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Beyond clinical utility: The multiple values of DTC genetics



Mauro Turrini ^{a,*}, Barbara Prainsack ^b

^a Centre for the Study of Techniques, Knowledge and Practices, University of Paris 1 "Panthéon Sorbonne", France

^b Department of Social Science, Health & Medicine, King's College London, United Kingdom

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ABSTRACT

One point of consensus in the otherwise very controversial discussion about the benefits and dangers of DTC genetics in the health domain is the lack of substantial clinical utility. At the same time, both the empirical and conceptual literature indicate that health-related DTC tests can have value and utility outside of the clinic. We argue that a broader and multi-faceted conceptualization of utility and value would enrich the ethical and social discussion of DTC testing in several ways: First, looking at ways in which DTC testing can have personal and social value for users – in the form of entertainment, learning, or a way to relate to others – can help to explain why people still take DTC tests, and will, further down the line, foster a more nuanced understanding of secondary and tertiary uses of DTC test results (which could very well unearth new ethical and regulatory challenges). Second, considering the economic value and broader utility of DTC testing foregrounds wider social and political aspects than have been dominant in the ethical and regulatory debates surrounding DTC genetics so far. These wider political aspects include the profound power asymmetries that characterize the collection and use of personal genetic data in many contexts.

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1. Introduction

Internet-based companies offering genetic testing services directly to consumers have been surrounded by controversy from the start. While some authors have celebrated the arrival of genome-wide tests on the online market as marking a revolution in patient empowerment, others have raised concerns about consumers receiving genetic risk information without medical advice. The main concerns have focused on the negative psychological effects that genetic or genomic risk-susceptibility data with low predictive value could have on test-takers (e.g. by causing stress or anxiety), the potential adverse impact of these tests on the broader healthcare services in terms of unnecessary requests for screening and diagnostic services, and the possible privacy violations of sensitive and personal data (for an overview, see [Caulfield and McGuire, 2012](#)). Risks are seen as particularly high for people without adequate genetic literacy ([Offit, 2008](#); [McGuire and Burke, 2008](#); [Leighton et al., 2012](#)).

Moreover, some social scientists and ethicists consider direct-to-consumer (DTC) genetics as the epitome of a particularly individualist or consumerist approach to healthcare (e.g., [Hunter et al., 2008](#); [McGuire and Burke, 2008](#); [Harvey, 2010](#)). Donna Dickenson recently

referred to DTC genetic tests as one of the most problematic instantiations of personalized medicine – a new model of healthcare directly linked to the private sector and dictated by narcissism and the ideal of personal choice ([Dickenson, 2013](#)).

In the context of health, the DTC genetics market has not, as some enthusiasts had predicted, become a large and lucrative industry. The DTC genetics market continues to be dominated by genetic ancestry testing; health-related testing forms a very small niche within this market ([Wright and Gregory-Jones, 2010](#); [Petroni, 2014](#)). But contrary to some predictions, health-related DTC testing has not disappeared either. One of the pioneers of human genome-wide tests, the California-based company 23andMe, celebrated its one-millionth customer last year. "Just fifty years ago", an e-mail sent out to customers in June 2015 read, "doctors were reluctant to tell their patients if they had cancer. The world is different today".¹ (Note, however, that the figure of one million includes customers who bought the test purely out of interest in their genetic ancestry; it also includes some number of people—perhaps many thousands—who received 23andMe's service for free). Moreover, new DTC testing services are emerging, such as personal microbiome analysis, offering users a genetic analysis of, for example, their gut bacteria. Providers of such services include both for-profit ([uBiome.com](#)) and non-profit (American Gut Project, British Gut Projects) organizations,

* Corresponding author.

E-mail addresses: mauro.turrini@univ-paris1.fr (M. Turrini), barbara.prainsack@kcl.ac.uk (B. Prainsack).

¹ E-mail received by one of the authors (BP), customer #54,472.

with the latter pursuing the aim of establishing an open-access database of microbial gut data.²

In recent years, a number of empirical studies have investigated the motivations, attitudes, and experiences of the general public and actual users of DTC tests. Findings from these studies paint a rather complex and partly contradictory picture (for a recent systematic overview of this literature, see Covolo et al., 2015). The main reasons for favorable attitudes towards these tests both among actual users and members of the public who had not taken a test have been their presumed medical importance and the potential for this information to prompt users to adopt a healthier lifestyle (McBride et al., 2009; Bloss et al., 2010; Cherkas et al., 2010; McGuire et al., 2009; Su et al., 2011; Savard et al., 2014). At the same time, both qualitative and quantitative studies of actual users of DTC genetics show no evidence for changes in anxiety levels, psychological health, diet, exercise or use of screening tests among DTC genetics users (Bloss et al., 2011, 2013; McGowan et al., 2010). Despite the absence of evidence for health-related behavior change, or psychological changes, however, most surveyed customers of DTC tests have been satisfied with the test experience (Bloss et al., 2010, 2011, 2013; McGowan et al., 2010).³ Why is this the case? If we accept that DTC genetic tests have little or no clinical utility – understood, in the narrow sense of the word, as the ability of a test to prevent or ameliorate adverse health outcomes such as mortality, morbidity, or disability through the adoption of efficacious treatments conditioned on test results (Grosse and Khoury, 2006; see also Khoury, 2003; Foster et al., 2009)⁴ – why do health-related DTC tests still exist? What utility and value do these tests have for test-takers, and for other actors?

2. DTC testing: Utility beyond the clinic

Let us first take a look specifically at what empirical studies say about why people take DTC tests. McGowan and colleagues interviewed early adopters of genome-wide DTC testing; they found that the two most common reasons for taking the test were to obtain health-related information and to learn about genetic risk factors (McGowan et al., 2010, 269). Another important motivation – not surprising in the group that this study focused on – was the desire to be on the vanguard of adopting new technologies. Other studies that analyzed the complexity and wide variety of practices around personalized genetic information showed

² These projects' websites strike a very different tone than DTC services that promise personalized genetic risk profiles; the Gut Projects' rhetoric revolves more around building a publicly accessible database to improve our understanding of the relationship between health and gut bacteria. Rather than receiving risk profiles, users see graphic representations of how their gut bacteria compare to other people whose bacteria have been analyzed. Although it remains to be seen whether users take their results as an incentive to eat healthier, more diverse diets, at this point, the question of what utility and value these tests have is still entirely open.

³ The Scripps Genomic Health Initiative is the first large-scale, longitudinal survey with several thousand voluntary participants who purchased a genomewide DTC test at a discounted rate from the former U.S.-based DTC company, Navigenics. The study sought to understand the behavioral and psychosocial impact of these data. Participants were surveyed for the first time when they decided to take the test, as well as three and twelve months after receiving the results. Out of the 3600 respondents who answered the initial survey, 1300 also completed both the three and twelve month follow-ups. The short-term follow-up survey after three months showed no measurable changes in anxiety, psychological health, diet, exercise or use of screening tests among these actual personal genomics users (Bloss et al., 2011). These findings contrast with those from hypothetical users (see, e.g., McBride et al., 2009; Cherkas et al., 2010; McGuire et al., 2009) and challenge some of the main assumptions in the discussion of DTC genetics: Here, test-results do not seem to have detrimentally affected test-takers; nor did results seem to have led to positive lifestyle changes. The twelve-month follow-up survey corroborated the trend found in results from the three-month survey and also indicated that customers felt rather satisfied with the test results, despite the lack of behavioral changes (Bloss et al., 2013).

⁴ There is no universally accepted definition of clinical utility. Besides narrow definitions of the term that focus on the impact that an action has on concrete health outcomes, other definitions of clinical utility comprise much wider ranges of usefulness, sometimes even including societal value (for an excellent overview see Grosse and Khoury, 2006). In this paper we use the term "clinical utility" to refer to a test's ability to affect health outcomes (via informing treatment choice, etc.), as we consider this the most specific definition with the highest analytic value.

that what users "get out of" DTC genetic testing has little, of anything, to do with clinical decision making. Respondents in empirical studies referred to the role of curiosity and fascination with technological innovations and genetics; interest in participating in biomedical research (Su et al., 2011; Vayena et al., 2014); pride or professional interest in being on the vanguard as early adopters of a new technology (McGowan et al., 2010); interest in experimenting with biosocial relationships or a more proactive patient-role (Ducournau and Beaudevin, 2011; Ducournau et al., 2011); or the "fun factor": a broad concept which encompasses the satisfaction of either taking part in promising and potentially useful research, or being part of a "cool" innovation (Vayena et al., 2012).

In all of these surveys it is difficult to distinguish between motivations to take a DTC test and the utility/value that DTC testing has for users. This is because when people are asked *after* having taken the test on why they took the test in the first place, there is no way of ascertaining on how they themselves separate motivations from utility; in light of the narrative structure of autobiographical memories it seems likely that in recalling motivations/expectations and ex-post utility of PGT, these notions of testing shade into one another.⁵

Both in terms of reported motivations to undergo testing and reported uses and thoughts about test results, another distinction that cannot easily be upheld is that between the personal and social domains. In a study carried out with volunteers in the British Twins cohort, for example, roughly 80% of those who said they were interested in taking a DTC test (5%–50% depending on the price of the service) said they wanted to do so to be able to convey risk information to their children (Cherkas et al., 2010). It is impossible, here, to describe such a (hypothetical) use of DTC test results purely as either a "personal" or "social" use – it is both. In studies with actual DTC genetics users, findings from Vayena et al.'s (2012) study in particular show the importance of curiosity, entertainment and enjoyment for people when they use test results to find genetic relatives online or in conversations with friends and family. In this survey of university students in Switzerland, the potential contribution to biomedical research was listed as the most important motivation for having these tests (Vayena et al., 2014). In addition, a qualitative study of online DTC test takers done in France found that all respondents had visited the dedicated blogs and forum run by the testing companies at least once. In some cases, they also used these platforms to share their own personal genetic information and establish, in the words of the authors, new forms of "biosociality" (Ducournau and Beaudevin, 2011; Ducournau et al., 2011).

Such findings undermine the portrayal of DTC genetic test takers as self-centered narcissists. The taking of DTC tests is typically not the solipsistic activity of an individual person, but something that is done with, or with reference to, family members, significant others, friends, or even society as a whole. In this sense, genomic information is personal and social at the same time: it is personal, but for *more than one person* (Laurie, 2001; Taylor, 2012; Widdows, 2013; Prainsack, in preparation). Reading one's "personalized" health report can be an entertaining and interesting activity that does not serve the purpose of obtaining actionable health information or exploring one's *genomic self*, but it also can be used to socialize on or offline, or to share data and information for social, research or philanthropic purposes.

Another possible use of personal genomic information obtained from DTC tests is the process of identity making. This aspect has been widely discussed within social science scholarship on DTC genetics (for an overview see Fishman and McGowan, 2014). In the early days of online genome-wide tests, journalists, biologists and other early adopters reported their experiences as genetic test-takers in the press, academic journals, and books (e.g., Duncan, 2009; Pinker, 2009; Angrist, 2010;

⁵ In fact, the Scripps Genomic Initiative was a longitudinal study that included an interview before the test and two follow-ups. However, the questionnaire collected information basically about users' concerns and not their motivations of undergoing susceptibility genetic tests (Bloss et al., 2010, 2011, 2013).

Franck, 2011). Celebrities and “ordinary” citizens alike seem to have enjoyed exhibiting and speaking about their genomic selves. Genomic information has been used to construct “auto-biologies”, i.e., narrative descriptions of one’s own identity based on biological data (Harris et al., 2015). Some people have published videos on YouTube, reporting their results, but also document the process itself, often filming themselves going through the different steps of the procedure, from spitting into a test tube to the impact of the first sight of the report, to interpreting the report and some of their ideas and feelings about it (Harris et al., 2014, *in press*). Other users have blogged about their test results on social networks, or used apps to visualize their results on mobile phones to show them to others. Genetic or genomic data can serve as a starting point to tell a story about ourselves, claim a place in the ongoing evolution of biomedicine, or contribute to medical research. Here it becomes apparent that the process of personal identity making is inherently relational; when genomic data are used to explore or reiterate one’s identity, these activities simultaneously build, change, and reinforce relations to others (see also Dheensa et al., 2015). These others can be family members, friends, or members of the same cultural or ethnic group, but they can also be society as a whole, e.g., when people make their data accessible for use in disease research. In some instances these explorations can have unintended consequences (e.g. Hughes, 2013; Doe, 2014).

Last but not least, another kind of utility that DTC testing can have is that people can use personal genomic information to do something that they consider good for others, or for society as a whole. They can establish or reinforce their identity as somebody who cares about others and practices solidarity by making their test results available to medical research via non-profit organizations such as openSNP (opensnp.org) or Open Humans (openhumans.org). The willingness of many people to use their genetic data in such a way is, however, also something that for-profit companies seek to harness for their own purposes. 23andMe, for example, makes strong use of the rhetoric of scientific democratization to enroll users as research participants willing to “share” not only their genomic data, but also their personal, and possibly familial and clinical histories (Spector and Prainsack, 2013). Customers are asked to answer “quick questions”, which take no more than a few seconds to answer, or fill in longer questionnaires about their physical traits, clinical histories, biological, and/or psychological characteristics. They can also participate in special projects tailored to people affected by specific diseases such as Parkinson’s disease or sarcoma. The company frames this as “joining the scientific revolution”.⁶ As we have argued elsewhere, the practice of genome sharing also denotes a new form of participation in an emerging model of healthcare based on self-produced and self-administered biomedical data (Turrini, 2015; Prainsack, 2014a).

By directly involving users in research projects, their personal genomic and clinical information can become socially, scientifically, or economically valuable. DTC genetics has also taken on the roles of being a resource for biomedical research, a strategy for more participatory approaches to healthcare, and a profit-making scheme.

3. The multiple values of genomes

Given the relatively small numbers of people worldwide who have taken a DTC genetic test, the considerable attention that online personal genetic testing has received in the media, in expert circles, and from policy makers, is somewhat puzzling (Wright and Gregory-Jones, 2010). An important reason for this is that DTC genetic testing and genomic testing do not fit neatly into the categories that dominate regulatory and discursive space (Prainsack, 2011; Wienroth and Rodrigues, 2015). This space presupposes not only a clear separation between experts and patients, companies and consumers, and health-related and non-health-related information, but also clinical and non-clinical

utilities. Practices and entities that fall in between these categories are thus problematic; for example, by excluding clinical professionals from the disclosure of genetic risk information to consumers, or by those consumers attaching value to DTC PG beyond predictive clinical value.

The clear boundaries between these categories used in regulation stand in stark contrast to the multiple goals that genomic information serves. Personal genomics tests can deliver probabilistic information about genetic predisposition to a disease, the presence of mutations that can be passed to a person’s offspring, the customization of nutrition or physical training (although these tend to be poorly validated), as well as insight into parts of one’s genetic ancestry. Clinical utility is not inherent to the material of the DNA sequence, but is produced by humans in conjunction with human-made artifacts, such as sequencing machines, algorithms to calculate risk information, and visualization graphics and decision aids. Far from being made of letters that can be read as a text, as suggested by the metaphors dominating the early days of the Human Genome Project, genomic information does not harbor intrinsic clinical, social, or personal meaning. Ironically, part of what personal genomics services – including some for-profit companies – do is to work with, and not against, this complexity, in order to exploit all the possible uses that genetic data may have. The initial resistance of DTC companies such as deCODE, Pathway Genomics, and 23andMe (only the latter is still in the DTC market) to clarify their position on the health-relevance of the test results, has so far been framed primarily in terms of entrepreneurial shrewdness or disingenuousness. But their resistance to clarifying the health-relevance of their testing services might also reflect the inherent uncertainty of most genetic information.

The concept of value is a good complement to utility in capturing the many ways in which genomic data can be used in the complex processes of the production, interpretation, circulation, storage, and sharing of genomic information. In economics, value is often used as something that can be calculated precisely, while utility is something broader, not precisely calculable, but subjective. In this paper, we use the term “value” in a broader sense, namely to refer to a person’s judgment that something is important to her. This importance could be of a pecuniary, emotional, identity-related, social, or any other nature. Value does not refer only to social, scientific and political value but also the economic sphere. Mapping the different kinds of value that personal genomic information holds in concrete contexts can help us see and address a wider range of opportunities and issues related to the utilization of genomic information than is currently the case. By referring to the “utility” of genomic information, in contrast, in this paper we refer to something that has *practical* value, irrespective of the value that the person attributes to it personally. This practical value could unfold in clinical decision-making (clinical utility), in providing entertainment or pleasure or relating to others (personal and social utilities), or other realms (see Foster et al., 2009).

DTC tests can have several layers of utility and value for test-takers but also for other actors such as testing companies, commercial researchers, and society as a whole. DTC tests can have educational and personal utility in teaching the test taker – as well as her friends or family if they accompany her in this process – about the nature of genomic information, including the ambiguities and limitations of it. For some people the process will be pleasurable or entertaining, adding to the personal value or utility (we do not, of course, mean to deny that the testing process can elicit negative emotions; we do not discuss this here, however, as this would not fall under utility or value). When test-takers use aspects of the testing process, or the test results, to engage with others or to articulate parts of their own identity, then DTC testing has social utility or value as well. If a person deposits genomic information in a repository or database used for scientific benefit, then this social utility or value can extend to the entire society, and it can, at the same time, unfold personal value as well: In all of the qualitative studies on actual users mentioned here, making somebody’s personal genetic or genomic data available to others was cited as a way to be

⁶ <https://www.23andme.com/en-eu/research/>.

personally involved in the progress of medicine and science, and, more broadly, “as a way to (be) part of something greater than (oneself)” (Su et al., 2011, 141).

Last but certainly not least, for the providers of DTC testing, the data and information that these tests yield can also have significant financial utility and value. The term that is often used for making one’s information available to others, “sharing”, evokes the excitement for a new glittering healthcare informed by genomics and the language of public benefit in commercial PG providers’ discourse, and seems to combine personal and social values with biomedical utility. Yet, the profound limits of that biomedical utility thus far and the stark power asymmetry between users and the organization providing the testing service – especially, but not only when it is a commercial company – complicates any purely optimistic picture. In the case of 23andMe, for example, despite the company’s strong rhetoric around participation and democratization, the degree to which the company is transparent to its users is very different from the degree to which its users are transparent to the company (Sterckx et al., 2013), and the influence that users have on how the company will use their data is very limited (Prainsack, 2014a, 2014b). Moreover, the company’s announcement in spring 2015 that it will enter the field of drug development (Herper, 2015) could be seen as indicating that the desire to make science more democratic and “open” has served mostly as a strategy to grow its proprietary database. The situation is different for non-profit initiatives that seek to encourage data-sharing for research for public benefit and organize the relationship with their users accordingly, i.e., work to make it more reciprocal and in some cases even solidaristic (Prainsack and Buyx, 2013).

4. Conclusion: Moving power asymmetries to the center of the ethical debate

Personal genomic data, even those related to health, are used for a wide set of values that go beyond narrow definitions of clinical utility. Far from being limited to the individual sphere, the values of personal genomic information are intrinsically social. People use their test results to learn more about themselves and their connection to others, to think about the future together with their family and friends, and/or to contribute to research. Bringing broader notions of utility and value to the debate on DTC testing is a necessary perspective to explain why people use DTC testing. Moreover, it changes the point of gravity of these debates, which so far have been focused on risks to test-takers, and on data protection and privacy. If health data are intrinsically social, privacy needs to be seen as a collective (Tubaro et al., 2014) and a social concern. Not only personal genomic data, but personal health data more broadly often disclose information about more than one person, and their production and use are embedded in social processes rather than solipsistic ones. As argued above, if I download my health records I am typically not merely doing this to “know myself” better. I am doing this to address my healthcare with my family and with my doctors, to be able to discuss my future and/or my concerns with my children or my partner, or to download my data to enable further analyses to be done by others. There is nothing exclusively individualistic about any of these practices, at least no more individualistic than gardening, cooking, or writing a book.

Yet privacy has also become a social concern because it has become a fundamental interest of people in light of the strong power asymmetries that dominate the information age. In societies where powerful corporations, including governmental agencies, are ultimately in the service of business interests, surveillance is no longer primarily a technology of government but a technology of economic value creation (Prainsack, in preparation). Because governments are too invested in pursuing economic objectives to curtail the power of large private corporations, the solution to the problem of surveillance (including DNA-based surveillance) cannot come from the government. Governments continue to issue and revise data-protection legislation, but they are no longer willing or able to hit large corporations where it hurts.

Solutions must thus also come from us, the citizens: from citizens who resist surveillance from both “Big Brother and Company Man”, as Jerry Kang et al. (2012); from citizens who demand to know what kind of information is held about them in public and private repositories; and from citizens who donate data to “information commons” that use data strictly for public benefit, instead of signing them over to those who monitor us for their own profit.

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