

[Personal genomic testing for cancer risk: results from the Impact of Personal Genomics \(PGen\) study.](#) Gray SW, Gollust SE, Carere DA, Chen CA, Cronin A, Kalia SS, Rana HQ, Ruffin MT, Wang C, Roberts JS, Green RC for the PGen Study Group, Journal of Clinical Oncology. 2016. EMBARGOED December 12, 2016.

*Most adults receiving elevated direct to consumer (DTC) personal genomic testing, single nucleotide polymorphism-based cancer risk estimates did not significantly change their diet, exercise, advanced care planning or cancer screening behaviors.*

[Consumer perceptions of interactions with primary care providers after direct-to-consumer personal genomic testing.](#) van der Wouden CH, Carere DA, Maitland-van der Zee AH, Ruffin MT, Roberts JS, Green RC for the PGen Study Group, Annals of Internal Medicine. 164(8): 513-522, 2016.

*This study, the first of its kind, describes the relationship between consumers DTC genetic tests and their primary care providers (PCP). Although the pre-testing survey showed that over 60% of participants anticipated sharing their results with their PCP, only 35% actually did. This discrepancy could be attributed to participant realization that not all genetic testing results required follow-up medical involvement.*

[Prescription medication changes following direct-to-consumer personal genomic testing: findings from the Impact of Personal Genomics \(PGen\) Study.](#) Carere DA, VanderWeele TJ, Vassy JL, van der Wouden CH, Roberts JS, Kraft P, Green RC for the PGen Study Group, Genetics in Medicine. 2016.

*This study analyzes consumer behavior after receiving pharmacogenomic results from DTC genetic testing. Pharmacogenomics results are those that indicate an atypical response to drugs because of a person's genetic composition and can affect how effective or harmful prescription medication can be for an individual. DTC genetic testing was found to report pharmacogenomics results often, though fewer than 1% of consumers reported changing their prescription medications in relation to these results.*

[Adopting genetics: Motivations and outcomes of personal genomic testing in adult adoptees.](#) Baptista NM, Christensen KD, Carere DA, Broadley SA, Roberts JS, Green RC for the PGen Study Group, Genetics in Medicine. 18 (9): 924–932, 2016.

*Although this study shows that adoptees that seek out DTC genetic testing are no more likely to change medical behavior than non-adoptees, the opportunity to gain insight on their genetic background (specifically ancestry and carrier status for family health history) cannot be understated.*

[The impact of personal genomics on risk perceptions and medical decision-making.](#) Krieger JL, Murray F, Roberts JS, Green RC, Nature Biotechnology. 34(9): 912-918, 2016.

*Consumers of DTC genetic testing were shown to significantly alter their risk perceptions in response to receiving their genotype results. Consumers who experience an increase perceived risk after testing were the most likely to affect follow-up medical actions, while those who reported a decrease in perceived risk were not likely to seek medical follow-up. This finding can be attributed to the likelihood of such participants to have received average, non-actionable results.*

[Implications of personal genomic testing for health behaviors: the case of smoking.](#) Olfson E, Hartz S, Carere D, Green RC, Roberts JS, Bierut L, Nicotine & Tobacco Research, 2016.

*Olfson et al suggested that smokers show a high level of interest in genetic risks of smoking-related illnesses. The experience of receiving direct-to-consumer genomic health risks did not appear to have obvious harms related to smoking behaviors (as in false reassurance), and had some potential benefits.*

[Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing.](#) Carere DA, Kraft P, Kaphingst KA, Roberts JS, Green RC for the PGen Study Group, *Genetics in Medicine*. 18(1): 65-72, 2015.

*In an effort to determine consumer self-efficacy in interpreting genetic testing results, this study surveyed participants before and after testing and collected demographic information. Prior to genetic testing, study participants demonstrated a high level of health literacy and comprehension of genetics. After undergoing DTC genetic testing results, the same participants claimed a lesser understanding of genetics and health literacy. This could be caused by an appropriate adjustment in perceived self-efficacy in participant understanding. Demographically, self-efficacy was only correlated to education level when compared to other demographic qualifiers.*

[Explaining, not just predicting, drives interest in personal genomics.](#) Meisel SF, Carere DA, Wardle J, Kalia SS, Moreno TA, Mountain JL, Roberts JS, Green RC. *Genome Medicine*. 7(1): 74, 2015.

*Through investigation of consumers' motives to undergo DTC genetic testing, research shows that consumers are particularly interested in genetic test results that explain conditions they already have, not just risks for diseases they may develop in future. This was found to be particularly true for more complex diagnoses, such as rare diseases or conditions without an established causation.*

[How well do customers of direct-to-consumer personal genomic testing services comprehend genetic test results? Findings from the Impact of Personal Genomics Study.](#) Ostergren JE, Gornick MC, Carere DA, Kalia SS, Uhlmann WR, Ruffin MT, Mountain JL, Green RC, Roberts JS for the PGen Study Group, *Public Health Genomics*. 18(4): 216-24, 2015.

*These research findings show that most participants correctly interpret hypothetical results that mimic DTC genetic testing reports. Participants were particularly astute at identifying appropriate risk for dominant trait conditions such as type 2 diabetes and colorectal cancer. The participants' interpretation did however show a decrease in comprehension of more difficult concepts, particularly the importance of carrier status of recessive traits and multifactorial disease risks.*

[Associations between self-referral and health behavior responses to genetic risk information.](#) Christensen KD, Roberts JS, Zikmund-Fisher BJ, Kardia SLR, McBride CM, Linnenbringer E, Green RC, *Genome Medicine*. 7: 10, 2015.

*Christensen et al, Genome Medicine showed that individuals who proactively seek Alzheimer's disease genetic risk assessment are more likely to undergo testing and use results to inform behavior changes than those who respond to genetic testing offers. This demonstrated how the behavioral impact of genetic risk information may vary according to the models by which services are provided and the methods by which participants are recruited into translational genomics research.*

[The impact of direct-to-consumer personal genomic testing on perceived risk of breast, prostate, colorectal, and lung cancer: findings from the PGen study.](#) Carere DA, VanderWeele T, Moreno TA, Mountain JL, Roberts JS, Kraft P, Green RC for the PGen Study Group, *BMC Medical Genomics*. 8(1): 63, 2015.

*Carere et al analyze the change in risk perception for breast, prostate, colorectal, and lung cancer before and after consumers received their results from DTC genetic testing. With the exception of lung cancer (which showed an elevated risk perception regardless of result), most participants felt a consistent or decrease in perceived risk of cancer after receiving average cancer risk.*

[Regulation: The FDA is overcautious on consumer genomics.](#) Green RC, Farahany NA: *Nature*, 505: 286-287, 2014.

*Green and Farahany discuss their concerns with the FDA's attitude towards DTC genetic testing and the response of 23andMe, particularly as it relates to the future of consumer health products and company transparency.*

[Design, methods, and participant characteristics of the Impact of Personal Genomics \(PGen\) Study, a prospective cohort study of personal genomics testing customers.](#) Carere DA, Couper MP, Crawford SD, Duggan JR, Moreno TA, Mountain JL, Roberts JS, Green RC for the PGen Study Group. *Genome Medicine*. 6: 96, 2014.

*The PGen study established a prospective cohort of consumers of DTC genetic testing which will provide the empirical data necessary to understand the psychosocial, behavioral, health outcomes and overall impact of commercial genomic profiling. The PGen study will integrate industry engagement with academic research through a partnership that could shape future protocol development.*

[Navigating a research partnership between academia and industry to assess the impact of personalized genetic testing.](#) Lehmann LS, Kaufman DJ, Sharp RR, Moreno TA, Mountain JL, Roberts S, Green RC: *Genetics in Medicine*, 14: 268-273, 2012.

*Lehmann and co-authors identify that the most efficient and mutually beneficial way to navigate the industry and academia partnership on DTC genetic testing is for both sides to remain transparent, clear of objectivity, and responsive to concerns on behalf of all involved parties.*

[Direct-to-consumer genetic testing: Reliable or risky?](#) Spencer DH, Lockwood C, Topol E, Evans JP, Green RC, Mansfield E, Tezak Z: *Clinical Chemistry*, 57(12): 1641-1644, 2011.

*Topol, Evans, Green, Mansfield and Tezak discuss DTC genetic testing and the evidence surrounding its benefits and drawbacks. These experts agree that DTC genetic testing results could have the ability to inform consumers of general genetic risks and health information, but that there needs to be sufficient evidence gathered which explains consumers' understanding of the results and the ability of the healthcare industry to support the supposed increase in genetic information used in healthcare decision making.*

[The future of direct-to-consumer clinical genetic tests.](#) Frueh FW, Greely HT, Green RC, Hogarth S, Siegel S: *Nature Reviews Genetics*, 12: 511-515, 2011.

*In response to the FDA's involvement in regulating DTC genetic testing, these five experts discuss the importance of gathering evidence against the speculative dangers and drawbacks of DTC genetic testing and the importance of appropriate regulation which benefits the public and patient population as well as it informs the industries distributing the tests.*