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THE GIFT OF SPIT (AND THE OBLIGATION TO RETURN IT)

How consumers of online genetic testing services participate in research

People can now send a sample of their saliva to an internet-based company in order to discover genetic information about themselves. Entering this 'direct-to-consumer' genetic testing (DTC GT) marketplace can result in enticement to engage in various forms of 'participatory' practices, such as taking part in genetic research. In this article, we analyse the research activities of one of the largest and best-known DTC GT companies, 23andMe. 23andMe research is based on what they term 'participant-led' research methodologies, which utilize a combination of consumers' genetic information and self-reported data in the form of completed online surveys. Our analysis shows that 23andMe presents research participation as a form of gift exchange, implying some kind of social bond. Social ties between the consumer-participant and 23andMe are integral to the company's 'novel' research agenda which relies on the ongoing aggregation of data from a loyal re-contactable cohort. We argue that the notion of gift exchange is used to draw attention away from the free, clinical labour which drives the profitability of 23andMe. We offer an account of a particular form of online research participation which differs from other kinds of participatory medical research. As medical research becomes increasingly driven by large data sets and internet-based research methods, we offer a timely analysis of emerging participatory practices.

Keywords participation; internet; Web 2.0; gift exchange; genetic testing; biomedical research

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Introduction

It begins with a mucilaginous dollop of spit, the kind of bodily excretion that causes you to heave when you see it on the sidewalk and flinch if a small part hits your cheek when someone speaks. A sample of saliva, so the genetic testing websites claim, will tell you more about yourself than you ever thought you wanted to know. And you will help to revolutionize medical research in the process.

You first hear about online genetic testing after scrolling through a newspaper article. Curious, and with some genetic knowledge from undergraduate biology up your sleeve, you order a genetic testing kit from a company called 23andMe. You find the website, open an account, provide some personal information and enter your credit card details.

Soon the kit arrives and, lying inside a glossy plastic nest, you find a little spittoon. It takes some time to gather the amount of saliva required for analysis (no bubbles allowed). Reading the instructions several times, you mix the specimen with the buffer solution and screw the cap on tightly. You slip it into a biohazard plastic bag and pre-addressed envelope. You complete some paper work, register online and drop by your local post office to send the package. Weeks later, when maybe you have forgotten all about it, an email arrives, informing you that your genetic results are ready to view online. You find your password and log in.

Online you find lists of diseases and conditions for which you are at an increased, decreased or average risk of contracting in the future, odds calculations and even a whole series of As, Cs, Ts and Gs¹ if you are interested in raw genetic results. But wait, there is more. Next time you log into your account, a pop-up box appears. It is 23andMe letting you know that their consent form has changed. You are now cordially being invited to participate in a research revolution.

23andMe is one of the largest and best-known online direct-to-consumer genetic testing (DTC GT) companies offering to unlock the genetic mysteries of your past (ancestry), present (human traits) and future (susceptibility to health conditions). More than 50 of these companies are currently registered, mostly in the United States and also Iceland, but beginning to appear in Australia, Canada, UK and Ireland (Genetics and Public Policy Center 2011). People who enter this DTC GT marketplace and provide a saliva sample (or cheek swab or blood sample) not only learn about their own genetic information, but also receive invitations to engage in various participatory practices. 23andMe invites its customers to share genetic information with other users, to find 'relatives', to post on community forums and more recently to become involved in research. In this article, we focus on this last form of participation.

Genetic testing sold through the internet has captured the interest of researchers in various disciplines such as ethics, law and sociology. However, to date, there has been little work examining the research activities of 23andMe. From the scant

literature available, focus has been on issues of a participant's privacy, the representativeness of research cohorts and the reliability of self-reported data (Hall & Gartner 2009, p. 54; Levina 2010, p. 6). 23andMe has attempted to address all of these concerns in various ways, with statements in their terms of service, blog posts and research articles about security, privacy and transparency (Do *et al.* 2011). While these are all issues of significance, there are other aspects of 23andMe's research agenda which deserve attention; issues which 23andMe has not addressed, and which concern the very core of their business practice.

Tutton and Prainsack have introduced some of these broader social and economic issues in their study of what they term a 'participatory turn' in disease research (Prainsack 2011; Tutton & Prainsack 2011). Their work compares DTC GT research practices to those of population biobanks, examining the 'entrepreneurial' subjectivities of DTC GT participants. We address participation in personal genomics research not only in relation to conventional medical research, but also in the context of Web 2.0 practices, an area which Tutton and Prainsack touch upon only briefly.

While there may be a 'participatory turn' occurring in the context of DTC GT, patients, citizens and 'experience-based experts' (Collins & Evans 2002) have been participating in scientific and medical research endeavours for centuries (e.g. Star & Griesemer 1989; Lawrence 2006; McCray 2006; Bruyninckx forthcoming). Patient advocacy group participation in particular has been discussed in relation to myopathies (Callon & Rabeharisoa 2003, 2008), human immunodeficiency virus (Epstein 2008), stem cell research (Langstrup 2011), autism and Tourette syndrome (Panofsky 2011). What differs in the 23andMe context is not only the kinds of agency attributed to research participants, but most importantly for this article, the digital dimension of participation, where online platforms, large data sets and computational abilities allow new kinds of participation in research. Our contribution to the citizen science/participatory patient literature is to examine internet practices which promise to have an impact on how data collection, research participation and medical research more broadly are considered.

In order to contribute to a better understanding of this emerging online genetic research participation, we offer a critique of 23andMe's recent research activities. The article is based on a discourse analysis which included the following 23andMe material, collected in July and August 2011: company web pages; all versions of informed consent forms, privacy statements and terms of service downloaded from the website; rules for participation in community forums; press releases; blog posts (the 23andMe blog is called *The Spittoon*); tweets; YouTube videos; patent applications; and research articles available on the internet published by 23andMe researchers, including two articles published in the open-access journal *PLoS Genetics* (Eriksson *et al.* 2010; Do *et al.* 2011) and one article published on the non-peer-reviewed website *Nature Precedings* (Tung *et al.* 2011). Finally, to inform our analysis we read forum posts on the

23andMe community pages.² Because we did not have informed consent from users however, we have not explicitly used forum material in our research.

In our analysis we draw upon, and bring together, two bodies of literature which have previously remained separate: internet studies scholarship concerning participatory culture and sociological literature concerning medical research participation. These literatures deal with remarkably similar themes such as gift exchange, empowerment, democratization of information and free labour. We utilize in particular three theoretical concepts: gift exchange (Mauss 1970), free labour (Terranova 2000) and clinical labour (Mitchell & Waldby 2010), which illuminate important aspects of online research participation. Gift exchange concerns reciprocity and sociality, whereas free labour and clinical labour concern the provision of services (data entry or physical work) in order to generate economic value. We explore these concepts in more detail later in this article. By bringing together internet scholarship and medical sociological literatures, with an analysis of a wide array of web material, we offer unique insights into the emerging area of online genetic research.

Novel methods: the ‘research-y’ part of 23andMe

I’m more interested in the research-y aspects of it. The fact that you guys have started actually asking questions and relating that to ongoing research I think is interesting. That direction is interesting. It just seems like it’s a great repository of information. (John G. (customer testimony posted by 23andMe on its website))

With significant fanfare and much champagne at one of their famous spit parties, 23andMe was launched in 2007 by Linda Avey³ and Anne Wojcicki. From the outset, the duo made it clear that with this company they wanted to develop research capacity and make a significant contribution to genetic research. A strong advocate for this approach has been Wojcicki’s husband, and co-founder of Google, Sergey Brin. With his genetically inherited ‘algorithmic sensibility’ (Goetz 2010), *WIRED* magazine suggests that this is the man who wants to ‘bypass centuries of epistemology in favor of a more Googley kind of science’ (Goetz 2010). These internet research ‘pioneers’ have an explicit goal not only in replicating and contributing to medical research, but most importantly, in *revolutionizing* research. 23andMe wants to build ‘an entirely new model for conducting research’ and ‘set the standard for web-based genetic studies’ (Eriksson *et al.* 2010, p. 17). The founders saw an opportunity to combine what they saw as an enthusiasm for participation on the internet with cheap genetic analysis, in order to create what they hope to be one of the world’s largest research projects.⁴ To power this revolution, 23andMe unveiled its research arm, 23andWe, in May 2008.

23andMe⁵ is based on what the company describe as ‘participant-led’, ‘patient-driven’, ‘consumer-enabled’ or ‘customer-driven’ research methodologies (Eriksson *et al.* 2010; Do *et al.* 2011).⁶ These methods utilize a combination of consumers’ genetic information, analysed from saliva samples, and self-reported data in the form of completed online surveys on the 23andMe website. On 15 June 2011, 23andMe reported that more than three-quarters of their 100,000 customers had agreed to take part in research activities, with 60 per cent having taken surveys and hundreds submitting research topics. To date, 23andMe has published three research articles based on this data: two genome-wide association studies (GWAS)⁷ (one for Parkinson’s disease and another for common traits such as freckling, ability to smell asparagus in your urine and sneezing in sunlight), and a study which replicated 180 known genetic associations for medically related conditions. Each article has been authored by company researchers and associates. An important aspect of these publications is the celebration and validation of web-based methodologies, so that authors emphasize not only how their research shows replication and novel genetic associations but also that online self-reported data is a ‘viable alternative to traditional methods’ (Eriksson *et al.* 2010, p. 2).

23andMe claims that its ‘novel study design’ (Do *et al.* 2011) is different from existing research models in three ways. First, 23andMe claims that its research process is fast. Brin exclaims, ‘generally the pace of medical research is glacial compared to what I’m used to in the Internet’ (cited in Goetz 2010). Slow research is seen to ‘hamper’ progress (Tung *et al.* 2011), with new computational technologies allowing fast analysis of large data sets, implicitly assumed to improve the nature of scientific research. While there may be calls for ‘slow science’ in some academic quarters,⁸ this is a reaction to a growing belief in science that speedier analysis and dissemination of results is a marker of ‘good research’. The 23andMe method means quick recruitment and time saved on collecting information from medical records, the common data source for more ‘traditional’ studies.

Second, 23andMe claims novelty through its ability to generate significant numbers of research participants. For 23andMe, large numbers outweigh errors that arise from self-reported data. Large population samples are needed to attain statistical power in genetic research, especially in GWAS which are detecting subtle genetic effects. GWAS are reliant upon and stimulating advances in information technologies which enable large data storing capacity. Substantial databases are created by 23andMe using what many genetic researchers would disregard: incomplete data or partially completed surveys; in all of 23andMe’s published papers self-reported data of varying degrees of completeness were used. 23andMe’s cohort is also unique in that it is continually expanding, with participants participating in multiple studies in parallel. Because new participants are joining the studies at all times, the results are also continuously changing (Eriksson *et al.* 2010, p. 15).

Third, 23andMe claim that their research approach differs from traditional research because it is completely ‘web-based’. While this seems to ignore the many material practices involved in this research, such as spitting or the lab work undertaken to analyse samples, the web-based methods are nonetheless represented and highlighted as a novel feature:

We’re at the beginning of a revolution that combines genetics and the Internet. Wikipedia, YouTube and MySpace have all changed the world by empowering individuals to share information. We believe this same phenomenon can revolutionize healthcare.⁹

23andMe’s methods do not rely on collecting information from paper records, nor are they any more geographically constrained than is the internet itself. 23andMe use the internet to recruit research participants from their user group through blog posts, tweets, forum posts and web announcements, as well as through a pop-up window at log-in. This approach is claimed to alleviate difficulties that many medical researchers find in enrolling participants (Williams *et al.* 2008, p. 1451; Allison 2009, p. 895; Terry & Terry 2011, p. 1), particularly participants who do not live near research centres; accumulating large enough data sets; and conducting costly and time-intensive research. We now turn to examine how these web-based research methods tie into 23andMe’s ‘participatory culture’.

23andMe’s ‘participatory culture’

Imagine again that you have sent in your money and your saliva to 23andMe. After providing your spit (see above), you answer some simple questions. Surveys such as ‘Ten Things About You’, ‘Health Habits’ and ‘Ten More Things About You’ appear regularly in your 23andMe account. These surveys are enticing and fun, even slightly addictive. The surveys look remarkably similar to the easy-to-answer surveys collecting consumer buying behaviour information in order to make personalized product recommendations on the ‘taste’ website Hunch. Rather than your favourite board game or holiday destination, 23andMe survey questions are about pulse rates, cholesterol levels, eye colour and family history, or they might simply ask, ‘Have you ever been diagnosed by a doctor with [Condition X]?’ 23andMe survey designers want to keep participation high by having only easy and quick tasks (Tung *et al.* 2011) that make ‘the survey-taking experience simpler, more interesting, and more rewarding’.¹⁰ This contributes to the pleasurable and recreational aspects of research participation. Involvement in some surveys is more elaborate, such as the Parkinson’s Disease survey which involves participants filling in a general medical questionnaire, contributing information about disease progression, other diagnoses, symptoms and response to medication (Do *et al.* 2011).¹¹

Participation is kept flexible – ‘participate in research at your own pace. Answer a few questions or answer them all’ – but it is always encouraged – ‘the more active you are in the community, the more you’ll get out of it’ (see Note 6). 23andMe acknowledges that only limited information can be obtained from the simple questions that most consumer-participants¹² answer in the brief surveys, and that more information may need to be obtained by going back to the cohort to ask more in-depth questions, and potentially even conduct in-person visits (Tung *et al.* 2011).

23andMe customers also ‘participate’ in research activities more implicitly. Various kinds of data are used by the company. Genetic data and self-reported data of those customers who provide informed consent are used explicitly as detailed above, but also the genetic data of all customers, regardless of consent, are used in aggregated sets for internal validation experiments, and to develop new features and products.¹³ User-generated content such as feedback on forums and blog comments continue to feed into the company research design. Users’ web activity is also collected through log files, cookies and web beacon technology, so that web behaviour data, including our own as social science researchers, are used by 23andMe in order to monitor use of their website, to improve their services and to tailor and customize content for customers.¹⁴

The participatory potential inherent in these research activities is indeed questionable. Participation in research essentially consists of ‘allowing 23andMe investigators to access your Genetic & Self-Reported Information’. A funding statement made in a 23andMe research article highlights this: ‘the study was funded by the participants, by 23andMe, and a grant from Sergey Brin [Google] . . . The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript’ (Do *et al.* 2011). Dolgin (2010, p. 954) argues that whilst 23andMe’s *PLoS* paper ‘bolstered the notion of decentralized, participant-driven research, all of the contributors remained relatively passive, doing little more than responding to a questionnaire and signing an informed consent form to share their data’. Ultimately, the company controls all forms of participation on the website, as outlined in the terms of service, rules for engagement on forums and in the 23andMe research design whereby 23andMe ‘enables’ consumers to participate (see Note 13).

The participatory culture of 23andMe medical research thus appears considerably different to disease-specific patient-organized research participation. We do not see the symmetrical forms of expertise which Callon and Rabeharisoa (2003) argue are created in a trading zone of circulating genetic and experiential information amongst patient advocacy organizations and professional researchers. Neither do we get a sense of the transformative potential of patients (Epstein 2008; Panofsky 2011, p. 32), or the emotional investment of patients and affected families hoping to advance diagnosis and treatment of their illness. The aim of this article however is not to focus on how participation is

limited but rather to look at how the research is being *represented* on the website, and what kind of participatory practices are emerging as a result. We focus particularly on how 23andMe represent research participation as a form of sociality, facilitated through gift exchange.

Sharing gifts under the genetic family tree

Through participation in medical research, individuals with no previous connection to each other are inducted into group membership via biological, biotechnical and biomedical processes, to form new biosocial groupings (Novas & Rose 2000; Epstein 2008). Similarly, through participation on the internet more broadly, new forms of network sociality are enacted between known and previously unknown individuals. Internet scholars have approached the sociality of participation in various ways. For some time, literature was divided between celebratory and culturally pessimistic viewpoints on the social life being promoted, created and resisted on the web (Rheingold 2002; Surowiecki 2004; Jenkins 2006; Karaganis 2007; Bruns 2008). Recently, more nuanced accounts have focused on how participation practices, technology, markets and politics are intertwined (Schäfer 2011) and paradoxical in terms of their potential to be both alienating and emancipatory (Proulx *et al.* 2011). Researchers are also highlighting the economic underpinnings of online participation (Terranova 2000; Goldberg 2011; Proulx *et al.* 2011), critically examining the broader cultural processes at work. We situate our research within these more recent approaches towards participatory cultures, recognizing that involvement in 23andMe research may be rewarding for the consumer-participant, but it is also financially rewarding for the company, and that while consumer and company may both be driven by an individualistic consumer culture, ultimately 23andMe accumulates the greatest (financial) benefit.

It is unsurprising therefore that 23andMe celebrates what it promotes as the emancipatory aspects of participating in the genetic research revolution. Enthusiastic statements made by participants are posted on the website and retweeted. 23andMe claims to provide a platform for users to have a voice and to have greater input in genetic research. In doing so, 23andMe utilizes two complimentary discourses concerning the democratizing and empowering potential of the internet and the democratizing and empowering potential of personal genomics.

Within this celebratory context, 23andMe promotes research participation as a form of gift exchange. In signing the consent form, rights to any financial gain from research endeavours are relinquished, instead gifts are offered, using the internet as a platform for the exchange. First, people offer their spit, swimming with cheek cells which hold the all-important DNA. This occurs initially as a commercial exchange, whereby the 23andMe laboratories analyse the genetic contents of the drool, and return the results back to the paying customer.

The remainder of the spit is discarded but the genetic information becomes part of a database. Customers are then offered the chance to be involved in research. This is when the meaning ascribed to the sample, or the genetic information derived from it (Tutton 2002, p. 537), becomes a 'gift', a gift from the paying customer to 23andMe researchers.

This gift however holds little value in itself. The power of GWAS is in large quantities of data, data which are a combination of genotypic¹⁵ and phenotypic¹⁶ information. Thus, 23andMe not only needs lots of DNA, but also needs to link this to consumers' personal information about their pulse rates, olfactory skills and neurological symptoms. This is where individuals are represented as engaging in further aspects of gift exchange, by providing personal information via the completion of surveys. As sharing this information takes time and effort, no matter how simple the questions are, 23andMe needs to give gifts in return, as incentives for participation (Eysenbach 2008, p. 6). These gifts are presented as returned results, acknowledgement and badges.

In much of the 23andMe web material, there is an emphasis on feeding research results back to participants:

We believe research is a two-way process, where participants are valued as partners in scientific discovery. As part of our commitment to involving everyone in the research process, we've launched 23andMe Research Findings [hyperlink], a regularly updated public gallery of some of the latest findings to come out of our ongoing research ... we still feel it's important to keep everyone updated on our progress, especially those who have contributed to the research effort.¹⁷

23andMe uses various platforms in order to share results with its users and participants, such as forum comments, 'Research Snippets' on the website, tweets and blog posts. Results are fed back to participants throughout the research process, from immediately after completing the surveys, when participants can see how they compared to others, to blog posts about recently published research articles. Participants also receive the gift of acknowledgement in these publications, being thanked for participating 'enthusiastically' (Do *et al.* 2011).

Embroidered onto the virtual lapels of research participants' profiles are badges of participation. These badges appear as green or blue dots near users' avatars, denoting them as 'research pioneers' or 'research trailblazers'. Like the badges offered to users for voting or posting comments on the user-generated online TV network Current TV (Fish *et al.* 2011, p. 31), and the banjos offered by Hunch for completing surveys and making recommendations, these icons are used as symbols and rewards of socially valued activity, encouraging further participation. 23andMe users are socialized into their cultural value, these gifts being visible signs to others of participation, their social value

confirmed through recognition and reputation (Proulx *et al.* 2011, p. 13). 23andMe consumer-participants can also become 'research captains' by recruiting other participants to form a research community. Captains supposedly have the opportunity to 'speak to the research team about what research is done and how' (Allison 2009, p. 898), although their involvement in current research conducted by 23andMe is unclear. Nonetheless, these discourses show that participation is rewarded, and the active, perpetually engaged, responsible citizen-consumer is promoted (Adams 2010, p. 192; Tutton & Prainsack 2011, p. 4).

23andMe thus uses a variety of internet platforms in combination, taking advantage, in its words, of the 'interactivity' of the web (Eriksson *et al.* 2010), not only to recruit participants, but also to accept and return what are offered as gifts, in its participatory culture. Digital gift exchange has become a topic of interest in internet studies in the last decade (Bergquist & Ljungberg 2001; Pearson 2007), particularly through the work of Barbrook (2005) who argues that gift exchange and market exchange not only co-exist but are symbiotic, in what he describes as a 'mixed economy'. In medical sociology, the notion of gift exchange has also been used to understand donation of bodily matter such as blood (Tutton 2002), semen (Tober 2001), stem cells (Waldby 2002) and organs (Shaw 2012). Many of these researchers recognize that human tissue can pass through various spheres of exchange, becoming a gift at one moment and a commodity at another (Lipworth *et al.* 2011, p. 805), the distinction between the two blurring (Tober 2001, p. 140). In the case of spitting for 23andMe, the human material is not 'donated', but rather begins as part of a commercial exchange, the customer paying for the company to analyse this material. It is 23andMe which then attempts to blur the material into part of a gift exchange.

Medical research and user-generated content online both rely on individuals contributing material without financial remuneration. While some participants may receive more tangible benefits from participation, such as access to drugs or payment for their online contributions, for most contributors to both medical research and other online forms of contribution, participation incurs intangible benefits such as enhanced self-worth, enhanced reputation, a sense of public good, personal satisfaction and the prospect of reward or reciprocity (Tutton 2002, p. 526; Pearson 2007; Williams *et al.* 2008, p. 1452; Hallowell *et al.* 2010; Li 2011; Lipworth *et al.* 2011). We focus now on one particular aspect of gift exchange: the obligations of reciprocity.

Reciprocal ties

According to anthropologist Mauss (1970), gift giving always entails reciprocal exchange and hidden ties of mutual obligation. The consumer can be read to have an implicit obligation to participate, to give gifts and to accept them in

return. This reciprocal exchange ties people together creating ‘social interdependencies’ (Bergquist & Ljungberg 2001, p. 308). In her study of the social media platform LiveJournal, Pearson (2007) writes that gift exchange is part of social practice that acts to ‘bond together participants, making the individuals feel connected and linked into something larger than their own immediate social (internodal) connections’. In this vein, our analysis suggests that 23andMe uses gift exchange as a way of trying to create social bonds with customers. According to social psychologists, stronger integrative bonds are formed when reciprocity is constant (Molm 2010, p. 125). 23andMe continuously offers gifts to its customers, to facilitate participation, and create stronger social ties to its research agenda.

In order to facilitate these social bonds, 23andMe fosters the development of communities, attempting to establish *communitas* (Turner 1969), perhaps even attempting to replicate the patient group models which have become so active in research. In their community guidelines, 23andMe state:

Write. Your contributions strengthen the community . . . Share. We want to provide you the opportunity to connect to and create communities around common interests, affinities and passions. (see Note 6)

Users are encouraged on various platforms to build research groups and comment on forums, as well as share genetic data with others. Sharing forms the basis of these communal and social bonds, and the framework for the research methodology.

While 23andMe promotes a sociable gift exchange within its formulated feel-good atmosphere (Prainsack 2011, p. 139), we argue that these bonds are ultimately created for the purpose of creating a network in order to build a large, unique and profitable database. Rather than a web of warm and fuzzy social connection, what 23andMe wants is a loyal, re-contactable cohort:

A platform like this one that maintains an ongoing relationship with the participants, including sharing data with them, may motivate individuals to participate and stay active in research . . . As we move into studies that require ever larger sample sizes . . . making optimal use of our resources will become a necessity. We believe that this model in which investigators maintain long-term relationships with research participants and facilitate their participation through online tools is a significant step in that direction. (Tung *et al.* 2011, p. 10)

The social ties created by 23andMe are superficial ties, implying a form of pseudo-regard rather than relations of regard (Offer 1997), in which sociality is established for the economic advantage of the company. A large recontactable cohort is a valuable resource for researchers wanting to perform longitudinal genetic research, particularly epigenetic research. 23andMe’s recent offer of

free tests to 100,000 potential customers of African descent¹⁸ further points to a likely emphasis on a 'representative' database of racially diverse research participants, a resource which may, in the long run, be a greater revenue generator than the genetic tests themselves.

The inconsistent language used to refer to participants reflects how the 23andMe business agenda is not made completely visible to consumers. On the 23andMe website encouraging participation, users are referred to as collaborators, advisers and contributors, whereas in research articles 23andMe state that they can 'improve replication success by taking advantage of our recontactable cohort' (Tung *et al.* 2011). In a TEDMED presentation, those who participate online are referred to by Anne Wojcicki as 'active genomes'.¹⁹

Social ties created through participation form a network, which expands. Sharing becomes good for the network, for the company (Levina 2010, p. 5). Communities become hollow in this light, the word arguably losing strength more broadly in the context of online cultural production (Schäfer 2011, p. 17). Collectivity emerges then independent of a sense of community (Proulx *et al.* 2011, p. 17). By providing resources for the research agenda of the company, the collective fuels profits, becoming a form of free labour.

Spitting for free

The gift exchange promoted by 23andMe creates social ties for the benefit of a research network, which we argue, following Terranova (2000), is based on free labour. Terranova argues that the various participatory activities of online users are in fact forms of free labour which are structural to late capitalist cultural economy. She writes that 'especially since 1994, the Internet is always and simultaneously a gift economy *and* an advanced capitalist economy. The mistake of the neoliberals (as exemplified by the *Wired* group), is to mistake this coexistence for a benign, unproblematic equivalence' (Terranova 2000, p. 51). The problematic nature of the economic underpinnings of online participation has been taken up more recently by other scholars (Goldberg 2011; Proulx *et al.* 2011) who, using a variety of empirical examples, further highlight how online contribution participates in the creation of economic value, forming the invisible labour force supporting informational capitalism (Proulx *et al.* 2011, p. 9). As Proulx *et al.* (2011, p. 10) write, 'the giants of the Internet industry are building their industrial and commercial empires through the aggregation of data supplied voluntarily and freely by Internet users'.

The kinds of free labour which 23andMe users undertake, in order to build this particular genetic testing empire, include spitting, posting (both packages and forum comments), logging in, filling in surveys and forming research communities. Consumer-participants also maintain their internet connections, hardware and software and visit the 23andMe website from time to time. 23andMe

rely upon all of these activities to perform research. The genetic testing company does not recognize consumer practices as free labour. 23andMe highlight the ease and simplicity of participation, stating that self-reporting is done with little effort:

Traditional methods of data collection – for example, using an existing medical record or a meeting between a researcher and each participant – can be costly, time-consuming and limit the number of people willing and able to participate. In contrast, 23andMe utilizes simple online surveys that can be completed anywhere at anytime. This allows people from all over the world to easily participate in our research on an on-going basis.²⁰

23andMe does perform some work of its own, by analysing the spit or by arranging for its laboratory scientists at the National Genetics Institute to do so. 23andMe also stores the genetic information. The company provides tools and a platform for consumers to access their raw data and create forums for consumers to exchange information. 23andMe writes that its recipe for research is to ‘give people tools, add passion, and shake’.²¹ The work done by 23andMe, however, is done to add biovalue (Mitchell & Waldby 2010, p. 336) – the value produced by reformulating living matter and living processes into matters of intellectual property and sources of profit (Waldby 2002, p. 310) – to the saliva sample, and economic value to the data, while fostering the network subjectivities crucial to establishing such a free labour force. Pálsson (2009a, 2009b) has previously identified these ‘biosocial relations of production’, commenting on how spitting work contributes to global networks and hierarchies involved in the manufacture of biovalue.

Participation in 23andMe research has similarities to other forms of online free labour, such as that required by Current TV and Hunch users. Participants perform simple tasks for rewards, while the companies benefit from the aggregated data. In a very literal Maussian sense of the gift, 23andMe customers give something of themselves through their engagement in 23andMe’s participatory culture. While contributing this bodily material may have initially taken place within the context of a commercial transaction, 23andMe transforms the sample into a gift for their research database. The consumer-participant not only performs free labour, but also performs clinical labour by spitting into the spittoon and submitting it for analysis, analysis that forms the heart of 23andMe’s research endeavour.

Mitchell and Waldby (2010, p. 334) define clinical labour as a form of embodied biomedical work that produces economic value. Clinical labour describes how individuals give clinics and commercial biomedical institutions access to their *in vitro* biology (Mitchell & Waldby 2010, p. 339), which is used as a primary resource. Emerging technologies are creating new forms of clinical labour, such as the contribution of genetic material, tissue samples and stem cells to biobanks.

Contributing bodily material, whether it is semen, spit or stem cells, is not only a physical act but also a symbolic gesture embedded with cultural value. While some forms of clinical labour are more onerous than spitting, such as submitting your body to daily tests as a ‘live-in guinea pig’ (Abadie 2010), thinking about spitting as a form of clinical labour nonetheless helps to understand the economic dimensions underlying consumers-participants’ activities.

Genetic information isolated from a saliva sample remains linked to the individual from which it derives, and further health information can therefore be linked to these specimens (Mitchell & Waldby 2010, p. 346). Through the aggregated forms of clinical and online free labour performed by thousands of customers, 23andMe has created a research resource with significant economic potential (Mitchell & Waldby 2010, p. 348). Following from Pálsson (2011), in many ways the participant can be seen to be taking part in the *coproduction* of bio-value, for the benefit of the company, rather than in more symmetrical forms of coproduction of scientific knowledge evident in studies of patient advocacy group involvement in research. 23andMe does not completely hide its economic intentions, although neither does it actively promote them. Statements about commercial gains can be found in the privacy statement where it is stated that:

23andMe may enter into commercial arrangements to enable partners to provide our service to their customers and/or to provide you access to their products and services. We may collect fees for these referrals. (see Note 14)

In this statement, 23andMe is acknowledging that it has a resource which gives it significant pharmaceutical (Prainsack & Wolinsky 2010) and diagnostic biocapital (Mitchell & Waldby 2010, p. 337). Data can be sold to any third party who is interested and with whom 23andMe wishes to enter into a commercial exchange. 23andMe has already linked with the biotech firm Genotech, one of its primary funders, for the purpose of conducting Alzheimer’s Disease research (Ray 2011), and has applied for patents regarding gene sharing and more recently, novel polymorphisms associated with Parkinson’s Disease.²² As a commercial business, 23andMe has a responsibility to provide a return to their numerous investors, who have invested more than US\$ 31 million over the last 5 years.²³ A transaction that begins as a commercial exchange ends in commercial exchange, and participation is formulated in profitable ways.

Conclusions

There is a growing interest in consumer involvement in medical research (Tutton & Prainsack 2011, p. 3), with self-reported data being used by an increasing number of online health organizations such as PatientsLikeMe (Allison 2009;

Wicks *et al.* 2011) and patients becoming more involved in searching for and choosing research trials. Medical research is relying more and more on networks of data and collections of tissues stored by research institutions (Lipworth *et al.* 2011). As the internet is increasingly incorporated into medical research designs, we will witness further iterations of online participation in medical research. 23andMe provides a rich and early example of what is celebrated as web-based, revolutionary research, which utilizes online tools to facilitate participation in genetic research.

Based on our analysis of 23andMe web material concerning its research arm 23andWe, we have argued that 23andMe uses various internet platforms to construct an 'empowering' participatory culture, drawing on the democratizing potential of the internet and personal genomics. In this context, 23andMe attempts to slip effortlessly from notions of commercial exchange to celebrate consumers' research participation as a form of gift exchange. The consumer-participant is presented as offering a saliva sample and personal information in exchange for gifts. Gift exchange implies social bonds which are integral to 23andMe's research method which relies on aggregated genotypic and phenotypic data from a loyal re-contactable cohort. More altruistic notions of participation and gift exchange are used by the company to draw attention away from what we have suggested is a form of free labour – contributing information on the internet through completing the surveys – and clinical labour – submitting the saliva sample for analysis. This free, clinical labour helps to build a valuable research and profit-making resource. While 23andMe does some work, in terms of organizing the analytical and research network and providing a platform for exchange, its work adds economic value to the 'gifts' offered by customers, value which benefits the company.

Often celebrated as an innovative means of empowerment and democratization, we have thus offered a more critical stance towards consumers' online participation in such research activities. We have shown that slippages are made easily between commercial exchange and gift exchange, in order for the company to enact a feel-good feeling of reciprocity and social ties. We follow in the footsteps of internet studies scholars who are interested in the paradoxical nature of internet participation, and who highlight the important synergies between participatory activities and revenue generation (Goldberg 2011; Proulx *et al.* 2011, p. 22). Our analysis recognizes that participation practices, technologies and markets are intimately connected, and that online participation has an inherent economic quality (Goldberg 2011, p. 744).

It is very likely that 23andMe research will have an impact on how medical research is conducted in the future (Tutton & Prainsack 2011, p. 2), and further examples such as the *Personal Genome Project* and the blog *Genomes Unzipped*²⁴ show how the internet is shifting genetic research in new directions. The internet changes the nature of research questions asked, ethical processes²⁵ the meaning of participation, consent and research dissemination. Research participants potentially have access to their raw data online and can personalize the

results of the genetic research in which they have been involved, something currently debated and under-realized in more traditional medical research (Lipworth *et al.* 2011, p. 799). Trust in the self-reported data of individuals about their own health behaviour, rather than their medical records, as well as sharing results so quickly with participants, also changes the nature of medical research, possibly fostering new kinds of relations of trust between research participants and researchers.

In this article, we have brought together two bodies of literature regarding internet participation and medical research participation, and an analysis of 23andMe web material, to contribute towards a critique of this emerging area of online participation in genetic research. We have focused on the *representation* of these cultural practices, using a commercial website as a starting point and our analysis reflects this. Users' actual practices are only barely visible as traces in the descriptions we offered in the Introduction, evidence of a gap in our understanding about who the consumer-participants are. It appears that this kind of participation is pleasurable, desirable and possibly even addictive (Brabham 2010), but we still need to examine why people participate, and how these motivations compare to other online and medical research participatory practices. We also need to learn more about how consumers understand the information they are sharing, and the consequences of their participation, as well as the social, political, geographical, technological and skill-based constraints on these practices (Henwood *et al.* 2003; Adams 2010). Questions arise concerning the kinds of subjectivities and collectivities being formed in these contexts that intermingle genetic and non-genetic identities, affecting how users engage with social groups and form social ties. While more research is needed on user practices²⁶ we also need to be cautious about how, as social scientists, we use data provided by participants online, particularly if we want to develop a critical analysis of the ways in which genetic testing companies are making use of material provided by participants.

Ethical questions also arise about the contribution of bodily material that is stored and accessible, raising concerns about identifiability and possible discrimination on the basis of genetics. These are concerns which add to those of sharing increasing amounts of personal information via the internet. How are third parties such as other researchers, pharmaceutical companies, law enforcement and insurance companies to be involved in this kind of research? What will be the fate of 23andMe's patent applications and how will they be enforced? Will 23andMe become an open repository of material for genetic analysis (Panofsky 2011, p. 49) or will it choose to sell its information to third parties? What are the ethical, political and economic implications of such choices? Finally, what impact will studies such as those performed by 23andMe, using 'messy', or incomplete, self-reported data, have on the gold standard of medical research; the randomized control trial? In summary, we can conclude that personal genomics research will continue to raise important questions about the forms and consequences of engaging people in research, particularly through the internet,

highlighting aspects of informational capitalism that are embedded in internet and medical research practices more broadly.

Notes

- 1 These letters stand for the base pairs of DNA: adenine, cytosine, thymine and guanine.
- 2 We could access these pages because one of the researchers was already a 23andMe customer before the research took place.
- 3 Linda Avey reportedly left the company in September 2009 but continues to make connections with 23andMe in her personal blog *The Life and Times of Lilly Mendel*.
- 4 <http://www.youtube.com/watch?v=pNnULCrYv2c> (29 July 2011).
- 5 For consistency, hereafter we will resume using the term 23andMe.
- 6 <https://www.23andme.com/you/community/guidelines> (7 July 2011) (archived by WebCite® at <http://www.webcitation.org/5zzn2BbH>).
- 7 This is a research method used by many genetic researchers, which entails rapidly scanning the genomes of individuals for comparison, in order to find variation.
- 8 See Pels (2003) and <http://slow-science.org>.
- 9 <http://spittoon.23andme.com/2008/01/21/the-power-of-we> (4 November 2011) (archived by WebCite® at <http://www.webcitation.org/62wRPYyb8>).
- 10 <http://spittoon.23andme.com/2009/01/05/23andme-the-first-annual-update> (22 July 2011) (archived by WebCite® at <http://www.webcitation.org/60N2TABcj>).
- 11 These participants were offered the genetic test at a nominal fee of US\$ 25 (Do *et al.* 2011).
- 12 We use this term following McGowan & Fishman (2008) use of the term ‘consumer-patient’, to imply the slippage that occurs between customer and participant in these research activities, both in regards to terminology used on the internet and the practices enacted.
- 13 <https://www.23andme.com/about/consent> (7 July 2011) (archived by WebCite® at <http://www.webcitation.org/5zsl3iOri>).
- 14 <https://www.23andme.com/legal/privacy> (7 July 2011) (archived by WebCite® at <http://www.webcitation.org/5zzn2Lt22>).
- 15 Genetic information.
- 16 Observable characteristics, behaviour, traits.
- 17 <http://spittoon.23andme.com/2011/06/16/23andme-research-findings-from-you-back-to-you> (22 July 2011) (archived by WebCite® at <http://www.webcitation.org/60MeO68xr>).

- 18 <http://spittoon.23andme.com/2011/07/26/roots-into-the-future> (4 November 2011) (archived by WebCite® at <http://www.webcitation.org/62wR76EGj>).
- 19 <http://www.youtube.com/watch?v=4g5pXnhIEjA> (29 July 2011).
- 20 <http://spittoon.23andme.com/2010/01/26/23andme-parkinsons-research-initiative-progress-update> (22 July 2011) (archived by WebCite® at <http://www.webcitation.org/60N0tEusP>).
- 21 <http://spittoon.23andme.com/2011/07/06/a-recipe-for-disease-research-give-people-tools-add-passion-and-shake> (22 July 2011) (archived by WebCite® at <http://www.webcitation.org/60Md3YntP>).
- 22 23andMe have since announced that this application was successful”?
- 23 <http://vator.tv/news/2011-01-07-23andme-adds-9m-to-series-c-round> (19 October 2011) (archived by WebCite® at <http://www.webcitation.org/62YLAXQJv>).
- 24 See <http://www.genomicslawreport.com> and <http://www.genomesunzipped.org>.
- 25 See Gibson and Copehnaver (2010) for a discussion of the ethical issues raised in relation to 23andMe research.
- 26 See McGowan *et al.* (2010).

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