

A Role for Storytelling in Improving Consumer Understanding of Genetic Testing

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THE U.S. FOOD AND DRUG ADMINISTRATION'S (FDA) October 2018 announcement that it has cleared a pharmacogenetic direct-to-consumer (DTC) test speaks to the American consumer's growing interest in precision health. The test's availability also adds complexity to an already challenging issue facing the genetics and wider health care communities: ensuring consumers have a grasp of how to interpret DTC results and what to do next; and how to best prepare health care professionals, and the health care system at large, to meet the increased demand generated by such testing. Could one of humankind's oldest social cooperation tools—storytelling—help? Neuroscience and public health behavior change research seem to suggest so.

As of the start of 2018, more than 10 million people had used a DTC genetic test. Projecting ahead to 2021, this figure could increase to 100 million (Khan and Mittelman, 2018). Increased consumer awareness will undoubtedly be a driver of this growth and a boon to industry. Ensuring that elevated awareness translates to appropriate action and outcomes is a significant opportunity for the health care community.

Findings from several years ago indicate that although the majority of consumers do recall their DTC testing results and perceive them as deterministic (are able to recognize that disease causes are multifactorial), misperceptions are likely, specifically around the scope of the tests and overestimating the tests' ability to inform future disease management and health care (Roberts and Ostergren, 2013). One can imagine pharmacogenetics will be an even trickier topic to understand.

Genetics experts, particularly counselors, can and do provide thorough, one-on-one education to consumers when they present for advice about DTC results or are referred for confirmatory testing. However, reaching consumers earlier, with awareness about basic genetic facts, what DTC testing can and cannot do, and how the various types of testing can inform personalized risk assessment and treatment approaches, would complement these efforts—and go a long way toward improving the public health. Doing so could help appropriate patients see the right health care professionals sooner and reduce unnecessary psychological distress and time and money spent addressing false positives. To maximize impact of awareness-raising efforts, the community would be wise to apply principles of good-old-fashioned storytelling.

Storytelling has thrived throughout human history because it has supported the development of civilization itself. It has fostered social cooperation, taught social norms, and led to greater

reproductive success for those individuals telling the stories (Smith *et al.*, 2017). Good storytelling is helpful in teaching because it grabs attention, facilitates understanding, and makes people more likely to act (Green and Brock, 2000; Zak, 2015).

Neuroscience research has implicated several mechanisms. Oxytocin, the hormone better known for its role in childbirth, floods the brain when a viewer is enthralled with a narrative, and is linked with prosocial behaviors, such as being motivated to donate money to a cause. These behaviors have been shown to increase after watching emotional narrative videos (Zak, 2015). Studies also have shown that neural coupling, in which the listener's brain begins to mirror the speaker's brain activity, occurs in storytelling. The higher the degree of this coupling activity, the better the listener was able to understand the story (Stephens *et al.*, 2010).

Marketers across industries have seized on these and other important neuroscience findings and are using storytelling to grow businesses and change behavior. Although further study is needed in health care, storytelling has been explored as a means to improve health literacy and deliver culturally relevant health interventions (Day, 2009; Briant *et al.*, 2016). Medical schools also have embraced training in narrative medicine as a means to increasing providers' empathy for patients.

The genetics and broader health care communities can apply these insights into large-scale awareness-raising initiatives that help reduce barriers to appropriate use of DTC testing. At the very least, storytelling principles may help galvanize the general public to dig a little deeper to learn more about their genetic information and what it may reveal.

Considerations for such efforts include the following:

- *Find the right storytellers.* Identify consumers and patients—of diverse ages and backgrounds—willing to share their experience from learning about testing through to taking appropriate action, as well as health care professional experts who can explain the process simply, and with the appropriate scientific and clinical context.
- *Focus on emotional story arcs and visuals, not statistics.* Stories have plot, conflict, and resolution. Build a story arc that starts with a beginning, has a problem (e.g., initial misperceptions and emotions surrounding testing), and then shows how the problem was resolved once a consumer learned more and received appropriate care. Avoid complex numbers and statistics; people will lose attention quickly.

- *Tell the stories in the right places.* Perhaps the most cited public health behavior change case study is the “truth initiative,” a national effort that has led to a significant portion of the recent decline in youth smoking rates. One key to its success has been ensuring its messaging is culturally relevant and connects with young people at the right places and times, and that lesson applies here (Truth Initiative, 2018).

Knowing your target audience inside and out—and how to reach them—is a crucial component of any behavior change campaign. For example, using local evening news programs, Facebook or e-mail marketing, or even movie theater public service announcements may resonate with Boomers, but not as well with Generation Z.

It is also important to note that stories do not have to be live action; considering podcasts, animation, or even “white-board” videos can be equally effective and done at lower cost.

- *Share stories for the greater good.* Identify ways to share stories you have collected. Hearing from a person “like me” can motivate a potential patient or family member to act. What is more, aggregating individual qualitative data adds color and nuance to the greater understanding of diseases and conditions.

Of course, awareness is just one part of the equation. Complementary efforts to educate health care professionals, and to promote open access from a policy and reimbursement perspective are also needed to ensure an informed consumer base is met with appropriate support. The story of where the explosion of DTC genetic information takes us is still being written, and the opportunity for genetics professionals, particularly counselors, to lead, is great.

References

- Briant KJ, Halter A, Marchello N, *et al.* (2016) The power of digital storytelling as a culturally relevant health promotion tool. *Health Promot Pract* 17:793–801.
- Day V (2009) Promoting health literacy through storytelling. *Online J Issues Nurs* 14.
- Green MC, Brock TC (2000) The role of transportation in the persuasiveness of public narratives. *J Pers Soc Psychol* 79: 701–721.
- Khan R, Mittelman D (2018) Consumer genomics will change your life, whether you get tested or not. *Genome Biol* 19:120.
- 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.
- Smith D, Schlaepfer P, Major K, *et al.* (2017) Cooperation and the evolution of hunter-gatherer storytelling. *Nat Commun* 8: 1853.
- Stephens GJ, Silbert LJ, Hasson U (2010) Speaker–listener neural coupling underlies successful communication. *Proc Natl Acad Sci U S A* 107:14425–14430.
- Truth initiative (2018) Truth campaign linked with decreased smoking and increased support for anti-tobacco social movement. Available at: <https://truthinitiative.org/research/truth-campaign-linked-decreased-smoking-and-increased-support-anti-tobacco-social-movement> (accessed December 4, 2018).
- U.S. Food and Drug Administration (2018) FDA authorizes first direct-to-consumer test for detecting genetic variants that may be associated with medication metabolism. Available at: <https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm624753.htm> (accessed December 4, 2018).
- Zak P (2015) Why inspiring stories make us react: the neuroscience of narrative. *Cerebrum* 2015:2.

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