

## Comment

### KNOW YOUR GENES. THE MARKETING OF DIRECT-TO-CONSUMER GENETIC TESTING

# From symptomatic to pre-symptomatic patient: the tide of personal genomics

**Marina Levina, Roswell Quinn**

*ABSTRACT: Personal Genomics Companies are an emerging form of biotechnology startup that bring rapidly advancing whole genome technologies to a variety of commercial venues. With a combination of direct-to-consumer marketing, social media, and Web 2.0 applications these companies seek to create novel uses, including entertainment, for what is described as predictive medicine – that is the use of genetic marketers to create health forecasts that would allow individual's healthcare to be tailored to their individual genomic data. In this brief piece, the authors use a critical cultural approach to question how this combination of genomics research, marketing, and communications technologies may alter both patient experiences and research processes. In it we argue these companies radically expand the definition of a patient by claiming all consumers are simply pre-symptomatic patients. Moreover, by placing genomic data on both the marketplace and cyberspace, personal genomic companies seek to create new avenues of research that alter how we define (and access) research agendas and human subjects. Therefore, beyond commonly discussed issues of ethics and privacy rights, Personal Genomics has the potential to alter both healthcare priorities and distribution.*

Personal genomics has a rapidly evolving history. An international collaboration of scientists sequenced the first draft of a human genome in July 2000. Since that time sequencing technologies have become increasingly efficient, while sequencing costs have decreased dramatically. We are now within reach of the 1,000 dollar genome, a figure that could potentially make genome sequencing much like other diagnostic tests. Direct-to-Consumer (DTC) genomics emerged in 2007 in this context as biotechnology start-ups began marketing genomic services directly to consumers. Well known DTC genomics companies include 23andMe, Navigenics, and Pathway Genomics. The former became a subject to much controversy when, in May 2010, it joined forces with Walgreens to offer over-the-counter consumer genomic tests. The FDA halted the plan, and in light of these rapid advancements Congress began to investigate regulation of the personal genomics industry and DTC products.

These new technologies have the potential to change the way we think about health, identity, and their interrelatedness. The purpose of many direct-to-consumer genomic services is to use a series of genetic markers to provide a biological forecast of an individual's susceptibility to disease. With this information such services attempt to tailor present day treatments, medical surveillance, and health behaviors to such predictions.<sup>1</sup> In addition, various companies offer more entertainment driven services that include ancestry information and opportunities to use social media and web 2.0 to join networks of individuals with similar results from genomic testing. Within this process, many DTC services seek to redefine the patient from a person with symptoms to a person in a constant pre-symptomatic state. In fact, as discussed below, much of DTC marketing focuses on pre-symptomatic state. This redefinition is a stark contrast to the well-established field of genetic medicine. Where genetic medicine primarily seeks to identify the molecular basis of an already evident disease, personal genomics seeks to redefine disease as a future rather than present event.

In this piece the authors use a critical cultural approach to genomics, personal health information, and public health to discuss the potential issues and pitfalls in labeling individuals pre-symptomatic through DTC marketing. While most critical responses to DTC have primarily dealt with ethical issues of the accuracy,

marketing and privacy of genomic tests, we contend that there are deeper social and cultural implications to marketing of DTC genetic testing. Primarily, we argue that one of personal genomics marketing's most basic social functions is to shift the concept of a patient from being with symptoms to being pre-symptomatic. This shift has two major outcomes. First, DTC genomics further blurs the boundaries between patient and consumer while creating larger markets for health related products. Moreover, these markets are co-constructed and reinforced by their contextualization within social media and networked relationships with other individuals. Second, the commercialization of pre-symptomatic genetic interventions could have public health consequences as personal genomic companies now offer medical services and research efforts similar to those previously residing within the public or charitable sectors.

At the 2010 Consumer Genetics Conference much of conversation outlined the budding relationships between these new technologies and the importance of pre-symptomatic conditions. Such conditions are ones in which an otherwise healthy individual has a positive genetic marker indicating risk for developing a disease. Heidi Rehm of Partners® HealthCare's Center for Personalized Genetic Medicine explained that a pre-symptomatic patient radically expands who is in need of healthcare services, creating a more profitable market. Felix Frueh of Medco delivered a lecture titled "Applied Pharmacogenetics - Yesterday's Patient Is Today's Consumer", in which he argued that patient is one who receives something (medical services, therapies, etc.) – and therefore assumes a passive role. Consumer, on the other hand, is one who acquires goods or services for direct use of ownership and assumes an active role. The transformation of the patient into a consumer has been an ongoing historical process, evolving throughout the last century.<sup>2</sup> Personal genomics, however, accelerates this trend by creating a wider pool of "patients" and, thus, consumers. Evidence of this can be seen in Bill Kimmerly of DNA Guide, blunt declaration that the genome is the ultimate pre-existing condition. Throughout the conference, other participants readily expanded upon Kimmerly's logic to include new forms of consumerism. For example, Dietrich Stephan, founder of Navigenics, and current principal of Ignite Institute for Individualized Health argued that each asymptomatic person should be treated as a potential consumer of personal genomics. The focus on pre-symptomatic conditions therefore helps turn patients into consumers of personal genomics and related healthcare services – again a profitable turn for market driven medicine.

In other words, the shift from symptomatic to pre-symptomatic conditions is made economically sensible through its redefinition of patient into consumer. These discourses are both scientific and personal. From examples of the BRCA-1 mutation's influence on breast cancer screening and genomically tailored chemotherapies to Brandon Colby of Existence Genetics confessing that data from his genome has made him "a patient [his] entire life," personal genomics becomes a gateway to an all inclusive healthcare market, i.e. all biocitizens would benefit from it.<sup>3</sup> The underlying assumption expressed by many participants was that this new genomic information could serve as a gateway to new medical goods and services, be it primary care, nutraceuticals, lifestyle coaching, or further testing. In other words, a marketing emphasis on pre-symptomatic.

Personal genomic companies' engagement with social media and their customers increasingly networked daily lives have further supported this transition from patient to pre-symptomatic consumer. Equipped with the slogan "genetics just got personal," 23andME asserts that it works largely as a genetic Facebook. Knowledge of one's DNA now facilitates socializing, building relationships, and entertainment. By merging social media and genomics, such services promote online social interactions and connectivity based on personal genomic data, allowing new understandings of self through these new relationships. Web 2.0 proliferates these understandings by constructing the self as a constant stream of information to be shared with other individuals in the network. Therefore, new understandings of oneself – or network subjectivity – provided by genomic data become interpreted through their relationships to other individuals' behaviors, statements, and genetic data posted within the network.<sup>4</sup> Moreover, network subjectivity reinforces consumer-based approach to genetic data as a commodity to be acquired, shared, and consumed for fun and profit.

Pre-symptomatic consumers must simultaneously construct new understandings of the self and grapple with the notion promoted by these companies that personal genomic data should be shared openly and avidly. As has been discussed elsewhere, the sharing of genomic information through new media is fraught with ethical considerations and difficulties.<sup>5</sup> We argue, however, that pre-symptomatic consumer identity and network subjectivity further complicate these matters by engendering new models of research and complicating established forms of research subjects protection. In fact, one expressed goal is to recruit virtual populations, who are already used to sharing their data through social media sites, to

share their data for purposes of genomic research conducted by research centers, pharmaceutical companies, and various other private industries. Industry leaders have called new forms of research emerging from DTC genomics “Research 2.0” – a new and collaborative scientific research model that fully utilizes Internet-based community building and resource sharing.<sup>6</sup> Recruitment in Research 2.0 is contingent upon explicit and implicit understandings of individuals as pre-symptomatic consumers and whose participation is contingent upon the diseases they might develop given their genetic predisposition. As these companies continue to champion a future world populated by pre-symptomatic individuals it becomes vital to question how DTC genomics and its marketing may effect and redefine understandings of the self, patients, and the safety and definition of potential research subjects.

Should such research and marketing initiatives – and associated discursive regimes – become a potent force in society, a final question raised would be what are the possible public health and health care delivery implications of DTC genomics and Research 2.0? For example, Sergey Brin, a co-founder of Google, has started to fund Parkinson research because a 23andMe genetic test revealed a LRRK2 mutation, which puts him at an increased, but not guaranteed, risk of developing Parkinson disease. As a profile in *Wired* magazine observes, Brin is the first philanthropist who began to fund scientific research, not because of the actual disease, but because of a genetic test.<sup>7</sup> Thus, Brin identifies a pre-symptomatic individual – someone who has not yet developed symptoms, but already thinks of himself as in part a Parkinson’s patient. However, this raises questions as to how would a shift in medical patronage – from those directly affected by a condition to those predicted to have it – alter philanthropic research funding, responsible for such 20<sup>th</sup> century medical advances such as insulin, oral contraceptives, and the polio vaccine.<sup>8</sup>

More importantly, beyond opening up biological information and genetic data to further capital development, the marketing of personal genomic services could result in the privatization of aspects of preventive medicine and public health. This could mark a major historical shift in the ongoing tensions between public health and preventive efforts on one hand and technologically focused biomedicine on the other, repackaging the goals of the former into the individualized, market driven commodities typified by the later.<sup>9</sup> The delivery of information concerning pre-symptomatic conditions is often linked to medical services provided by genomic companies – from primary care to screening and lifestyle modifications. As personal genomics gain attention and private funding, this cultural shift could affect the equitable distribution of preventative medical services. Matters of prevention have long been the aegis of state or non-governmental organization, not corporate America. As private genomic companies seek to market predictive medicine, traditional public health aims – diet, exercise, environmental protections, cancer screening, and generalized healthcare maintenance – are being explained by possible future conditions determined by genomic testing rather than current problems. If they are successful in changing understanding of diseases from patients to pre-symptomatic consumers, how will it affect the scope and impact of traditional public health activities?

In conclusion, we contend that current controversies surrounding direct-to-consumer genomics and its marketing illustrate a cultural change in understanding who and what patients are. In this scenario we are all patients and potential consumers of genetic data that may portend future disease. Personal genomics remains an exciting and rapidly evolving field that holds much promise. It adds new complexities to the unfolding history of biotechnology by influencing subjectivity, the networking of new biotechnologies with new communications technologies, and the ever-expanding role of research within medical practice. Its discursive focus on the pre-symptomatic consumer, however, requires us to further investigate, question, and discuss the socio-cultural, political, economic dimensions of a genomic data derived on the market place and imported into a wide variety of fields.

## Notes and references

<sup>1</sup> For more consumer based examples see C. Brandon (2010), *Outsmart your genes: How understanding your DNA will empower you to protect yourself against cancer, Alzheimer's, heart disease, obesity, and many other conditions*, New York, N.Y., Perigee Trade.

<sup>2</sup> N. Tomes (2001), *Merchants of Health: Medicine and Consumer Culture in the United States, 1900-1940*, *The Journal of American History* **88**(2): 519-547.

<sup>3</sup> Consumer Genomics Conference, Haynes Convention Center, Boston MA June 2-4 (2010).

- <sup>4</sup> M. Levina (2010), *Googling Your Genes: Personal genomics and the discourse of citizen bioscience in the Network Age*, *Journal of Science Communication* 9(1): 1-8.
- <sup>5</sup> S.S. Lee and L. Crawley (2009), *Research 2.0: Social networking and direct-to-consumer (DTC) genomics*, *American Journal of Bioethics* 9(6-7): 35-44.
- <sup>6</sup> [www.23andMe.com](http://www.23andMe.com) (accessed February 2011).
- <sup>7</sup> T. Goetz (2010), *Sergey Brin's search for a Parkinson's cure*, *Wired* 2010 July, [http://www.wired.com/magazine/2010/06/ff\\_sergeys\\_search/all/1](http://www.wired.com/magazine/2010/06/ff_sergeys_search/all/1) (accessed June 2010).
- <sup>8</sup> The history of medical research is populated by multiple forms of patronage, from individual to charitable and military. However, it is important to question the implications of patronage based on a predication of disease occurrence in an individual who can afford genomic testing versus more traditional patronage based largely on actual disease and population health. On relationships between patronage and the development of insulin see M. Bliss (1992), *The discovery of insulin*, Chicago, University of Chicago Press, U.S.A.; oral contraceptives see L. Marks (2001), *Sexual chemistry: A history of the contraceptive pill*, New Haven: Yale University Press; and vaccines see K. Hoyt (2002), *The role of military-industrial relations in the history of vaccine innovation*, PhD dissertation, Massachusetts Institute of Technology, U.S.A.
- <sup>9</sup> A. Brandt and M. Gardner (2000), *Antagonism and accommodation: Interpreting the relationship between public health and medicine in the United States during the 20<sup>th</sup> Century*, *American Journal of Public Health* 90(5): 707-715.

### Author

Marina Levina is an Assistant Professor at the Department of Communication at the University of Memphis. Her research focuses on critical cultural studies of science, technology and medicine, visual culture, and media studies. Currently, she is working on a book manuscript titled *Pandemics in the Media* (under contract with Peter Lang Press); an edited collection *Monstrous Culture in the 21<sup>st</sup> Century* (first editor with Diem-my Bui); a book chapter on biocapital and biotechnology in the film *Splice*, and articles on anticipation and affect in health information technology; biocitizenship and network subjectivity in personal genomics, and autoethnographic study of identity in personal genomics. She can be found at [www.marinalevina.com](http://www.marinalevina.com). E-mail: [mlevina@memphis.edu](mailto:mlevina@memphis.edu).

Roswell Quinn is currently an internal medicine resident at the University of Utah Medical Center. His PhD work in communications research focused on the privatization of the life sciences during the second half of the 20th century, with particular focus on the pharmaceutical industry. E-mail: [roswellquinn@gmail.com](mailto:roswellquinn@gmail.com).

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