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Tracking the Human: Posthumanism, Ethics, and Critique in Health Tracking Technologies

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Tracking the Human:
Posthumanism, Ethics, and Critique
in Health Tracking Technologies

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in
Communication

By

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2016
This Dissertation of Todd Christopher Woodlan is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

Chair

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2016
# TABLE OF CONTENTS

Signature Page ........................................................................................................ iii

Table of Contents ................................................................................................... iv

List of Figures ......................................................................................................... v

Vita ......................................................................................................................... vi

Abstract of the Dissertation .................................................................................. vii

INTRODUCTION ....................................................................................................... 1

CHAPTER 1 Reclaiming the Human in Posthumanism ....................................... 21

CHAPTER 2 Diabetes Self-care Techniques ......................................................... 55

CHAPTER 3 Biopower and Quantified Self ......................................................... 104

CHAPTER 4 Genetic Capital .................................................................................. 150

CONCLUSION ......................................................................................................... 188

WORKS CITED ....................................................................................................... 200
LIST OF FIGURES

Figure 1: Visualization of blood glucose measurements and running.......................... 84

Figure 2: Visualization of blood glucose measurements and running, text added ...... 85

Figure 3: Finn’s visualization of sleep quality .......................................................... 121

Figure 4: Finn’s visualization of sleep quality .......................................................... 122

Figure 5: Finn’s visualization of his sleep stages ...................................................... 124

Figure 6: Finn’s visualization of his sleep stages ...................................................... 125

Figure 7: McCurdy’s visualization of Myasthenia Gravis flare ups ......................... 129

Figure 8: Wolfram’s visualization of email volume.................................................... 139

Figure 9: Wolfram’s visualization of email volume.................................................... 140

Figure 10: Wolfram’s visualization of email volume.................................................. 140

Figure 11: Wolfram’s visualization of events .......................................................... 141

Figure 12: Wolfram’s visualization of email data alongside events ......................... 142

Figure 13: 23andme heightened risks ...................................................................... 160

Figure 14: 23andme recommendations ..................................................................... 162
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ABSTRACT OF THE DISSERTATION

Tracking the Human:
Posthumanism, Ethics, and Critique
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by

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Doctor of Philosophy

University of California, San Diego, 2016

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This dissertation attempts to identify a new way in which individuals are using health tracking technologies to create localized versions of what counts as human. These new versions of the human stand in opposition to the humanist model of the human, which posits a universal model that should be replicated in individuals through techniques of self-care – a model that has proven to be deeply problematic by defining the human largely as rational, white, male, and Western and excluding those who do not fit this model. However, the new forms of the human that emerge from
contemporary health tracking technologies rely on individual datasets, making it
difficult to expand the resulting model of the human to a population at large and create
a universal model along the lines of traditional humanism. Moreover, these models
can create a basis upon which others can engage in self-critical dialogue with their
own data, creating unique models of self-care that promote localized ideas of health.
Here, in the decline of a universalized notion of “the human” and the rise of a risky
type of sharing, this dissertation will show that it is possible to see the beginnings of a
type of humanism – one that retains the idea of _a_ human in place of _the_ human in
order to re-invigorate Enlightenment ideals of critique, justice, and ethics.
INTRODUCTION

The Star Trek episode “Space Seed,” which first aired in 1967, opens with the USS Enterprise crew beaming onto a mysterious ship filled with sleeping people, all within glass containers. Dr. McCoy pulls out a black box and points it toward one of the sleeping bodies. The box allows him to collect vital signs such as temperature and heart rate, even though the physical body of the person is isolated away from the machine. These vital signs initially read as typical, but the heart rate quickly drops, allowing McCoy to identify a potential medical emergency and act quickly to free the body from its cryogenic chamber. The person trapped is saved from death. Ironically, he turns out to be the future nemesis of the crew, the genetically modified Khan.

Although the device that McCoy uses to diagnose and save Khan, called a medical tricorder, is almost unremarkable amongst the other retro-futurist technology of Star Trek, it is perhaps one of the most significant. It allows for a portable solution to quickly and accurately read medical metrics while also continually processing these metrics for real-time feedback on the patient’s health. The usefulness of the medical tricorder may be hidden behind much of the other flashier Star Trek technology like phasers or transporters, but it has not been lost on the contemporary medical community. Practitioners currently rely on a number of different, bulky devices to perform the same tasks as the tricorder, including thermometers, heart rate monitors, and blood pressure cuffs. Creating a portable all-in-one device would greatly aid in the ability of practitioners to assess and diagnose patients easier, more frequently, and in -
less accessible locations. In the past few years, industry efforts have been mobilized to create such a device.

The XPrize Foundation is one such effort. The foundation has created a $10 million award for the first company which successfully creates a product that approximates much of the functionality behind the Star Trek device. Appropriately called the Qualcomm Tricorder XPrize, the reward requires that the device must be small and portable, while still able to (1) accurately diagnose 16 health conditions (anemia, atrial fibrillation, chronic obstructive pulmonary disease, diabetes, Hepatitis A, leukocytosis, pneumonia, otitis media, sleep apnea, stroke, tuberculosis, urinary tract infection, absence of conditions, airborne allergens, cholesterol screen, food-borne illness, HIV screen, hypertension, hypothyroidism/hyperthyroidism, melanoma, mononucleosis, osteoporosis, Pertussis, shingles, and strep throat) and (2) monitor five vital signs (blood pressure, heart rate, oxygen saturation, respiratory rate, temperature).¹ Though this is a tall order, there are currently seven finalists working toward a solution. Scanadu is the forerunner among these finalists, launching a successful Indiegogo campaign in 2014 and shipping to early backers in 2015. The device is called the “Scout” and, after being placed on the user’s forehead for a few seconds, provides information on heart rate, core body temperature, blood oxygenation, and systolic and diastolic blood pressure.² The data is then sent to a mobile app, where the user can access the raw data as well as commentary by the app that helps interpret the data.
Much like the medical tricorder in *Star Trek*, Scanadu hopes that their Scout product will make gathering medical data on individuals easier by putting it in the hands of the patients themselves. The website boasts that the device will be “your doctor’s new best friend” and that the user can “check [their] health as easily as [their] email.” The concept behind the device seems to be to bring the hospital into the daily life of the individual and to promote a healthy style of living.

On first glance, Scanadu’s focus on self-monitoring appears to be in line with Michel Foucault’s claim that clinical medicine is concerned with not just curing illness, but in placing an individual under surveillance to understand their issues. This constant observation is termed the “medical gaze” and sees illness through direct observation of bodies, rather than through laboratory controlled experiments that isolate viruses, bacteria, cells, or other factors that make up the disease in order to understand it. A technology like Scanadu would exemplify Foucault’s notion of the gaze, extending the ability of medicine to observe the individual beyond the walls of the hospital itself and away from a physically-present practitioner that conducts tests. A medical tricorder-type device would allow the individual to continue medical surveillance within their own home, incorporating the gaze within everyday life and allowing the individual to order their lives in a way that reflects medical recommendations.

The danger of the medical gaze lies in the institutionalization of medical knowledge, which becomes concerned with “completed scanned multiplicity of individual facts” rather than “completely observed individuality.” With a large
amount of observed data, medicine becomes concerned with creating the idea of a normalized, healthy human and then attempts to order the life of individuals to fit that particular conception through guidelines for healthy living. Scanadu and the image of a medical tricorder would seem to fit well with Foucault’s normalizing medical gaze: it would provide medical researchers with large amounts of data from many individuals that could be processed to either find the typical human or could be fed back to the individual to show how they are falling short of ordering their lives in the “proper” manner.

However, the discourse surrounding Scanadu and other health-monitoring technologies disrupts these notions significantly. Unlike the medical tricorder in *Star Trek* and many contemporary health-monitoring devices, Scanadu is meant to be used by the individual to collect data for both the practitioner *and* the individual to analyze, ostensibly allowing the individual to be more than the target of a medical gaze. The Scanadu website asks the visitor to “Imagine a future where you can know yourself best” and proclaims that “Finally, information about our body is not locked away inside the walls of a hospital.” Moreover, the Scout is “designed to provide you with access to valuable data which your body provides every day” and will allow “anyone to capture important physiological data.” Here, the focus is not on collecting data for the hospital, but collecting data that the user can analyze, providing the opportunity for a “completely observed individuality” rather than a “completely scanned multiplicity of individual facts.”
While Scanadu remains under development, a large market for wearable devices with similar, but more limited capabilities has emerged in recent years. Yearly revenue for wearables is projected to reach 19 billion dollars in 2018, a tenfold increase since 2013. Devices that specifically track health metrics make up a significant portion of this market, as accelerometers like Fitbits become commonplace and as health-tracking software gets automatically bundled with the latest iOS release. Scanadu and market-ready tracking devices allow the individual to carry a greater responsibility for their own healthcare, but also potentially gains a greater freedom to manage their own care in ways outside of strict medical control. Much like Scanadu seeks to reorganize the relationship between medical practitioner and patient, wearable health tracking devices provide an opportunity to examine how medicine’s idea of a “normal” human body can be called into question as individuals begin to monitor their own health.

Even as health tracking technologies provide an opportunity to open up the medical definition of the human, they also encourage their users to engage in two potentially harmful processes that replicate a single, medically-sanctioned idea of the human. The first comes from placing responsibility on the individual to manage their own health through increased modes of surveillance and oversight. Through these methods, individuals are pushed toward replicating the social idea of what can be identified as a “normal” individual or, to borrow Rosemarie Garland Thomson’s term from disability studies, the “normate.” Examples of this include patients with chronic conditions who are recommended a set of self-care procedures to keep their condition
under control or health tracking devices like the Fitbit that set a standard number of steps to walk in a day for the user to be “healthy.” In these cases, medical knowledge sets a standard by which people are supposed to order their lives and care for themselves. Such a standard replicates a generic idea of what a proper “human” can be and places the onus on the individual to follow through with acting accordingly to preserve their health.

The second process emerges when individuals are converted into quantifiable metrics, which can include steps taken, calories consumed, genetic markers, happiness levels, or anything else that can be measured. An individual could then be excluded from societal, economic, or medical spheres based on how favorably their metrics compare to a baseline. Examples of this include long-term loans being denied to people exhibiting genetic markers with a high likelihood of developing early-onset fatal diseases or healthcare being denied to individuals who do not record a certain amount of exercise on a tracking device.

However, in practice, placing responsibility on the individual to manage their health also results in a greater freedom to manage medical self-care regimes in ways other than those prescribed. Case studies of diabetics, for example, show that doctor recommendations often get misunderstood or ignored because they do not fit easily into the busy lives of individuals. As a result, the individual makes assessments and choices about how to assemble a self-care regime. Health tracking technologies get used in a similar way, as groups like Quantified Self take the data from Fitbits, sleep trackers, and other wearables to create their own, unique protocols for losing weight,
sleeping, or any number of other tasks. The difference between the ideal of self care techniques and the ways that those techniques play out in every day life point to a disjunct where medical technologies encourage greater oversight and surveillance, but in a way that puts the responsibility of analysis in the hands of the individual, allowing them to come to conclusions through analyzing a large dataset that applies only to their situation. In turn, the idea of a normate human also breaks apart, opening itself up to a multitude of different configurations.

With the ability to apply large-scale data observation and analysis on the individual level, it is now possible to create the image of a “normal” human that applies only to a single individual. In turn, institutions such as medicine and government that operate based on the assumption that there is a normate model of the human must reconfigure their engagement with individuals. It is the twofold purpose of this dissertation to examine how contemporary medical self-tracking technologies begin to change the idea of the human and how institutions deal with this newly reconfigured individual who does not necessarily embody the normate idea of the human.

Chapter One will trace the emergence of contemporary ideas of the human and how both medicine and technology have reconceptualized the human. This discussion will provide a basis for shaping later analysis on how medical self-tracking technologies are used, as well as the larger theoretical implications with society and institutions. Taking Foucault’s cue that contemporary medicine’s idea of the human has roots in eighteenth century thought, this chapter will focus on the human’s
appearance in Cartesian and Enlightenment philosophy and later articulation in the
development of technology and medicine. Descartes initial starting point, as a division
of mind and body, has been influential in the way that medical discourse has
continued up until the twenty first century. For Descartes, the human was the only
entity capable of rational thought and stood as a unified entity apart from the world
around it.\textsuperscript{8} Other objects such as animals or machines may occasionally appear to
possess reason, but this is just an illusion created by instinct and pre-set mechanisms,
respectively.\textsuperscript{9} Kant took this idea further, claiming that humans are responsible for the
value, form, and meaning of the world as a whole.\textsuperscript{10} Both thinkers created a radical
type of anthropocentrism that resulted in the formulation of a “proper” type of human
that possesses rationality and stood as a unified being at the center of the world. Such
a theorization had extreme consequences when individuals did not fit that definition of
human. Michel Foucault points to this in his writings on madmen, who allegedly did
not possess reason and the techniques of power utilized by institutions to encourage
such individuals to act in ways that made them proper, healthy humans.\textsuperscript{11}

Thinkers like Michel Foucault, Katharine Hayles, Neil Badmington, and David
Roden have recognized the potentially dangerous applications of humanism and
attempted to move away from humanism in recent years. While Foucault has focused
primarily on how the human has been (re)configured through various institutions,
Hayles, Badmington, Roden, and have looked at how contemporary technology has
changed conceptions of the human – specifically with regards to feminist,
postcolonial, and racial issues – engaging in what they call “posthumanist” critique.
Though the posthumanists are often influenced by Foucault, they typically deal with technologies such as artificial intelligence, games, and social networks rather than specifically medical technologies. Putting them in dialogue with Foucault’s identification of medicine as a significant point at which humanism emerges has the potential to show how contemporary medical technologies change ideas of the human.

The chapter, therefore, examines the different ways that posthumanism and the related theories of transhumanism and Object Oriented Ontology have attempted to get beyond the radical anthropocentrism of Descartes and Kant through a focus on the individual’s situatedness within an environment of non-human actors. But, as Halliwell and Mousey and Badmington point out, posthuman theories are not entirely “post” because they do not completely jettison the idea of the human. Instead of trying to remove the idea of the human entirely, chapter one looks to Foucault’s articulation of the divide between the Enlightenment as an ethos of self-critique and the humanist doctrine of a normalized, ideal figure of Man. This difference, typically collapsed in posthumanist critiques of humanism, will be the basis of a move to ask if it is possible to view the human as a type of subject involved in constant self-examination within a larger context that constantly disrupts notions of an over-arching normalization. Moreover, the chapter asks if it is possible to have a sense of ethics and justice – qualities intimately tied with humanism – without the central, unified figure of Man.

The second chapter will take Foucault’s lead in looking to medicine to find a type of subject involved in a form of self-critique that calls into question the anthropocentric humanist formulation of the human. While this dissertation would not
disagree with the possibility of self-critique happening in short-term medical interventions like treating a wound or seasonal flu, examining how self-critique plays out over individuals living with disease brings forward more of the issues of how patients deal with illness and self-care. These individuals are forced to (1) adhere to a larger medical idea of what the model patient and “healthy” individual should be, much in the way that humanism presents a model human and (2) take on much of that responsibility themselves of producing and maintaining health, as in the ideal Kantian individual who makes their own decisions. Examining case studies of how patients with chronic diseases manage this tension provides a concrete instance of how humanist and Enlightenment ideals are collapsed within contemporary medical discourse, yet still opposed in many ways.

This chapter will take diabetic patients as the primary focus, as they must constantly engage in self-care practices directed by medical standards, even if they are also not completely restricted in their daily lives. Except in the most advanced and extreme case of the disease, most diabetics are not bound to their homes or have extremely visible signs of the disease. They are able to act as model humanist humans in many ways, which also allows them assume a large degree of freedom in managing their own disease, often pushing the boundaries of medical oversight.

By looking at case studies of diabetics, this chapter examines how self-care affects a diabetic individual’s life over the long term and how medical practice has increasingly moved to the home, requiring patients to constantly monitor their health. As patients are required to do more of the day-to-day operations of dealing with their
disease, doctors engage in different methods to attempt to get the patients to care for themselves in particular ways. One of these is concordance, where the doctors promote an “open exchange of beliefs about medicine” in order to convince (rather than order) the patient to perform particular methods of self-care when they are away from the hospital.\textsuperscript{12}

However, even with a less paternalistic model of care that has as its goal actively involving patients in decision making processes, patients still do not precisely follow the doctor’s orders. This chapter uses case studies found in medical papers to look at the different ways that patients go about critiquing their own regimes of self-care while also engaging with the medical community’s reaction to the various regimes. By using case studies, it will be possible to show the divide between how patients manage their condition through day-to-day operations, while also providing the medically-sanctioned assessment of those self-care regimes.

Some of these regimes will be shown to be completely patient-directed and against the orders of the doctor (such as patients believing that their diabetes needs to be fed high amounts of sugar constantly). Others will modify the recommendations of the doctor to fit their own needs and beliefs (for example, taking the prescribed insulin, but modifying the dosage). The most important way of changing the way care is administered will be shown to be through the examples of Vivienne Ming and Doug Kanter, who both used contemporary health tracking technologies to monitor their illness and collect large amounts of data. Though this data is similar to the type collected by health institutions, it is analyzed primarily by the patients themselves and
allows them to create a new regime of care that is personalized and not always aligned with medical recommendations. This change in how medical care is enacted creates a situation whereby the rational, unified figure of the human breaks down, replaced by a unique type of individual that constantly engages in self-critique, does not fit a normalized model of “the human,” and is situated amongst a number of different, often non-human actors.

The type of care Ming and Kanter engage in is further theorized in Chapter Three by looking at self-reported case studies from the group known as Quantified Self. The tagline of Quantified Self is “self knowledge through numbers,” a slogan that equates the self with the data it produces by going about various activities throughout the day. Quantified Selfers collect data about processes ranging from steps taken to places visited to microbes in the gut to the amount of work done in a particular time. These datasets can be visualized and compared to each other to gain insight into an individual’s unique circumstance. Case studies provide specific examples for how these datasets play out.

Where examining the self-care techniques of diabetics in Chapter Two looked at a way that medical recommendations are modified and put into practice in different ways, case studies of Quantified Selfers presented in Chapter Three demonstrate how individuals create their own methods of self-care outside of specific medical recommendations. These methods of self-care may have a loose basis in medical studies or doctor recommendations, but many of them become highly personalized and do not adhere to the universal, normate idea of how a patient should respond to
interventions into their way of living. By identifying ways that alternative self-care practices emerge, this chapter begins to show how the concept of a “human” can be retained, but also not generalized to a larger, universalized idea of “the human” that must provide the blueprint for all individuals to order their lives.

Chapter three claims that while the data collecting within Quantified Self seems to be a type of self-surveillance and a way of intensifying self-care practices that make someone into a “normal” human, its effects are altogether different in practice. Quantified Self proves to be an application of biopower, a technique of power identified by Foucault as a way to track metrics related to the lives and bodies of a population: births, deaths, overall health, and factors that cause these to vary. These statistics provided a basis upon which institutions could create guidelines for how individuals should order their lives. In the case of Quantified Self, however, institutional authority is not just reproduced over the individual through tracking health metrics. Instead, technologies normally applied to track populations are limited only on the individual level. This results in an attempt to subvert the creation of an over-arching, abstract concept of what a “normal” human would look like, which could in turn be used as a mechanism to control populations.

This chapter takes as its starting point the three main characteristics of biopower identified by Nicholas Rose and Paul Rabinow, two of the most prominent contemporary commentators on biopower. Their conclusions are analyzed along with corresponding Quantified Self projects to show that while QS generally fits into their notion of how biopower operates, it operates on the individual level rather than on the
level of the population. Ben Finn’s attempt to track and learn about how different variables affect his sleep demonstrates Rose and Rabinow’s claim that biopower creates truth discourses about the vital character of human beings. However, in Finn’s case, the truth discourse created about sleep patterns only applies to Finn’s unique sleeping situation and can only be used as a starting point for other Quantified Selfers’ studies of their own sleep patterns. Likewise, Kim McCurdy’s analysis of her own chronic condition comes out of a medical necessity to work on her individual habits in order to avoid falling ill. It illustrates Rose and Rabinow’s claim that biopower works by providing a strategy for intervention on large groups of people in the name of health. However, McCurdy’s case presents a unique situation because she utilizes data collection methods normally used to monitor populations on a single individual – herself – creating an intervention in the name of health that applies to a population of one. Lastly, Nancy Daugherty’s project presents a realization that Quantified Self projects mostly serve to encourage an active participation in mindfully attending to oneself through the act of tracking, rather than a specific roadmap to fix a particular issue. This lines up with Rose and Rabinow’s point that biopower is the process by which individuals engage in “modes of subjectification” where they work on themselves according to certain practices of the self. In each case, the Quantified Self project engages in a form of biopower, but analyzes the data of a single individual to create a truth discourse that is limited to a single individual, rather than generalized to fit the population as a whole.
Chapters Two and Three illustrate how individuals work alongside medical technologies to create new forms of subjectivity that do not attempt to fit into an outside, normalized concept of the human. Chapter four asks whether or not the type of individual formed through health tracking technologies can operate within a larger institutional setting. Where the previous chapters examine case studies of individuals and their methods of self-care, chapter four traces the single case of how one particular health-tracking service, 23andme, operates at the intersection of governmental/medical institutions, the for-profit genome sequencing market, and individual users interested in open source genetic databases. 23andme provides a particularly useful example of self-tracking within the larger institutional landscape as its structure replicates the tension between humanism and Enlightenment individualism present in the previous chapters. The company relies on large-scale studies of genetic data to create a normative model of the human for the user to compare itself against. At the same time, the service also gives the individual information about their health along with some guidance on how they can use the data to engage with critical self-care practices. It is also this very tension – between access to medical data and the implication that the user must create self-care practices around the results – that led the FDA to step in and regulate the company. Within this dialogue between company, government, and consumer, the issues of humanism and Enlightenment values identified in other chapters play out on an institutional level.

23andme is a company that analyzes an individual’s spit for genetic markers that could indicate particular traits, health conditions, or ancestry details. In 2013, the
FDA claimed that 23andme was a medical device and forced them to stop providing their service, pending approval. Two years later, 23andme was cleared to provide the test again, albeit with a limited range of reports. While many users look to this service to get general information about their genetic makeup, many also share their data with the hope of others using it for beneficial research. The tension here between individuals wanting information, a company selling a product, and a governmental agency attempting to establish regulations highlights a development in contemporary medical technologies where humans no longer become local instances of diseases (as in Foucault’s history of medicine discussed earlier), but become reconfigured as capital through the storage, use, and re-selling of their genetic data.

This realignment of individuals with capital reflects Wendy Brown’s warning that market rationality currently permeates social, governmental, and institutional systems, reconfiguring individuals as capital and making the maximization of various forms of monetary and non-monetary capital the primary goal of different spheres of life. In terms of 23andme, this means gathering genetic data about a person to be used in future studies to profit the company as well as creating users that are concerned with investing in a future, healthy self. Brown claims that life ordered around market rationality carries with it the removal of the promise of equality, justice, and freedom that has come to be associated with democracy. She argues that “the cultivation and expression of distinctly human capacities for ethical and political freedom, creativity, unbounded reflection, or invention” get pushed aside as life
becomes an issue of winners and losers within deregulated marketplaces each trying to 
enhance their position at the cost of others.\footnote{16}

The logic surrounding 23andme becomes significant because it provides an 
instance thoroughly organized by market rationality and the idea of investing in 
one’self to make a “better” person, but at the same time it actively encourages the types 
of democratic activities that Brown worries about losing in an economically-organized 
society, namely the ability to limit institutional power and the disappearance of a 
platform of critique that allows instances of inequality and injustice to emerge.\footnote{17} Yet, 
the service does not point to an emergence of a utopian rule by popular sovereignty or 
a return to \textit{homo politicus}, where individuals are political beings. Instead, we see the 
beginnings of an individual who utilizes information about their genetic makeup to 
increase their own health-related capital while simultaneously publishing this 
information online, putting themselves at risk for potential mis-use of their data for the 
benefit of other individuals and the general population.

The process of configuring the individual as capital, but in a manner that does 
not necessarily circumvent the promise of liberal democracy happens in several ways. 
First, 23andme’s model revolves around providing information and guidance to the 
user about how to engage with their data, but there is no clear, universal metric for 
how the user can increase their capital in a way that can be relevant within a 
marketplace. Finding out about particular genetic qualities allows a person to 
understand more about how their bodies work and engage in practices of self-care, but 
these findings are not always accurate or applicable outside personal development.
The second way in which genetic home tests configure the individual as capital is through the governmental response to regulate the service on the side of the consumer. Brown brings up a number of examples where neoliberal and market logic dictates that governmental decisions play out typically in favor of corporations’ rights based on principles of free speech. However, in the FDA’s case against 23andme, the service was actually paused in order to put in proper regulations to protect the consumer. The third way is an extension of this obligation to protect the individual. Some users of 23andme have taken their data and published it online for anyone to use for research or individual experimentation, putting themselves at great risk for future mis-use of data for the possibility of helping others. Here, individuals do not become isolated sites of capital accumulation at the expense of others, but rather act in shared self-interest and capital accumulation. This chapter argues that 23andme may create users, corporations, and governments that operate within a market rationality. But, the relation between these entities actually creates a subject that opens up the possibility for a renewed interest in the “ethical and political freedom, creativity, unbounded reflection [and] invention” that Brown sees as lacking.

Overall, this dissertation attempts to identify a new way in which individuals are using health tracking technologies to create localized versions of what counts as human that disrupt some of the damaging tendencies of humanism to exclude those types of individuals who do not fit the normate model of the human. These new instances of “the human” rely on individual datasets and cannot be expanded in the same ways as clinical medical knowledge to apply to populations as a whole or create
a normative version of what it means to be human. However, these models can create a
basis upon which others can engage in self-critical dialogue with their own data,
creating unique models of self-care that promote localized ideas of health. As shown
in the open source genetic data-sharing networks emerging around services like
23andme, there is also a significant community willing to put themselves at risk to
share their own data so that others may benefit. Here, in the decline of a universalized
notion of “the human” and the rise of a risky type of sharing, I hope to show that it is
possible to see the beginnings of a type of humanism – one that retains the idea of a
human in place of the human in order to re-invigorate Enlightenment ideals of
critique, justice, and ethics.

3 Scanadu | Home

Brown 43

Brown 208
In the early twenty-first century, the integration of human and machine has become increasingly commonplace, bringing renewed interest to the boundaries of the human. People with failing hearts get pacemaker implants, individuals with bad eyesight undergo Lasik eye surgery to correct their vision, the hard of hearing can get cochlear implants to improve their auditory senses, and broken bones are enclosed in custom-printed 3D casts. On the other end of the spectrum, humans use technology to improve their own ways of functioning. Extreme examples of bodily enhancement are “grinders” – people who “hack” their body and install various DIY implants into their bodies. One such implant is a neodymium magnet placed on the pads of the fingers that allows the individual to feel surrounding electromagnetic fields, such as microwaves or surrounding magnets. Another is an RFID (radio frequency identification) chip that emits a unique signal and can be used to unlock electronic devices such as computers.

These medical operations, among countless others, present a unique transition whereby computers or other electronic sensing devices are introduced into the human body to expand the ways it can work and sense within the world. By incorporating technology into the body in this way, contemporary use of technology is calling into question a long-held division between the human and machine that, unlike previous versions of this critique, looks at machines not just as objects without consciousness,
but as potential agents for creating new forms of consciousness and possibilities of interacting within the world.

Where advocates of these new technologies see a utopian world where the human can be fixed or improved through technology, many scholars see these technologies as deeply problematic, at best advocating a failed vision of leaving the body behind and, at worst, reinscribing power structures that disempower and exclude individuals who do not fit the appropriate type of human. These scholars, generally grouped together under the title of “posthumanists” – or more specifically, critical or cultural posthumanists – provide a critical examination of technology that is able to take into account cultural, social, ethical, and ontological issues surrounding the introduction of new technologies. Posthumanism’s ability to approach these topics is couched in a belief that the primary quality of “the human” has, for centuries, been understood to be heavily skewed toward the Western, rational, white, male subject, which marginalized groups such as women, non-Western cultures, individuals with particular disabilities, and non-rational modes of thought. Posthumanism looks to contemporary technologies as a way to show both the previous assumptions which have been tied to the human as well as identify possible ways that these technologies allow those assumptions to be reconfigured within new subjectivities. By creating legitimate forms of subjectivity outside of what has traditionally been called “the

* The type of posthumanism that I will be discussing concerns what is commonly termed critical or cultural posthumanism. This particular type of posthumanism stands opposed to the posthumanism of thinkers like Fukuyama who see posthumanism as meaning post-human and examine what a new, non-human person would look like. For more information on the differences between the types of
human,” posthumanism attempts to create an ethical engagement with these formerly marginalized groups and legitimize them in legal, social, and cultural realms.

However, it is necessary to note that posthumanism should generally be understood as post-humanism, not post-human. In attempting to open up the human for different modes of subjectivity, many forms of posthumanism end up advocating for a different type of human, not a wholesale rejection of it. The exact ways that this occurs will be examined below, demonstrating that the overall hope of posthumanism is to create a type of subjectivity that affords the possibility of multiple configurations of the human, which in turn devalue the Western, rational, white, male subject position. This chapter will provide an overview of posthumanism as a project of critique of the rational subject arising from humanism that is deeply involved in redesigning ethical considerations in the twenty first century. The following chapters will take up these theories of posthumanism in relation to medical technologies – an area that has been deeply embedded in generating the figure of the human since the rise of clinical medicine in the eighteenth century – to show how contemporary medical technologies are able to retain a constant critical engagement of “the human” while also promoting ethical engagement with others.

The form of humanism that provides a basis for posthumanism began to take hold as the dominant Western conception of the subject in the 17th century. During this time, thinkers such as Descartes began to posit the existence of a type of core

humanity, a particular essence that created an entity that could be designated “the human” or “Man.” For Descartes, this essential human characteristic was reason, which gives both the power of judgment as well as the ability to tell the human from the non-human. Identifying reason as a uniquely human characteristic served to create a boundary between human and non-human. The human became that which possessed reason and the non-human became that which did not. The non-human included inanimate objects such as trees, rocks, houses, or any number of other objects. It also included organic entities such as animals that appeared living, as humans did, but could not rationalize. Using rationality to draw a line between Man and non-Man, Descartes and subsequent humanists started to isolate the human as a subject that did not rely on these lesser, non-reasoning forms to exist. Consciousness and rationality were their own entities and could be studied independently of outside factors like physical surroundings, culture, and society.

At times, the appearance of rationality could emerge in other objects, most notably the animal and the machine. Descartes claimed that animals appear living because they sometimes exhibit speech, as in the case of a parrot or a monkey that communicates ideas with its species, and have a certain amount of dexterity in certain tasks. However, animals cannot communicate their thoughts to humans, nor do they surpass humans in performing all types of tasks. Thus according to Descartes, “they have no reason at all. It is nature which acts in them according to the disposition of their organs, just as a clock, which is only composed of wheels and weights, is able to tell the hours and measure the time more correctly than we do with all our wisdom.”
For Descartes, the animal is not human because it is mechanistic and cannot reason on its own, instead operating on instincts and reactions that do not require introspective thought. Indeed, Descartes claims that if an automata were created that looked and acted like an animal, “we should not have had any means of ascertaining that they were not of the same nature as those animals.”

Like animals, machines for Descartes may give off the illusion of human-ness, but they are not able to truly reason or think critically and, thus, are not truly human. If humans were to encounter a machine masquerading as human, they would be able to note two things that betray the machine: (1) its incorrect use of language and (2) its inability to outperform a human in every task, even though they may do better in some. In each case, the machine gives itself away because it does not always act as a rational being, even if it initially appears that way. Though Descartes was referring to seventeenth century automata, contemporary examples underscore his points clearly as well. For example, Apple’s Siri program comes installed on all new iPhones and allows the user to interact with the phone’s operating system by asking questions or giving voice commands. Siri can understand natural language, which allows the user to speak as they would to any other person, rather than being restricted to certain preset commands. Most of the time the program works well, answering the user’s questions or providing the data requested. Sometimes, however, Siri mis-hears the command and provides something entirely different than what is asked for, or cannot perform a task because it is not programmed to do so. When this happens, Siri’s limitations as a machine are glaring. In a more extreme example, a machine such as a
blender may chop up food much better than a human might, but it can’t play chess to the same degree or work out complex mathematical equations.

Placing reason as the centerpiece for the determination of the human also brings the mind to the forefront. In opposition to the mind, the body exists “as a machine which, having been made by the hands of God, is incomparably better arranged, and possesses in itself movements which are much more admirable, than any of those which can be invented by man.” The body itself becomes linked with the non-human “machine,” capable of only performing pre-programmed movements and actions. The human body may be a better machine because it is created by God, but it is still subject to its natural needs (food, water, sex, etc.), unlike the mind that can think for itself through rationality. For Descartes, the body may be a part of a human body, but it is a part that is not integral to the formation of the human. Because the rational mind develops independently of the body and, often, is distracted by the natural needs of that body, the body is something that stands in opposition to a rational human.

This focus on the rational mind as the locus of the human creates a subject that may be encapsulated within a body, but is constantly trying to reach beyond that body. The body encasing the mind as well as the outside world full of non-human objects, animals, and machines are all encountered by the subject, but they do not constitute it. This opposition is the boundary of the human: the human is “human” because it is not an animal and not a machine. Defining the human in this manner gives rise to a series of oppositions such as subject/object, rational/irrational, wild/tame, etc. Many
examples of this division do indeed create a distinct line that allows the human and nonhuman to appear completely separate. A doctor, for example, tends to possess reason and operate much as we understand a “human” to, while a toaster can hardly be said to possess reason.

The emergence of humanism during the Renaissance set the stage for humanism’s role in the Enlightenment, which followed shortly thereafter over the course of the seventeenth and eighteenth centuries. The parallel existence of humanism (a mode of thought) and the Enlightenment (a historical period) resulted in an important turn in thought that would last for the next several centuries.\textsuperscript{10} On the one hand, the Enlightenment privileged liberation, justice, and actions that came from one’s own choices and opinions. Humans should use their rational skills to liberate them from fear and oppression.\textsuperscript{11} The Enlightenment saw the rise of new political, social, and philosophic ways of thinking that focused on the benefits of rational thinking and scientific exploration into the workings of the world. By implementing rational and scientific projects, Enlightenment thinkers were able to make apparent progress toward the ideals of “justice” and “freedom.” Writing in the late 1700’s and reflecting back on the intellectual movement, Immanuel Kant characterized the past centuries as “man’s emergence from his self-incurred immaturity,” meaning “the inability to use one's own understanding without the guidance of another.”\textsuperscript{12}

Kant’s move emphasizes that the important aspect of being human comes not just from the possession of rationality in general, but an individual’s expression of that rationality unswayed by any outside influence. Requiring that the individual use its
own rationality to critique the world results in an ideal type of subject that is autonomous and should act without any outside cultural, social, or institutional interference. With a proper maturing and use of reason, Kant claims that humans will be free. By this, he means a “freedom to make public use of one's reason in all matters.” Here, it is possible to see an expression of the humanist subject as a potential solution for the Enlightenment problems of justice and freedom through its ability to think on its own and the organization of society in a way that allows for an individual’s public use of reason without fear of punishment. 

Kant’s elision between Enlightenment ideals and humanism introduced a significant change into the way that humanism operated – and continues to operate – by orienting it around anthropocentrism. Kant’s thought has been characterized as a type of “transcendental humanism” which put forth the idea that the primary organizing principle of the world is the human mind, which actively imbeds the world with value, form, and meaning. Here, the human is not just the only entity capable of rational thought, but the very origin of the world itself – a divine being. This idea stood in contrast to the earlier humanism of thinkers such as Descartes that posited a rational and human-independent world governed by mathematical laws and left space for a non-human God. Kant became the turning point for a type of humanism that put

* The heightened sense of individualism will be examined in more detail in the following chapters as a complicated and paradoxical force within the humanism/Enlightenment way of thinking. Chapter 2 demonstrates that among patients with chronic diseases, the push toward individual responsibility started as a way to internalize medical procedures and a certain type of subjectivity, but then actually worked against reproducing a particular medical subject by allowing individuals to make choices that sometimes go against doctor recommendations. In Chapter 4, individualism will be seen as a mode of thought tied with the extension of neoliberal free market principles to everyday life, affecting the ability of individuals to engage within the political sphere.
the human completely at the center of philosophical thought. This radical anthropocentrism continued through philosophers influenced by Kant, including Hegel, Husserl, Heidegger, and others who make claims that “identify the conditions of possible knowledge or meaning with facts about human subjectivity.” For these thinkers, an understanding of a noumenal world is not possible. We are limited only to the concept of reality that we can know and access as humans. This radical anthropocentrism also becomes the focus for numerous posthumanist critics, who seek to decenter the rational mind as the main organizer of the world.

One of the initial moves in decentering the human was to position humanism not as a natural construct that accurately reflected reality, but as culturally, socially, and historically situated. Nietzsche was one of the first to claim humanism as an empty concept that did not objectively reflect reality, while critics like Foucault, Gramsci, the Frankfurt school, and psychoanalysts all worked to undo the authority of humanism in the late twentieth century in different fields. “Man” or “the human” came to be recognized not as a fully formed being to be discovered or a particular entity that had internal unity that science and philosophy helped to discern or identify. Nor was Man the transcendental subject that created the world, as in Kant’s humanism. Rather, Man was an idea or a “figure of speech” formed through epistemes that constructed him, notably the Enlightenment and its focus on reason. Dangerously, this figure did not herald the age of justice and ethical consideration for others that Kant and Enlightenment thinkers had hoped, but rather served as a historically-, culturally-, and socially-specific figure that could be used in processes of exclusion.
Often, justice and freedom became issues for individuals who straddled the line between human and non-human, according to the precepts of humanism. Examples that blurred the line between human and nonhuman posed ontological and bureaucratic questions as to what being “human” entails and who could be the recipient of justice and freedom. For instance, a human-looking body with a non-rational or “brute” mind is one of these blurred boundaries as it appears biologically human yet does not meet the qualification of possessing reason. One such historical example is hermaphrodites who were considered criminals because they could not be clearly classified as man or women. Such a configuration could not easily be reconciled with laws regarding marriage and unions between individuals that relied on the strict male/female designation, resulting in the hermaphrodites being outside of bureaucratic protection. Aside from sexual variations, requiring humans to have both a body that appears human and a rational mind resulted in a problematic characterization of individuals with mental disabilities or less “civilized” ways of socializing. These individuals were labeled non-human because they do not conform to a pre-determined idea of what it means to be “reasonable”. Identifying different, “proper” characteristics in order draw a boundary around the human results in oppressive power structures that normalize certain behaviors and qualities. Different forms of “reason,” configurations of the body, or ways of being are pushed aside for a regime of reason that is actually historically situated and subjective rather than, as it claims, completely objective and reflective of some type of human essence.
The intersection of law and medicine were the primary ways that this type of exclusionary humanism was enacted. Law identified a type of model citizen that, along humanist lines, would be rational and knowable to themselves. This, combined with Enlightenment individualism, created a type of person that was culpable for their actions and, as a result, could be charged with crimes. If a person transgressed the law knowingly, they deserved the punishment handed down by the law. Foucault provides an example of this intersection between humanism, law, and medicine in the case of Henriette Cornier. Cornier was a house servant who, in the early nineteenth century, killed her neighbor’s infant daughter in a calm, premeditated manner. The ensuing trial revolved around whether or not Cornier was in possession of reason when she carried out the act. Though she appeared to be in control of her senses and in possession of a rational mind throughout the murder, as evidenced by her planning and demeanor, she also did not appear to have a motive. Additionally, she did not appear to have the qualities typically associated with dementia or hysteria. She appeared mad, having no reason for her action. This creates a difficult situation that the law was not poised to deal with. Cornier appeared both reasonable and un-reasonable at the same time, requiring the law to be applied but without a justification for being exercised. The law had to turn to an outside authority to provide a justification for the exercise of punitive power (she had a particular motivation for performing her act) or a rationale for not acting (she was, indeed, demented). Classifying the act as mad, as outside the bounds of legal or medical explanation, could not be tolerated because it had no corresponding legal action. Psychiatry was brought in to classify Cornier as subject to
a “barbarous instinct.”22 This “barbarous instinct” partially attempts to bring back in delirium as an explanation for Cornier’s acts, but only because it has not yet fully been formulated through psychiatry. Over the course of the next century, “instinct” becomes “a whole domain of new objects” that “are impulses, drives, tendencies, inclinations, and automatisms. In short, they are all those notions and elements that, in contrast with the passions of the Classical Age, are not governed by a prior representation but rather by a specific dynamic in relation to which representations, passions, and affects have secondary, derivative, or subordinate status.”23 Transferring “madness” into “instincts” allows psychiatry, and the penal system it is intertwined with, to exert a certain amount of control over acts that seem to lack reason. There may not have been a conscious motivation for the acts, but there was an identifiable system, presented by psychiatry, that could make sense of the acts and put them in a logical pattern which could be understood by authorities. The “mad” act or the madman is no longer outside the purview of the reason-based legal system through the justification of the medical field, allowing the act (and the person performing the act) to be legible to the law and able to be tried in a court of law.

By bringing together the application of law and medical assessment of patients, Foucault was able to identify a type of logic at work that created a “normal” idea of the human. Chapter 2 will look into detail as to how the medical field changed throughout the eighteenth century, but for the purposes of laying out a framework of posthumanism the most important point is that the philosophic underpinnings of humanism have not been only theoretical or philosophical, but have created a type of
logic that has be integral in the formation of medical and governmental institutions. For many scholars these restrictions and the broadening of control to encompass aspects of citizens’ lives represent some of the more nefarious results of humanism. The abnormal citizen cannot be tolerated within a humanist-based society, requiring control apparatuses to be put into place that produce a particular subject who regulates themselves in particular kinds of socially acceptable ways in accordance with certain norms. As a result, the posthumanist critique of humanism centers around not critiquing the existence of the human for its own sake, but in trying to move beyond radical anthropocentrism in order to deal with these issues of exclusion and ethics that present themselves as effects.

One of the ways that this critique occurs is a shift from focusing on the particular qualities of what made up the “human” toward a concentration on the technological milieu that the subject found itself in and created itself out of in an attempt to identify the forces behind process of exclusion. The subject no longer constructed itself on the basis of an inherent rationality or a higher-order human processing ability that separated it from other living entities and inert objects. Instead, the subject was constructed hermeneutically and culturally from technologies that would express a certain way of being. The subject was one that emerged out of technology and held no inherent unity outside of its historical position. What counted as a “fully formed” and ideal human changed over the course of years, removing the possibility of finding any sort of distinctive, immutable essence. The task of posthumanist critique became to pull apart what the figure of the human was at any
given point and shed light on the assumptions and predispositions that went along with it. The hope was that by performing this critical action, new forms of subjectivity could emerge that would work against oppressive power structures.

The field of critical (also known as cultural) posthumanism began to emerge in the late twentieth century in response to a particular historical moment happening parallel with the greater critical attention to humanism that started with Nietzsche. Whereas automata had been a site of concern for humanism since the time of Descartes, mid twentieth century investigations into artificial intelligence began to reinvigorate framings of human consciousness into completely rational terms, specifically so they could be reproduced within a computer. Here, it is possible to see the beginnings of an attempted elision between man and machine that had previously been a hard boundary. As technological development moved to replicate the human, utopian visions of man/machine hybrids that improved on the initial human character emerged, putting aside the autonomous self that originated with Descartes.\(^{25}\) The humanist framework runs into issues when reconciled with contemporary technology that either replicates rationality without a body (as with cybernetics and artificial intelligence) or combines man with machine (as with the concept of the cyborg in science fiction). By trying to reverse engineer the human as a computer, AI researchers continued the search for a type of human essence that could be reconstructed in electronic form. In doing so, they created new types of subjectivities that have been the basis for critical posthumanism.
Called “transhumanism,” this mode of thought tries to amplify human qualities and make them better through integration with technology. Transhumanists hope that technological innovation will add to “the limited toolkit of traditional humanism” by extending the human beyond its “natural” limitations. As a result, the humanist values of reason and autonomy could be made more prominent, essentially becoming “better” individuals by becoming more rational humans and making stronger, healthier bodies through the use of contemporary technologies. Just as it tries to do away with the ailing body and imperfect human form, transhumanism ends up solidifying many of the centuries-old discourse surrounding what makes up the human. The ultimate goal is to leave the human body behind and replace it with a technological one. Such a feat would only be possible if – in a very humanist manner – the only identifiable element of the human was consciousness and rationality, and not the body that housed it. These are the grinders and self-experimenters such as Kevin Warwick mentioned above.

Transhumanists often support the idea of “downloading consciousness” into a computer, an idea championed by researcher Hans Morevac in his book Mind Children and perpetuated by thinkers such as Ray Kurzweil. According to Morevac, Kurzweil, and other transhumanists, it is possible to identify the underlying organization of thought and create a computer that mirrors that organization. With enough computing power and enough storage space, it would then be possible to scan the human mind and move it into a computer, much like copying a CD or a file.
Yet Kurzweil and many other transhumanists still retain hope that consciousness will eventually be able to be transferred to a machine. By modifying their own body – or doing away with it entirely by moving consciousness into a machine – and making it “better,” transhumanists hope to move beyond the limitations of the human body in order to isolate the elements of rationality and self-knowledge away from the faulty operations of the body that cause it to decay or be bounded within its own skin. Often for transhumanists, a “better body” means one that cannot die.*

Ironically, the endgame of transhumanism is not necessarily a good solution for humanists who privilege Enlightenment values of autonomy and individualism. At the extreme end, integrating consciousness into computers would create a collective intelligence, much like the Borg on Star Trek, and eradicate the ability of a human to work as an individual.29 Becoming “more human” in the liberal humanist sense that requires a unified, self-knowing individual is less possible within this scenario, as the ability to replicate consciousness and share information easily erases the borders between individuals. Within the transhumanist ideals, rationality remains central but is not necessarily coupled with a unique and autonomous individual or the celebration of a diverse and culturally rich population. Issues of ethics and justice are less important here because the population is homogenous, sharing a single hive consciousness.

* An argument could be made here that removing the ability to die would also radically change our subjectivity. Existential thought and Heideggerian phenomenology both focus on how orientation toward death organizes our being. If we were to take away that ability to die, it would follow that how our being is organized would be changed in a way even more drastic than if we were to take away or change our bodies.
Utopian techno-fantasies such as those advanced by Morevac and Kurzweil occurred (and are occurring) alongside bodily-centered advancements in technology (prosthesis mentioned above, as well as health tracking technologies addressed later in this dissertation) and a critique of humanism. Where transhumanists see these as potentially creating better humans, scholars like Katherine Hayles, Neil Badmington, Donna Haraway, and others take these discourses as the flawed start of a possibly liberating move away from the figure of the human in general. The transhumanists’ desire to shed the body is impossible and a dangerous argument for homogeneity, but it does point to a malleability of the body and identity connected with contemporary technologies that move beyond the figure of the human championed by humanism.

While critical posthumanists (and the off-shoots of Object Oriented Ontology and Speculative Realism discussed below) push for a radical anthropocentrism that looks for alternative subjectivities and non-human ways of being, I will argue alongside critics like Braun, Halliwell, and Mousley, that posthumanist discourses are actually “humanisms with a vengeance” that reproduce the figure of the human. Even the aggressively anti-anthropocentric Object Oriented Ontology and Speculative Realism do not deny the existence of human consciousness, only deny its primacy. However, far from being just a failure of posthumanism to achieve its goal, I claim that posthumanist discourses are able to reconfigure the human in a way that separates Enlightenment goals of ethics, justice, and critique away from needing a universal figure of Man as a referent. In this way, the anti-anthropocentrism of posthumanism can be read not as not a project to destroy any sort of human figure, but to move
toward creating a subject that occupies multiple identities and subject positions in order to promote ethical engagement with other individuals.

As a type of proto-posthumanist, Donna Haraway anticipated and influenced the critiques of later posthumanists in her feminist critiques of humanism. For Haraway, humanism works through aligning itself with an apparent objectivity within technology and science that covers over the “unmarked positions of Man and White” propagated through these discourse. The rational, unified, and universal figure of Man that humanism advocates is shown in her work to be deeply and problematically gendered and racialized. To combat the exclusionary figure of Man, Haraway advocates for an identity politics based on the figure of the cyborg, a schema that has provided the basis for other posthumanist thinkers.

For Haraway, the cyborg erases the boundary between human and machine. Not only does this move beyond the strict humanist divide between man and machine, the ability to integrate technology into the body allows the human body to expand beyond itself into the surrounding environment. As she claims in later works, moving beyond the concept of the human that appears objective (while still being distinctly male and white) involves understanding the body as situated and connected to surrounding environment and technologies. By embracing this situatedness, interaction, and changeability through prosthesis and body extension, it is possible to

* Haraway ardently claims that she is “not a posthumanist” (When Species Meet 19), but her work is often referenced by posthumanist scholars. Moreover, in the same work that she denies her allegiance to posthumanism, she claims that she does have “posthumanist whisperings” in her ear (73). For the purposes of this chapter, it is less important to figure out definitively whether Haraway herself claims to
create new forms of human subjectivity that can be used to advance different configurations of gender and race.

Without relying on a single, unified state (as in more traditional humanism), Haraway’s cyborg is free to constantly reconfigure its identity and self through its situatedness within a particular environment. Without a concrete identity or a single ideal configuration of the human to work toward, there is also no “myth of original unity, fullness, bliss and terror, represented by the phallic mother from whom all humans must separate” that allows the cyborg to emerge.\(^{33}\) This original myth in the humanist tradition is the moment at which the subject becomes an individual, autonomous, rational being that is, at the same time, always white and male.

Haraway’s call to recreate identity politics and dismantle gender norms gets pulled into other posthumanist projects that emerged in the 1990s. Katherine Hayles is one of the most prominent posthumanists. She in particular has targeted transhumanism as a potentially dangerous über-humanism for the similar reasons that Haraway has identified in traditional humanism. In her book *How We Became Posthuman*, Hayles outlines the general principles of the posthuman\(^*\) (what I have above termed “transhumanism”):

First, the posthuman view privileges informational pattern over material instantiation, so that embodiment in a biological substrate is seen as an accident of history rather than an inevitability of life.

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\(^*\) Note that here – and throughout her book - Hayles uses the term posthuman to denote discourses and practices that attempt to create a new, better human through technology and prosthesis. I’ve used the term ‘transhumanism’ to make the opposition to posthumanism more clear. Hayles, Haraway, Badmington, etc. all are critical of transhumanist/posthuman claims and goals, but see positive possibilities in developing posthumanism.
Second, the posthuman view considers consciousness, regarded as the seat of human identity in the Western tradition long before Descartes thought he was a mind thinking, as an epiphenomenon, as an evolutionary upstart trying to claim that it is the whole show when in actuality it is only a minor sideshow. Third, the posthuman view thinks of the body as the original prosthesis we all learn to manipulate, so that extending or replacing the body with other prostheses becomes a continuation of a process that began before we were born. Fourth, and most important, by these and other means, the posthuman view configures human being so that it can be seamlessly articulated with intelligent machines. In the posthuman, there are no essential differences or absolute demarcations between bodily existence and computer simulation, cybernetic mechanism and biological organism, robot teleology and human goals.34

These views fit very much in line with the transhuman tenants above that seek to improve on the human condition by augmenting it with technology. However, these transhumanist/posthuman projects have not yet been realized, nor do they accurately portray the differences between AI and embodied, environment-dependent human consciousness. The transhumanist belief in moving consciousness from human mind to machine requires a belief that “mental states...are substrate-independent” and could exist in “arrangements of matter very different from human bodies.”35 It is the very arrangement of body, consciousness, and surrounding environment that allows “the human” (or what appears to be the figure of the human) to emerge. Changing the arrangement would result in a much different type of subject, if not erase the possibility of subjectivity entirely. For transhumanists, this would be a failure of their project to create a better human.

The types of technologies utilized in transhumanist projects do, however, have liberating potential. Even as she warns that we must not forget the body, Hayles points to the devaluation of the body within contemporary technological discourse as a move
that also opens up the potential for types of identities that do not fit into the normate model of the human as long as we remember to include materiality within critical analysis.\textsuperscript{36} Reconfiguring identity as a fluid consciousness that does not depend on rationality or a stable embodiment pushes aside the autonomous liberal subject of humanism that exists opposite and apart from an anthropocentrically ordered world of objects. As a result, the posthumanist subject becomes embedded within the world and is no longer entirely distinct from that world, nor is it the transcendental subject of Kantian humanism.\textsuperscript{37} Human agency becomes the ways that consciousness can move within, order, and interact with these surroundings rather than its ability to cut itself off from its surroundings to engage in autonomous rational thought and order the world, as in Kant.

Critics of posthumanism have latched on to this inability of posthumanism to completely forego identity and the human as a central talking point. They argue that posthumanism ends up less a complete break from humanism and more of a rearticulation of humanism. Scholar Bruce Braun writes:

> What often goes unnoticed is that by historicizing the posthuman we end up recentering the human: the human is that being that ‘once was’, but which has been ‘eclipsed’ or ‘transcended’. Here's the crux: such posthumanisms require the figure of ‘Man', and in so doing, become humanisms with a vengeance, for they produce as a historical fiction precisely that which they imagine to have left behind. In this sense, posthumanism's fevered celebration of the posthuman is of a kind with humanism's mourning of the passing of ‘Man'. We must ask, then, whether our posthumanisms have themselves become ‘anthropological machines', unwittingly accepting the same story of the human and its passing…, merely coding positive what they code negative?\textsuperscript{38}

Braun makes a point that is backed up by Hayles, Badmington, Derrida, and others that if we look at posthumanism in the context of how it arose, we see that
posthumanism not only must *build off* of the idea of the human initially constructed by humanism, it must also keep that idea of the human generally in tact.\textsuperscript{39} To allow the human to extend beyond the body and to become completely entwined with technology in new ways of being, there must be an idea of “human” to start with. Similarly, the body is not necessarily completely sloughed off, but rather extended and added to by means of prosthetic extensions. Hayles observes that posthumanism can become dangerous in this manner because posthumanism’s extension or amplification of the liberal humanist subject carries with it the possibility of replicating power structures bound up with that type of subjectivity.\textsuperscript{40} The type of subject privileged through humanism is a subject with autonomy and rationality. As in Descartes’ framework, there is the threat of individuals lacking that rationality being excluded from the category of the human, thus removing any sort of ethical obligation toward them. In posthumanism, if the rationality and autonomy of the humanist subject is enhanced through its encounter with technology rather than completely re-worked, it carries the same danger toward those who do not meet the normative requirements of being a humanist subject.

However, I would argue that the goal of posthumanism is not to put aside the figure of the human for its own sake, but to dismantle the power structures that emerged from humanism that are largely dependent on a stable, universal figure of the human. Critical posthumanists take on the multiplicity and situatedness of consciousness to create fluid identities that work against universal constructs of the normate human. If anything, posthumanism brings to the forefront latent anti-humanist
ideals present within humanism itself\textsuperscript{41}. Halliwell and Mousley in particular have analyzed humanism not as a monolithic, singular set of ideas but as a multiplicity of different strains that often act in a self-destructive and paradoxical manner. These include subsets such as the “romantic humanism” of William Shakespeare, Karl Marx, and Helene Cixous that does not automatically discard feeling for a focus on reason; the “civic humanism” of Mary Wollstonecraft, Jurgen Habermas, and Stuart Hall that identified citizenship as the underlying essence of humans; and the “spiritual humanism” of Walter Benjamin, Martin Luther King Jr., and Julia Kristeva that retained the relevance of God within the need for humans to come into their own.\textsuperscript{*} For them, humanism and anti-humanism are part of the same structure, one that can be saved from irrelevance and potentially dangerous situations by focusing not only on the question of what comprises human essence, but by focusing on the critical and self-critical spirit of humanism. Humanism contains within itself the seeds of its own self-reflection that has presented a series of problems and issues beyond just attempting to locate reason as the single important aspect of the human.

The critical humanism of Haraway and Hayles attempt to position the subject as malleable and situated in order to open up possibilities for gender and race, but more recent scholarship has looked at examining the situated aspect of posthumanism. Object Oriented Ontology and Speculative Realism both seek to create an ontology of

\textsuperscript{*} Halliwell and Mousley include a number of other specific types of humanism that include anti-humanist elements. It is also worth noting that the thinkers that Halliwell and Mousley place into these categories are not always strictly traditional humanists. For example, Foucault, Baudrillard, and Haraway are included in a “technological humanism” section, though each author could easily fit into a posthuman or anti-human model. For Halliwell and Mousley, this fluidity of categorization is precisely
objects and move away from anthropocentric discourse. The primary goal here is not, as with the critical posthumanism of Haraway and Hayles, primarily a feminist project, but rather an attempt to not get stuck re-articulating humanism and re-asserting it as the only form of ontological investigation. Even so, Object Oriented Ontology and Speculative Realism can potentially open up ethical dimensions not covered in the critical feminist posthumanism.

To move beyond a human-centered approach to theory, Speculative Realists argue that rather than continuing with critical posthumanism’s textual deconstructions of subjectivity, anthropocentrism can only be undone by shifting philosophical concern away from subjectivity and toward the “cosmic throng of nonhuman things.”42 Such a move operates in direct opposition to the transcendental humanism of Kant that places the human as the organizer of the world and Descartes’ humanism that positions consciousness as the only certainty. For OOO and Speculative Realism, objects outside of human consciousness can also organize the world in particular ways, creating a space for non-anthropocentric subjectivity. Notably, this change in thinking comes with a focus on “intentionality.”

The problem of intentionality began as a way to deal with one of the major side effects of the Cartesian identification of “human” and “non-human.” Humans, for Descartes, possessed rationality, which became identified with consciousness, or the Cogito. Non-human elements were located in the world or reality, apart from the rational, conscious Cogito. The relation between the human and non human posed an
issue and following this Cartesian split, two strains of thought emerged: realism and idealism. Realism claimed that the world was primary and that our experience of objects outside our consciousness reflected how those objects actually existed. Realism became problematic when dealing with more abstract concepts like morality, agency, sensation, and illusion. Idealism, however, claimed that our experience of the world was entirely created by consciousness and that access to any sort of “true” reality was called into question. This strain of thought worked well with addressing the abstract concepts that realism could not handle, but had difficulty justifying a shared world of experience and objects among different people.

In response to some of the issues stemming from the hard division between realism and idealism, phenomenology emerged, bringing with it the idea of intentionality. Beginning with Husserl, phenomenology called into question both the concrete existence of a world outside of consciousness and the privileging of consciousness as the creator of its own experience. Through a re-investigation of how consciousness operates, Husserl found that even without assuming a “real” world outside consciousness, there were still phenomena that presented themselves to consciousness. Moreover, consciousness did not exist without being directed toward that phenomena. “Intentionality” is Husserl’s term for this directedness of consciousness toward objects in the world. Through intentionality, the phenomenological subject organizes consciousness and the world, but in a way that still allows for the existence of outside objects. For Husserl and other
phenomenologists, intentionality points to the interconnectedness of consciousness and the world while also incorporating the notion of a continued, constantly changing living within this world. Consciousness cannot be created without the encounter with some sort of phenomena that exists outside of it, within a world. Likewise, intentionality gives meaning and shape to objects within a world, which otherwise could not exist as anything recognizable as a “world.” This intentional relation is constantly being acted out as “lived reality” as phenomena present themselves to consciousness and consciousness intends toward them.*

Within this phenomenological structure, technology occupies a unique position. Though many forms of technology could be said to be “in the world” (to be objects that are presented to consciousness) they also, to a degree, change how other objects within the world are presented. Heidegger was one of the first to address this issue with his discussion of tool use in Being and Time. He describes the use of a hammer, pointing out that we become unaware of the tool itself as long as it is working and performing the function we are attempting to use it for. In this process, the hammer becomes what he calls “ready to hand.”*43 For Heidegger, because we are not focused on the physical tool itself when it is working properly, the tool is actually incorporated into consciousness and affects how we intend the world. We begin to see things as things to be hammered (nails, rocks that should be broken apart, metal that

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* As Verbeek points out in {Verbeek 2005 @ 109-110}, the focus on interrelation between human and world is characteristic of later phenomenology, while classical phenomenology is more aligned with a philosophy of consciousness. Again, it is not my intent to give a full history of phenomenology here, but rather to identify the main issues that are later taken up by postphenomenologists and philosophy of technology.
needs to be pounded into shape) or not to be hammered (screws, glass cups, antique vases). If we were to change tools, our experience of the world would change as well. A level, for example, would cause objects we encounter to be put in terms of how parallel to the ground they are (or are not) and do little to draw our consciousness toward the hammerability of particular objects.

Heidegger later expanded this analysis of tool use to point out that technology changes the way in which the world is revealed to us in general, not just when we are specifically using the tool. In his essay “The Question Concerning Technology,” he makes the claim that modern technology such as hydroelectric plants causes us to see the world as a “standing reserve” of resources that we can uproot and use for our own purposes. It is not important to identify whether this is an accurate description of how modern technology shapes the world for us; it is useful only in so far as it draws attention to how it is one of the first moves in phenomenology toward describing technology’s affect on consciousness’s essential experience of the world. We do not see the world in terms of standing reserve only when we are actively engaged in using the hydroelectric plant as something ready to hand. We constantly see the world in terms of standing reserve because we are constantly engaged with a type of technology that causes us to view the world in this manner.

For Heidegger, the primary question is how to understand how the tools affect the being of the human, or Dasein. As Graham Harman, Ian Bogost, and other Speculative Realists have pointed out, this leaves out the question of the being of the tool itself.44 The tools in Heideggerean thought are only important in so far as they are
part of a situation involving a person. In the above example, the hammer itself remains unimportant until it is used by a person hammering and becomes present at hand (or ready to hand). For the Speculative Realists, this leaves a large area of potential analysis undeveloped and “condemn[s] philosophy to operate only as a reflexive meta-critique of the conditions of knowledge.” To avoid this trap, Speculative Realists claim that reality has to be independent of human subjectivity in order to be called reality and, therefore, must be inherently nonhuman and “weird.” A human-independent reality also results in the potential for analysis of the elements of that reality: what have traditionally been called objects. Bogost calls for Speculative Realism to examine the relations between objects outside of their involvement with humans. He gives the example of an udon noodle:

For the udon noodle, the being of the soup bowl does not intersect with the commercial transaction through which the noodle house sells it, or the social conventions according to which the eater slurps it. Yet there is no reason to believe that the entanglement in which the noodle finds itself is any less complex than the human who shapes, boils, vends, consumers, or digests it.

Here Bogost tries to break apart the human elements that the noodle would normally be wrapped up in (commerce, social conventions of eating) and creates a call to focus on how the noodle becomes entangled with the other objects around it. These objects could include the other ingredients in the soup, the bowl itself, the microbes and particles in the air, or the spoon that dips down into the bowl periodically. For Bogost, such an examination would give an idea of what the being of the udon noodle is and expand philosophical investigation beyond just the conditions behind which human knowledge is created.
Bogost makes the claim that Speculative Realism, and specifically his sub-field called Object Oriented Ontology, succeeds where posthuman discourses have failed. He says that “posthuman approaches still preserve humanity as a primary actor. Either our future survival motivates environmental concern, or natural creatures like kudzu and grizzly bears are meant to be elevated up to the same status as humanity.”

Moving beyond anthropocentric discourse for Bogost and other Speculative Realists means not centering discussion on how objects exist for humans or how they change human consciousness, such as in Heidegger’s example of the hammer. This is not to say, however, that human consciousness or human concerns do not figure into Object Oriented Ontology or Speculative Realism. Human consciousness is a factor in these examinations, but not the central point. As Bogost himself points out, understanding the intentionality of a particular technology from its own point of view (an “objective phenomenology” or the “weird,” nonhuman reality) is impossible for human consciousness simply because human being is not the same as the being of a technological artifact. We do not know what it is like to be an x-ray because we are not x-rays. We do not know the inner workings of an udon noodle’s being because we are not udon noodles. The closest we can come to understanding this “weird phenomenology” is through analogy and metaphor, by putting it into a form that can be processed by human consciousness. We can perform a phenomenology of an udon noodle by placing it within a context of objects that are engaged with human intentionality, such as the bowl, the soup, and the spoon. Analyzing the intentionality of a car, for example, would also not result in an objective presentation of exactly
what it means to be a car. Instead, it would involve looking at the possibilities that emerge from cars: new understanding of distance and time, potential for crashing, different social status from owning a particular car, etc. We can only create an ontology of the car that says that it intends in a way that sees the world like a system of objects that each require calories, like an engine that requires fuel. Object Oriented Ontology and Speculative Realism attempt to take materiality and the effects of objects on situations and power relations into account.

Due to the radical de-privileging of the human with Object Oriented Ontology and Speculative Realism, it would seem that it also does away with the potential for developing the feminist aims of other strands of critical posthumanism. By removing subjectivity from a privileged place and concentrating on the ontology of objects, there appears to be no room for a politics of identity or developing a method of working against oppressive gendered and racial power structures. Or, to an even worse end, the hidden white, male objective viewpoint of humanism would be reinscribed within critique, undoing the work of earlier feminist posthumanists.

The navigation of this divide is difficult even from within Object Oriented Ontology and Speculative Realism, where the scholars developing the field are very aware of the feminist origins of their emerging field. The focus on objects does

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* A recurring track at the Society for Literature, Science, and the Arts conference in recent years has been organized around Object Oriented Feminism and investigated what OOO Feminism would look like. Hayles, Bogost, Morton, and others have all presented at this panel at various times.

Responding to the 2010 panel, Bogost pointed out that the discussion didn’t really provide a definition of OOOF, but that doing so would have been counter to the spirit of OOOF and resulted in a “domestication” of the area of study (http://bogost.com/writing/blog/object-oriented_feminism_1/). Instead, the panel ended up arguing for a flexible line of critique that “making insides and outsides
downplay subjectivity and identity as the central focal point of critique, but as Levi Bryant argues, this does not mean that investigations into power relations disappear. To the contrary, the major goal of Object Oriented Ontology is to trace power relations over a broader spectrum that includes and starts from objects. By beginning with objects, Object Orient Ontology seeks to explain what sort of material forces are involved in the creation of categories of gender, race, class, etc.

As with the critical posthumanism of Hayles and Haraway, I would argue that Object Oriented Ontology does not completely eradicate the human, but provides an opportunity to move beyond the humanist tendency to provide a single, universal model for what should be human. Where Hayles and Haraway point to a multiplicity of identity that disrupts overarching concepts of gender, Object Oriented Ontology allows us to explore the situatedness of the human and begin an examination of the milieu of intentionalities, technologies, and power relations that influence identity and subjectivity. From this methodology and critique it is useful to re-examine the domain intimately connected with the formation of the human within humanism: medicine.

The current state of medical practice provides a fruitful landscape to perform this task. While Lasik surgery and cochlear implants represent a use of technology that promote a certain ideal of how a human body should function, other groups take these same technologies and use them for ends that can not be universalized into a common, shared notion of the human. Notably, these groups include individuals who engage accessible and welcoming, whether they involve rights, ideals, identities, or everyday practices.” The following chapters of the dissertation are, in many ways, an investigation of what making “insides and
with self-tracking practices. This can include diabetics who adapt doctor’s orders to their own lives as they organize regimes of insulin injections, food consumption, and exercise in unique ways. It can also include members of the Quantified Self movement, who track various aspects of their lives in order to find out information about themselves and to assemble large amounts of health data that can bolster data collected by medical institutions. Much like Object Oriented Ontologists, these self trackers begin with no assumptions about identity and use technology to provide different perspectives on how they should organize their practices of self-care. From the results of these tracking practices, as will be shown in Chapter 2 and 3, these individuals organize ad hoc identities that are constantly in flux and constantly being critiqued. They do not fit a normative model of what it means to be human, but limit the scope of their construction of the human to a single individual. At the same time, however, these identities will be shown in Chapter 4 to be engaged in an ethical engagement with one another in a way that does not rely on a shared concept of the human, but a mutual respect for multiple possibilities of being human.

5 Descartes 109
6 Descartes 107
7 Descartes 107

outsides accessible" would look like as individuals use health tracking technologies to disrupt various stable subject positions, institutional models of the human, and identities.
Descartes 107


Kant


Foucault "Abnormal" 131


Haraway, Simians, Cyborgs, and Women. 188

Haraway, Simians, Cyborgs, and Women. 151


Hayles 2-3

See Hayles and Derrida

Hayles 286-87

Halliwell 15

Rodenn


Bogost 30
Bogost 7. Also note that this is one of Bogost’s main criticism of the strikingly similar actor-network theory. Bogost claims that in Latour’s theory, “analysis still serves the interest of human politics”

Bogost 64. Again, Bogost is working primarily from OOO, a similar yet slightly different system of thought than postphenomenology.


OOO and SR are fairly new and developed by scholars heavily involved with contemporary technology, so much of the discussion and clarification happens through blogs, Twitter, and other social media platforms.


<https://larvalsubjects.wordpress.com/2012/05/29/ethics-and-politics-what-are-you-asking/#comment-133863>. As noted above, much of the development of OOO and SR occur on blogs and online forums. This particular comment was referenced by Bogost when explaining the politics of OOO and SR.
CHAPTER 2
Diabetes Self-care Techniques

The previous chapter identified principles of exclusion as a major issue that arises from the proliferation of humanism, even as humanism has claimed to uphold Enlightenment values of justice, ethics, and critique that should result in a more democratic and inclusive society. Various posthuman critical theories have identified the figure of the normate human as a dangerous construct that limits political, social, and economical engagement for groups that are non-Western and non-white (post-colonialism), non-male (feminist and gender studies), or unhealthy (disability studies). While the logic of humanism works through a variety of different areas and institutions, medical practice is one of the most significant because, as Michel Foucault points out, it not only lays claim to what a “healthy” individual is, it also dictates how a person should attempt to fit into society at large. One such example began in the 1960s, when the Women’s Health Movement pointed out that the current medical and legislative systems did not account for the bodies of women. The Women’s Health Movement’s original target was reproductive rights, but this quickly expanded to incorporate the lack of women as the object of clinical studies, participants in clinical trials, and senior investigators involved with the trials. By positioning women as a different type of body that needed a different type of medical care, the Women’s Health Movement recognized the inability of a universal, normate model of the human to accurately cover all people and identified that universal model of the subject to be heavily gendered as male.
Beyond the Women’s Health Movement and other liberation movements of the 1960s, the postmodern turn in the late twentieth century resulted in critiques of “the human” in areas such as gender studies, post-structuralism, post-colonialism, post-Marxism, and postmodernism at large. * While each field had a different goal, many of them rested on the idea that the subject created by the idea of Man reflected a rational Western male sensibility and excluded a particular type of individual, resulting in an imbalance of power. For gender studies, the excluded subject was the non-heterosexual male subject, including female, LGBT, and queer subjects. For post-structuralism, the normative subject in general was called into question, as the legitimacy of the characteristics making up the “typical” human was shown to be baseless. † Post-colonialism identified the non-Western subject as the excluded individual. Post-Marxism looked at the ways in which hegemony and class identity

* Note that many of these fields owe a debt to Foucault’s writings, but that is not to say that each came about as a direct result of Foucault’s thought. Rather, they are brought up to point to a shift in thought in the late twentieth century that called into question the existence of a “normal” human.

Unpacking the entirety of each of these disciplines’ relation to a critique of a “normal” subject would warrant a much larger investigation than is within the scope of this paper. However, for some information on each, see:

Gender Studies: Julia Kristeva, *The Kristeva Reader*; Gayatri Spivak, “Can the Subaltern Speak”; Judith Butler *Gender Trouble* and *Bodies That Matter*; and Luce Irigaray, *The Sex Which is Not One*


Note that this is far from an exhaustive list in each category.

† It is worth noting here that Foucault often falls into the post-structuralist category.
benefit particular subjects at the cost of others. Many of these areas of study overlap with the others and is seldom mutually exclusive.\

Along with the critique about who can be “human,” posthumanism began to question what could be human. The posthuman emphasis on embodiment, dispersal of consciousness, decreased focus on rationality as a defining characteristic of the human, and the body’s ability to integrate with technology makes an attempt at creating a non-anthropocentric subject.† Medical technologies like glucose monitors, accelerometers, and activity tracking software all play a large part in posthumanist discourse, as they are prime examples of how technology can be used to privilege information about the body and de-center focus on consciousness. As chapter one shows, however, these technologies provide information on a human body, putting them in line with the observation of Hayles, Derrida, and others that posthumanism actually retains some type of subject that could be called “the human.”

Posthumanist technologies may retain some idea of “the human,” but it drastically reconfigures that notion in ways that allow it to be constructed along much more unique, flexible lines. Such a construction is prevalent in chronic illness, where self-care techniques are employed not to enable full recovery from a disease, but as a necessity to continue normate biological life by suppressing symptoms and delaying fatal complications. Diabetes provides a strong example of these types of self care.

* Also note that often, many of the scholars within these categories disagree with each other or have varying degrees to which they move away from the idea of a naturalized concept of the human.
† This definition comes from Hayles, N Katherine. How We Became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics. N.p.: University of Chicago Press, 1999. See Chapter 1 for a more complete exposition of posthumanism.
techniques, as it is considered an incurable disease that can be kept under control with proper management and rules laid out by medical practice. With the rise of contemporary technologies such as continuous blood glucose monitors and an increased emphasis on patient self-care, diabetes care integrates the body with technology in a way that is neither strictly managed in clinical settings, nor left entirely up to the patient. Additionally, the discourse surrounding diabetes care views the diabetic patient as an embodied individual that is defined just as much by the characteristics of the disease as they are by their consciousness, as in posthumanism. Thus diabetes becomes not an abstract disease that needs to be dealt with, but a set of practiced object. Defining diabetes in terms of a “practiced object” takes it out of the clinical setting and into the lives of the patients while emphasizes the techniques of care the patients use. Though diabetics do visit the doctor for some treatment, they do most of the work caring for their disease on their own. The life of the patient has to be organized around the limitations and affordances of diabetes: certain food must be avoided, exercise regimes must be followed, and medicine must be taken at certain times. Diabetes, then, becomes more than just a “thing” that the patient has or doesn’t have, but a whole new set of practices and relations in which the patient engages. By becoming more than an object that can be studied in isolation from the body it inhabits, diabetes disrupts the medical gaze to produce a unique subject that creates a model of a “normal human” that only applies to itself even as it references clinical medical knowledge.
Twentieth century medical discourse has found that diabetes affects how the body processes its main source of energy: glucose. Non-diabetic bodies break down food into glucose, or blood sugar, which then moves to the bloodstream in order to be used by cells in the body. But in order for this process to occur, the hormone insulin must be present in order to convert the glucose into a usable form. Diabetic bodies have a pancreas (the organ that produces insulin) that does not create enough insulin or contains beta cells that are unable to use the insulin that is produced. This means that the glucose from food builds up in the bloodstream and comes out of the body through the urine instead of being used for energy.

There are three main forms of diabetes: Type 1, Type 2, and gestational diabetes. Type 1 diabetes is a condition whereby the body destroys the insulin-producing cells in the pancreas, a particular type of islet cell called beta cells. Without

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* The cross section of at-risk individuals for diabetes is particularly interesting. Much of the literature divides it among one of two lines: race and weight. Gender is addressed, but instances of diabetes are roughly equal between men and women. The exact cause of Type 1 diabetes is unknown, but it does appear more often in whites than it does in non-white individuals. Type 2 diabetes occurs often in “African Americans, American Indians, some Asian Americans, Native Hawaiians and other Pacific Islander Americans, and Hispanics/Latinos” according to the National Diabetes Information Clearinghouse. Additionally, Type 2 diabetes is typically associated with obese and overweight individuals, linking the disease to unhealthy eating habits.

There is a good deal of work that could be done to analyze diabetes in terms of producing an idea of essential qualities belonging to particular races or the link to particular socio-economic statuses. Additionally, looking at diabetes in terms of the “War on Fat” and increase in health consciousness could prove interesting discussions.

However, this chapter is primarily concerned with the role that diabetes management plays in constructing a body with a particular relation to the posthuman. I am more interested in how the diabetic individual situates themselves within a nexus of other subjects, objects, technologies, and medical discourses than I am looking at the place of diabetes within culture, though that aspect of diabetes could provide insights into particular power structures and hierarchies.
a way to produce insulin, the Type 1 diabetic has to take insulin daily in order to avoid diabetic ketoacidosis, or a potentially fatal diabetic coma.\(^6\) Type 2 diabetes, unlike Type 1, is linked to certain conditions of life, including older age, obesity, family history of diabetes, previous history of gestational diabetes, physical inactivity, and certain ethnicities.\(^7\) In this type of diabetes, the body cannot process the insulin that it does produce and creates a resistance to that insulin. Over time, the body lowers its production of insulin, which in turn disrupts the body’s ability to turn glucose into energy and leads to kidney disease, nerve damage, eye problems, and stomach problems.\(^8\) Gestational diabetes is considered one of the three main types, but is temporary – not chronic like Type 1 and Type 2 – and only occurs during pregnancy. The cause of gestational diabetes is unknown. There are other types of diabetes, but they are much less common. This paper will focus more on Type 1 and, to a lesser extent, Type 2 diabetes because they are both chronic conditions that better exemplify the need to order life within the context of the disease over the long term. Other forms of diabetes may also demonstrate some of the issues discussed, but they do so in a more subtle or partial way.

Typical symptoms of diabetes include an increase in thirst and urination, hunger, weight loss, blurred vision, fatigue, and slow healing sores.\(^9\) These symptoms can occur suddenly in Type 1 diabetics, but some Type 2 diabetics can go years without seeing direct symptoms. They can also be mild or severe depending on the

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situation. Many of these symptoms appear during “hypoglycemic attacks,” when the body needs more glucose, when too much insulin is present (i.e. through insulin injections), or when alcohol has been consumed. Hypoglycemic attacks can be treated by adding more glucose to the bloodstream, sometimes by the diabetic individual themselves but in serious cases medical personnel have to attend to the individual.

Type 1 and Type 2 diabetes are both chronic conditions that do not have a definitive “cure,” but must be constantly managed in order to avoid the body shutting down. A new pancreas can not simply be transplanted into the individual and no medicine will remedy diabetes permanently. The disease must be lived with in perpetuity and the focus of contemporary medicine has been on managing the symptoms while also trying to avoid the emergence of major attacks on the body, such as ketoacidosis (a diabetic coma). The diabetic individual must constantly manage their disease and engage in the basic therapies of “healthy eating, physical activity, and taking insulin (in the case of Type 1 diabetics) or monitoring blood glucose (in the case of Type 2 diabetics).”

The current institutional medical knowledge has changed drastically since the first mention of diabetes in 1500BCE in Egypt and India. During this period, the disease was characterized not by the body’s inability to produce insulin, but according to the excessive urination it caused in those afflicted with it and its excessively sweet character. From its initial identification, diabetes has been connected with various technologies and self-care techniques. One of the first techniques of diagnosing
diabetes was to observe the attraction of ants and flies to the urine of a diabetic.\(^\text{13}\) Originally, medical knowledge had a very different model from contemporary medicine and focused on attempting to locate and eliminate the cause of diabetes.\(^*\) The Greek physician Aretaeus of Cappadocia first hypothesized that the disease originated in the bladder and kidney, but then attributed it to the bite of the mythical Dipsas serpent.\(^\text{14}\) In the 17th century, Thomas Willis shifted the focus of medical knowledge of diabetes from the causes to the symptoms. He noted that patients urinate frequently and that the cause remained unknown. Even with hidden origins, he believed that the disease could be cured by “restoring balance between the body’s various humors” – a claim that would not hold up against current standards of medical knowledge creation and legitimation.\(^\text{15}\) For Willis, the primary goal was functional: to remove the signs of the disease and return the patient to a healthy state. Each case was unique and called for its own curing method. Restoring the balance in humors for one person may require a slightly different process than in another person. Overlooking the cause of the disease in favor of alleviating the symptom of urination continued up until the eighteenth century, when the clinic became the foundation of medical practice.

With the introduction of the clinic, medical knowledge began to shift from taking the individual patient’s affliction as a unique case toward understanding disease as part of a larger system. Foucault observes that the eighteenth century saw medical

\(^*\) Locating the cause of disease did not entirely disappear in later versions of medicine, but the way it was enacted changed. At various points in time, other targets of research included trying to eliminate symptoms, trying to harmonize the balance of humors in the body, locating the afflicted organ, examining the disease on a molecular level, etc. before the current iteration that, according to Foucault,
knowledge as the creation of a “‘map’ (repérage): a symptom was situated within a
disease, a disease within a specific ensemble, and this ensemble in a general plan of
the pathological world.” Here, symptoms were more than just an affliction in a single
patient that could be cured, restoring the patient to health. Instead, the symptoms
indicated the presence of a disease that had its own properties and could manifest itself
in any person. And, more importantly, could be studied as an object in and of itself.
Disease became more than a directly observable symptom that must be treated, as with
Thomas Willis’ focus on diabetes treatment in the 17th century. Instead, as David
Armstrong points out:

the symptom, as of old, was a marker of illness as experienced by the
patient, but to this indicator was added the sign – an intimation of
disease as elicited by the attentive physician through the clinical
examination. For example, the patient's symptom of abdominal pain
might be linked to the sign of abdominal tenderness that the physician
could discover; but neither symptom nor sign in itself constituted
illness: both pointed to an underlying lesion that was the disease

As Armstrong claims, the symptom was no longer the endpoint of treatment in the 17th
century. It became a marker of a larger process taking place that spanned not only the
individual body of the patient but an affliction that could affect any human body. Such
a shift in thought began the process of thinking of the disease as an object separate
from its manifestation in the human body. This understanding of how symptom, sign,
and disease interacted became codified medical knowledge that expanded into a larger
way of thinking that directed the actions of patient and doctor, as well as entire
populations. The process of linking a sign to its corresponding disease did not occur

views disease as an entity that exists outside the body and can be studied independently of its individual
on the direct patient-doctor level, but rather by the doctor’s ability to apply a larger body of knowledge to the specific case. As Foucault writes, the support of this new medical system “was not the perception of the patient in his singularity, but a collective consciousness, with all the information that intersects in it, growing in a complex, ever proliferating way until it finally achieves the dimensions of a history, a geography, a state.” Moreover, in “the clinic…one is dealing with diseases that happen to be afflicting this or that patient: what is present is the disease itself, in the body that is appropriate to it, which is not that of the patient, but that of its truth.”17 As eighteenth century doctors encountered disease within the clinical setting, the disease as an abstract object that could stand on its own eclipsed the idea of a patient with symptoms that needed to be treated. By examining this disease, doctors could figure out how it worked and, potentially, create a cure for all cases of the disease.

As knowledge of disease emerged as a geography of information that extended beyond the body of the singular patient, that knowledge also began to encompass entire populations that could be managed so as to express a medically-defined normative set of health standards. Diseases became an object that were contagious and could be passed among bodies in populations, not just isolated cases. To contain diseases, the work of the doctor was not just to heal the sick, but to help coordinate society through organizing knowledge in a manner that gave them administrative power over the “conditions of life, housing, and habits, which serves as the basic core for the ‘social economy’ and sociology of the eighteenth century.”18 Individuals were manifestations in patients.
directed to follow public health’s proscription for a particular way of life that would allow them to approximate “normal” and “healthy.” Foucault termed this new reach in medical knowledge and organization “medico-administrative knowledge” to emphasize the way medicine informed a general technique of health that affected all areas of life in the eighteenth century.  

As it expanded beyond the doctor-patient encounter, medico-administrative knowledge revolved around creating the idea of a universal model of the disease and its manifestation. The main issue was not the unique case of the disease, but its relation to a generalized system of disease that could apply to multiple cases. This resulted in a shift of focus from curing or understanding the individual patient in its unique manifestation of the disease into the creation of an abstract body of knowledge on disease that could be continually added to and modified.

Matthew Davis, who is himself diabetic, identifies this shift away from the patient toward the construction of a body of medical knowledge in the writing of two authors on diabetes: John Rollo and Valentine Mott. Both authors write at the turn of the 19th century and seek to add to a body of medical knowledge about the disease, where the patient is not a unique case but an instance of the larger, abstract disease. To do this, Rollo and Mott both follow the process unique to 19th century medicine that Foucault identifies as “the medicine of sick organs.” In this type of medicine, the sick organ is identified, then the doctor explains how that organ became sick, and then finally indicates how the illness could be stopped. In his work The History, Nature and Treatment of Diabetes Mellitus, Rollo identified and verified the existence of diabetes
through blood tests after recognizing the already known symptoms of “weight loss, keenness of appetite, clear urine, wasting of flesh” and recording several new symptoms as well. He then identifies the stomach as the primary organ of concern and makes an attempt at countering “the disastrous effects of ‘luxurious living’” by “reversing the production of urine and reducing the amount of sugar in the blood stream by altering the quantity and quality of food ingested.” Specifically, Rollo suggested avoiding vegetables and consuming mostly meat. As with the typically 18th century “medicine of sick organs,” Rollo here identifies the stomach as the organ causing diabetes, claims that the organ became sick through too much luxurious food, and recommends that the process be reversed by proper eating. Mott’s process builds on Rollo’s, first identifying the disease in the same manner as Rollo and asserting that it comes from a sick stomach. However, he is unable to cure the disease according to Rollo’s method of dietary modifications, so he advocates bleeding the patient. When this failed, he turns to administering laudanum, opium, and arsenic, which also do not cure the disease.

Rollo and Mott’s lack of success is less important than the methods they utilized in engaging with the disease. The process that they followed was repeated by other 19th century physicians and created a body of medical knowledge that relied on observation and speculation. The sick patient was no longer the sole subject of these medical investigations, but was interpellate into a set of practices whose aim was to create a “coherent ‘theory’ of diabetes treatment” that was universally applicable. As with other investigations into medical afflictions, this “coherent theory” of diabetes
treatment became not just a method of restoring the patient to health through the application of universal principles, but a method of governing the patient’s life by formulating a system of how the patient should care for himself. In the case of 19th century diabetes treatment, these life-governing recommendations came through repeating Rollo’s meat-centric “animal diet” and adding the suggestion that patients engage in physical activity.²⁴ Doctors such as the prominent Charles H. Pile and Charles B. Brigham claimed that even though these measures would not cure diabetes, they would help the patient live a longer life.

Importantly, production of knowledge about diabetes in the 18th and 19th century took place in the clinic through studying patients and their afflictions. Previously, patient care had taken place within the homes of patients, a practice medical historians term “Bedside Medicine”.²⁵ Within Bedside Medicine, the natural place of disease was located in the home, among the patient’s typical surroundings and family. It was in that location that the individual case of the disease could be identified and cured. However, the shift to clinical medicine (also called “Hospital Medicine” by some medical historians) and the growing desire to de-individualize care in favor of building a body of medical knowledge also moved the site of patient care to the clinic. The clinic existed as a neutral space, untouched by the individual characteristics of the home, in which the disease could be isolated and identified “without the contaminants of extra ‘noise’” – i.e. germs. By creating a neutral space, the clinic further extracted the individual from their diseased body, making the patient an instance of the disease that could be studied and broken apart in service of a corpus of medical knowledge.
Frederick Banting and Charles Best are largely credited with being the first to develop insulin as a treatment for diabetes and, in the process, dramatically changing the way that diabetes care was enacted. Banting and Best performed experiments in the early 1920s removing the pancreas of a dog and observing the resulting diabetes. By then grinding up the pancreas and injecting it back into the dog, Banting and Best were able to alleviate the dog’s symptoms of diabetes. The extract that resulted from grinding up the pancreas was named “insulin.” By 1923, Eli Lilly was mass producing insulin as a treatment for diabetes. In the following decades, research on insulin continued, resulting in increased availability and a synthetic version.26

Banting and Best’s experiments coincided with a shift in how medical knowledge was created at the beginning of the twentieth century. The clinical knowledge of the eighteenth and nineteenth centuries was amplified through the rise of the laboratory. N. D. Jewson has pointed out that in Laboratory Medicine, “the patient was removed from the medical investigator’s field of saliency altogether.”27 Labs conducted research on diseases without the patient present, instead focusing on the “fundamental particles of organic matter.”28 Diabetes care was no different. Where Rollo and Mott examined single patients to draw out facts about diabetes and then recommended cures to those specific individuals (even as the cures were based on abstract knowledge of the disease), Banting and Best looked at the function of the pancreas and the chemicals within it. Their first subject was neither human nor diabetic, as with Rollo and Mott. The dog that they examined did not have the disease until they removed its organ, and only then did they have a patient that was a diabetic
subject. It was only after they had significant successful results from injecting the dog with “insulin” that Banting and Best tried the treatment on humans. The development of refined and synthetic insulin in the following decades also occurred within the laboratory, away from physical patients. As with clinical medicine, these experiments were performed with an eye toward adding to the archive of medical knowledge surrounding diabetes. In turn, this knowledge could be used to proscribe “healthy” ways of living for populations that would, theoretically, result in the disappearance of the disease. In a radical extension of the configuration found in clinical medicine where “doctors and patients…are tolerated as disturbances that can hardly be avoided”, laboratory experiments surrounding diabetes in the 20th century removed contact with the doctor and patient entirely. The individual appeared here only as an abnormal, unhealthy subject that must be treated because they did not follow the medico-administrative guidelines set out by laboratory medicine.

As the research aspect of clinical/laboratory medicine’s investigations into diabetes moved further toward a dissolution of the unique patient in the service of creating a totalizing body of knowledge on the disease, it failed to find a cure for the disease. The discovery of insulin was a success for prolonging the life of diabetes patients and finding the processes at work behind the disease. But, it was unable to fully restore the diabetic patient to a consistently healthy state and moved the focus of

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* An investigation into the significance of the shift to animals rather than human patients could also be carried out here. Though this project is concerned with the role of the human within discourse, I am more concerned with how human subjectivity is formed within processes of self care rather than how it plays out directly within the laboratory setting.
the medical discourse to the methods of treatment and disease management. As Davis points out:

Diabetes did not develop from an incurable, fatal disease into a curable ailment. Instead, insulin is an ongoing form of treatment. The symptoms, methods of diagnosis, or causes of diabetes are no longer important places for an investigation of the cultural construction of the diabetic body. Instead, the focus radically shifts toward treatment, i.e. the manner in which the diabetic patient negotiates the medical discourse in order to regain control of bodily ebbs and flows.\(^\text{30}\)

Davis’ remark points to the unique character of diabetes (and many chronic illnesses) whereby the clinical/laboratory model of medicine cannot completely dissociate itself from the patient. The disease cannot be dealt with only in the sterile and neutral space of the clinic or laboratory, but must rather take into account the patient’s negotiation “of the medical discourse in order to regain control of bodily ebbs and flows.” As diabetes research moved increasingly toward abstraction and creating knowledge of the disease on the molecular level, the actual processes of diabetes care moved in the opposite direction, engaging the patient in a complex system of acceptance, cooperation, and resistance that required treatment to take into account the individual’s everyday, embodied experience. The discovery of insulin as a treatment for diabetes allowed the patient to manage their diabetes from the home, rather than the clinic, under the direct supervision of a doctor. In order to deal with their symptoms, patients could now administer insulin of their own accord. They became “physicians unto themselves.”\(^\text{31}\) While the patient takes on this burden, they are either ordering their techniques of care according to the directions of doctors and medical

\(^*\) As noted above, this was actually the dog’s ground up pancreas, not refined insulin. I use the term
knowledge or modifying that system, whether intentionally or unintentionally. In the late 20th century and early 21st century, this process involves the patient examining their own blood sugar levels through a glucose monitor and then injecting a particular amount of insulin depending on their sugar levels. The patient has a certain dosage of insulin recommended by their doctor and informed by the medico-administrative body of knowledge surrounding diabetes, but it is ultimately up to the patient to marshal the care and monitor their actions. Such a relation between knowledge and day-to-day care creates new spaces for control that extend into the life of the patient, but also open up sites of resistance.

The “treatment” for diabetes is, in many ways, unique because it focuses not so much on the administration of particular medicines, but on the ordering of a particular form of life that occurs at the intersection of medical practice and the patient’s own agency in following medical prescriptions. Rather than a straightforward instance of the medical gaze disciplining the patient, the actions of the patient drift among willing submission to the medical gaze, a conscious refusal to follow the treatments provided by clinical medicine, and attempting to respond to unexpected actions of the body that have no identifiable cause. Illnesses such as asthma, bipolar mood disorder, Crohn’s disease, epilepsy, and other chronic conditions all require the continuous administration of medication while diabetes discourse also privileges eating properly and being somewhat active, even in the case of Type 1 where the effectiveness of “insulin” here for simplicity.
these techniques are not as drastic as with Type 2 diabetes. Moreover, the patient has significant control over their dosage of insulin rather than administering an amount pre-measured by a doctor, moving a large portion of the responsibility of care to the patient themselves.† Such a move provides a situation whereby clinical medicine is responsible for the overall well-being of the patient, yet the patient must direct their own day-to-day care. In effect, clinical medicine provides guidance based on claims for the patient’s well-being, rather than discipline over the patient’s actions. Disciplinary actions, formerly a product of the medical gaze, become self-imposed on the patient as they willingly manage their disease informed by the suggestions of clinical medicine in order to lessen symptoms and have a functional body. The issue, however, is when clinical medicine cannot account for the individual embodied situation of the patient, requiring the patient to override or supplement medical knowledge with their own methods of managing care. By examining the cases of Type 1 diabetics, it will be possible to see how patients engage in techniques of self care based on medical recommendations in order to manage their disease, but also go beyond those recommendations to fit their unique circumstances by utilizing various tracking technologies. These digressions are seen by medicine as a noncompliant patient, yet such noncompliance proves necessary to manage the disease in everyday life.

* See below for a more in-depth discussion of this issue, but some Type 1 diabetics are recommended strict control even though research has shown that strict control is only significantly effective with Type 2 diabetes.

† This is not to say that some of the points that I make about diabetes management could not pertain to other chronic illnesses, only that diabetes presents an extreme case that makes these points come out
Scholar Matthew Davis recounts his own experience with diabetes as a way to demonstrate clinical medicine’s apparent increase in the regulation of daily life for an ideal patient – an account that seems to go along with Foucault’s notion that medicine attempts to create a model of the “healthy” human. Though Davis himself believes that his experience maps onto the model of the medical gaze, it is possible to see small breaks in his process of self-care and treatment, which point to the patient as not just willingly engaged in reproducing the medical gaze, but also a necessary force in changing medical recommendations to fit an individual situation. Davis observes that when he was first diagnosed with Type 1 Diabetes, the treatment protocols were much more lax. But in recent years, management of his disease has come under closer scrutiny by his doctors even though he is largely responsible for enacting the recommendations outside of the clinic. This shift, for Davis, represents the ever-expanding control of the medical gaze into the daily life of the compliant patient. He writes:

[Initially, i]nsulin was used to lower blood sugar levels, but tight control was not encouraged, and many common diabetic complications were considered unavoidable. Although glucose levels for a non-diabetic individual vary between 80 and 120 milligrams of glucose per deciliter of blood (mg/dL), my doctor advised me to maintain blood glucose levels below 200 mg/dL, and to not bother adjusting my insulin levels if these goals were met. As this advice demonstrates, ‘adequate training is still not obligatory. Instead, simply handing the patients insulin, syringes and a book telling them to get on with it and become streetwise by a process of trial and error is still considered an option’ (Berger and Mühlhauser, 1993, p. 322). My diabetes controlled in this manner, visits to the doctor became necessary only once a year.\footnote{more clearly. Any chronic illness requires a significant amount of the life of the patient (and, many times, close friends and family) to be ordered.}
When he was first diagnosed, Davis had a certain degree of freedom with his program: there were infrequent visits with his doctor and he could decide when and where to take his insulin. But, there was still some medial oversight. His doctor recommended that he keep blood glucose levels below 200 mg/dL – an amount based not on the makeup of Davis’ own body, but on the general and abstract recommendations originating in clinical medical knowledge. Additionally, Davis’ entire treatment program of blood glucose monitoring and insulin injections was handed down from clinical medical knowledge. He was instructed to keep these glucose levels throughout the day as he performed his daily tasks, not only during his doctor’s visits. Davis could make some choices about how to administer his treatment while still remaining compliant according to the recommendations of the doctor.

Davis goes on to show how in recent years clinical medicine has attempted to increase its control over the regulation of his treatment. These changes came in the wake of the findings of the Diabetes Control and Complications Trial, a clinical trial conducted from 1983 until 1993 that found that progression of diabetes-induced eye, kidney, and nerve damage could be contained by keeping blood glucose levels as close to normal as possible.\(^{33}\) The official recommendation of the American Diabetes Association then became to encourage patients with any type of diabetes to have extremely tight control over their glucose levels throughout the day. For David this treatment, called “intensive therapy,” involved “new goals for blood sugar levels, more frequent checking of blood glucose levels, and twice as many daily injections of insulin” as well as “a week-long diabetes management course, and [an increase of]
visits to the doctor to four times per year, with additional appointments with dietitians, nurses, podiatrists, and eye doctors.” He points out that even medical knowledge does not deem this method of treatment effective for his own case of Type 1 diabetes, though the ADA recommends all individuals with diabetes follow this plan. In Davis’ view, this shift in treatment was designed primarily to reaffirm “the doctor's role in assisting the patient to achieve control over his or her errant body, thus minimizing the patient's feelings of autonomy in guiding his or her own treatment.” As with Foucault’s clinical medicine, the treatment recommendations utilize discourses of creating a healthy patient paired with treatment protocols to which the patient cannot have direct access. According to Davis’s account, through submission to the medical gaze and its ordering of daily life, the patient begins to act like a normate human as conceived by clinical medical discourse.

Davis presents an account of expanding medical control throughout process of self-care in diabetes management that is backed up by the suggestions of the medical field itself. To increase the frequency of checking glucose levels for diabetic teens, Anderson et al recommends increasing parent involvement. Borus and Laffel provide a review of multiple studies and come to similar conclusions, advising not only increase in parental involvement, but also increase in provider contact through text, email, and follow-up visits. These recommendations are in line with Davis’ fear that diabetes management has increased the oversight of the medical gaze into daily life. These studies give justification for increased contact with care providers outside of the bounds of the clinic while bringing in family members to act as watchful eyes that
encourage compliance. However, even these recommendations do not provide an absolutely compliant patient. Individuals often do not put into practice the required medical directives, for reasons ranging from lack of knowledge to conscious unwillingness to unexpected bodily reactions to situations that do not allow self care to be administered (such as being at an upscale dinner or napping).

The persistent lack of this perfect patient has become a focus of a great deal of medical discourse in the twentieth century.\textsuperscript{36} As medicine expanded its knowledge beyond its own domain into medico-administrative knowledge that spanned social relations and ways of life, it also became concerned more with how well the patient complies. In the early twentieth century, this involved adding nutritional supplements to food and engaging with food producers to recommend a dietary regime that could be packaged and sold.\textsuperscript{37} Here, doctors used market forces, food regulations, and other systems of administrative knowledge to ensure patient compliance to clinical recommendations. In the early-to-mid twentieth century, the development of antibiotics – what Haynes and others call the first “truly effective” medicine – allowed for doctors to become even more concerned with compliance and the ordering of individual patients’ lives.\textsuperscript{38}

Thousands of studies have been done to identify the causes of noncompliance and potential ways to fix the problem.\textsuperscript{39} R. Brian Haynes, one of the major commentators on compliance, summarizes these, stating that compliance with short-term treatments can be helped through a combination of “clear instructions; recalling non-attenders; patient self-monitoring of compliance and/or treatment outcomes;
enhancement of social support; ‘contingency contracting’ and rewards or reinforcement for high compliance; and group discussion and supervised self-management.40 He also notes that long-term compliance aids must be constantly administered by a doctor otherwise the patient will slip back into noncompliance.41

Other researchers such as Katie Buston present causes for noncompliance that put the burden squarely on the patient. She lists forgetfulness, ineffective medication, denial, difficulty using apparatuses, inconvenience, embarrassment, fear of side effects, and laziness as major causes to noncompliance.42 Buston, as with other researchers, advocates for more clinically-sanctioned information to be provided to the patients or better communication on the part of the doctor to increase compliance. Scholars like Haynes and Buston view the patient as an initially non-compliant subject that must be disciplined through clinical oversight and engaging with medical knowledge. It is medicine’s duty not necessarily to make the patient well or to bring the patient into the process of producing medical knowledge, but to organize the patient’s habits, treatment protocols, and everyday life in a way that fits with medical best practices.

But even as some medical scholars have developed ways to try and increase compliance in patients through interaction with doctors and medical knowledge, there has been a push-back on the formulations of noncompliance from sociology, anthropology, and even medicine itself. From the perspective of social scientists and humanities scholars, compliance is a particularly troublesome issue because of the technologies of control that it uses. Anthropologist James Trostle points out that even
under different names, “compliance” becomes an ideology that asserts control over the patient by the doctor, allowing the doctor to perform a judgment and apply a label rather than understand the point of view of the patient. In place of talk of compliance, Trostle argues for a behavioral definition of compliance that can extend to types of care originating outside of the medical field directly. These can be patient-created methods of care, or other non-specialists.

Though scholars like Haynes and Buston do not directly address the power dynamics found within discourse of compliance, many commentators from within the medical community advocate giving up some of medicine’s authority to examine the lives of the patients and the reasons behind noncompliance. Fiona Ross writes that compliance is typically the responsibility of the patient, but her research has shown a number of issues with both the drug delivery system and professional practice that lead to patient noncompliance. According to her, because of these systematic shortfalls, it is necessary to put some of the blame for noncompliance on the part of the medical system itself in addition to the individual responsibility of the patient.

Other commentators are more radical, echoing Trostle’s claim that compliance becomes an ideology that asserts a doctor’s control over the patient. Speaking from within the medical industry, Chatterjee calls compliance a “paternalistic” process that organizes the doctor-patient relationship along the lines of a parent-child relationship. Where Trostle sees this as a larger ethical issue, Chatterjee (like Ross) is concerned with the waning health of noncompliant patients. Chatterjee advocates for a process begun in the UK called “concordance.” This process tries to position the
doctor and patient as equals and insists that, “there should be an open exchange of beliefs about medicines upon which both prescribing and medicine taking decisions may then be based.” For advocates of concordance, this “open exchange” and cooperative decision making process is meant to provide the doctor with the point of view of the patient, illuminating potential reasons for noncompliance and possible solutions.

What is important about concordance is not necessarily that it opens up a space to unseat the medical gaze in its entirety. Nor does it truly reverse or remove any expression of disciplinary power between doctor and patient. Concordance does, however, create two changes to the techniques of care within medico-administrative knowledge. The first is that it puts the doctor in the position of convincing the patient of treatment rather than telling them or ordering them. The doctor holds a responsibility for the well-being of the patient, but must also renounce a demand that the patient’s well-being can only be achieved through the exact application of recommendations based on clinical medical knowledge. Chatterjee, for example, disdainfully remarks that compliance “has certain connotations, such as submitting to and obeying instructions” with non-compliance thus regarded as “deviant behavior” by the medical industry. In discourse of concordance, the doctor is still the expert and possesses unique knowledge about the disease afflicting the patient, but the patient can question the legitimacy of that knowledge or choose not to follow a doctor’s recommendation presumably based on this knowledge without being labelled as abnormal or irrational. Instead, as Chatterjee points out, “it may be sensible, safe, and
in the interest of the patient to be non-compliant” because of issues such as reactions to certain drugs. Conrad agrees, claiming that what appears as irrational non-compliance is often the patient’s way of asserting control over their disease. Whereas clinical medicine hinges on the exclusion of “deviants” that do not follow orders, the concordance model claims a knowledge of the truth of disease, but does not marginalize those that disagree in the same way. Instead, clinical medicine’s idea of a disease’s “truth” must be able to be articulated within multiple contexts that are determined by the patient. In this way, the noncompliant patients do not become abnormal per se, but are subjects that need to be assimilated into medical gaze by means other than fear of adverse health effects or doctors’ direct orders. The complicity of the patient that has always been present in clinical medicine’s use of self care now requires that patient also understands the logic behind the recommendations, not just follow them with an assumption that they will promote health.

The second shift that occurs through concordance is the focus on the everyday life of the patient. The disease no longer exists only in the abstract, as in the clinical or laboratory model, but rather as lived experience. Though medical knowledge still originates within the clinic or the laboratory, it undergoes a shift when it encounters the life of the patient. Compliance-based discourse assumes that the patient will order her life around doctor’s recommendations about when to take medicine, exercise, eat, etc. Concordance assumes the opposite: that medical recommendations will have to be modified based on the unique situation of the patient. Certain drugs may, as in Chatterjee’s example, cause adverse reactions to a patient. Or, as in any of Haynes’
examples, patients may misunderstand the treatment procedures, lack social support, forget to take medicine, or any number of other reasons.

In both of these shifts, we see medico-administrative knowledge not only critiquing itself in order to be understood within the context of the patient’s individual understanding, but also opening itself up to acknowledge the existence of differences in class, gender, and other identities that do not emerge within the laboratory or clinic. In a study by Buabang, for example, it was found that noncompliance with hypertension medication in Ghana came from a lack of funds to buy the medicine. Even Buston’s identification of “embarrassment,” difficulty with the apparatuses, and denial as potential causes of noncompliance point to socially- and culturally-situated factors influencing the degree to which patients follow doctors’ orders.

Diabetes care recommendations echo these issues with concordance. For example, Robert M. Anderson, publishing in *Diabetes Care*, suggests five changes to the traditional medical that will help bring patients into the fold:

1. Doctors should recognize that the patient is in control of decisions about care; 2. Practitioners should be information sources and impart knowledge onto the patients instead of blindly ordering them; 3. Pejoratives like adherence, compliance, and noncompliance should be eliminated; 4. Medical schools should train doctors as “mentor[s], advisor[s], and coach[es]”; and 5. The patient should be made aware of a unique patient-provider relationship that emerges from the management of diabetes.

These recommendations are patient-centered, but they still do not give the patient the power to produce medical knowledge. Instead, the patient is treated as a type of subject that can *understand* medical knowledge, even if they cannot produce it. By
hearing the rationale behind the decisions in care regimes the patient is assumed to buy in to the process, still becoming complicit in the reproduction of the medical gaze.

Though concordance ends up as a reproduction of the clinical medical gaze, there are individuals working to the side of the medical field to take on concordance’s claim to open up medical regimes of self care to account for the individual, while also allowing the individual to produce medical knowledge about their own body. Many of these individuals belong to a group called Quantified Self, a loosely collected group of people who use a variety of health-tracking technologies to record aspects of their health. Chapter Three deals in detail with Quantified Self as a larger phenomenon, but this chapter introduces several individual projects because they are examples of a systematic way of re-organizing health care that is beginning to gain popularity internationally. Quantified Self presents itself less as a directive about what should be tracked and more of a methodology on how to track. The goal is to create large sets of data over a variety of different areas and analyze them using n=1, the assumption that they will only apply to a single person. The projects in this chapter are limited to diabetes-related projects, but they can include anything from tracking movement to emotion to time spent using certain computer programs.

Doug Kanter has presented at Quantified Self meet ups and generally uses the principles of the group. He has collected over 300 data points a day from an insulin pump and two glucose monitors. He combines this with data about his lifestyle, such as where he is or what he eats to create a database of information that he can access. Kanter’s diabetes was not radically out of control and he was not necessarily
managing it in a way that clinical medicine would disapprove of. His motivation for tracking came from his own desire to learn about his diabetes and how it played out in his life. Though he was not necessarily “unhealthy” by clinical standards, Kanter wanted to become healthier.

Kanter observes that often new diabetes patients are overwhelmed by data and have difficulty understanding what is going on with their disease and their own bodies. His main focus was on creating visualizations of his data that would draw his attention to particular trends or potential problems with his disease that may not emerge as clearly through more traditional methods of self care. One of these visualizations was a circle that consisted of blood glucose measurements taken throughout the year, coupled with how much running he was doing:
Figure 1: Visualization of blood glucose measurements and running
http://databetic.com/?p=304

Kanter explains the colors on this graph:

The main image shows 91,251 blood sugar readings from my Dexcom continuous glucose monitor (CGM). Each colored line shows one day. January 1 is at the top, with days progressing clockwise around the circle. Lines grow longer with more readings for that day. Blood sugars are color-coded and grouped based on the reading. I represented the in-range readings as white to make it easier to spot the days where my blood sugar control was not as good. High blood sugars are a colder colors, low blood sugars are warmer.54

He also added text around this graph to note events happening in his life:
From these graphs, Kanter was able to “merge medical data and information from ‘the rest of [his] life’” in a way that would be impossible through the current system of clinical medicine because it would be too personalized and unable to fit into a body of medical knowledge that abstracts the individual. Kanter’s visualizations subvert that process, creating a highly individualized set of data that draws attention to aspects of how his individual body performs the disease that could not necessarily be extrapolated to fit every case of the disease. In Kanter’s case these data points and conclusions centered around his running. After analyzing the data, his conclusion was that the more he ran, the less insulin he needed, up until he was running 30 miles per week, where the insulin dosages remained constant. After he ran a marathon and stopped training, Kanter’s need for insulin dosages spiked dramatically. Kanter’s instance is not part of a larger “truth” about diabetes, but an isolated finding about the relationship between diabetes and his own body – specifically his own body as it runs
– that only applies to Kanter. Moreover, and somewhat counterintuitively, this data and the resulting conclusion focus on grounding his diabetes as a phenomenon that exists within his body. The disease no longer becomes an abstract configuration of glucose levels and insulin treatments, but a disease that is embedded within a body that responds to activity in a way that can only be pinpointed by looking at data tied to that specific body.

By collecting data and producing visualizations, Kanter disrupts the clinical medical model in two ways. The first is that he collects data that is only applicable to his own case and does not seek to add to a larger, abstract body of knowledge about diabetes as a disease. Kanter’s models project information about the disease, but the disease is taken to be a particular, embodied case that takes into account medical facts about diabetes in general while also holding the possibility that his particular instantiation may be different in some ways. Here the individual case is, on the one hand, more important than the archive of knowledge about the disease. The disease become a part of Kanter’s body, reacting to his actions, his training, and the situations that he puts himself in. The strength of Kanter’s method lies in the fact that he records a large amount of miscellaneous data about his life that he can then link to insulin need. Some of this is passively recorded (such as steps taken or miles run via activity monitors), other data is actively recorded (such as filling out a spreadsheet with

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* This is not to say that the findings are not useful to other people or that someone else could have the same results, only that Kanter’s conclusion could not be assumed by another individual in the same way that larger truths of diabetes can be transferred between patients. For example, laboratory medicine has proved that insulin deficiency is the cause of diabetes, a fact that can be applied to any diabetic to some degree.
location). Through this large dataset, he is able to find unexpected ways that diabetes manifests itself in his body. The link between running and insulin need may not be entirely surprising, but it can be found more easily through Kanter’s process than by a clinical medical process. Clinical medical studies of diabetes typically look at relatively sedentary individuals and do not anticipate higher-level athletes that can run marathons like Kanter.* Even though Kanter’s process leads him to a conclusion about his own body, his methods serve as a potential (but not authoritative) model for other diabetes patients and the medical discourse at large. The model is presented as an option for other patients to take and make their own, with the understanding that the model could, and most likely will, have to be modified for each case.

Kanter’s case may seem to put control of diabetes entirely into the hands of the patient, but this is not the case. Such a move would be a return to the pre-clinical model of medicine that was patient-directed, but there are two reasons this is not the case. The first reason for this comes from Foucault’s claim that early, premodern medicine “believed that the only possible locus for recovering from disease was the natural environment of social life, the family.” Moving the care of disease to the home served to alleviate costs for the state while medical discourse posited that “in the family, the disease was in a state of ‘nature’, that is, in accord with its own nature and freely exposed to the regenerative forces of nature. The gaze that is turned upon it by those close to the sick person has the vital force of benevolence and the discretion of hope.” For those that had no family, the hospital was created to serve in place of the

* Also see the case study of Felix Ming below for a more difficult-to-identify link between the body and
family. In terms of Kanter’s care, the shift toward home self-care and self-organization of life initially seems to re-introduce this idea that the home and family is the ideal source of care. The physical space of the home is prioritized, as in pre-clinical medicine, and both types of medicine are more economically viable for the state, but the gaze that is levied onto the patient varies in each case. In pre-clinical medicine, the patient’s home provides a space in which they are subject to a “benevolent” and “hopeful” gaze of family and friends. Contemporary diabetic care serves to reproduce medical discourse by directing the actions of the individual and creating an individual complicit in performing those actions. The gaze at work within Kanter’s diabetic home care does not aim to amplify the type of care present at the home and nurture the disease by placing it within “regenerative forces of nature.” Instead, the gaze here is one that is displaced from the clinic and serves to neutralize the space of the home, encouraging Kanter to engage within a strict regime that replicates the clinical setting as much as possible, even if he was partially responsible for identifying ways that the care should be enacted. The home becomes a type of treatment center in its own right. Within the hospital setting, the patient would, in theory, be subject to strict dietary schedules and foods choices; made to adhere to an exercise plan; and given pre-measured dosages of insulin where necessary. As they exit the hospital space and move toward the home space, the patient is expected to

* In *The Birth of the Clinic*, Foucault continues to trace how the hospital initially arose to perform these functions but slowly shifted due to a number of forces. By the time the hospital had become an institution, it had drastically changed from the original concept of it as a place to care for those who had no family.
adhere to these same recommendations, regardless of the “natural” home state surrounding them. Kanter still performs these types of actions and attempts to order his home in a way that helps him manage his disease, though his actions are directed by his own data analysis as much as by more traditional clinical recommendations.

The second and third manners that the shift of care from hospital to home falsely appears to be a shift toward a pre-clinical medicine come from Jewson’s descriptions of what he calls “Bedside Medicine,” the same early 18th century medical practice that Foucault describes. Jewson describes the patient in Bedside Medicine as an individual entity, claiming that “the vision of the sick-man institutionalized within the tenets of Bedside Medicine was that of a conscious human totality – a viewpoint that transcended, not merely united, the distinctions of psyche and soma found in modern medicine.” Whereas clinical medicine (occurring in the early 19th century for Jewson) breaks apart the patient into abstract elements that can be measured and tested with the aim of adding to a corpus of medical knowledge, Bedside Medicine focused on the actual patient, who “appeared…in a guise similar to that in which he appeared to himself, i.e., as an individual and indivisible entity.” The shift toward the patient as a collection of abstracted knowledge of a disease had not yet occurred. The “person oriented role system” of Bedside Medicine is a way of organizing where judgments about others are made in terms of the individual attributes of persons rather than their formal statuses, decisions being open to negotiation and discussion between the members of the group on the basis of their particularistic ideas and interests. Members
attain their location in the role system through a process of mutual exploration of personal identities.58

Kanter’s increased attention toward himself does position himself as part of a lived environment and a unique body that exceeds absolute control of clinical medicine. Such a configuration does bring in a notion of individuality in the sense of being a part of a single, unique circumstance and needing a personalized type of care. However, this is not a direct return to preclinical Bedside Medicine as Kanter is not a “conscious human totality” beyond the purview of medical knowledge. He is situated within a larger context of being a unique body within a unique environment and objects that affect how care can be administered, but Kanter also exists as a manifestation of the larger, abstract concept of diabetes. This is one of the primary areas in which we see the Kanter and other diabetic patients as a posthuman subject and unable to return to the same place it holds in a pre-clinical model of medicine: the patient is intimately connected with its environment, embodied, capable of being transferred into an informational pattern, yet able to incorporate medico-administrative technologies based on clinical medicine such as blood glucose monitors into their person.* Kanter, as with most contemporary commentators on diabetes care, does not advocate for a complete break with medical care, even as he sees himself as a unique case. Rather he insists on looking at how to manage a relationship between medical recommendations of care, how his own body manifests diabetes, and the his own

* For a more detailed account of what makes up the posthuman, see chapter 1
surroundings, acknowledging that the patient and its associated disease will always be part of a network of other forces.

Diabetes, then, is a unique disease in the sense that it disrupts much of the clinical model of medicine by including the individual as a source of legitimate medical knowledge, yet it does not result in a return to Bedside Medicine by disposing of clinical medical knowledge or the overarching medical institution. Instead, it creates new forms of knowledge and techniques of power that radically reorganize the patient/medical knowledge nexus. The issue of noncompliance is the primary disruption in this model, as it shows the dual nature of the clinical medical gaze’s attempt to regulate chronic disease. Clinical medicine must, for logistical and economic reasons, shift the burden of care to the individual, but this process moves the site of care away from the clinic toward a space that clinical medical discourse has aligned with irrationality, nature, and unknowability. Such a move and re-spatialization is an attempt to reclaim home-based self-care under the umbrella of the medical gaze and clinical medicine’s recommendations for care. However, the lives of the patients constantly act outside of the proscriptions of the medical gaze while still applying some of the recommendations. Patients are often seen to be “out of control” and frequently labelled as noncompliant, an issue that labels the patient engaging in self-chosen everyday activities as a deviant. Alternatively, patients are advised to realize that their own knowledge of their disease is incomplete and they should supplement it with clinical medical discourse by “continuously engag[ing] in fresh discussion in order to ensure that the right interventions are chosen – hereby actively
avoiding that provider and patient believe that they have finished discussing the aspects of accepting, understanding and knowing." Encouraging the patients to learn is suggested with the assumption that they will seek out approved medical discourses, but as Kanter demonstrates and the example below will reinforce, this often results in patients working outside of clinical medicine to create their own medical knowledge and regimes of self care that works alongside medical knowledge.

Creating these tangential medical knowledges requires a re-appropriation of medical technologies by patients to create supplemental and alternative discourses. In these cases, medical institutional knowledge still remains central to diabetes management, but the patients utilize the techniques of clinical medicine to create their own databases of information that identify the patient as an individual case. Legitimacy of these discourses comes partially from the legitimacy of the medical tradition that it appropriates, the applicability of those discourses to everyday life situations that are often not accounted for by clinical medical recommendations, and the ability of the technologies to identify ways that the patient’s body operates in a unique fashion. Here, the archive of information collected by the patient serves not to add to a larger body of knowledge on the disease, but to create a singular instance of a diseased patient that may or may not apply to other cases.*

* As in Foucault’s concept of clinical medicine or Jewson’s laboratory medicine, whereby medical practitioners perform research to create a map of a disease that exists outside of the individual case within a patient.
One instance of this tendency can be seen in Vivienne Ming’s efforts of tracking her son’s diabetes. Like Kanter, Ming is loosely connected to Quantified Self and has presented the follow project at Quantified Self meetups. Ming is a neuroscientist whose son has Type 1 diabetes. When she found out about her son’s disease, she and her husband began to use their training as scientists to attempt to help their son, Felix. To do this, they tracked and recorded various parts of his life, including what he ate, his activity levels, blood glucose levels, etc. Felix was hooked up with a Dexcom continuous glucose monitor, Omnipod insulin pump, Fitbit accelerometer, and Basis activity/heart rate monitor. She then took a spreadsheet with this information to her son’s doctor, who refused to take the data and said that it would be impossible for Ming to interpret the data about the disease because it is endocrinology, a realm of medical knowledge inaccessible by anyone other than a specialist.

The initial encounter between Ming and her doctor becomes an encounter between: (1) the possibility of legitimate interpretation of medical data by a patient that can account for a single, unique instance of a disease without assuming it to be an exact replica of the disease writ large and (2) clinical medical discourse’s twin goals of helping the patient while also reserving the ability to interpret medical knowledge and requiring the patient to submit to the medical gaze for care. The doctor views the

*Vivienne Ming* - Tracking My Son’s Diabetes on Vimeo. vimeo.com. Web. 14 Jul. 2014. <http://vimeo.com/81272562>. The examples here are come primarily from Quantified Self (QS) talks, though many individuals have been using these methods since before QS existed. For the purposes of this paper, QS is seen primarily as a rallying point for individuals already managing care in a particular way. The following chapter will engage in a more in-depth analysis of QS itself.
disease as impermeable to untrained vision. Only the medical gaze can unearth the secrets behind it. As in Foucault’s clinical medicine and Jewson’s Hospital Medicine, the doctor views Felix’s case not as a unique patient with a disease, but as an instance of the disease that can only be identified and treated by the doctor. Without access to the knowledge of clinical medicine, Ming cannot properly understand the disease, even though she can see the patient herself. But what is especially interesting about this case is that Ming’s data is collected according to a process of clinical medicine. She adhered (at least loosely) to scientific standards of data collection and presented the data in a format that should have been recognizable to the doctor. Her data was rejected not necessarily because the format was illegitimate according to medical standards, but because the data applied only to a single patient and could not be understood within the framework of clinical medicine that requires the patient to be a non-unique instance of a disease. Further disqualifying the data, it was also collected outside of a unbiased clinical setting. By injecting the patient back into the medical data, it made the data illegitimate in the eyes of medical discourse. No absolute “truth” of diabetes could be discerned from Ming’s data, so clinical medicine would not consider it as legitimate material for analysis. But for Ming – and many individuals currently undergoing treatment for chronic illness – the “truth” of the disease and the ability to understand it does not lie within an archive of clinical knowledge, but within data collected from the individual instance of the disease as it is present within Felix. It is not necessary to be trained in endocrinology in order to see the disease, only to be attentive to various aspects of how the disease affects the child’s life. For Ming and
her husband, it is possible to act outside of medical discourse and engage with some sort of “truth” of the disease.

This truth ended up to be particular to Felix’s case and not necessarily applicable to other cases of diabetes, a quality that goes directly against the medical truths uncovered by clinical medical knowledge, which seeks to institutionalize facts about the disease in general. Though the data Ming and her husband was not accepted by their doctor, they continued to collect data and look for ways that it could figure into treatment plans for their son. The most drastic way that they used this data was to create a model for insulin injections that was particular to Felix and his daily habits and the way that Felix’s stress hormones interacted with his diabetes, not necessarily in line with the recommended program the doctor suggested. Over several years, they were also able to point out environmental factors that affected Felix’s blood glucose that would not have been caught by traditional clinical models. In one case, Felix’s readings were showing high blood glucose following breakfast on weekdays caused by the anxiety of going to school. Traditional clinical models of care would have only caught the readings of high blood glucose following breakfast as a general pattern and been unable to link it to his body’s processing of anxiety of going to school. Ming and her husband were able to modify their model of insulin dosages to account for the specific stress of going to school and the needs of Felix’s body. Whereas traditional clinical models would attempt to extend this link between stress and blood glucose levels to all diabetics, the Ming’s data analysis can only apply to Felix.
Ming’s case demonstrates a way in which diabetic patients take the technologies of clinical medicine and use them in a way that reforms clinical knowledge to take into account the patient as an entity within the context of everyday life. The data that Ming collects uses the processes of medicine and engages with the larger body of knowledge, but creates an individual data set that forms a unique knowledge of a singular patient. Felix still goes to the endocrinologist and still uses insulin therapy, a treatment that originates in clinical and laboratory medicine, but that insulin is administered on a schedule set by Ming based on the data collected about how Felix’s body interacts with his diabetes. Ming is able to construct her own system of truth from the data and tests that she and her son conduct that works alongside the larger system of medical discourse. The findings that Ming, Felix, and her husband come across add to an archive of possible truths for various instances of the disease, but do not (as in clinical medicine) serve to add to an abstract and objectively factual archive of medical knowledge. Ming shares her results through talks, but not to demonstrate that her method or her findings are always applicable to every case of the disease. Instead, she looks to show an individual case – that still refers to the sum of cases of the disease – that may provide a clue for another patient seeking to enact a treatment plan.

Here we see a reconfiguration of power as the medical gaze is questioned by the patient’s practices of self-care outside of the clinic. As Ming demonstrates, patients who engage in self care can now create modes of treatment that run alongside and interact with medical discourse, rather than reproducing them directly.
Enforcement of these treatments occurs on the level of the individual and the self, away from the direct oversight of the clinic, allowing these alternative treatments to take root within the lives of individual patients.

Both Ming and Kanter create their practices of self-care within a gap in the medical system previously occupied by discourses on noncompliance and concordance. As clinical medicine required that individuals take on more responsibility managing their own disease, it became evident that even well-intended application of disease management recommendations were difficult to put into practice. Patients with chronic diseases like diabetes were recommended strict control of their self-care regimes. Diabetic patients were told by the American Diabetes Association to practice strict control over their diet, exercise, blood glucose levels, and insulin administration, regardless of their type of diabetes. Not only was the efficacy of this recommendation questionable, many patients could not practice the desired level of strict control because of a lack of knowledge, busy schedule, lack of access to materials, unexpected bodily reactions (e.g. scarring over an injection site, unresponsive fat cells, odd levels of hormones from anxiety or sadness, etc.), or any number of other factors.

These patients were initially labelled noncompliant and told to regain control over their treatment regimes or face the dangerous possibility of failing health through complications with their disease. Concordance, a newer model, sought to bring patients back into the fold by providing them more information about the rationale for certain treatment regimes. As noted above, though concordance tried to relate to the
patient as an individual through a more compassionate provider, this model served to only reproduce the medical gaze within patients and failed to fully re-work a system of medical knowledge that could account for a patient with unique circumstances.

In between a medical model of care that required the individual to take on more responsibility for care and an embodied, lived experience that often disrupted attempts to perform those recommendations, Kanter and Ming developed their processes of self-tracking and self-care. From the perspective of medical knowledge, they appeared noncompliant by refusing some medically-sanctioned regimes of care in favor of finding their own. However, by utilizing scientific data gathering and medical technologies, they were able to produce knowledge about their diseases that was not completely outside of clinical medicine. When Kanter adjusted his insulin levels according to how much he was training and when Vivienne Ming adjusted Felix Ming’s insulin administration in response to anxiety levels, both did so in order to keep their blood glucose levels within clinically-approved ranges. Here, Ming and Kanter have given legitimacy to their noncompliance in medical terms; by generating knowledge about their disease to find their own technique of self-care, they have maintained control over their disease.

These two examples no not just reorder methods of self-care, but do so by reorganizing the model of the human that acts as the foundation for medical recommendations of self-care. As noted above, clinical and laboratory medicine rely on a concept of the human where individuals bodies matter less than a generalized archive of knowledge about humans in general. Individual humans are compared to
this archive in order to diagnose any abnormalities or disease. However, in Ming and Kanter’s case, their tracking procedures allow them to create a localized idea of their own embodied situation. Such a model is able to take into account specific aspects of their body (hormones released by anxiety, insulin absorption with regard to training) and environment (how school affects anxiety, which affects blood glucose levels) – aspects that could not be accounted for within a more traditional model of clinical and laboratory medicine.

Moreover, projects like those of Kanter and Ming do not assume that the exact ways that the bodies operate are completely known. Only by collecting data can the operations of the individual body emerge and, even then, those insights are continually tested through data collection. Ming’s case exemplifies this most strongly, as the initial reason Vivienne began data collection was an unexpected drop in glucose levels in Felix’s blood. Emphasizing the body in this manner reflects a type of subject acts against the humanist model, refusing to take consciousness as the central characteristic of being human and does not assume a completely knowable self.64 Instead, these projects begin to create a type of subject that appears most posthuman because it can learn more about itself by integrating tracking technologies into its body, whether by removable devices like FitBits or through invasive devices like continuous glucose monitors.* Much like the criticism of posthumanism in chapter 1 has pointed out, the

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* There are two different ways to view this. The first is through Hayles’s claim that technology can be articulated seamlessly with the body (Hayles, N Katherine. How We Became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics.: University of Chicago Press, 1999. 2-3.). This will be analyzed in detail in the following chapter, but the initial assumption is that there is a significant link between the body and the data recorded on a tracking device. Consistent data is believed to give a
figure of the human is still retained in the projects of Ming and Kanter, even if it is not based explicitly on consciousness or a single, abstract concept of “the human.” Even so, care is radically re-worked to open up space for patients to participate in the knowledge-creating process and directing their own self care. The next questions that emerge are: (1) whether this type of knowledge creation can be expanded to instances of subject formation outside the medical field and (2) whether this process can indeed bring about a renewed interest of ethics, justice, and critique even though it fails to completely discard the human.

Chapter three looks at several different instances of Quantified Self projects that, like Ming and Kanter, track various metrics to monitor one’s health. Unlike Ming and Kanter, these Quantified Self projects involve managing more general aspects of well-being that are tied to clinical medical recommendations, but also exceed them. These include finding ways to sleep better, keeping Myasthenia Gravis under control, and increasing overall happiness. The chapter will claim that in each of these cases, it is possible to see technologies usually used to control populations being applied on the individual level: a form of biopower that does bring the methods of subject formation representation of the body that can be manipulated and analyzed to learn more about the workings of the body.

The second view is one of Object Oriented Ontology or Speculative Realism. In this view, as noted in chapter 1; Roden, David (2014-10-10); Posthuman Life: Philosophy at the Edge of the Human (Kindle Locations 735-737); and Taylor and Francis. Kindle Edition, the objects present a different type of ontology about the world. The data presented would be a glimpse into how those technologies configure the world. According to the Object Oriented Ontologists and Speculative Realists, we would not, strictly speaking, be understanding a new ontology of the world by looking at this data, but interpreting it and appropriating it for human use. This would be to take a function view of Object Oriented Ontology and Speculative Realism that still includes the human within the interpretative process, as with the critiques brought up in chapter 1.
identified in this chapter outside of dealing with exclusively chronic disease. Chapter four will address how this type of subjectivity operates within institutions to begin to address the second question posed above concerning issues of justice, ethics, and critique.


6 "Diabetes A-Z."
7 "Diabetes A-Z."
9 "Diabetes A-Z."
11 "Diabetes A-Z."
15 Davis 72
17 Foucault *Birth of the Clinic* 59
19 Wolfe 53
20 Davis 74
21 Davis 74
22 Davis 74
23 Davis 74
24 Davis 76-77
25 Armstrong 393. It is also worth noting that Foucault does not use this term, though he does describe a similar process.
Doug Kanter - "A Year of Diabetes Data
Doug Kanter - "A Year of Diabetes Data
Foucault The Birth of the Clinic 39
Foucault The Birth of the Clinic 39-40
Jewson 625-26
Foucault The Birth of the Clinic 39
Vivienne Ming - "Tracking My Son's Diabetes 4:00
Foucault Birth of the Clinic 39
Vivienne Ming - "Tracking My Son's Diabetes 3:18
CHAPTER 3
Biopower and Quantified Self

As the previous chapter demonstrates, when patients engage in techniques of self-care for chronic conditions like diabetes, they often stray from the explicit orders of medical professionals. Patients often fail to understand medical recommendations, use methods of care from non-medical sources, or simply just forget some of the steps. Some patients, like Doug Kanter and the Ming family take the data collection techniques of clinical medicine and create medical truths about a disease that apply only to a single patient. In doing so, these patients also reconfigure the humanist attempts of clinical medicine to create the factors that comprise “the human” into an attempt to create “a human” with its own unique characteristics and sense of self-assessment. When this process happens, the techniques of data gathering used in medicine are reconfigured for use by a single patient, rather than “patients-in-general”.

With the shift in focus from large-scale patient groups to single individuals, the power relations between medical institutions and individuals undergoes a large shift as well.

The underlying organization of practices in these projects involves navigating (1) institutional knowledges that form the basis of recommendations for how individuals order self-care and (2) how individuals put those knowledges into practice. As shown in the previous chapter, patients do not completely replicate institutional recommendations, but they also do not work completely outside of them, either. Patients submit to self-care protocols largely because they desire to increase their health. Willing engagement with self-care techniques creates a situation whereby
individuals become complicit in reproducing the larger institutional structures of medical knowledge. The concept of “biopower” can be useful to understand this designation. First popularized by Michel Foucault, this model claimed that institutions aim at regulating populations by focusing on the body and overseeing large trends in health-related data via “biopolitical” institutions like the state and clinical medicine.* By gathering large amounts of data on populations, a normate model of a citizen or human could be created. This normate model was reproduced in individuals not through the threat of violence, but through a desire on the part of the individual to be a healthy person.

Biopower worked alongside disciplinary power, but at a macro level. This technology centered on caring for life, but often to the exclusion of other forms of life. Contemporary self-tracking technologies used for self-care in chronic patients fall very much into processes, creating large quantities of data to be analyzed in order to construct the idea of a norm. Unlike 20th century expressions of biopower, however, these self-tracking technologies do not attempt to exclude individuals from the larger social or political sphere based on whether or not they contain particular characteristics found in “normal” humans. Instead, the analysis of a single person over time forms the idea of the “norm,” allowing biopower to operate diachronically on an

* This chapter will focus on Nikolas Rose and Paul Rabinow’s extension of Foucault’s concept of biopower because they are working from a standpoint that includes medical and scientific iterations of biopower. Other thinkers, however, have significantly developed theories of biopower in other areas. The most notable include Giorgio Agamben (in Homo Sacer) and Michale Hardt and Antonio Negri (in Empire). These scholars do not appear in this dissertation because they focus more on the application of sovereignty (Agamben) and biopolitics’ intersection with capitalism (Hardt and Negri), which are to the side of the discussion. Further work could be done as to how self-tracking technologies develop.
individual with many facets rather than synchronically on a population with many individuals.

The practices of scientist Larry Smarr illustrate of how self-tracking technologies can be used on the individual level rather than just at the level of the population, reorganizing how biopower plays out. In the early 2000s, Smarr wanted to lose weight, even though he was within acceptable and clinically established ranges. He decided to do this through the traditional method of counting calories and exercising, but also used newer technologies, some of which are widely available on the consumer market and some that required his special access as director of the California Institute for Telecommunications and Information Technology at UC San Diego. For months, he used an accelerometer called a FitBit to track how many steps he took a day, which allowed him to figure out how many calories he burned. He also recorded what he ate and tried to balance out protein, carbohydrates, and fat while making sure his caloric expenditure exceeded his caloric intake. With such minute tracking and all factors apparently accounted for, he should have been losing pounds quickly. But, the results did not match up to the expected outcome and his body wasn’t responding in the way that it should have been. He was losing weight, but not nearly the amount that he should have lost, according to his calculations and what would be considered typical according to contemporary medical recommendations. Smarr believed there was an unaccounted for variable and he began experimenting to find out what that variable was.

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sovereignty and capitalism, especially taking into account some of the issues brought up in chapter four
Knowing he was pre-diabetic, Smarr began to monitor his blood to check for abnormalities. He soon noticed that he had high levels of C-Reactive Protein, a protein that rises in response to inflammation and a marker that his body was constantly inflamed. Though this wasn’t the answer to Smarr’s weight loss issue, it was an indication that something outside of the expected was going on inside his body. He then began to monitor his stool for various nutrients and had his DNA analyzed to see if he was at risk for any particular diseases that may not have surfaced yet. Eventually, Smarr’s data showed that not only was he was at risk for Crohn’s disease, but that it may have already started to manifest itself even though he experienced no symptoms.²

Wanting to fix the problem before it became a serious condition, Smarr took his findings to the hospital and discussed the possibility of having Crohn’s with his doctor. Because he had no symptoms and was functioning “normally” at the time, he was told to come back when he noticed actual symptoms. Several weeks later Smarr’s symptoms began to appear and subsequent trips to a new doctor resulted in a confirmation that he did indeed have Crohn’s disease.

Smarr’s case may have ended in a successful diagnosis before the onset of symptoms, but critics warn that constant self-analysis is not necessarily always a good thing. H. Gilbert Welch, professor of medicine at the Dartmouth Institute for Health Policy and Clinical Practice has observed that with enough data, anyone can find something wrong with themselves. Welch compares Smarr’s self-tracking with a recent trend where people would order and analyze their own full-body CT scans.

of this dissertation.
Most of these individuals found something “wrong” with them that would encourage them to take action on a non-symptomatic condition. For Welch and other critics, forecasting health issues from data carries the risk of unnecessary and costly surgery and interventions, potentially damaging a patient’s health to solve an issue that might not even manifest itself. He calls for people to recognize that “abnormality is normal,” meaning that no actual example of the normate model of the human exists – every body will be a variation on it.

Though Welch remains skeptical of projects like Smarr’s, self-tracking projects and the idea that “abnormality is normal” are indications of a shift in how clinical medicine operates. Smarr was able to construct a set of data similar to the type of datasets that create an idea of a normate, healthy human. By using technologies that were, in the past, only applied to populations, he is able to create health metrics for only his body. Smarr’s body may be “abnormal” with respect to the population at large, but by collecting a large enough dataset, he can find regularities within that abnormality and create a picture of how his body operates over time. For example, at the beginning of his process, he tracked his eating habits and his movement over time to create a picture of what a typical day would look like. Movement and food intake over a single day mattered less than it did over the course of time. Additionally, creating a model of eating and movement that could be applied to anyone was not the goal, even though statistical analysis and a “norm” was Smarr’s focus.

Smarr first compared the data he collected on himself to what normate individuals can expect to lose when they eat less calories than they expend. Finding
this model of the individual inapplicable to his situation, Smarr looked to other areas that he could track to figure out what was going on. By analyzing his blood and stool, he was able to again create a picture of his bodily operations over time that served as a baseline for comparison, rather than using a more typical model established by medical studies across populations. When Smarr’s doctor failed to identify the disease, the tension between institutional practices that look at the individual patient in relation to a norm created from a population and a medicine of the patient that creates a norm from a set of data originating within the individual becomes apparent. The doctor was unable to identify the disease because the model of a Crohn’s patient could not account for someone who is about to show symptoms, whereas Smarr’s model could show how his body was beginning to deviate from its own normalized state.

Smarr may have taken his self-tracking tendencies to the extreme by measuring his activity and his nutrient and protein levels, but his experience presents an example of a growing trend where people monitor aspects of themselves to create an archive of knowledge about themselves that can be interrogated. By taking a wide approach to recording various markers such as nutrient density in stool, levels of protein in blood, caloric intake, and daily activity, Smarr constructed a set of data about himself that allowed him to identify and reconfigure not just how he used healthcare, but how he engaged in practices of self-care. Instead of going to the doctor with a symptom, he went with a set of data that gave an even more complete picture of how his body operated as an intricate system. The markers and signs that Smarr used in his diagnosis were ones that demonstrated what could be gathered through a
technological filter: how many steps he took, how much C-Reactive protein was in his blood, how many calories he was consuming. Smarr was able to observe himself through the lens of technological data-gathering as a subject that could always potentially be sick and in need of care. Moreover, Smarr’s collection of data only applied to himself. Unlike clinical medicine’s research on disease that constructed an idea of an abstract disease that could manifest itself in a particular patient, Smarr’s data could not necessarily be extrapolated to apply to anyone else. His dataset served to create a picture of himself as always unhealthy (much along the lines of Welch’s criticism), but in unique ways that would not necessarily be found in others. Such a configuration is in stark contrast to clinical medicine’s method of dealing with knowledge about patients and disease that assumed a diseased and unhealthy state could be fixed, returning a patient to a normate state of health.

Alongside Smarr, a number of similar self-tracking evangelists operating outside the boundaries of clinical medicine have emerged and gained considerable attention in the media. The rise in self-tracking has been covered by news outlets such as the New York Times, the Economist, and Vanity Fair, while also producing a TED Talk and countless blog posts. The most visible manifestation of these movements is the group Quantified Self, created by Wired editors Kevin Kelly and Gary Wolf. Quantified Self (QS) began with the emergence of smaller and cheaper self-tracking devices such as wearable Bluetooth-enabled accelerometers, wireless body fat scales, and mobile phone apps. With these new tools, it was possible to track exactly how many steps someone took in a day or to record exactly how many calories were
consumed and then look at that data over a large period of time to find trends. Wolf and Kelly began to organize meet ups where self-trackers would assemble and share stories about how their lives had changed through self tracking.

Some of these stories are as simple as tracking whether or not regular coffee consumption helps with concentration. Other stories are more epic, as in the case of Sky Christopherson, an elite cyclist who noticed that he was having increasing difficulty recovering from his training. By tracking his sleep over the course of several months, he realized that the temperature of his room was causing him to get less deep sleep, an important aspect of sleep for building muscle. He wouldn’t sleep as well in the summer as he did in the winter. Even though the fluctuation in temperature was only a few degrees and the change in total deep sleep time was gradual over the course of a few months, plotting the data on a graph provided a clear indication of the issue. After looking at this data and coming to this conclusion, Christopherson purchased a pad that could be placed on his mattress to decrease the bed temperature to 66 degrees. His sleep improved and so did his training, culminating in a world record some months later. Like Smarr, Christopherson’s results produce a unique subject that needed to “fix” a health-related problem by collecting data.

The informal slogan that Kelly and Wolf came up with to explain their movement was “self-knowledge through numbers.” Finding out more about what it means to be a “self” means sifting through measurable data and numbers that are recorded through technological apparatuses. Though QS binds itself to data and numbers in this way, calling it quantification is somewhat misleading. The movement
has “quantified” as one of the two words in the name, but quantification does not happen in QS according to the same usage in the hard sciences. Quantification here operates by collecting data and plotting it in different ways in order to observe a pattern, but the process is very loose. The data does not have to be collected according to hard science standards or even be repeatable by another experiment or another person. These are not experiments that necessarily adhere to the scientific method or produce “knowledge” that is objective, absolute, or universal.

For the QS movement, though the data is not collected according to strict standards of rational inquiry, the “self” still becomes coterminous with the data collected about that self through technology. For example, Smarr first attempted to lose weight by counting calories and macronutrients and comparing his findings to calories burned as recorded via an accelerometer. He then began to record numerical data about the levels of nutrients and the presence of various proteins that he retrieved by running his stool and blood through a series of tests that looked for certain markers. Christopherson created graphs of deep sleep versus ambient room temperature as recorded through the Zeo, a sensor attached to a headband that he wore while he slept. What started as a feeling of unhealthiness in Smarr and fatigue in Christopherson made its way into numbers before revealing an aspect of themselves (Crohn’s disease) or their environment (the temperature in Christopherson’s room) that required modification. The data is not gathered for the purpose of large, statistically significant experiments or to find a scientific insight into humanity as a
Nor is it thrown out if it doesn’t meet the standards of a “proper” scientific experiment since the accuracy of the data as an objective mirror of reality is less important than the consistency over time. The data is highly individualized to find some aspect of the individual that has yet to express itself.

Wolf describes this aspect of QS as “the macroscope applied to the individual human,” where data collected from as many facets of life as possible can be applied to a single individual without needing to be justified as being important or relevant to everyone. He points out that “within the ’n=1’ of the individual is an ’n=∞’ of times, actions, and places.” This means that a single person is statistically significant enough to be the basis of unlimited conclusions about that individual without needing to reference studies done on populations. The individual here does not become one instance of a population trend (as in traditional medicine), but the intersection of multiple different identities and traceable actions that happen over the course of time.

QS is unique because it takes scientific methods of investigation that would usually apply only to large-scale studies and tailors them to a single person, focusing on the individual’s unique, yet measurable aspects, rather than the individual’s similarity to or deviance from the statistical norm. The “human” is no longer constructed as a uniform entity that adheres to certain statistically significant and medically-legitimized characteristics, but an individual and embodied entity that can be examined from multiple viewpoints.

* Though in tools like the FitBit accelerometer and the Zeo sleep monitor, user data is collected into a larger pool that is used for research. The implications and use of this will be discussed below.
By eliminating a generic idea of the human, QS is also able to bring out a potential process for reducing normative ideas of what being human means. Smarr is, in one sense, abnormal because he cannot lose weight through decreasing calories as should be expected of a “typical” human. But at the same time, this designation does not come with the assumption that he must be somehow made “normal.” Here a “norm” becomes a starting point for an individual to assess their own situation and, potentially, come up with different conclusions that might differ from those of a medical professional. The abnormal/normal divide becomes less relevant because the goal is to find out how an “individual operates within the world” and to create a set of data that only applies to a single entity, not create universal characteristics for individuals to exemplify. The relationship between abnormal and normal is changed so that the normal does not become a teleological ideal, but a suggested entry way into exploring an individual’s subjectivity. For example, Christopherson does not have a sleeping problem that has to be medically diagnosed and treated according to what is “normal,” but reacts to environmental temperature in particular ways that can be modified according to specific goals (in this case breaking a world record). The findings of Smarr, Christopherson, and others do not become integrated into a general institutional knowledge of what it means to be human or into a large archive of knowledge about a specific disease. QS actively disrupts the tendency to institute the concept of a “healthy man” as the ideal subject that Foucault has identified in modern medicine.12
Though a large focus of QS projects seem to enact a disciplinary mode of power by increasing self-surveillance and internalizing certain practices of self-care, it would be more accurate to say that these projects are an instance of biopower applied on the individual level rather than the population level. Foucault initially discussed biopower in volume 1 of *The History of Sexuality*, claiming that it arose in the late seventeenth and eighteenth century as a procedure of power that focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary.

Rather than necessarily being a negative aspect of power, biopower’s purpose was “to invest life through and through”. QS fits well within these parameters as the main directive is to quantify the different operations of the body. Like Foucault’s notion of biopower, QS looks at the mechanics of life behind a body, seeking to form numerical, quantifiable datasets about the level of particular aspects on one’s health and the surrounding conditions that cause those health conditions. Many QS projects are concerned with helping the individual to live healthily and to promote life within the individual, just as biopower’s aim is to “foster life.”

Within QS, however, the scope of the data collected is limited to the individual body by compressing technology and data processing techniques that are typically applied to larger populations with the goal of finding universal characteristics about that population’s health.

For Foucault, biopower created a new dynamic between the individual and governing institutions called biopolitics, whereby biopower became integrated into the operations of administrative institutions. The sociologist Nicholas Rose and
anthropologist Paul Rabinow are two of the major scholars that have worked on developing the concept of biopower. Rose’s work revolves around the intersection of science, governance, and human identity, of which biopower plays a significant role. Rabinow’s work focuses on knowledge production, ethics, and reinventing anthropology. He has become one of the preeminent commentators on Foucault, especially in the area of ethics. Though they each have written independent works, their collaborative work on biopower has taken the sketch provided by Foucault and expanded it into a much more developed concept that applies to contemporary workings of power, especially in the ways that medicine and governance overlap.

Rose and Rabinow explain the shift toward biopower by claiming that “every citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being” while at the same time these “health-related aspirations and conduct of individuals” is governed at a distance by institutions. These governing bodies include governmental, social, medical, and other administrative institutions that have the capability of directing the life of individuals.

For QS, this process is not completely ejected, but it is significantly changed. By looking at case studies of Quantified Self projects, it is possible to demonstrate how people within Quantified Self exemplify the type of biopower that Rose and Rabinow develop, while also reducing biopower’s scope to the individual level rather than reproduce biopower at the population level. As shown with Smarr, Christopherson, and with QS projects discussed shortly, there exists a strong push for
an individual to take on more responsibility for their own health. Smarr collected his own data and made an early diagnosis just as Christopherson combed through his sleep records to find potential issues with his sleep quality. However, the element that changes with QS projects is the ability of the individual to create datasets and produce conclusions that apply only to the individual; and this in turn calls into question the absolute authority of governing institutions to direct care and the mechanics of life, as those institutions do not have direct control over how life is administered. If the medico-administrative institutions no longer have the final say in the model of a normal patient that serves as a reference point for the patient’s own health, the function of those institutions changes drastically. As the QS projects discussed below demonstrate, the medico-administrative institutions may lose some of their ability to direct self-care, but they do not disappear entirely. Rather, they continue to work with individuals, becoming more flexible to take into account the possibility of \( n=1 \), an individual patient that has its own markers of health and may digress from the “normal” member of a population.

Rose and Rabinow further clarify the workings of biopower by outlining three major characteristics: it creates truth discourses about the vital character of living human beings; it contains strategies for intervention upon collective existence in the name of life and health; and individuals engage in subjectification processes where they work on practices of the self in relation to certain authoritative truth discourses in the name of life, health, and/or the health of the population. In the first characteristic, where biopower is said to work through truth discourses about the “‘vital’ character of
living human beings,” these discourses are propagated through authorities believed to be experts on a particular subject.\textsuperscript{15} QS works in this same manner, but within a much different scope. Much of the discourse surrounding the techniques employed by Quantified Self occurs through presentations given by self-experimenters. QS conferences and meetings generally have a show and tell format where presenters are encouraged to answer three questions: “What did you do?” “How did you do it?” “What did you learn?”\textsuperscript{16} Through these questions, the presenter appears as an expert on a particular revelation about their own body. The findings typically revolve around health-related discoveries that include everything from observing heart health following heart attacks\textsuperscript{17} to creating digital representations of health metrics\textsuperscript{18} to improving sleep.\textsuperscript{19} Likewise, the content on the official Quantified Self website generally takes the form of videos by Quantified Selfers explaining their projects and their findings along with a call to be flexible and collaborative in the process of experimentation.\textsuperscript{20} Here, as in Rose and Rabinow’s formulation of biopower, QS has experts dealing with the vital character of living humans, but in a way that also makes that authority accessible to any individual that wants to go through the process of experimentation. This also limits that authority, however, and makes the revelations about vital human characteristics applicable \textit{only} to the individual giving the presentation. The truth discourses of QS are ones that are understood as true as they relate to the particular individual who found them although they are also presented as \textit{possibly} true for anyone else. The role of authority here is not to dictate a truth to be
followed, but to present a way of experimentation and working on the self that can be tried by others and may or may not prove applicable.

By way of example, consider the case of Ben Finn: presenting at a London Quantified Self Meetup Group, Finn described the process behind his attempt to become an expert on his sleeping habits. For most of his life, he had trouble getting to sleep, would constantly wake up at night, got up late, and was constantly tired during the day. To fix these problems, Finn decided he would research potential solutions through various medical websites and Google Scholar and then experiment on himself. His goal here, as in all QS projects, is not to definitively figure out whether or not certain sleep aides work for everyone or to find a normalized way of helping sleep that works universally. Finn’s aim, instead, is to identify a personalized regime of care that can help his sleeping habits. The audience members listening to the talk take these conclusions as unique traits of Finn and a possible method of increasing sleep quality that could be applied and tested on themselves.

His primary method of tracking was a phone app called SleepCycle paired with paper and pen by his bed and an Excel spreadsheet. The app was installed on his phone, which was then placed in his bed while he slept. By using the built-in accelerometer, the phone was able to record how much Finn moved around in his sleep and guess how much time he spent in different sleep cycles and create a sleep quality number. Finn recorded this number, raw data from the app, and notes he took when he would wake up in the middle of the night into an Excel document to see how well he was sleeping.
From his Internet research, Finn identified 21 different factors that he could test. These included when he ate dinner; whether he consumed alcohol, caffeine, hot milk, a banana, or the chemical 5-HTP before going to sleep; whether he exposed himself to orange or blue light; whether he had any distractions such as dawn light, noise, a hot room, an unfamiliar room, stress, or illness; and whether he exercised, meditated, or performed relaxation exercises before bed. All of these factors were linked either by reputable medical studies or widely accepted belief to affect sleep quality in normal individuals. However, these factors were identified through experiments on large populations and affected a statistically significant portion of individuals. For Finn, this did not mean that they would automatically affect his sleep, but only that they were starting points. Expertise on Finn’s vital character of sleep could not originate in large-scale studies, but had to be affirmed through self-experimentation.

This re-orientation of who is able to acquire expertise on the individual body is a drastic change in the way that biopower works. QS projects do begin with the admission that medical knowledge has validity and truth to it. Population-based studies and experiments are seen as useful information about bodies and medical researchers are still labeled experts on vital character of the body. But, this vital character is limited to a population that does not materialize within everyday life. The body for QS projects exists as a part of a single individual that may or may not reflect conclusions from studies on the normal population. The limits of institutional biopower as something that only applies to non-lived, abstract populations begin form
as QS projects see medical studies as truths, but truths that do not necessarily apply to the lived, everyday body.

In order to create knowledge and truth about the individual body, QS projects adopt biopower-based experimentation methods but apply them to single bodies, not larger populations. For Finn, this means modifying the different factors he identified over the period of 113 days and creating graphs of the data in relation to the resulting sleep quality score. Consider two examples of these graphs:

![Figure 3: Finn’s visualization of sleep quality](http://londonqs.github.io/qs/meetup-content/2014-10/qs-sleep.pptx)
Figure 4: Finn’s visualization of sleep quality

The first graph shows the effect of different bedtimes on Finn’s sleep quality score. There is no medically sanctioned optimal bedtime for a normal body and the sleep score is a somewhat arbitrary number made up by SleepCycle, so Finn’s experimentation here was not a comparison with pre-existing medical knowledge, but used the metrics of sleep health in the creation of new knowledge loosely connected to the medical field. He points out in his talk that he hoped to find a large spike that would indicate a very obvious optimal time to go to sleep. However, the variation between sleep times was minimal, effecting the sleep quality score by only about one or two points in either direction. He observed that even so, the data more or less just
said that going to sleep slightly earlier was typically better, backing up what he calls a more or less common sense conclusion.

The second graph is much more interesting. As with the first graph, it does not show a large spike one way or the other in terms of a single factor that could help or improve sleep. Nor does it show one factor that has an opposite of the intended effect. Noise, stress, and unfamiliar sleeping situations all had negative effects, just as medication had a slightly positive effect. What was significant about these results, however, is that Finn’s sleep could only really be disrupted, not helped. A large number of factors all would decrease his sleep quality while none presented a drastic increase in quality. For Finn, this provided the knowledge that his sleep quality was mostly improved by the subtractive process of minimizing distractions rather than the additive process of incorporating new actions into his routine or aides like medicine. Here, Finn came to a conclusion that does not necessarily go against medical knowledge, as many of the negative influences of his sleep quality score are backed up by scientific research and common sense, but manifests itself in a very particular way by showing that some medically proven sleep aides do not work. As with traditional biopower, it is possible to see a type of expertise on the body arise in Finn’s study, but in a way whereby the expert has knowledge limited to a single body even as the technologies used to create that knowledge remain very similar to those used in large-scale biopower operations.

To continue his investigation into the vital character of his body through sleep analysis, Finn also utilized a program called sleep.io to go through his sleep data and
recommend a change in sleep schedule to optimize his sleep. Initially, a graph of Finn’s typical night of sleep looked like:

![Graph of Finn’s typical night of sleep](http://londonqs.github.io/qs/meetup-content/2014-10/qs-sleep.pptx)

**Figure 5**: Finn’s visualization of his sleep stages

In this graph, Finn’s time in a particular sleeps stage is represented by the blue bars, with deeper sleep being a longer bar. He realized that he may have been sleeping for a long time, but his sleep was fairly light. Sleep.io allowed him to recognize this pattern and change his sleep schedule in order to condense it into less time, but deeper sleep. After allowing for progressively less time to sleep, he trained his body to sleep in a way that would create the following graph:

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* Note that this graph is a mock up from Finn’s presentation and not an actual graph. This explains the odd time designations at the bottom. A true graph would most likely run from zero to eight at the bottom.
Here, the total amount of time is decreased and the time in deep sleep is kept constant or increased slightly. Finn was essentially able to remove the periods of restlessness from the middle of his sleep cycle by allowing seven hours for sleep instead of the typical eight. By sleeping less he was actually able to sleep better.

Though Finn does create his own conclusions and find ways that the vital character of his body operates in ways different from what would be expected, he does not stray too far from the technologies that produce relations of biopower. He examines his body as a set of data that can be construed statistically, though these statistics are for a single body over time rather than multiple bodies. Additionally,
many of the metrics that he uses go very much in line with traditional medical knowledge. The importance of deep sleep, for example, comes from medical knowledge and is not questioned by Finn. However, dismantling medical knowledge as a whole is not the goal of Finn’s project or other QS projects. Rather, it is to apply the technologies of biopower and the ways of creating knowledges about populations in order to make them line up with everyday experience, which in this case is a single body caught at the intersection of a variety of factors affecting sleep.

The second of the three aspects of Rose and Rabinow’s version of biopower is that it must contain “strategies for intervention upon collective existence in the name of life and health.” This underscores Foucault’s assertion that biopower works on populations alongside disciplinary power. Disciplinary power served to work on the individual body whereby institutions worked through interventions and regulatory controls to enact “a biopolitics of the population.” By looking at large-scale studies of a population’s health, biopower was able to create the idea of a “norm” that could be enforced politically and socially to determine who could receive biopower’s ability to foster life. These strategies were addressed toward different populations and involve ways of defining forms of genetic or biological citizenship. Particularly dangerous, these strategies often bring up categories of race, ethnicity, gender, religion, etc. in order to enhance the condition of life of one group while dismissing others.

For QS, this part of biopower slightly modifies Rose and Rabinow’s claim. Many QS projects do focus on intervention in the name of life and health, but they do not focus on collective existence in the same manner that traditional biopower does.
For example, Smarr’s project originated as a plan to lose weight and Finn’s project was an attempt to live a healthier life through improved sleep. The bulk of the apps and devices used by Quantified Selfers target health-base metrics that include: number of steps in day (accelerometers like the FitBit, Basis, Mio, and others); sleep quality (e.g. the now defunct Zeo, Sleep Cycle, and countless other iPhone apps); and calorie consumption (e.g. MyFitnessPal or a simple spreadsheet). The one app created by Quantified Self is a tool to export data from Apple’s HealthKit health data aggregator into a “a simply-formatted table so that you can make health, fitness, and other discoveries by exploring your own data.” The data that this app exports is exclusively health-related: daily/hourly reports on active calories; blood alcohol content; blood glucose levels; diastolic and systolic blood pressure; body fat percentage; body mass index; body temperature; caffeine consumption; cholesterol; cycling distance; electrodermal activity; flights of stairs climbed; heart rate; inhaler usage; lean body mass; number of times fallen; oxygen saturation; respiratory rate; weight; and consumption of a number of vitamins, minerals, and macronutrients. Also along the lines of Rose and Rabinow’s formulation of biopower, the QS app makes the data available to users so that they can tinker with the data and create “discoveries” about their health data which can then be used as the basis of a plan for changing or modifying aspects of life and health for the individual. Looking at QS in terms of biopower allows us to see these moves as techniques of governmentality and population control that are being re-appropriated by individuals and used to create
subjects that are unique iterations of the “normal” subject produced by institutional medicine.

Even as the sentiment behind QS is to do work on the life and health of a body, as in biopower, it strays from the traditional formulation of biopower because it does not act on populations at large, but on a single body. The n=1 slogan of QS proves to be extremely significant in this regard: it demonstrates the QS idea that the individual can be converted to a dataset, but significant in its own right and not necessarily as a single part of a population. In Smarr’s case, for example, he did not compare his food intake and movement to what should be healthy for the general population. Instead, he took his overall food intake and movement as its own dataset with its own ideal “healthy” range. Likewise, Finn examined his own sleep patterns as a function of a single body over time, not in relation to a larger population. In the n=1 mentality of QS, biopower’s effect on “collective existence” means not the collection of multiple bodies spread out over space and time, but tracking a single body as it moves through time to understand aspects of life and health.

Katie McCurdy is an example of how tracking information about a single body can be used for health-related interventions. She makes the claim that even though some people may self-track from a sense of narcissism or vanity, one of the major reasons for self-tracking is “medical necessity.” By this, she means the need to maintain oversight on chronic conditions so that medically-sanctioned changes can be introduced into a person’s lifestyle to allow them to continue to live healthily. Such a process is very similar to Rose and Rabinow’s claim that biopower works through
creating strategies for intervention on collective health and life. But, again, in the case of McCurdy and other QSers, these strategies operate on the individual level and not the level of the general population.

McCurdy has an autoimmune condition called Myasthenia Gravis, which causes weakness in voluntary muscles. In order to better communicate with her health care providers, she created a data visualization that included developments in her autoimmune disease, gastrointestinal issues, when she started or stopped certain medications or made any dietary changes. A selection of this data visualization looks like this:

![Figure 7: McCurdy’s visualization of Myasthenia Gravis flare ups](http://quantifiedself.com/wp-content/uploads/2012/03/KM_med-timeline.png)

The aim of these visualizations was twofold. McCurdy wanted to create an overall picture that could tell a story about her past health to her doctors and was more accurate than the “blurry picture” typically provided through forms and quick interviews with patients. She also wanted to demonstrate to her doctor a connection between gastrointestinal issues and Myasthenia Gravis flare-ups that couldn’t be explained by existing medical models but had occurred for McCurdy since she was 13.
What is interesting about McCurdy’s process is that medical knowledge retains a privileged place as the source of what the interventions on health should be while the data that gives rise to the assessment comes from the actions of the patient. In her words: “The patient is providing contextual information about his or her OWN situation that compliments the doctor’s past experience, expertise, and test results,” a move that gives precedence to medical knowledge as a way of providing guidance for self-care while making the individual the basis for judgments about that guidance. The technologies of biopower – expert medical knowledge and a focus on ordering the life of the patient – do not disappear and the power dynamic is not simply reversed by the patient directing their own care. McCurdy’s case acknowledges medical knowledge as legitimate and necessary for “healthy” life, but also assesses that knowledge according to an individual case. The goal of medicine’s intervention into McCurdy’s practices of self-care is not to bring her in line with what a “normal” human would be, but to anticipate and deal with issues that arise as she lives with her disease. Much as with Finn’s case, the “normal” human that McCurdy uses as a basis for comparison of her own state is the image of herself created over time. Through visualizations and graphs, she is able to understand how she reacts to certain drugs and how her symptoms are interrelated, providing a basis for a plan to intervene on various aspects of her health.

For Rose and Rabinow, biopower’s operations on the life and health of populations expands to create “biosocial collectivities” such as “race, ethnicity, gender or religion, as in the emerging forms of genetic or biological citizenship.”³² By this, Rose and Rabinow mean that the techniques of biopower attempt to modify the life
and health of populations in such a way that certain individuals both identify and are identified with a particular community or nation while others are excluded. The principles of exclusion here are based on how well an individual lines up to a pre-determined concept of what is “healthy”; those that are deemed “unhealthy” are either excluded from the community or forced to re-configure themselves to fit that idea. In cases like McCurdy’s, these principles of exclusion are not put into play exactly as Rose and Rabinow conceive it. On the one hand, medical knowledge is the originator of many concepts of what processes of self care are healthy or sufficient to support life. McCurdy still brings her data to a doctor, who then interprets it and prescribes different treatments. Through these treatments, she is able to decrease the expression of her symptoms and fall more in line with a typical level of health for an individual in her larger social and national context.

This would seem to place responsibility back on the individual to adhere toward larger notions of health by self-tracking. Yet, McCurdy does not take over all of the tasks usually attributed to the medical institutions. She collects a large amount of data, organizes it, and makes assessments, but still relies on conversations with a doctor to make final judgments. By creating an archive of individual data and an initial interpretation, she performs an important task that changes the scale at which biopower operates. By tying any medical analysis to a set of data from a single individual, McCurdy does not allow the resulting conclusions to become an accurate baseline for the “normal” healthy state of any individual. Any assumptions about her health conditions or how to treat them are limited solely to her individual instance. In
this way, biopower inserts itself into the life of McCurdy, but does not expand to create a biosocial collectivity determined by institutional medical knowledge.

The third characterization of biopower brought up by Rose and Rabinow foregrounds the ways in which individuals engage in “modes of subjectification” or “work on themselves, under certain forms of authority, in relation to truth discourses, by means of practices of the self, in the name of their own life or health, that of their family or some other collectivity, or indeed in the name of the life or health of the population as a whole.”33 Just as Rose and Rabinow’s second point spoke to the way that large-scale institutions intervened into the lives of individuals and created collectives based on a certain expression of health and life, their third observation about how biopower works speaks to the ways that individuals internalize certain discourses to intentionally line up with certain institutional expectations of how they should order their lives.

The examples of Smarr, Finn, McCurdy, and other QSers seem to fall in line with this aspect of biopower. Each of these individuals took it upon themselves to create a regime of self-care to change certain aspects of their life in order to be healthier. Smarr tried to lose weight and also to pre-empt the onset of his Crohn’s disease. Finn found a list of actions to avoid in order to sleep better and trained his body to sleep more efficiently in less time. McCurdy used her data to organize her life in a way that lessened her Myasthenia Gravis symptoms in ways sanctioned by a medical professional. In each case, the QSer works on themselves in the name of health according to a form of authority or in relation to a truth discourse. Significantly,
however, these authorities and truth discourses do not arise from institutions, as in the traditional formulation of biopower. They first originate in the individual and are then filtered through medical knowledge. Applications of biopower are always a navigation between individuals and institutions, but in the case of QS projects, the individual becomes the arbiter of what type of knowledge justifies a certain type of intervention.

As QS projects allow self-care procedures to be assembled by the individual instead of the medical institution, the justification also becomes slippery. Medical knowledges, as shown in the previous chapter, seek to work on the abstract level, creating a generalizable body of knowledge about a disease that de-individuates circumstances. As the analysis of biopower shows, this body of knowledge then becomes the basis for a justification for administering life through regimes of self-care. But in QS projects, this justification does not become fixed; it constantly changes through time, depending on the individual’s unique circumstances. As a result, the focus is not on building a large archive of knowledge about medical conditions that can then be utilized in processes of marking entities as normal or abnormal, but on the process of self-care itself.

Nancy Daugherty’s QS project demonstrates this tendency. Daugherty initially began to use devices such as the FitBit and Aria solely to record her movements and weight in order to learn from them, much like Smarr. She did want to lose weight through the technology, but her primary goal was to track herself just for the sake of tracking. She initially expected the technology to present data to her that would tell her what needed to be changed, as traditional medical knowledge would diagnose a
disease and recommend a treatment. However, this turned out to be, as she states, a “miserable failure” because she would be very dedicated to tracking a particular aspect of her life for a few weeks and then would become bound up in a stressful situation and forget to continue recording what she set out to track. She was left with a “wasteland of empty biometric profiles,” aside from a year’s worth of data about her weight. Her data was incomplete by any sort of rigorous scientific standards and would not be able to give her any sort of definitive answer on how to reach her goal, like the QSers mentioned above. By looking at a graph of what weight data she did have, however, she found that it correlated directly with her emotions. Stress at work or in her personal life made her weight go up while her tracking went down, and less stressful periods or instances when she had more time to exercise caused her weight to go down at the same time her tracking increased. Oddly enough, even with Daugherty’s inability to fully integrate the technology into her body or life, the gaps in tracking provided by the technology still created a compelling and instructive picture of her self. This was not an incomplete or partial set of data after all, but a set of data that showed a different picture than she expected to find.

After identifying the connection between weight and tracking, Dougherty then began to track her emotions in an organized manner along with the biometric data that accompanied them. She would find when she had the most energy during the day, when she felt happy or sad, and biometric data like movement, sleep, and heart rate. The most significant thing that Dougherty found did not come from the data itself, but from her reaction to the actual process of tracking. She points out that the more she
tracked, the less the data meant to her because “just by tracking [her] emotions, [she] was completely changing them.” By paying more attention to what her emotions were at any given moment, Dougherty found that she could manage them better, creating more positive ones and avoiding or countering negative ones. To help her pay more attention to her emotions at any given moment, Dougherty created a string of LED lights connected to a sensor that could tell when she was smiling. Her device would record when she smiled and it would give her immediate feedback through the blinking lights so that she could then bring her attention to how she was feeling. The sensor would also give feedback to tell her when she had not smiled in a while, blinking to encourage her to engage in a positive emotion. For Daugherty, “self knowledge through numbers” did not just mean knowledge emerging through static numeric data sets, but knowledge emerging from the creation of those numbers.

For Daugherty, the data and the self she formed through that data was less important than the introspection provided by the process of self-monitoring. Picking up a term used by other QSers and Buddhist tradition, Dougherty calls this “mindfulness,” a process she describes as “observing inward” and “the act of observing ourselves with openness, curiosity, and acceptance.” Mindfulness is, in QS, “regulating your attention to the moment, observing without judgment.”* In her

* Ramirez, Ernesto. *QS and Mindfulness Quantified Self*. quantifiedself.com. Web. 28 Feb. 2013. <http://quantifiedself.com/2013/02/qs-and-mindfulness/>. There is an interesting connection here with Husserl’s concept of the phenomenological reduction, which is a way of looking at the world without preconceived or socially-constructed judgements. In both cases, the subject enters into a certain frame of mind that does not take anything for granted and attempts to bring out how we interact with the world in ways that we may not otherwise be aware of. In this sense, the QS process is much like phenomenology put into everyday practice. For more on the phenomenological reduction see Husserl’s *Ideas II*. 
project, her main goal ended up being an attempt to better herself through controlling her emotions, but in order to do that she had to make herself aware of an aspect of herself, namely how she interacted emotionally with environments and individuals. It was not the technology itself that performed this task through raw data, but rather facilitated Dougherty’s introspection and attention to her emotions by allowing her to look at her self in a particular way. As she notes, this introspection actually became a habit through her use of technology to the point where the data just provided verification of what she was doing rather than a basis for action in and of itself.

Dougherty’s project falls very much in line with Rose and Rabinow’s third observation about biopower. The actual act of tracking and the introspection that results is largely the point of her project, creating a practice of the self where she attempts to make changes in her habits and way of life in the name of health. This case is unique in relation to biopower because it still acts under certain forms of authority and truth discourses, but they do not stem solely from the medico-administrative complex as in the more traditional model of biopower. By collecting her own, somewhat incomplete data, Dougherty is able to become an authority on herself and the workings of her body. The conclusions that she draws – namely that paying attention to her emotional state positively effects her mental health and weight – are ones that do not necessarily go against medical knowledge but do not derive from sanctioned medical studies. Like McCurdy and Finn, Dougherty’s project utilizes the technologies of biopower but forms knowledge outside of the medico-administrative institution.
For Rose, the application of biopower becomes a political discourse of risk avoidance, where the state and medical institutions argue that we should minimize harm to our bodies in order to avoid economic effects on the economy, such as days of work lost to sickness or increased insurance costs for everyone.\textsuperscript{36} To an extent, QS fits into this model as projects are largely focused on boosting physical and mental health. However, the discourse around many of these projects center around increasing personal health for its own sake or for the benefit of the individual themself. Smarr, Finn, and McCurdy all used QS principles and biopower technologies to become healthier individuals, but their primary motivation was not to live up to society’s expectations of them or become more efficient solely to produce more capital. Smarr and McCurdy were attempting to get a medical condition under control so they could live comfortable lives and Finn was trying to minimize sleep issues that were affecting his own well-being. In each of these presentations, work was not a primary concern for the QSers.\textsuperscript{*}

By removing work as a motivator, the discourse surrounding QS projects becomes one of introspection and self-knowledge. Daugherty, for example, began her project trying to lose weight but then ended up creating a process whereby she attracted attention to her own emotional state through her process of “mindfulness.” The end goal of her project is greater knowledge of her self and how she works within certain social contexts so that she can be “happier.” While the individuals who engaged in these projects thus far all had a distinct goal in mind when they began their

\textsuperscript{*} See chapter four and the conclusion for a more detailed examination into how health tracking
tracking, many QS projects track for its own sake. As Daugherty pointed out in her presentation, the act of tracking has the ability to focus attention on the processes of self-care and aspects of the individual that would otherwise be hidden. Unlike traditional biopower, the biopower found in QS projects has personal exploration as its primary goal.

If the projects thus far considered all highlight the importance of personal health and development however defined, Stephen Wolfram’s project is one of the best examples of tracking and self-monitoring for its own sake. Though he is not explicitly aligned with QS, Wolfram calls his tracking “personal analytics” and utilizes many of the techniques that QS projects use and could be said to be a precursor to the movement. As a pioneer in computer use, programming, and technology, Wolfram began tracking various aspects of his life from early on. Starting around 1989, he tracked his email usage and then began to also record keystrokes, phone calls, steps, and calendar events. For years, he did very little with this data, aside from having an automated program email him reminders about what happened the previous day. In 2012 he finally began to sift through the data and see what sort of information about himself he could garner from it. That means that for about 23 years, Wolfram collected data about his work habits and his productivity but did not use it for any specific purpose.

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*technologies figure into labor and risk.*
Wolfram began by running the data through an analysis on Wolfram|Alpha Pro. This program sorted through all of the different variables and allowed Wolfram to output a number of different types of graphs. Some of these graphs plotted the number of emails alongside the time of day they were sent:

![Figure 8: Wolfram’s visualization of email volume](http://blog.stephenwolfram.com/2012/03/the-personal-analytics-of-my-life)

Others plotted the daily volume of emails:

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And still others showed the number of different recipients:

**Figure 10:** Wolfram’s visualization of email volume
http://blog.stephenwolfram.com/2012/03/the-personal-analytics-of-my-life

Unlike typical science experiments, Wolfram had no hypothesis when he was collecting this data, nor did he come up with one as he was creating the graphs. These graphs were all generated in order to see if there was anything interesting or significant in the aspects of his life that he could track. Wolfram used this data as a way to create a vision of himself that had been filtered through a software program and could be held up and interrogated. The email tracking programs had their own particular intentionalities that allowed Wolfram to look at himself in terms of time and email – something that would not be possible for him without the software designed to
reveal it. This is not meant to be a complete picture of who Wolfram is or what he does, but it allows for a particular aspect of himself to emerge that comes from the data and from the intentionalities of the technology used to gather it.

The data in the above graphs draw a picture of Wolfram as a very constant individual with an increasing need to use email, but it also serves as a record of important life events. The first graph shows a gap in email usage between 6am and 12pm from 1990 to 2002. In 2002, there is a dramatic change where Wolfram tends to no longer send emails from 3am to 9am. In the 1990’s, Wolfram was working on a book and restricted his work to the nighttime to minimize distractions. Here the data does not necessarily contradict or open up any new insights into Wolfram as a person, but reinforces knowledge of habits that he already had. The data and the graphs do, however, present a portrait of Wolfram through the lens of email-tracking technology.

Wolfram’s calendar data shows a similar story. He plotted the number of events based on time of day over the course of years:

Figure 11: Wolfram’s visualization of events
http://blog.stephenwolfram.com/2012/03/the-personal-analytics-of-my-life

As would be expected, when he was working nocturnally on his book Wolfram had few events. After 2003, Wolfram’s reintroduction into the daytime world and
increasing sociality becomes evident in the graph. He becomes busier, but still is remarkably consistent in having few events in the morning and nighttime as well as having an event-free family dinner time slot around 6-8pm. Like the email data, this graph does not show any revelations about Wolfram or his working habits, but serves as a record of a particular aspect of himself that he can divorce himself from and examine.

After creating dozens of graphs and looking at alternative ways of sorting through the data, Wolfram compiled a comparison graph of all of his information:

![Figure 12: Wolfram’s visualization of email data alongside events](http://blog.stephenwolfram.com/2012/03/the-personal-analytics-of-my-life)
His analysis of the data, again, does not relay any surprise, but is still reassuring:

The overall pattern is fairly clear. It’s meetings and collaborative work during the day, a dinner-time break, more meetings and collaborative work, and then in the later evening more work on my own. I have to say that looking at all this data I am struck by how shockingly regular many aspects of it are. But in general I am happy to see it. For my consistent experience has been that the more routine I can make the basic practical aspects of my life, the more I am able to be energetic—and spontaneous—about intellectual and other things.38

Wolfram’s personal analytics project becomes not a way of making a distinct change, but reflects a part of the QS process whereby the data becomes the basis upon which questions are generated. Wolfram’s project involved collecting data for its own sake, rather than in the service of a particular project. Moreover, the act of tracking allowed him to visualize routine and habits that he was already engaging in. This is significant because Wolfram did not use the tracking software to help integrate specific habits or behaviors into his own life in the way that biopower seeks to organize daily life by providing standards and guidelines for healthy living. Instead, Wolfram was able to create a concept of what his life looked like from the data, which could then be extrapolated into what a “healthy” or “unhealthy” life might look like. In this case, Wolfram showed graphically how he spent his time when he finished his book, providing an example of successful project management that could be used in his own future projects or as a blueprint for other people to follow. Or, for example, if Wolfram became sick or depressed, he could attempt to map it onto a graph of how his working hours had changed at the beginning of the sickness, exploring one possibility for the origin of the sickness.
On the one hand, QS projects could be seen as a way to identify and remove the hidden operations of institutional biopower. By collecting large data and showing emerging patterns (as Wolfram does, for example), it could be possible to find ways that individuals have unintentionally ordered their lives according to perceived healthy or unhealthy habits. Many QSers seem to do this. Smarr, Finn and Daugherty all used self-tracking to see how their lives were being adversely affected by certain habits that they could see the effects of, even though they could not identify the case. Smarr and Daugherty each attempted to find what poor habits were causing them to gain weight. Finn tried to identify factors that were causing him to lose sleep. In each of these cases, identifying the offending causes of health issues also draws a line around the limits of biopower. The QSers are able to find out what authoritative health-related suggestions they are implementing in their daily life and how successful each of these are. Potentially, this would allow for individuals to create a body of knowledge that undercuts the authority of medico-administrative knowledge by allowing for health-related knowledge that applies only on the individual level and sometimes explicitly goes against proven medical guidelines. Finn would be a prime example of this, as he found that many of the typical suggestions for fixing sleep issues didn’t work for him.

However, this conclusion would fail to acknowledge that Quantified Self projects themselves represent an expansion of biopower and still often work in tandem with population-based health studies. As demonstrated above, many QS projects follow Rose and Rabinow’s formulation of biopower, encouraging individuals to work on themselves in the name of health and perpetuating the role of the “expert,” even as
its influence is diminished. Moreover, the heavy emphasis on presenting projects to others as possible solutions for their own problems, opening up data sets for others to experiment on, and Big Data-style data logging all retain the necessity of an institutional component. Quantified Self then appears to be more of a reconfiguration of institutional biopower rather than a complete removal.

Even though it does work around and with medico-administrative institutions, QS still reconfigures biopower in important ways. QSers use technologies that allow tracking to be significantly compressed. Because the technologies are smaller, more affordable, and able to track passively, individuals are able to collect types of data previously only available in large-scale population based studies. The n=1 basis for QS projects allows the data of a single individual to serve as the basis for any conclusions about health or normative ways of organizing life. A normate subject still exists, but it is a single individual throughout time that interacts with a particular environment, not an abstract concept of the normate human created from the average of large populations to be applied to single individuals. Being "human" in a Quantified Self sense means adjusting self-care techniques according to a data-driven picture of oneself throughout time, rather than comparing oneself to an ideal, abstract human in general. Instances such as when Smarr or Ming brought their doctors large amounts of data bring out the changing biopower landscape that QS is a part of. These three individuals all had data that would allow them to be considered experts and successfully identified the manifestation of certain diseases, but the medical industry

* See previous chapter for Ming’s story.
was not set up to incorporate this type of expertise into treatment. Doctors were unable to understand the data and had difficulty understanding it for the purposes of treatment and diagnosis. This resulted in Smarr’s condition only being officially recognized after it had manifested itself and begun to exhibit typical symptoms and Ming going outside of the medical recommendations to create her own insulin administration plan for her child.

McCurdy represents a move toward a new treatment protocol that is more indicative of the changes that QS can potentially implement within the current structure of biopower. She is able to work with her doctor for more targeted treatments, but provides much of the data herself and plays a large part in what factors are examined. Here, she still engages within a system of biopower, but the institution changes its assessment of McCurdy’s situation largely based on data she collects. The top-down model of biopower whereby an institution forms knowledge, makes recommendations based on a norm, and coerces individuals to conform to those norms with threats of exclusion do not make a strong appearance here. Instead, knowledge and recommendations form from analysis of the individual and are then integrated into institutional recommendations for self-care.

Instances such as Daugherty’s project of working on her mood through mindfulness and attention to smiling demonstrate how this aspect of QS projects can move beyond the actual site of the clinic to everyday life while still engaging with the individual. Daugherty collects her own data and directs her experiment, but with the institutionally-sanctioned idea that being happier more often is beneficial for health.
However, unlike McCurdy and others, she does not visit a clinic but rather comes to this conclusion through a common-sense approach that is influenced by medical knowledge. Her project represents the potential of QS projects to work within medico-administrative knowledge, yet outside the physical space of the clinic in a way that privileges individual data over population-based data.

These projects all represent how biopower can become reconfigured on the individual level. They also illustrate the changing relationship between patient, data, and medico-administrative knowledge. But they only take us so far in understanding how the structure of the institution and the policies that they follow are changed with the rise in self-tracking and self-care through individual datasets. As the next chapter will demonstrate, equating the individual with a dataset has larger implications when medical and governmental institutions also begin to see the individual in this manner. By quantifying parts of the individual and attempting to improve certain aspects according to metrics of health closely resembles what Wendy Brown has identified as a sort of neoliberal logic at work. This logic attempts to integrate market principles into everyday life and governance techniques. The next chapter will examine what happens to the relationship between individual and institution when the individual becomes capital in the form of data.
HealthKit works by consolidating data from a number of different apps and the hardware of the iPhone itself. However, this data is generally locked into HealthKit and the uses are limited. The QS app exports this data for people to use. Much like Finn’s project above, the creation of a tool to export this health data serves to make the individual the expert in their own data.


McCurdy

Rose and Rabinow 197


Ramirez QS and Mindfulness

Rose, “The Politics of Life Itself” 5

Stephen Wolfram Blog

Stephen Wolfram Blog
CHAPTER 4
Genetic Capital

Quantified Self practices demonstrate how techniques of biopower normally applied to populations can be utilized on an individual level to produce knowledge and, in turn, unique subjects. However, these subjects do not entirely escape involvement with larger institutional structures such as medicine and the government. As demonstrated in chapters two and three, subjects engaged with the changing practices of self care still rely on medical knowledge to understand their health and how their bodies operate with social and environmental contexts over time, even if they adapt that medical knowledge to their own purposes. In response to the demand for individual access to medical data, companies like 23andme have emerged to provide data previously guarded by the medical community. 23andme is the most popular DNA analysis service, giving users access to a range of variations among their genes that indicate ancestry and mark certain physical and health-related traits. On the very basic level, users take the results from a 23andme test and learn about their susceptibility to a host of diseases and conditions, including gout, alcoholism, and breast cancer. On a more complex level, users upload their data to services like OpenSNP where the data becomes publicly available for experiments and testing.1

While 23andme is pitched as a product for individuals to use and learn more about their genetic makeup, the actual business plan involves more than just selling kits and providing information to consumers. The results of those tests become an important revenue stream for 23andme as the company sells access to its large
database of genetic information. 23andme not only sells access to the database to outside institutions, it uses the database for their own research studies and, recently, began laying the groundwork for developing pharmaceutical drugs.  

As 23andme develops the uncharted territory of personal genome testing, it also has come under fire by the FDA for providing potentially dangerous information. If a person has access to their predisposition to certain diseases or conditions, there is the assumption that they will take action to prevent unhealthy conditions from manifesting themselves, even if the person does not know the medically appropriate actions to take. This concern about taking uninformed action led the FDA to send a warning letter to 23andme in November of 2013, requiring them to cease operations until proper oversight could be established.

The tension here between individuals wanting information, a company selling a product, and a governmental agency attempting to establish regulations highlights a development in contemporary medical technologies where humans no longer become local instances of diseases (as in Foucault’s history of medicine discussed earlier), but become reconfigured as capital through the storage, use, and re-selling of their genetic data. This aligns with Wendy Brown’s warning that market rationality currently permeates social, governmental, and institutional systems, reconfiguring individuals as capital and making the maximization of various forms of monetary and non-monetary capital the primary goal of different spheres of life. In terms of 23andme, this means gathering genetic data about a person to be used in studies to profit the company later as well as creating users that are concerned with investing in a future, healthy self.
Brown claims that life ordered around market rationality carries with it the removal of the promise of equality, justice, and freedom that has come to be associated with democracy. She says that “the cultivation and expression of distinctly human capacities for ethical and political freedom, creativity, unbounded reflection, or invention” get pushed aside as life becomes an issue of winners and losers within deregulated marketplaces each trying to enhance their position at the cost of others. The logic surrounding 23andme becomes significant because it provides an instance thoroughly organized by market rationality and advances the idea of investing in oneself to make a “better” person, but at the same time it actively encourages the types of activities that Brown worries about losing in an economically-organized society, namely the disappearance of a platform of critique that allows instances of inequality and injustice to emerge. Yet, the service does not point to an emergence of a utopian rule by popular sovereignty or a return to *homo politicus*, where individuals are political beings. Instead, individuals utilize information about their genetic makeup to increase their own health-related capital while simultaneously publishing this information online for others to use, putting themselves at risk for potential mis-use of their data for the benefit of other individuals and the general population.

The process of configuring the individual as capital, but in a manner that does not necessarily circumvent the promise of liberal democracy happens in several ways. First, 23andme’s model revolves around providing information and guidance to the user about how to engage with their data, but there is no clear, universal metric for how the user can increase their capital in a way that can create a common marketplace
where capital can be exchanged. Finding out about particular genetic qualities allows a person to understand more about how their bodies work and engage in practices of self-care, but these findings are not always accurate or applicable outside personal development. The second way is through the governmental response to regulate the service on the side of the consumer. Brown brings up a number of examples where neoliberal and market logic dictates that governmental decisions play out in favor of corporations’ rights based on principles of free speech. However, in the FDA’s case against 23andme, the service was actually paused in order to put in proper regulations to protect the consumer. The third way is an extension of this obligation to protect the individual. Some users of 23andme have taken their data and published it online for anyone to use for research or individual experimentation, putting themselves at great risk for future misuse of data in exchange for the possibility of helping others. Here, individuals do not become isolated sites of capital accumulation at the expense of others, but rather act in shared self-interest and capital accumulation. This chapter argues that 23andme may create users, corporations, and governments that operate within a market rationality, but the relation between these entities actually creates a subject that opens up the possibility for a renewed interest in the “ethical and political freedom, creativity, unbounded reflection [and] invention” that Brown sees as lacking within a neoliberal society.

23andme may currently dominate the discourse around personal genomic testing, but it was not the first company to provide the service. DeCODEme, based in
Iceland, was allegedly the first company to offer personal genome testing.*

DeCODEme started in 1996 as an off-shoot of its parent company, deCODE Genetics. Like 23andme, the price point for deCODEme was initially set at around $1000. Unlike 23andme, deCODEme leveraged the scientific legitimacy of its parent company, deCODE Genetics, to appear more reputable while still marketing the results of the test as interesting or entertaining rather than for diagnostic purposes.⁷ In 2012, deCODEme was shut down when deCODE went bankrupt and was sold to Amgen.⁸

Alongside 23andme and deCODEme, Navigenics was yet another major personal genome services. This company presented itself as a “sober, responsible reflection on the information present in its customers’ genomes.”⁹ The reports generated by Navigenics provided more detail and more context for users than 23andme while also initially focusing more on the medical side of genome analysis. Like deCODEme, Navigenics folded around 2012, and was sold to Life Technologies.¹⁰ Of the “Big Three” personal genome testing services, only 23andme remains, though there are smaller companies that exist. These testing services are generally relegated to more boutique companies like Knome, which offers full genome sequencing for around $100,000.¹¹

23andMe works by collecting a vial of spit from each user. The vial is then sent back to 23andMe, which outsources the actual analysis of the DNA to another

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* The first goal of deCODE Genetics was to create a national database of Icelandic genetic data in order to find genetic factors for common human diseases, based on the presumption that Icelandic people
company, Illumina. The data that Illumina sends back to 23andMe contains information on the mutations within the base pairs of DNA. These mutations are called single nucleotide polymorphisms, or SNPs, and are responsible for the different genetic code between people. 12 23andme then compares the results with scientific studies and creates a profile for the user. The profile contains raw information about the SNPs that have been tested, a note about how reliable the tests are, an analysis of how likely the user is to have a trait or condition, and some rough suggestions on how to prevent the condition if it is a debilitating medical issue.

One of the more obvious uses of 23andme’s health-related data is to anticipate the emergence of future health conditions that range from various forms of cancer to schizophrenia to gout to sickle cell anemia to Tourette’s syndrome. 13 Providing this type of information lends itself to users taking precautionary measures to ensure a healthy future, as evidenced by the section labeled “What You Can Do” in the results section of the user’s account that provides a rough guide for actions a person can take to avoid or minimize the onset of some conditions. This usage seems to reflect Brown’s main claim that individuals are increasingly concerned with improving themselves in the present as an investment in a better future self. In everyday life, individuals become what Brown calls homo oeconomicus, a person concerned with maximizing different forms of capital through their activities, whether it is “education, health, fitness, family life, or neighborhood.” 14 Institutions reflect this change as well. Online dating sites, schools, gyms, and other businesses claim “the

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were fairly genetically homogenous. The project was bound up with a host of ethical, political, and
importance of maximizing return on investment of affect” while governmental entities like the Supreme Court characterizes “free speech as the right to advance or advertise one’s worth without this worth being monetized.” For Brown, the dominant logic in contemporary, neoliberal Western society comes in the form of the marketization of all activities – including those informed by genetic predispositions.

She outlines three main characteristics of *homo oeconomicus*. The first is that *homo oeconomicus* is always and everywhere *homo oeconomicus*. Subjects are always configured in economic terms and never as alternative types of subjects, such as political subjects. The second characteristic is that the *homo oeconomicus* subject becomes human capital looking to increase its value and competitive position, rather than engage in exchange or interest. By this she means that individuals have begun to find ways to improve themselves for the future. By way of example, she foregrounds a number of cases that include “investing” in a liberal arts education (rather than learning for its own sake) in order to enhance one’s future marketability or investing in one’s appearance in order to attract a partner. The third characteristic is that financial or investment capital becomes the primary model for *homo oeconomicus*, in place of productive or entrepreneurial capital. Subjects are less concerned with creating actual products or engaging in exchange to increase forms of capital. In place of this productive and entrepreneurial model, subjects perform actions that seek to increase the future value of the self. For Brown, examples of these actions include gaining social media followers and likes, gaining a ranking for all different types of social criticisms.
activities, and education or certification for certain skills. Importantly, the logic of investment causes decisions about “education, training, leisure, reproduction, [and] consumption” to be judged solely in terms of how well they can increase the value of a future self.\textsuperscript{18}

The pervasive logic of \textit{homo oeconomicus} has not only set the stage for products like 23andme that allow individuals to find areas of themselves to work on with the hope of increased health metrics. That logic is perpetuated through the service itself. The test results configure the user as a set of genetic data that could be desirable because it has a low percentage chance of manifesting a condition or undesirable because of an increased risk of certain unhealthy conditions. Within the service, users are reduced to this profile of potential conditions that can be manipulated for a future healthy self, removing other aspects of the self such as personality, general happiness, social or cultural connections as indexes of health and happiness.

Beyond the self-creation of the user as \textit{homo oeconomicus}, Brown claims that “we are human capital not just for ourselves, but also for the firm, state, or post national constellation of which we are members.”\textsuperscript{19} The logic of capital accumulation moves throughout the individual and any surrounding institution or social structure. This move appears within the business model of 23andme when the personal data of users is configured as potential financial capital and sold to other companies. 23andme may be the main service left within the field and have a large number of users, but it is not without financial issues. The company is not currently profitable, running off of over $126 million of investment funding from companies like Google and investors
like Russian billionaire Yuri Milner, who has funded Facebook, Twitter, and
AirBnb. The personal tests each cost $199, but they are not the main source of
income that 23andMe hopes to cultivate. 23andMe aims to get as large a data pool as
possible in order to license out that information to research universities and other
organizations. Companies like 23andMe have already worked with the Parkinson’s
Institute and Autism Speaks to further genetic research on those respective diseases.
In a similar manner to the way Google and Facebook collect user data for advertising
purposes, 23andMe hopes to make the genetic data of its users a product for other
companies. Immediate results of this business model have culminated in a number of
published papers by 23andMe researchers. These include informational facts like
identifying the SNPs related to a person who identified a soapy taste in cilantro or
genetic variants that lead to linked eyebrows (commonly called a “unibrow”). Other,
more medically oriented studies have included identifying personality and health traits
that appear alongside Parkinson’s disease and linking certain ancestries with
Parkinson’s and skin cancer.

As Lenzer and Brownlee point out, “in a clever reversal, companies are getting
research subjects to pay—rather than be paid—to become research subjects.” Not
only are the users of 23andme potentially engaging in self-creation along the lines of
investing in a healthy, future self, they are becoming human capital for researchers and
experimenters investing in the future of medical knowledge. Though increasing future
health may seem like a worthwhile goal, Brown raises the concern that if humans
become capital for institutions concerned with their own survival, the subjects are not
guaranteed any form of security or protection. Many analysts have voiced similar concerns with the data collected by 23andme. Individual data may be lumped with genetic information from other people and anonymized, but that data can still be used by a variety of researchers without approval from the individual. Once the customer submits their spit for analysis, they essentially write off their ability to control what happens to that data their spit generates. An even larger concern is the unpredictability of future genetic research. Current 23andme users also waive their rights for their data to be excluded from future research: they waive their rights to inclusion in research that does not yet exist but could involve any number of ethical, profitable, or personally questionable areas.

For Brown, market rationality may underlie the structure of 23andme and its potential uses, but her worries about the larger effects of that rationality do not necessarily follow. She brings up the concern that “all market actors are rendered as little capitals (rather than as owners, workers, and consumers) competing with, rather than exchange with each other,” a situation where the individual becomes not just isolated, but acts in a way that opposes any sort of collective action. While the user of 23andme does become a “little capital” through a unique genetic profile and various design choices within the 23andme interface, the scope of 23andme’s suggestions and the limitations of data application fail to create a larger marketplace acting as a zero sum game and Brown’s concern of homo oeconomicus as inherently competitive does not necessarily emerge.
23andme’s organization encourages users to pick their own method of incorporating the data into their daily practices. Each page shows results of the rest in a way that provides the raw information about genomes that affect certain physical characteristics, drug responses, inherited conditions, and health risks and very little guidance as to how to use the information. On the pages for each individual genetic trait, 23andme shows relevant studies, a brief assessment of the data, an explanation of the condition, and a rating designating how solid the findings appear to be. In the case of potential health risks, a short list of things the person can do to prevent the condition is presented alongside the other information. Each condition is tied with columns that show how reliable the related studies are, the user’s risk, the average risk, and a comparison with the average risk:

<table>
<thead>
<tr>
<th>NAME</th>
<th>CONFIDENCE</th>
<th>YOUR RISK</th>
<th>AVG. RISK</th>
<th>COMPARED TO AVERAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gout</td>
<td>4</td>
<td>35.7%</td>
<td>22.8%</td>
<td>1.57x</td>
</tr>
<tr>
<td>Gallstones</td>
<td>4</td>
<td>11.1%</td>
<td>7.0%</td>
<td>1.58x</td>
</tr>
<tr>
<td>Restless Legs Syndrome</td>
<td>4</td>
<td>2.5%</td>
<td>2.0%</td>
<td>1.25x</td>
</tr>
<tr>
<td>Ulcerative Colitis</td>
<td>4</td>
<td>1.7%</td>
<td>0.8%</td>
<td>2.21x</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>4</td>
<td>0.47%</td>
<td>0.34%</td>
<td>1.37x</td>
</tr>
<tr>
<td>Dupuytren's Disease</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hay Fever (Allergic Rhinitis)</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart Rhythm Disorders (Arrhythmias)</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keboid</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male Breast Cancer</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male Infertility</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Meningioma</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Narcolepsy</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 13: 23andme heightened risks
https://www.23andme.com/you/health/risk/
Clicking on a condition gives an overview of the condition followed by the user’s results as a percentage chance of getting the condition, an explanation of the results, and suggestions for how to decrease the risk of developing the condition. The presence of an “average risk” contextualizes the data within a larger population, but does not position the members of that population as potential competitors. If an individual’s risk is small or decreases through some action on their part, the overall average risk of the population remains functionally unchanged. Likewise, if the average risk of the population decreases, it does not come at the cost of the individual. Information about the larger population does not become an analysis of competitors, but a way to situate one’s own susceptibility to a condition.

A tab at the top also allows direct access to the actual markers that appear in the user’s genome as well as a brief summary of what those markers mean. In the 23andMe interface, the user can see the relevant data, but only has a brief interpretation and no clear guide for how to use that information within a set of practices. The service may be a “medical device” in terms of engaging with medical knowledge, but it still remains an “information product” in the sense that it does not show a set of best practices or regime of self-care, leaving that decision up to the user. The service leaves much of the techniques of self-care open for interpretation by the individual. For example, the suggestions for avoiding gallstones appears as:
What You Can Do

Assuming the ethnicity setting above is correct, your test results indicate you are at increased risk for gallstones based on genetics. Family history and non-genetic factors can also influence your risk. While some risk factors are unavoidable (female gender and increased age), there are steps you can take to reduce your risk.

**Maintain a healthy weight**
Obesity is associated with increased risk of gallstones. Paradoxically, rapid weight loss (due to extreme diets or gastric bypass surgery) is also a major risk factor for gallstones. There is also evidence that physical activity is protective against gallstone formation.

**Learn your family medical history**
While there are non-genetic factors that increase risk for gallstones, there is also evidence that having a family member with the disease increases your risk. The U.S. Surgeon General’s My Family Health Portrait tool can help you assemble your family medical history.

**Connect with relevant groups**
- International Foundation for Functional Gastrointestinal Disorders
  888-964-2001

**Talk with a genetic counselor**
A genetic counselor specializes in helping people understand genetic disorders and genetic test results. Learn more about genetic counseling here.

**Figure 14:** 23andme recommendations
https://www.23andme.com/you/health/risk/

The first suggestion, maintaining a healthy weight, does not outline specific parameters for what a “healthy weight” means or how much physical activity the user should engage in. Rather, it serves as a starting point for the user to research more and act on their own. Though this information is an interpretation of the data and a parameter in which self-care can be enacted, it is also partial. The user cannot act on this information alone, but must actively search for more specific guidelines on how to avoid gallstones. The last three points – learning family history, connecting with relevant groups, and talking with a genetic counselor – also providing starting points for action and not specific guidelines in and of themselves.

On the one hand, these suggestions seem very much to fit into Brown’s claim that market rationality substitutes top-down commands and orders with “best practices”. The term “best practices” refers to “organically gestated procedures validated by experience and success,” or a flexible trial-and-error procedure that gets developed over time. Instead of a strict set of rules or steps that an individual must
take to perform a task, best practices are a constantly updating collection of recommendations on how to engage in a task. These recommendations change as they are tested and new methods are discovered, but they are always evaluated according to how well they increase capital for the future. Best practices are an issue for Brown because they are not industry-specific and can move fluidly between different spheres, potentially infiltrating political life and causing it to operate among market principles, assessing politics according to how well it creates value for the future and maximizes competitive advantage.\textsuperscript{27} Positioning decisions in this way de-politicizes decisions by appearing objective, even though there are assumptions made about what is “best” that can potentially alienate groups of people. Best practices can be overturned by \textit{better} practices, but the end goal or underlying logic cannot be questioned because the practice itself is value-neutral and justified through experience.\textsuperscript{28} Additionally, not only does politics become organized according to market principles, it actual dissipates into the market itself, removing “the need for legal, political, or ethical interference from the state or any other source.”\textsuperscript{29} When overall return on investment becomes the primary concern, politics does not become concerned with the well being of its subjects in terms of justice or equality.

Again, 23andme would appear to fall in line with Brown’s assessment. The data presented through the service does not create a solid set of rules or regulations. The user only sees their chances of getting a disease and a rough guide as to how they should proceed. The user has to formulate their own protocol for becoming healthier through the revelations in the data, test it on their own, and modify it according to
their findings as they would when formulating best practices. Though 23andme may encourage a critique and revision process with regard to practices, the scope of the resulting practices becomes limited to only the individual, an important point that would make a large-scale application of any set of best practices developed through 23andme data difficult.

Best practices assume the flattening of “government, business, and knowledge endeavors” into a single, market-driven episteme that provides recommendations for individuals to follow. 30 23andme not only configures the interface so that the individual must engage in the process of collecting and assessing information on their own, it also actively fragments different forms of knowledge, rather than attempting to condense these forms into an organic whole. 23andme performs this dispersal of information because of the shaky, contextual, and inconclusive nature of the test results that has caused them to push the user toward other sources of information to be able to make sense of the data. Though the genetic map of a person can be read through 23andMe’s DNA sequencing, creating the entire map is very expensive and understanding what that map means proves very difficult. There are millions of SNPs and research is still underway to determine the connection between particular SNPs and the expression of certain traits or the manifestation of diseases. 31 Schwartz points out that genetic tests like 23andme do not provide conclusive evidence of diseases or traits belonging to a person:

The information provided by such companies is based on studies—of more or less validity and reliability—of associations between specific single-nucleotide polymorphisms and individuals’ risks and characteristics (Fox 2008). Such genetic information is necessarily
partial even if it is valid: a patient with below-average genetic risk of lung cancer may well have higher-than-average overall risk, due to a heavy smoking history. There is basically no evidence at present that these sort of genetic tests contribute to health or improve healthcare.  

This observation by Schwartz brings to light the inconclusiveness of the tests. Though the tests do reference some scientific studies and illuminate some interesting information about a person’s genomic profile, there are many more factors that contribute to the expression of traits found within gene variations. The process becomes even more complex when multiple SNPs are connected to a trait, often with differing effects on the expression of that trait. For example, one SNP connected to Type 2 diabetes has been shown to increase the risk of diabetes by 17 percent. Another SNP decreases the risk by 15 percent. Figuring out how to average these risk percentages out to a number that the consumer can easily understand is one of the difficulties for 23andMe. An early interview by Wired magazine quotes the 23andMe founder as stating that, “A lot of this is unknown. It's totally experimental. …No one has looked at all eight diabetes markers together. They've all been identified individually, but they don't know exactly how they work together.” In the case of the diabetes-related SNPs, 23andMe decided to multiply the risks together, though other methods advocate adding the two risks together. Because of the large number of factors that go into identifying a correlation between SNPs and traits, 23andMe has to choose which SNPs to test, providing results to the consumer that require the consumer to assess the legitimacy of the results on their own and figure out how the data can best be used.
Even with the varying reliability of different markers, 23andMe chooses to give the user as much information about their genome as possible, a process that competing companies have called into question. Parthasarathy points out that 23andMe tests for a particular SNP as soon as there is research connecting it with a trait or health condition. Other companies, like the now defunct Navigenics, have in-house scientists do an internal review of the scientific literature before adding a SNP to their tests to ensure that the studies connecting SNP with a condition are reliable and consistent.

In addition to the choices made about which SNPs to analyze, genomes themselves do not completely determine particular characteristics or are not necessarily a good indication of certain health risks. Ethicist George Annas points out that family history is often a better way to determine if a person will develop a particular disease. Other researchers have also noted that the interaction between environmental and genetic factors play a significant role in disease development, especially for neurodegenerative diseases. This points to an odd tendency within the discourse around personal genomic testing: the medical community upholds the humanistic clinical and laboratory structure of medicine by claiming the authority of studies while also presenting a type of subject that cannot be understood by clinical medicine. If genetic markers had a 1:1 correlation with the expression of traits and conditions, it would be a straightforward case where clinical medical knowledge about a user’s genome could be used to determine aesthetic traits like hair and eye color; informative aspects of the patient like whether they can taste cilantro; and important
health traits like whether or not they will develop breast cancer. Here, these traits and
health conditions would not rely on the individual patient, only the processing of the
necessary information that was extracted from the body of the patient and run against
the findings of particular studies. Yet, the arguments against 23andMe from the
medical community claim that this process isn’t possible with genetic information.
The admission that family history and environmental factors play a large role in illness
requires the inclusion of the individual patient and their surrounding circumstances in
order to properly understand genetic information. The arguments from the medical
community against 23andMe suggest that it is actually impossible to diagnose or
understand genetic information without also understanding the contextual situation of
the patient themselves. As with the shift to posthumanism, there is a shift from the
user that can possess an objective set of “good” characteristics toward a user that is at
the nexus of a number of different environmental, social, and cultural factors that
make it difficult to generalize the worth of an individual according to universal
standards.

The variable reliability of conclusions drawn from the genetic tests and the
relatively lax standards by which 23andMe add SNPs and utilizes contextual
information has implications for the responsibility of the user. The “evidence” links
on the 23andme results point to the US National Library of Medicine, the “My Family
Health Portrait” link goes to the Surgeon General, and the “International Foundation
for Functional Gastrointestinal Disorders” link directs users to a nonprofit
organization that is partially funded by the National Institute of Health. In each case,
the user is pointed away from 23andMe toward a medically sanctioned information source that may or may not agree with the 23andme results, requiring the user to make their own decisions based on their knowledge of their own situation about what information is applicable. The test results for each individual position genetic information not as describing qualities inherent in the patient, but as potential facts about the individual that may or may not be true and may or may not be applicable to their life. 23andme encourages the user: (1) to become engaged in learning about oneself for its own sake and (2) to provide their own set of guidelines on how to handle their health. The user must create their own regime of self-care by picking and choosing elements from different areas of knowledge (medico-administrative, 23andme test results, etc.) and evaluating them according to their own unique circumstance, a process of creating an individual set of best practices for health management.

In this instance, the company relies on the institutional medical knowledge and points the user back to the medico-administrative institution for a definitive take on the information they’re provided while also encouraging the user to create their own method of interacting with the data. 23andMe pushes the user to work alongside, but not within, the medical institution and take into account their own unique situation when deciding how to proceed with their genetic data. Such a user begins to resemble Kant’s ideal Enlightenment individual discussed in earlier chapters who acts on its own without the guidance of others, demonstrating the potential manifestation of Kant’s mature Enlightenment subject within the neoliberal project. The user of
23andme is encouraged to make their own decisions based on their own research and not take any data at face value, no matter if it is presented by 23andme, the medical community, or a support group. However, Brown would point out that the user’s resulting critical engagement still has the ultimate goal of investing in future health and attempting to modify the body to become “healthy” according to medico-administrative standards, even if the specifics of those standards have some flexibility.

Beyond the 23andme interface itself, the service allows individuals to download their genetic data. Dozens of other services have been created to provide alternate ways to analyze the data according to different metrics, newly released information and studies, specific mutations not found in the 23andme report, and other areas. Because of the ability to process the data in other ways, users are given the option to investigate and learn about the data more than they would with a restrictive service that holds all of the data on their servers or, even more extreme, only allows for a proprietary interpretation of the data to be accessed by the user. As with the inclusion of outside sources of information and the lack of a specific, 23andme-sanctioned format for formulating one’s regime of self-care, the ability to download data point to a move toward giving the user the ability to make their own set of best practices by engaging with the data.

Pushing the 23andme users to make their own decisions also points to an underlying logic that the creation of identity through “best practices” does not rely on a uniform, agreed-upon standard of what is “human.” If users must construct their own plan for using their genetic information, it means that not only the user’s goals, but
also the manifestation of that user’s ideal identity is highly personalized and situated among genetic, environmental, and social factors. The quest for what makes up the human as a universal concept in humanism shifts throughout 23andme and such a quest is instead replaced by a prompt to create a singular and unique individual with its own goals and understanding of genetic data, much like the QS projects in chapter three. The individual, by being reconfigured as capital through a set of best practices based on genetic data, then becomes a unique entity while still existing under the umbrella of the human.

23andme’s opening up of data interpretation by providing information rather than diagnosing illnesses or recommending prevention programs is a purposeful move that stems from their ongoing issues with the FDA, a legal back-and-forth that appears to reign in unauthorized interpretation of medical information by users but actually serves to give a governmental stamp of approval onto the service. On November 22, 2013, the FDA sent a letter to 23andme demanding that it stop selling its genome sequencing kits without approval. Even though the company had been in business for several years at that point, in 2013 the company began to increase marketing efforts pushing the health aspects of the test. For the FDA, this was a very significant shift that would classify 23andme as a “medical device” rather than an “information product.” The FDA’s statement claimed that 23andme was “a device…because it is intended for use in the diagnosis of disease or other conditions or in the cure, mitigation, treatment, or prevention of disease, or is intended to affect the structure or function of the body” and required that it go through the same approval process as
other medical devices. Ultimately, the FDA approved 23andme to operate as an over-the-counter device in October of 2015. These included carrier status reports on inherited conditions like Cystic Fibrosis, Sickle Cell Anemia, and Hereditary Hearing Loss.

Such an intervention on the part of the FDA is significant because it brings to light the ways that corporate interests end up being supported by governmental organizations that are supposed to be put in place to protect citizens. By appearing to engage in the areas of medical diagnosis and disease prevention, 23andme attempted to speak with the authority otherwise reserved for medical professionals without actually being a medical entity. It could allegedly identify diseases before they manifested themselves within individuals and could suggest steps to avoid the disease. These actions were previously situated squarely within the domain of clinical medicine, which had a monopoly on the creation and interpretation of knowledge pertaining to disease. As 23andme attempted to use medical knowledge in an unsanctioned manner, the already existing medico-administrative institutions – led by the FDA – demanded that it conform to the structure of that knowledge via oversight by the medical community and government.

Additionally, the FDA is not a medical institution but a governmental agency put into place to “[protect] the public health by assuring the safety, efficacy and security of human and veterinary drugs, biological products, medical devices, our nation’s food supply, cosmetics, and products that emit radiation.” A large part of this stated purpose is ostensibly to curtail any medical practices that could be harmful
to the general population of the US. Nonetheless, the FDA works in tandem with medical institutions to organize society according to parameters set by the medical community and, in the case of 23andme, by corporations dealing with medical data. As evidenced by the note to 23andme, the FDA tries to ensure that any entity operating with reference to medical knowledge is supervised and does not provide “dangerous” advice to people.

23andme’s designation as a medical device and the late 2015 approval of certain tests by the FDA with little changes to the presented data demonstrate the problematic situation that occurs when individuals and companies outside of the medical profession create and analyze medical knowledge in non-sanctioned ways. Such a shift moves the formation of medical knowledge outside of the bounds of the clinic, the location that Foucault and others have identified as the source of medical knowledge from the 18th century onward. In the clinic, disease and other conditions could be studied without the interference of the “extra ‘noise’” found in the home or other non-isolated locations. The context of everyday life was bracketed within the clinic, which provided a controlled, sterile environment within which disease would be examined and understood. Within this context, the patient was not an individual and unique entity, but rather a location upon which disease manifested itself. By entering the clinic, the patient became primarily an object that could be examined under the medical gaze to find out information about a disease. Studying the individual patients did not reveal anything about the person themself, but facts that
could be added to a body of knowledge surrounding a particular disease, which in turn was abstracted from the context of everyday life surrounding it.

With the rise of personal genomics testing, assessment of the patient moves from the sterile and secluded location of the clinic back to the home and is overseen not by the medical experts, but by the patients themselves, regulated by governmental organizations like the FDA. In the case of genetic testing, not only does the test itself move beyond the clinic walls through commercialization, the information becomes utilized by institutions and individuals in an economic manner. Bandelt et al point out that in personal genetic testing, “the commercial utilization of many scientific advances is unfortunately not only frequently out of step with the cutting edge of the science itself but also several steps ahead of the governmental and social regulations that the use of these advances require.”

In these tests, the consumer not only engages with genetic information without direct oversight, but also accesses information that may or may not line up with medically-sanctioned knowledge.

The division between FDA and 23andme illustrates Brown’s claim that in a market-driven, neoliberal society, knowledge becomes part of a single network of government and corporations. However, the division complicates her claim that law becomes subject to business interests rather than protecting citizens and that the main danger of the homo oeconomicus age comes when concern for public good and citizenship disappears. As market rationality covers over all aspects of life, the political sphere becomes affected as well. Liberty, equality and freedom are no longer portrayed in terms of the freedom for self-rule or equality among people. Overlaying
market principles onto political discourse changes these to mean a freedom of economic exchange, liberty to pursue increase in capital, and equality through lack of regulation. Such a shift causes the governmental and regulatory institutions to no longer be concerned with protecting the individual but instead focus on corporations, allowing them to write laws and operate with little oversight and regulation. Humanism disappears, replaced by a focus on human capital.

Brown examines four court cases demonstrating the erosion of popular power: *Citizens United v. Federal Election Commission* (resulted in large corporations being able to finance elections), *AT&T Mobility LLC v. Concepcion* (decreases the ability of workers to come together to fight corporate abuses), *Wal-Mart Stores, Inc. V. Dukes et al* (restricts private and public sector workers’ ability to cooperate), and *Ozanne v. Fitzgerald* (also restricts ability of private and public sector workers to band together). According to Brown, these decisions are an indication that “more than merely being abandoned, legal supports for popular power are discursively identified in neoliberal reason as unacceptable blockades in a (mystical) free market.” The law here becomes less concerned with promoting the wellbeing of citizens and more focused on assuring the ability of the market to function without restriction. The most egregious instance of this privileging of market forces occurs in *Citizens United*, where speech becomes reconfigured as capital, whose flows must be protected even at the cost of individuals’ free speech. As Brown reads it, the *Citizens United* decision equated speech as capital that must be protected by claiming that speech “proliferate[s] and circulate[s]” in ways that can “be wrongly impeded and
encumbered, but never quashed,” that it “is the capital of the political marketplace” which “circulates freely only when corporations are not restricted in what speech they may fund,” that speech is “innovative and productive, just as capital is,” and that it “the power of speech and the power of government [are] in direct and zero-sum-game opposition to one another.” Speech, an important medium for political expression and engagement for individuals, becomes reconfigured as capital that can be accumulated by both corporations (as persons) and individuals. Speech also becomes subject to the same logic of market rationality whereby any form of government restriction becomes an impediment to the “dynamism, innovativeness, and generatively of speech.” In this way, not only does law become a vehicle to protect the free market, but, even more concerning for Brown, legal decisions use this logic to make citizens vulnerable to entities with more money and more influence.

23andme provides an alternative example to Brown’s concern about market rationality taking over legal decisions because the FDA’s intrusion into the operations of 23andme purport to limit the speech of 23andme in order to protect citizens. Yet, the eventual loosening of the restrictions on 23andme that allow them to provide the data from some tests essentially unchanged fails to really limit 23andme’s speech in practice. Unlike Brown’s examples, however, the ability of 23andme to offer genetic information about traits and characteristics (not just ancestry information) also removes restrictions on information that users can have about their own bodies.

Within this situation, both the company and the user gain a degree of free speech and unrestricted access to information, but the user takes on a particular risk
that the company does not. In addition to the risk of potential future abuse of the user’s data, the user’s risk that forms the basis for the FDA’s ongoing main concern is the inability of the consumer to properly assess genetic data without a professional, causing the potential for extreme or unreasonable action on the part of the consumer as they take on the ability to interpret medical data. Without proper medical knowledge or a context to interpret that knowledge, the medical community feared that the individual would engage in certain risky behaviors or fail to take proper steps to prevent certain diseases. Examples of this include users that find themselves at low risk for a condition such as lung cancer continuing to smoke cigarettes or users that find themselves at high risk for breast cancer having expensive and risky mastectomies.*

The FDA’s letter spoke to this when it claimed that, “serious concerns are raised if test results are not adequately understood by patients or if incorrect test results are reported” and elaborated that the patients may attempt to improperly manage a disease or become noncompliant during treatment because of test results.54 Additionally, when a user finds out their own genetic data, they also gain some insight into the genetic data of relatives, some of whom may not wish to know about major conditions like breast cancer. Professionals in the medical field echo these sentiments, agreeing that the personal genome tests could have some utility in medicine, but would require professional oversight by a genetic counselor because of the potential danger they pose to individuals and their families.55 Positions differ as to whether the individual

* Angelina Jolie is a very high profile case of someone who had a double mastectomy after getting a genotype that pointed toward a high probability of breast cancer.
should have direct access to the results coupled with counseling or if the individual should only be allowed to receive the counselor’s analysis of the results.

Here, the issue of who is free to interpret the data is present, but another issue arises: that of the user’s reaction to the data. The major fear is that improperly interpreted knowledge will make its way to the individual and cause them to react in a way that is either unnecessary or harmful to themselves. On the institutional side, and often in tension with arguments advocating restricted use of genetic tests, the FDA and medical communities appeal to the obligation of doctors and government to help patients. The tests do provide more information about the patient and bring up ethical issues within medicine about the requirement of the doctor to inform the patient about potentially harmful conditions, even when the reliability of the personal genome tests are sometimes shaky. Analysis within medical institutions in response to the FDA’s warning and rise of personal genome testing rarely calls for an all-out ban on the tests, but rather a re-working of both how the data is presented to the patient from the company providing the test and how the medical institution is set up to handle the data. Patients with access to data can provide more information to doctors, but at the same time the doctors must be trained to be able to walk through the data with the patients. At the moment, interpretation of genetic data is not a highly developed skill in many medical professionals, though many medical scholars have called for this type of knowledge to be required learning for new doctors.

The reorganization of access to and distribution of information in personal genomics testing points to a move whereby legal, medical, and individual entities may
act in a decidedly neoliberal manner that protects the open market, but in a way where corporate and individual interests are not necessarily directly opposed. When patients can look at their own SNPs and evaluate the validity of studies on their own to create individualized treatment plans, they take on a risk of misusing that data, but they also have the possibility of identifying diseases or conditions before they become an issue.

As the 23andme customer becomes the main assembler of their own risky self-care practices, user groups have emerged that act in direct opposition to Brown’s warning that Enlightenment principles of justice, ethics, and critical inquiry disappear as *homo oeconomicus* becomes concerned only with its competitive position within a zero sum marketplace. Many 23andme users voluntarily share their genetic data, consciously taking on additional risk to themselves with the hope of helping others understand their genetic data, becoming part of a larger research project, or possibly gaining more insight into their own genetic makeup through engagement with others. Websites like OpenSNP, Harvard’s Personal Genome Project, DIYGenomics, and SNPedia promote their service by stating that users can contribute their genome to, as in OpenSNP’s tagline, “learn more about their results, get the latest primary literature on their variations and help scientists find new associations.”56 Superusers armed with their genetic data upload their data to servers where it is combined with the data of other people and made available to anyone that wants to access it. These can include institutional researchers as well as hobbyists who have no professional training.

Participating in these genetic social networks may increase one’s own capital through the promise of beneficial genetic discoveries or social position within a
community of other uploaders, but it does so only obliquely. Though they are potentially participating in wide-scale research projects that could result in discovering the root cause of diseases or increasing the health of the population, there is little immediate benefit for an individual user. In many services, the data could be downloaded by someone without participating and there is no monetary compensation for uploading data. The data is not explicitly tied with a real-world identity, so there is no individual recognition of participation. Stephen Friend, the director of the open science-supporting non-profit Sage Bionetworks, says that genome sharing systems “imagine a system where the patient says, ‘I want my data. I want it open. I want researchers to work on it. I want them to share it.’” The vision here is a network where individuals donate their genetic information as an obligation to help researchers and other individuals looking to learn from their genetic information. Contributors share their genetic data in order to aid in the potential creation of new discoveries or cures that would benefit the population at large, a move that shows an obligation to care for one’s neighbor rather than to engage in cut-throat competition with them.

This sense of obligation comes at a cost to the user, however. OpenSNP, for example, provides a bullet point list of potential complications that could arise from sharing genetic data through their service:

• Data uploaded to the internet can not be fully deleted, there may always be a backup somewhere

• By publishing data you expose information about you and your next of kin worldwide

• Genetic and medical information can be used by employers, insurance companies and the government to know more about you than you would like
• New findings about your genotypes can be negative. As with many of the privacy issues mentioned above, OpenSNP warns of exposing information about oneself and one’s family, workplace and insurance-based discrimination based on the data, distressing information about oneself, and unknown future consequences. Yet, even with these warnings, OpenSNP has over 4,000 registered users and 2,400 users with uploaded data.*

The formulation of the risks of uploading genetic data versus the benefits demonstrates a shift in what can be considered threatening to an individual. The potential risks listed by OpenSNP and other commentators on privacy are not harmful in and of themselves. A digital backup of genetic information or even a fully-accessible public record of someone’s genetic makeup does not immediately cause harm to an individual, even though those are the types of concerns that are explicitly brought up. Instead, the use of that information has the potential to create the most harm. Employers and health insurance companies may be restricted from making decisions based on genetic data, but other important services such as long-term disability, life insurance, or home loans could potentially use that data to block individuals. Advertising and product purchases could potentially also be linked to genetic data, as the startup Miinome has attempted to do.58

These concerns exist as concerns because of a market logic of competition that seeks to maximize the benefit of a corporation or individual at the expense of another.

* This number is not particularly large considering that OpenSNP allows for data from 23andme, deCODEme, and FamilyTreeDNA and that 23andme alone has genotyped over one million people.
It also contains the type of humanist logic discussed in chapter one that sets up a standard for what can be considered “human” and then excludes individuals who do not fall within those parameters. For example, a company can minimize risk by denying a person a long-term loan if their genetic data indicated a high chance of a fatal or debilitating illness that shows up early in life, potentially keeping the person from paying back the loan. Or, in a Minority Report-esque situation, individuals with genetic markers indicating aggression or certain tendencies aligned with criminal misconduct could be incarcerated before committing any actual crime. As has been the case with gender, race, mental illness, and other traits that differ from the medically sanctioned norm, genetic markers could be used to classify a person as non-human if their genetic data was made public.

Currently, these issues are hypothetical. There has been no widespread use of genetic data to exclude or include people from a group or a major breach of ethical use of the data, though there is a precedent in instances such as US health insurance companies that deny coverage based on pre-existing conditions. Miinome, one of the few companies with an explicit mission statement toward using genetic data in a questionably commercialized way, has stalled and they have updated their outreach efforts very little over the past two years. However, the benefits from sharing data have made some progress. OpenSNP, Genomera, Snpedia, and Promethease all provide more information about genetic data to their users soon after the data is uploaded, even though very few of the open sourced studies using the information

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However, the number is significant considering that this service is not highly publicized and that it is
have made headway. With this imbalance of hypothetical (yet very serious) risks opposed to actual insight into one’s own genomic information, it is possible to see how some users are not only less concerned with being excluded from institutional operations because they lack some aspect of being “human,” but also expect the data to be used only in non-harmful ways. Some have called for a “Hippocratic oath” for people accessing genetic data where it is used only with good intentions. Such a call points to an underlying assumption of shared obligation whereby users put themselves at risk with the assumption that others will not misuse sensitive information. The sense of justice and equality that disappears in Brown’s account of *homo oeconomicus* makes a reappearance in these social media services, even though it does not necessarily translate to the political sphere.

In order to make this move toward a logic of obligation, the underlying idea of the human has to be radically shifted as well. Brown claims a loss of humanism because the human becomes capital, but the way that 23andme and genetic data-sharing services allow users to take control of their data demonstrates a refiguring of humanism by replacing “the human” with a single, self-critical individual.59 Users assemble their own set of knowledge about their genetic data from assessments by companies like 23andme along with governmental and medical sources and then share their own data and findings with others with the intent of helping. This changes the goal of self-care from concordance with treatment protocols (as outlined in chapter growing.

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5 This process occurs parallel to 23andme’s selling of genetic data to research companies, which is more aligned with more traditional clinical medicine that seeks to understand disease in general.
two) and instead becomes a unique course of action based on the user’s unique makeup (as in the QS projects of chapter three). Institutions like 23andme and the FDA have reconfigured themselves to work within this shift by acting as providers of information and protectors of the users, even if the institutions differ on how that protection should be enacted.

On the one hand, this brings the human back into the equation, centering treatment around the body and the existence of a person behind the data. The patient becomes the focus instead of the disease and issues of ethical responsibility to oneself and the larger community that can benefit from access to open source genetic data come to the forefront. Yet, at the same time, this human is not necessarily the same normalized construct that exists in the 19th century conception of Man outlined by Foucault. As 23andMe’s larger project based around gathering information and adjusting correlations between SNPs and certain traits shows, what is “normal” becomes fluid and changeable depending on the data. Moreover, the results of the tests are presented as chances of manifesting a certain trait or disease, not as inevitabilities. If a 23andMe user’s genetic data shows that they should have brown eyes but they have green eyes, the data is shown to be wrong and the user is not labeled an anomaly.

The patient in personalized genetic testing is, like in many theories of posthumanism, an entity but not the central one. As critics of 23andMe are quick to point out, genetic data is faulty not just because the studies are often shaky, but because there are many other factors that go into the expression of certain traits. As noted, these include environmental factors as well as hereditary data and even some
unknown aspects of how genes work. The individual here is not cut off from context but a rallying point for all of these different factors.

Personalized genome testing also presents a move toward the body, but the body as part data and part lived experience. The basic premise of 23andMe and similar companies is that SNPs can be decoded into pure information to give a type of map for various aspects of a person’s body. As in Hayles’ version of posthumanism, the individual becomes synonymous with data that can be moved, interpreted, and copied. Yet at the same time, personal genomics testing requires the extra step of embedding that data back onto the life of an individual to test its accuracy, linking the data with a singular body and precluding the possibility of downloading that data into another, identical body as in AI.

As personal genomics shows, when posthumanism comes into contact with medicine the result does not become a wholesale rejection of the human, a disposal of the body, or a clean extension of medico-administrative methods of control into daily life. Nor does it result in individuals becoming engaged in a zero sum competition where they try to maximize their own position. Instead, it is possible to see a way where the individual becomes reconfigured as capital through the genetic information, but operates with an obligation to help others, even though that action may place the individual at risk. Such an act displays the qualities of justice and equality that Brown worries have disappeared within a society functioning according to neoliberal principles of open markets. As demonstrated by the open source communities that share genetic data, some individuals using these services believe that their information
will not be used incorrectly and can help others who are suffering from conditions that can be treated with a larger pool of genetic data for research.

Though Brown calls for a renewed engagement with the political sphere, she also claims that it is not democracy itself that encourages equality, justice, and critique, but rather an ethos that can be found within democracy. Such an ethos can be found in the individuals creating databases of genetic data, but it occurs outside of the political. They do not engage with governmental organizations or seek to change policy, though they generally support the de-regulation of services like 23andme so that, theoretically, more data can be accessible to more people. These open source databases operate within a deregulated marketplace with the belief that increasing one’s capital does not have to be a zero sum game based on competition, but has the potential to be a mutually beneficial activity.

5 Brown 43
6 Brown 208
9 Macarthur and Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000. Welcome to the Age of Genomics." *Wired* 17 Nov. 2007 for info on how Navigenics positions itself differently than 23andMe
12 Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000" 9.
14 Brown 31
Brown 31
15. Note that she traces a lineage of *homo oeconomicus* from Adam Smith to Jeremy Bentham to Foucault. Her main modification is that *homo oeconomicus* focuses on investment rather than entrepreneurialism, i.e. focusing on putting work on oneself now for future gain rather than producing things or engaging in labor.

Brown 33
16. Brown 32


21. Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000" 12-13
23. Goetz, Thomas. "23andme - AU, DE, FR, & EU - Research." Parkinson's is a heavy focus for 23andMe research because family members of some of the founders have had the disease.

25. Brown 36
26. Brown 139
27. Brown 141
28. Brown 136
29. Brown 140
30. Brown 139
31. Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000" 11
32. Schwartz.pdf @ 27
33. Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000" 11
34. Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000" 11
35. Goetz, Thomas. "23AndMe Will Decode Your DNA for $1,000" 11. It’s worth noting that the exact process 23andMe uses isn’t available for review and much of the literature on how 23andMe makes decisions or creates its algorithm may no longer be applicable, as changes in field come about quickly.


"23andMe Genetic Service Now Fully Accessible to Customers in New York and Maryland."


Foucault Birth of the Clinic 29


Brown 39

Brown 41-42.

Brown 42

Brown 152-53

Brown 153-54

Brown 159-60

Brown 160

FDA Letter


OpenSNP,


SNPedia

"Miinome - It's in Your DNA." Web. <miinome.com>. It is important to note that the startup has largely been quiet for the past few years. Their social media pages have not been updated in at least twelve months.

Brown 42
CONCLUSION

This dissertation started with a warning about the dangers of the figure of the human as well as a promise about the ethical possibilities that it could create. In these final pages of the dissertation, it is necessary to step back and see how the health tracking technologies that have been analyzed navigate this space between danger and promise. The danger posed by the figure of the human comes by identifying a single model of the human, as in Cartesian humanism. By isolating a set of characteristics, it was believed that we could improve ourselves by amplifying particular parts that were beneficial. These characteristics generally matched up to a Western, white, and male figure that did not allow for any alternative forms of legitimate humans. This model of the human carries with it a tendency toward exclusion and disempowerment that has taken multiple forms. Colonialism and racism identified the non-European individual as a lower, less human form of being, justifying the invasion and subjugation of entire non-Western civilizations. Gender has been similarly configured, as the initial figure of the human was configured along male/female lines. The female figure was positioned as a less rational, weaker gender, which provided a reason to relegate them to the domestic sphere. Genders outside of the male/female binary were completely covered over and excluded from public life within this model. Within the medical field, unhealthy individuals, especially those who were “mad” and lacked reason, were criminalized for many years and placed in prison instead of given treatment. This is not an exhaustive list, but some of the major areas that have been targeted by critical theorists in recent years.
But, the other side of the human is a promise of better things to come. The promise of the human is one of Enlightenment ideals: justice, ethics, and constant critique of self and institution that keeps oppressive power structures at bay – ironically some of those same power structures that are built on the humanist project itself. Critical posthumanists see these as currently in a state of flux, goals that fail to come to fruition with the initial Cartesian humanist project, but still not quite realized with posthumanist critiques that scrutinize the human. Likewise, Wendy Brown has identified these as principles very much in danger at the turn of the twenty first century as neoliberal logic begins to take hold and direct our everyday lives. Justice, ethics, and critique remain principles to strive toward, though newer technologies have changed the way that they function in relation to the human. Kant’s call to use one’s own reason as the path to ethical engagement with the world seem less relevant in a posthumanist world operating on principles of biopower. Being self-sufficient is no longer as clear-cut as just forming one’s own opinions, but instead involves a complex interaction between institutionally-formed knowledges and a particular style of enacting those knowledges in everyday, embodied life. As Brown points out, individualism often ends up being less about creating one’s own opinions and more about internalizing neoliberal methods of population control. Health tracking technologies provide a salient example of how these forces play out, as they are used for promoting one’s own health and the health of others through a critical examination of the body, but still require interaction with and internalization of institutional knowledge.
I have positioned posthumanism as a way of moving between these two poles, trying to keep the promise of the human alive while mitigating as much of the dangerous, normate models of the human like gender, race, healthy bodies, etc. as possible. Criticism of posthumanism that it does not completely get beyond the human seems to miss much of the point of posthumanist critique. Posthumanists claim that the figure of the human is deeply problematic, but only because it is claimed as the only type of legitimate subjectivity. As the only type of viable subject, the figure of the human can then be used as a justification for exclusion and processes of de-legitimation that pose the serious threat to identity politics and Enlightenment values. Critical posthumanism teaches us not to attack or valorize the human itself but look to the ways that the figure is used by institutions to justify the exclusion of particular individuals and to think of alternative ways of positioning the human – namely decentering it in favor of an embodied way of looking at the world that includes objects and environmental factors as important actors. The question of critical posthumanism becomes: how do or how can we understand the human without reinscribing humanism?

One of the most important spaces where this tension plays out is in the medical field, one of the original institutional legitimators of humanism. Contemporary health tracking technologies illustrate a crucial area in which the balance between the dangers of exclusionary identity politics and the promise of ethics, justice, and critique is being reformed. Fitbit, MyFitnessPal, beddit, ResMed’s S+, and other devices that track bodily activities aim to help users become healthier according to a certain
clinical medical model of what a healthy human looks like. Users can set goals for number of steps taken in a day or hours slept and get recommendations on how to bring that more in line with the ideal. The intended use of these products is, on the surface, very much a reinscription of a universal human figure. The apparent objectivity of the recommended number of steps, calories consumed, or hours of sleep attached to that figure ostensibly treat racial, gender, ethnic, and situational differences as inconsequential. Moreover, the Big Data component of these technologies has the potential to insert clinical medicine into even more aspects of everyday life. With more data on more people and more health-related processes, medicine could integrate itself into previously untouched aspects of life. Yet, groups like Quantified Self work concurrently to disrupt the ability of these technologies to create a unified idea of the human. The n=1 slogan of Quantified Self creates a space where the figure of the human can be a singular entity with its own set of characteristics, legitimized by medical knowledge and brought back into the sphere of political and social participation. Unlike the human figure within humanism, this individual is expected to differ from the normate model of the human. There is no ideal or universal human that provides a basis for whether or not the Quantified Self individual can engage with political and social life, creating the potential to allow previously excluded identities to gain legitimacy within the public sphere. Moreover, by removing the normate human as a starting point, previously unknown identities can emerge. This figure is a type of human that follows the posthumanist model of an embodied and fluid subject without also completely discarding the figure of the human.
This dissertation has shown that contemporary medical technologies not only deal with the opposing dangers and promises of humanism, but they also bring out the inherent qualities within humanism that create this tension in the first place. Humanism upholds individuality, a trait that manifests itself in a neoliberal society as each citizen takes on more responsibility for their own self-care. But, as Chapter 2 points out, this shift in care to the patient opens up a space for alternative forms of knowledge production. As tracking technologies become more ubiquitous in the lives of patients, they begin to make decisions – both good and bad – that are based on their own research and conclusions, not necessarily the orders of doctors. With regard to the overarching ethical issues surrounding humanism, these types of decisions can be liberating, but they also carry with them the risk of care that actually does decrease the health of the patient. As the patient begins to take on responsibility not just for enacting a clinically-recommended regime of self-care, but in initially creating that regime, they also take on the responsibility for making poor decisions about their health. Medical professionals are still obliged to help fix these issues, but not ultimately responsible for the final outcome. The clinical and laboratory models of medicine may devalue the actual person as they create large bodies of knowledge about diseases in general, but they have also resulted in a great quality of life for many individuals. Examples of this increase in quality of life discussed earlier include the discovery and proliferation of insulin. Awareness of diabetes has been around for many centuries, yet there was little that could be done to manage it. Laboratory medicine in the early twentieth century discovered its relation to insulin and then
found a way to isolate insulin, providing a way for patients to manage their disease.
Continued laboratory research developed cheaper, synthetic insulin, which in turn
allowed an affordable and accessible way for management of the disease. Here,
laboratory medicine may not have completely taken into account the unique,
embodied situation of the patient, but was still able to come up with a way to control a
disease that had not previously been manageable.

More than just create new knowledges, self-tracking and self-care procedures
that occur outside the clinic and hospital walls significantly reorganize how power
operates. Quantified Self projects engage in a type of biopower that limits its scope to
the individual. By narrowing the focus to construct a coherent model of a single
individual throughout time rather than a cross-section of a population at a particular
moment in time, these projects take techniques of power used to legitimize an over-
arching, normate model of the human and reduce it to a legitimization of multiple,
unique human models. These are not just new knowledges for their own sake; they are
knowledges that move from the macro to the micro and facilitate an integration of
temporality into how the human is constructed. A constantly shifting and individual
figure of the human emerges alongside the posthuman hope of multiple recognized
identities. The human begins to account for varied iterations that go beyond the white,
male, Western, rational human while also allowing an individual to shift that identity
over time and different contexts. This is a type of anti-anthropocentrism akin to what I
identified in Chapter 1 as a crucial part of critical posthumanism. The move against
the figure of man here is not an outright rejection, but a move away from the human as
an abstract or universal figure that can be used to exclude or disempower individuals. But discarding the figure of the human in favor of this particular type of anti-anthropocentrism also holds the danger of losing types of collective identity. Stable, pre-existing identity is not always the root of oppressive power structures, as excluding some people also means including others. Ethnicity, for example, brings particular groups of people together in ways that provide a social safety net and a shared culture. If the scope of the human is reduced entirely to the individual, how do groups of people share in and create a single identity? Nationalism, culture, and ethnicity become more difficult to imagine in a world where the guidelines of self-care practices come from one’s own research and conclusions and instability is built-in to the process of identity creation through constant critique.

Related to this is a question that the final chapter has attempted to deal with: is it possible to have an ethical relation through self-tracking projects that are not just localized in nature, but also require translating the individual into measurable quantities? Quantified Self projects and related technologies like 23andme function by collecting data about individuals and turning them into numbers, charts, and graphs (often by selling it). On the one hand, as non-human ontologies like Object Oriented Ontology and Speculative Realism address, this creates an opportunity for insights about an individual that would not otherwise be knowable to the human. A Fitbit, for example, has its own ontology that allows it to relate the movement of the human body to the ground and to energy expenditure.¹ Likewise, productivity-tracking apps like RescueTime record how long certain computer programs are used, providing data
that can be interpreted and overlayed on top of other situational data (where the person is, how they were feeling that day, etc.) to come to conclusions about how someone works. This type of data is a numerical version of an individual’s actions or situatedness within an environment. And, they allow for the creation of a unique model of a human, while also providing a measurable way to increase or decrease a particular force in someone’s life. A person can lose weight by using a Fitbit to make sure they expend more energy in a day than they consume. Or, they could use RescueTime to increase hours spent on a task or to find the optimal number of productive hours in a day.

But, as Wendy Brown claims, this also can potentially be a dangerous extension of neoliberal logic that could obscure human relatedness and sense of mutual responsibility by changing them into measurable quantities rather than approaching them through engaged, critical discussion within the demos. 23andme is a prime example of opposing positions of life quantification. The actual business of 23andme survives by selling kits as well as renting out its databases for research and doing their own research. People do not pay for a private screening of their DNA so much as they pay for some information and then inclusion in further money-making opportunities for 23andme itself. There is, again, the promise of cures for diseases and increased information about what SNPs are tied to different traits. But, there is also the danger of genetic information that can be tied to individuals falling into the wrong hands that can use it to exclude the 23andme users from jobs, insurance, or social spheres. I pointed to a community of individuals with genetic data who believe in
open source data and share their genetic information online for others to use. This does show the possibility for a public sphere of information sharing and research into genetic conditions that is not done for immediate, individual capital gains. Yet, it also retains the danger of information mis-use, as well as the potential of undercutting the main revenue stream for companies like 23andme. If users provide their own data for free online, there is little reason for companies to rent out the 23andme database. Loss of significant income could cause 23andme to shut down, removing the ability to get the genetic data to these users in the first place.

Brown’s observation that the principles of caring for one’s fellow humans and engaging in political critique that limits institutional power are not built in to any one system is a salient point. These principles are advanced by a certain ethos that expresses itself (or doesn’t). Because of this fact, it is important to pay attention to how a system of governmentality is enacted, not necessarily focus on creating a better system. This claim holds especially true with the technologies presented in this dissertation, many of which are recently developed and recently available on the market. In an appropriately neoliberal way, they have few governmental restrictions on them and there is no clear way to regulate them, as the case of 23andme shows. Because of the open-ended ability to use these technologies, the danger of lapsing into using these technologies to reinforce a neoliberal logic is especially concerning. However, the open-endedness also brings forth a spirit of critique, as people learn how to use the technologies. Such a spirit of critique has the potential to oppose neoliberal
logic, as long as it is not lost through an institutionalization and corporatization of these technologies.

One of the major underlying currents of the Quantified Self movement is a penchant for having the latest gadgets and figuring out how to use them or using modular devices like Arduinos and Raspberry Pis to measure a part of one’s life. Embedded within this hacker mentality is also an excitement of new discoveries and the desire to share with others through open source channels. Just as with democracy, these elements of critique and desire to help others by sharing one’s own insights about health are not built in to the technology itself. The same logic that encourages individuals to put together their own devices or self-care plans is the same logic that privileges individual advancement over collective advancement. In the projects of Quantified Self and the communities sharing genetic data, the promise of a re-invigoration of ethics, justice, and critique seem to be at the forefront, but the danger of lapsing into individual self-interest is always lurking.

As these technologies develop, it will be necessary to continue to critique how they relate to our notions of the human. I have identified a current tendency toward the posthumanist promise of the human as a malleable figure central to ethics. New technologies and their use in Quantified Self projects allow for situated, temporal self-care regimes for individual people, but they could just as easily be used as a basis to bring about a return to the normate, humanist idea of the human. 23andme is already doing this with their large databases of genetic data that advance a laboratory model of medical research. Fitbit is moving toward this as well, holding much of their activity,
heart rate, and geolocation data behind restrictive APIs that do not integrate with other popular health tracking services like Apple Health. Large companies like Under Armor are getting into the health tracking game as well, buying up services like MyFitnessPal that holds a database of people’s meals and food intake. If kept open, these services could provide a service to individuals and radically restructure how medicine conceived of the human and its place within the world. Fitbit data, for example could be used to identify irregular heartbeats that predict heart conditions. MyFitnessPal data could be exported and tied to other biometric data like heart rate, blood pressure, or sleep to identify how particular foods or eating patterns affect health markers. Or, by integrating biometric data with location data from apps like Move that trace everywhere a person goes, it would be possible to identify how the surrounding environment affected well being. Conclusions could include whether or not a particular city encourages a person to walk more. Or, if a large number of people in an area began to have blood pressure or heart issues suddenly, it could be possible to identify a chemical spill or changing air quality issues. But if kept closed, these services could fail to provide any real benefit toward the larger health industry. Keeping data closed prevents it from being re-contextualized, processed, and combined with other data in unique ways. Without the ability to perform these tasks, data stays behind proprietary software and is reduced to the uses approved by the company that owns it.

The purpose of this dissertation has not been to identify a new form of the human so much as argue for a way of attending to the human that can encourage
relations between the self and others based on individual circumstance, rather than how well the individual fits within the normate human model. Legitimizing multiple, shifting identities through medical discourse encourages individuals to take other individuals on their own terms, while also requiring institutionalized recommendations of self-care to take into account an individual’s unique, embodied circumstance. This model also does not seek to contain the human within an identifiable set of characteristics, but assumes it to be a process of development that always critiques and exceeds itself. Self-tracking technologies may be the primary site that this focus on the human occurs, but these technologies are entwined with the governmental, medical, and corporate interests that will affect how the use of the human is developed in coming years. Making sure that governmental, medical, and corporate institutions stay open to models other than the traditional, humanist human remains vitally important, especially at points of emergence and integration of those technologies like we are experiencing now.
WORKS CITED


