studies. *Curr Genet Med Rep* 1:182–200
- Shields AE, Burke W, Levy DE (2008) Differential use of available genetic tests among primary care physicians in the united states: results of a national survey. *Genet Med* 10:404–414