

Comment

Know your genes. The marketing of direct-to-consumer genetic testing

Alessandro Delfanti

ABSTRACT: Genetic testing promises to put the ability to decide about our life choices in our hands, as well as help solve crucial health problems by preventing the insurgence of diseases. But what happens when these exams are managed by private companies in a free market? Public communication and marketing have proven to be crucial battlefields on which companies need to engage in order to emerge. This issue of JCOM tries to shed some light on the communication and marketing practices used by private companies that sell direct-to-consumer genetic testing, from single genetic mutations to whole genome sequencing.

A new market has emerged in the last few years, one in which consumers are people willing to know more about their genes, one that faces several problems of communication. In this market the product that is sold is data regarding one's Dna. This information can involve more than a single mutation, with a clear relationship with a pathological condition. Personal genomics services give customers information regarding a broad array of mutations, most of which are just a tiny part of a complex multifactorial condition or have no solid science showing any correlation with any disease. On the market are tests as bizarre as genetic profiles that are used to find the right match for a lonely heart. But this is no big deal vis-a-vis tests for conditions as important as obesity, psychiatric pathologies, diabetes and so on. Genetic testing promises to put the ability to decide about our life choices in our hands, as well as help solve crucial health problems by preventing the insurgence of diseases. But what happens when these exams are managed by private companies in a free market? Public communication and marketing have proven to be crucial battlefields on which companies need to engage in order to emerge.

This market is, in fact, often based on online services, not only to order and buy products, but also to organise, consult, and use genetic information. In this sense, direct-to-consumer genetic testing is a market that is increasingly similar to several other markets, in which online sales are only one aspect of the relationship between consumers and company. Websites are additionally used as tools to gather valuable information about consumers, or even to put to work the data they produce for free - famous examples are Amazon or eBay. Yet the genes market is characterized by a very peculiar novelty: it sells services related to health and medicine. On the one hand this is nothing new: patients have always had the chance to buy medical treatments and services from private companies. On the other hand, the most significant novelty when it comes to genetic testing is that consumers here do not need physicians to act as intermediaries between themselves and the information produced by these tests. This has changed the marketing approaches undertaken by companies in order to expand their customer base and maintain it. As some of the papers in this collection highlight, one of the main goals of the companies that sell direct-to-consumer genetic testing is to transform people into pre-symptomatic patients. This issue of JCOM tries to shed some light on the communication and marketing practices used by private companies that sell direct-to-consumer genetic testing, from single genetic mutations to whole genome sequencing.

Timothy Caulfield tries to separate useful, or at least vaguely predictive, services from others that are clearly preposterous, with no relation with any kind of solid science. In his work, Caulfield urges the scientific community and policymakers to tackle the issue of the often unclear, incomplete or exaggerated data that is provided by these companies. After all, the claims of companies associated with direct-to-consumer marketing are driven by profit.

According to Marina Levina and Roswell Quinn, even deeper issues are at stake here. One of the main issues raised by direct-to-consumer genetic testing is that through their marketing practices they seek to include all consumers in a new class of pre-symptomatic patients, thus changing patient experiences.

Also, they analyse the use of genetic data collected by companies and circulated online as new datasets for biomedical research.

Pascal Ducournau and Claire Beaudevin have drawn a picture of the state of direct-to-consumer companies, by analysing the marketing strategies of approximately 40 of these companies and by conducting online ethnography of their customers. According to the authors, the companies' marketing is not only based on the increasing medicalisation of industrialised societies, but also on the exploitation of important social phenomena. Healthism is the rise of personal health as a core social value; the growing individualisation of biopolitics means that citizens are more and more willing to bypass traditional biomedical institutions; finally, offering a form of network sociality based on the online sharing of genetic information, companies exploit the rhetoric of democracy and participation embodied by social network websites.

Discourses of participation and on the active role of customers in defending their health are also the focus of Donato Ramani and Chiara Saviane. Their commentary is based on work on genetic testing for neurodegenerative disorders and highlights the important differences that clearly separate one pathology from another. As these authors show, the marketing strategies of personal genomics companies are not designed to better inform individuals, but to sell a product, and this problem is reflected in the quality of their communication. According to Ramani and Saviane, a critical approach is needed in order to guarantee respect for the rights of patients.

Finally, Jenny Reardon points to a more general aspect of the relationship between genomics and communication. Personal genomics companies face more than a mere problem of communication due to their need to overcome doubts and critiques with a good marketing strategy. They are struggling to interpret the difference between noise and meaning in a scientific enterprise that to date has gathered massive amounts of information without finding a way to re-orient itself to solve human needs. Here the nature of genetic information is itself at stake, and the issue is not simply one of marketing.

HOW TO CITE: A. Delfanti, *Know your genes. The marketing of direct-to-consumer genetic testing*, *Jcom* **10**(03) (2011) C01