

Consumer and Healthcare Provider Motivations and Concerns for Personalized Genomic Sequencing

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BACKGROUND

- Genetic testing has extended beyond providing a diagnosis in affected individuals into the realm of prevention in asymptomatic/healthy individuals.
- Prior to developing a personalized genomic test geared towards unaffected individuals, Ambry performed a unique market research study to assess the level of interest in personalized genomic testing among average healthy individuals and healthcare providers (HCPs).
- Objectives included understanding current perceptions, motivations, specific health interests, and concerns about personalized genomic testing among one of the largest cohorts to date.
- We used the information to guide the development of this new test, and to responsibly address the associated genetic counseling needs and concerns.

METHODS*

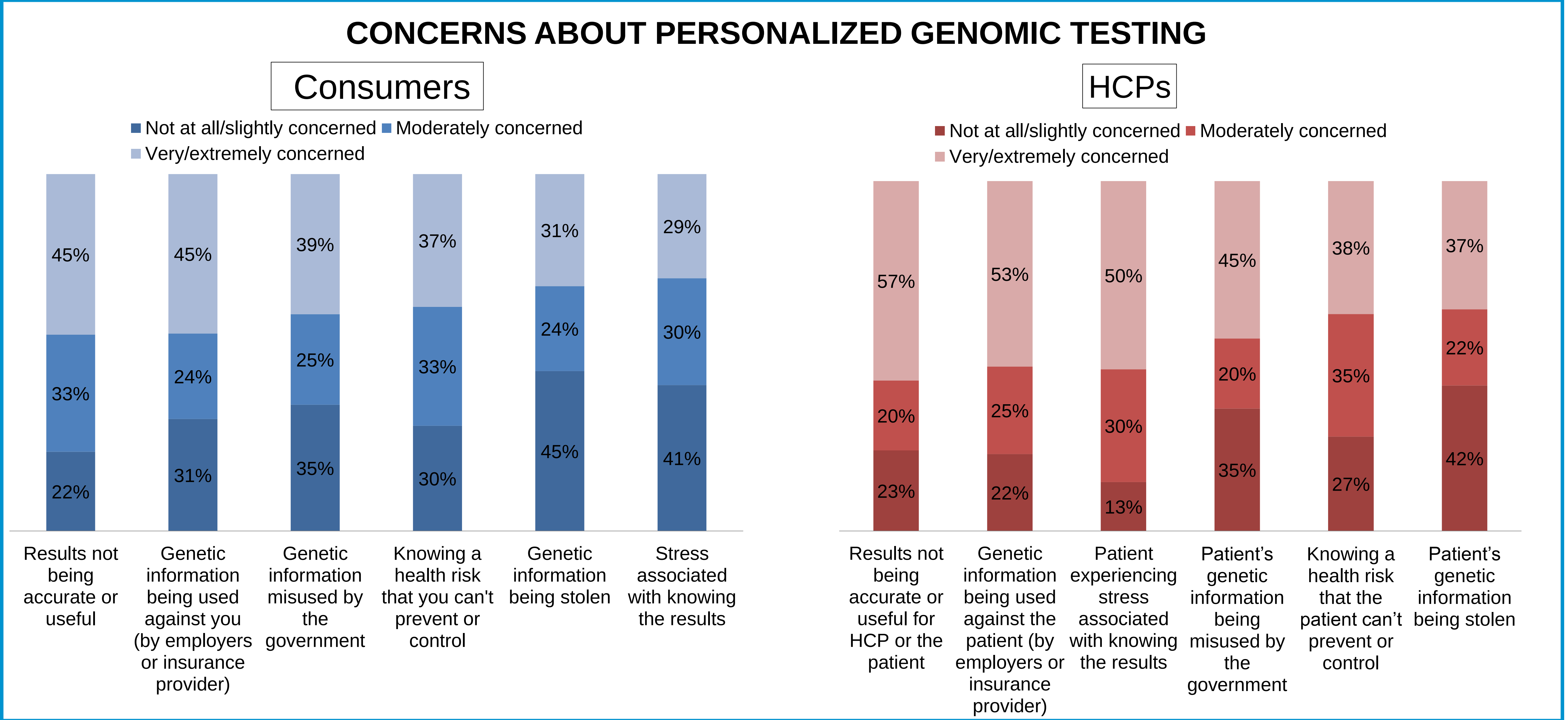
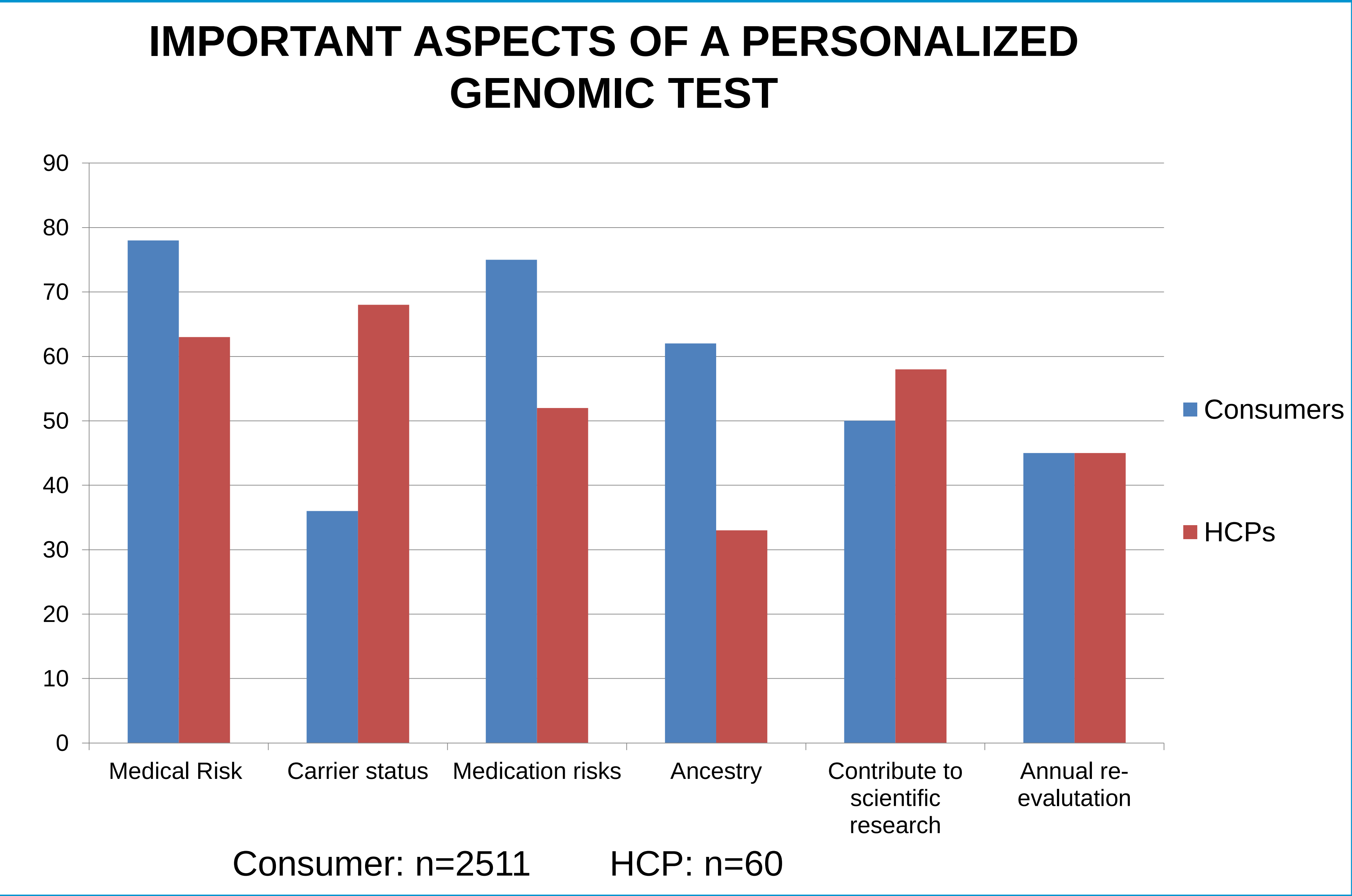
Qualitative

Consumer	6 Two-Hour Focus Groups	Irvine, CA January 31, 2017 Chicago, IL February 02, 2017	n=35 Consumers ~6 Participants per Focus Group	- Mix of genders - Ages 25-55 - Household income of \$100,000+ - Have family history of disease but not personally affected - At least somewhat concerned and proactive about their health
HCP	Telephone Depth Interviews (TDIs)	February 06, 2017 February 14, 2017	n=8 HCPs Total 3 Primary Care Physician 2 Obstetrician/Gynecologist 2 Nurse Practitioner/Physician's Assistant (NP/PA) 1 Doctor of Osteopathic Medicine	- Board certified/eligible 3-32 years in practice - More than 65% of time in direct patient care

Quantitative

Consumer	15-minute Online Survey	March 03 – March 14, 2017	n=2511 Consumers Total	- US Resident - Household income of \$75,000+ - No affiliations with healthcare or genetics companies
HCP	15-minute Online Survey	March 27 – April 04, 2017	n=60 HCPs Total - n=24 Obstetrician/Gynecologist - n=21 Primary Care Physician - n=10 Nurse Practitioner/Physician's Assistant (NP/PA) - n=5 Doctor of Osteopathic Medicine	- Board certified/eligible 2-30 years in practice - Does not practice in public clinic or government/VA hospital - More than 65% of time in direct patient care - Has recommended or prescribed genetic test in past 3 months - No affiliations with healthcare or genetics companies

*Data from qualitative research was used to design the quantitative study . This study was designed and carried out in conjunction with IPSOS healthcare



CATEGORIES OF INTEREST

- Consumers top-ranked aspects of a personalized genomics testing:
 - Personal medical risk (78%)
 - Cancer (96%)
 - Heart disease (75%)
 - Neurological (68%)
 - Diabetes (40%)
 - Depression/anxiety (17%)
 - Cystic Fibrosis (9%)
 - Tay-Sachs (5%)
 - Medication risks /pharmacogenomics (75%)
 - Ancestry (62%)
- HCPs top-ranked aspects of a personalized genomics testing:
 - Carrier status of the patient (68%)
 - Medical risks for the patient (63%)
 - Contribution to scientific research (58%)

KEY TAKEAWAYS

Consumers:

- 47% (1190/2511) of consumers surveyed were interested in a genetic test that includes medical risk factors for themselves, risk for their children (carrier status), pharmacogenomics, and ancestry.
- The biggest areas of concern included: accuracy/usefulness of testing (45%), genetic discrimination (45%) and misuse of genetic data (39%).
- 43% of consumers preferred to go through their own primary physician for testing and management.

HCPs:

- 48% (29/60) of HCPs would prescribe/order a personalized genomics test for their patient and were most drawn to family planning and medical risk assessment.
- Concerns were similar to consumers: accuracy/usefulness of testing (57%) and employer/insurance discrimination (53%) as the highest concern but expressed additional concerns including anxiety, knowledge gaps, and other burdens on the HCPs.

Overall:

- Both consumers and HCPs are interested in personalized genomic testing for unaffected individuals and they share similar concerns.

DISCUSSION

- These results provide a framework for offering personalized genomic testing to unaffected individuals, help inform us about genetic counseling issues unique to this type of testing, and highlight an anticipated surge in demand for these services.
- In light of the industry's current expansion to include genetic testing for unaffected individuals, this study highlights the differences in the reason/interest for testing between consumers and HCPs while highlighting their similar concerns.
- With a growing interest of personalized genomics tests among consumers and the limited number of genetics experts, HCPs will need to be prepared to order, address questions and understand results.
- As a community, we should be prepared about the role price/insurance coverage will play in the growing demand for testing and improve education about genetic nondiscrimination laws.