

UnDeNiAble Risks:
A Critical Discourse Analysis of the 23andMe Website

by

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of the requirements for the degree of Master of Arts

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Abstract

This thesis attempts to answer the question, what are the implications of translating data from our bodies into data about risk? This thesis presents a critical discourse analysis of the personal genomics web-service 23andMe. It is the author's contention that new information technologies, such as 23andMe, sensationalize risk, particularly risk of genetic disease and undesirable traits, and, in doing so, encourage certain behaviours such as self-surveillance, lifestyle management, and potentially, future genetic intervention and/or manipulation. This argument is contextualized by literature that illustrates the changing nature of the relationship between doctors and patients and the emergence of new claims for authoritative knowledge about bodies and medicine. These new technologies, such as the services provided by 23andMe, have significant implications for the ways we conceive of and know information about ourselves and our bodies.

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Chapter 1: Introduction

Introduction

“Community, Identity, Stability.” Grand words. “If we could boganovskify indefinitely the whole problem would be solved.” Solved by standard Gammas, unvarying Deltas, uniform Epsilons. Millions of identical twins. The principle of mass production at last applied to biology. (Huxley, 1989, p. 7)

Fear of the controlled consequences of eugenics, both authoritarian and liberal¹, has been expressed in dystopian texts in literature and film, such as Aldous Huxley’s (1989) *Brave New World* and Andrew Niccol’s (1997) film *Gattaca*. While *Brave New World* depicts a society where there is a strict caste system involving only three genetic models of humans, *Gattaca* shows a society where individuals’ genotypes are evaluated for potential employment and even potential relationships. As such, both texts envision societies where genetic discrimination has suffocated individuals’ freedoms and identities. Science fiction in general is said to “explor[e] the dreams and nightmares around science and technology in the modern world” (McNeil, 2007, p. 24) and provides a way for us to hypothesize about where developments in science and technology will take us as a civilization, in an entertaining way. Although these texts are fantasy, their underlying concerns are increasingly relevant in reality as technology continues to advance at a rapid rate.

¹ “Liberal eugenics” has been defined as the view “that people should be able to choose genetic enhancements for their offspring, should these become safely available” (Fenton, 2006, p. 35). This ideology “would not lead to genetic alterations being imposed on whole populations by way of state policies”, but rather “gives primacy to the individual’s own values and conception of what constitutes a good life” (Fenton, 2006, p. 35). As such, “the role of the state in a program of liberal eugenics is merely to facilitate rather than to impose eugenic choices” (Fenton, 2006, p. 35).

Gregor Mendel is recognized for first developing “a clear, analytic picture of heredity (“Mendel, Gregor Johann”, 2007). His research was first published in 1866, but not recognized for its importance until it was rediscovered in 1900 (“Mendel, Gregor Johann”, 2007). Since then, his work has been valued as providing “the basic tenets of genetics” (“Mendel, Gregor Johann”, 2007). Scientists have built upon the theories of genetic inheritance introduced by Mendel and others and have come so far as to sequence entire genomes, including the human genome in 2003 via the Human Genome Project (U.S. Department of Energy Office of Science, 2008a). The Human Genome Project has generated technology and resources with applications promoted as including “molecular medicine; energy sources and environmental applications; risk assessment; bioarchaeology, anthropology, evolution, and human migration; DNA forensics (identification); agriculture, livestock breeding, and bioprocessing” (U.S. Department of Energy Office of Science, 2008b). With these technological advancements come significant moral and legal implications. As José van Dijck notes, “DNA-manipulation and genome research stir up profound agitation over the integrity of the human body and the corrosion of human identity” (1998, p. 7). This is true in both fiction and reality.

This thesis is concerned with the topic of information about our bodies, with a particular focus on genetic information. In general, I am interested in the nature of this information, how we receive this information, how we accept such information as facts (or we don't), how this information becomes knowledge (or doesn't), and how this affects our self-awareness and how we conceive of our bodies. It is my contention that information about our bodies can have profound psychological effects, especially on

individuals afflicted with disease or with risk of developing disease. Information relating to disease risks and potential means of fatality brings to our attention the fact that we are mortal beings and that, one way or another, we will die. Our bodies will stop functioning due to internal and/or external causes. The advanced nature of the type of information we can now acquire about our bodies and data about risks and probabilities of undesirable outcomes raise the question, how much do we want to know? Is some information too sophisticated that it verges on invasive and fundamentally disturbing? Most importantly for this project, what are the implications of translating data from our bodies into data about risk? This last question is the research question that this thesis will attempt to answer.

With this thesis, I will examine the emergence of new information technologies that democratize medical information and present information about our bodies to us in new ways. More specifically, I will focus on discourses relating to genetic risks, which encourage obligation and responsibility on the part of the individuals at risk. More specifically, my thesis statement is that new information technologies, such as my case study, 23andMe, sensationalize risk, particularly risk of genetic disease and undesirable traits, and, in doing so, they encourage certain behaviours such as self-surveillance, lifestyle management, and potentially, future genetic intervention and/or manipulation². To “sensationalize” means to attempt “to provoke interest by including material that is exciting, shocking, salacious, etc.” (Bisset, 2004, p. 942). I would argue that risk discourse conjures up thoughts and feelings of danger and uncertainty. As such, by

² While the term “sensationalize” can suggest exaggeration at the expense of realism, I do not mean to suggest this with my use of this term.

employing risk discourse and bringing attention to risks, particularly genetic disease risks, 23andMe prompts physical reactions from its users and prospective users by presenting worrisome information in such a way. I would suggest that the purposes behind these efforts include the promotion of consumerism for private corporations and health promotion for governments; however, this thesis will focus more on the communication of these discourses and not the underlying motivations. I will contextualize my argument by suggesting that the nature of the relationship between doctors and patients has changed over time, due in part to challenges to authority posed by post-modernity and the emergence of new claims for authoritative knowledge about bodies and medicine. These new technologies, such as the services provided by 23andMe, have implications for the way we conceive of and know information about ourselves and our bodies.

Theoretical Framework

My second chapter will contextualize these arguments by first introducing key concepts as developed by Michel Foucault, and second, reviewing the literature on social medicine and the cultural studies of science. I will review Foucault's conceptualization of power and self-surveillance. In short, Foucault argues that power reaches "into the very grain of individuals, touch[ing] their bodies and insert[ing] itself into their actions and attitudes, their discourses, learning processes and everyday lives" (1980, p. 39). We internalize "an inspecting gaze" (Foucault, 1980, p. 155), which functions as an "invisible but unverifiable" power of surveillance. Social medicine scholars assert that, as medical imaging technologies become more and more sophisticated, the relationship between

physicians and patients in Western society becomes increasingly mediated. This changing relationship is also described within a discussion of issues of power and hegemonic influence on the public. The cultural studies of science literature examines the cultures of health, illness, science and medicine and the intersection of these arenas with the mass media. This literature focuses on representations of medical knowledge and the body in the media. The purpose of examining these two bodies of literature is to illustrate the importance of medical and health discourses within our society and to provide evidence of the fact that these discourses are wound up with issues of power and risk. I will synthesize these fields of knowledge to setup a theoretical framework for my case study of 23andMe.

My third chapter identifies an area that is not sufficiently covered in the literature described above: the ways in which medical technologies touch our daily lives and have the potential to affect the way we conceive of and understand ourselves and our bodies. In my third chapter, I will demonstrate that various technologies today perform a “panoptic sort” (Gandy, 1993), categorizing individuals based on personal data without reference to the context from which the data emerged. I will touch on several concepts that are relevant to my study of 23andMe: the panoptic sort, the computerized database, the Internet, and social networking sites. These technologies all deal with the collection and organization of personal information, for various applications and purposes. Consumers and users receive various benefits from these services in exchange for providing personal information and privacy with little to no concern with the implications of such disclosure. I argue in this chapter that we interact with data about ourselves

everyday and, increasingly, this includes interacting with medical information beyond the confines of a medical institution such as a doctor's office or a hospital.

My case study is an examination of the website 23andMe. This fourth chapter will provide a detailed example of a medical technology that translates raw data about its users into information about their bodies and discourses about risk and prevention that is shared with these users, here in the form of online text. I will situate this service within its current sociocultural context and relate it to issues of power, expertise, and self-surveillance, as well as the panoptic sort, personal data, and personal use of technology.

Case Study: 23andMe

23andMe, Inc. (2007) is a private company that provides a web-based personal genomics service. The term personal genomics refers to the genotyping³ and analysis of individuals' genomes. Personal genomics service providers, private companies, have initiated an exchange with the public of essential genetic information for profound information about the makeup of these users' bodies. The 23andMe website offers patrons analysis of their personal genome in exchange for a one-time fee. In early 2008, this fee was \$999 (Walch, 2008). In September 2008, 23andMe lowered the cost to \$399 to further "democratize personal genetics" (23andMe, Inc., 2008d). As of July 2009, 23andMe began offering a "limited edition" named the "Research Edition" for only \$99 (The 23andMe Team, personal communication, 2009). This limited account allows users to "try a limited set of the core features of 23andMe for a quarter of [their] regular price,

³ 23andMe, Inc. (2009ii) defines genotyping as "the process of determining which genetic variants an individual possesses. Genotyping can be performed through a variety of different methods, depending on the variants of interest and resources available. At 23andMe, [they] look at SNPs, and a good way of looking at many SNPs in a single individual is a recently developed technology called a "DNA chip"."

and support research at the same time” (The 23andMe Team, personal communication, 2009). 23andMe does not disclose how many users they have acquired.

While patrons of the website may be lured by its potential to unmask their future health problems or to uncover new information about their ancestry through personal genomics, it is the intention of the creators of the site to achieve “the greatest innovation in health care in the coming century” by collecting “a database of at least 100,000 genomes, which scientists will then be able to access for further study” (Walch, 2008, pp. 312-313). This database could be “endlessly recycled for a myriad of disease studies” without the strings that would come along with “the time-intensive process of gathering blood samples and securing permission from donors” (Walch, 2008, pp. 312-313).

I discovered 23andMe when reading an issue of *Vogue* magazine last spring. In an article written by Abigail Walch (2008), the company was personified by its two co-founders Linda Avey and Anne Wojcicki. Walch portrayed Avey and Wojcicki as brilliant entrepreneurs while also focusing on the fact that they are also women in a male-dominated world of biotechnology. What struck me about the article was the discussion of unlocking information about our bodies to which we would not otherwise have access. This information about our selves can trigger thoughts and feelings about our mortality, about the essence of what makes each one of us unique, and what characteristics, traits, and risks we are passing on to the next generation. Since the article in *Vogue* in May 2008 proclaimed that 23andMe “could be the greatest innovation in health care in the coming century” (Walch, 2008, p. 313), 23andMe has continued to garner a very impressive level of media attention. Not only have Oprah and Dr. Oz (Harpo Productions,

2008) praised and endorsed the service on syndicated television and Oprah's website, *Time* magazine named 23andMe's "Personal Genome Service" as its "Invention of the Year" (Hamilton, 2008). However, not everyone is singing 23andMe's praises. In the spring and summer of 2008, New York State's Department of Health and California's Department of Public Health issued letters to genetic testing companies, including 23andMe, warning that genetic tests must not be conducted without the involvement of a doctor and doing so may result in fines and/or jail time (Kincaid, 2008; Langreth & Herper, 2008). The government's concern is reportedly that "casual DNA testing... trivializes the importance of genetic information" and "many health care professionals worry that any amount of genetic information could be misinterpreted" (Kincaid, 2008). 23andMe argues that these laws should not apply to them because "23andMe's services are not medical... they are educational" (Langreth & Herper, 2008). There is clear conflict between governmental agencies, the health care community, and 23andMe, Inc. and its supporters. This conflict stems from concern about both influence over patients and the ownership of the collected data.

It should be noted that 23andMe is not the only personalized genetics website. Navigenics and Helix Health are two other prominent web-based personal genomics companies (Mesko, 2007). What makes 23andMe the most interesting to me, and thus the focus for this case study, is two-fold: first, 23andMe's adaptation of the social networking style of website; second, the fact that Google is a top investor in the company (23andMe, Inc., 2009i) and has significant connections to 23andMe, to be discussed

below. 23andMe's close relationship with Google allows for great power and influence, unachievable by its competitors.

The History of 23andMe

Cofounders Avery and Wojcicki are educated and experienced in the field of biotechnology: Avey has a B.A. in biology from Augustana College and over 20 years experience in the biopharmaceutical industry and Wojcicki has a B.S. in biology from Yale University and 10 years experience in healthcare investing in biotechnology (23andMe, Inc., 2009f). Wojcicki happens to be married to Google co-founder Sergey Brin (Hamilton, 2008), although the 23andMe website does not share this information. However, it seems to be pertinent information when Google is said to have donated "almost half the \$8.9 million in funding raised by [23andMe]" (Hamilton, 2008). The fact that 23andMe Inc. is, literally and figuratively speaking, married to Google Inc. has significant implications considering that Google is "the most powerful search engine on Earth" (Halici & Mayer, 2007).

Further evidence of the strong ties between Google and 23andMe can be drawn from a lecture entitled "Opportunities for Pharmacogenomics and Personalized Medicine" on February 22, 2006 (Altman, 2006). This lecture was part of the "Tech Talks at Google" series, many of which are videotaped and made available online at Google Video (Google, 2009). The online video of this lecture has an introductory caption that explains that "Tech Talks are designed to disseminate a wide spectrum of views on topics including Current Affairs, Science, Medicine, Engineering, Business, Humanities, Law, Entertainment, and the Arts" (Altman, 2006). What is not stated,

however, is that these lectures in their live form are given to Google staff and therefore the topics selected must be relevant (and potentially profitable) to Google Inc. This lecture in particular is given by Russ B. Altman, Professor of Bioengineering, Medicine, and Computer Science at Stanford University.

Altman's (2006) lecture is on the topic of personalized medicine, but more specifically, his particular research interest of pharmacogenetics. Altman says that the lecture is meant to "get a conversation started to see if there's any interest in what we're doing and potential further interactions." This statement makes it clear that this lecture is not simply pedagogical, but it is also an opportunity for business development. He explains that pharmacogenetics and pharmacogenomics are the study of "how genetic variation leads to variation in the responses to drugs." The aim of Altman's research is to work towards "genome-informed medicine", which would "predic[t] who is at risk" of "adverse reactions" for various drug treatments (Altman, 2006). Altman identifies a major challenge to this movement as being "the lack of a health information infrastructure in the United States" (Altman, 2006) and therefore no reliable and efficient way to deliver this information to medical practitioners. In the question and answer period at the end of the lecture, an audience member asks about health care providers' access to patients' genotype information. Altman answers that options include having the information embedded in a chip and inserted into individuals' bodies, an electronic card, central government database, or finally password-protected on Google (Altman, 2006). He mentions that he has "written a little bit about a distributed patient-controlled system where the genotype is measured" and given to the patient (Altman, 2006). The patient is

then able to provide their genotype to health care providers or researchers, if they so desire. Altman notes that this arrangement is “within reach”, needing only “sociological agreement” or “somebody to do it and do it well” (Altman, 2006).

Soon after this lecture, Professor Altman became an advisor to Linda Avey and Anne Wojcicki’s start-up company 23andMe (23andMe, Inc., 2009e). 23andMe, Inc. was founded, just two months after Altman’s presentation to Google, in April 2006 and its website was launched on November 19, 2007 (23andMe, Inc., 2007). In a segment covering the launch, CBS News correspondent John Blackstone (2008) explains that “23andMe aims to do for genetics what Google did for the Internet: make it easy and accessible for those curious about their DNA.” Considering the enormous power and influence of Google on the world of computer technology and the potential power of an assembly of genetic information collected from the population, this statement bears critical reflection.

Methodology: Critical Discourse Analysis

The concept of “discourse” emerged in the 1970s concurrently within various social science and humanities disciplines (Wodak *et al.*, 1999, p. 7). As such, various meanings and approaches have been attributed to the term (Wodak *et al.*, 1999, p. 7). Ruth Wodak *et al.* explain that this “has led to considerable semantic fuzziness and terminological flexibility” (1999, p. 7). Susan Yell (2005) identifies two main uses of the term, the first within the field of applied linguistics and the second by scholars influenced by Michel Foucault:

To sum up this difference very briefly, within linguistics, discourse refers to language in use, while for Foucault it is a power/knowledge formation,

which may be manifested in language (or other symbolic forms) but is not reducible to linguistic patterns. So discourse analysis undertaken from a linguistic standpoint, “emphasizes language as a system and then looks to discourse analysis to explain how various contextual factors affect language in use” (Pennycook, 1994, p. 115), while Foucault’s project is to examine the links between “power as it functions within institutions and the creation of knowledge and truths” (Threadgold, 2000, p. 49). (Yell, 2005, p. 15)

Yell further explains that Foucault’s “concern with power and the project of ‘demystifying discourse’” makes his work attractive to critical discourse analysts (2005, p. 15). Foucault remarks “that the citizens of modern democracies are controlled” by “the pronoun of expert discourse, organized in what he calls ‘regimes of truth’ – sets of understandings which legitimate particular social attitudes and practices” and create “targets for social control and influenc[e] the form the control itself will take” (Foucault as quoted by Cameron *et al.*, 1999, pp. 141-142). The importance of Foucault to this project will be further elaborated on in my second chapter.

Critical Discourse Analysis is one of many approaches to discourse analysis. Emerging in the field of linguistics in the 1970s, discourse analysis represents “an attempt to characterize talk and texts longer than the sentence or clause, which had been the upper limit of linguistic analysis prior to this innovation” (Pomerantz & Fehr, 1997, p. 66). Discourse analysts were interested in “the pragmatic aspects of language use in semiotics, ... [and] the power of words ... to legitimate and maintain established hierarchies without the awareness of those disadvantaged by the system” (Pomerantz & Fehr, 1997, p. 66). These interests “spawned [separate] productive streams of research which, over time, have become intertwined in complicated ways, each borrowing concepts and methods from the others as the need and interest arose” (Pomerantz & Fehr,

1997, p. 66). It is difficult to clearly separate these approaches from each other as “they have converged on a number of issues,” including the assumption that “language can be used to enact social actions,” the “concern for the role of context in sense production” and the attempt to “capture the perspective of the participants in interactive sequences” (Pomerantz & Fehr, 1997, p. 66).

The difference between discourse analysis and CDA is that the term “critical” infers a particular “intellectual-political orientation” towards academics, influenced by the Frankfurt School:

Whatever its subject matter or methodology, essential to doing ‘critical’ research would be the adoption of a self-reflective perspective, one that is, first, conscious of the social and discursive nature of any research practice, and second, takes seriously the Foucauldian reminder that the production of knowledge is always bound up in a network of power relations. (Ang, 2001, p. 178)

Critical Discourse Analysis can be applied as a research method, a methodology, a research strategy, as well as a form of intellectual advocacy. Teun A. Van Dijk explains, “CDA is not so much a direction, school, or specialization” (2001, p. 352). Instead, it provides “a different “mode” or “perspective” of theorizing, analysis, and application throughout the whole field” (van Dijk, 2001, p. 352).

Critical Discourse Analysis is not a homogeneous paradigm (Wodak *et al.*, 1999, p. 7). Fairclough and Wodak, key figures in the history of CDA themselves, identify eight distinct approaches to CDA (including their own): French discourse analysis, critical linguistics, social semiotics, sociocultural change and change in discourse, socio-cognitive studies, discourse-historical method, reading analysis, and finally, the Duisburg School (1997, pp. 262-268). Norman Fairclough’s (1989) *Language and Power* is

considered to be *the* key CDA publication (Blommaert & Bulcaen, 2000, p. 454).

Fairclough's methodology, with which he studied the British discourse of Thatcherism, "offered the synthesis of linguistic method, objects of analysis, and political commitment that has become the trademark of CDA" (Blommaert & Bulcaen, 2000, p. 454).

Fairclough identifies himself as embodying an approach to CDA he calls "sociocultural change and change in discourse," since he and his colleagues have "focused upon relationships between sociocultural change and discursive change" (Fairclough & Wodak, 1997, p. 264).

CDA has been criticized for its claims to a distinctive critical stance and for really only revealing "the particular discourse perspective of the interpreter... [which] has no more authority than any other" (Widdowson, 1995, p. 169). However, Wodak *et al.* disagree, arguing that what differentiates CDA from the crowd is that it "does *not* pretend to be able to assume an objective, socially neutral analytical stance" (1999, p. 8, emphasis added). In fact, the particular perspective of the interpreter is considered important in CDA and recognized through self-reflexivity (Wodak *et al.*, 1999, p. 8). CDA has also been criticized for being "too language-oriented", "too power-oriented", and for suffering from "a certain methodological fragmentation" (Toolan, 1997, pp. 83-99). Michel Toolan suggests "standardization of methods, questions, assumptions and parameters... [which would likely] strengthen the method, clarify it, and make it both more teachable and more learnable" (1997, p. 99).

CDA and Online Content

Critical Discourse Analysis is primarily used to analyze content in newspapers, magazines, and “other print and broadcast media, as well as interviews” (Mautner, 2005, p. 811). CDA has great potential for the analysis of online content, because of the fact that “web technology has significantly extended the *discursive* repertoire available, allowing new modes of representation as well as the construction of new identities and relationships” (Mautner, 2005, p. 820, emphasis added). Furthermore, as “discourse on the web is now a key factor in construction representations of reality and social relationships, while also establishing new conventions for both textuality and intertextuality” (Mautner, 2005, p. 821), CDA can help researchers explore these areas. Scholars that have used CDA as a methodology to study online sources of data include Jay L. Lemke (1999, 2004), Alison Piper (2000), Michael Billig (2001), Maria Cheng (2002), William J. Poser (2002), Kay Richardson (2001), Carmen Rosa Caldas-Coulthard (2005), Paul McIlvenny and Pirkko Raudaskoski (2005), Lemi Baruh and Mihaela Popescu (2008), Jaffer Sheyholislami (2008)⁴. As Gerlinde Mautner (2005) explains, CDA has not been applied to online content as much as would be anticipated:

Although the world wide web has become a popular object of and tool for different kinds of semiotic and linguistic investigation, critical discourse analysis (CDA) does not seem to share this enthusiasm in equal measure. The contemporary relevance of the web as a key site for the articulation of social issues should make it a prime target for critical discourse analysts with a political and emancipatory brief. Nonetheless, CDA publications are still predominantly based on conventional, non-electronic sources of data. (Mautner, 2005, p. 809)

Mautner hypothesizes that CDA practitioners avoid analyzing Internet sources due to the boundless nature of the Internet, its diversity and multiplicity of speakers, the fact that it’s

⁴ The majority of this list is courtesy of Mautner’s literature review (2005, p. 811).

always changing, as well as “issues related to textuality, interactivity and multimodality” (2005, pp. 815-819). The challenge that I think will be most relevant to my project is the “borderless” nature of hypertext (Mautner, 2005, p. 819). Due to the vast number of links and subpages, researchers must clearly and carefully define the parameters of their study with this added complexity in mind. Researchers must also “take interactivity into account, not only as a matter of principle, so as to do justice to the rich affordances of the medium, but also because of the social significance [they] have for a particular social practice” (Mautner, 2005, p. 820).

My Application of CDA

In this thesis, I will employ Critical Discourse Analysis (CDA) to analyze the 23andMe website to determine what discourses, specifically about the genetic makeup of our bodies, disease risks and prevention, are inherent in the written text. As the literature of social medicine and the cultural studies of science will demonstrate, information about bodies, and medicine and health in general, may seem to be apolitical, however this information is loaded with significant implications and assumptions and warrants interrogation. CDA allows academics to examine these discourses and uncover the power of this type of messaging.

My analysis will be presented in the following way. The data from each subsection of the website will be analyzed one at a time in the following order: I will first examine the account home page followed by My Health and Traits, Family and Friends, My Ancestors, 23andWe, and finally Community. Specific analytical tools, borrowed from CDA practitioners, will be employed. First of all, over-lexicalization will be

borrowed from Peter Teo's (2000) study of racism in the news. Teo describes over-lexicalization as occurring when "repetitious, quasi-synonymous terms [are] woven into the fabric of... discourse" (2000, p. 20). This functions "as a pragmatic strategy of encoding ideology" into the text (Fowler *et al.* as quoted by Teo, 2000, p. 20). The text will be analyzed to see whether there are vocabulary chains, which reflect attempts to create particular images in the consumers' minds.

Local meanings, metaphors and euphemisms used by 23andMe will also be interrogated in my thesis. Local meanings will be borrowed from Teun A. van Dijk (2000). In his study of what he calls "new racism", van Dijk argues that since "the new racism... avoids explicitly racist labels, and uses negative words to describe the properties or actions of immigrants or minorities, ... special 'codewords' may be used" (2000, p. 39). Furthermore, "much of the information in discourse... is implicit, and supplied by the recipients on the basis of their knowledge of the context and of the world" (van Dijk, 2000, p. 40). Therefore, CDA practitioners should examine implications and presuppositions within texts. Van Dijk (2000) also examines metaphors and euphemisms. The metaphor is an important device that several of the scholars in the social medicine and cultural studies of science fields have examined⁵. The above analytical tools will be used for the analysis of textual elements of the 23andMe website.

⁵ Several of the authors involved in *Wild Science* examine the use of metaphors as a strategy of communicating scientific information to the public. Anne Beaulieu explains that "the brain is understood through metaphors of communications and integrated systems which collapse the image of the brain as territory, and the brain as machine" (2000, p. 41). José van Dijck points out the danger of metaphors of the human genome as a language – an image she notes is "prevalent in the popularization of genome research" (van Dijck, 2000, p. 69). She argues that this metaphor should be extended "into the realm of literature ... to show that DNA opens up whole new worlds of interpretation" (van Dijck, 2000, p. 70).

I will not analyze the graphical elements of the website, as I am more interested in the translation of raw genetic data into verbal descriptions of probabilities and risks.

CDA practitioners generally assume the existence of “a dialectical relationship between particular discursive acts and the situations, institutions and social structures in which they are embedded: the situational, institutional and social contexts shape and affect discourse, and, in turn, discourses influence social and political reality” (Wodak, de Cillia, Reisigl & Leibhart, 1999, p. 8). Therefore, discourse and social practice are theoretically inseparable. Discursive themes will be drawn from the website and related to the greater social contexts of the services offered, following Norman Fairclough’s (2001) methodological framework.

Norman Fairclough’s approach to CDA presents “a three-dimensional framework for conceiving and analyzing discourse” (Blommaert & Bulcaen, 2000, p. 448).

Fairclough (2001) explains that Critical Discourse Analysis involves an examination of the relationship between these three levels of meaning:

In seeing language as discourse and as social practice, one is committing oneself not just to analyzing texts, nor just to analyzing processes of production and interpretation, but to analyzing the relationship between texts, processes, and their social conditions, both the immediate conditions of the situational context and the more remote conditions of institutional and social structures. (Fairclough, 2001, pp. 20-21)

While the text (in this case the website) will function as the primary unit of analysis, following Fairclough’s approach, the analysis will move beyond the text and also examine the processes and social conditions of production and interpretation as well as the larger social contexts.

Implications

If I successfully support my thesis statement – that new information technologies, such as my case study 23andMe, sensationalize risk, particularly risk of genetic disease and undesirable traits, and in doing so, they encourage certain behaviours such as self-surveillance – the following implications should stem from this study. First of all, these technologies support preexisting power structures within society and help to maintain a certain level of stability in terms of the health of the population. Secondly, genetic information technologies, such as 23andMe in particular, present genetic information about risks as information that should be dealt with and followed up on by its users. This suggests that we are moving towards a society where genetic intervention is becoming acceptable and desirable, or as Habermas describes it, assuming “the license to control the physical basis which “we are by nature”” (2003, p. 28). Where will we draw the line? Who will make these decisions – scientists, government officials, or private companies like 23andMe? These are questions that must be considered to ensure we do not endanger the nature of humanity, as we know it.

Chapter 2: Medical Information and the Pursuit of Health

Introduction

The trouble about always trying to preserve the health of the body is that it is so difficult to do without destroying the health of the mind. (Chesterton, 2009)

Personal genomics builds upon a tradition of medical imaging, a variety of instruments and tools “designed to facilitate the search for the internal causes of external symptoms” (Sterne, 2003, p. 101). Increasingly, medical imaging technologies are being used in the name of prevention as opposed to diagnosis and treatment - personal genomics would be one example; mammograms and other cancer screening technologies would be others. Medical imaging technologies are “designed to operate within the parameters of a set of social relations, and [they help] cement and formalize these relations” (Sterne, 2003, p. 101). For example, the stethoscope supported “the doctor-patient relation, the structure of clinical research and pedagogy, and the industrialization of medicine” (Sterne, 2003, p. 101). The development of medical imaging technologies is significant, as they are increasingly more powerful “disciplinary techniques for observing and analyzing the body, so as to make it more available for manipulation and control” (Gandy, 1993, p. 24). While this manipulation and control may in fact be in an effort to make individuals more healthy or safe from disease and death, the use of such technologies infers a power relationship that should be interrogated.

Power, as Randall Bartlett defines it, involves “the ability of one actor to alter the decisions made and/or welfare experienced by another actor relative to the choices that would have been made and/or welfare that would have been experienced had the first

actor not existed or acted” (as quoted by Gandy, 1993, p. 18). There are undoubted effects of new medical imaging technologies – potentially these effects include a change in the way we understand and perceive our bodies. With the development of medical imaging technologies comes the development of discourses and messaging with which to interpret the data presented. Since science is based on empirical evidence, the information disseminated by the scientific community comes with authority and often a sense of infallibility. However, scientific facts are *communicated*.

This chapter will illustrate the importance of medical and health discourses within our society and will provide evidence of the fact that these discourses are wound up with issues of power and risk. It will also set the stage with a theoretical context with which to understand the place of 23andMe within society and culture. First, the importance of the work of Michel Foucault will be elaborated on. Foucault’s concept of “self-surveillance” will be introduced as a key term for this thesis. Second, two key bodies of literature will be described: social medicine and the cultural studies of science. Key works from both disciplines will be presented thematically. Third, I will connect these findings with ideas about health promotion and the concept of “healthism.” Finally, I will provide some concluding remarks regarding risk discourse, in particular, informed by the preceding literature review.

The Importance of Michel Foucault

The work of Michel Foucault (1965, 1973, 1978, 1979, 1980, 1982, 1994, 2003) is significant for this thesis. Not only was his conceptualization of the term “discourse” important, as discussed in the introductory chapter, but also, without his critical analyses

of the medical institution and surveillance structures, this thesis would not be possible.

I will now summarize a few of Foucault's most important theories, in terms of relevance to my project.

In his first major work, *Madness and Civilization*, Foucault (1965) examines the shift from the conception of "madness" in the fourteenth through the eighteenth century to the conception of "mental illness" in the nineteenth century, from confinement to medical treatment. In his next major work, *The Birth of the Clinic*, Foucault illuminates the idea that "the exact superposition of the 'body' of the disease and the body of the sick man is no more than a historical, temporary datum" and that "we are only just beginning to detach ourselves from" this perception (1973, p. 3). He argues that this "space of *configuration* of the disease and the space of *localization* of the illness in the body have been superimposed, in medical experience, for only a relatively short period of time" (Foucault, 1973, pp. 3-4). To be more specific, this period "coincides with nineteenth century medicine and the privileges accorded to pathological anatomy" (Foucault, 1973, p. 4). Colin Gordon describes the book's significant achievement:

It demonstrates how the conceptual and epistemological mutations effected in medical knowledge during the first decades of the nineteenth century were bound up with the re-definition of the social and medical function of the hospital, the incidence of revolution and war on the organization of and relations between medical teaching, research, and practice, the ethical epistemological and political transformation of the relation between medicine and its patients and of the professional status of medical personnel, and the complementary projects of a science of the individual case and a hygienic policing of an entire population. (1980, p. 243)

The lasting legacy of this work is the promotion of scrutiny of medical ‘facts’ as discourse that should be interrogated and not necessarily taken at face value and as innocuous or natural.

Foucault’s (1978) three-volume *History of Sexuality* aimed to “create a history of the different modes by which, in our culture, human beings are made subjects” (Foucault, 1982, p. 208). It is in volume one of this series, *The Will To Knowledge*, that Foucault (1978) introduces the concept of “biopower.” He uses the term “to describe the operating logic of the modern welfare state which “is characterized by increasing organization of population and welfare for the sake of increased force and productivity”” (Terry, 1989, p. 33). Foucault explains that biopower “is concerned with measuring, categorizing and managing the human species” while also treating “the body as an object to be manipulated and made productive through disciplinary practices, which result in the making of the “docile body”” (Foucault as quoted by Terry, 1989, p. 33).

In *Power/Knowledge*, Foucault identifies an overall shift in the nineteenth century towards the protection of “the body of society” (1980, p. 55):

It is this social body which needs to be protected, in a quasi-medical sense. In place of the rituals that served to restore the corporal integrity of the monarch, remedies and therapeutic devices are employed such as the segregation of the sick, the monitoring of contagions, the exclusion of delinquents. The elimination of hostile elements by the *supplice* (public torture and execution) is thus replaced by the method of asepsis – criminology, eugenics and the quarantining of ‘degenerates’... (Foucault, 1980, p. 55)

In the same vein, he also argues that “a physiological, organic knowledge of [the body] became possible” “on the basis of power over the body” (Foucault, 1980, p. 59). It can be

concluded then that the “medical gaze” (Foucault, 1973, p. 9) intrinsically objectifies the body and thus dominates the patient(s).

Alexandra Howson explains that Foucault’s theories have been “used to examine how techniques of surveillance in the twentieth century have created new knowledges and orthodoxies in and around the body” (1998, p. 222). His work is considered to be so significant, Howson suggests, “because of the way in which he placed the body as central to the development of medical epistemology” and also for “providing a framework for sociological exploration both of these practices which constitute the body, and those which contribute to the constitution of self” (1998, p. 222). As Sarah Nettleton and Jonathan Watson explain, thanks to Foucault, “a central thrust of contemporary studies of the body is ... that the body itself has a history and so it is possible to write the history of the body” (1998, p. 4).

Foucault contends that ‘power’ does not exist as an entity, but that it “exists only as exercised by some on others, only when it is put into action, even though, of course, it is inscribed in a field of sparse available possibilities underpinned by permanent structures” (1994, p. 137). It follows that this power “cannot be located; it is everywhere and therefore also inside us” (Vaz & Bruno, 2003, p. 273). This external power working within us can be further conceptualized using the idea of self-surveillance:

Self-Surveillance

Self-surveillance can be defined “as the attention one pays to one’s own behaviour when facing the observational gaze of others whose opinion is deemed relevant” (Featherstone, Atkinson, Bharadwaj & Clarke, 2006, p. 73). The concept of

self-surveillance is introduced by Michel Foucault (1980) in *Power/Knowledge*.

Foucault conceptualizes power as reaching “into the very grain of individuals, touch[ing] their bodies and insert[ing] itself into their actions and attitudes, their discourses, learning processes and everyday lives” (1980, p. 39). He argues that, in modern society,

...there is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorizing to the point that he is his own overseer, each individual thus exercising this surveillance over, and against himself. (Foucault, 1980, p. 155)

For Foucault, it is Jeremy Bentham’s Panopticon prison that exemplifies the “invisible but unverifiable” power of surveillance involved that encourages self-surveillance (Foucault, 1979, p. 201). He extrapolates that society in general is ‘panoptic’: “We are, says Foucault, ‘in the panoptic machine, invested by its effects of power, which we bring to ourselves: since we are part of its mechanism” (Robins & Webster, 1999, p. 179).

Sarah Nettleton writes, “the technologies of discipline rely *increasingly* on the patient... to assess themselves – to monitor their own progress or assess their own lifestyles” (1992, pp. 148-149, emphasis added). This self-surveillance reflects a current era of what David Armstrong (1995) calls “Surveillance Medicine” and what Jane Ogden describes as a time when “the individual has become at risk from his or herself” (1995, p. 413). This shift of focus from external threats to those found inside our own bodies reflects a shifting battle for the power and influence over the population’s physical bodies by corporations, the government, and the health care community.

Social Medicine and the Cultural Studies of Science

There are two bodies of literature that are important to this thesis: social medicine and the cultural studies of science. Social medicine is a branch of medicine that focuses on the social factors involved in sickness and health. Social medicine became a recognized academic discipline in the 1940s (Porter, 2006, p. 1667). In 1945, George Rosen published an article in the *Bulletin of the History of Medicine* entitled “What is Social Medicine?” In this article, Rosen argues that the concept of social medicine originated in the nineteenth century with health and social reformers Jules Guerin, Alfred Grotjahn, and Rudolph Virchow (Porter, 2006, p. 1167). These men were “concerned with developing the political role of medicine in creating egalitarian societies” (Porter, 2006, p. 1167). In 1848, Virchow defined the founding principles of social medicine:

(1) the health of the people is a matter of direct social concern; (2) social and economic conditions have an important effect on health and disease, and these relations must be subjected to scientific investigation; and (3) the measures taken to promote health and to combat disease must be social, as well as medical. (Virchow as quoted by Holtz, Holmes, Stonington & Eisenberg, 2006, p. 1664)

In the 1920s and 30s, “research programs such as the National Health Survey (1935) shifted medical interests from the biological problem of infectious disease to the social, economic, and personal impact of chronic diseases” (Young, 1984, p. 107). It is at this same time that medical discourse in general “moved to an ecological perspective, embedding biological facts in social and experiential realities” (Young, 1984, p. 107).

After the Second World War, social medicine was institutionalized, but in different ways in different geographic contexts (Young, 1984, p. 107). Dorothy Porter identifies two contrasting instances (2006, p. 1668). First, she describes social medicine as found in

Latin American (LASM), which “focused on social transformation” (Porter, 2006, p. 1668). An example of the effects of this social medicine is Che Guevara’s ““revolutionary medicine”, which hinged on the training of all health-care professionals, including physicians, in the social origins of illness and the need for social change to improve health conditions” (Porter, 2006, p. 1668). This philosophy “played a profound role in the Cuban, Chilean, and Nicaraguan revolutionary governments’ reform of medical and health-care systems and education” (Porter, 2006, p. 1668). On the other hand, within the “Anglo-American context” at this time, there was “the rise of “lifestyle medicine””, which worked on “a model of prevention ... primarily focused on changing *individual* behavior rather than addressing the social structural determinants of health and disease” (Porter, 2006, pp. 1668-1669). Porter posits that the state of social medicine in this context “remained closely bound to the bio-psycho-socio-model of chronic disease that underpinned lifestyle-based, behavioral models of prevention after the Second World War” (2006, p. 1670), until recently:

Recent political developments in chronic disease prevention, specifically with respect to tackling obesity, may encourage yet another paradigmatic shift. This shift may re-link Anglo-American social medicine with its roots in social structural analysis of disease etiology and with the continued socioeconomic structural analytical focus of LASM. (Porter, 2006, p. 1670)

She concludes with an endorsement of “a greater integrated international social medicine discourse” which she suggests “may be the best fit to confront the challenges of understanding a new global order of health, disease, medicine and the disparities of care and resources” (Porter, 2006, p. 1671).

Four contemporary scholars in the field of social medicine whose work is particularly relevant to this project are David Armstrong (1995), William Ray Arney and Bernard J. Bergen (1984), and Sarah Nettleton (1992). Works by these scholars, as described below, provide key ideas relating to the place of medicine in today's Western society. This literature asserts that the developing history of medical imaging technologies is related to issues of power and inherently linked to the changing dynamic between physicians and patients in Western society. The literature shows that, as technologies advance, that relationship becomes increasingly mediated. It follows that these messages are communicated (by way of various media) to individuals with the underlying and hegemonic intention of suggesting particular methods of management of the bodies of said individuals.

The cultural studies of science examine the cultures of health, illness, science and medicine and the intersection of these arenas with culture and, more specifically, popular media. Including feminist cultural studies of science and technology (or, of technoscience), this "movement" has "transformed understandings of science and technology and provided ways of analyzing their development and significance" (McNeil, 2007, p. 1). This field encompasses literature that is very diverse due to "the creative use, adaptation and transformation of the resources of [various] academic disciplines" (McNeil, 2007, p. 147). The cultural studies of science provide "historically grounded analysis" (Marchessault & Sawchuk, 2000, p. 2) and view "science as a social activity" (Wyer, Barbercheck, Giesman, Ozturk & Wayne, 2001, p. xxiv). This means that, "from a social constructivist perspective, the method and the knowledge that results

from [the scientific method] are socially constructed” (Wyer et al., 2001, p. xxiv). This perspective sees the body as “always a signified body” (Oudshoorn, 2001, p. 201). Nelly Oudshoorn argues that “our perceptions and interpretations of the body are mediated through language, and in our society, the biomedical sciences function as a major provider of this language” (2001, p. 201). Scholars that practice the cultural studies of science promote the contestation of “essentialism in biomedical discourse” (Oudshoorn, 2001, p. 209) and focus on the ways in which medical knowledge and information about the body is presented to the public via various media.

Literature Review

In order to present the relevant arguments of leading scholars in both social medicine and the cultural studies of science, I will divide the literature up by the following four key themes: technology, surveillance and power, genetics, and health and society. This literature review will provide the reader with key conceptual tools that will be referenced in the remaining chapters of this thesis.

i. Technology

Wild Science: Reading Feminism, Medicine and the Media, edited by Janine Marchessault and Kim Sawchuk, is a collection of articles that examine discourses apparent in the explosion of “health culture... in the sphere of consumerism” (2000, pp. 1-2). The first chapter of *Wild Science* sets the stage for further discussion of scientific exploration of the human body and new technological representations of the body disseminated to the public by way of the media. Kim Sawchuk’s “Biotourism, Fantastic Voyage, and Sublime Inner Space” presents a textual analysis of the 1966 film entitled

Fantastic Voyage and explores the “persistent cultural fantasy that one can travel through the inner body, a bodyscape which is “spatialized” and given definable geographic contours” (2000, p. 10). She identifies “the biotourist” as being “a new facet of human subjectivity” that arises from “this complicated tangle of political, economic, cultural and technological discourse” (Sawchuk, 2000, p. 10). With the latest medical imaging technologies, “our most infinitesimal cells, molecules and genetic structures [are being rendered] into images on a scale that we can more easily comprehend” (Sawchuk, 2000, p. 9). Sawchuk (2000) thus makes a connection between a science fiction film and new scientific technologies that are being employed today. “Fantastic” biotourism has been achieved by a variety of medical imaging technologies such as the ultrasound, the x-ray, personal genomics, etc.

Catherine Waldby contributes a chapter to *Wild Science* entitled “The Visible Human Project”⁶ and has written a book of the same name⁷, also published in 2000. Both works examine “the virtual anatomy “atlas”” (Waldby, 2000a, p. 25) that is the Visible Human Project: “Complete, anatomically detailed, three-dimensional representations of the male and female human body... available on the Internet” (Waldby, 2000a, p. 25). Waldby notes the similarities between the Visible Human Project and the Human Genome Project as both reflect technological attempts “to map out the topography of the human species”, by creating “a large yet finite information database, a spatial, graphic ordering which acts as a digital archive, retrievable through computer networks” (2000b, p. 37). As biomedical projects such as the Visible Human Project continue to present

⁶ The full title of this chapter is “The Visible Human Project: Data into Flesh, Flesh into Data.”

⁷ The full title of the book is “The Visible Human Project: Informatic Bodies and Posthuman Medicine.”

human bodies as walking data archives, there will continue to be “implications for vivacity, health and illness... and the relationships between life and death” (Waldby, 2000b, p. 110). Waldby’s work on the Visible Human Project is significant in that it shows “an exemplary instance of biomedicine’s relentless refiguration and textualisation of the human body according to instrumental logic of knowledge, the particular organization of its tools, rather than according to a pre-existing biological organization” (2000b, pp. 7-8).

Electronic Culture: Technology and Visual Representation, edited by Timothy Druckrey, is a collection of articles that primarily deal with our technologically enhanced field of vision and the effects of technological advancements on our identities. Several chapters confront the idea that “our understanding of the world and of “nature” [is becoming increasingly] secondhand” (Stone, 1996, p. 6). As Allucquère Rosanne Stone notes, “images on screen, images of events that we will never ourselves experience, subatomic collisions, the DNA helix, movement of ions within synapses” have become part of what we consider “reality” (1996, p. 6). Jean-Louis Comolli explains that the “social multiplication of images” in the late nineteenth century lead to “a geographical extension of the field of the visible and the representable” (1996, p. 109). This extension of our bodies and our senses (sight, in particular) is made possible by technologies, and most specifically the computer.

Bill Nichols argues that the computer functions as “an icon and metaphor that suggests new ways of thinking about ourselves and our environment, new ways of constructing images of what it means to be human and to live in a humanoid world”

(1996, p. 121). As mentioned above, our world, our reality is becoming increasingly understood in terms of “computed point elements” which, as Vilem Flusser argues, brings up the epistemological and existential problem of having to understand ourselves and the world around us as “digital apparition[s]” and “swirling point-potentialities” (1996, pp. 242-243, 244). He suggests that this digital worldview is “suggested to us by the sciences and presented to our eyes by computers” (Flusser, 1996, p. 243). Sherry Turkle describes the computer as “an evocative object because it provoke[s] self-reflection and stimulate[s] thought” (1996, p. 362).

Joseph Dumit’s (2004) book entitled *Picturing Personhood: Brain Scans and Biomedical Identity* is an anthropologist’s examination of the use of brain scan images in the mass media. Dumit argues that these images “make claims on us” by categorizing types of brains and therefore types of people (2004, p. 5). He explains that “by showing extreme differences between two states, these [brain scan] images appear to collapse a diverse array or continuum of people into two kinds” (Dumit, 2004, p. 157), which can be seen as problematic. Dumit questions not only the “social and institutional components of brain-fact production”, but also “how cultural identification and intuition coincide with these representations of reality so that we are persuaded to take them as true” (2004, pp. 6-7). Dumit introduces a concept called “objective self-fashioning”, which he describes as the process of “how we take facts about ourselves – (about our bodies, minds, capacities, traits, states, limitations, propensities, and so on) – that we have read, heard, or otherwise encountered in the world and incorporate them into our lives” (2004, p. 164). The importance of this concept is that medical information stemming from medical

technologies, whether it be from brain scans or personal genomics, can have profound effects on the way individuals perceive themselves and on the ways individuals live their lives.

Overall, the most important lesson from Dumit's study is that, "as readers, all of the processes of translation of facts, from one location and form of presentation to another, should be imagined when we critically assess a received fact" (Dumit, 2004, p. 5). Furthermore, he argues "we should try to become as aware as possible of the *people* who interpret, rephrase, and reframe the facts for us (the *mediators*)" as well as "critically assess the structural constraints of each form of representation – peer review, newsworthiness, doctor presentations to patients (the media)" (Dumit, 2004, p. 5).

ii. Surveillance and Power

David Armstrong's article entitled "The Rise of Surveillance Medicine" outlines the transformation of the dominant "medical perspective" from the early eighteenth century to today (1995, p. 393). "Library Medicine" lead to "Bedside Medicine"; "Bedside Medicine" gave way to "Hospital Medicine"; and finally, Armstrong argues that "a new medicine based on the surveillance of normal populations can be identified as beginning to emerge early in the twentieth century" (Armstrong, 1995, p. 395). Armstrong calls this new perspective "Surveillance Medicine" (Armstrong, 1995, p. 395). He argues that this involves an "extension of a medical eye over all the population", "sweep[ing] across innovative spaces of illness potential" (Armstrong, 1995, p. 400, 403). This perspective "turns increasingly to an extracorporal space – often represented by the notion of 'lifestyle' – to identify the precursors of future illness" (Armstrong,

1995, p. 401). It is Armstrong's conclusion that this "surveillance machinery deployed throughout a population to monitor precarious normality delineates a new temporalised risk identity" (Armstrong, 1995, p. 403).

Arney and Bergen identify a lack of concern within medical sociology "with how patients think of themselves or how patients objectify themselves" (1984, p. 3). They argue that this absence has led to neglect of "the significance that the process of the self creating itself as an object has for the self's relations of power with medicine" (Arney & Bergen, 1984, p. 3). They attempt to address this issue with their book *Medicine and the Management of Living*. The focus of the book is on medical discourse: "We need to understand the history of modern medicine as a history of restructurings of a discourse on life and death," they argue (Arney & Bergen, 1984, p. 20). They make an important observation that "the locus of medical power is no longer the hands and eyes of the physician but is instead located in larger, pervasive structures that exert their force on physicians and patients alike" (Arney & Bergen, 1984, p. 167). The overall conclusion made by Arney and Bergen (1984) is that the medical field no longer focuses on the treatment of disease and the prevention of death, but rather the maintenance and management of life. According to reviewer Allan Young, Arney and Bergen's arguments are tied to three important assumptions:

(a) people's life-worlds are strongly affected by the dominant discourses of their times; (b) one of our dominant discourses, the Western medical discourse, has helped shape an undesirable life-world for us; and (c) the critical social sciences, by grasping the connection between discourse, knowledge, and power, have an emancipatory potential in this regard. (Young, 1987, p. 119)

These assumptions have clear implications from a social medicine perspective. As Virchow argues, medical *and* social measures must be “taken to promote health and to combat disease” (as quoted by Holtz *et al.*, 2006, p. 1664). Arney and Bergen (1984) would argue that one of these social measures would be critical analysis of medical discourses by social scientists and thus an illumination of the effects of medical discourses on the publics’ ‘life-worlds.’

The final chapter in *Electronic Culture* is a very provocative, and fairly radical, piece of work entitled “The Coming of Age of the Flesh Machine.” This chapter is written by the Critical Art Ensemble, “a collective of five artists of various specializations dedicated to exploring the intersections between art, technology, radical politics, and critical theory” (Critical Art Ensemble, 2008). The authors identify three control mechanisms in society: the war machine, the sight machine, and the flesh machine (Critical Art Ensemble, 1996). They describe the war machine as “the apparatus of violence engineered to maintain the social, political, and economic relationships that support its continued existence in the world” (Critical Art Ensemble, 1996, p. 391). They explain that the sight machine goes hand in hand with the war machine, “mark[ing] the space of violent spectacle and sacrifice, and [controlling] the symbolic order” (Critical Art Ensemble, 1996, p. 391).

The main argument of this article is that the flesh machine, with its goal of a “world of global eugenics” (Critical Art Ensemble, 1996, p. 392), has finally been “turned on, and, like its siblings the war machine and the sight machine, it cannot be turned off” (Critical Art Ensemble, 1996, p. 394). A central tenet of these machines is

that “vision equals control” (Critical Art Ensemble, 1996, p. 396). Here, the authors describe the workings of the flesh machine:

Not surprisingly, much of the funding for the flesh machine is intended to develop maps of the body and to design imaging systems that will expedite the process (of which the Human Genome Project is the best-known example). From the macro to the micro no stone can remain unturned. Every aspect of the body must be open to the vision of medical and scientific authority. Once the body is thoroughly mapped and its mechanistic splendor revealed, any body invader (organic or otherwise) can be eliminated, and the future of the body can be accurately predicted. (Critical Art Ensemble, 1996, p. 396)

Thus, as the Critical Art Ensemble argues, as the flesh machine invades and visualizes our human bodies, it gains power and control. The Critical Art Ensemble, unlike other scholars referenced above, deals more with domination through medical imaging technologies than with their effects on identity and perception.

Sarah Nettleton’s (1992) *Power, Pain and Dentistry* is also concerned with domination. Nettleton examines the practice of dentistry as a case of institutionalized “disciplinary power” (1992, p. 106). Nettleton argues that “a fundamental dimension of disciplinary power is surveillance,” the most effective of which is “the examination” (1992, p. 107). Dentistry, of course, involves examinations of the teeth and patients are generally encouraged to attend check-ups every six months to ensure oral health is maintained. Nettleton problematizes the seeming natural existence of dentistry by explaining that the concept of oral health has a history:

We have seen that the mouth with teeth is a variable object, it was created and recreated throughout the nineteenth and twentieth centuries. It is not an unequivocal, discrete entity which exists independently of its location. Whilst the words mouth and teeth have remained, what has been seen, known and understood has changed. We might say therefore that the dental gaze has reconstituted the object of its attention. What dentists observe is

not a reflection of a definitive natural object or simply the effect of their sensory perception but rather an object that has been constituted by a disembodied gaze. (1992, p. 106)

Therefore, as the mouth and teeth became differentiated from the rest of the body, with its own specialized needs for treatment, the overall need for dentistry was constructed.

Nettleton identifies dentistry as “an example [of] technologies and techniques that have permeated the body, the individual, the self and the population throughout the nineteenth and twentieth centuries” (1992, p. 106). This statement implies that the values of dentistry have become internalized by Western society. Individuals therefore feel obliged to take care of their teeth on their own and also consult their dentists for professional assistance. Nettleton explains that, in general, such “technologies of discipline rely increasingly on the patient, the prisoner or the student to assess themselves – to monitor their own progress or assess their own lifestyles” (1992, pp. 148-149). In other words, self-surveillance is being encouraged more and more as a form of disciplinary power. Nettleton urges scholars “to direct [their] attention towards researching the ways in which various institutionalized disciplines look at bodies; how they describe, assess, clarify and work upon them” (1992, p. 127).

iii. Genetics

Thomas Lemke’s “Susceptible Individuals and Risky Rights: Dimensions of Genetic Responsibility” revolves around the effects of “increasing genetic knowledge” on individuals (2007, p. 151). Lemke argues that “the discourse of genetic responsibility tends to undermine guaranteed rights and the freedom of choice concerning genetic tests by establishing imperatives of duty toward oneself and others” (Lemke, 2007, p. 152).

He notes that this discourse, and its “construction of “at-risk individuals, families, and pregnancies”, leads to moralizations “on deviant behaviour”, assignments of “guilt and responsibility”, and also to the conclusion that “only those who act responsibly draw the correct, that is, risk-minimizing and forward-oriented, conclusions from this range of information” (Lemke, 2007, p. 161).

The aim of Karen-Sue Taussig’s “Genetics and Its Publics: Crafting Genetic Literacy and Identity in the Early Twenty-First Century” is to investigate “whether and how the practices emerging with new genetic knowledge engender new kinds of selves, persons, and citizens” (2007, p. 192). She argues “that we are in the midst of a profound world-view shift regarding genetic causality and responsibility for human health, engendering new biopolitical regimes and related social and embodied practices” (Taussig, 2007, p. 192). Within this context, Taussig identifies a change in the conceptualization of individuals and their bodies:

...The contemporary biopolitics being forged by desires for genomic medicine configures persons as biosocial citizens whose bare life is essential for the production of knowledge and control of the health of individuals and populations and whose ethical life is being crafted as demanding participation in the knowledge production process. (2007, p. 192)

The critical implications of genomics research, according to Taussig, are that they “mak[e] claims on transforming conceptualizations of health and illness, on how people imagine their relationships to each other, on human variation, and even on understandings of what it is to be human” (2007, p. 193).

In the epilogue of *Biomedicine as Culture*, Dumit and Burri conclude that “the struggle to incorporate genetic results, partial probabilities, and preventative strategies

into one's life involves an experimental search for metaphors on the side of subjects as well as by doctors and researchers" (2007, p. 227). They note that while "genes are potent objects to think with", "gene information is not so persuasive... if it contradicts one's life experiences" (Dumit & Burri, 2007, p. 227). It is therefore impossible to anticipate individuals' reactions to genetic information, but suffice to say that this type of information is powerful and consequential in terms of influence on identity and lifestyle.

Also on the topic of the discourses surrounding the human genome is Janine Marchessault's (2000) chapter on David Suzuki's *The Secret of Life* documentary, a four-part series on DNA, broadcast on the BBC and then PBS in 1993. Marchessault points out the ways in which the documentary conceives of the body as information (2000, p. 62). With her analysis of the scientific information that is presented as factual by narrator David Suzuki, Marchessault intends to "bring an historical dimension to the popular representations of the human genome [and] to draw out some of the differences and similarities between the old and the new biology, the distinctions between eugenics and genetics" (2000, p. 56). She first problematizes the seemingly straightforward nature of the human genome:

... Life is far more complicated and unruly than the double helix would lead us to believe. Obviously, the reduction of life to a model, or the body to a program, carries severe implications for social identities and political agency. (Marchessault, 2000, p. 56)

Marchessault concludes that the philosophy behind eugenics is still influential today (2000, p. 63). She notes that, although the ideal of "racial perfection" has been replaced by an ideal of "individual health", this "new biology" similarly places value "on standards of normalcy, standards defined according to a norm signified by the singularity

of *the* human genome and against an ever-growing list of genetic diseases”

(Marchessault, 2000, p. 56, 63).

A book often cited by these authors is Evelyn Fox Keller’s (1995) *Refiguring Life: Metaphors of Twentieth-Century Biology*. This book is a compilation of three essays that, as the title suggests, examine the metaphors employed in the field of biology, specifically the field of genetics. Keller notes that the use of language and the *communication* of scientific information is generally overlooked and not considered to be important in the scientific field: “Scientists usually assume that only their data and theories matter for scientific progress, that how they talk about these data and theories does not matter, that it is irrelevant to their actual work” (Keller, 1995, p. 10). She argues that “the ways in which we talk about scientific objects are not simply determined by empirical evidence but rather actively influence the kind of evidence we seek (and hence are more likely to find)” (Keller, 1995, p. 35). Therefore, scientific discourses should be analyzed, because of the potential cognitive and political power of this type of communication (Keller, 1995, p. 11).

The focus of Keller’s book, as mentioned above, is the field of genetics research. She focuses particularly on the importance of technology in the development of this field and how these developments have affected scientific conceptions of the body:

... We now have different ways of talking of the body (for example, as a computer, an information-processing network, or a multiple input-multiple-output transducer) but that, because of the advent of the modern computer (and other new technologies), we now have dramatically new ways of experiencing and interacting with that body. (Keller, 1995, p. xvii)

In the chapter in which she analyses “the discourse of gene action”, Keller notes the attribution by scientists of “causal power” or agency to human genes and asks “to what extent does it reflect the facts of a particular disciplinary culture... and is it just a way of talking? Is it not also a way of thinking, a way of seeing, and a way of doing science?” (1995, p. 3).

Irma van der Ploeg puts forth “the notion of body ontology” as a way “to describe the way the human body is implicated in a process of co-evolution with technology – information technologies, but also surgical, chemical and genetic and visualization techniques, and combinations of these” (2003, p. 64). She explains that “over the past century, various developments, mainly in medical science, have resulted in a set of body ontologies that ... quite explicitly construe the body in terms of flows of information and communication patterns” (van der Ploeg, 2003, p. 64). One such body ontology is the one generated by the field of genetics (van der Ploeg, 2003, p. 64). This body ontology “takes the building blocks of the body to be “information”: the human genome and DNA itself are codes to be broken in order to enable us to “read” the “blueprints of life”” (van der Ploeg, 2003, p. 64). Every human being “has a unique genetic pattern that is intrinsically one of the most personal things anyone can know about us” (Brin, 1998, p. 90). The personal and individual nature of DNA raises questions in regards to control of genetic information:

Does this mean a sovereign citizen should therefore *control* any scientific or commercial use of the specific patterned sequence of coded letters representing his or her DNA? ... Are personal data a commodity? Are individuals endowed by their Creator, or by natural law, with an innate proprietary power of the words, images, and factual details of their lives? (Brin, 1998, p. 90)

Individuals' genetic information can now be seen as valuable – to researchers, and to private companies like 23andMe, Inc., that coordinate with researchers.

iv. Health and Society

In Joseph Dumit and Regula Valérie Burri's introduction to *Biomedicine as Culture: Instrumental Practices, Technoscientific Knowledge, and New Modes of Life*, they describe the "biomedicalization of society", a societal transformation that has occurred since the mid-twentieth century (2007, p. 4). This transformation involved "a growing number of aspects of life [becoming] defined as medical problems" and "a medical perspective increasingly appl[ying] to realms which ha[d] not been considered as medical before" (Dumit & Burri, 2007, p. 4). Within this context, "health has become a moral responsibility [and] the management of illnesses and health risks [has become] defined as a personal duty to be fulfilled" (Dumit & Burri, 2007, p. 4). The book is contextualized within what they call "emergent "bioscapes"... terrains that are characterized by indetermination, standardization, post-medical demands, partial evidence, and logics of obligation" (Dumit & Burri, 2007, p. 9). Of great importance to the contributors of this book are "the genetic assumptions of biomedicine", as they prompt a "reencoding [of] the categories of health and illness, of normality and pathology" (Dumit & Burri, 2007, p. 2). Burri and Dumit argue that these assumptions transform the relationship "between nature and culture in the life sciences [and] in society in general" and "rais[e] fundamental questions about cultural backgrounds of biomedical practices and its consequences for society and people's identities" (2007, p. 2). In fact,

they identify “statistical models of risk and probabilities as well as new genetic knowledge and emerging technologies [as now] incorporated and handled within daily life, and they [have] become part of everyday conversations” (Dumit & Burri, 2007, p. 4). The implication of this “entangled nature of biomedical knowledge and technology in everyday life” is that it “encompasses the transformation of how the body is constructed, seen, and talked about” (Dumit & Burri, 2007, p. 5).

José van Dijck’s *Imagination: Popular Images of Genetics* investigates “the role of images and imagination in popular representations of the new genetics since the late 1950s” (1998, p. 3). By “imaginings” van Dijck means “what we want to believe, what we project or imagine that science and technology can do for us in the future” and “the lubricant that ties in ideological concepts and scientific inventions” (1998, p. 1). She explains that biotechnology was a product of Wall Street in the 1970s, reflective of a marriage between science and commerce (van Dijck, 1998, p. 96). Due to an initial lack of “product”, “investors and the public had to rely to a large extent on images – images that helped them imagine what a gene was and what genetics could do” (van Dijck, 1998, p. 96). Accordingly, “a need to predict and cure genetic diseases” was created at this time (van Dijck, 1998, p. 97). Although, as van Dijck notes, “only a tiny percentage of the population is endowed with diseases that can be unambiguously ascribed to genetic causes” (van Dijck, 1998, p. 8), “genetics became a story of crippling disease and glimmering hope for prevention and cure” (van Dijck, 1998, p. 97). Van Dijck explains that this image has been promoted in the “public arena in which not only scientists, but also journalists, activists, politicians and others present their own and each other’s views,

using an array of rhetorical techniques” (van Dijck, 1998, p. 16). It is from this arena that the “dominant meaning of science” (van Dijck, 1998, p. 16) is produced.

Health Promotion and Consumer Culture

So far, the literature of social medicine and the cultural studies of science have shown that we live in a society where surveillance (and self-surveillance) is pervasive. The ‘medical gaze’ surveys the masses, promotes self-management of day-to-day health, and points to lifestyle analysis for risk assessment. Medical power is dispersed throughout power structures. Medical discourse affects individuals and their ‘life-worlds.’ As such, it is both medical and social measures that are required in order to promote health in today’s society. The literature also demonstrates that society has experienced a vast ‘biomedicalization.’ Medical discourses are important as they often influence what scientists look for and what they look at, in terms of research and analysis. Medical discourses often categorize individuals into constructed, distinctive groups. This categorization often involves dichotomies: healthy and unhealthy, at risk or not at risk, etc. This type of categorization leads to a burden of moral responsibility on the part of the categorized individual, especially if the medical information involved is genetic. This information has effects on relationships and social perceptions. Health culture increasingly involves consumerism and virtual tourism of the body. Finally, it is most important that medical facts must be interrogated.

Unfortunately, those in the greatest danger in terms of needing medical attention and/or intervention are those without the resources to help themselves – time and money. Due to the neoliberal environment we live in today, here in Canada and other developed

nations, our health services have come to rely heavily on the private sector. This can be evidenced by the dominant health policy discourses. Dennis Raphael (2008) of the University of Toronto has identified three within public policy and the media's coverage of public policy in Canada: "Health promotion", "population health", and "healthy lifestyles". In 1986, the World Health Organization held the "First International Conference on Health Promotion" in Ottawa. In the charter adopted at this conference, the WHO defines "health promotion" as follows:

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being. (Raphael, 2008, p.1)

Raphael identifies Canada as "a leader in the development of health promotion concepts" (2008, p. 483). However, he goes on to explain that "in reality, health promotion in Canada – and its ambitious agenda for community action and public policy in the service of health – has always served as a marginal discourse in the Canadian health policy arena" (Raphael, 2008, p. 484). Raphael argues that this failure is due to the "liberal political economy" that Canada exhibits (2008, p. 484). In this system, the marketplace is "the primary institution and arbiter of resource distribution – political, economic, and social – within a society" (Raphael, 2008, p. 484). Raphael notes that since the 1990s, neo-liberalism has more or less defeated health promotion:

Living conditions have deteriorated for the most vulnerable, governments have abdicated much of their responsibilities for assuring citizen health,

and the concept that citizens and communities should be assisted in gaining control over the determinants of health has dissolved. (2008, p. 487)

Population health, first introduced by health economists Robert Evans and Greg Stoddart in 1991, reflects the belief “that it is the social environment, of which health care systems are a relatively small part, that determines health” (Coburn, Denny, Mykhalovskiy, McDonough, Robertson & Love, 2003, 392). The discourse of population health emerged in the 1990s, growing “out of efforts by the Canadian Institute for Advanced Research to identify what they termed the determinants of health” (Raphael, 2008, p. 487). Raphael explains that some believe that this discourse “displaced health promotion... in terms of government departments, health policy rhetoric, and distribution of research funding” due to its compatibility with neo-liberal ideals and “government willingness to turn over policy development to an outside institute” (2008, p. 487).

Finally, Raphael identifies “healthy lifestyles rhetoric” as “lifestyle messaging” about “making healthy choices in the service of health” such as “healthy diets, physical activity, and reducing tobacco use” (2008, p. 488). This messaging, Raphael argues, is disseminated “on a daily basis by government agencies, public health agencies, disease associations and the media” (2008, p. 488). He notes “massive amounts of government spending, media attention, and health sector activities being lavished on ‘lifestyle’ approaches to health promotion”, identifying the “obesity epidemic” as a noteworthy example (Raphael, 2008, p. 490). Raphael suggests that these messages distract the population from dealing with important issues: “Food bank use and homelessness may be increasing across Canada and employment and working conditions may be deteriorating,

but every Canadian believes that the primary determinants of health are diet and physical activity” (2008, p. 488). What is important about Dennis Raphael’s identification of these three health policy discourses is that these discourses play a hegemonic role in Canadian society and affect perspectives of the population on health issues as well as the implementation of government health initiatives.

Raphael’s identification of health policy discourses in Canada is relevant to this project, because they suggest that those whose health is considered important in society are those who have enough time, money and resources to play an active role in their well-being. This state is heightened by the corporatization of services such as 23andMe’s personal genomics. Only affluent individuals can afford to decode their genes and also make changes to their lifestyle in order to decrease certain risks.

In her journal article “Seeking Health Information on the Internet: Lifestyle Choice or Bad Attack of Cyberchondria”, Tania Lewis (2006) examines the consumption of health information by way of the Internet. She identifies “personalized health websites” such as RealAge.com as being “part of a broader trend across the media” (Lewis, 2006, p. 521). She argues that “from television to the print media, health issues today are increasingly talked about in terms of individual rather than governmental or social responsibility” (Lewis, 2006, p. 521). Similar to Raphael, Lewis notes “a shift in the language of public health and health promotion more generally” in that these days “media coverage tends to focus on the notion of the healthy responsible citizen as an essentially self-managing and self-monitoring subject” (Lewis, 2006, p. 521). She explains the nature of this messaging:

In the new public health paradigm, citizens are encouraged to direct and shape their own health biographies as they would any other aspect of their lives. Health here is not treated as something external to or outside of the control of the individual but instead is embraced as part of a broader linking of ideas of the body, self and lifestyle. (Lewis, 2006, p. 522)

This shift towards responsibility for one's own health is accompanied by "a shift which has seen health increasingly packaged as a 'lifestyle' issue, particularly in the popular media" (Lewis, 2006, p. 535). Lewis proposes that any negative reactions to online health information, as expressed in medical literature, suggests "a recognition that doctors are no longer necessarily the sole holders of health knowledge and that many consumers are now increasingly taking control over their own health care management" (Lewis, 2006, p. 535). Therefore, such online sources of medical information bring up questions and "anxieties over what gets counted as legitimate health knowledge" in Western society today (Lewis, 2006, p. 535).

Lewis argues that "more than any other media form, the Internet offers the possibility of accessing highly specific, personalized and often specialized knowledge about health issues" (Lewis, 2006, p. 536). As a result, "online health consumption increasingly involves an internalization of once primarily governmental techniques of public health and health promotion" (Lewis, 2006, p. 536). The conclusion of Lewis's research is that "online health consumption does not easily fall into one simple model but tends to be embedded in questions of social identity and the pressures and constraints of everyday life" (Lewis, 2006, p. 537). The implication of this conclusion is that "understanding the role that contemporary media forms like the internet play in people's health management, then, involves focusing less on 'quality' issues and media

'messages' and more on how people's health and lifestyle choices are structured at a social and everyday level" (Lewis, 2006, p. 537).

In a similar vein, Davi Johnson examines "brain-based self-help books" as a genre and aims to answer the following research questions: "First, how is the visual authority of brain images utilized to translate neuroscience into a comprehensive program for living? Second, what are the personal, social and political effects of this translation of neuroscience and its active uptake by public audiences?" (2008, p. 148). Johnson describes these self-help books as "rhetorical mechanisms" worthy of study "because the constitution of active citizens and the alignment of individual and state interests are at least partially the outcomes of persuasive process" (2008, p. 149). Johnson argues that this genre of self-help books "disseminat[e] neuroscientific ways of thinking, speaking and acting to individuals" (2008, p. 149). Johnson explains that the discourses found in these self-help books serve biopower, as conceptualized by Foucault: "First, all of life is rendered in calculable, scientific form and second, individuals are interpellated as active agents who can act to improve their health through techniques of self-government and self-management" (Johnson, 2008, p. 149). Johnson notes that "the movement of neuroscience as a comprehensive knowledge for daily living coincides with" the concept of "healthism" (2008, p. 149).

Healthism: A New Religion?

Health, as a concept and a goal, has been amalgamated with ideas of "morality, success, and good citizenship" (Dworkin & Wachs, 2009, pp. 39-40). Dworkin and Wachs argue that we have lost "the ability to define the *image of a healthy body*... based

on critical measures of health (cholesterol, pulse rate, blood pressure, cardiovascular fitness, pulmonary function, and so forth)” (2009, pp. 39-40, emphasis added). Rather, “an *image of health* becomes paramount” as “panoptic mechanisms” have directed the public “to internalize self-surveillance of the surface of the body” (Dworkin & Wachs, 2009, pp. 39-40). Not only do we pursue a particular, socially constructed idea of physical perfection on the outside, but we also seek to perfect our inner make-up by systematically identifying and attempting to annihilate risks to our health. We are socialized not only to employ self-surveillance of the exterior of the body, but also concealed characteristics right down to the genetic level. This perspective has been conceptualized with the term “healthism” (Dworkin & Wachs, 2009, p. 11).

“Healthism” was coined by Robert Crawford in 1980 (Dworkin & Wachs, 2009, p. 11). This concept is based on the argument that “contemporary capitalist culture is infused with notions of “health” and health promotion [in ways that] reveal assumptions about normality, well-being, and morality (and are not necessarily healthy)” (Dworkin & Wachs, 2009, p. 11). Crawford argues that “like medicine, healthism situates the problem of health and disease at the level of the individual. Solutions are formulated at that level as well” (Crawford as quoted by Dworkin & Wachs, 2009, p. 11). Crawford and other scholars identify healthism “as part of the project of neoliberalism where it is “an ideologically insidious force, which by elevating health to a super value a metaphor for all that is good in life... [it] reinforces the privatization of the struggle for generalized well-being” (Crawford as quoted by Dworkin & Wachs, 2009, p. 12). As Nikolas Rose

(1996) explains, the place of experts has shifted within advanced liberal democratic society. This advanced liberalism, he argues,

seeks to degovernmentalize the state and to de-statize practices of government, to detach the substantive authority of expertise from the apparatuses of political rule, relocating experts within a market governed by the rationalities of competition, accountability and consumer demand. It does not seek to govern through “society”, but through the regulated choices of individual citizens, now construed as subjects of choice and aspirations to self-actualization and self-fulfillment. Individuals are to be governed through their freedom. (Rose, 1996, p. 41)

This trend can be seen in the recent “technology-mediated democratization of health care knowledge and tools”, which could potentially bring us to a day when “a suitably motivated consumer/patient [is] in a position to be their own primary care provider”

(Kahn, 1997, p. 192). As Kahn explains,

With a better-educated populace and increasing access to health care information through the mass media, we are witnessing a shift away from the deification of our healers, many patients now see themselves as consumers instead of supplicants, and health care professionals as educated, but fallible mortals, providing a consumer service. And as in other areas, a larger proportion of these consumers are desiring a more active role in the decision-making and are seeking out providers that support this desire. Furthermore, the individual health care consumer is increasingly becoming empowered to engage in fairly sophisticated self-care and health-promotion activities, with or without professional assistance for problems formerly requiring medical intervention. (1997, pp. 192-193)

An implication of this shift is that since medical information and/or advice is becoming a commodity, private entities such as corporations are gaining power over the population:

“Whenever knowledge is a scarce good, it confers power on its possessors” (Randall Bartlett as quoted by Gandy, 1993, p. 19).

Monica Greco (1993) writes about the healthism movement in her article “Psychosomatic Subjects and the ‘Duty to be Well’: Personal Agency Within Medical Rationality.” Greco defines healthism as “the idea of one’s health as the enterprise of oneself” and explains that “healthism posits a fundamental faculty of choice applicable towards preserving one’s physical capacity from the event of disease” (1993, p. 357). She concludes that “a moral responsibility has become associated with prevention” (Greco, 1993, p. 370). Greco also notes that there are an infinite number of preventative strategies ranging from “think[ing] positively in the face of stress... to the self-monitoring and modification of physiological responses” (1993, p. 370). As Davi Johnson explains, health has been “expanded from a biomedical concept into a general *telos* of self-improvement or rubric for the type of being individuals aspire to in a moral way” (2008, p. 149).

Returning to Davi Johnson’s work on brain-based self-help literature for a moment, the conclusions drawn from his research are that since self-help “initiatives are taken up at the behest of the individual, for their own improvement, they appear to be apolitical” (2008, p. 159). However, Johnson cautions that “in terms of neoliberal government, practical neuroscience plays an important role in constituting efficient and adaptable citizens, or “healthy” individuals who are also “healthy” citizens who participate in effective government” (2008, p. 159). Therefore, this type of literature and messaging should be interrogated in order to uncover its sociopolitical implications.

Healthism reflects the idea that “the contemporary ideal body is that of the civilized body, subject to highly conscious and rational control” (Lupton, 1995, p. 70).

Deborah Lupton explains that “one can explain current norms around the government of the body in terms of taste” (1995, p. 70). She points to “dieting, watching one’s weight and exercising” as examples of favourable activities and to obesity, the consumption of unhealthy foods, “unfirm” bodies, and the habit of smoking as “considered poor taste” in today’s environment (Lupton, 1995, p. 70). Lupton argues that “all medical conditions are subject to moral judgements, based on such concepts as personal responsibility for illness and the patients’ compliance with medical advice” (1995, p. 71).

A century ago, Émile Durkheim observed “that judgments of right and wrong were coming to be based on the findings of scientists rather than on the teachings of religious leaders or philosophers” (Glassner, 1992, p. 247). Lupton argues that, today, “in this secular age, focusing upon one’s diet and other lifestyle choices has become an alternative to prayer and righteous living in providing a means of making sense of life and death” (1995, p. 4). Lupton equates a personal health risk assessment to a religious confession:

Individuals are incited to tell their ‘sins’ to the health worker, or else their bodies provide mute testimony to their self-indulgence (if found to be overweight or to have a high blood cholesterol reading, for example). Once the assessment is finalized, judgement is passed upon participants, and they are given appropriate ‘penances’ to perform to re-establish bodily, and moral, integrity. (1995, p. 82)

Furthermore, she argues that risk has now replaced the “notion of sin” (Lupton, 1995, p. 89). It is the discourse of lifestyle risk, in particular, that inspires the guilt and “responsibility of individuals to avoid health risks for the sake of their own health as well as the greater good of society” (Lupton, 1995, p. 90). Peter Marsh (2001) echoes Lupton by explaining that this “notion of ‘lifestyle correctness’, founded largely on narcissistic

health ideals, has come to shape the direction of people's lives in ways which once characterized the power of formal religions."

Shari L. Dworkin and Faye Linda Wachs (2009) contextualize this line of argument specifically within that of consumer culture:

...With the advent of consumer culture, the salvation once derived through the soul (and its confessions) has moved to the body and the flesh. The body, then, does not simply become a sign of mortality (or immortality) by being matched by moral (or immoral) acts, but the body generates the sign of morality in consumer culture that becomes the moral act itself. While once the sins of the individual were thought to be written on the flesh, simply not having perfect flesh is now viewed as a sin in and of itself. (Dworkin & Wachs, 2009, pp. 14-15)

Joachim Knuf and John Caughlin's (1993) article entitled "Weighty Issues: Semiotic Notes on Dieting as a Secular Ritual" presents the findings of their semiotic analysis of diet advertisements. Despite the fact that research shows that "dieting only works in the short term" and "can cause health problems", it is a \$40 billion industry in the United States (Pagliassotti, 2003, p. 1). Knuf and Caughlin argue that dieting is a "formal rite of passage" (1993, p. 174) within secular contemporary society:

... Ritual performances of this type have three parts: They begin by separating individuals (or groups) from the rest of society, canceling their current social status. This separation phase focuses on the contradictions of the present state of affairs and on the necessity of change. Ritual participants are next conveyed into a liminal state in which transformations and processes of structural change are effected. This liminal state often has spatio-temporal dimensions isolating it from its environment, so that the continuity and stability of the wider social system is not compromised by the individual change process. The integration phase of the ritual finally resolves the initial contradictions by accommodating process in the structure and reintegrating participants into the same structure, but in new positions. Ritual, then, is a mechanism for the accommodation of necessary change in a neutral environment that protects the social order itself. (Knuf & Caughlin, 1993, p. 174)

They conclude that health “is becoming an artifact, a commodity to be purchased from health care providers and manufacturers alike” (Knuf & Caughlin, 1993, p. 177).

The implication of these arguments is the suggested God-like power of the media today. If scientists are the new religious leaders, health risk assessments are the new confessions, health risks are the new sins, and dieting is a ritual, it follows that the media function as scripture. Dworkin and Wachs argue that “readers employ the messages provided by [media] texts as they learn to self-surveil with respect to the cultural ideals promoted” (2009, p. 10). There are pervasive messages disseminated by the media that “produce a “culture of lack” and an endless array of products to assuage the lack, or at least the stigma of possessing it” (Dworkin & Wachs, 2009, pp. 10-11). Redemption can be achieved by living a ‘healthy lifestyle’, which means literally buying into the health industry in one way or another. Governments often provide information about how the population can protect itself about common threats (such as the flu) (see Public Health Agency of Canada, 2009). Although they are not promoting the consumption of particular consumer products, they are contributing to the culture of healthism and risk.

Conclusion

It goes without saying that medical research and health care development aim to maintain the health of the public, preventing and treating illness to improve the length and quality of life. As explained above, there is an increasing focus on lifestyle and prevention, placing the responsibility of health maintenance on individuals. Deborah Lupton explains that health promotion content tends to use “euphemisms, metaphors and metonyms [such as] ‘weight problem’ or ‘smoking habit’” instead of more negative terms

such as “the dying body” (1995, p. 64). Lupton argues that in these attempts “to contain, control and deny the reality of death, such representations have the paradoxical effect of locating death everywhere, requiring constant attention to keep it away” (Lupton, 1995, p. 64). François Ewald argues, “there is no risk in reality” (1991, p. 199). Such a category is “purely socially constructed, for nothing is a risk in itself until it is judged to be a risk” (Lupton, 1995, p. 79). The use of the word “risk” as opposed to “danger” reflects a rhetorical strategy to insinuate neutrality and precise calculation (Lupton, 1995, p. 80). As such, risk discourse is “a political strategy, a way of negotiating the dialectic between private fears and public dangers” (Lupton, 1995, p. 80). In fact, risk is so pervasive in our society (Featherstone *et al.*, 2006) that Jennifer Terry argues, life “is commonly described in terms of risks, suspicions, fear, and increasing violations to personal autonomy” (Terry, 1989). Jane Ogden argues that in today’s society, “risk is no longer external to the self” but rather “the risk to health is conceptualized as an internal, malleable and manageable self. The risk to health comes from the individual’s presence or absence of self-control which manages and masters the changeable drives that expose the body to threats” (1995, p. 413). Due to an apparent mix of genetic inheritance and lifestyle choices, “in the late twentieth century the individual has become at risk from his or herself” (Ogden, 1995, p. 413). Not surprisingly, all of society can be seen as being at risk in one way or another, therefore there is an abundance of consumers with needs waiting to be satisfied by products and services.

The literature review has shown that notions of risk and lifestyle have become important in today’s culture. Anthony Giddens explains, “the more tradition loses its

hold, ... the more individuals are forced to negotiate lifestyle choices among a diversity of options” and participate in “reflexively organized life-planning, which normally presumes consideration of risk filtered through contact with expert knowledge” (1991, p. 5). He identifies this experience has “a central feature of the structuring of self-identity” (Giddens, 1991, p. 5). This idea of the development of self-identity and self-knowledge in reaction to risks will be discussed further in the next chapter, as part of a larger discussion of categorization and locating oneself within communities.

Chapter 3: The Panoptic Sort and the Communication of Personal Data

Introduction

As Sonja Olin Lauritzen and Lars-Christer Hyden note, there is a significant amount of literature on “the impact of medical technologies [on] the organization of health care, professional practice as well as patients’ experiences” (2007, p. 1). However, they note a “lack of knowledge about these rapidly changing scenarios in health care and the ways medical technologies intervene into our lives and affect our ideas about the healthy and the ill body, our self-identity and relations to others” (Olin Lauritzen & Hyden, 2007, p. 1). This chapter will contribute to the theoretical basis for my case study, which will endeavour to help fill this gap in the literature. I will demonstrate that various technologies today perform a “panoptic sort” (Gandy, 1993), categorizing individuals based on personal data without reference to the context from which the data emerged. I will touch on several concepts that are relevant to my study of 23andMe: the panoptic sort, the computerized database, the Internet, and social networking sites. These technologies all deal with the collection and organization of personal information, for various applications and purposes. Consumers and users receive various benefits from these services in exchange for providing personal information and privacy with little to no concern for the implications of such disclosure. I argue in this chapter that we interact with data about ourselves, in various forms, everyday. Increasingly, this data includes medical information, as we live in a culture that can be described as being obsessed with the concept of health and risk prevention.

The Panoptic Sort

The “panoptic sort” was conceptualized by Oscar H. Gandy, Jr. (1993). Gandy uses this term to describe “the complex technology that involves the collection, processing, and sharing of information about individuals and groups that is generated through their daily lives as citizens, employees, and consumers” (Gandy, 1993, p. 15). He argues that the panoptic sort “is used to coordinate and control ... access to the goods and services that define life in the modern capitalist economy” (Gandy, 1993, p. 15). Gandy describes this technology as “discriminatory”, “institutionalized”, lawful, and “efficient” (Gandy, 1993, p. 15). In other words, it is pervasive and powerful.

Gandy’s panoptic sort builds upon Foucault’s concept of “normalization”: “a system of finely graded and measureable intervals in which individuals can be distributed around a norm – a norm which both organizes and is the result of this controlled distribution” (Gandy, 1993, p. 10). Gandy’s panoptic sort deals specifically with automated technologies that assess and categorize individuals by their personal information, as entered into a database. An important aspect of the panoptic sort is prediction:

Predictability, the reduction of uncertainty about individual behaviour, is a valued aspect of social systems and the social relations within them. Power may be seen as the ability to act in such a way as to induce a desired and predictable reaction. It is in the pursuit of improved predictability that the panoptic sort is engaged, and it is calibrated on the basis of a limited amount of information about a great number of individuals. (Gandy, 1993, p. 45)

The consequence of such categorization and prediction, Gandy argues, is victimization due to decontextualization (Gandy, 1993, p. 18). He explains, “the circumstance cannot

be recaptured; an assessment will always be incomplete” (Gandy, 1993, p.-18). It is also problematic that this decontextualization “reflects an institutionalized bias; a bias established by race, gender, class, culture, and consciousness” (Gandy, 1993, p. 18).

David Lyon explains that while “categorization is endemic and vital to human life, especially to social life”, what he calls “institutional categorization” came into its own with the “analytical, rationalizing thrust” of modernity (2003, p. 21). Lyon explains that the emergence of modern institutions “meant that those who were citizens, employees, and, in time, consumers found themselves with institutional or organizational identities that had to be calibrated with their self-identities” (Lyon, 2003, p. 21). Lyon goes on to explain that computers reinforced this “social power of information” (Lyon, 2003, p. 22):

For one thing, the records of those organizational identities, long ago relegated to filing cabinets, seldom disturbed, are now on the move. Data doubles—various concatenations of personal data that, like it or not, represent “you” within the bureaucracy or the network—now start to flow as electrical impulses, and are vulnerable to alteration, addition, merging, and loss as they travel. For another, the ongoing life of the data doubles now depends upon complex information infrastructures. This may help to democratize the information; it may equally lead to tyrannies. (Lyon, 2003, p. 22)

Lyon’s *Surveillance as Social Sorting: Privacy, Risk, and Digital Discrimination* is based on the premise that such “surveillance is not simply a contemporary threat to individual freedoms, but that, more insidiously, it is a powerful means of creating and reinforcing long-term social differences” (2003, p. i).

In today’s plugged-in society, we all disclose personal information to a variety of sources every day. Banking, shopping, social networking can all be done online. We can

access the Internet from our desktops, our laptops, and our cell phones. Interactions, transactions, and relationships in general, “no longer depend on embodied persons being co-present with each other. Abstract data and images stand in for the live population of many exchanges and communications today” (Lyon, 2003, p. 18). Manuel Castells explains that computers “make possible the gathering, processing, and using for specific purposes of a mass of individualized information, so that our name can be printed, or the offering personalized, or an offer mailed out, or beamed in, to millions of individuals” (2004, p. 342). Since this surveillance system “relat[es] to each one of us on a personal basis”, there is a sense of “a myriad of well-wishing “little sisters”” as opposed to “an oppressive “Big Brother”” in Orwellian terms (Castells, 2004, p. 342).

However, these “well-wishing” forces are driven by a motive David Brin identifies as *revenue* (1998, p. 89). He explains that information has been described as the “money of the future”, a variation on the saying “knowledge is power” (Brin, 1998, p. 89). In his book, *The Transparent Society: Will Technology Force Us to Choose Between Privacy and Freedom?*, Brin argues that “soon, computers will hold all [our] financial and educational records, legal documents, and medical analyses that parse [us] all the way down to [our] genes” (1998, p. 8). He warns that “the choices we make regarding future information networks – how they will be controlled and who can access the data – will affect our own lives and those of our children and their descendents” (Brin, 1998, p. 8).

This overall surveillance structure gathers “personal and group data in order to classify people and populations according to varying criteria, to determine who should be

targeted for special treatment, suspicion, eligibility, inclusion, access, and so on” (Lyon, 2003, p. 18). The important implication stemming from the concept of the panoptic sort is that it “affects people’s lifestyle choices... and their life-chances” (Lyon, 2003, p. 20). For example, as Lyon explains, “if you won’t accept the cookie that reports your surfing habits to the parent company, don’t expect that information or access will be available” (2003, p. 20).

It is a fact that “details of our lives are recorded and preserved by hundreds of entities, often commercial in nature” (Battelle, 2005, p. 11). John Battelle points out that consumers “trade some of [their] privacy” for the “convenience, service and power” that services such as the search, recommendation networks, and email afford (2005, p. 12). Underlying these dealings is an implicit and assumed agreement between users and service providers that users’ personal information will be kept “secure, free from unlawful government or private search and seizure, and under [their] control at all times” (Battelle, 2005, p. 15). It is generally understood that companies “might use [their] data in aggregate to provide ... better and more useful services” and assumed that individuals will not be identified “personally through [their] data” nor would their data be used “in a manner that would violate [their] own sense[s] of privacy and freedom” (Battelle, 2005, p. 15).

The Power of the Database and the Search

The electronic database is a very important technology within the information society of today (Chow-White, 2008, p. 1173). They are central to “the process of sorting and storing data, networking information and constructing knowledge” (Chow-White,

2008, p. 1173). Lyon observes that “everyday surveillance depends increasingly on searchable databases” (2003, p. 20). The database is an important concept, which will now be discussed in relation to the concept of “the search” (Battelle, 2005) and surveillance. Personal information, resulting from activities such as “transactions, interactions, visits, calls, and other activities”, is transformed into “codes, usually processed by computers” (Lyon, 2003, p. 13). These codes “are the invisible doors that permit access to or exclude from participation in a multitude of events, experiences, and processes” (Lyon, 2003, p. 13). Information is organized and categorized, resulting in classifications “designed to influence and to manage populations and persons thus directly and indirectly affecting the choices and chances of data subjects”, in a virtual manner (Lyon, 2003, p. 13).

Mark Poster sees “computerized databases” as an example of what he calls “the mode of information”, also known as “electronically mediated communication” (2004, pp. 398-401). Poster’s main argument is that “the mode of information enacts a radical reconfiguration of language, one which constitutes subjects outside the pattern of the rational, autonomous individual” (2004, p. 398). As such, this technology helps to construct a subject “that is multiplied, disseminated and decentered, continuously interpellated as an unstable identity” (Poster, 2004, p. 398). Poster argues that the control of personal information compiled in databases is a very important concern, especially “as the economy relies more and more upon information” (2004, p. 401). He explains that individuals’ actions are documented by “trails of digitized information which are regularly accumulated in computer databases” and that this information is being

“arranged into profiles, forming more and more detailed portraits of individuals” (Poster, 2004, p. 402). Similar to Gandy’s (1993) argument that the panoptic sort is dangerous due to its decontextualization of information, Poster notes that “databases are inherently limited and restricted structures of information” (2004, p. 402). While databases may provide speedy information retrieval, its “simplification of data drastically distorts” reality (Poster, 2004, p. 402).

Poster (2004) refers to Foucault’s work for insight into the impact of databases in society:

Foucault theorized, first, power in relation to a specific social formation, the panopticon, which has direct application to databases; second, the relation between social phenomena and the subject that is relevant to the case of databases; and third, the relation between discourse and practice, ideas and action, attitudes and behaviour in a way that permits the understanding of databases outside the limitations of the paradigms of liberal and Marxist theory. (Poster, 2004, p. 403)

Poster applies Foucault’s theory of the panopticon to databases and argues that they “constitute identities for each individual and they do so regardless of whether the individual is even aware of it. Individuals are ‘known’ to computer databases, have distinct ‘personalities’ for them and in relation to which the computer ‘treats’ them in programmed ways” (2004, pp. 403-404). Furthermore, Poster argues that “databases... operate as a super-panopticon” as they “work continuously, systematically and surreptitiously, accumulating information about individuals and composing it into profiles” (2004, p. 404). It is less invasive than a prison, “yet it is no less efficient at its task of normalization” (Poster, 2004, p. 404). Also, due to the efficiency and connectivity of computers, “databases ‘survey’ us without the eyes of any prison guard and they do so

more accurately and thoroughly than any human being” (Poster, 2004, p. 405).

Searchable databases, with the ability “to process personal data for various purposes”, have become “a key trend of today’s surveillance” (Lyon, 2003, p. 14). Lyon observes that “access to improved speed of handling and richer sources of information about individuals and populations is believed to be the best way to check and monitor behaviour, to influence persons and populations, and to anticipate and pre-empt risks” (2003, p. 14).

The true power of the database and the search can be illustrated by the example of Google. Google “transformed access to information” with its “PageRank” algorithm (Halici & Mayer, 2007). Since its creation in 1997, Google has moved beyond its search engine beginnings and now offers several free features and services including Google Reader (an RSS feed), Google Calendar (shareable calendar), Google Chrome (web browser), Google Maps (provides maps and directions), Google Earth (provides satellite views of the world), and Gmail (email service). Ozan Halici and Jurgen Mayer (2007) state that Google cofounders Sergey Brin and Larry page “pursue a great vision”, which they call “The Google Master Plan”: “Any kind of information will be accessible to anybody, controlled by Google itself, with the credo ‘don’t be evil’”. They argue that “Google is methodically collecting personal data” by scanning all Gmail emails, and by using cookies and collecting account information (Halici & Mayer, 2007). They suggest that “Google can create incredibly detailed dossiers on every one of us” and note claims from former CIA agent Robert David Steele that “Google is cooperating undercover with the US government, including CIA” (Halici & Mayer, 2007). All of this information

leads Halici and Mayer to the fact that “Google is conducting research in the fields of molecular biology and genetics” and the associated concern that Google could accumulate genetic information of its users on top of all of the information it already has (Halicı & Mayer, 2007). These concerns become extremely relevant when examining the development of 23andMe, which has close ties with Google. The implications of these facts will be discussed in the next chapter.

The Effects of Medical Technologies on Life Worlds

The term “life world”, coined by Edmund Husserl (1970), is based on the idea that “all our human knowledge is built on the lived everyday experience of the world” (Olin Lauritzen & Hyden, 2007, p. 5). By taking on “an abstracting attitude towards our own experience... we become self-reflective” (Olin Lauritzen & Hyden, 2007, p. 5). This term has also been used in the field of biology along with a related term “umwelt” (Roth, 2000, p. 235). Both of these terms have been used “to designate an environment that is irreducibly related to the organism” (Roth, 2000, p. 235). An underlying theory here is that “organism and environment are inseparable and form only one unitary system” (Roth, 2000, p. 235). Husserl’s use of the term is less biological and more sociological in nature, but it suggests the same symbiotic relationship between living being and environment thus highlighting the importance of context.

Olin Lauritzen and Hyden explain that while medical technologies are generally “part of medical practice”, they “can raise problems that are not part of the medical world but are part of the everyday world” of patients (2007, p. 6). An example of such a problem is “when some sort of deviance is found, the patient has to make a decision...

The moral problem is here part of the patient's life world, his or her hopes and expectations, and can only be answered in that context" (Olin Lauritzen & Hyden, 2007, p. 6). On top of risks related to lifestyle and environment, Kavanagh and Broom (1998) identify risk "embodied in the individual" (Tegern, 2007, p. 159):

Health risks create a set of challenges for people who are diagnosed, such as translating population characteristics into personal meaning, coping with uncertainty, interpreting the possibility of illness in the non-appearance of symptoms, and mobilizing supervision and risk reduction. (Tegern, 2007, p. 159)

As Tegern explains, "people construct risks through lenses tinged with elements of group attachment and of experiences of their in-groups and selves, in terms of both the contemporary imagery that they are exposed to and from past misfortunes" (2007, p. 159). The concept that diseases "include the patient's life and lifestyle, and that the disease has consequences in the life of the patient in ways that potentially affect the treatment" (Olin Lauritzen & Hyden, 2007, p. 8) has become generally accepted by those in the medical profession. As a consequence, doctors and medical specialists now discuss information with their patients that is "generally associated with the life world of the patient; and in ways that give the medical professional the possibility to both advise and negotiate these matters" (Olin Lauritzen & Hyden, 2007, p. 8).

Olin Lauritzen and Hyden note that patients are increasingly bringing information they have retrieved themselves, most prevalently from the Internet, to discuss with their doctors (2007, p. 8). Sillence, Briggs, Harris and Fishwick corroborate this observation, by noting that "the Internet can... influence health behaviour through a process of careful reflection, cross-checking of information and discussion with the doctor, family and

friends” (2007, p. 356). The Internet provides an avenue for patients to enhance their relationship with their doctor and “counterbalance [the] information (or lack of it) provided by the doctor” (Sillence et al., 2007, p. 356). By conducting a longitudinal study of group discussions of thirteen individuals with hypertension, Sillence *et al.* found that “the Internet afforded increased feelings of social support and identity and gave the participants valuable time to explore alternative approaches to healthcare” (2007, p. 356). They conclude, “it is the users of Internet information rather than authors or professional experts who decide what and how material is accessed and used” and, as such, “decisions concerning the selection of online material, and evaluations of its trustworthiness and quality will always be influenced by peoples’ own particular motivations and cognitive biases” (Sillence *et al.*, 2007, p. 357). The use and application of information found on the Internet “depends in part on the existing nature of the patient-physician relationship and in part on the patient’s existing attitude towards his or her health” (Sillence *et al.*, 2007, p. 357), an attitude that relies heavily on various factors within his or her life world.

Today, in what Nikolas Rose and Carlos Novas call “the contemporary age of biomedicine”, we experience “a range of struggles over individual identities, forms of collectivization, demands for recognition, access to knowledge and claims to expertise” (2002, p. 7). Within this context, there are “new spaces of public dispute about the minutiae of bodily experiences and their ethical implications” as well as “new objects of contestation, not least those concerning the respective powers and responsibilities of

public bodies, private corporations, health providers and insurers and individuals themselves” (Rose & Novas, 2002, p. 7).

Jürgen Habermas identifies “the detraditionalization of lifeworlds [as] an important aspect of societal modernization; it can be seen as a cognitive adaptation to objective conditions of social life which, as a consequence of the implementation of scientific and technological progress, have time and again been revolutionized” (2003, p. 26). However, he warns that “scientific theories which intrude upon the lifeworld... do not essentially touch on the *framework* of our everyday knowledge, which is linked to the self-understanding of speakers and actors” (Habermas, 2003, p. 105). Rather, “learning something new about the world, and about ourselves as beings in the world, changes the *content* of our self-understanding... The closer scientific findings approach our bodily existence, the more disconcerting they seem for our self-understanding” (Habermas, 2003, pp. 105-106). For example, Habermas is concerned that “genetic manipulation could change the self-understanding of the species in so fundamental a way that the attack on modern conceptions of law and morality might at the same time affect the inalienable normative foundations of societal integration” (2003, p. 26).

Identity, the Internet and Social Networking Sites

The concept of identity is “richly [and] hopelessly... ambiguous” (Brubaker & Cooper, 2000, p. 6). Rogers Brubaker and Frederick Cooper identify five different ways of understanding identity: “as a ground or basis of social or political action” (Brubaker & Cooper, 2000, p. 6); “as a specifically *collective* phenomenon” (Brubaker & Cooper, 2000, p. 7); “as a core aspect of (individual or collective) “selfhood” or as a fundamental

condition of social being” (Brubaker & Cooper, 2000, p. 7); “as a product of social or political action” (Brubaker & Cooper, 2000, p. 7); or “as the evanescent product of multiple and competing discourses” (Brubaker & Cooper, 2000, p. 8). For the purposes of this thesis, the term will refer to what Brubaker and Cooper describe as a fundamental part of “selfhood”, which “point[s] to something allegedly *deep, basic, abiding, or foundational*” (Brubaker & Cooper, 2000, p. 7). This view of identity treats it “as something to be valued, cultivated, supported, recognized, and preserved” (Brubaker & Cooper, 2000, p. 7). My conception of identity involves individuals’ self-awareness and self-definition. Therefore, it involves a recognition and interpretation of one’s traits. This self-definition infers a distinction between individuals’ selves and others. This definition and knowledge of oneself is “always a construction no matter how much it feels like a discovery” (Calhoun as quoted by Castells, 2004, p. 6).

The intersection of identity production and the Internet has become a significant area of study (Broad & Joos, 2004, p. 924). Kendal L. Broad and Kristin E. Joos argue that “the tremendous growth and use of the Internet has inspired the emergence of new types of social interaction” (Broad & Joos, 2004, p. 924). This new form of interaction involves “new writing selves interact[ing] in ... cyberspace, selves lodged and created in the virtual reality of the electronic text” (Denzin & Lincoln as quoted by Broad & Joos, 2004, p. 924). These selves are “faceless, electronic”, and “located in simulated communities” (Denzin & Lincoln as quoted by Broad & Joos, 2004, p. 924). Research on this topic “reflects different understandings of self and identity” (Broad & Joos, 2004, p. 924). While early analyses “assume modern notions of identity, grounded in the

assumption that one's self is located in the physical body", scholars today do not necessarily follow this line of thinking (Denzin & Lincoln as quoted by Broad & Joos, 2004, p. 924). Recent studies have "assume[d] that the Internet is a space where "real selves" can be produced, in terms of cultural contingencies" (Denzin & Lincoln as quoted by Broad & Joos, 2004, p. 924). However, Broad and Joos argue "that the Internet is an arena where, today, "deprivatized" selves are "publicly" produced" (Denzin & Lincoln as quoted by Broad & Joos, 2004, pp. 924-925). They find the Internet to be "an important arena for inquiry about the production of postmodern selves", particularly "for those renovating a "troubled" self, those facing personal challenges and stigma" (Denzin & Lincoln as quoted by Broad & Joos, 2004, p. 926).

danah boyd argues that, since "there are no bodies [online] in the corporeal sense" and "identity information... typically written on the body" is lacking, "people must engage in explicit acts to write themselves into being" (2008, p. 121). It is on social networking sites where this creation of virtual selves can be seen most literally. Social networking sites (also known as social network sites), the first of which was introduced in 1997 (boyd & Ellison, 2007, p. 214) are defined "as web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system" (p. 211). Social networking sites, such as MySpace, Facebook, and many others, "have attracted millions of users, many of whom have integrated these sites into their daily practice" (boyd & Ellison, 2007, p. 210). The creation of personal profiles involves "fleshing out

the fields as an act of self-presentation” (boyd, 2008, p. 121). Profiles, the “backbone” of social networking sites, “is generated using the answers to [a series of] questions, which typically include descriptors such as age, location, interests, and an “about me” section” (boyd & Ellison, 2007, pp. 211-212). Profiles often include an option to include a photo (boyd & Ellison, 2007, p. 212). Other significant elements of social networking sites include “public display[s] of connections” and the ability to write “private messages and comments” to other users (boyd & Ellison, 2007, p. 212).

Profiles are self-generated and provide users an outlet to define (and redefine) themselves narcissistically in the ways they’d like to be presented to others in their social networks. Social networking sites function as glorified databases, compiling personal information, and sharing this data among users. This shows the true proliferation of personal information that is out there, so to speak. Not only are corporations and other institutions compiling information about individuals, individuals are also contributing their own information to online communities and social networks. The process of profile development should not be taken for granted, for, as Sherry Turkle writes, “technology catalyzes changes not only in what we do but in how we think. It changes people’s awareness of themselves, of one another, of their relationship with the world” (1984, p. 13). Profiles on social networking sites provide frameworks through which people define themselves in particular ways and perceive of others within these same frameworks. Different sites have different *modus operandi* and accordingly different criteria and parameters for their users’ profiles. 23andMe, for example, enables a limited amount of personalization of profiles, due to the specialized nature of the web-service. For example,

23andMe users' favourite movies are irrelevant within the logic of the site. However, these profiles are a key part of their "community" section, allowing people to feel connected and relate to other real people and users of the site.

Conclusion

As noted above, there is a "lack of knowledge about these rapidly changing scenarios in health care and the ways medical technologies intervene into our lives and affect our ideas about the healthy and the ill body, our self-identity and relations to others" (Olin Lauritzen & Hyden, 2007, p. 1). This chapter has shown that various technologies today perform a "panoptic sort" (Gandy, 1993), categorizing individuals based on personal data. This information is examined without reference to the context from which the data emerged. The panoptic sort, the computerized database, the Internet, and social networking sites all deal with the collection and organization of personal information, for various applications and purposes.

Both consumerist databases and social networking sites have a history of controversy surrounding privacy. The debate is based on the fact that while users upload information and data about themselves, this information is personal and yet becomes the property of the service provider. As mentioned above, by giving up ownership of personal information and privacy, consumers and users of these services gain convenience and opportunities that they would not otherwise have (such as the ability to connect with friends and family on Facebook or receiving a discount by using a loyalty card that tracks purchases). Clearly, the enormous slice of the population that uses these services has determined that the benefits outweigh the costs.

The essence of 23andMe is the exchange of an individual's genetic information for an explanation of said individual's genetics disease risks, probabilities about inherited genetic traits, and information about their ancestry. The sensational nature of disease risks, the step closer to unlocking the mysteries of life and death, provide a very compelling distraction from the questionable act of sharing your genetic information with a private corporation and the related complicated issues of privacy, ownership and consent.

Chapter 4: A Critical Discourse Analysis of 23andMe

Introduction

23andMe is an example of the translation of data from a medical imaging technology into information about bodies. I will analyze the content of the 23andMe website in terms of discourses, particularly about risk and prevention. I contend that 23andMe sensationalizes risk and encourages certain behaviours such as self-surveillance, lifestyle management, and potentially, future genetic manipulation. This chapter will provide a detailed examination of the 23andMe website and will relate my findings to the theories and concepts introduced in my previous chapters. I will conclude this chapter by discussing the broad social relevance of this project and the implications of a personal genomic service such as 23andMe.

Data & Method of Analysis

The data for this case study is comprised of the 23andMe website; more specifically, I will examine the demo account, which allows prospective participants an exploration of all of the features that the 23andMe site has to offer on their website, without actually purchasing the saliva kit or providing genetic information and thus ensuring an objective stance as much as possible. The demo account includes what 23andMe calls their “example family”, named “the Mendels”: “The Mendels are a real family of European descent who have been genotyped through the 23andMe service. They have agreed to be used as examples on our website though we have changed their names” (23andMe, Inc., 2008c). As the 23andMe “Getting Started Guide” explains, once users log in they are taken to their “own account home page, which acts as a jumping-off

point for exploring [their] data” (23andMe, Inc., 2008b, p. 1). There are five subsections of the 23andMe website for signed in users:

1. My Health and Traits tells you how your data relates to scientific research on the genetics of physical characteristics, including disease.
2. Family and Friends compares you to other people who have signed up with 23andMe and shared their information with you.
3. My Ancestors traces your ancestry and compares you genetically with people from around the world.
4. 23andWe allows you to take surveys and learn about ongoing research at 23andMe.
5. Community allows you to ask questions and share stories with your fellow 23andMe users. (23andMe, Inc., 2008b, p. 1)

The complete contents of the demo account home page, these five subpages, and various other relevant sections⁸ such as the terms and conditions and help pages, will be analyzed using Critical Discourse Analysis. More specifically, I will analyze the content of each section by applying the following analytical tools (if applicable), as described in my first chapter: Over-lexicalization, local meanings, metaphors and euphemisms, and then implications and presuppositions. For each section, I will finish my analysis by adopting Fairclough’s (2001) method of intertextual analysis. This will involve making connections between the data and findings from the 23andMe website and the larger context within which this website and its discourses were produced.

Data Analysis

1 Overview of the 23andMe Website’s Design and Navigation

The overall layout and design of the 23andMe website is consistent throughout the home page and the various subsections. The banner across the top of the page features the 23andMe logo and slogan “genetics just got personal” on the left hand side

⁸ These other relevant sections will be determined when analysis of the above five subsections lead to questions regarding genetic terms, legal issues, etc.

(23andMe, Inc., 2009ee). On the right hand side there is the main navigation menu: The first link brings you to the user's home page (23andMe, Inc., 2009ee). The second link is labeled "genetics 101" (23andMe, Inc., 2009ee) which brings users to a type of 'Frequently Asked Questions' section of the website (ex. What is a gene?) (23andMe, Inc., 2009I). The third link is labeled "blog" and brings users to "The Spittoon", an external blog "written by the people of 23andMe" (The Spittoon, 2009). The fourth link across the top of the website is labeled "help" and brings the user to the "help/contact us" page where they can download the "Getting Started Guide" or find answers to questions such as "What does 23andMe do for me?" and "Do you store my sample?" (23andMe, Inc., 2009v). Finally, the last link is to "log out" (23andMe, Inc., 2009ee). Underneath this navigation menu is a search bar enabling users to "search [their] account" (23andMe, Inc., 2009ee). There is also a button to "turn guides on", which involves pop-ups that provide tips and descriptions of different features on the site (23andMe, Inc., 2009ee).

There is a second navigation menu that is consistent throughout the site (23andMe, Inc., 2009ee). This second menu is found in a column on the left side of the window (23andMe, Inc., 2009ee). This menu features links to the five main subsections of the website, as identified above, and links to the subpages for each subsection (23andMe, Inc., 2009ee). There is also a link to a sixth subsection labeled "account" which features links to "Genome Sharing", "Inbox", "Settings", and a second link to "Help/Contact Us" (23andMe, Inc., 2009ee).

1.1 Local Meanings, Metaphors and Euphemisms

The 23andMe website has clearly adopted a Web 2.0 style, in terms of its design and its messaging. Web 2.0 is a way of conceptualizing the “second era of the web, which allows people to use it not just to access or publish information but to interact with each other” (Griffiths, 2008, p. 42). The main idea is that Web 2.0 “connects people” whereas its predecessor, Web 1.0, “connects documents” (Franklin, 2008, p. 38). The new technologies involved in Web 2.0 enable a “humanizing of business” (Griffiths, 2008, p. 45). The 23andMe website features a horizontally divided layout with colour-coded sections that provide different functions within the same page. It provides an attractive and clean presentation format. It also has numerous communication devices such as a messaging function, a contact us section, and a blog. As Olin Lauritzen and Hyden explain, in order to influence patients to adjust their lifestyle or take preventative measures, “it can be seen as necessary not only to talk *to* the patients, but above all *with* the patients” (2007, p. 8). A one-way communication structure when dealing with genetic information would not be ideal.

1.2 Implications and Presuppositions

23andMe’s tagline “genetics just got personal” (23andMe, Inc., 2009ee) is reminiscent of the feminist assertion that “the personal is political” (Patterson & Corning, 1997, p. 5). It seems that 23andMe uses this wording to acclaim its democratization of genetic information by freeing it from the confines of the medical industry and providing it directly and personally to (paying) customers. What is implied here is that this is a more personal service than you would receive from a medical practitioner. Interestingly

enough, the “personalized” service is not really that personalized in that the findings and results are automated and not written especially for individuals by individuals. There is not one specific person or doctor to care for users on an individual basis.

2 Account Home Page

The account home page is mainly made up of links to subsections of the site (23andMe, Inc., 2009aa). The main section of the page is dedicated to “New at 23andMe”: A list of new articles, surveys and features (subsections of the site to be discussed below) (23andMe, Inc., 2009aa). Below this news section there are links to three “Recent Community Posts” (another section that will be discussed below), with the users’ photos, usernames, post titles as well as links to the answers to their posts (23andMe, Inc., 2009aa). Finally, there is a section of the right-hand side entitled “Help/Contact Us” with links to download the “Getting Started Guide”, links to the “Frequently Asked Questions” page (23andMe, Inc., 2009aa), and a graphic that links to the 23andMe store. There is a limited amount of content for analysis here, however, since this is the welcome screen that introduces the user to the personalized service, it is still important to examine the language used on this basic page.

2.1 Over-lexicalization

The 23andMe user home page is labeled with a “home” icon and the word “me” in the left-hand side navigation menu and labeled with another “home” icon and the username of the account in the banner navigation menu located in top-right (23andMe, Inc., 2009ee). “Welcome to you” is the introductory statement on this page (23andMe, Inc., 2009ee). The subheading that follows reads “Explore, share and discuss your DNA

using our simple and powerful tools” (23andMe, Inc., 2009ee). The emphasis of this page is clearly on the user. There is repetition of personal pronouns: “me” (first person singular), “you” (second person singular), “my”, “your” and “our” (possessive) (23andMe, Inc., 2009ee). This vocabulary chain suggests an interactivity, sharing, and closeness between the user and the company. The words “explore”, “share” and “discuss” (23andMe, Inc., 2009ee) further encourage this feeling of interactivity.

2.2 *Local Meanings, Metaphors and Euphemisms*

The direct naming of users’ accounts as “you” and the introductory statement “welcome to you” (23andMe, Inc., 2009aa) indicate that 23andMe *defines* their users by their DNA. This assumes that users are interacting directly with their DNA and their essential selves. What this metaphor suggests is that 23andMe is able to define its users. In reality, they are able to present simply probabilities about certain genotypes and phenotypes, which are “influenced by both your genes *and* your environment” (23andMe, Inc., 2009jj, emphasis added). This naming suggests that 23andMe takes an essentialist stance in regards to genetics. Although they do acknowledge that there are many different factors at play in regards to what makes us who we are, the whole point of the 23andMe website is to allow users to interact with their own genetic information. 23andMe interprets this information and presents this information in a certain way, both textually and graphically. This presentation of genetic information presents particular views of the individual and defines them in particular ways.

The approach of 23andMe suggests that they are appealing to an essentialist perspective. Essentialism can be defined as follows: “The belief that things have a set of

characteristics which make them what they are, and that the task of science and philosophy is their discovery and expression” (Bisset, 2004, p. 324). As Susan A. Gelman explains, “according to essentialism, categories (such as “boy,” “girl,” or “intelligence”) are real, in several senses: they are discovered (rather than invented), they are natural (rather than artificial), they predict other properties, and they point to natural discontinuities in the world” (2003, p. 3). As discussed below, 23andMe presents the data of its users (“you”) in ways which categorize the user as having the disease risk or not, being a carrier or not, having a trait or not, having a particular ancestry or another, and so on. In doing so, 23andMe suggests that these qualities are *determined* by their genes.

2.3 *Implications and Presuppositions*

The design of this page is very reminiscent of social networking sites like Facebook (www.Facebook.com) with an emphasis on logging in to ‘yourself.’ Another similarity is that this home page provides a list entitled “New at 23andMe”, which provides a variety of new ways to interact with ‘yourself’ (23andMe, Inc., 2009ee). Below this “New at 23andMe” section is a section called “Recent Community Posts” which features three posts from 23andMe members (23andMe, Inc., 2009ee). These three posts are illustrated by the user’s photo, the title of the user’s post, a link to “View answers” with an indication of how many answers there are, and finally, it indicates the username of the author of the post (23andMe, Inc., 2009ee).

At the bottom right-hand side of the window, there is a graphic of a 23andMe saliva collection kit with the accompanying text, “Need more kits? Visit the store” (23andMe, Inc., 2009ee). This graphic links to the 23andMe store where users can

purchase more saliva collection kits, if desired (23andMe, Inc., 2009dd). The question that comes to mind when examining this graphic is ‘why would you need more kits if you’re already “explor[ing], shar[ing] and discuss[ing] your DNA” (23andMe, Inc., 2009ee) here on 23andMe?’ The answer can be deduced by looking at the page for the 23andMe store. First of all, there is a limited time “Multi-Pack Special” where if you buy two or more kits you can save \$50 on each kit (23andMe, Inc., 2009dd). Secondly, there are some guidelines and links on the right hand side of the page including one link that says “Using kits with infants and toddlers?” (23andMe, Inc., 2009dd). When this link is clicked, a small window pops up with the following text:

Can I use the saliva collection kit for infants and toddlers?

The saliva kit we provide for participation in our service is not optimized for children under three years of age. If you are purchasing a kit for an infant or toddler, it may be difficult to obtain the required amount of saliva. (23andMe, Inc., 2009gg)

Therefore, the “Need more kits?” messaging on the account home page is implicitly suggesting that users may want to order subsequent kits for their family members and/or children. An assumption that underlies this messaging is that having your child’s genome mapped is completely acceptable; the only problem being that it may be difficult to collect enough saliva. There are no ethical questions or privacy issues implicated here.

3 My Health and Traits

The “My Health and Traits” section of the website is divided into two tabs: “Clinical Reports” (23andMe, Inc., 2009m) and “Research Reports” (23andMe, Inc., 2009r). The 23andMe “Getting Started Guide” explains that “Clinical Reports [provides] information about diseases, conditions and traits for which there are genetic associations

supported by multiple large, peer-reviewed studies” (23andMe, Inc., 2008b, p. 2).

Additionally, the genetic associations presented in these reports must “have a substantial influence on a person’s chances of developing the disease or having the trait” (23andMe, Inc., 2008b, p. 2). The “Research Reports”, on the other hand, provide “information from research that has not yet gained enough scientific consensus to be included in [the] Clinical Reports. It also includes established research that does not have a dramatic influence on a person’s risk for a disease” (23andMe, Inc., 2008b, p. 2). The footer on each page in this “Health and Traits” section of the website reads “the genotyping services of 23andMe are performed in LabCorp’s CLIA-registered laboratory. The results presented here have not been cleared or approved by the FDA but have been analytically validated according to CLIA standards” (23andMe, Inc., 2009m; 2009r).

Clinical Reports

The “Clinical Reports” tab is broken down into four categories: “Disease Risks”, which lists “the five diseases for which a person’s calculated risk is highest relative to average” (23andMe, Inc., 2008b, p. 2); “Carrier Status”, which lists “conditions for which one or more genetic variations has been clearly demonstrated to cause a disease with almost, if not complete, certainty” (23andMe, Inc., 2008b, p. 2); “Traits”, which “describe physical attributes completely determined by genetics” (23andMe, Inc., 2008b, p. 2); and finally, “New and Recently Updated”, which lists the “newest and most recently updated Health and Traits topics” on 23andMe (23andMe, Inc., 2008b, p. 2). By clicking on the name of a condition listed underneath any of these categories, users are brought to a “full report” on the topic (23andMe, Inc., 2009m).

On this main “Health and Traits” page listing the “Clinical Reports”, the list of top “Disease Risks” in particular features a quick bar chart juxtaposing the user’s risk and the general population’s risk of developing that particular condition (23andMe, Inc., 2009m). Some conditions on this page are differentiated with a sex icon to specify that that condition is sex-specific (for example, “Prostate Cancer” is followed by the male symbol) (23andMe, Inc., 2009m). The information presented in the report for these conditions will “only apply to one sex” (23andMe, 2009hh). There are also conditions that are identified with a lock symbol and labeled as “opt-in report[s]” as opposed to explicitly identified with the name of the condition (23andMe, Inc., 2009m). As the 23andMe website explains, these reports may indicate “substantially increased odds of developing the disease” in question (23andMe, Inc., 2009o). Due to this fact, users may not want to know about the personal risks and may choose not to access the data on this topic:

Because of the potential impact of this report, [they] require that [users] opt-in before viewing [their] results. It is possible to use the rest of the 23andMe service without viewing [the] results for this disease. In addition, no one else can see [the] data for this disease, including those with whom [the user has] basic and extended sharing. (23andMe, Inc., 2009o)

In the demo account for Greg Mendel, these conditions include Parkinson’s Disease and BRCA Cancer Mutation (23andMe, Inc., 2009o).

At the top of all reports (“Disease Risks” reports, “Carrier Status” reports, and “Traits” reports), 23andMe indicates how many “reported markers” are referred to in this particular “Clinical Report” (23andMe, Inc., 2009p). These markers are also known as SNPs of the genome that have “been found to be independently associated with [the

disease] risk” (23andMe, Inc., 2009q). Each report is divided into a combination of the following six tabs: “Your Data”, “How It Works”, “Timeline”, “MD’s Perspective”, “Resources”, and “Technical Report” (23andMe, Inc., 2009q).

If users click on the heading “Disease Risks” on the “My Health and Traits” page they are brought to a view that lists all “Disease Risks” reports within the following categories: “Elevated Risk”, “Decreased Risk”, “Typical Risk”, and “Opt-In Reports” (23andMe, Inc., 2009o). The following information regarding these diseases is provided on this page: Name, “Absolute Risk”, “Relative Risk”, and “Last Updated” (23andMe, Inc., 2009o). The numbers, presented as percentages, in the “Absolute Risk” column indicate the risk that a person with your genotype will develop the disease during his or her lifetime. The bars to the right compare that number with the average risk for a person of [the user’s] ancestry” (23andMe, Inc., 2009o). The numbers found in the “Relative Risk” column “compare the risk of developing a disease for a person of [the user’s] genotype to the average. A relative risk greater than 1.2 is considered Elevated; a relative risk less than 0.8 is considered Decreased” (23andMe, Inc., 2009o).

At the very top of some “Disease Risks” reports, there appears a disclaimer-like message, highlighted in yellow (23andMe, Inc., 2009p). An example of one, for the Parkinson’s Disease report, is as follows: “Keep in mind that estimates of Parkinson’s risk due to the G2019S mutation in the LRRK2 gene vary greatly. While it is well established that the mutations effect is very strong, there is no consensus about its exact magnitude” (23andMe, Inc., 2009p).

As mentioned above, the “Disease Risks” reports are broken down into three tabs (23andMe, Inc., 2009p). The “Your Data” tab of the “Disease Risks” reports is broken down into three sections: First, a brief overview of the disease; Second, the “Your Genetic Data” section, which itself is broken down into the subheadings “Odds Calculator” and the “Marker Effects” (23andMe, Inc., 2009p). The “Odds Calculator” “compares [the user’s] genetic risk of developing a disease with the average”, based on “the ethnicity and age range selected in the pulldown boxes” on the page (23andMe, Inc., 2008b, p. 2). Below the “Your Genetic Data” label there is a bar that reads, “Show information for [pulldown box for user] assuming [pulldown box for ethnicity] ethnicity and an age range of [pulldown box for age category]” (23andMe, Inc., 2009q). The pulldown box for user allows users to select their own data or another person’s to which they have access (23andMe users can share their accounts with other 23andMe users, a feature which will be described below) (23andMe, Inc., 2009q). The pulldown box for ethnicity provides the following options: European or African (23andMe, Inc., 2009q). Directly underneath this box is blue-coloured fine print that reads, “Where’s mine?” (23andMe, Inc., 2009q). Clicking on this link provides users with a pop-up window that explains why there are only two options available:

Unfortunately, because of where and how biomedical research is funded, there are comparatively few studies looking for genetic associations in populations that form a minority in the countries where much of the latest research takes place. In other words, most of the associations reported in Health and Traits have only been confirmed in populations of European ancestry. For example, only one SNP has been confirmed as associated with risk of type 2 diabetes in African samples. While we at 23andMe do actively look for associations that have been repeated in populations other than the original study population, we can only report data published by the scientific community at large. We feel it would be inappropriate to assume

that studies performed in populations of a particular ethnic composition apply to everyone. (23andMe, Inc., 2009q)

Finally, the pulldown box for age category provides the following options: 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, and 75-79 (23andMe, Inc., 2009q).

Selecting different combinations of user, ethnicity and age category leads to different outcomes illustrated by two graphics below. The first graphic illustrates the number of people with the same ethnicity and same genotype out of 100 people that will contract the disease within the age range selected by the user (23andMe, Inc., 2009q). The second graphic illustrates the average number of people of the selected ethnicity out of 100 that will contract the disease within the selected age category (23andMe, Inc., 2009q). The text beside this graphic explains that this “Odds Calculator” provides an “estimated incidence of [the disease] due to genetics for someone with [the user’s] genotype. The 23andMe Odds Calculator assumes that a person is free of the condition at the lower age in the range” (23andMe, Inc., 2009q). Furthermore, this calculation “only takes into account effects of markers with known associations that are also on [their] genotyping chip” (23andMe, Inc., 2009q). Below this “Odds Calculator” section, there is a “Genes vs. Environment” section of the page, which estimates the heritability of the condition and compares this to the influence of environmental factors (23andMe, Inc., 2009q). These various factors that can increase risk of developing the disease are briefly described here as well (23andMe, Inc., 2009q).

The next section on this page is entitled “Marker Effects” and is illustrated with a bar chart:

The chart shows the approximate effects of the selected person's genotype at the 5 reported markers. Higher, red bars indicate increased risk from the average, while lower, green bars indicate decreased risk from the average. The light gray bars show the maximum possible effects for the possible genotypes at the marker. (23andMe, Inc., 2009q)

Below this data is a section labeled "Talk with the Community" and features "Recent Posts in [the disease in question]" (23andMe, Inc., 2009q). Finally, the bottom of the page provides information about the SNPs associated with the disease risk as well as a list of citations (23andMe, Inc., 2009q).

The "How It Works" tab provides an explanation of the biological nature of the disease, with references and links (23andMe, Inc., 2009q). The "Timeline" tab provides a timeline of "major discoveries" related to the disease in question (23andMe, Inc., 2009q). The "MD's Perspective" tab provides an interview between 23andMe and a physician concerning the disease (23andMe, Inc., 2009q). Here, there is a disclaimer:

The material presented in MD's Perspectives does not necessarily represent the views or perspectives of 23andMe or other physicians. These materials may discuss therapeutic products that have not been approved by the US Food and Drug Administration and off-label uses of approved products. A qualified healthcare professional should be consulted before using any therapeutic product discussed. (23andMe, Inc., 2009q)

The "Resources" tab is introduced with the following message:

The information presented on 23andMe is not intended as medical advice and should not be used for diagnosing, treating, or preventing disease. If you have questions about your genetic information and its relation to the latest scientific findings, here are resources you may find helpful, including available tests, interactive tools, and professional organizations and individuals in your local area. (23andMe, Inc., 2009q)

This tab is divided into four sections: "Counselors", which provides a search option for genetic counselors in the user's area (23andMe, Inc., 2009q); "Interactive Tools", which

provides a list of external links to “web-based tools and resources” (23andMe, Inc., 2009q); “Support Groups”, which provides contact information for national support groups and networks related to the particular disease (23andMe, Inc., 2009q); and “Disclaimer” (23andMe, Inc., 2009q). The disclaimer reads as follows:

Publications, links, and other information found on this site are not intended and should not be used as a substitute for professional medical advice. 23andMe provides links to third party websites operated by organizations that are not affiliated with 23andMe and that do not have contracts to provide content or services through the 23andMe website. 23andMe does not endorse and is not responsible for the privacy practices of these sites. (23andMe, Inc., 2009q)

Finally, the “Technical Report” tab identifies the “gene or region” and the “SNP”, charts detailing the “SNP used”, “genotype” and “adjusted odds ratio”, descriptions of this information, and citations (23andMe, Inc., 2009q).

On the main “Health and Traits” page under the heading “Carrier Status”, 23andMe lists a variety of diseases and either identifies the user as having the “Variant Present” or the “Variant Absent” (23andMe, Inc., 2009m). “Variant Present” indicates that the user “possesses one or more genetic variants linked to a particular condition, but is not necessarily affected by it. These variants could be inherited by this person’s children” (23andMe, Inc., 2009m). “Variant Absent” indicates that the user “does not possess [the] genetic variant. It is possible he or she may have other variants linked to this condition that cannot be detected by 23andMe” (23andMe, Inc., 2009m). At the very top of some “Carrier Status” reports, there appears a disclaimer-like message, highlighted in yellow. An example of one, for the Cystic Fibrosis report, is as follows: “Please remember that the DeltaF508 mutation is only one of more than 1,000 in the CFTR gene

that can cause cystic fibrosis. Its absence does not rule out the possibility that you may carry another genetic variation that causes the disease” (23andMe, Inc., 2009n).

The presentation of the “Your Genetic Data” section of these reports differs from the presentation found in the “Disease Risks” reports (23andMe, Inc., 2009n; 2009q). First of all, the “Carrier Status” reports do not feature pulldown boxes for ethnicity or age like the “Disease Risks” reports do (23andMe, Inc., 2009n; 2009q). Secondly, in the “Carrier Status” reports, there is a chart with three rows and three columns, as opposed to two graphics (23andMe, Inc., 2009n; 2009q). The first column labeled “Who” is where the users are identified beside their particular genotype, which is identified in the second column labeled “Genotype” (23andMe, Inc., 2009n). There are three possible genotypes determined by the combination of genes inherited from the user’s parents: Two copies of the particular genetic mutation, one copy, and no copies (23andMe, Inc., 2009n). The third column is labeled “What It Means” and provides a description of each genotype in terms of whether the person has the disease or is a carrier of the disease in terms of probabilities (23andMe, Inc., 2009n). The rest of the report is consistent with the presentation of the “Disease Reports” (23andMe, Inc., 2009p; 2009n).

The third section of the “Clinical Reports” tab is the list of “Traits Reports” (23andMe, Inc., 2009m). 23andMe defines “traits” as “physical attributes completely determined by genetics” (23andMe, Inc., 2009m). Examples of these traits include “easily detectable phenotypes like eye color, but also more subtle traits such as resistance to the Norwalk virus” (23andMe, Inc., 2009m). Like some “Disease Risks” and “Carrier Status” reports, some “Traits” reports feature a disclaimer-like message, highlighted in

yellow across the top of the “Your Data” page (23andMe, Inc., 2009n; 2009p; 2009s).

An example of one, for the Resistance to HIV/AIDS “Traits” report, is as follows: “Keep in mind that even if you have the DD genotype at this SNP (i.e. you have two copies of Delta32 version of CCR5), you are still susceptible to infection by certain types of HIV” (23andMe, Inc., 2009s). The presentation of the “Your Genetic Data” section of these reports is similar to the “Carrier Status” reports (see description above) (23andMe, Inc., 2009s; 2009n). The rest of the report is consistent with the presentation of the “Disease Reports” (23andMe, Inc., 2009p; 2009s).

Research Reports

The “Research Reports” tab within “My Health and Traits” provides four charts: “Elevated Risk”, meaning that the user has “one or more higher-risk markers for this condition”; “Decreased Risk”, meaning that the user has “one or more lower-risk markers for this condition”; “Typical Risk”, meaning that the user has “either all typical-risk markers, or a split between negative, positive and typical markers for this condition”; and “Traits”, which includes research reports on a collection of genetics-determined physical traits (23andMe, Inc., 2009r). These charts are organized by three columns: “Name”, “Research Confidence” and “Last Updated” (23andMe, Inc., 2009r). You can choose to sort by any of these three categories (23andMe, Inc., 2009r). “Research Confidence” is defined by a four-star rating system, where four stars represent a high level of confidence in the findings (23andMe, Inc., 2009r).

The reports themselves have a message written in fine print at the top left corner of the page, below the banner: “Intended for research and educational purposes. Not for

diagnostic use” (23andMe, Inc., 2009t). This message does not appear on any previously analyzed reports, as described above. All “Research Reports” have one of two disclaimer-like messages highlighted in yellow. Reports with a “Research Confidence” of four stars feature the following message appearing across the top of the page:

This information is included in our Research Reports section because it does not establish a large enough increase in risk to be included in our Clinical Reports section. For a disease to be included in Clinical Reports, the riskiest combination of genotypes must increase a person’s odds of developing the condition by a factor of three or greater and elevate absolute lifetime risk to at least 5%. (23andMe, Inc., 2009t)

The second appears on the rest of the reports on the right hand side beside the “About [the condition]” text. The following message is found on all “Research Reports” with less than four stars: “This Research Report includes results from studies that still need to be confirmed by the scientific community. It also includes topics where there may be contradictory evidence. The results of these studies are not conclusive” (23andMe, Inc., 2009u).

The “Research Reports” with less than four stars have only one tab: “Your Data” (23andMe, Inc., 2009u). Those with a “Research Confidence” of four stars have the six tabs used in the “Clinical Reports” (23andMe, Inc., 2009t). In fact, the presentation of “Your Data” of these four-star reports match the presentation of “Disease Risks”, as described above (23andMe, Inc., 2009t, 2009p). The data in the “Research Reports” with less than four stars, however, is presented in the following way. Underneath the “About [the condition]” description, there is a description and summary of the study from which 23andMe has gathered their information (23andMe, Inc., 2009u). This description includes the journal and study size (23andMe, Inc., 2009u). It is noted whether or not

there have been any replications and if there are any contrary studies (23andMe, Inc., 2009u). Finally, the applicable ethnicities and the marker are identified (23andMe, Inc., 2009u). Following the identification of these aspects of the study, there is a paragraph-long summary of the study's findings. To the right of this information is a chart, similar to the ones found in the "Clinical Research" "Carrier Status" reports described above (23andMe, Inc., 2009u, 2009n). Finally, below this "Your Data" section, there are citations and a "Talk with the Community" section (23andMe, Inc., 2009u).

3.1 *Over-lexicalization*

The language used in the "Clinical Reports" and "Research Reports" creates a vocabulary chain of danger: Risk, carrier, odds, susceptibility, and resistance. To counter this vocabulary chain is another that deals with support: Counselors, tools, resources, support groups, and professional medical advice. 23andMe extrapolates risks from users' genetic information and transfers responsibility for prevention to the users themselves. 23andMe inform their users of a variety of risks to their wellbeing, provide information regarding support, and leave the responsibility to act on it up to them.

The clinical and research reports section is made up of an almost exhaustive list of genetic disease risks and genetics-determined traits. The list of disease risks is quite overwhelming. Ewald's (1991) argument that risks do not exist until you identify them as such resonates here. As such, it could be pondered how many risks are too many to define? When does it become fear mongering? The risk discourse used by 23andMe's website may also cause victim blaming (although the users may not be victims yet, they will be if they do not do all they can to prevent the onset of the condition in question). As

Lupton explains, “the discourses of risk and testing serve to cast certain individuals and groups as dangerous, either to themselves or others, based on apparently objective medical and epistemological classifications derived from statistical principles” (1995, p. 105).

3.2 *Implications and Presuppositions*

The language used in various “Disease Risks” reports creates a clear and persistent division between genetic information about disease risks and medical advice. There are repetitive disclaimers explaining that genetic information from 23andMe is not “professional medical advice” (23andMe, Inc., 2009q), as described above. The fact that some reports provide a “MD’s perspective” (23andMe, Inc., 2009q) explicitly differentiates the MD from 23andMe. However, the use of the word “clinical” in “Clinical Reports” contradicts this denial of medical expertise. “Clinical” is defined as being “of or for the treatment of patients”; or in other words, “involving the study or care of actual patients” (Bisset, 2003, p. 174). The identification of reports on certain conditions as “opt-in” reports implies that the genetic information concerning these conditions is particularly sensitive and consequential. It is 23andMe’s intention to provide medical *information* to its users, not medical *counsel* or *advice*. Interestingly, these disclaimers pale in comparison to the Terms and Conditions section of the 23andMe website:

The genetic information provided by 23andMe is for research and educational use only. ... [T]he genetic information you receive from 23andMe is based on scientific research, and cannot be relied upon at this point for diagnostic purposes. Genetic discoveries that we report have not, for the most part, been clinically validated, and the technology the laboratory uses the same technology used by the research community has

also not yet been validated for clinical utility... The Services Content is not to be used, and is not intended to be used, by you or any other person to diagnose, cure, treat, mitigate, or prevent a disease or other impairment or condition, or to ascertain your health. You should always seek the advice of your physician or other appropriate healthcare professional with any questions you may have regarding diagnosis, cure, treatment, mitigation, or prevention of any disease or other medical condition or impairment or the status of your health. 23andMe does not recommend or endorse any specific course of action, resources, tests, physicians, drugs, biologics, medical devices or other products, procedures, opinions, or other information that may be mentioned on our website. As explained on our website, 23andMe believes that (a) genetics is only part of the picture of any individual's state of being, (b) the state of the understanding of genetic information is rapidly evolving and at any given time we only comprehend part of the picture of the role of genetics, (c) only a trained healthcare professional can assess your current state of health or disease, taking into account many factors, including your current symptoms, if any, and (d) our testing service is not licensed by the relevant state and federal authorities for genetic testing conducted for health and disease-related purposes. (23andMe, 2009mm)

This description of the recommended uses of information from the 23andMe website equates their services with something as unreliable and trivial as a horoscope. This language downplays the potential impact that the risk discourses communicated by 23andMe could have on individuals.

23andMe endorses disease support groups and provides links to nation-wide support group websites within its reports. It also provides a community section, to be described below, that allows users with risks in common to share and discuss their experiences. This demonstrates that 23andMe takes an ecological perspective, supporting the idea that disease and health exist within a social context (Young, 1984, p. 107). In a study of online support groups, David P. Brandon and Andrea B. Hollingshead found that these groups "can form a valuable supplement to one's social network, and may be beneficial in providing people with the social support they seek" (2007, p. 149). A key

feature of online support groups is anonymity (Brandon & Hollingshead, 2007, p. 149).

Another benefit is that this “text-based type of interaction can work therapeutically in itself because it forces individuals to formulate a coherent story of their situation that can improve their understanding of it” (Brandon & Hollingshead, 2007, p. 149). Online forums such as the one 23andMe also connects people around the world, unrestricted by time limitations (Brandon & Hollingshead, 2007, p. 149).

4 Family and Friends

There are two pages within the “Family and Friends” heading on the sidebar: “Compare Genes” and “Family Inheritance” (23andMe, Inc., 2009ee). The “Compare Genes” allows users to “compare [themselves] to family and friends across various genetic traits” (23andMe, Inc., 2009j). They can either be compared “One-to-Many” or “One-to-One”: These are the two separate tabs on this page” (23andMe, Inc., 2009j). In both cases there is a clickable list of traits on the right hand side of the page (23andMe, Inc., 2009j).

In the “One-to-Many” tab, there are two diagrams that identify the “genetic similarity” (regarding the particular chosen trait) between a group of people including the user him or herself, friends and family with whom the user has sharing capabilities, and also what I will call ‘generic ethnic models’: For example, a “Chinese Person”, a “Nigerian Person”, and a “Japanese Person” appear on the Mendels’ “Compare Genes” page (23andMe, Inc., 2009j). It can be assumed that there is no “European Person” listed, because of the fact that the Mendels are of European-descent themselves. The genetic similarity between these people is illustrated in two ways. First, there is a half circle

divided into five half rings (23andMe, Inc., 2009j). The closer to the centre of the circle the people are placed indicates “increasing similarity” to the person in the centre of the diagram (23andMe, Inc., 2009j). For example, when Greg Mendel is in the centre, his daughter Erin Mendel is identified in the ring closest to the centre while the “Nigerian Person” is identified in the ring farthest from the centre (23andMe, Inc., 2009j). The second illustration of genetic similarity appears below this first diagram (23andMe, Inc., 2009j). The second illustration shows the “percent similarity over 577505 total SNPs” (23andMe, Inc., 2009j). It lists the friends, family and generic models for other ethnicities and indicates the “percent similarity” (23andMe, Inc., 2009j). The names appear in order from most similar to least similar (23andMe, Inc., 2009j). When the name of any of the listed individuals is clicked that person becomes the centre of the diagram and is compared to the rest of the group (23andMe, Inc., 2009j).

The “One-to-One” tab allows users “to compare one person to any other person on many traits” (23andMe, Inc., 2009j). There are two pulldown boxes where users can choose the two names of whom they’d like to compare genes (23andMe, Inc., 2009j). Users are then able to click on a combination of traits for comparison all at once (23andMe, Inc., 2009j). The genetic similarities are presented as percentages: For example, Greg Mendel and Alan Mendel are “81.81% similar” in terms of “genes related to bitter tasting (43 SNPs) and “91.98% similar” in terms of “genes related to Circadian Rhythm (349 SNPs)” (23andMe, Inc., 2009j).

The “Family Inheritance” page is broken down into two tabs as well: “Genome View” and “GrandTree” (23andMe, Inc., 2009k). Both tabs have the same list of traits

down the right side of the page as the “Compare Genes” page (23andMe, Inc., 2009k; 2009j). On both tabs, the “Tell me how to use this feature” popup explains that “this feature needs family members” and urges the user to “purchase [the] service for more of [their] family members in [the] online store” (23andMe, Inc., 2009k). The “Genome View” feature provides information regarding the particular sections of users’ chromosomes that they share with relatives (23andMe, Inc., 2009k). In other words,

Genome View shows which parts of two related people’s genomes appear to be inherited from a common ancestor. In reality, the genome is organized into 22 pairs of chromosomes, plus the sex chromosomes (two X, or one X and one Y). We show only one chromosome out of each pair, but we colour them to show whether one copy is identical (i.e. half-identical), or both copies are identical (i.e. completely identical) between two people. If you select a trait from the list, you can see which genes associated with the trait lay in the stretches of common inheritance. (23andMe, Inc., 2009k)

This description of the Genome View goes on to explain “comparing parents to children”, “comparing grandparents to grandchildren”, “comparing siblings”, and “comparing unrelated individuals” (23andMe, Inc., 2009k). It is explained that “two unrelated individuals will have no completely identical or half-identical stretches in their genomes. If they do, however, it is an indication that the two individuals are in fact related” (23andMe, Inc., 2009k). The “Genome View” provides two pulldown boxes for the selection of two individuals for comparison (23andMe, Inc., 2009k). The individuals listed are the same as those listed in the “Compare Genes” pulldown boxes: friend, family, and generic ethnicity models (23andMe, Inc., 2009k, 2009j). The genomic comparison is illustrated here with a genomic bar chart of sorts (23andMe, Inc., 2009k). Each line is a pair of chromosomes which are colour coded in terms of “estimates”: Half-identical sections are coloured light blue, completely identical sections are coloured dark

blue; not identical remains white, not enough information is coloured grey, and “genes/regions associated with the selected trait” are indicated with a red triangle (23andMe, Inc., 2009k).

The “GrandTree” tab “allows you to trace the inheritance of genes from grandparents to grandchild” (23andMe, Inc., 2009k). This view provides an illustration of a three-generation family tree (23andMe, Inc., 2009k). It first appears in a generic form, with each box identified as “mother’s father”, “mother”, “son”, etc. (23andMe, Inc., 2009k). Below this illustration is a box, labeled “click and drop your relatives onto the GrandTree above”, that lists all friends, family and generic ethnicity models (23andMe, Inc., 2009k). The illustration features a button labeled “Recalculate” which, when pressed, determines the “inheritance pattern” for the particular trait selected (for example, endurance) (23andMe, Inc., 2009k). Once the calculation has been processed, the illustration is updated with a colour-coded demonstration of the inheritance flowing from one relative to another (23andMe, Inc., 2009k). Two text boxes also appear which provide a description for each side of the family: For example, “For this set of genes, Alan Mendel (Son) inherited 5 genes from Ron Risher (Grandpa) and 6 from Margo Fisher (Grandma)” (23andMe, Inc., 2009k).

4.1 Implications and Presuppositions

The “Family and Friends” section of the website emphasizes “similarity” between users. However, similarity with some presupposes difference with others. While the word “difference” is not used, it is clear that 23andMe has provided what I call “generic ethnic models” in order to provide the user with examples of genetic information very different

from their own, relatively speaking. The fact that they have taken “real genotype of actual individuals” (23andMe, Inc., 2009kk) from various ethnicities implies that different ethnic groups are essentially different from one another. This “polarized identification” promotes what Teun A. van Dijk describes as an “Us versus Them” stance (2000, p. 42).

5 My Ancestors

The “My Ancestors” section of the website is divided into four pages: “Maternal Line”, “Paternal Line”, “Ancestry Painting” and “Global Similarity” (23andMe, Inc., 2009ee). The pages for “Maternal Line” and “Paternal Line” are presented in the same way and will be discussed as such (23andMe, Inc., 2009aa; 2009bb).

Maternal Line and Paternal Line

The “Maternal Line” page explains that “your mitochondrial DNA determines your maternal haplogroup” (23andMe, Inc., 2009aa) and the “Paternal Line” page explains that “your Y chromosome DNA determines your paternal haplogroup” (23andMe, Inc., 2009bb). Haplogroups are described by 23andMe as follows:

Haplogroups are families of [Y chromosome (paternal) or mitochondrial DNA (maternal)] types that all trace back to a single mutation at a specific place and time. Technically, every new mutation creates a new haplogroup, but geneticists only label the ones that help them trace significant events in human prehistory, such as the migration of people to the Americas or the expansion of agriculture from the Near East. (23andMe, Inc., 2009aa; 2009bb)

Both “Maternal Line” and “Paternal Line” pages are broken down into three tabs: “Map”, “History” and “Haplogroup Tree” (23andMe, Inc., 2009aa; 2009bb). Consistent among the three tabs on the “Maternal Haplogroup” and “Paternal Haplogroup” pages are the

following sections (23andMe, Inc., 2009aa; 2009bb). On the right hand side of the page is a box of text that indicates the haplogroup, the age of the haplogroup, the region it originates from, its populations, and a “highlight” which provides a key piece of trivia about the haplogroup (23andMe, Inc., 2009aa; 2009bb). Below this box is a list of “Your Family and Friends” with their haplogroups identified, as well as a list of “Famous People” with their haplogroups identified (23andMe, Inc., 2009aa; 2009bb). Finally, there is a “Tell Me About...” section of the page that lists clickable topics such as “mitochondrial DNA” and “discrepancies in haplogroup assignments” which, when clicked, provide a pop-up that provides further information (23andMe, Inc., 2009aa; 2009bb).

The “Map” tab first identifies the haplogroup “with a capital letter (occasionally, two) designating a major branch on the [Y chromosome tree (paternal) or mitochondrial DNA (maternal)] with a well-established common ancestry” (23andMe, Inc., 2009aa; 2009bb). In addition to this capital letter, there is often also “a series of numbers and lower-case letters, each corresponding to a subsequent branch on the tree” (23andMe, Inc., 2009aa; 2009bb). The main focus of this page is the world map that illustrates “where most of the people with [the particular] haplogroup lived prior to the age of European exploration, about 500 years ago” (23andMe, Inc., 2009aa; 2009bb). 23andMe explains that the reason for this chosen time period is due to the fact that “before that time people moved a little less, and rarely moved between continents. Therefore the map reveals where, in a general sense, people with a particular haplogroup lived for thousands of years” (23andMe, Inc., 2009aa; 2009bb). Below the map is a brief description of the

haplogroup (23andMe, Inc., 2009aa; 2009bb). The “Maternal Line” description for Greg Mendel is as follows:

Haplogroup V originated in Iberia during the Ice Age. After a last burst of cold conditions roughly 12,000 years ago, migrations carried the haplogroup northward along the Atlantic coast and through central Europe to Scandinavia. Today it is found in a wide variety of populations from the Basques of Spain to the Saami of Finland. (23andMe, Inc., 2009aa)

Below this description is a link to the 23andMe “Human Prehistory Video” (23andMe, Inc., 2009aa; 2009bb), an animated video that tells the story of human evolution (23andMe, Inc., 2009w). Finally, below this link is a list of “Recent Posts in [the user’s haplogroup]” (23andMe, Inc., 2009aa; 2009bb). The “History” tab provides a more extensive description of the haplogroup than the one that appears on the “Map” tab (23andMe, Inc., 2009aa; 2009bb). At the bottom of the historical description, there is a link to show the sources for this description (23andMe, Inc., 2009aa; 2009bb).

The “Haplogroup Tree” tab in the “Maternal Line” page provides an illustration of the “Tree of All Maternal Haplogroups”, which links users and their friends and family on a flow chart (23andMe, Inc., 2009aa). The “Haplogroup Tree” tab in the “Paternal Line” page provides the same illustration for “All Paternal Haplogroups” (23andMe, Inc., 2009bb). 23andMe describes the chart as follows:

At the left edge of the tree is the common [maternal or paternal] ancestor of all living people, the [“MoM” or “PoP”] or [“Mother of all Mothers” or “Papa of all Papas”]. To the right are [his/her] descendants represented by green haplogroup labels, or “leaves.” Blue head-and-shoulder icons next to a haplogroup label indicate that you or your friends belong to that haplogroup or one of its subgroups. If a haplogroup includes lower-level subhaplogroups, its green label will have a + sign on the right side of the label. Click the + sign to reveal lower level haplogroups. There may be additional haplogroups-within-haplogroups, so keep an eye out for more + signs. (23andMe, Inc., 2009aa)

The “leaves” on the “Haplogroup Tree” are clickable and their selection changes the information on the “Map” and “History” tabs to match (23andMe, Inc., 2009aa).

Ancestry Painting

The “Ancestry Painting” page promises to “trace the ancestry of [the user’s] chromosomes, one segment at a time” (23andMe, Inc., 2009x). The page provides an illustration similar to the one found on the “Genome View” tab within the “Family Inheritance” page (23andMe, Inc., 2009x; 2009k). There is a pulldown box for the selection of the individual whose chromosomes the user would like to examine (23andMe, Inc., 2009x). Each line here is a pair of chromosomes, colour coded in terms of “geographic region”: Europe is dark blue, Asia is orange, Africa is light green, and areas that are “Not Genotyped” are represented by grey (23andMe, Inc., 2009x). 23andMe explains that “solid segments indicate that both chromosomes come from the same geographic region” while “dual-coloured segments indicate chromosomes from different geographic regions” (23andMe, Inc., 2009x). At the top of the page, above the illustration, there is a prominent indication of the date of the last update of this page (23andMe, Inc., 2009x). When clicked, a pop-up appears with the following explanation:

Some customers may notice a difference between their current Ancestry Painting and the one they saw when this feature was first introduced. We have made this feature more accurate by accounting for how far back in time people with ancestors from multiple regions acquired their combined ancestry. Customers whose parents come from widely separated geographic regions are most likely to see changes; those with earlier ancestors from more than one continent may also see a difference. (23andMe, Inc., 2009x)

To the right of the illustration is a chart that has the selected individuals name identified and a legend that identifies the percentage of the chromosomes that come from

each region (23andMe, Inc., 2009x). For example, 100% of Greg Mendel's chromosomes originate from Europe, 0% from Asia and Africa (23andMe, Inc., 2009x). In addition to the Mendels' friends and family, the following generic ethnicity models are available for this feature: "African American Man", "African American Woman", "Berber Woman", "Cambodian Woman", "Italian Man", "Indian Man", "Native American Woman", "Senegalese Man", "Uyghur Woman", "Chinese Person", "Japanese Person", and "Nigerian Person" (23andMe, Inc., 2009x). For all of these models, there appears a brief (and specific) description in this chart that does not appear for the Mendels (23andMe, Inc., 2009x). It can be as brief as "this is a sample individual from the HapMap Nigerian population" or as long as the following example:

Most African Americans today trace a large part their ancestry to sub-Saharan Africa as a result of the slave trade. Over the generations since, both Europeans and Native Americans have intermarried with African Americans and contributed ancestry, as seen in the ancestry painting of this man, self-identified as African American. In fact, one of this man's chromosomes appears to be fully European across the whole genome, so it is likely that one of his parents was European. (23andMe, Inc., 2009x)

Below this chart is a map entitled "Worldwide Examples" which allows users to "click on the icons in the map... to see example paintings of individuals from across the globe" (23andMe, Inc., 2009x). Finally, below this map there is another "Tell Me About" list of topics including "why only three populations are used" and "why it says I'm European/African/Asian when I'm really an American/Australian/South African" (23andMe, Inc., 2009x).

Global Similarity

The “Global Similarity” page features two views: the “basic view” and the “advanced view” (23andMe, Inc., 2009y; 2009z). The “basic view” illustrates individuals’ “genetic similarity to groups of people from around the world” with a three-dimensional bar chart transposed on a map of the world (23andMe, Inc., 2009y). 23andMe explains, “the longer the bar, the more similar [the individual] is to the people from that region. These bars are scaled to show geographic diversity, but [users should] keep in mind that *all humans are more than 99% similar to each other genetically*” (23andMe, Inc., 2009y). Above the map, the date of the last update is identified (23andMe, Inc., 2009y). When the date is clicked, a pop-up explains that “the Global Similarity feature was updated to include two additional reference populations: Ireland and Germany. We also made adjustments to the similarity algorithm to improve the accuracy of your results” (23andMe, Inc., 2009y). Below the map is a two-dimensional bar chart with each region⁹ listed (23andMe, Inc., 2009y). Both the bars here and on the world map are clickable (23andMe, Inc., 2009y). The region associated with the selected bar is described in a text box found to the right of this two-dimensional bar chart (23andMe, Inc., 2009y). 23andMe refers to these regions as “reference populations” and describes their use as follows:

23andMe maintains a database with genetic data from populations all over the world. Each column on the Global Similarity map represents your similarity to groups of these populations from major world regions. Not all regions of the world are represented; 23andMe is currently working to expand the database by adding data for new populations. Check back as new

⁹ These regions include Northern Europeans, Southern Europeans, Near Easterners, Central Asians, Northern Africans, North Americans, South Americans, Siberians, Eastern Asians, Oceanians, Eastern Africans, Southern Africans, Central Africans, and Western Africans (23andMe, Inc., 2009y).

data become available! Currently the reference database includes only data that are publicly available. All individuals with genotypes in the database consented to participate in the genetic studies that led to publication of the data. (23andMe, Inc., 2009y)

The “advanced view” allows users to select an individual “to highlight which global populations they most resemble” (23andMe, Inc., 2009z). The illustration here is not a world map, but resembles one:

The advanced view of global similarity does not take actual geographic location of any of the people displayed into account. It is created using only the genetic data of real people. However, because the genetic differences between people in different parts of the world are largely a product of the geographic distances that isolated their ancestors, this view does resemble a geographical map. (23andMe, Inc., 2009z)

This illustration is produced using “a standard mathematical technique called multidimensional scaling (MDS) to produce the map. It takes the set of genetic distances between a bunch of people and uses them to make a two-dimensional map” (23andMe, Inc., 2009z). The idea is that “the closer [an individual is] placed to a group of reference individuals on the map, the more likely it is that [their] ancestors came from the same place as the reference individuals” (23andMe, Inc., 2009z).

The illustration is colour-coded by “reference population”: “European” is yellow, “Near Eastern” is green, “African” is light purple, “Central/South Asian” is brown, “Native American” is grey, “East Asian” is pink, “Oceanian” is dark purple (23andMe, Inc., 2009z). When users zoom in on a particular “reference population”, this group is broken down into further subcategories that are also colour-coded (23andMe, Inc., 2009z). For example, “European” includes “Basque” in light green, “Northern European” in dark green, “Eastern European” in darkest purple, “Southern European” in orange, and

“Sardinian” in ice blue (23andMe, Inc., 2009z). Some of these subcategories are also clickable and break into further colour-coded subcategories (23andMe, Inc., 2009z). To the right of the illustration is a legend indicating the marker for the selected individual, for their “connections” and “sample populations” (23andMe, Inc., 2009z). Below this legend is a text box that shows a description of the “sample population” that has been selected from the map (23andMe, Inc., 2009z). For example, here is the description for “Italy Sardinian”:

The Italian island of Sardinia gets its name from a term historically used for seafaring peoples. Its population and culture have remained distinct from the mainland for centuries, due to the island's relatively isolated Mediterranean location. Today's Sardinians are descended from the people of the Nuragic civilization that constructed thousands of stone towers around the island 3,000 to 4,000 years ago. Sitting along an important Mediterranean trade route, the island has been a desirable acquisition for many neighboring countries for thousands of years. The first of many invasions took place about 3,000 years ago when the Phoenicians, with the help of the Carthaginians, took power. Although Sardinia is a now part of Italy, it is an autonomous region and the Italian government recognizes the 2 million Sardinians as a population distinct from other Italians. 23andMe's reference database includes 28 representatives of the Sardinian population living in Sardinia. (23andMe, Inc., 2009z)

Again, below this description is a “Tell Me About...” list of topics including “my placement on the Global Similarity plot” and “interpreting my plot if I’m of mixed ancestry” (23andMe, Inc., 2009z).

4.1 *Implications and Presuppositions*

The “My Ancestors” section of the website focuses on the geographic orientation of the user’s ancestors. According to Peter Chow-White, this reflects the “concerted efforts” of the medical industry in today’s day and age “to distinguish population groups from racial groups... [e]ither by using geographically oriented concepts such as

“geographic ancestry,” specific names for groups, or indicating where race is used to indicate environmental rather than biological factors” (2008, p. 1192). Chow-White points out that although HapMap¹⁰ members say “they do not use race but geographical ancestry to define the population groups”, “it would be remiss to overlook the significance of choosing the three major racial groups, African, Asian, and European, that have largely defined the social construction of race” (2008, p. 1187).

6 23andWe

The “23andWe” section of the website is broken down into three pages: “Introduction”, “My Surveys”, and “Featured Research” (23andMe, Inc., 2009ee). The “Introduction” page provides the basic information regarding 23andWe, a service that, 23andMe boasts, “has the potential to produce valuable insights more quickly and less expensively than traditional methods” (23andMe, Inc., 2009c). Three headings appear on the “Introduction” page: “23andWe is a new approach to genetic research”; “Participating is as easy as taking an online survey”; and “Collective action is the key to 23andWe” (23andMe, Inc., 2009c). Underneath these headings, 23andMe explain that the 23andWe approach allows users to “initiate, advise and participate in research via the Internet” and “be actively involved in research studies, guided by 23andMe scientists and collaborators” (23andMe, Inc., 2009c). Participation involves completing surveys available via the “My Surveys” page (23andMe, Inc., 2009c). 23andMe describes these surveys as “interesting”, “fun”, and “designed to collect information for developing and

¹⁰ HapMap was a “multi site, international venture between science teams in Canada, China, Japan, Nigeria, the UK, and the US” (Chow-White, 2008, p. 1186). This project aimed to map “haplotype blocks of different populations in China, Japan, Nigeria, and the US”, not only for comparison’s sake, but “to piece together the blueprint of human life... by way of the assembly of the haplotype blocks” of these groups (Chow-White, 2008, p. 1186).

conducting research projects that aim to find the genetic roots of everything from serious conditions like Parkinson's disease to simple physical characteristics like left-handedness" (23andMe, Inc., 2009c). Below this text is a big green button that reads "Next: Start participating in 23andWe" (23andMe, Inc., 2009c). This link brings users to the "My Surveys" page (23andMe, Inc., 2009a). On the right hand side of the "Introduction" page there is a list of "Frequently Asked Questions" concerning 23andWe in particular and a link to download 23andMe's "open letter to the science community", requesting proposals for research collaboration (23andMe, Inc., 2009c; 2009II).

The "My Surveys" page proclaims, "23andWe begins with you. Learn about yourself while contributing to research" (23andMe, Inc., 2009a). Below this title is a list of clickable "related topics": "About 23andWe", "Featured Research", and "23andWe FAQ" (23andMe, Inc., 2009a). The main focus of this page is the "Featured Research Survey" (23andMe, Inc., 2009a). It is currently "Where Are You From?" (23andMe, Inc., 2009a). There is an illustration of a family portrait to the left and a description of the survey to the right (23andMe, Inc., 2009a). This description explains that "many questions [regarding human ancestry] remain unanswered, especially about how the lives of our prehistoric ancestors shaped the world we know today" (23andMe, Inc., 2009a). With the results of this survey, 23andMe hopes "to fill some of those gaps in our shared prehistory" (23andMe, Inc., 2009a). Below this featured survey is a list of other surveys within three categories: "Core 23andWe Surveys", "Research Topics", and "My Health & Traits" (23andMe, Inc., 2009a).

The “Core 23andMe Surveys” include the following: “Where Are You From?”, “Health Habits”, and “What Do You Do?” (23andMe, Inc., 2009a). These surveys are differentiated from the rest as providing “*critical* background information for 23andMe research” (23andMe, Inc., 2009a, emphasis added). There are seven “Research Topics” surveys: “Ten More Things About You”, “Optimism”, “Ten Things About You”, “Handedness”, “Pigmentation”, “Footedness”, “Ocular Dominance” (23andMe, Inc., 2009a). These “Research Topics” surveys aim “to break new ground by making connections between genetics and disease or traits” (23andMe, Inc., 2009a). There are eight “My Health & Traits” surveys: “Just a Little Bite”, “The Eyes Have It”, “Does Milk Do Your Body Good?”, “A Sticky Question”, “Think Pink”, “Tortoise or Hare?”, “A Hint of Bitterness”, and “Feeling Flush” (23andMe, Inc., 2009a). These surveys are designed “to confirm known associations or find new ones in cases where some genetic factors are already known” (23andMe, Inc., 2009a). Clicking on any of the survey titles brings users to the survey for completion (23andMe, Inc., 2009a). Once most surveys have been completed, users are able to compare their results with the 23andMe community (the data is presented as percentages) (23andMe, Inc., 2009a). Some of the surveys, however, do not provide this opportunity, providing the following message: “Securing your privacy is of great importance to us. Please note that due to the sensitive nature of some of this information, results comparing your answers to the 23andMe community will not be given for this survey” (23andMe, Inc., 2009a).

The “Featured Research” page opens with a Flash slideshow labeled “A new paradigm for genetic research” (23andMe, Inc., 2009b). The first slide introduces

23andWe, similar to the “Introduction” page (23andMe, Inc., 2009a, 2009c). The subsequent slides are identified as follows: “How does research work at 23andMe?”; “Data collection”; “Data preparation”; “Data analysis”; and “Publication” (23andMe, Inc., 2009b). Within this slideshow is another link to download the “open letter to the science community” (23andMe, Inc., 2009b). Below this slideshow is a list of “Featured Research Projects” (23andMe, Inc., 2009b). There are currently five listed here: “Ancestral Origins”, “Pigmentation”, “Optimism”, “Handedness”, and “Parkinson’s disease and web-based clinical assessment” (23andMe, Inc., 2009b). Each project is described as follows. First, it is identified by name and the date of the last update is indicated (23andMe, Inc., 2009b). Next, there is a paragraph-long description of the background surrounding the project and the objectives (23andMe, Inc., 2009b). Finally, the “Research Stage” is indicated (for example, “data collection” and “study initiation”) (23andMe, Inc., 2009b).

6.1 Over-lexicalization

The “23andWe” section of the website stresses the active role of the user in their research. A vocabulary chain stressing interactivity is created with words including “initiate”, “advise”, “participate”, “actively involved”, and “begins with you” (23andMe, Inc., 2009a).

6.2 Implications and Presuppositions

As explained above, 23andMe (2009a) does not share the results of some surveys in the name of “security [users’] privacy.” However, what is not explained here is who the information is shared with outside of the 23andMe community. As their open letter to

the science community explains, 23andMe (2009ll) encourages collaboration with outside sources. Another implication found within this section of the website is that “featured” research is outlined for 23andWe members, however this seems to imply that other research (not “featured”) is being conducted but not reported here.

7 Community

The community section of the website is made up of only one page: “23andMe Community” (23andMe, Inc., 2009ff). The first heading that appears reads “Explore Recent Posts in Community” (23andMe, Inc., 2009ff). Below this heading are recent posts divided into four categories: “Health & Traits”, “Maternal Line”, “Paternal Line”, and “Product Discussion” (23andMe, Inc., 2009ff). Each of these categories is clickable and will bring the user to a page devoted to that category. Within these categories are also subcategories related to specific diseases, traits, and topics (for example, breast cancer) (23andMe, Inc., 2009h). Below these recent posts is another heading that reads “Most Popular Posts” (23andMe, Inc., 2009h). Here there are the title, name and photo of the community member and link to answers are displayed for the five most popular posts (23andMe, Inc., 2009h). On the right hand side of the page is a heading that reads “People” (23andMe, Inc., 2009h). Underneath this heading is a subheading that reads “Recently active” and the photos of twelve recently active community members (23andMe, Inc., 2009h). These photos are clickable and bring users to the “Member Profile” pages of these members (23andMe, Inc., 2009h, 2009cc). This “Member Profile” page provides a photo, name, personal details (sex, birthdate, birthplace, current residence, ancestry, about me), and the member’s “Community Activity” (23andMe, Inc.,

2009cc). The next heading on the “23andMe Community page” is “Community Manager” which appears right above a photo and the message “chiah.: Welcome to the community. I’m here to help!” (23andMe, Inc., 2009cc). Chia H (as her name appears) also has a “Member Profile” which says, “Please feel free to ask me questions or if you need help! If I don’t know the answer, I will do my best to get the information for you” (23andMe, Inc., 2009g). Her “Community Activity” shows that she frequently responds to other members’ posts on behalf of 23andMe (23andMe, Inc., 2009g). Finally, the last subheading on the “23andMe Community” page is “About Community” and provides links to “Read our Community Guidelines” and “See our FAQ on Community” (23andMe, Inc., 2009ff).

7.1 Implications and Presuppositions

The “23andMe Community” section of the website (23andMe, Inc., 2009ff) is the part that is the most similar to social networking sites such as Facebook and MySpace. There are series of threads where members communicate with each other and discuss genetics-related topics (23andMe, Inc., 2009ff). Users are able to subscribe to particular topics, so they can be sure to catch all related posts (23andMe, Inc., 2009ff). The photo of the posting member appears beside their post (23andMe, Inc., 2009ff). Their username is clickable and brings users to their “Member Profile” page (23andMe, Inc., 2009ff). This “Member Profile” page is very similar to profile pages on other social networking sites: Personal details such as birthdate, birthplace, about me, etc. (23andMe, Inc., 2009g; 2009cc). The information provided about each member here is quite sparse, unlike more socially-oriented sites such as Facebook (www.Facebook.com). The interactivity

available here is located within the message board section. These forums provide a space where users with common traits, risks, interests or questions can communicate with each other and feel connected. The interactivity with the “community” as well as the surveys and personalized information attracts consumers to buy into the 23andMe phenomenon. What underlies this social networking-like online service, however, is the fact that the company is acquiring each member’s genetic information and using it to achieve their own goals. The implications of this will be discussed further below.

Intertextual Analysis

Processes of Production and Interpretation

23andMe demonstrates an initiative by a private company to obtain medical information from individuals that the company would see as potential consumers of their product. This product is an interpretation or translation of these consumers’ genetic information. This system allows this company to maintain surveillance over the genetic make-up of the population of its users and allows this company to have power over their genetic information. This arrangement is reflective of the “Surveillance Medicine” environment that Armstrong (1995) identifies, as described in my second chapter. 23andMe promotes an internalization of particular messages about health, medical normalcy, and risks, as well as a type of Foucaultian self-surveillance. The major issue that arises in the context of 23andMe is that they are running a business within the private sector, meaning they are driven to make a profit. This profit is made off of interpreting raw data from individuals’ bodies and translating this into information about risks and probabilities in relation to the health of these individuals. The reason that I believe the

commercial aspects of 23andMe are important in terms of this thesis is that they are profiting off of information that they cannot even fully vouch for and that there is little to no accountability inherently involved here.

The 23andMe website stresses that it provides medical information only, not medical advice. They recommend support groups and contacting medical professionals for further discussion once they inform their users of their disease risks and genetic make-up. As mentioned above, although 23andMe has medical professionals as advisors (23andMe, Inc., 2009e), the “personalized” service is not really that personalized in that the findings and results are assumedly automated and not written especially for individuals by individuals. There is not one specific person or doctor to care for users on an individual basis. Furthermore, the corporation, 23andMe, Inc. itself is not a doctor and therefore has not taken the Hippocratic Oath. There are obvious ethical implications of providing medical information without taking this oath. However, 23andMe argue that their services “23andMe’s services are not medical”, but rather, educational (Langreth & Herper, 2008). 23andMe do not actually conduct the gene tests themselves, but “simply [manage the] web portals that disclose the results of tests performed by contract labs” (Langreth & Herper, 2008). As Steven Pinker (2009) points out, “personal genomics will be more recreational than diagnostic for some time.” He suggests that one of the reasons for this is that “the affordable genotyping services”, such as 23andMe, “don’t actually sequence your entire genome but follow the time-honoured scientific practice of looking for one’s keys under the lamppost because that’s where the light is best” (Pinker, 2009).

Analysts can misinterpret correlations by being unaware of the presence of an influential nearby gene or variant and therefore not see the entire picture of the situation.

Once users have submitted their saliva samples, 23andMe claims ownership of this biomedical substance, but not the data derived from these samples: “Your saliva, once submitted to and analyzed by us, becomes our property. Any genetic information derived from your saliva remains your information” (23andMe, Inc., 2009mm). However, it remains unclear how participants can participate in research studies if they are in control, ownership-wise, of their genetic information. The 23andMe Terms of Service state, “by your participation in the 23andMe service you contribute your genetic information to our research effort to study various aspects of human genetics in an attempt to better understand the human genome” (23andMe, Inc., 2009mm). Although 23andMe, Inc. does not claim ownership of its users’ genetic information, they admit to leveraging this data by using it as data for research efforts (23andMe, Inc., 2009mm). Therefore, they are using data that they do not own without providing transparent communication about this use. I would suggest that the implications of this type of collection and use of genetic information are similar to the implications that Troy Duster identifies for the genetic screening of newborns:

These registries, now in their beginning stages, are part of the *machinery in place* (organizational, institutional, legal and physical) which will slowly, subtly, sometimes imperceptibly, help shift the refraction of human traits, characteristics, behaviors, disorders, and defects through a “genetic prism.” (As quoted by Gandy, 1993, p. 77)

It is also clear that 23andMe, Inc. has a high level of ambition. 23andMe’s ties with Google Inc., the statements that Google has made about their interest in marrying the

search with genetics, and the immense power and influence that Google has provide evidence that the wheels behind making personal genomics a force to be reckoned with are definitely turning.

Social Conditions of Production and Interpretation

23andMe, Inc. is an American company and is primarily marketed to American consumers. Health care in America is not only considered to be poor quality (in comparison to health care in other developed nations), but it is also expensive (Fox, 2007). A study by Rogers and Mead concluded that peoples' perspectives on pursuing health-related advice online "was linked to pre-existing styles of interaction with health professionals" (Sillence and Briggs, 2007, p. 357). Those who pursue advice actively from medical professionals in person are more likely to pursue advice actively on the Internet. No matter what country you are located; it takes time and money to pursue healthy living. Therefore, it seems that a focus on genetics is a step towards an efficiency of healthcare, of sorts. According to the logic of the discourse of risk, if we focus on risk prevention right at the source, perhaps humanity can avoid "illness, disability and disease" and the accompanying "costs upon the public purse" entirely, ensuring all can employ "useful role[s] in society" (Lupton, 1995, p. 90).

Congressman Patrick J. Kennedy recently proposed a bill entitled the "Genomics and Personalized Medicine Act", which aims "to secure the promise of personalized medicine for all Americans by expanding and accelerating genomics research and initiatives to improve the accuracy of disease diagnosis, increase the safety of drugs, and identify novel treatments" (GovTrack.us, 2008). Although this bill has not passed as of

yet, it demonstrates that personalized medicine is on politician's radar screens. While this description of personalized medicine sounds ideal, it raises the question, will/should personalized medicine be in the hands of the government or corporations such as 23andMe? This bill also suggests a potential slippery slope towards eugenics. If scientists are successful and genomics research leads to ways to prevent diseases, will they also uncover ways to prevent undesirable traits? This question relates to definitions of normalcy and ideals. The "new eugenics" is a perspective that strives for "better human offspring" (Rabino, 2003, p. 378). "Better" here would mean "health, longevity, intelligence, and the like" (Rabino, 2003, p. 378).

Mahowald, Levinson, Cassel, Lemke, Ober, Bowman, Le Beau, Ravin and Times (1996) argue that women are especially affected by the new genetics:

Although [these] issues are relevant to individuals, families, and society at large, women, because of their central role in reproduction and caregiving, are affected not only differently but also more significantly than men by the information emerging from the [Human Genome Project].

One implication of this is that women are more likely to endure "political and social pressures" if they "are carriers of genetic diseases [and particularly] do not have independent financial resources to care for affected children" (Mahowald *et al.*, 1996, p. 241). Mahowald *et al.* point out that "the availability of prenatal genetic testing has increased third-party involvement in individual women's reproductive decision-making by family members, physicians, insurance agencies, and society" thus raising "concerns about possible constraints on women's autonomy" (1996, p. 260).

Conclusion

The main sections of the 23andMe website that I have analyzed communicate personal genomics as a particular type of information about the body. This information is presented in such a way, as it seems factual, objective, scientific and apolitical. It is presented primarily in terms of medical risks to users' wellbeing. However, at the same time, the 23andMe Terms of Service (2009mm) page paints a very different picture. Here, the information about the body presented by 23andMe is undercut by claims that this information is simply for educational purposes and that it should not influence any sort of action other than to inspire a visit to the office of a medical professional.

The "Clinical Reports" and "Research Reports" provide undeniably compelling data about disease risks, susceptibility, resistance, and avenues for support and advice. Individuals are provided information about a long list of conditions, some of which are a high risk and others low. While the individual may already be aware of some of these risks due to family history and whatnot, there are undoubtedly other risks that the individual learns of directly from their 23andMe account. 23andMe, Inc. has decided to provide this information to its users, drawing attention (or sensationalizing) disease risks, no matter how uncertain the association or how dire the risk. For those with very serious genetic risks, a face-to-face appointment with a geneticist would perhaps be more appropriate. For those unaware of any genetic risks, it is questionable whether or not 23andMe's evaluation of their risks would be beneficial or whether it would do more harm than good.

In my next chapter, I will synthesize these findings with the key terms from chapters one through three and discuss them in terms of overall implications. Conclusions

will be drawn, the contribution of this project to the existing body of literature will be discussed, and directions for future research endeavours will be recommended.

Chapter 5: Discussion and Conclusions

With this thesis, I have illustrated that new information technologies, such as personal genomics, are emerging, democratizing medical information and presenting information about our bodies to us in new ways. I have argued that personal genomics in particular have led to discourses about future risks, in the biological and genetic sense; discourses that encourage obligation and responsibility on the part of the individuals at risk. Furthermore, I have argued that new information technologies, such as my case study 23andMe, sensationalize risk, particularly risk of genetic disease and undesirable traits, and, in doing so, they encourage certain behaviours such as self-surveillance, lifestyle management, and potentially, future genetic intervention and manipulation.

As Armstrong (1995) points out, the nature of the relationship between doctors and patients and the medical institution in general have changed over time, due in part to challenges to authority posed by post-modernity and the emergence of new claims for authoritative knowledge about bodies and medicine. We are now still within the period of “Surveillance Medicine” (Armstrong, 1995), however, I would suggest that we are moving towards a new era where personal genomics and other self-help initiatives play key roles in preventative medicine. I imagine that this new period would see even greater personal access to information about our bodies, more autonomy in terms of decisions regarding sources of medical advice, treatments and preventative strategies.

It is my contention that people are expected to monitor their own health more and more, adjusting their lifestyles in reaction to certain risk factors. This thesis has shown that, from *The Oprah Winfrey Show* to the federal government to 23andMe.com, the

public is bombarded by messages encouraging self-surveillance everyday. The medical gaze is ubiquitous as a result of the biomedicalization of society. We are all expected to pursue a state of “health”, a lack of illness and disease, to fit in the ideal, “normal” category. Data about our health, medical issues, and now even genetic make-up, is being collected and sorted in massive databases. The panoptic sort of our financial records and legal documents by faceless corporations is worrisome enough, but it is medical (especially genetic) data that is particularly sensitive, considering the potential discrimination that could be caused by such information in the wrong hands. Not only are there deep concerns about privacy, but also there are major implications in regards to the effects such information could have on individuals’ life worlds. In the case of 23andMe especially, the use of technology and an online social network platform, users’ identities can be greatly impacted by such personal information as the description of their genetic make-up and genetic risks.

Although the 23andMe website notes that “all humans are more than 99% similar to each other genetically” (23andMe, Inc., 2009y), the entire personal genome mapping process by 23andMe stresses this remaining 1% of genetic difference among individuals. The 23andMe website generates a discourse of “Identity Construction through Difference”, where individuals are shown how their own traits, disease risks, and ancestry make them special and differentiate them from others. With the announcement “welcome to you”, 23andMe attempts to help users discover information about themselves that they wouldn’t otherwise have access to. People are drawn to the site and convinced to pay the one-time registration fee due to curiosity about this information that

can contribute to their self-understanding and identity. 23andMe employs essentialist logic, and the information provided to its users is limited by the idea that the qualities that differentiate individuals from each other are determined by genes. This “Identity Construction through Difference” discourse reflects Gandy’s (1993) concept of the panoptic sort. The users of 23andMe are seen by the personal genome mapping technology as having a number of qualities (traits, disease risks, and ancestry) that deviate in varying degrees from a norm. Users are grouped into categories defined by 23andMe. Since the 23andMe service is web-based, there is no interpersonal communication as there would be between a doctor and patient. Therefore, the context and information about environmental factors are not taken into account in 23andMe’s analysis.

While the “Identity Construction through Difference” discourse takes advantage of the narcissistic tendencies of 23andMe’s prospective and current users, encourages introspection, and celebrates each individual’s unique nature, there is another altogether different aspect and effect of the 23andMe experience. This second discourse can be named “Genetic Responsibility”. This discourse is ominous and can be unsettling. With the website’s strong focus on disease risks and carrier status comes encouragement of preventative measures, lifestyle management, and taking advantage of community and support groups. This discourse promotes self-surveillance; taking responsibility for your genetic makeup and keeping an eye on both individuals’ health and the health of their families. The website also clearly advocates participation in genetic research endeavours, particularly their own.

In my introduction, I asked the following research question: What are the implications of translating data from our bodies into data about risk? This thesis has indicated that the implications include an internalization of obligations to self-survey and to modify one's lifestyle in hopes to prevent disease and illness. While this is most certainly not the first time medical information (or advice) has been provided by a body outside of the medical profession, I believe that personal genomics web-services may be a significant milestone in terms of private companies providing a very specialized service using advanced medical technologies and providing personalized medical information directly to consumers/users. I do not believe that this is simply a novel fad, but rather I believe that there is much more to come. Our inherent curiosity about ourselves in addition to our demand for on-the-spot information will ensure that personal genomics and online personalized medicine will only continue to grow and become increasingly important. The problem is that such automated services have no moral accountability or obligation to do the best they can for its patients, as it not only has not taken the Hippocratic Oath, but also views its patients as users/consumers. Although 23andMe claims they only provide medical information and not advice, there is a responsibility that comes with such information and the implications of providing such information must be confronted.

Contributions to the Literature & Directions for Future Research

By analyzing the 23andMe website from a critical stance, this thesis provides a valuable perspective on the burgeoning field of personal genomics and the nature of its online communication. While this thesis has touched on the potential impact this service

can have on individuals, their life worlds and identities, further research on the experiences of users of personal genomics would be valuable, especially longitudinal studies. Another contribution that this thesis makes is that it highlights the shift from medical communication being interpersonal communication to becoming mass communication. Although 23andMe provides “personal” genomics, there is no one-on-one consultation with a living, breathing human being on the other side of the computer screen. Even though 23andMe employs a web 2.0-style, encouraging discussion with other users on the message boards, the communication flow with the company itself is very one-directional.

Today, “61% of American adults look online for health information” (Fox & Jones, 2009, p. 2) and use Internet sources as a supplement to “traditional sources of health information” (Fox & Jones, 2009, p. 7). The social networks that people turn to for information about health and health care now includes online sources (Fox & Jones, 2009, p. 7). This is a significant fact. As more and more companies jump on the personal genomics bandwagon, among other direct-to-consumer medical technologies and services via the Internet, there will be increasing opportunity for communications scholars to examine the messages and rhetoric employed in these online ventures. As more and more people start to use the Internet as a source for medical information or information about their bodies, there will be increasing opportunity for communications scholars to examine the effects of such information on these users/audiences. As medical information becomes increasingly democratized, so to speak, this information should continue to be interrogated so as to encourage critical thinking on the part of the consuming public.

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