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Using lessons learned from BRCA testing and marketing: What lies ahead for whole genome scanning services

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In Matloff and Caplan's assessment of direct-to-consumer (DTC) marketing of BRCA testing the authors posit that Myriad Genetics has set "a precedent for other private companies developing genetic tests that will be considering if, and how, to engage in DTC" (1). Since the introduction of the BRCA genetic test a new set of DTC personalized genome services have entered the marketplace and are available for purchase on the Internet. Companies marketing these services include 23andMe, deCODEme, and Navigenics, which offer whole genome scans for \$985 to \$2,500 and Knome, which offers full genome sequencing for \$350,000. These services offer consumers the possibility of learning their individual genetic risk factors for a range of diseases although each company puts different emphases on using genome scans for making diagnostic recommendations for health and lifestyle behaviors, genetic ancestry tracing, tracing heritability patterns, and social networking. Using Matloff and Caplan's lessons learned from the DTC marketing and clinical application of BRCA testing as a launching point, here we look ahead to the potential impact of marketing whole genome scanning services, considering implications for both consumer-patients and their health care providers. This commentary compares and contrasts the ethical challenges posed by services which offer to scan an individual's whole genome with those posed by BRCA testing and marketing.

The individualization of healthcare and understanding health in terms of genetic risks can be situated within broader political trends towards neoliberal approaches to various sectors of the political economy, promoting individual responsibility for one's health, including vigilant self-surveillance to manage genetic health risks (Lemke 2004; Novas and Rose 2000). In the case of genetic testing for breast cancer, Press, Fishman and Koenig (2000) have argued that the significance of this medical intervention has been co-constituted by a strongly-held cultural fear of reproductive cancers and the contemporary dominance of the risk model of medicine in the United States. Together these two political rationalities have generated a market for genetic risk assessment for breast cancer which may not have a mirror in the market for genome scanning. Mobilizing an image of an "at-risk" community comprised of "informed, empowered, autonomous women" (Matloff and Caplan this issue, 7), Myriad has certainly drawn on a risk-based approach to individualized health. Advertising of DTC genome scans also portrays its client base as informed, empowered and autonomous, but the fear tactics that Matloff and Caplan reported in BRCA marketing may not have the same kind of cultural salience in the genome scanning market.

While the BRCA test is considered to have clinical utility, at this point whole genome scans are not yet considered to be clinically useful (Hunter, Khoury and Drazen 2008). This may

explain why DTC marketing materials for whole genome scans are currently presented more as an informational product than as a personalized medical service. Accordingly, the marketing of genome scans draws less on a fear-based mechanism and more on neoliberal governing rationalities appealing to an as-of-yet nebulous community of consumers. These rhetorical tools include invoking knowledge as power (“With this knowledge comes power” (Navigenics 2008)), a libertarian rights based approach to access to information about oneself (“We believe that your genetic information should be controlled by you” (23andMe 2008)), and individual responsibility for health management to catalyze potential consumer-patients (“Your Genes. Your Health. Your Choices.” (DNA Direct 2008)). As the consumer base for these services is undefined at the moment, it will be important to interrogate how Foucauldian “technologies of the self” like whole genome scans produce subjects with a “need” for control over and responsibility for their own genomic information and how they conceptualize the “power” that genome scans are purported to provide for them. To date very little is known about who has and who will take up whole genome scanning services, and as Matloff and Caplan’s assessment of BRCA testing implies, the ways in which DTC marketing is presented to targeted groups has an impact on who uses these tests. As the availability of these tests increases, we can no longer rely upon anecdotal evidence regarding how consumers are responding to DTC marketing. Thus, it is imperative to track not only the ways in which genome scanning is marketed to consumers, but also to whom and who among those target groups actually responds.

In addition to DTC advertising, Myriad Genetics has also implemented an ad campaign directed towards healthcare professionals in a position to order the BRCA test for their patients, otherwise known as direct-to-provider (DTP) marketing. Matloff and Caplan argue that the danger of Myriad marketing their service DTP is that the entrepreneurial company is a biased source of information for physician education about the benefits of the test, and thus should not be trusted to prepare providers to offer the BRCA test. The authors’ concerns regarding DTP marketing of genetic testing services may not carry over to DTC marketing for genome scanning services because while both services are advertised directly to consumers in public media outlets, potential consumer-patients of the BRCA test are obligated to request the test from their healthcare providers. In contrast, genome scans are truly available direct-to-consumer as they can be ordered straight from the Internet by individuals interested in purchasing the service. Thus, the traditional trajectory of genetic testing from basic research to clinical trials to clinical dissemination may be disrupted by the uptake of genetic research findings by industry to market directly to consumers (Offitt 2008). In this context, in which whole genome scanning is emergent, what relevance will physicians have if they no longer serve as gatekeepers to accessing genomic information? The key, we believe, is in the continuing salience of the doctor-patient relationship particularly in interpreting complex medico-scientific information, diagnostics and in developing individual health plans.

Along these lines, Matloff and Caplan raised the ethical concern that primary-care providers are not prepared to address the complexities of genetics that are required to educate patients about whether BRCA testing is right for them and to interpret test results. This concern may only be exacerbated by the introduction of genome scanning services into the market. If physicians are not equipped to provide adequate genetic counseling regarding a single genetic marker, then how can they be expected to interpret whole genome scans which have been developed and marketed outside of the medical-industrial complex? This issue has the potential to frustrate and confuse consumer-patients should they desire medical interpretation of their genome scan results. Additionally, it may further strain an already overburdened medical system should providers feel obliged to run further tests based on the results of DTC genome scans.

To conclude, Matloff and Caplan's claim that Myriad Genetics is setting the bar for how other DTC genetic services will be marketed to the public is informative and provides some cautionary tales to heed, although the ethical challenges posed by the marketing of a medical genetic test like the BRCA genetic test cannot necessarily be generalized to the whole field of DTC genetic and genomic services. There are similarities between the rhetorical tools used in DTC marketing of the BRCA genetic test and whole genome scanning, particularly in trying to mobilize individuals to take responsibility for their health and that genetic knowledge empowers consumer-patients. They are similar in that both types of services are marketed to the population as a whole, but these services do not have clinical utility for most of the population, thus there is a concern that enticing the population to make use of these services is simply a ploy for companies to make money from services without a known medical benefit for most people. This is particularly worrisome as healthcare providers are solicited by patients to provide genetic testing and interpret results of tests and scans, as both types of services have the potential to raise healthcare costs overall. A major difference between these services though is that healthcare providers serve as intermediaries in the BRCA testing market while consumer-patients have direct access to whole genome scans via the Internet which raises the potential for access to personalized genetic information without adequate counseling and interpretation of results. Even if DTC marketing of whole genome scans is not drawing on fear tactics to attract consumers as advertising of BRCA testing has, the novelty value of obtaining genetic information via the Internet needs to be situated within the social-historical context in which genetic information is largely used for medical purposes and as such consumers may interpret it as informative for healthcare decision-making. Lastly, the distinction between an intended "at-risk" community of potential BRCA test consumers and consumers of whole genome scans must be underscored. The need for empirical data assessing the uptake of both BRCA testing and whole genome scans is paramount. In the coming years it will be important to track the reception of DTC genome scanning services by consumer-patients and healthcare providers to see if in fact the challenges presented by BRCA testing and marketing and ethical concerns raised by personalized medicine bear out in the emerging field of whole genome scans and sequences.

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