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**The Making of Ignorance:  
Epistemic Design in Self-Tracking Health**

by

Meena Natarajan

A dissertation submitted in partial satisfaction of the  
requirements for the degree of  
Doctor of Philosophy  
in  
Information Management and Systems  
in the Graduate Division of the  
University of California, Berkeley

Committee in charge:  
Professor Paul Duguid, Co-chair  
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Fall 2016

**The Making of Ignorance:**  
**Epistemic Design in Self-Tracking Health**

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Meena Natarajan

## ABSTRACT

### **The Making of Ignorance:**

### **Epistemic Design in Self-Tracking Health**

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Meena Natarajan

Doctor of Philosophy in Information Management and Systems

University of California, Berkeley

Professor Paul Duguid, Co-Chair

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This dissertation contributes to emergent scholarly work on the dynamics of ignorance in the production of power. Drawing on my study of the health self-trackers who identify under the banner of the “Quantified Self,” I examine the “choreography” of ignorance in two intersecting forces that arbitrate the experience of illness and well being. The first force reflects an emergent phenomenon of individuals co-opting the computational gaze of contemporary mass surveillance and turning it onto the embodied self, a redirection that sees its most vibrant and experimental manifestation in this self-tracking community. The second embraces newly formed and structured efforts that redistribute the attention of American medical science from treating illness to preventing illness. This new medical imperative is anchored to the individual, now called on to adopt tracking technologies not only as an act of self-care, but also as a remedial intervention into the very institutions and scientific processes that many self-trackers believe have failed them. Institutional actors, however, present such pursuits as a “democratization” of American medicine. The Quantified Self provides the anchoring social context from which I access the interplay of these two forces, allowing me to illustrate how three engagements with ignorance — selectivity, uncertainty and obscurity — are implicated in failures of epistemic justice.

Ethnographic attention to ignorance remains minimal. Thus, the task of studying ignorance requires epistemic innovations. I explore Charis Thompson’s framework of ontological choreography as a tool to capture and analyze how ignorance is orchestrated to produce desired goals. I argue that the rhetoric of democratization of American medicine and the Quantified Self ethos is largely in service to the perceived needs of dominant groups and the establishment science the individual is called to help reform. I conclude that an analysis of ignorance offers an avenue to examine how novel technologies, new movements and fantastical speculations, all invested in rendering our bodies as “data,” reinforce existing dynamics of power.

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# 1 Introduction

My day in the near future will entail routines like this: I have a pill making machine in my kitchen, a bit smaller than a toaster. It stores dozens of tiny bottles inside, each containing a prescribed medicine or supplement in powdered form. Everyday the machine mixes the right doses of all the powders and stuffs them all into a single personalized pill (or two), which I take. During the day my biological vitals are tracked with wearable sensors so that the effect of the medicine is measured hourly and then sent to the cloud for analysis. The next day the dosage of the medicines is adjusted based on the past 24-hour results and a personalized pill produced. Repeat everyday thereafter. This appliance, manufactured in the millions, produces mass personalized medicine. (Kelly, 2016:173)

Kevin Kelly, writer, futurist and Bay Area counterculturist, is a self-described “protopian” — a protopian, he says, is a person who believes in incremental progress, where technological advancements usher in a few more choices and just a little bit more freedom (Brockman and Kelly, 2014). Unlike a utopian, Kelly states, a protopian understands that with these new options, will also arrive new problems. In his protopian fantasy, Kelly dreams of mundane things — taking his medication and supplements in his kitchen. Co-opting the cybernetic concept of the feedback loop, he envisions himself connected to a sleuth of prosthetic sensors that extract his biology in the form of “information”, setting in motion a continuous process of analysis and incremental augmentation towards an optimized embodiment. Typically, the hallmark of a cybernetic fantasy is the belief that human consciousness can be extracted from flesh bodies and transmitted without loss or modification, the body is merely a vessel, and that too, an expendable one (Hayles, 1999). However, the obstacle in Kelly’s orientation to embodiment is not the fact of a single flesh body that we must traverse our lives in — bodies are embraced in the countercultural ethos of the Bay Area after all (Zandbergen, 2011) — but the concerning reality of inevitable illness.

Susan Sontag writes of this predicament: “Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (Sontag, 1978: para.1). This dissertation examines the two strands that braid Kelly’s fantasy and arbitrate the two worlds of the ill and the well. First, is an emergent phenomenon of individuals appropriating the computational gaze of contemporary mass surveillance and turning it onto the embodied self, a redirection that sees its most vibrant and experimental manifestation in the community that Kelly has helped shape since 2008 — the Quantified Self. The second, is a shift in the orientation of those who treat illness, from ensuring the health of populations to attending to the unique and individual manifestation of wellness and disease, moving from treatment to prevention. In following the informational quest to deny illness an opportunity to manifest and consume us, in this dissertation, I ask what else is denied?



Kelly's "protopian" view suggests that these changes bring new problems — I consider how the denial of knowledge is orchestrated to intensify those that already exist.

In the first section of this introductory chapter, I briefly describe the self-tracking phenomenon that Kelly and Gary Wolf of *Wired* magazine, captured and fashioned into a community called the Quantified Self (QS). I explain how the individualized, computational pursuits of self-trackers intersect with recent calls by digital health proponents for the democratization and reform of American medicine. In the second section, I trace my research trajectory from exploring health information in developmental contexts in India to my three-year ethnographic study of this Bay Area phenomenon; noting that in both cases, a complex process of knowing and not-knowing characterize the pursuit of well-being. In the third section on the primary theoretical frames deployed in this dissertation, I draw from emergent scholarly attention to ignorance as an object worth examining, ignorance that is not merely a void or the negative of knowledge, but ignorance that co-exists with knowledge, that substantiates knowledge with its own contours and influence (Chua, 2009). Ethnographic treatment of ignorance is nascent (Mair, Kelly and High, 2012), and the strategies and theories we've deployed to study knowledge may not necessarily crossover to the study of ignorance (Tuana, 2008) — I introduce Charis Thompson's (2005) notion of ontological choreography as a framework to grasp the functions of ignorance in the intersecting social contexts explored in this dissertation. I propose that an analysis of ignorance offers an avenue to examine how novel technologies, new movements and fantastical speculations, all invested in rendering our bodies as "data" can reinscribe existing dynamics of power.

### **1.1 Self-tracking and the "democratization" of American Medicine**

A computational turn marks the everyday experience of illness. This turn is characterized by individuals appropriating consumer biosensors and surveillance technologies to produce their own medical self-experiments and knowledge. A wide array of devices and services, ranging from activity trackers, wireless heart sensors, at-home biomarker testing kits, consumer genome sequencing to wearable sounds sensors that listen to the state of your joints, help interrogate who gets to claim expertise on health and how. The self-surveillance, monitoring and tracking practices that characterize this turn is nothing new. Many of us keep count of things that we're told are important — the metrics that predict future opportunities or the signifiers of well-being and longevity. The Pew Research institute found that 69% of Americans monitor at least one health indicator, tracking their own health but sometimes also tracking for others in their role as caregivers (Tracking for Health, 2013). Self-tracking, in some, cases is not an option, as in diabetes, where it can mean the difference between life and death. Medical authorities often prescribe self-tracking for various mental and physical illness that require close monitoring and management (Lupton, 2013). However, even when self-tracking is pervasive in some form or the other in our lives, it's not often deployed as a method through which we try to understand and develop ourselves on a daily basis — self-tracking is most often seen in the kingdom of the ill. In its traditional instantiations, self-tracking is not a practice that we name, collectivize around, unpack or seek novel methods and technologies to enhance. Yet it is here that self-tracking in the

QS community, distinguishes itself. The QS community began and coalesced around the idea that self-tracking and measurement are powerful methods towards greater self knowledge and improvement (Kelly, 2007) — self-tracking in health, the QS ethos suggests, could mean we won't have to visit Sontag's kingdom of the ill, and if we absolutely must, self-tracking will guide us back to safety. This ethos is often, in practice, as qualitative as it is quantitative (Davis, 2013). Self-tracking individuals in the QS voluntarily initiate and sustain diverse practices of conscious self monitoring and experimentation, a practice Lupton (2014) terms “reflexive self monitoring.” Self-trackers turn their gaze inwards, armed with a collage of tools, sensors and apps that render various aspects of the self in the language of data.

Inventor R.Buckminster Fuller, whose counter-cultural legacy informs the QS founders and the ethos they shape, was an avid self-tracker as well, capturing his life every 15 minutes from age 20 till his death at 87 years old (Sanford, 2003). Fuller considered his documentation of himself known as the ‘Dymaxion Chronofile’ as an offering; in a reflection piece titled “Guinea Pig B” he refers to his project as “a living case history” (Fuller, 1983, in Zung, 2002) of an individual's experiences across the different points in history that his life encompassed. By using himself as an anchoring point, Fuller intercepted the different social currents that shaped his life. Although, most self-trackers do not embark on such monumental self-tracking projects, the auto-ethnographic orientation of self-tracking practice helps shape “reflective capacities” (Boesel, 2013a) around contemporary debates on technological mediation of personal lives.

Self-tracking practices in the QS are individualized experiments that are often then delivered and received as a contribution to a communal QS methodological toolbox, through a meeting format called the “Show & Tell.” This has a strict presentation format that requires answers to three questions: what did you do, how did you do it, and what did you learn? The personal stories told in these presentations evidence how tracking technologies are often appropriated by consumers in a manner that partially accepts, but also denies the intentions and goals of the producers. In many ways, that communal toolbox can be thought of as a collection of tactics (De Certeau, 1984) for living and becoming with data, where self-trackers enact a form of subversive agency as described by De Certeau, through the everyday practice of manipulating surveillance technologies and the creative reinterpretation of algorithmic judgements.<sup>1</sup> These data tactics are shared and examined in these meetings but also in blogs, and forums. Such mechanisms for participation, and the consequent communal engagement with self-tracking and data, results in a sort of consciousness raising: consciousness of how we all have a stake in contemporary debates on measurement, surveillance, algorithmic determination and big data — consciousness of how the personal is political. When engaged through a reflective lens such as in QS, self-tracking can function as inverse surveillance, where subjects of surveillance examine regimes of control through participant observation (Mann et al, 2003). In the case of QS, self-trackers are turning their gaze outwards by first turning it inwards, using the very methods, frameworks and technologies of the dominant medical and technological establishment.<sup>1</sup>

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<sup>1</sup> Thank you to Dawn Nafus for suggesting De Certeau in this analysis, and helping me consider and articulate self-trackers' co-option of the surveillance gaze, and their political stakes.

In collectivizing around a widespread practice and advocating for its legitimacy, QS sees itself as contesting the paternalism of institutionalized medicine (who gets to demonstrate medical expertise?) and academic scientific knowledge production (Boesel, 2013b). It also sees itself in critical dialogue with the logic and aspirations of big data, while still being deeply intertwined and dependent on those very frameworks for its resistance (Nafus and Sherman, 2014). This entanglement of multiple stakeholders in the practice of self-tracking and their ensuing co-dependency, suggests fertile ground for analyzing and contesting the various narratives of the body and health that authorize these engagements. For this reason, the QS as a field site offers a powerful anchoring point to intercept the different social currents that shape our contemporary understanding of health and well-being, including the second strand of developments captured in Kelly's pill machine fantasy — the call for a “predictive, preventive, personalized, and participatory medicine” (Hood, 2011). In the chapters that follow, I analyze how this new imperative is anchored to the individual, now called on to adopt tracking technologies not only as an act of self-care (chapter 4), but also as a remedial intervention into the very institutions and scientific processes said to have failed them (chapter 4 & 5). Multiple trajectories in computation, healthcare, and data sciences coalesce at this juncture, and a sense of imminent change, even a revolution in American medicine drives a push for self-surveillance at scale.

When the revolutions were occurring in 2011 in Tunisia and Egypt, predominantly propelled by the young oppressed citizens who would express and organize themselves via social networks and exploit the digital world, sharing pictures and videos, I tweeted: “Tunisia...Egypt...American Medicine?” In fewer than one forty characters, this conveyed my sense of urgency for consumers to provide the impetus for new medicine a New medicine that is no longer paternalistic, since the doctor does not necessarily know best anymore. (Topol, 2013:x)

Topol (2013), himself a cardiologist and a leading proponent of digital and wireless medicine argues in his book, *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care*, that this new medicine will come to be because of a “super convergence” of Silicon Valley innovations, a convergence that only the individual can effectively leverage:

All the other forces that could come to bear — doctors, the life science industry, government, and health insurers — are incapable of catalyzing this transformation. At the same time, the democratization of medicine is taking off. You, the consumer, are going to be needed to make it happen. There is one theme, one reason, why this creative destruction is ready to go. It is because for the first time in history we can digitize humans.” (Topol 2013:vi)

A diverse set of actors have begun to push for the genre of “democratization” that Topol evangelizes. In 2015, President Barack Obama announced in his State of the Union address, a government funded Precision Medicine Initiative (PMI) that seeks to “collaborate” with patients to better understand the environmental, genetic and lifestyle triggers for various intractable diseases, with the initiative referring to such cooperation as “patient powered research” (The White House, Office of the Press Secretary, 2015). In the near future, the promise of precision

medicine is not so much the development of drugs and treatments that are unique to the biological circumstance of each individual, but the ability to categorize individuals based on genetic propensity and other variables into groups; such categorization can help health systems develop and deliver preventive interventions with more precision and efficacy (National Research Council, 2011). A key objective of PMI is convening a cohort of over a million volunteers who will “donate” their data towards advancing medical science (The White House, Office of the Press Secretary, 2015). Although Topol (2013) and others consider such efforts as part of the democratization he proposes — a cultural shift that considers the patient as an epistemic partner with power to effect decisions — the design of participation in these initiatives suggest something else: that patients submit voluntarily to extensive surveillance, donate themselves to the cause of medical science, in the hope that one day, they will access services that are more customized for their unique embodiment.

However, many patients who enter the QS and adopt its modality of inquiry, feel they don’t have the time to wait — in fact, #wearenotwaiting is the hashtag associated with some diabetics who developed an artificial pancreas to personalize the management of their disease when device makers did not address their concerns (Lewis, 2015). Notions of individuality and experimentation are central to the QS ethos as I describe in chapter 3, and it seeks to fashion citizen scientists who create an alternate science, built on a sample size of one. However, as I show in chapter 5, the rhetoric of precision medicine is ontologically fluid and able to subsume the citizen science orientation of the QS. The voluntary in-situ data collection evidenced in the QS becomes an alluring resource for medical authorities looking to aggregate and harness such data towards the PMI genre of goals. This dissertation examines the dynamics of and tensions between these two contemporary forces over a three year period: a self-tracking phenomenon that turns the surveillance gaze onto the embodied self, as evidenced in groups like the QS, and the recent re-orientation of medical science from treatment of illness to prevention. In the section that follows, I describe the research trajectory that led me to the subject of study in this dissertation, and the kinds of questions I was primed to ask. After this look back, I describe the main theory that frames the analysis in this project.

## **1.2 Tracing my research trajectory**

My experience prior to this doctoral research was in Human-Computer Interaction (HCI), a field of study that examines the relationship between people and technology with the goal of designing contextually relevant, easy to use, enjoyable interfaces and systems. The emergent field of Information Communication Technology and Development (ICTD) is an allied field, that applied HCI goals and processes to international development objectives. ICTD practitioners and researchers tended to perceive issues of development as an affliction particular to the Global South. In my early doctoral work, I was immersed in similar ideas and pursuits, involving ethnographic work in my home country of India. In the traditions of HCI, my ethnographic methods were in service to computing and design projects (Dourish, 2006). Both HCI and ICTD tend to construct adverse human circumstances as problems of information as several other fields of study in this dissertation do as well, with technology solutions enabling “users” to access the

right information, at the right time, in a manner that was relevant to their circumstance. Underpinning this worldview is an uncomplicated and idealistic connection between “information” and “empowerment.” ICTD researchers considered many development problems through a “plumbing metaphor.” Imagine a network of pipes; on the one end is an entity with information that the individual, group or organization at the other end desperately needs. Along the network of pipes are various obstacles that produce inefficiencies in how information flows to that abject recipient languishing without the right information. The technological task is to remove all obstacles in the path, connecting the two parties, with information flowing like water to where it’s needed most. Receiving this information, in the eyes of ICTD, is fundamentally “empowering” for the “users” of its systems. However, concepts of “information” and “empowerment” were for the most part, left unexamined and under-explored during my socialization in ICTD discourse.

In my first fieldwork experience in the summer of 2011, in the western Indian city of Ahmedabad, Gujarat, my task was to mediate the relationship between two organizations. The first organization, Awaaz.de was a brand new ICTD social enterprise at the time, an outcome of Neil Patel’s doctoral research from Stanford University and Tapan Parikh’s research group at UC Berkeley. Awaaz.de leveraged the ubiquity of mobile phones across the socio-economic spectrum in both urban and rural India to create knowledge-sharing platforms with spoken voice. The voice based social networks Awaaz.de created, helped overcome literacy deficits in some Indian communities that various Non Governmental Organizations (NGOs) wanted to support. That is, literacy was the obstacle that prevented the NGO’s expertise from flowing to its constituents and empowering them, and Awaaz.de remedied that problem by building a system that used spoken voice instead. A typical implementation of Awaaz.de would involve a partner NGO with expertise in a domain like agriculture, and an interactive voice response system managed by Awaaz.de where farmers in the NGO’s domain could leave voicemails asking questions and receive responses from experts tailored to their local contexts (Patel et al, 2010). Awaaz.de was also used for peer-to-peer sharing of knowledge (Patel et al, 2012) and for the NGO to push information to all its constituents with mass broadcasts. The flow of information, unlike many information provision interventions, was multi-directional in Awaaz.de projects, placing it in a rather novel and unique category in the ICTD milieu at the time.

I spent my summer, researching use cases and developing relationships with local NGO partners; the goal was to see how Awaaz.de’s voice based social media service could be put to use to provide health information to communities perceived as deficient in critical forms of knowledge necessary to produce positive health outcomes. Much of the analysis by NGO workers, the social enterprise and myself as a researcher was around how the Awaaz.de system would be implemented. We tended to ask the following questions most frequently. What kinds of information did people desire and need? What kind of information did NGOs want to disseminate? How did people conceive of privacy? And, how might literacy levels intersect with the usefulness of these systems? Although, there was evidence in the field of the efficacy of Awaaz.de in altering agricultural practices especially given its Q&A model, whether the information we would communicate through this system for other use cases, would in fact

change practices was rarely up for interrogation in research pursuits. This is a pattern of ICTD research endeavors that doesn't trouble what impact information disseminated will have but follow an imperative to instantiate access, a mediating cog connecting the two ends of "information" and "empowerment" in the plumbing model described earlier. In addition, the social enterprise and the NGOs I worked with had prior success with information sharing models, and were funded to facilitate these models of dissemination as their main objective. Given these goals, the genre of research questions at play were appropriate.

My intent in illustrating these patterns here is to make apparent the assumptions that directed the trajectory of my own questions. For example, this section of my research left uncomplicated the idea that ignorance was the problem and dissemination of information, the right kind, accessible in local languages and relevant to the recipients contexts was the solution. I did not think to interrogate how the subjects of the NGO were being constructed as "not knowing" or how various absences in knowledge became critical forms of absence necessitating these technology interventions. The centrality of tools in these research pursuits directed what could be known or even understood about these settings. When an NGO rejected the technology or there were significant barriers to adoption, these issues did not warrant a deeper analysis of how these technologies were intersecting with socio-cultural structures as there were always other "use cases" waiting to be discovered. The construct of technology like the concept of information underwent little examination.

In the summer of 2012, I took a different approach, where an existing system was not the central focus of my fieldwork but instead I was curious about how low-income women with HIV (Human Immunodeficiency Virus) considered privacy in my home city of Chennai. This focus on HIV+ women and privacy was prompted by a grant opportunity and our research groups emergent interests in sensitive information, and how it may be transmitted. A design question was still central; if we were to consider a platform, we would first need to understand how notions of privacy differed among relevant groups. My access to HIV+ women was mediated by a local NGO run by HIV+ women, an access that was in fact quite limited. But what was evident right away, was the fact that it wasn't so much the lack of information about HIV prevention that was a barrier in this population (low-income women married to men who were identified as high risk by the state) but the fact that information was incompatible with the circumstances in which they could become actionable — structural conditions, gender roles, issues such as stigma all intersected rendering information received unusable (Natarajan & Parikh, 2013). This experience helped trouble the information flow and dissemination models that anchored my ICTD training and helped me understand the limits of informational interventions in health projects, and surfaced how informational technologies intersect with larger cultural and institutional norms.

Observing that many ICTD technology interventions — designed with information flow assumptions described above — had roots in research institutions in the United States, I was curious about how contemporary North American researchers considered development and how their narratives about technology-enabled progress manifested locally in the United States, and traveled through international development interventions to the kinds of settings that I studied in

India. It was this question that led to my online search to find mobile health and digital health events and my serendipitous discovery of the QS; I was hoping to configure a field site in the United States, to observe and explore the questions I had come to have through my experience in India.

After my first encounter with the QS, described in the following chapter, I kept going to QS gatherings in both LA and the Bay Area. Given my background in technology-enabled development and interest in participatory processes, what I initially saw in the QS gatherings, was a local and situated appropriation of mobile devices towards well being and health, sometimes in conversation with the health care system and many times, in response to the failures of institutional medicine — QS actors presented self-tracking as a challenge to current dynamics of epistemic power. This kind of local appropriation of information technologies was one that many ICTD researchers I knew aspired to discover or materialize for their own interventions in the Global South but had trouble doing so, with most interventions using participatory processes to gather requirements and use cases for design, rather than for the community — in a position of epistemic equity with researchers — actively directing the course of the intervention. The QS presentation of self-tracking appeared to suggest a desire for participation, akin the Scandinavian origins of cooperative practices and design where prospective users of technology were not only involved throughout the design process, contributing to specific features of the technology, but were also able to make key decisions about research and development directions (Bjerknes, Ehn & Kyng, 1987). The QS offered, as I saw it then, an anchoring point, through which I could begin exploring ideas around progress, participation, privilege and marginality as they relate to the body and technology in the United States. In these ways, my project continues in the tradition of ICTD but examines the concept of “development” back home at its origins (Sachs, 1992; Escobar, 1995).

In addition, my trajectory and particularly my experience examining HIV/AIDS prevention information, primed me to look at how known health information was engaged through the self-tracking modality of inquiry. As my participation in the QS cultural context evolved, I began observing a pattern where white, educated, mostly male and upper-class individuals with significant cultural capital, conveniently forgot or denied widely disseminated health information and recommendations, rendering them as unknown until their self-tracking practice and process delivered the same recommendation as a finding. Take as an example, the case where a self-tracker launches an extensive and tedious experiment to identify the cause of his fatigue, attempting various creative interventions in the process, only to find after considerable effort that he felt less tired when he got a good night’s sleep. Although, a personal process of discovery allow individuals to feel a greater sense of ownership to health information and a greater sense of efficacy in producing health outcomes (Kazdin, 2012), the widely disseminated advice to get a good night’s sleep in order to prevent fatigue was not introduced early in the experiment, but discovered after many other interventions failed.

Unlike the cases I observed in HIV prevention, there were no structural conditions or social norms that prevented these self-trackers from deploying the health information they had, they

just did not see such information as necessarily relevant to them unless their data revealed that it was, and in which case, it was often perceived as a novel discovery of their own. Another kind of engagement with knowing and not knowing, was found in personal storytelling about failing self-tracking processes that nevertheless worked to help such practices persist (examined in chapter 4). In the self-tracking stories I observed, a sophisticated process of narrative development emerged, dependent on the production and maintenance of both knowledge and ignorance. In what follows, I discuss the theoretical frameworks that helped me unpack such processes at both the individual and social levels.

### **1.3 Ontological choreography and the social construction of ignorance**

There are two theoretical frameworks that I bring together in this dissertation: Charis Thompson's (2005; 1996 as Charis Cussins) notion of 'ontological choreography' and scholarship on the social construction of ignorance (Proctor and Schiebinger, 2008), including philosophical theorization on race and epistemologies of ignorance (Sullivan and Tuana, 2007; Mills, 1997, 2008). Contemporary reworking of key ethnographic concepts and approaches (Clifford and Marcus, 1986) positions as an imperative the examination of ignorance in the accounts of informants (as detailed in chapter 2); however, attention to ignorance remains minimal (Mair, Kelly and High, 2012), limiting the emergence of methodologies to examine ignorance. Thus, the task of studying ignorance requires epistemic innovations (Tuana, 2008). In this dissertation, I explore the framework of ontological choreography as a tool to capture and analyze ignorance as an ethnographic object.

Thompson developed the notion of 'ontological choreography' through her ethnography of an infertility clinic. In her analysis, she asked, what exists in a treatment program and in the narratives of patients? And, what kind of relationship exists between those things? She explains how various actors in the clinical setting choreographed the relationship between different things in a manner that was role specific, flexible, personalized, strategic, and functional. Thompson (p. 204) states of the ontological engagements evidenced in the accounts of her informants: "I call this process of forging a functional zone of compatibility that maintains referential power between things of different kinds, ontological choreography." As scholars of ignorance have pointed out, ignorance is not merely an absence of knowledge but an entity that always co-exists and substantiates knowledge (Chua, 2009). Thus, Thompson's framework provides an entry point to the ethnographic study of ignorance as it allows us to note and surface ignorance as an object that also exists in the practices and narratives of self-tracking health — when ignorance is conceived as a thing that exists, when it is no longer an absence, we can track ignorance and its influence in the dynamic and shifting ontological choreography of self-tracking health. Given the centrality of ontological choreography in my analysis, in what follows, I first describe Thompson's theorizing in detail and the argument it helps her assert, before reviewing scholarship on the study of ignorance that I draw into a conversation with ontological choreography in subsequent chapters.



A long drawn out process of attempting pregnancy typically configures an orientation to one's body that is characterized by close monitoring and research, a self-directed medicalized gaze develops. When men and women seek treatment in infertility clinics after their own efforts have failed (Thompson focuses primarily on women given the significant cultural focus on women's reproductive capacity in cases of infertility), their bodies undergo a more amplified and extensive process of "un-black boxing" (Cussins, 1996:581) as they pass through the series of objectifying steps involved in treatment. Some humanistic and feminist theorization of infertility treatments, Thompson notes, have frequently critiqued the objectification involved. Thompson's ethnography, however, challenges the argument central to such critique, which suggests that "selves need to be protected from technological objectification to ensure agency and authenticity" (p.179). Instead, she suggests "objectification is only sometimes a reductive state in opposition to the presence or goals of a subject" (p.179), as evidenced in how Thompson's patient informants appropriate such objectification, re-author various stages of clinical and technological intrusion; and choreograph the things that exist: people, bodies, organs, objects, technologies, ideas, goals, in a narrative that helps them, as patients, persist through the treatment process with a felt sense of agency. The objectification that critics surface, is itself grasped as one thing, that is then willingly embraced by patients to produce themselves as parents. There are several explanatory components and mechanisms that are significant in this process — I describe them below.

An important concept in Thompson's analysis is the idea of the "long-range self", an ontological innovation or end state that her informants seek to embody when treatment is successful, in this case, the informant as "pregnant" or now "parent." Thompson borrows a literary device called the "synecdoche" — a synecdochal connection is ascribed when a part of something is understood as representing the whole, and vice versa (Percival, 2010) — to articulate how the different parts that a woman is disassembled into during the unblack-boxing process, are understood by her and other actors as still representative of her as a whole, and connected to her long-range self. She explains that as long as treatment is still underway, the objectification inherent in the process is experienced with a sense of agency, as the synecdochal connection between those states of objectification and the long-range self is still intact (Cussins, 1996). For example, during infertility treatments, parts of the woman's reproductive tract are conceptually separated and perceived as a singular mechanistic entity, "enabled to display properties in their own right" (p.584); this conception helps doctors consider what might be dysfunctional in the organ, and potentially "fix" it. Rachel Prentice (2012) evokes a related concept which she terms, "tactical objectification" referring to the socialization that equips a doctor to see the body both as an object and personhood as appropriate for medical action and goals. For the patient, this manner of considering parts of her body in mechanistic terms supports the idea that her body can be fixed, increasing her chances of pregnancy, or ontologically innovating the long-range self. Any separations or distanced rendering of her embodiment such as extracted eggs, quantified lab results, etc., maintain synecdoche by absorbing the personhood of the patient (Cussins, 1996).

If we were to consider this phenomenon in self-tracking, it's not that quantification reduces people to merely numbers (Morozov, 2013), but in a self-initiated self-quantification quest, the

numbers absorb the personhood of the self-tracker — the numbers go through a process of projected humanization, instead of the person undergoing de-humanization. Since synecdoche is maintained between parts of the self rendered as numbers and the self as a whole, the quantification is not necessarily experienced as reductive and objectifying — but this synecdochal connection is not experienced by the gaze of another, perhaps leading to the misperception of self-trackers' self-quantification as likely objectifying and disempowering. Often, researchers in conversation with self-trackers in the QS warn that a measurement focused episteme neglects other ways of knowing. However, this line of critique neglects to see how much of the “objective” experimentation narratives found in self-tracking involve strong subjectivity. In practice, these modes of inquiry are already enmeshed and ontological choreography helps surface their co-dependence in self-tracking cultures. In addition, Thompson (2005) notes a pattern of subservience to physicians in the treatment setting; women saw the physician as a “point” in the “critical trail” (Cussings, 1996) that will lead them to pregnancy, the “medical gaze” of the physician and technical interventions all had utility, as these points in the trail are still synecdochally connected to the long-range self.

However, when treatments fail, the synecdochal connection breaks, that is, it becomes evident that such objectification of a woman's body is not going to produce her as “pregnant” and “parent” — at this point, the woman feels increasingly alienated from her body and the interventions to which she has been subjected. During treatment, women described their process in highly technical and diagnostic terms. When treatment failed, women's accounts of why it failed signal to a synecdochal rupture: they state that the treatment wasn't personalized to them, that they didn't have agency, that their expertise about their own bodies were not taken into account (Cussins, 1996) — that is, a treatment process that was objectifying from the get go, is only now perceived as objectifying, and patients began to feel stripped of their personhood. This pattern of analysis is also evident in the accounts in my fieldwork of patients who have been misdiagnosed, and inadequately treated while facing chronic illnesses. In fact, the patient empowerment movement that stems from the perceived failure of the health care system — the severed synecdochal connection between health care services and individual health — of which the self-tracking patients in the Quantified Self are an instantiation, take these three factors of agency, personalization and patient expertise as central to a better healthcare experience as well.

Thompson noted that when treatment consists of a series of failed attempts, followed by success, the patient perceives all past failures as merely a stepping stone towards pregnancy — retroactively, those moments of failure re-connect in a synecdochal sense to the long-range self pursued during treatment. Even when women account for their success, the objectification inherent in the process that led to their pregnancy recedes in their accounts; instead, the technical interventions they were subjected to become “inevitable or invisible or irrelevant” (Cussins, 1996:594). Patients attribute their success to luck or the high-quality personalized care they received, and at times, they resist considering the diagnostic and treatment factors that led to their pregnancy. The “dysfunctional” organs that were once separated and examined through a mechanistic lens are now re-integrated into a sense of self.

Not only was this phenomenon of synecdochal connections evident in women's orientation to technical interventions in the treatment process but also in relation to concepts like genes, and the friends and family they choose to assist them in their reproductive goals (Thompson, 2005). In cases where a woman chooses an egg donor based on the ethnicity of the donor, she projects a racialized sense of her own personhood onto the donor and her genes, who is then rendered as able to transmit that personhood onto her future child. In another instance, an African American woman described her decision to choose either a friend or her sister as her donor, as an extension of the established social practice of looking after each others children in her community. If we can look after each other's children in our everyday life, why not during pregnancy? In addition, in cases of surrogacy, the surrogate mother would put in considerable effort to willingly objectify herself as merely a "womb." This objectification anchors and maintains the synecdochal connection between the patient and her long-range self as the legitimate mother. If the surrogate were to assert a different identity, then the synecdochal connection becomes vulnerable, risking the experienced integrity of these mechanisms. Let's revisit Thompson's definition — "I call this process of forging a functional zone of compatibility that maintains referential power between things of different kinds, ontological choreography" (p.204) — we can see now how the maintenance of synecdoche is the key element of ontological choreography and this synecdochal dynamic is one I will draw on throughout the dissertation.

In chapter 4, I borrow this notion of ontological choreography to examine how the personal narratives of patients seeking to produce desired health outcomes through self-tracking, rest on a sophisticated re-authoring of components of self-tracking and illness that is functional in helping self-tracking persist in the pursuit of their long-range selves. This analysis described in chapter 4, and in particular, the story of overcoming migraines, was pivotal in my analytical process as it offered a way to examine how self-trackers engaged forms of ignorance or "not knowing" in their personal narratives of health and self-tracking. Next, I introduce scholarship on the social construction of ignorance, focusing on some of the seminal work on epistemologies of ignorance. In the very first QS meeting, Wolf suggested while speculating about how much one individual could possibly learn in their lifetime, "There are some glitches: learning some things can interfere with knowing other things" (as summarized in Roberts, 2008). In what follows, I describe various glitches pertinent to QS process of knowledge production, surfaced by theories of ignorance.

Some scholars refer to this domain of study as agnotology, a term coined by Robert Proctor (2008), a historian of science and technology. Proctor's (2008) early work examining the tobacco industry's systematic production of doubt in the public about the link between smoking and cancer was pivotal in his sustained pursuit of ignorance as an object of study. Philosopher, James Frederick Ferrier originally used the term agnoiology to theorize ignorance as only that which is unknown or ignored and on which knowledge exists or is attainable (Proctor, 2008). Works under the umbrella of agnotology take as a given, more often than not, the idea that ignorance, systematically produced needs to be remedied by exposing how that ignorance has been held in place, foregrounding correct or alternative knowledge or paying attention to hitherto unexamined objects/phenomena, even when such ignorance may be functional for some actors. Proctor and

Schiebinger (2008:vii) state in introducing their edited volume titled *Agnotology: The Making and Unmaking of Ignorance*:

Our primary purpose is to promote the study of ignorance, by developing tools for how and why various forms of knowing have ‘not come to be,’ or disappeared, or have been delayed or long neglected, for better or for worse, at various points in history... The idea is that a great deal of attention has been given to epistemology (the study of how we know) when ‘how or why we don’t know’ is often just as important (as epistemology), usually far more scandalous, and remarkably under-theorized.

There are three categories of ignorance that Proctor (2008) offers that are also evidenced in the QS cultural context. When we commonly talk about ignorance as a deficit in knowledge that we must remedy, we are referring to the first category of ignorance Proctor (2008) describes — “native state” ignorance. Such absence of knowledge occurs naturally where “knowledge has not yet penetrated” (p.4) and diminishes over time as more attention is paid to the void. This kind of ignorance acts as a “prompt” (p.5) that impels scientific knowledge production. In its ability to motivate knowledge pursuits, Proctor sees native state ignorance as a resource: “The world’s stock of ignorance is not being depleted however, since (by wondrous fortune and hydra-like), two new questions arise for every one answered” (Proctor 2008:5). Native ignorance can also be foolish or innocent, but there is general agreement that such states must be overcome. Self-tracking projects are activated by a sense of the native state ignorance about our bodies and ourselves. The pursuit of diagnostic closure by self-tracking patients without diagnosis, for instance, is fueled by the need to overcome deficits in how one’s illness is grasped and how it becomes actionable. In the process, ignorance about biosignals — a naturally occurring ignorance given our inability to perceive those hidden signals without technological intervention — becomes a popular object of examination.

Proctor’s second category is called “lost realm” or “selective choice” where ignorance emerges as a byproduct of decisions we make on where and what to focus our attention; some native states get addressed and others remain ignored. In scientific practices, we often understand such ignorance as transient, as more and more domains come under study, we envision that the areas we once neglected will eventually be known — “Science is like mowing a lawn: you can choose any place to start, but things end up looking pretty much the same” (Proctor, 2008:7). However, of concern is the ignorance that never gets addressed: “This is a different sense of selectivity: that knowledge switched onto one track cannot always return to areas passed over; we don’t always have the opportunity to correct old errors. Research lost is not just research delayed; it can also be forever marked or never recognized” (p.7). Proctor uses an example from Londa Schiebinger’s (2008) work tracing the kinds of knowledge and goods that colonizing Europeans chose to bring back from the terrains and cultures that their expeditions exploited. A notable absence was natural abortifacients like the peacock flower, likely deemed of little value when European states were looking to grow their populations, and of little interest to male naturalists who were part of such conquests. Such selectivity creates a lost realm — Schiebinger (2008)

argues: “One wonders what easy, safe, and effective methods of birth control and abortion have been lost to women because innocent plants have become entangled in the web of history and wide-ranging cultural politics” (p.159). Although, empirically hard to capture, one could speculate how this form of ignorance may be particularly pertinent in the QS, given the decisions self-trackers must make about what to track and various behavior modified by findings — a prior self cannot be recovered for examination ever again. In chapter 3, however, I use ethnographic data to examine how selectivity in epistemic priorities shape the QS cultural context, serving to maintain aspects of white privilege while preventing a historically engaged orientation to difference, which ultimately disempowers the white majority from challenging institutional medical science.

The third category Proctor (2008) describes is called a “strategic ploy.” The lost realm category of ignorance is a passive construct as ignorance emerges as a side effect of selections we make; in this final category, ignorance is seen as “actively constructed” in order to accomplish an end goal. For example, in Proctor’s own research of the tobacco industry, he reveals the systematic production of doubt in the public by selectively appropriating scientific notions of evidence, to challenge the connection between smoking and cancer — central to this ploy is the use of uncertainty; tobacco lobbyists repeatedly claimed that the scientific evidence presented was not enough to prove that tobacco causes cancer and that more and more research was needed to quell the uncertainty. A similar tactic of inducing uncertainty was deployed in the denial of climate change and the effects of pollution (Oreskes and Conway, 2008). In chapter 4, I show how such uncertainty and similar claims that gathered evidence is inadequate are actively woven into dynamic personal narratives to produce ongoing and sustained self-tracking commitments in negotiating illness, even in the absence of health outcomes. Unlike the nefarious intent underpinning the likes of the tobacco industry and climate change deniers, I show how the tactic of uncertainty can also produce hope and a form of resilience in the face of adversity. In chapter 5, I examine a different production of uncertainty — the act of obscuring. I show how medical authorities interested in aggregating self-tracked data obscure notions of participation — central to the values of the QS community — by obscuring the difference between citizen scientists and data donors. In doing so, they engage the QS participatory framework, while creating an access point in that framework that fulfills their own needs for data. In addition, I show how minority groups are obscured in discussions on sample representativeness, in a fashion that prevents participants from being able to grasp the “other” as an epistemic equal, further entrenching the racial privilege of QS members.

In the examples of agnotology theory described above, the primacy of knowing, its value, outside of privacy and protection of vulnerable subjects, is still maintained. In another set of research, critical scholars of race, study how epistemologies of ignorance sustain racial contracts — in particular the phenomenon of “white ignorance”, a set of cognitive norms of assessment and patterns of belief forming that help maintain white supremacy (Mills, 1997; 2008). Here, the focus is not, what do many white people not know/acknowledge about racial injustice, for example, but how do they keep not knowing even in the face of evidence? Charles Mills (2008) describes such ignorance as an “inverted epistemology” in its active effort to dismiss social

truths shared by minority groups and render racial ignorance as knowledge. Mills' thesis on ignorance is seen as seminal in this emergent genre of scholarship. His work on white ignorance issues a corrective to the absence of race and ignorance in discussions of epistemology; he begins his book with a black folk aphorism: "when white people say justice, they mean just us." (Mills, 1997) introducing his argument that the theoretical notion of the "social contract" rests on a racist ideology, a racial contract that excludes people of color from the protections and entitlements offered to citizens by the state; race has been a significant entry point in considering the production and maintenance of ignorance, and consequently, injustice. Following Mills, Shannon Sullivan and Nancy Tuana (2007) shaped the next significant text on ignorance titled *Race and Epistemologies of Ignorance* (2007). Both these texts, grounded in philosophy and close reading of literary work, examine "practices of not knowing that are linked to and often support racism" (Sullivan and Tuana, 2007:3). This scholarship on race and epistemologies of ignorance is particularly useful in examining what it means for a movement intersecting with health reform in the United States to be largely comprised of white individuals (chapter 3). How does whiteness influence the structures of this community, their engagement with knowledge and ignorance, and the specifics of their counter-conduct assertions? What are the implications for racial justice in medical science and practice?

In the same volume, Linda Martin Alcoff (2007) writes of the epistemologies of ignorance and identity: "noting the ways in which cognitive situatedness can be correlated to group identity cannot lead to a replacement of epistemic considerations for identity considerations. The point remains that the problem is in the cognitive norm, not in the identity per se, and so we need to focus on isolating and identifying these dysfunctional norms and understanding how they operate" (p.50). Mills also suggests that the phenomenon of white ignorance is not an indication of individual failing and can not be understood as the sum of individual acts, but is a meta level phenomenon that stems from how dominant racial groups are socialized. In a similar vein, although, not explicitly a study of ignorance, Bonilla-Silva's (2009) arguments in *Racism without Racists: Color-Blind Racism and the Persistence of Racial Inequality in America*, also helps us understand how racial inequities persist through the transformation of blatant forms of racism into more subtle reworkings. This work is particularly pertinent as it exposes how notions of individualism, free-will and self determination, akin the values of the QS epistemic ethos I describe in chapter 3, are innocently complicit in furthering racial injustice.

One might ask why racial epistemologies of ignorance are important to consider in a rather racially homogenous community whose intended goals do not involve racial justice. And certainly, when I first chanced upon these theories of ignorance, I was not asking these questions, deriving instead from these theories, a framework for how ignorance can also be functional. However, as the QS came into conversation with public health stakeholders (examined in chapter 5), its homogenous nature became constructed as a "diversity problem" that damaged the representativeness of self-tracked data, and the QS was now called to address this bias in order to more fully engage the interests of state and institutional science actors. Such calls have engendered QS discussions on equity and highlighted my own outsider status as a woman of color, which I deploy as an instrument in theorizing race in the QS. I draw from theories on

white ignorance to examine how the ways in which QS structures its dominant knowledge exchange platforms, and its de-historicized embrace of difference, create a rather weak platform for minority groups also invested in health reform. Further, in chapter 3, I draw from Hoagland's (2007) guidance that a key characteristic of white racial ignorance is the mechanism of "denying relationality" — the failure to see how white racial identity and representation is mutually constituted by the representation of minority groups — I argue that this denial functions to jeopardize the capacity of dominant groups to contest institutional medical science that has failed them as well.

These different theories of agnotology help me understand how knowing and not knowing are functional, even when they might not be intentional, in shaping the possibilities and limitations of the contemporary self-tracking conversation found in the QS. In each subsequent chapter of this dissertation, I account for specific facets of agnotology and racial epistemologies of ignorance: selectivity in chapter 3, uncertainty in chapter 4, and obscurity in chapter 5. As mentioned earlier, ethnographic study of ignorance have only recently emerged (Mair, Kelly and High, 2012) and methodologies to examine ignorance as an ethnographic object are still emergent. The framework of ontological choreography guides my analysis of ethnographic encounters. In chapter 3, I ask how certain beliefs formed without evidence, shared and internalized in specific cultural fields like Silicon Valley — what Bourdieu refers to as Doxa (1992); "there are many things people accept without knowing" — are woven into the QS epistemic choreography. In particular, the Doxa that technological advancement is imminent and inevitable, anchors the QS ethos and also helps sustain self-tracking practices even when they produce no relief in chronic illness as I show in chapter 4. In chapter 5, I show how negotiations between various actors coming together in partnership to create a "Quantified Us" obscures participation to ensure epistemic dominance. In order to analyze what's at stake when knowledge pursuits are predicated and dependent on various ignorance products, I derive from theories described above on the social construction of ignorance (Proctor and Schiebinger, 2008) and racial epistemologies of ignorance (Mills, 1997, 2008; Sullivan and Tuana, 2007; Bonilla-Silva, 2009). I argue that the absence of a racial analysis in the toolbox of "reflective capacities" developed by the QS serves to limit its emancipatory potential for everyone involved.

#### **1.4 Organization of this dissertation**

In this introductory chapter, I highlighted two intersecting phenomenon: self-tracking and precision medicine, that run through the entirety of this dissertation. I traced my research trajectory and outlined the theoretical frameworks I deploy in my analysis in subsequent chapters. In chapter 2, I describe the different interconnected sites and positionalities that were relevant in my research, outlining their characteristics. I then explain how I defined and constructed the field site wherein I examined the QS phenomenon. I recount the manner in which I was socialized as a researcher through my interactions with QS leaders, and the norms of the QS cultural context I accessed through such social processes. I explain how QS leaders negotiate the expertise of researchers, entrepreneurs and public health stakeholders; in what ways do the QS leaders defend the QS cultural context from 'experts' and in what ways are the activities in

the QS milieu co-opted by such expert and entrepreneurial actors? In this chapter on methodology, I locate my fieldwork in ethnographic methodology, specifically contemporary approaches like multi-sited fieldwork (Marcus, 1995) and ethnographic study of ignorance. In doing so, I hope to provide the context through which my findings and analysis in subsequent chapters are best understood.

In chapter 3, I examine the selectivity found in the strategic design of the QS cultural context by the QS leaders. I describe how Wolf and Kelly envisioned and designed the QS as a space to bring and discuss a self-tracking phenomenon that was already under way. I describe key structuring elements that draw boundaries around what constitutes legitimate practice and knowledge in the QS cultural milieu: insights generated through data mediated investigation of personal experience. I show how an epistemology of personal experience, not quantification, is what attains a privileged status in the QS discourse. I situate this emphasis on personal experience as the legitimate path to self knowledge in gnostic epistemologies of experience and libertarian world-views that counterculture rhetoric in the Bay Area have historically drawn from (Zandbergen, 2011). I problematize the turn to experience as expertise using critiques of a similar turn to ‘local’ and ‘difference’ in development history and standpoint epistemology. In chapter 3, I examine how such epistemic commitments of the QS produces a glitch, an ignorance that “emerges as a by-product” (Smithson, 2008:214) — a color-blind (Bonilla-Silva, 2009) style ideology that claims to embrace difference, while ignoring historical inequities, thereby reinscribing functional forms of ignorance that serve to maintain white privilege, limiting the reflective capacities (Boesel, 2013a) essential to challenge institutional medicine and medical injustice.

Chapter 4 explores the productivity of uncertainty. How do self-trackers engage uncertainty while negotiating the prospects of debilitating illness? I use two cases of self-tracking illness and the framework of ontological choreography to reveal the private re-authoring of disempowerment and uncertainty using technology, numbers, data, experiments, woven into a dynamic and functional narrative. I show how patients in each case, design their relationship to uncertainties, sometimes producing new forms in order to renew their ability to hope for a better future. I show how self-tracking becomes a coping mechanism in the face of bodily adversity and the choreography of its components engenders a form of resilience. In addition, this chapter shows how the self-tracking concept is flexible enough to accommodate the highly personalized narratives of each case. In the chapter that follows, I show how the contours and meaning of self-tracked data are shaped to engage the needs of larger stakeholders.

Chapter 5 focuses on the act of obscuring. I examine self-tracked data as a “boundary object” (Star and Griesemer, 1989) upon which different actors attribute different meaning. In particular, I focus on how medical authorities and QS leaders conceive of the expertise that self-tracked data bestows on the individual or groups engaged in self-tracking. Drawing from work on the “politics of boundary objects” (Huvila, 2011), I argue that medical stakeholders enact dominance by subsuming the QS aspiration for self-trackers to be seen as equal partners in advancing medical science, by obscuring the meaning of participation that hinges on self-



collection of data; we go from citizen science to “data donations”, and back and forth. This production of ambiguity around the meaning of self-tracked data, and the participation it evokes is functional, as the QS framework is partially supported, and left able to engage the ontological shifts. In the second section, I show how participants in the QS Public Health Symposium, motivated by a new imperative to produce a more ethnically representative sample in aggregated self-tracked datasets, attempt to grasp the “other” they’ve been called to “value”; I argue that by obscuring the “other” through a deficit framework that serves to question the ability of minority groups to participate as equal epistemic partners, the actors in the Public Health Symposium enact positions of racialized power and reinscribe white privilege. In these two ways, I argue, the act of obscuring serves to maintain power.

In the concluding chapter, I bring together the different ways in which the new self-tracking culture persists and limits its potentiality for reform by producing and keeping in place various forms of ignorance. I argue that the rhetoric of QS and its negotiations with institutional medical science is largely in service to the needs of dominant social groups and the establishment science the individual has been called to reform.

# 2 Studying Self-Tracking in the Quantified Self

## 2.1 Discovering the Quantified Self

In 2012, artist Benjamin Grosser created a critically acclaimed browser extension that erased all quantification from the Facebook interface. The ‘Demetricator’ hid numerical interface descriptions of your Facebook self — how many friends you had, how many people liked your post and when. Instead, it would state “some people” liked or commented on your post “recently” and so on, circumventing any impulse to measure and scrutinize interactions on the social network, and any ensuing sense of pleasure or dismay. The Demetricator was a small but refreshing intervention into the liminal anxiety that I experienced using Facebook. Many other people found relief and the Demetricator was written about in several critical internet art venues, with one reviewer referring to it as the ‘Unquantified Self’ (Smith, 2012). It was only in the context of this critical intervention, that I’d ever remembered hearing the term *quantified* together with the word *self*. Around a year later, on the 6th of March, 2013 to be precise, I scrolled down a Google results page, while searching online for digital and mobile health events in Los Angeles, spotting a link to the “Quantified Self” at the very bottom. I thought the name was likely in jest — perhaps even another critical project. I remember opening it, curious and excited, and finding an actual group of people who were planning to “meetup” the very next day to discuss their common interest in voluntary self surveillance and measurement, under the guiding slogan of the organizing entity — “Self knowledge through numbers.” Intrigued, I created a profile on meetup.com just like many other QS participants. I joined the local QS group in Los Angeles, paid the suggested \$5 donation to attend its meeting the next day and introduced myself.

This chapter describes what would become a three year multi-sited (Marcus, 1995) ethnographic engagement with this self-tracking movement and allied digital health events, primarily in northern and southern California, between 2013 and 2016. In what follows in this first section on my ethnographic entry into the QS, I introduce my first meetup held the day after my serendipitous online discovery of the QS, drawing out the characteristics of QS cultural context that produced ethnographic challenges. In the second section titled, ‘Studying the Quantified Self’, I explain the ways in which I negotiated those challenges to define and contour (Burrell, 2009) the QS phenomenon investigated in this dissertation, and describe the different interconnected sites and positionalities that were relevant in my research, outlining their characteristics. In the third section, titled ‘On becoming a Quantified Self researcher’ I recount the manner in which I was socialized as a researcher through my interactions with QS leaders and self-trackers, and the norms of the QS cultural context. I explain how QS leaders negotiate

the expertise of researchers, entrepreneurs and public health stakeholders in the QS cultural context, to shape their terms of participation. In describing my immersion, I bring into view how my positionalities function as epistemic instruments in my interrogation of the QS phenomenon, offering both opportunities and constraints.

### **2.1.1 QS Meetup, March 7th, 2013, Los Angeles**

The Union Pacific Railroad's "Piggyback" yard is infamous, the unknown seat of Los Angeles' industrial era, a rail yard rumored to be almost impossible to see. Right next to the Piggyback yard, is the Brewery Art Colony, where Two Bit Circus, the host for tonight's Quantified Self (QS) meetup is housed. "We're inventors, developers & performers who are creating the future of fun" Two Bit Circus announce on their Twitter page. I bump into another woman trying to find the entrance; we hurry along the edges of hundred year-old warehouses looking for this year-old startup, in the dark, using our iPhones to light our way. We make small talk, she says she tracks steps with a Fitbit — having recently discovered the QS on the meetup.com website she is curious to find out more. It's her first time too. We walk towards a lit up fabrication space where we see a few people still working. They point us to the right entrance. We enter; there are exposed beams on the ceiling, an explosion of sticky notes on boards all around us and dust on the cement floors. It smells like laser cutters.

I recognize the QS organizer from his page on meetup.com. I introduce myself, hoping he doesn't recognize my name from the rather presumptuous message I sent earlier that day saying, I too, wanted to "Show & Tell" my reflective maker project that night, fully ignorant of the strict rules around what can be shown and said in a QS Show & Tell. He reveals no recognition and says, "welcome" and points me to a table of appetizers and wine. People start coming in. There are around thirty people including seven women.

"What are you tracking?" asks a man who seems to have come straight from work; he works at a local university in finance, I learn later. "Nothing at the moment. I tracked food, 6 years ago, but nothing now, just curious," I respond — having thought to have a self-tracking story before arriving, and re-discovering my tracking project from many years ago. The woman I found the venue with joins us. The two of them are now chatting, sharing notes and tips on various self-tracking topics:

"My Fitbit thinks I walked a step when I go over a bump in the car." (Chuckling)

'I wear a temperature sensor for sleep tracking because dips in temperature are a better indicator of sleep than motion.' The man pulls up his sleeve to show us the temperature sensor.

"I read a study that said that if you have more than 350 friends on Facebook, you are definitely a narcissist."

While the presenters for that evening are getting ready, a few of the regulars discuss different sensing devices like the Jawbone Up, the Basis watch, Affectiva, and several others; some of which haven't even been released yet. One person says referring to the anticipated devices, "they are mythical by the time you actually see them."

The self-tracking presentations, or the "Show & Tells" as they are called in the QS are starting. The projector turns on and we gather around. There are five talks this evening. It all starts with a person from the Two Bit Circus, talking about a tracking technology they used to monitor bio-signals of a veteran suffering from PTSD, which they then used to direct him, when stressed, to a special chair that would play soothing music, and emit aromatherapy scents to help alleviate trauma. This isn't a self-tracking talk, but a story from an 'Extreme Makeover Home Edition' episode that employees at Two Bit Circus helped design. The other talks include a woman who shares how she improved her biomarkers using a nutrition website that uses blood analytics to recommend dietary plans, a company for which she now works. She also talks about her work developing a "personal happiness formula" through a website called the Ultimate Answer. Next, a grad student from USC Cinematic Arts, who shows a series of "data worlds" where environments and objects, capture and respond to location and well being of inhabitants using inputs like heart rate monitors. She shows 3D printed artifacts, that represent individuals traversing a university building, a "gift" she says that the "building gives its inhabitants." This also is not a self-tracking story, I note. She requests ideas and data from the audience to develop more "data worlds", "location aware health" and responsive ambient environments. The organizers cut this request short, telling her to ask in the online forums and assures her she will get responses there. She later tells me how much she loves alternative representations of data, and wants to create representations that evoke the effects of the biofeedback that really helped her, but most people, she says with an expression of dismay, "just really seem to like their charts and spreadsheets."

Another graduate student shares his tracking project to understand how he manifests his strengths and values in his daily life using experience sampling. He is inspired by the philosophy of positive psychology and technology-enabled behavior change techniques developed by B.J.Fogg. Were all his values getting daily exercise? Is there a dark side to some values, like honesty? Yes, apparently, he says "it's not always good to be honest with your girlfriend." He tracked how he felt around different people; mentioning a friend that makes him considerably upset.

The final talk is by a young man, that the Los Angeles QS organizers spotted in a different conference. His work — a device that renders brainwaves as music — is not a typical Quantified Self project either, but the organizers found it intriguing, and extended an invitation to present at the meetup. He talks about how his friend used his device to listen to her own brain, while suffering from severe withdrawal symptoms from weaning off the antidepressant, Zoloft. He suggests that the "brain works in a musical way" and the subconscious will use patterns to maintain equilibrium. He describes his friend's brain as "disharmonic" at first, but over time her symptoms lessened when her brain was able to "regulate itself." He is not a neuroscience expert

or a musician, he says he is “just a hacker.” People crowd around him after the talks and I join small talk with his fiancée: “Well, it’s so great for him to be here”, she says in response to the great enthusiasm, “where we’re from, people like to talk but they never actually do anything, they don’t build. They just talk.” He demos the device he built later and the self-tracking enthusiasts in the room listen to each other’s brain waves. He asks the person trying his device to close his eyes and be still. It changes the music, still beautiful, but calmer. Then he asks him to listen to just one instrument, concentrate and that one sound increases in frequency; he opens his eyes and things are upbeat again; alpha, beta, theta waves; there are no numbers, just music. The QS organizer, also a doctoral student states at the end of his presentation, “Well, I really hope you will quantify this. I look forward to that.”

### **2.1.2 Features of QS as a field**

There are several aspects of this entry and the characteristics of this QS meeting that are relevant to my methodology. First, I accessed this meeting in the same manner as many others who venture into QS self-tracking events. I found it online; my informants often discovered the QS through media articles or followed an trail of a device they were interested in — such as an activity tracker like the Fitbit — landing in a QS online forum where members are interrogating their step-count data. Some others encounter the QS on the meetup.com website while looking for local meetups to join and opportunities to meet new people. Like me, most of them paid the \$5-10 donation and introduced themselves prior to attending the meeting. I did not stand out as a new participant, I did not need to have self-tracked before, and my presence was not questioned. Rather, I was welcomed in the same manner as everyone else and my request to present my own Show & Tell was subject to the same rules I will detail in sections that follow. I even discovered that one of the speakers that night shared a common friend with me; as I would repeatedly discover throughout my fieldwork, I was socially connected to the networks that intersect with QS attendees even before I arrived at my first QS event. This entry is a departure from classical ethnographic research where the researcher negotiates access to a field site far from home, is often unmarked, and slowly encultured through participant observation, eventually acquiring a productive and partial insider status.

The second aspect to note is the academic and entrepreneurial presence that characterized this meeting and would do so in the many meetings to come. There were graduate students like me presenting a Show & Tell; the QS organizer was in a doctoral program as well. The activities of the QS, either tangentially or directly figured in all of our dissertations. In addition, like many other QS meetings, there were entrepreneurial stakeholders, who either offered resources such as the space to hold the meeting or presented a tool that they were professionally associated with through a personal self-tracking story. Running through the introductions prior to this meetup and others, I’ve also noted artists, activists, doctors, parents, caregivers and many other varied positionalities. The members of the QS cultural scene have diverse stakes and interests in self-tracking; many are interested in QS group as a research site, as a resource and an audience for their self-tracking product, and a community to bring and share their self-experimentation; such movement in and out of multiple worlds by the players in the QS cultural context troubles the

idea that a stable set of prototypical QS members focused primarily on self-tracking and its outcomes as the end goal were awaiting discovery.

Third, the topics investigated, the tools deployed, and the practice they fashioned, often overlapped with my own daily concerns and life experiences, and those of my friends and family as well, initially blurring the boundaries between self-tracking activities presented in QS meetings and ones I observed outside. Not only did these activities transcend the multiple domains I negotiated as a researcher and a student, but they repeatedly cut across the different locales of my own life. These factors presented several initial ethnographic challenges and opportunities. In the following section, I situate my own positionality further, describe how some of these entanglements described above resolved as I became further immersed in the QS cultural context, and as I contoured the QS phenomenon to examine the facets that were aligned with my research trajectory and interests. In describing in detail my trajectory and encounters in this study, I hope to outline the particular context through which my findings on self-tracking should be interpreted.

## **2.2 Studying the Quantified Self**

### **2.2.1 An Insider/Outsider from multiple perspectives**

As mentioned in the introductory chapter, the ICTD experience I had in India led to my curiosity about progress narratives in American digital health care discourse. Forsyth (2001) considers such turn back to the west as bringing “anthropology home” as opposed to traditional patterns of ethnographic research, involving a western researcher studying a quaint rural setting with little similarity to her informants. However, unlike that western researcher for whom, the culture under study is foreign, I might consider my positionality through my insider/outsider status in all the environments I have studied thus far; in the settings I conducted ethnographic work in India, although I was Indian, the socio-economic difference between me and my informants meant I was still also an outsider. In my study of the QS, I am an outsider as an immigrant, woman of color researcher in a largely white environment of both self-trackers and other researchers. My positionality might be read through the category that Spivak (1990; as cited in Subedi, 2006) calls the “wild anthropologists” — postcolonial researchers occupying the role of the “intellectual” most typically attributed to white scholars (Subedi, 2006). However, as an individual shaped by the Silicon Valley and Berkeley technocultural infrastructure, associated with counter cultural social milieus from which the QS also springs forth (chapter 3), living for reasons outside my research interests in both San Francisco and Los Angeles, the two sites of my fieldwork — I am also an insider. Abu-Lughod (1991:137) calls such a positionality in anthropological work the “halfie” — a researcher “whose national or cultural identity is mixed by virtue of migration, overseas education, parentage.” However, in one way, the dichotomy of insider/outsider does not necessarily arise in the QS. Burrell (2009) notes that even in contemporary ethnographic work that involve a western researcher studying a remote or foreign locale, the locals often identify the ethnographer through their familiarity with various social and racial markers; acquired through increasing media exposure to global cultures. As a movement

that actively invites new members and loses others, the QS does not have a similar group of stable “locals” apart from the founding members and organizers. Although, there are regulars and old timers, the constant influx of new members meant that I was also simultaneously unmarked.

In relation to self-tracking practice and the concerns of the QS members — although, I cannot recall encountering the term ‘self-tracking’ before — as early as 2008, I initiated a digitally mediated self-tracking project around nutrition in Ithaca, NY, a few months prior to the very first in-person QS meeting in the Bay Area. Around the same time, I also took to investigating in my own academic and personal projects, how wearable technology could be designed and used to introspect and reflect on our bodies, as a complement to what was then an emergent pattern of wearable technology design focused on augmenting human bodies. I had several practices and interests in common with the many people who found the QS conversations around self-knowledge and tools intriguing. Throughout my research of the QS, I was also a patient, which introduced another vector through which I was both insider and outsider. In yet another way, I will examine in a subsequent section, the QS socializes researchers into its community, in a manner that also re-makes academic researchers in the ethos of QS.

Unlike many ethnographic researchers who slowly become an insider in their field site of study through a process of enculturation, while retaining the ability to detach through their outsider status and separation from the field (Burrell, 2009), I did not need to become an insider. The insider/outsider status that several of my multiple positionalities made possible from the beginning, meant that the ways in which I could engage my insider views or detach and enact my outsider positions were numerous, requiring a certain intentionality; my experience as a patient motivated my close examination of the narratives of two self-tracking patients with intractable illness in chapter 3. In chapter 3 and 5, my ethnographic account of color-blind style ideology and white ignorance is anchored in and directed by my racial difference in relation to the predominant demographic of the QS. In these ways, my positions act like instruments for interrogating the QS phenomenon. In a subsequent section on ignorance as an ethnographic object, I revisit this concept to make explicit my role in defining the “knowledge” (Smithson, 2008) that I argue is excluded or obscured by the social practices of the QS. In what follows, I describe how I discerned a unique QS phenomenon relevant to my research trajectory from the network of sites where such complex intersections of identity and positionality arose.

### **2.2.2 Constructing the Quantified Self as a field site**

In that first encounter with QS on the meetup.com website, I expected to meet a special group of people, rather exceptional in their interest on self surveillance. I soon discovered, however, that people who attended QS meetings, often intersected with many other new and energized sites including DIY maker movements and citizen science activities; one QS organizer also ran the synthetic biology and biohacking space called BioCurious, and I would see QSers at wearable technology and fashion events both in Los Angeles and San Francisco. During the early stage of my study, I hung out at some of these other sites and also happened to intern at Autodesk, where the lead of the bio/nano programmable matter group was an early participant in QS meetups and

instrumental in Autodesk's sponsorship of QS. At the time, Autodesk had started actively promoting and incorporating the maker movement, acquiring DIY focused companies like Instructables; I took workshops at one of San Francisco's largest makerspaces called TechShop and also at Los Angeles makerspaces where upcoming Fashion technologists like artist Anouk Wipprecht taught workshop attendees about wearable computing, helping me with my own wearable sensing project. I would see my San Francisco neighbors, with whom I typically had little interaction, at QS meetups sharing rather personal details about their lives. Students in my department would also develop QS tools in the classes I was a teaching assistant for, and many would look to self-tracking data for data visualization projects; the QS phenomenon informed other graduate student researchers consideration of biosensors and was often viewed as a potential source of participants for large scale studies on sensing technologies. In these ways, it was unclear where QS began and ended as a field site, revealing the fluid and intersecting nature of cultural formations and landscapes (Marcus, 1995; Burrell, 2009).

As briefly noted earlier, many of my friends, coworkers and family members used self-tracking apps and wearable biosensing devices. These apps and devices were often integrated into our social activities in subtle and not so subtle ways. Their individual relationships to the tracking device often mirrored those of regulars at the QS meetups. When I shared notes with one of my advisors about how the fitness tracker not only captured your activity but sometimes even determined when you were active, quoting one of my informants to illustrate this point: "If I forget to wear my fitbit, there really is no need to exercise that day" they left a comment empathizing: "Because this is exactly my relationship to my Nike Fuel band, I totally get it!" People around me were self-tracking constantly. Burrell (2009) suggests that in contemporary ethnographic practice, where the field is understood in such porous ways; where objects, people and metaphors (Marcus, 1995) are followed in and out of criss crossing sites; researchers are faced with the task of drawing out and centering a coherent phenomenon that goes beyond specific geographical locations. This involves making decisions throughout the course of fieldwork, and not just in the early stages, as ethnographic objects shift in a fluid manner; necessitating an ongoing and iterative process of strategic decision-making.

In the early stages of my research, the first element that helped outline my field site was the nature of conversations and concerns that typified the QS meetings. As my immersion in these different entangled worlds and practices evolved, I was able to discern and foreground a self-tracking ethos that was particular to the QS, helping me distinguish self-tracking mind-sets shaped by the QS cultural context from the practices of many others who used self-tracking technology. In particular, the QS conversation was directed towards developing what Boesel (2013a) calls "reflective capacities" around self tracking as an epistemic instrument that binds members of the QS together. The individuals outside of the QS cultural context didn't see themselves as "self-trackers", their engagement with self-tracking did not have the intentionality displayed in the QS; they did not see self-tracking as a significant method for self knowledge, they did not convene with other self-trackers to talk about their data or share methods. Although many people self-tracked, their conversations surrounding self-tracking were limited, especially in analyzing methodology and tools, and advocating for such typical QS concerns like data



access, rights, privacy and ownership. The active effort to develop “reflective capacities” directed towards self-tracking practice was not apparent in the same way. In addition, they did not see self-tracking as a way to assert their expertise to authorities. Even if individuals who attended QS meetups often passed through the interconnected spaces described above, the conversations they had in the QS were still distinct. The epistemological priorities evidenced in the QS cultural context then, is its own form of collective contouring that shapes both the “production and productivity” of both knowledge and ignorance (Mair, Kelly and High, 2012) as examined in chapter 3.

As I progressed further in my participant-observation, I found the second stable component that would direct my attention and bound my field site. My focus on the QS sharpened when the technology in the QS and their perceived possibilities started to anchor an emergent and intentional activist discourse, one where QS began to see itself as a player in health reform in the United States, directing conversations around patient expertise and autonomy, in a manner that went beyond regular gestures to ‘patient empowerment’ within health care discourse (Sharon, 2016), as I had seen signs of in my first few QS meetups influenced by my own trajectory in mHealth research in India. The QS leaders adoption of such an agenda helped me re-focus towards my original research motivations after an initial phase of expansion into the diverse goals and concerns surrounding self-tracking. Even though, the people who traverse the QS scene are heterogenous, in their active shepherding of the QS conversation around health reform and patient advocacy, the QS leaders and organizers became increasingly important as the epistemological and structural commitments they made would determine which kinds of people and stories could participate and inform this activist turn. Thus, in chapter 3, I examine the founding story and the ways in which the QS leaders structure the QS cultural context, foregrounding the opportunities and limits that they both intentionally and inadvertently produce as the QS platform becomes an intermediary between self-trackers, and medical science stakeholders. In a ‘taking stock’ of the various ways in which the QS has now been discussed, Boesel (2013a) distinguishes between the lower case “quantified self” and titlecase “Quantified Self.” The first term refers to the general practice of self-tracking that many people adopt across different life circumstances, and the second term, “Quantified Self” refers to the group founded to intentionally explore and experiment with self-tracking practice; the anchoring site of this dissertation. In the following section, I describe the sites of my QS immersion and the ones I discovered by following self-tracking objects, people and metaphors, and include a description of the demographic characteristics of the people who participated.

### **2.2.3 Field Sites**

During the course of my fieldwork, the meetings I attended were held by the organizing entity called the QS labs:

Quantified Self Labs is a California-based company founded by Gary Wolf and Kevin Kelly that serves the Quantified Self user community worldwide by producing international meetings, conferences and expositions, community

forums, web content and services, and a guide to self-tracking tools. (Quantified Self blog, '*About the Quantified Self*')

The QS labs organized three main types of QS in-person gatherings between 2013 and 2016: the QS meetups, the QS Global Conference and the QS Public Health Symposium.

### **2.2.3.1 The QS Meetups**

The first type of QS gathering is referred to by self-trackers and QS organizers as “meetups” using the terminology of the website [meetup.com](http://meetup.com) through which these meetings are organized. The very Bay Area character of the QS was highlighted by greater activity in this region compared to other geographical sites in the US. Internationally, QS meetups have been organized in 5 continents; the US sees the highest concentration of these meetings, followed by Europe. QS meetups tended to occur every few months in the Bay Area and a little less often in Los Angeles. I attended meetups in both these cities; the Los Angeles meetups usually saw around 30 attendees, while the Bay Area meetups often had a little over 100 people signed up. People often hear about the QS through the media or encounter the QS on the [meetup.com](http://meetup.com) website, and sign up as a member of their local QS page, receiving email notifications when a new meetup is planned. Attendees were typically asked to pay \$10 for access to the event. This money supports the local QS organizers in paying for drinks and appetizers at their events, and organizing future meetups (Wolf, n.d). The Bay Area meetups were around two hours long with the first section of the meeting devoted to mingling, with opportunities for startups and corporations building self-tracking tools to demonstrate and pitch their products; such entrepreneurs are often referred to as “quantpreneurs” in the QS. The [meetup.com](http://meetup.com) website allows the QS organizers to ask people when they sign up whether they have a self-tracking project that they would like to share — the QS organizers use the messages from this mini survey as one source to discover and curate self-tracking talks. The second section of the QS meetup, one I will go into greater detail in Chapter 3, consists of self-tracking presentations called the “Show & Tells” where individual self-trackers present their tracking project structured by three guiding questions: What did you do? How did you do it? What did you learn? The final section is a Q&A with some informal socializing afterwards. The presentations in LA tend to be less curated and often have disguised product pitches in the form of a personal story. The Bay Area presentations sometimes do as well, but the personal stories are often more substantial in the self-tracking component. In general, the Bay Area meetups tend to appear more curated and polished, following the “Pecha Kucha” style of presentation; around ten minutes with the slides automated to keep quickly moving forward in the presentation.

These meetups were hosted by various startups, incubators and corporations in their office and conference spaces and less frequently in university spaces. Around 2013, several women in the QS started the QSXX meeting for women identified self-trackers, which occurred more sporadically than the other QS meetups, often held at feminist hackerspaces in San Francisco. The global annual sponsors of the QS during my fieldwork were Autodesk and Intel, with other sponsors including personal genomic company, 23&Me and Scanadu, a consumer medical

device company. In addition, interested individuals and companies could become “Friends of the QS” and support the QS financially. The QS lists several startups and a few individuals as “Friends of the QS” including Gordon Bell, whose extensive lifelogging project at Microsoft Research ‘MyLifeBits’ was one of the QS co-founders, Kevin Kelly’s inspiration (2016).

### **2.2.3.2 The QS Global Conference**

The second type of QS gathering is the QS Global Conference. During the early part of my fieldwork, there were two global conferences a year, with one in San Francisco with approximately 400 attendees and another in Amsterdam with around 230 participants.

If you've never been to a QS Conference before, here's what to expect: our meeting will be hands-on and interactive, with user-defined workshops on mood, data visualization, sleep, ethics, and many other topics. We'll also have some of the most interesting speakers from QS Show & Tell Meetups around the world reprise or update their talks for all of us, along with plenary session discussions of current topics in the technology and culture of self-tracking. If you are an advanced user, designer, inventor, entrepreneur, journalist, scientist, or health professional, please join us at the beautiful San Francisco Presidio Golden Gate Club at the foot of the Golden Gate Bridge for two days of collaboration and inspiration! (QS 2013 Global Conference Website)

I attended this conference in 2013 in the Presidio in San Francisco and in 2014 in Amsterdam, organized in collaboration with a group of European QS enthusiasts. These two-day conferences include an eclectic set of Show & Tell presentations, primarily sourced and curated from various QS local meetup presentations. There are breakout sessions on various topics that spark the curiosity of self-trackers, facilitated by one or two experts who run these sessions in a short workshop style. People can pitch breakout sessions and many researchers use this as an avenue to engage self-trackers on various topics. Although, academics and entrepreneurs cannot present a Show & Tell unless it involves a personal tracking story, they can share their research and offer their expertise in what the QS called “office hours.” In the 2013 San Francisco conference, office hour was set up during lunch at different tables — conference attendees could choose to learn about the researcher’s study or an entrepreneur's tool and/or ask for assistance or feedback on their self-tracking projects in the researcher’s area of expertise. Through these structures and rules, the QS organizers leverage experts as a resource while also setting limits on how and where they can share their expertise. Although I didn’t hold an “office hours” of my own, I did play a role in organizing and facilitating activities at this conference, which I describe in a later section on my socialization as a QS researcher.

### **2.2.3.3 The QS Public Health Symposium**

The third type of QS gathering is the annual QS Public Health Symposiums (QSPH) held in Calit2, University of California, San Diego (UCSD) which I attended in 2015 and 2016. This

event is sponsored by the Robert Wood Johnson Foundation (RWJF) and supported by UCSD Calit2 and the Office of the CTO at the United States Department of Health and Human Services (HHS). Key figures in the organization of this event, apart from the co-founder Gary Wolf are: Larry Smarr, the founding director of Calit2, a renowned scientist who self-diagnosed his Crohn's disease using self-tracking data before there were any discernible symptoms, a story I will examine in Chapter 4; Susanna Fox, the CTO of U.S. Dept of Health and Human Services and former director of Pew Research on health; Steve Downs, the RWJF Chief Technology and Strategy Officer; and Kevin Patrick, a professor and physician at UCSD. The original impetus (Wolf, 2016) for these events was a request by Brian Sivak — the CTO of HHS at the time — asking Wolf to help develop collaborations between public health researchers and the QS community. The QS Public Health Symposiums are designed as invite-only events, where entrepreneurs, tool makers, public health and medical researchers convene to discuss how self-tracking data could be put to use to for public health endeavors and debate the terms of such collaborations, examined in chapter 5. The day prior to the QSPH is a symposium called Human Data Exploration at the same venue. Although, I don't have precise numbers, I noted some overlap in attendees and topics, with more emphasis on the complexities of data ownership and rights.

I extended my sites outside of gatherings organized by the QS labs, typically following a QS tip. These venues were helpful in understanding the perspective of health care practitioners and entrepreneurs, and how they considered self-tracking in their own practice. The main events were the UCSF Health eHeart Patient Powered Research Summit, 2014, San Francisco and the Body Computing Conference held at University of Southern California (USC) in 2015 and 2016 in Los Angeles. I describe these particular sites in greater detail in chapter 5. In addition to following the concept of self-tracking to these other spaces where it was interrogated, the influx of physicians and researchers from various other contexts brought different perspectives on self-tracking into the QS gatherings. In this way, my situatedness in the QS allowed me to “intercept” (Burrell, 2009) and grasp the larger activity and debates around self-tracking of which QS was one context.

The people who attended all these events were mostly white and appeared from higher socioeconomic status, typically in their late 20s and older; the majority appeared to be in their 30s and 40s. The other ethnicities represented, less frequently, were people of South Asian and East Asian descent. The QS Public Health Symposiums saw a larger group of South Asian and East Asian attendees, however, they typically did not identify as self-trackers, instead expressing interest in studying self-tracked data from a medical research and practice perspective. Although QS meetups and conferences tend to be largely male identified, the public health symposium and other digital health sites saw more women identified participants.

#### **2.2.3.4 Research Material**

My participant observation for the most part was conducted in public venues in such conference and meetup settings. In all these settings, I introduced myself as a UC Berkeley PhD student and

researcher studying self-tracking. I conducted semi-structured interviews with people that I met at these venues at various locations in Los Angeles and the Bay Area. I did not interview individuals who self-tracked but did not attend these meetings, that is, those who typified the lower-case “quantified self” that Boesel outlines. My research included public online networks; I followed many of the leading innovators and thinkers I encountered at these meetings on social media, where they often posted interesting articles and research on the concepts and objects of study in this dissertation. In addition, QS organizers communicated with members through several channels, including a ‘what we are reading’ newsletter which helped me grasp the kinds of debates they were engaging. The QS events are almost always recorded and most of the talks are then posted online on the QS blog, allowing me to cross check my notes with online videos. There are many talks in this dissertation that I watched in person and then revisited multiple times online. Given the public nature of QS self-tracking and sharing, in my analysis in subsequent chapters, I use the real names of people who have delivered public talks available online. In the case of interview data or conversations that are not easily accessible publicly, I have anonymized and removed identifiers as much as possible. In addition to video recordings of events, sometimes other attendees would post summaries of the QS meetups or write blog posts of their experiences which was helpful in understanding how others experienced the same meeting and triangulate the facts of those meetings. My last fieldwork research was in the second week of May, 2016 at the QSPH event in San Diego. In the next section, I summarize the prior sections and introduce a shift towards unpacking my socialization by the QS participants, through which I re-emerged as an outsider.

#### **2.2.4 Shifting from participant observation to observant participant.**

This research follows a contemporary ideal of ethnography that can be traced back to the 1980s wherein a break from classical forms of ethnography can be located (Clifford and Marcus, 1986). This break followed an unraveling of the concept of “culture” that underpinned anthropological inquiry where ethnographic accounts of culture asserted a coherent knowledge system that connected members of a particular geographically bounded, typically subaltern, community. As the role of the ethnographer and their writing practices came under closer scrutiny — citing Wagner (1975), Clifford foregrounds how ethnographies were “caught up in the invention, not the representation, of cultures” (p.2). The traditional ethnographic grasp of culture as a bounded and coherent system, both led ethnographers to take at face value the seemingly coherent accounts of informants, and directed the written articulation of what was in fact a partial and incomplete perspective, as a coherent system. Instead, Clifford (1986) claims ethnography as a kind of fiction, as the term captures the partiality, and processes of selection and exclusion, involved in fashioning an ethnographic account, determined by disciplinary traditions and intended audience, and the varying levels of authority held by ethnographers to represent cultures other than their own. Postmodern modalities such as multi-sited ethnography emerge from the destabilization of the traditional culture concept, the criticality directed towards “representation” and the acknowledged partiality of the ethnographer’s understanding. In Marcus’s (1995) divergent “multi-sited” ethnographic ideal, the ethnographer moves away from the single sited

inquiry of the past to an exploration of the “circulation of cultural meanings, objects, and identities in diffuse time-space” (p.79).

With that challenge to the culture concept, also came a challenge to an anthropological focus on knowledge that relegated the relevance of ignorance; ignorance was under-theorized as merely an absence where knowledge had not yet permeated:

Established ways of thinking about ignorance tend to take knowledge as their primary object and to see ignorance as a purely negative phenomenon, as the null state that obtains when the flow of knowledge is interrupted. In this view, ignorance can have no characteristics and no effects other than those that follow from the absence of whatever knowledge is lacking (Mair, Kelly and High, 2012:3).

During the 1980s “crisis” of anthropology, Clifford and Marcus (1986) called for an examination of ignorance that emerges as a byproduct of an “imperfect mode of knowledge” (p.8). However, ethnographic attention to ignorance has still been minimal. Mair et al (2012) explain that the entrenched emphasis on knowledge production was influenced by a corrective that ethnographers wished to enact by showing how the indigenous and subaltern people they studied were embedded in sophisticated knowledge systems, unlike their depiction that denied their capacity as legitimate knowers. The depiction as “ignorant” is an enactment of power and epistemic dominance where indigenous knowledge is posited as inferior, legitimizing the rejection and relegation of such subaltern knowledge as unworthy of academic study (Vitebsky, 1993; as referenced in Mair, Kelly and High, 2012). This begets a certain caution, and ethics that suggested complicity of ethnographers who described subaltern engagements with ignorance. However, this resistance to ignorance stems from the simplistic understanding of ignorance as a void. Mair et al (2012), in one of the first volumes on the anthropology of ignorance, draw attention to ignorance experienced as “valued states, produced and sustained intentionally, sometimes as the result of significant effort” (p.6). I follow Mair et al’s (2012) advice for ethnographic study of ignorance by unpacking the practices that are shaped by and produce ignorance; the articulated logic of engagements with ignorance, the communication of ignorance and its regulation, and how ignorance is functional.

In the traditions of contemporary modalities of ethnographic research, I followed a practice and its tools — self-tracking and its technologies — as it manifested within communities I was already a part, those I found online, and followed offline across multiple geographical locations such as Berkeley, San Francisco, Los Angeles, San Diego and Amsterdam. During my ethnographic immersion, the QS — as a community that interrogates its chosen epistemic instrument of self-tracking — was also fashioning a certain ethnographic orientation and trajectory for itself. In many ways, this dissertation follows this investigative trajectory of the QS and the development of what Boesel (2013a) terms its “reflective capacities.” In contouring the field site (Burrell, 2009); further defining and foregrounding a distinct phenomena in the subsequent chapters, I draw out the components of such reflective capacities that are relevant to

its foray into health care reform in the United States, directed by my own trajectory studying technology-mediated healthcare. In doing so, I examine the ignorance that such reflective capacities produce through a process of selectivity in chapter 3; the strategic interactions with uncertainty in negotiating illness in chapter 4; and how the act of obscuring is functional in maintaining white privilege, and establishing the dominance of medical stakeholders in chapter 5. I argue in this dissertation, that such production of ignorance limits the capacity of QS platform to effectively challenge institutional medical science and practice.

Unlike traditional forms of ethnographic research, the insider/outsider orientations shaded my positionality in relative and shifting portions. My socialization in the QS cultural context and the slow strengthening of my outsider status as I progressed through a blurred and confusing medley of insider/outsider positions through my participant observation allowed me to access the epistemological commitments that the QS leaders repeatedly make; in chapter 3, from my position as an immigrant, and a woman of color, I deploy race as an entry point to examining the ignorance produced as an outcome of those epistemic priorities. In addition, I use racial epistemologies of ignorance to examine QS proponents' grasp of the "other" in chapter 5. From my experience as a patient, I was motivated to examine the careful choreography of knowing and not knowing as a coping mechanism in the face of bodily adversity in chapter 4; I share Romain's (2012) entry point of hope in her study of egg-preserving women, in examining the design and utility of uncertainty or temporal ignorance. Important differences and tensions emerged in my QS socialization, outlining a QS ethos and my own role as an academic more clearly.

However, such socialization was also possible because of my serendipitous discovery and natural entry into the QS resulting in an orientation akin the "observing participant" put forth by Marek Kaminsky (2004), wherein the researcher "enters a community through a similar social process as its other members, is subject to similar rules" and adopts a role through which research is pursued. Kaminsky's orientation originated in his own arrest in communist Poland in 1985, where as a sociology and mathematics graduate student, aligned with the solidarity movement, he was caught smuggling books deemed illegal at the time. Finding himself in jail with a sociologists sensibility, he deployed his training to document and examine the culture of prisoners as he was socialized into that very culture. Although, our circumstances cannot be further apart, we share a common process of entry as the other members of our respective field sites, and were subject to regulation and disciplining of our knowledge pursuits; in addition, understanding prison culture involved a close examination of the various choreographies of knowledge and ignorance of both others and oneself. In the following section, inspired by Kaminsky's account, I describe how I was socialized as a researcher through my interactions with QS leaders and self-trackers at various meetings organized by the QS labs.

## 2.3 On becoming a Quantified Self researcher

### 2.3.1 Privileging an episteme of personal experience

I was first initiated into what I describe as the “QS epistemic ethos” when I assisted QS organizers in a project to document visualizations of self-tracking data. In collaborating on this project, I learned of the privileged status attributed to an episteme of personal experience in the QS cultural context, analyzed in greater detail in chapter 3. A few weeks after my first encounter with the QS, another meetup was planned, this time in Berkeley. I discovered through a peer in my department that the QS leaders were looking for students from the School of Information to help with data visualizations for their upcoming global conference. This student, who was self-tracking her health at the time, was a regular at the QS events and at my second QS event, she introduced me to the QS organizers including the co-founder, Gary Wolf. After the event, I reached out to Wolf, volunteering to help out and told him about my master’s thesis where I studied visual data mining and early stage decision-making. He responded with enthusiasm and said he wanted to produce a reference library of personal data visualizations that would inspire and help QS self-trackers to explore their data in new ways. Wolf and another QS organizer then visited me at Autodesk where I was interning for the summer (as noted above, Autodesk was also the annual sponsor of the QS and volunteered its gallery space for several QS meetups) and we discussed how I might collaborate with another volunteer in curating a library of QS visualizations. Here, and in subsequent conversations, Wolf emphasized my playing an editorial role, finding interesting visualizations and adding my own commentary. I started scouring the internet looking for visualizations of self-tracking data while the QS organizers requested submissions from people who would be attending the conference.

People sent in screenshots of their visualizations along with a comment on what they learned and I started looking through them, selecting ones I thought would communicate the range of topics in the QS and visualization types that could be helpful in analyzing self-tracking data. However, the “curated” gallery soon came to include almost all the visualizations submitted which grew to around 60 at the request of the QS community organizer. He highlighted the courage it takes for people to share their personal data and the importance of acknowledging their contributions. Where people submitted visualizations that were in fact screenshots of the apps they were looking to pitch, the organizer told me to leave them out if they did not include a personal story, and where an entrepreneur did include a personal narrative with their pitch, I was asked to leave only the personal narrative and take the pitch out. In Chapter 3, I delve deeper into this strong emphasis on personal experience in the QS, and examine the possibilities and limitations it begets. At the conference, the visualization gallery was displayed on a large screen with a laptop for viewers to interact with the data representations and leave comments if they so chose. It was also announced in the opening keynote of the conference, with Wolf acknowledging my assistance in ‘curating’ it. Such mentions led to new conference goers engaging me as if I was a part of the QS organization team but other regular attendees were used to different researchers assisting the QS in various ways. While planning this visualization gallery in prior QS meetups with Wolf, our interactions and my proximity to him led to meetup attendees associating me with



the QS team also; several of them even thanked me for organizing such a great set of talks that evening, when in fact, I had played no part in such organization.

### **2.3.2 Tracking the QS while being tracked by the QS**

Shortly before the conference date where the visualization gallery would be displayed, I was also asked to co-facilitate along with another volunteer, a break-out session on data visualizations when the person scheduled to facilitate it dropped out. We managed to put together a set of questions to lead the session, and structured much of it as mini group discussions. What followed helped me understand how in the QS, researchers are also subjects of tracking and surveillance. One attendee appeared to pay very close attention and took notes furiously even when we as facilitators introduced ourselves, and then throughout the entire session. This man's name was Mark Carranza and starting in 1984, he's been capturing his thoughts, ideas and observations in a DOS software, which he's left unmodified since 1992 (Wolf, 2009). I would later watch a little aghast as he gave a presentation in the closing keynote, searching his database called the MX (for "memory experiment") live during the Q&A, and pulling up records of ideas from multiple years, all connected in his database. The reassurance I felt observing that one of our breakout participants seemed attentive and engaged, quickly dissipated, as I realized I too had been documented all that while in the MX, as memory prompts along with millions of other entries. I tried considering it as another form of note taking, just like students in a class or lecture would jot down short notes as memory prompts, perhaps even in similarly enduring formats, but it was still quite unsettling as I discovered the pervasive nature of such "lifelogging" around me at QS events, especially given a lack of regulations around how these recordings would be handled.

Wolf (2009) gestures by directing the reader to a wikipedia link in his blog post about Carranza that his MX project refers to Vannevar Bush's (1945) speculative design called the Memex, a searchable memory and informational prosthesis described in his 1945 article, 'As We May Think.' I note that little information is documented online about Carranza but he was an early QS participant, having presented in the third QS meetup ever organized. Other early inspiration for QS founders such as Kelly (2016) include Gordon Bell, whose "total recall" lifelogging project supported by Microsoft was also inspired by Vannevar Bush's Memex vision. I remember Gordon Bell, with a sleuth of wearable devices, some hung around his neck, documenting everything around him and chatting with me about my visualization installation at the conference. I know that I am also in Bell's photographic documentation and my brief conversation about the visualization gallery is also in his database. I am now largely resigned to electronic surveillance by other people during informal sessions and conversations at QS events; however, I was still a little taken aback as I read Kevin Kelly's book (2016) in which he describes Bell's assertion that if there was one logging modality he would keep, it would be voice recordings. Bell explains that it's very useful when there is a disagreement to go back and review the conversation (Kelly, 2016), and Kelly enthuses about this specific utility of audio recordings too.

It is hard to discern whether one is being audio recorded in these settings but photographic and video surveillance are abundant at QS conferences. In 2014, I noted a new tool called the Narrative worn by several conference attendees, a small photo device that can be clipped onto the clothes of the self-tracker, which automatically captures ambient contexts every minute that it is worn. In general, there is no formal or informal process of consent to this lifelogging. At the QS 2013 conference, I observed ongoing discussion on developing new etiquette for such circumstances like saying “don’t lifelog me.” It was in this conference that I first learned about how pervasive tweeting during conversations had become — with breakout session participants sometimes having their head down in their laptop the whole time, only to discover later that they were tweeting what was being said for those who couldn’t be at the conference. In addition, the QS organizers create video recordings of all Show & Tell talks and Q&As, at conferences and its meetups in the Bay Area as mentioned earlier. This documentation is obvious, but its extent is not always apparent. For example, in the latest 2016 QS Public Health Symposium, although I could see cameras pointed at the speaker, it was only when the video of the entire event including breaks was uploaded, did I note that there were cameras facing the audience from up above and their operators were zooming onto individuals asking questions; I was documented in such imagery even though I did not participate in the main discussions. In these many ways, as I was tracking the evolution of the QS culture, I was also being tracked and archived often unbeknownst to me.

### **2.3.2 Interactions with self-trackers**

Self-tracking individuals in the QS feel a strong sense of ownership to their data and uphold, in the QS events, the primacy of personal experience in self-expertise. Although, the QS leaders and organizers are welcoming of researchers — and many individual self-trackers were happy to share their experiences in an interview — I also encountered an ambivalent and sometimes adversarial stance towards researchers studying self-tracking at QS venues. In addition, the privileged status of personal experience in QS knowledge production, challenges the subordinate status that personal experience holds in many academic knowledge production frameworks. In my fieldwork, these differences created several palpable moments of tension between different stakeholders interested in the QS.

One of the most striking instances of a clash of world-views was in a breakout session I attended that sociologist Whitney Boesel and professor of cognitive systems Jakob Eg Larsen organized for QS researchers to share their projects with each other, and possibly foster collaborations. This meeting was the second in their series. After some minimal discussion on how we might all organize, the meeting quickly took a turn, seeming more and more like an academic venting session. One woman in this breakout session said that the organizers were very strict about what could be shared in the main QS sharing format — the Show & Tell. When she approached them asking to present her observations of the QS, she was repeatedly turned down on the grounds that Show & Tells needed to include a self-tracking component — a personal story. Her self-collected data on the QS did not qualify. Although she was upset at not being able to give back to the community what she had discovered in studying them, she still seemed respectful of the QS

policy. Then some researchers in the room began complaining that many self-trackers they encountered weren't following scientific practices and that they would do well to learn from academics how to do "real" science, incorporating amongst other things, practices like citations and peer review, and communicating projects in a format other than videos so that it wouldn't be as inconvenient for researchers to analyze.

Boesel (2013c) in her blog post and analysis of this meeting calls this genre of complaints "QS is bad science." A division quickly developed between different researchers based on epistemological leanings; one woman suggests that not everyone in the room was a positivist. Another next to me said referencing such assertions that she wasn't interested in "observing or whatever" but instead just wanted to know if the biosensing devices self-trackers use actually work. The academic self interest was abundant, with some others, such as statisticians, enthusiastic about the voluntary in situ data collection that they could aggregate and channel into their own research projects if only the self-trackers did their projects with more rigor. Boesel (2013c) calls this genre of excitement around *n of 1* studies, and fantasies around free data: "QS is great science." Not all researchers had such complaints or ambitions for self-tracker data with many visibly uncomfortable about the nature of the debates. One man, a researcher himself and also an individual I remember as a key QS organizer in Europe said: "It's very frustrating to sit in this room right now and hear the conversation that, 'This isn't meeting my needs to meet my tenure track,' when every single one of us has a professional organization to go present at" (as cited in Boesel, 2013c). He brought back into view the QS ethos of personal meaning making, pointing out that scientific rigor was not what QS self-trackers sought, in addition, it was important to remember that scientific processes were in fact the very thing that had failed them.

I think that the presentations that I've heard in the last day and a half have been from people that had some medical issue, they went to the doctor, the doctors couldn't solve it, they gave up because they were so pissed off, and [they] tracked something, and then came back and told the story about how they discovered what was really wrong with them. And to sit in a room with a bunch of academics saying, "Oh, no, no, no, you gotta do the scientific process"—that failed to help the person—there's something fundamentally wrong with this conversation. (as cited in Boesel, 2013c).

This kind of debate in the QS was one important way in which I was able to see academic socialization and anxieties, however varied in their epistemological leanings, from a distance. Most of the venues that my fieldwork involved were public venues in that anyone could attend them. This meant that I wasn't introduced to people gathered at most of the QS meetups as an academic studying the QS. However, in small groups in LA, there was time set aside for introductions, and I would say that I am a student at UC Berkeley studying the Quantified Self and also describe any tracking projects I was doing. During socializing time, other attendees would ask me about my research and why I was interested in the QS. Many of them would ask me what my observations were and what I found interesting, sometimes challenging my view, and actively theorizing the QS themselves. Zandbergen, a dutch anthropologist (2011) in her

study of the New Edge cultures of the Bay Area experienced similar conversations with many of her informants also trained in similar disciplines as her. Kelty (2003; cited in Zandbergen, 2011) suggests this is common when the researcher and informants hold similar cultural capital.

QS leaders often use the analogy of a mirror in referring to self-collected data, and how it becomes functional in self reflection. My socialization as a researcher in the QS constantly held up a mirror to the identity I was developing as a “scholar” within academia. The participants in the QS events, whether researchers or not, were also foregrounding and making explicit academic culture, and defining the QS ethos, often in opposition to academic values. These QS interactions repeatedly made it clear that highly trained researchers and self-tracking individuals in the QS are equals, only stories and self-expertise communicated through self-collected data was accorded status.

This strong anchoring norm led to many researchers starting self-tracking projects of their own, as did I, soon collecting a set of self-tracking devices and apps including activity trackers like the Jawbone Up which I diligently and enthusiastically wore for three months. During my early experience with the device, I discovered many things about myself; even if I wasn’t intentionally setting aside time to exercise, I was already getting about the 10000 steps it recommended through my daily commute between San Francisco and Berkeley. I wasn’t sleeping as well as I’d thought — and I made sure to shake my hand so my Jawbone “knew” that I wasn’t sleeping yet when I was lying awake at night — I felt what you might describe as “cared for” when the Jawbone suggested I should get more sleep. However, my fantasy that I had a little companion pet in service to my well being, quickly led to feeling somewhat “betrayed” when I found a tweet from Jawbone suggesting more sleep to everyone. Often, the ‘personalized’ recommendations were in fact quite generic it turned out. The data it visualized was also no longer new or useful and soon its ‘persimmon’ color that I picked with a great consideration began to appear increasingly hideous and jarring, refusing to blend in with my clothing, and I stopped self-tracking steps, abandoning the tracker in a drawer where it still resides two years later — following unwittingly, the attrition trend with activity trackers often discussed in the digital health venues I observed.

Although, the QS norm initiates such explorations, the immersion in the QS ethos, also started influencing how I considered problems I encountered in my life. I started implementing QS tips such as creating my own Google Form based survey, bookmarking it on my smartphone and using it as a self-tracking tool to capture my subject of self-study. One of my researcher friends, who was beginning a new romantic relationship would get excited about how she could “self-track my relationship!” Self-tracking then became a way to participate and gain legitimacy in the QS context and our current lives became fodder for self-tracking material. Many of us went on to give our own Show & Tell presentation, often working in the critical academic points we wanted to make into our narrative of our personal experience. In these ways, I became a participant as a self-tracker, a participant as an organizer, and a researcher shaped by the QS ethos nevertheless still negotiating its terms to assert my own academic identity and probe its culture. However, the chasm between my researcher identity and self-tracker identity remained in other social

interactions in the QS. This tension was productive because it helped me outline what self-trackers felt was legitimate in their gatherings.

The friction between researchers from academic or other institutional settings and self-tracking individuals in the QS who didn't identify as researchers, often despite their extensive investigative data practice, was also evidenced in several other venues. My first such encounter was at a QS meetup in San Francisco. One of the members of the QS Labs introduced me to a few QS regulars at that event, including a white woman, with a similar educational background as mine. She was a fitness enthusiast and working on her own startup in the domain. When asked about my research, I told her I was studying self-tracking in the QS — she seemed quite excited and encouraging. We exchanged contact details and continued to meet other people. The Show & Tells for that evening started with one of them featuring an anthropologist from a corporate research lab who had been studying the QS for around a year at the time. She started her talk describing her interests in numeracy and how historically anthropologists study cultures outside their own, with her slide containing a picture of a white male anthropologist surrounded by dark skinned “natives” and then she pointed to the audience of largely white privileged men and women and said “you are my natives.” This talk was followed by a series of other talks including one about a woman who tracked her values, and another who tracked sexual harassment on the streets when she moved to San Francisco. After the talk by the anthropologist, I would notice the woman I had met earlier stare at me periodically, without the friendliness that characterized our earlier interaction.

After the Show & Tells, we chatted again and she appeared a little guarded — she said that when she met me she thought it was fascinating that someone was studying the QS, but after the talk by the anthropologist, she realized there were several researchers studying them and that made her just uncomfortable. Is it creepy? She nodded and said yes. Caught of guard, I tried to explain why the QS community was so interesting to researchers and quickly shifted the topic to the talks that evening, when that didn't seem to be helping. We both had very different perspectives on the talks — she was befuddled by the talks that I liked, calling them too “abstract” and when I said I appreciated the talk on sexual harassment on the streets, she said she just didn't understand it: “I just don't feel intimidated by people” she asserted, and thought the commentary and gestures the woman tracked on the streets of San Francisco didn't really fall under what she considered harassment. Another white woman joined us and they both agreed. This was also unsettling for me, to hear two women downplay another woman's concerns of safety in the new city she found herself, and dismiss what I thought was a rare critical self-tracking project that deployed personal experience to take on an important social issue, just because it didn't match their own experience. I immediately attributed this to the woman's social position, and the fact that she was a white woman taller than all men in that room that day, and continued to feel uncomfortable at the lack of solidarity with other women who may not feel the same sense of personal empowerment. Such moments were influential in my wondering what was at stake when QS positions personal experience as the legitimate starting point for critical engagement with broader issues, in chapter 3 I examine the ignorance that is produced through such frameworks. My interactions with these two women over subsequent meetings tended to be confusing,

friendly and tense for the most part helping to highlight the boundaries that make an insider — a QS self-tracker is a person who only self-tracks and studies themselves when in the QS milieu.

### **2.3.3 Interactions with researchers**

It wasn't only with other self-trackers that a shared cultural capital was pertinent. The QS is a crowded field of researchers and especially in the beginning, there was a sense of anxiety around who was studying what and if there was any overlap. In my initial socializing with other researchers, I found that sometimes they expressed concern about who had which idea first; spotting one researcher articulating an observation in a breakout session, another would worry that they had accidentally taken from them — “we're all thinking about the same things” — later checking in with the other researcher to make sure that no such appropriation occurred. Other discussions included scholars assuring each other that research is fundamentally collaborative, that there is no such thing as originality, and academia really needs to start re-considering its emphasis on individual achievement, extending the typical critique of individuality in the QS into their intellectual homes as well. I learned in these settings, especially with sociological researchers to focus on my background in design and human-computer interaction; I talked about how I was interested in the mediating role of the interface, which was both a transient interest during my fieldwork and tended to sooth any concerns of overlap; once in a conversation with a QS organizer, my interests were re-framed in the tradition of QS broad interpretations of tools I examine in Chapter 3; he rearticulated my research interests back to me: I was studying the “medical” establishment as an “interface” to the body.

In addition to the ambiguity around ideas and authorship, the presence of numerous researchers blurred our understanding of our positionality as well; was I a researcher or another researcher's QSer? For example, there were often multiple people with ethnographic leanings, observing and participating in the same conversation with self-trackers, making it unclear whose interview was taking place and whether we were all each other's informants too. In addition, I've been interviewed informally several times about my relationship with my activity tracker and also formally, on self-tracking food as part of another doctoral students dissertation research. The emphasis on personal experience in breakout sessions meant that we also got to know each other in ways that are not typical in a professional setting — in the 2014 QS conference in Amsterdam, for example, in a session on grief tracking led by two academics, everyone in the room shared a story of a personal tragedy or loss, shifting how we saw each other. Eventually, a certain camaraderie developed with researchers sharing what they had noted with each other and theorizing together different aspects of the QS during breaks and walks between two talks. This kind of immersion helped me observe how many of us who gravitated towards each other were often spotting the same things and critiquing different aspects of the QS in similar ways, surfacing our shared academic sensibilities and internalized disciplinary worldviews. However, when I presented my work in an academic conference, I noticed that this was only true of researchers who took an ethnographic approach. In addition, the circumstances and life situations I was observing and studying in the QS, also marked my own life. These varied experiences of similarities and differences inform my decisions on which aspect of my positionality and identity

I would leverage in my analysis of this movement; my experiential advantage as a person of color and a patient allows me to examine whose interests and whose epistemic framework the QS's foray into health reform is designed to engage, and my experience as a patient allows me to ask how a self-sustaining self-tracking practice, functional as an immediate form of coping mechanism might prevent collectivizing around policy and structural conditions that in fact prevent positive health outcomes.

There are several limitations I encountered as well. Although, I interviewed individual self-trackers about their everyday self-tracking practices, I was not able to observe their activities in-situ; interview questions would sometimes initiate a process of thinking out aloud about components of self-tracking that the participant had not considered before, however, the accounts of self-tracking activities and processes analyzed in sections of this dissertation are largely self-reported and infused with participants' own retrospective analysis. In addition, my particular strategy of contouring focused on how the QS was shaping an epistemic community (Haas, 1992) by developing "reflective capacities" (Boesel, 2013a) around self-tracking and positioning it as a significant modality of inquiry worthy of attention and legitimacy. In focusing on the formation of an epistemic community, I risk missing the other ways in which self-tracking is appropriated outside the QS cultural context that defy the QS epistemic ethos described in following chapter 3. I address this issue by looking at how self-tracking is considered in other digital health venues, but hope to widen the sites where I consider its uptake in the future. In addition, the larger absence of people of color and consideration of race in the QS fields, directed my analysis of whiteness and white epistemologies of ignorance in this dissertation. Thus, an analysis of how people of color may also deploy ignorance in a tactical fashion, as a form of resistance as well, was outside the scope of this phase of my research on data cultures. Lastly, as an epistemic community in formation, the structuring beliefs and norms of the QS are also evolving. This dissertation, then, should be read as capturing a specific moment in the evolution of the Quantified Self and its relationship with institutional medical science.

## **2.4 Conclusion**

In this chapter, I laid out the multi-sited ethnographic trajectory and the process of selection, and exclusion that underpins the analysis in the coming chapters. The self-tracking phenomenon is diffuse and cuts across multiple intersecting social worlds. Anchoring myself to the QS social context allowed me to intercept the other ways in which self-tracking is understood as it relates to health reform through the objects, metaphors and people I followed out of the QS, and through the diverse set of actors who came into the QS. Through the QS socialization I describe in detail, I show the interactions that helped me discern a distinct QS phenomenon, centered on examining self-tracking as an epistemic practice; in this investigative orientation, all actors are equal and a personal self-tracking story is the legitimate marker of a QS insider. In the introductory chapter, I laid out the theoretical engagements with ignorance, in this chapter, I described the positionalities I leveraged to study ignorance as an ethnographic object.

In the chapter that follows, I describe how Wolf and Kelly envisioned and designed the QS as a cultural context to bring and discuss a self-tracking phenomenon that was already under way. I hone in on the key structuring elements that draw boundaries around what constitutes legitimate practice and knowledge in the QS cultural milieu: insights generated through data mediated investigation of personal experience. I consider the privileged status of an epistemology of personal experience in QS discourse. I situate this emphasis on personal experience as the legitimate path to self knowledge in gnostic epistemologies of experience and libertarian worldviews that counterculture rhetoric in the Bay Area have historically drawn from. I problematize the turn to experience as expertise using critiques of a similar turn to ‘local’ and ‘difference’ in development history and standpoint epistemology. I examine how the emphasis on a de-historicized and apolitical epistemology of personal experience in the QS cultural context produces an ignorance that “emerges as a by-product” (Smithson, 2008) in the style of color-blind ideology (Bonilla-Silva, 2009); an ethnocentrism and libertarian worldview that has historically been instrumental in maintaining the power positions of dominant socio-economic groups by denying historical inequities. The epistemic ethos of the QS I argue, limit its capacity to engage minority groups and also, its own ambitions to effectively challenge the establishment science that has failed some of its members.



# 3 Selectivity and the Quantified Self's Epistemic Ethos

“What can a little man effect...in the face of the formidable power of great corporations, great states, and all their know-how, guns, monies, armies, tools and information? The individual can take initiatives without anybody's permission. Only individuals can think, and can look for the principles manifest in their experience that others may be overlooking because they are too preoccupied with how to please some boss or with how to earn money...It became evident that the individual was the only one that could...think in a cosmically adequate manner.” (R.Buckminster Fuller, 1963 in Krauss & Lichtenstein, 1999:13)

“In the long term, we probably want to bury the quantification, the numbers, I think the quantification aspect of it, in terms of data coming out will remain but we're just not evolved to deal with numbers, we're not ready, our brains aren't really good in dealing with lots of numbers, we don't do statistics very well, we're not really a number animal. What I think the long term direction of this is that we want to use these sensors to give us new senses.” (Kelly, 2012, in Goetz, Kelly and Wolf, 2012)

In his 2013 book, *To Save Everything, Click Here: The Folly of Technological Solutionism*, Evgeny Morozov — known for his work on techno-utopianism — writes a scathing critique of the quantification in the self-tracking phenomenon found in the Quantified Self (QS). In his reading of this community, he sees a reductive allegiance to numbers as central to the QS ethos: “The movement's fundamental assumption is that numbers can reveal a core and stable self — if only we get the technology right” (Morozov, 2013:232). I encountered Morozov's analysis soon after I first started my ethnographic study of the QS, and like many other researchers who have in fact stepped foot in a QS meetup, I couldn't reconcile the characterization Morozov offered with what I saw in the community. Natasha Dow Schüll, a cultural anthropologist, also a researcher of self-tracking, expressed her concern in an interview with Morozov: “I worry that the QSers you quote — mainly from media reports — serve a bit too readily as straw men for your argument. I mean, it's almost too easy to make fun of them as you do! I wonder what you might be missing by ignoring their actual practices.” Morozov shot back, “There's no way I'm going to go spend time with them — I can't stand them!” (Schüll, 2013). Morozov is not unique

in his revulsion. The pairing of the term *quantified* with the word *self* has been fairly controversial for the QS, routinely provoking both knee-jerk reactions, and calls to caution among scholars and others who encounter the term for the first time; the central concern being the rather precarious idea that our ‘selves’ can be measured and read as numbers, which the QS slogan: ‘self knowledge through numbers’ does not do much to allay.

In reviewing the academic response to the QS phenomenon, Tamar Sharon and Dorien Zandbergen (2016) distinguish between two patterns of sociological critique and analysis of the QS; the first reads self-tracking practices as predicated on the belief that numerical data is both neutral and objective in accessing truths about oneself; this assumption leads to what Sharon and Zandbergen call the “data fetishism” critique. Critics argue that the consequent focus on measurement erases the complexity inherent in aspects of the self that members of the QS claim to investigate, and re-inscribes specific narratives of neoliberalism and biopolitics that locate individuals as both the source and solution to structural problems (Morozov, 2013; Lupton, 2015).

The second, more recent trajectory of research that Sharon and Zandbergen (2016) delineate acknowledges the relevance of earlier critique, but offers a different set of insights derived from practice. Using an ethnographic approach they articulate how self-trackers deploy quantitative data in ways that defy the expectations of the “data fetishism” critics; self-tracking practices can act as a form of resistance to institutionalized knowledge production with QS challenging who gets to demonstrate scientific and medical expertise and how, what Boesel (2013b) calls “the Occupy of science and medicine” — an activist trajectory that intersects with the democratization imperative Topol (2013) evangelizes. Nafus and Sherman (2014) describe a form of “soft resistance” where self-trackers are in critical dialogue with the logic and aspirations of big data, while still using its very frames for their subversion. Sharon and Zandbergen (2016) also point to how the categories and normative values embedded in self-tracking apps and services are not always uncritically inherited in practice, and describe the many “other values” through which self-trackers appropriate data into their everyday lives. Thus, ‘*quantified*’ is perhaps the most nebulous term in the QS cultural milieu. Kevin Kelly (2012), the QS co-founder says of its eclectic approach to quantification: “Basically, we say if you think you are doing quantified self stuff, you are.” What self-trackers mean by quantification is typically, but not always, something other than what is understood in scientific communities; in the QS cultural context, quantification is attributed heterogenous meanings and diverse functions.

If quantification is subject to such interpretive flexibility, then what are the stable components of the Quantified Self’s epistemic ethos? In the last chapter, I introduced the ways in which QS leaders shape what counts as legitimate expertise in the QS. In this chapter, I examine the countercultural origins of the epistemological commitments that the founding QS leaders repeatedly make in structuring and directing the conversation around self-tracking in the QS cultural context, and the consequences of those epistemic priorities. Although, QS members are characterized by diverse motivations and goals, their stories still encounter and enter the QS platforms of knowledge exchange through the structures that QS leaders enforce, driven by the

epistemological commitments they value. These commitments become more pertinent as the QS begins to position itself as an intermediary between public health stakeholders, and self-tracking individuals engaged in voluntary and prescribed self-tracking, actively shaping the ways in which self-tracking practices, and the data generated are deployed and engaged by institutionalized medicine, public health, or corporate and policy stakeholders (examined in greater detail in chapter 5). This activist foray into healthcare reform comes through a growing critical engagement with self-tracking as an epistemic practice, suggesting the early formational effort involved in configuring QS as an epistemic community that can influence policy level changes (Haas, 1992). Sociologist, Whitney Erin Boesel (2013a) describes the conceptual and analytical evolution she has observed since her first encounter with the QS in 2010:

I argue that Quantified Self's most central object of concern has slowly shifted from the tools people use to track, to the data those tools and other self tracking practices generate, to self tracking practices as meaningful ends unto themselves, to developing 'reflective capacities' not just through self tracking practices, but in regard to self tracking practices. (Boesel, 2013a)

How do the epistemological commitments that surface in the QS cultural context, contour and limit such reflective capacities? In the first section of this chapter, I describe how these commitments rest not on quantification but on an epistemology of personal experience, technological mediation, the embrace and celebration of difference, and individual control of narrative and interpretation. I situate this libertarian framework in the counter-cultural legacy of the QS and its "cybergnostic" traditions. In the second section, I examine what kind of critical engagements, counter conduct assertions, and alternative science such an epistemic framework enables: criticality around privacy and data ownership garnered through personal experience, the creation of a platform for patients disenfranchised by traditional diagnostic and treatment structures, and the "n of 1 framework" that posits the 'anecdote' as a legitimate form of counter-expertise in medical sciences and computational cultures where a sample size of 1 has typically had little legitimacy. In the recent past, as the QS leaders oriented subsets of the community towards a more conscious advocacy role in American health reform, the leaders have been called to address a diversity problem; despite the gracious, welcoming and inclusive gestures of the QS leaders, its members remain largely homogenous — financially privileged white men, and to a lesser degree, white women. In this chapter's concluding section, I deploy a racial lens — in particular, the notion of "white ignorance" (Mills, 1997) — to argue that whether intended or not, the structural elements of the QS platforms of knowledge exchange limits its capacity to become a platform for minority groups to advocate for similar values of participatory medicine; it produces a color-blind (Bonilla-Silva, 2009) style ideology that claims to embrace difference, while ignoring historical inequities, thereby re-inscribing functional forms of ignorance that serve to maintain white privilege. However, this privilege is limited, as it denies the racial relationality that has historically configured the white body and shapes how it is understood in medical contexts as I show in the concluding section. In de-historicizing difference, the QS dismisses critical analytic tools from its epistemic toolbox, limiting the ability of the majority

white population to gain the self-knowledge and the bodily expertise they seek to challenge institutional medicine.

### **3.1 The Quantified Self's countercultural roots**

The two cofounders of the QS, Gary Wolf and Kevin Kelly, are writers and executive founding editors of *Wired*, a magazine that has shaped and amplified a certain optimistic and celebratory orientation to technology, grounded in the counter-cultural legacy of Silicon Valley (Turner, 2006). The unwavering faith in technological futures that infuse its writing has also engendered some amount of notoriety; Duguid calls *Wired* the “propaganda organ of the digital age” (2007, p.2) and Theodore Roszak, the historian who coined the term “counterculture” in 1969, refers to its writers as “the yea-saying techies..who see an endless frontier of technological wonders and amazements ahead” (Roszak, 2000, para.4). Wolf — who began writing at *Wired* under Kelly’s editorial leadership, chronicled as using the terms “reporter” and “utopian” to introduce himself at the first QS meetup (Roberts, 2008) — presents his two decades at the magazine in somewhat more neutral terms: “*Wired* built a culture around technology; it was how we participated and thought about technology rather than technology itself” (Wolf, 2012). In search of the next technocultural phenomenon of significance to capture, Kelly and Wolf were struck by advancement in sensing technologies that could now be easily embedded into body-borne devices, and intrigued by an allied trend of people appropriating these technologies to track and understand themselves, while also sharing and discussing their projects online (Wolf, 2010). What stood out for Wolf and Kelly about these emergent patterns was the use of quantification and the language of computing to consider the personal (Kelly, 2016). In their observation, they understood such appropriation as “bringing computing just so close that it’s almost indistinguishable from yourself” (Wolf, 2012). The term Quantified Self then captures a characteristic of an unfolding technological trend and the QS blog was envisioned as a platform to build a similar cultural context and conversation, just as they had at *Wired*, investigating this time the computational turn in self-reflection and self-knowledge.

In 2008, they held their first meeting of self-tracking enthusiasts in Kelly’s living room in Pacifica, California, which impelled Wolf and Kelly to pivot from the QS blog as another journalistic venue to organizing face-to-face gatherings in the tradition of the legendary Homebrew Computing Club, where Bay Area computer enthusiasts shared their personal experiments — what they’d hacked, built and learned — inspiring others in the meetings towards their future explorations and inventions. Similarly, the QS meetings — the Show & Tells — captured “the new emergent culture of technology in the wild, among the people who are actually doing it” (Wolf, 2012). Wolf describes his Aha moment at that first meeting:

This was the most amazing moment I thought, some guy walks in late — we are having beverages — we are about to introduce ourselves. Kevin said “okay you came in late, you go first” instead of giving a little discourse, the guy just (..) opened his computer and he showed us the most amazing visualization, of every minute of his time over the past, I think, year, and he said, okay, well, this is who

I am, I am going to show you something about myself, rather than tell you something about myself, and then the light bulb went off. (Wolf, 2012, in Goetz, Kelly and Wolf, 2012)

At the QS 2015 Public Health Symposium, seven years later, an invite-only event designed to engage public health and medical innovators curious about self-tracking practices, Wolf walked over to a table where several of us attendees had gathered to chat at the reception; he was curious about how the women at the table were considering self-tracking. When one professor said that she was using activity trackers — a device that senses and counts ‘steps’ — with older populations and they get terribly excited to share their data with their peers, Wolf empathized, recounting that QS origin. When they first got started, he said, they noticed quickly that it was the community that got people excited, to be able to look at each other’s data and share methods. That’s when they knew that their role was to help people share (Wolf, 2015, Informal conversation, QS Public Health Symposium). It’s this act of sharing who you are and what you discovered about yourself with tools and self-collected data — rather than say, “a little discourse” as Wolf put it — that is privileged in the QS. Much of Wolf and Kelly’s enthusiasm is fueled by their belief that self-trackers are at the threshold of something much bigger; pioneering an exploration of how new self-surveillance gadgets can be put to use for self-discovery.

So it is very utilitarian, in other words, this is sort of the tool based view of the world, this is what the origins was like. Hey, there are tools there, if there are not tools, there should be tools. What are people going to do with these tools? So there wasn’t any kind of, larger sense of ‘people should live by numbers.’ (Kelly, 2012, in Goetz, Kelly and Wolf, 2012)

In fact, Kelly (2012) likens the numbers in the QS to the computers of the Homebrew Computer Club: “the numbers are an impediment just like the computers were: you had to build your own computer.” The motivation for Kelly, is in identifying the characteristics of tools and exploring the possibilities they promise, a long standing personal passion typified in his other famous website, ‘Cool Tools’ where since the year 2000, he’s been posting reviews on a comprehensive array — just like self knowledge in the QS, which as Wolf (2012) claims is acquired by “using numbers in the broadest sense” the tools in Kelly’s online catalog too, are “defined broadly as anything that can be useful” — be it a hand tool or an idea. Kelly (2008) in a retrospective of the Cool Tools website, says in publishing “short, always positive, useful” reviews, he followed the tradition of the Whole Earth Review, an offshoot of Stewart Brand’s iconic Whole Earth Catalog, another seminal Silicon Valley counterculture magazine, where Kelly was also a writer and editor; a legacy that would eventually lead him to Wired. Brand, an influential figure since the 1960s in the Bay Area’s countercultural scene; along with Kelly and other writers in the '80s and '90s, was instrumental in integrating the values and world-views of San Francisco hippie culture with that of Silicon Valley’s technologists, re-positioning computers as a tool for revolutionary world-making and “personal liberation” (Turner, 2006). Ever on the lookout for alternative cultures and trends, they created spaces for collaboration — organizing hacker conferences, for instance — and subsuming as Turner (2006) describes, the attendees cross generational

individual experiences tied together by a “hacker ethic” into the Whole Earth ethos and circle of countercultural activity, and positioning Brand as their representative; Turner (2006) states of this particular co-option “Brand has gathered a normally geographically dispersed community under a single roof and literally given it voice” (p.139).

In identifying a computational trend and connecting it with a self-tracking phenomenon already underway, organizing gatherings to give what was never before a “community” a “voice” through the QS platforms of knowledge exchange, and positioning self-tracking as a tool for personal empowerment and a platform for challenging the paternalism of the American medical establishment, the QS is the recent child in an illustrious, and sometimes infamous line of countercultural phenomena that have called the Bay Area home since the mid-twentieth century.

The connections don’t stop there. In many ways, the QS could be considered emblematic of Silicon Valley’s libertarian values (Turner, 2006, Borsook, 2000) that underpin the likes of Wired and the Homebrew Computing Club: a group of elite, white and mostly male members, organized in a non-hierarchical network, using technology to manifest their self conception as representative of humanity, and rational agents with inherent autonomy to control their life paths and their environments; The QS model of collaborative sharing and innovation, perceived and presented as individual achievement — self mastery and self diagnosis in this context — is also characteristic of Silicon Valley entrepreneurial cultures (Saxenian, 1996). Seen from another allied Bay Area legacy, that Zandbergen (2011) draws out through her recent ethnography of ‘New Edge’ scenes, we could also read QS as a descendent of a ‘gnostic tradition’ that infused early countercultural activities. Zandbergen (2011) traces the term ‘New Edge’ to another cyberculture magazine, Mondo 2000, founded in Berkeley in 1989, a few years prior to Wired — “The magazine brought together celebrations of new ‘edgy’ technoscientific concepts, gadgets and future visions with a very ‘New Agey’ discourse of self-spirituality and spiritual evolution” (p.8). Historicizing the epistemic frames of the New Age, she highlights its reliance on gnostic epistemologies of experience: “Only through direct, inner experience could one achieve a higher understanding of the true nature of self and of reality at large” (p.6). The “reality” experienced outside of individual judgement and experience is seen as distorted by norms and mainstream enculturation, a cultural indoctrination furthered by scientific and religious institutions that obscure and prevent true self awareness (Zandbergen, 2011).

In her dissertation, Zandbergen investigates a contemporary adaptation of gnostic tradition, ‘cybergnosis’ which she says characterizes New Edge discourse where the same goals of self awareness and liberation from mainstream society, is achieved through the use of cybertechnologies as typified in Mondo 2000 and other New Edge scenes. New Edge subcultures appropriate emergent technologies of the time into projects of self-seeking, just as the QS community co-opts/adapts to prominent technoscientific concepts of this contemporary moment: data science and digital self-surveillance, as a means towards similar goals of individualized self-knowledge, grounded in similar epistemologies of direct personal experience, driven by a shared suspicion of institutional prescriptions for the good life.

In her description of cybergnosis, Zandbergen (2011) urges us to consider the significance of bodies, in response to critical theorists of cyber-spirituality, who she says, tend to further a certain stereotype of the Bay Area nerd, as aspiring towards a disembodied life state, seeing the body as a prison they must escape to be liberated, a depiction that is only partially true of New Edge:

This stereotyped 'geek culture' is only part of the social reality in relation to which New Edge is shaped. Apart from the obvious fact that also seemingly disembodied 'nerds' have bodies and live in specific material conditions, we need to understand New Edge also against the background of a Bay Area cultural environment where bodies and nature have great significance: dance, the celebration of 'hands-on' creation, nature camp-outs and sexual experimentation play significant roles in the constitution of New Edge. (Zandbergen, 2011:12)

An embrace of the body is seen throughout QS, in the predominance of projects on physical well being, covering an expansive range, including sexuality, and in the emphasis on a do-it-yourself approach to technology. I see a continuation of the cybergnosis faith in “information” as a liberating force, underpinned by an understanding of information as pervasive — out there in the environment and in here, in the body — captured through bodily senses and self-reflection, not just technology (Zandbergen, 2011) with little interrogation, however, of the differences between what is captured by the body and what is read by technology. In the tradition of New Edge, the concept of “sensing” foregrounded by the emergence of biosensing technologies, occupy the speculative orientation of the QS in two distinct but related ways: — How can self-tracking act as training wheels to calibrate and heighten our awareness of bodily information we might typically miss or ignore? How can we use biosensing technologies to augment our capacity to sense our bodies in ways we cannot with our natural senses alone? In QS conversations, the story of a woman who used an ovulation tracker and developed over time, a new ability to sense when she was ovulating, on her own, with greater accuracy than the devices she had used to self-track (Boesel, 2012) illustrates the first sensing quest. The second vision is most often illustrated by the story of Udo’s whimsical belt; Kelly (2012, 2016) often highlights this tool that sprung out of the hackerspace Noisebridge in 2004 in San Francisco, where a German engineer named Udo, hacked together a belt with a set of smartphone vibrators and a digital compass. The belt was programmed to provide tactile feedback of orientation: “When Udo put the belt on, he could feel northness on his waist” says Kelly (2016). Eventually, after wearing the belt for a bit, Kelly continues: “Udo had an unerring sensation of north.” He was able to sense north even without the belt. Kelly is excited that people were able to “feel” an embodied sense of north and he wants to be able to “hear” and “see” the hidden workings of our own bodies. Even if sensors and other devices don’t eventually lead you to acquiring an independent new sensing capacity, they can all work together as a system of technologies, he suggests, that serve your embodied awareness of your internal health state and the ambient environments in which you find yourself. He says in his new book on what he considers immanent and inevitable technological forces: “You’ll eventually wear these. By taking this information and feeding it back not in numbers but in a form we can feel, such as a vibration on our wrist or a squeeze on our hip, the device will equip

us with a new sense about our bodies that we didn't evolve but desperately need" (Kelly, 2016). When Kelly states in the opening quote to this chapter that he expects the quantification in self-tracking to recede, replaced by sensors that "give us new senses", he is referring to these two kinds of sensing tweaks to our embodied experience. In these ways, the body is central to the QS ethos.

Although, both Kelly and Wolf also hold strong positivist beliefs about the objectivity of numbers, they do not enforce that view on the self-tracking individuals who come to the QS, curating, instead, talks that reveal a broad range of personal interpretations of quantification; they highlight personal meaning making using data as prompts. In the different ways the founders consider the QS, its origins and its future, they foreground technology mediated personal experience and self-expertise; doing, tinkering, collecting, building, and experimenting are exciting drivers of curiosity and self-awareness. Kelly's primary desire is not so much that we deploy these technologies and the data they produce to transcend our bodies or enact the cybernetic dream of a data-enabled "disembodied" embodiment (Hayles, 1999) as the end game, but instead, scaffold and support us in learning to feel our way to self-expertise; whereas Wolf, having expressed less enthusiasm for new embodied sensing modalities and more desire for objective measures, might refer to his QS goal as self-objectivity, still attained through personal experience. What's missing in both the "New Edge" cultures that Zandbergen describes and in the libertarian frameworks of the QS, is an engagement with the body as racialized, placed in a hierarchy, attributed varying levels of humanity and perceived as sensing differently. In the QS, the idea that we are all different is celebrated and actively engaged; this difference is understood as inherent to the individual, and difference produced through the individual's position in intersecting categories of race, class and gender amongst others is relegated. In the concluding section, I bring into view the relevance of interrogating difference that stems from bias. In the next section, I describe the primary structural element of the QS platform, the Show & Tell presentation, and its function in defending an episteme of personal experience.

### **3.2 Defending an episteme of personal experience in the QS social context**

It's not surprising or unreasonable that a community advocating self-tracking for self-knowledge would prioritize personal experience. It is the personal after all that is being investigated. What is striking is how carefully and systematically knowledge gained through personal experience is guarded from other ways in which we might investigate ourselves in the QS cultural scene. This priority is most visible in QS Show & Tells, a rather strict presentation format that requires answers to three questions: what did you do, how did you do it, and what did you learn? Anyone can start a QS Show & Tell meetup, anywhere in the world. Organizers do not need the permission of the QS labs, but they are, however, offered recommendations on how to structure their local meeting and their exploration of self-tracking. Gary Wolf (2011) advises new organizers:

Let anybody share a self-tracking project, within the constraints of time and common sense. Slickness or charisma are unimportant. Every talk about actual



practice has value because it lets us learn and think about one person's approach. Since the goal is collaborative learning, rather than killing time through entertainment, a speaker who is struggling due to nervousness, confusion, or lack of preparation can be helped along by questions from the group.

These recommendations keep the focus on the original QS intent, sharing personal experiments with data and technology; it also makes the work involved in organizing meetings simpler as Wolf (2011) explains to aspiring QS organizers, "Once you commit to hearing personal stories of self-tracking, you no longer need to worry much about recruiting speakers." Participants in a QS meetup witness articulations of a data-mediated personal approach to self knowledge and often also connect with the presenter's vulnerability, their honest confessions and brave revelations about their weaknesses and the things they hope could be better. In the Bay Area and Los Angeles, I am yet to note a speaker struggle in such presentations to the extent that the audience or the organizers step in to help; in fact, many talks in the Bay Area go through a process of vetting and polishing, where personal experience — humble, honest, vulnerable — is still often enough, slick and charismatic. Regardless, this presentation style induces a certain camaraderie and empathy among participants, who rarely feel condescended upon by authoritative or esoteric expertise. Foregrounding authenticity in such a performative space is functional in evangelizing self-tracking, it produces a sense of familiarity in audience members by connecting self-tracking to universal concerns, human failings and aspirations; self tracking is normalized through this modality of presentation, and in doing so, QS more effectively markets self-tracking. The QS does not disallow self-tracking projects that access other forms of knowledge, but request that they first be mediated through experience.

We like scientific theories, demos of tools and apps, and philosophical speculation. But in the context of a Quantified Self Show & Tell they distract unless they are grounded in actual attempts at self tracking and self-experiment. When theory or demonstrations are embedded in an account of personal experience, however, they work great. Tell us what you've done, how you did it, and what it means to you, before making the leap to speculative assertions or entrepreneurial self-praise. Your listeners will learn more, and everybody will have a better time. (Gary Wolf, 2011)

The specificity of these instructions is in response to the explosion of a self-tracking and wearable technology market that followed the early self-tracking experimentation Kelly and Wolf observed online, and grew alongside the QS, often infiltrating the space to capture what self-trackers were interested in and market new technologies. In addition, at the time of my 2013 entry, QS was growing in momentum, with local meetups organized all around the United States and many cities in Europe, along with annual global conferences in San Francisco and Amsterdam. It had caught the attention of entrepreneurs, academics, activists, artists, technologists, policy makers and health care experts. One engineer and startup CEO says that in the early days, the people who attended the QS meetings were far more "nerdy" and obsessed with data, barely making eye contact; he says he used to be one of the more extroverted people

there but nowadays, he sees himself as one of the more introverted people in QS meetings (Informal conversation, QS Public Health Symposium, 2016). The Show & Tell is the primary structural element that protects the spirit of the QS and the status of its chosen epistemology of personal experience, from entrepreneurial and state interests, academic, scientific and philosophical theorizing, in keeping with the counterculture anti-corporate, anti-government, and anti-institutional stance.

Central to much of QS health tracking is a claim of skepticism, about the applicability of larger bodies of institutionalized knowledge, such as medicine, and public health, to the individual self. Many QS self-trackers believe that the population-level goals of public health and the scientific models of institutional medicine compromise the attention paid to individual variability, not just in relation to others, but also, in relation to different moments in one individual's life course. One impetus in many casual, and illness-driven QS experiments is to see if the causes and effects that science attests really exist in our bodies, not the average body of public health; a desired outcome of such experiments over time is to create one's own norms. In a related approach, the presentation of biomarker and sensing tools marketed for such experiments position scientific findings as unreliable and incomplete, and possibly invalid given individual differences, similar to the counterculture distrust of institutional science and state prescriptions.

In addition, in only speaking for oneself in QS Show & Tells, self-trackers hope to avoid that paternalism they critique. As one self-tracking individual describes: "I can't tell you what you should do about your problem because I don't know. I can only share what I did and what I learned, in case you find something that might be useful to try...self-tracking is not narcissism, it's humility" (QS global conference, closing keynote discussion, Amsterdam, 2014). There exists a tacit agreement that telling people what to do or challenging individual meaning making are against QS etiquette. One leading QS proponent once told me that it is unethical to place a narrative arc on someone else's data; only the owner of the data — and by owner, QS proponents means the person who is the subject of the data and therefore its rightful owner — can control the interpretation. The paternalism embedded in the devices that generate said data, the normative goals some self-trackers are motivated to pursue or the limits of individual agency are not always critically engaged but when they are, it is through personal experience as the starting point.

In 2015, wondering how self-tracking could be put to use towards activist goals — a kind of tactical self-tracking — anthropologist Dawn Nafus and I approached Wolf with a workshop proposal; we expressed our excitement about locating possibilities for different critical positions in self-tracking both within the QS and beyond, and imagined communal activist self-tracking projects together with QS self-trackers. Wolf was encouraging and generous in suggesting that he would even dedicate a QS meetup to such explorations. Another QS leader, he suggested was also questioning whether the emphasis on individual experience compromised the pursuit of systematic change and his intuition was that honing our capacity for self-objectivity would help strengthen such cooperative efforts. The three of us discussed how we might organize or bring people who were thinking along those terms together, and facilitate a conversation around what

the notion of critical could mean in the QS context. In helping us think through a starting point for the workshop, Wolf envisioned the scenario wherein a critical orientation may emerge; when a person whose self-collected data has failed to provide solutions, when they've not been able to resolve their problems independently, they may then speculate whether there are larger structural issues at play. He wondered if there were people in the QS cultural context who might have done such an analysis, connecting their self-tracking findings to their socio-cultural contexts. He suggested that this experiential point of origin would signal an openness to the kinds of critical considerations we had hoped to engage, preferring it over a gathering where people with pre-specified critical positions patronize the audience by attempting to impose their "positions" on others.

The experiential prerequisite Wolf necessitates constrains the kinds of issues that the QS self-trackers could potentially galvanize around or even acknowledge exist in the QS cultural context — explored in the final section of this chapter — but in maintaining the focus on the individual's experience from several angles, the QS does support self-tracking individuals in the experience of their personal stake in the complexities, opportunities and limits of data. In the following section, I examine the critical and political explorations that such epistemological priorities and values have engendered.

Thus far, I've described how Wolf and Kelly designed the QS as a cultural context that coalesced and amplified, a tool based self-tracking phenomenon that was already under way. In this cultural arena, notions of quantification capture a characteristic of some emergent technologies and the ways in which they engage our biology, our embodiment. The QS leaders and the early self-trackers who convened in Kelly's living room in 2008, and continued to meet across different locations in the Bay Area, saw their self-tracking practice as an experiment — how can these new tools be put to use to understand the self? Quantification, as I have shown, is considered in rather broad terms, as a means rather than an end; often an interim modality to effect desired change and a method by which to enhance our own sensing capacities. It is an epistemology of personal experience that attains a privileged status in the QS. In tracing the lineage of the QS leaders and the ethos they evangelize, I have brought into view how the emphasis on technology-mediated self-expertise is grounded in the libertarian leanings of Silicon Valley, but also, the countercultural and 'cybergnostic' traditions of the Bay Area. Next, I examine the critical and political interrogations supported by its epistemic ethos and evidenced in the QS cultural context.

### **3.3 Criticality engendered by the QS episteme**

The primary realm of critical engagement in the QS is around privacy, data access and ownership. The QS leaders view their digitally mediated self-seeking as a bold experiment in what personal and surveillance data can do for the individual (Watson, 2013), and through the use of these tools, identifying and advocating for what data services, medical institutions, insurance companies, regulatory bodies, connected devices and sensing technology must ensure for the individual. At this juncture in the QS trajectory, not all self-tracking projects adopt digital technologies, but when they do, a few technologies are created through DIY projects, some

fashioned out of bits and pieces of existing digital tools, some appropriated for novel purposes, and some absorbed as they come into an ever shifting interconnected ensemble of technologies, all in service to the goals of the self-tracking individual and, increasingly, to the interests of the entities that produce these devices. It is in such digital entanglement that self-trackers and their data have become so visible, alluring and available to numerous interests, including peers, employers, corporations, data scientists, public health institutions, insurance agencies, academic and medical research, and the state (Lupton, 2014), thereby warranting critical discussions on privacy and ownership.

Debates on these topics with a variety of stakeholders are an important feature of self-tracking conversations within the QS global conferences and public health symposiums. In the QS global conference in 2013, Kelly focused his ending keynote on a reflexive and provocative concern: “the world that we don’t want may come through the success of the Quantified Self we do want.” This critical engagement with a practice that QS has itself brought to the forefront and a self-tracking market that it has inadvertently helped create, is ongoing and comes through the ‘big tent’ policy that Nafus and Sherman (2013) describe; in the audience, at QS events, are scholars, students, activists, patients, doctors, therapists, care-givers, technologists, designers, data scientists and entrepreneurs. The discussion and collaboration that ensue makes the QS a moving target and a rather complex phenomenon to capture. However, this trajectory of critical movement, one informed by experience rather than a pre-specified political stance, is a natural outcome of the fast paced change in technological access of private life, and in fact, it is in this dynamic reflective and critical process that QS becomes relevant as a “community” for individuals to bring and interrogate an age old practice of keeping count, regardless of whether their self-tracking is optional or not. It is not only the reflective capacities (Boesel, 2013a) that are fashioned in the QS around its chosen modality of inquiry that make it attractive as a community, but its ability to provide a platform for patients who either have to self-track to manage their illness or chose self-tracking as a response to their disenfranchisement from traditional medical systems.

“I found my community! This is my community!” Henry says to me as he leaves one of his first QS meetings. Having suffered from migraines for over 20 years, he had recently started a self-tracking project which would eventually grow into an extensive self-tracking mission to find the culprit for debilitating pain — a case I will examine in greater detail in the next chapter — and in that moment at the Skydeck, a Berkeley startup incubator where the QS meeting was held, he sounded excited and relieved that his self-tracking practice, born outside the QS, recommended by doctors and practiced alone, may have found a welcome home. Anne Wright (2014), a strong proponent of the self-tracking ethos, describes a similar delight in finding the QS years after she initiated a QS-style health tracking project on her own: “In parallel with going to the doctors, getting sent to the next specialist, doing the next test until they gave up on me, I started doing things like taking pictures of what I was eating, logging what I was eating, playing with heart straps and stuff like that, and this was years before I had ever heard of QS. So you can imagine how I felt when I finally heard of QS, I was like, my family!” (Wright, 2014).

The individuals who voluntarily subject themselves to technologically mediated surveillance in the QS are not necessarily distinct from those who have no option. Doctors often prescribe self-tracking as part of a self-care routine for various other chronic illnesses that require close digital monitoring and management (Lupton, 2013). Many such people bring their experience, desire for community and curiosity for new self-tracking techniques to the QS. In the last three years, as QS has increasingly engaged with health care reform in the United States, organizing symposiums that bring together experts in medicine, public health, policy, and technology to advocate for the expertise of the patient, individuals for whom self-tracking is not an option — such as diabetics — are frequently at the forefront of this collectivizing. Unlike many disease-based support groups (some long term self-trackers cannot identify a patient group given a lack of diagnosis) in the QS, you are first a person who self tracks, and only then a person with illness. This inversion, where illness based identity recedes, and a common practice comes to the forefront, offers a space to both share expertise and draw from a diversity of self-tracking practices outside your condition, revitalizing the practice of self-tracking whether optional or not. QS celebrates the difference that makes you an outlier — gives it dignity — and through its episteme of personal experience inadvertently creates the sample size of 1 as legitimate ground for knowledge.

A significant QS intervention to note is rendering its chosen epistemology of personal experience into a statistical lexicon: “a sample size of one.” QS attempts to re-establish what they call the ‘anecdote’ as a legitimate form of data and knowledge transfer in the computational and data cultures from which the QS also emerges — cultures where the anecdote is regularly denounced as non-data. “Knowledge” in QS is situated, contextual and highlights difference. In health projects, self-trackers work to establish their own norms, their own healthy ranges and generate hypotheses grounded in their embodied experience. In such projects, the focus on the personal, the story of a single individual, highlights most importantly, difference in bodies, well-being, disease and life course and stands in contestation to that “average” of public health research and its consequent prescriptions for a good life. Self-experimentation may also often be the last resort when diagnostic systems fail some individuals, or treatment programs are found inadequate. Single subject experimentation are not at odds with scientific research practices, however; there is in fact a long standing legacy in medicine where scientists and physicians have adopted self-experimentation as a moral imperative, arguing that it is unethical to subject a patient to risks and interventions that the scientist and doctor are not willing to take themselves (Altman, 1998, Solhdju, n.d). This mode of self-experimentation was sometimes driven by an unwavering curiosity on the part of researchers (Kerridge, 2003), but largely in service to generalizable knowledge about the body and to expedite medical innovations. QS self-trackers sometimes refer to academic articles on self experimentation, evoking its history in medical science; QS also sees physicians who use self-tracking to manage their own illness (I’ve heard several of them talk about how they are “closeted self-trackers” with their medical colleagues); they offer advice to other non-expert self-trackers so that single-subject experiments in the QS begin to meet standards of evidence acceptable in their clinical research. The physician, having discovered that his own institutional frameworks are unable to treat his illness, still uses his self-tracking

experience and offers *n of 1* techniques as a method in a traditional QS Show & Tell, like any other self tracker.

Although *n of 1* has other assorted functions in the QS outside of what Greenfield also notes as “counter-conduct” (see Greenfield, 2016 for detailed analysis), several years ago, the assertion “the QS is the antithesis to big data” began to mark QS introductions to newcomers at its gatherings. This addition to the QS narrative seemed partly in response to the great excitement big data enthusiasts have for the QS; the collection of data through a voluntary process, in situ, consistently over time makes the QS a treasure trove for researchers and entrepreneurs. In fact medical researchers and entrepreneurs in QS meetings argue that this is precisely the data that is required to make healthcare more personalized to the individual so it doesn’t need to rely on the “average” that has traditionally driven diagnosis and treatment, and with emphatic calls to self-trackers, researchers request “data donations” for large scale longitudinal studies, urging Quantified Self to consider the “Quantified Us”, an argument I will examine in greater detail in chapter 5, unpacking the participants’ grasp of minorities not represented in the QS but required to make the Quantified Us sample more statistically representative.

These forms of criticality described above suggest an activist potentiality that attract people who are disenfranchised by the medical system and seek to deploy digital technologies, with calculated risk towards acts of self-care. However, although the QS sees some minimal representation from minority groups such as South and East Asians (primarily in its public health stakeholder meetings, and that too as researchers and practitioners, and not self-trackers), many disadvantaged minority communities are largely absent. In the following section, I examine how the QS epistemic framework supports forms of ignorance that maintain white privilege, thereby limiting its capacity to become a more inclusive platform for advocacy. In addition, I explore how the QS epistemic ethos may serve to limit its potential for white populations as well.

### **3.4 How does QS maintain white privilege and limit the potential of its platform?**

In critical race studies, two allied concepts help us think about frames that reinscribe white dominance: white ignorance (Mills, 1997, 2008) and color-blind ideology (Bonilla-Silva, 2009). White ignorance refers to a set of structuring beliefs and patterns of perception that white groups are socialized into that prevent accessing and therefore, engaging with “social truths” of racial inequity. These patterns of “miscognition” are not the result of individual failing, they cannot be analyzed as an “aggregate of individual mistaken white beliefs” but as a “particular optic, a prism of interpretation, a worldview...” (Mills, 2013: 217, 218) that direct perceptions of reality through a stable and invisible “white racial frame” (Feagin, 2010 as cited in Mills, 2013). The theoretical focus of the lens of white ignorance is not on what white people don’t know about racial injustice, but how do they keep not knowing even in the face of evidence (Mills, 1997).

One pattern of miscognition that maintains white dominance is contemporary color-blind ideology. In his book, *Racism without Racists: Color-Blind Racism and the Persistence of Racial Inequality in America*, (Bonilla-Silva, 2009) delineates four frames through which color-blind

racism operates to further racism, not challenge racism: abstract liberalism, cultural racism, naturalization, minimization of racism. In his research, white interviewees deploy a “minimization of racism” frame, where they acknowledge racism as leading to discriminatory practices that damaged the opportunities available to minorities in the past, but believe that those discriminatory practices are no longer at play; when they are operational, they are read as the exception rather than the norm. Instead, the compromised life chances that minorities experience in the United States are analyzed through a “cultural racism” frame. This frame morphs older forms of overt racism that grasped non-white racial groups as biologically inferior, into an optic that now suggests the barriers to success are located within the culture of minority groups, not their biology; inequity, this frame suggests, exists because of cultural difference. Through “naturalization” white individuals are able to perceive contemporary patterns of segregation as natural; rationalizing separation through beliefs that suggest, for instance, that we’re naturally drawn to others like ourselves. These three frames work to support white belief that current inequities are not due to racism but other factors, which both strengthen and derive from the abstract liberalism frame (Bonilla-Silva, 2009), a frame that aligns with the libertarian leanings of the QS: abstracting from political and economic liberalism, white “color-blind” ideology configures a worldview that contemporary society is characterized by equal opportunity, individualism and choice, and therefore, any institutional or state intervention to correct racial injustice through policies such as affirmative action are misplaced, and in fact discriminatory to white people (Bonilla-Silva, 2009).

In approaching this analysis, I began by asking how I might access these concepts in the QS cultural context where the larger absence of people of color and engagement with issues of race are what’s ethnographically present. Absence presents a methodological problem in the study of ignorance; while also motivating analysis of why such absence may persist. I draw inspiration from the analysis of colorblind ideology and white ignorance to ask, how might the frames of the QS epistemic ethos prevent what’s currently absent from ever entering or obscure what is present and needs greater acknowledgement; thereby serving to reinscribe white ignorance and white privilege? I analyze the boundaries that are set by QS epistemic practices. As mentioned in chapter 2, I’ve followed recent work that takes ignorance as an “ethnographic object” (Mair, Kelly, and High, 2012) and focused on the ways in which practice directs how ignorance is transmitted, regulated, and socially contingent. There are four components of the QS epistemic framework that intersect in ways that are pertinent: personal experience as a point of origin, individual difference, narrative/interpretative autonomy and control, and an individualized sociality (the community in the QS tends to function more as an audience for individualized story telling, rather than participants in social meaning making). How might these frames intersect and deflect attention from ignorance and its corollary, injustice?

First, I examine how these components allow critical viewpoints to remain unacknowledged and uninterrogated; as we’ve seen in the last section, the QS organizers and leaders repeatedly enforce a focus on personal experience in their primary platforms of knowledge exchange such as the Show & Tell. This emphasis on personal experience is predicated on the assumption of universal individual difference, which the ethics of interpretive autonomy and control, protects in

an anti-paternalistic embrace. However, this framework is instrumental in maintaining the ethnocentrism of a privileged elite, it authorizes their “not knowing” unless there is evidence in the form of their own self-collected data. When counter-evidence arises out of another’s individual experience, the epistemic ethics of the QS — the narrative/interpretative autonomy and control, and individualized sociality components — suggests that individual can only share their data story and not use it to challenge the interpretation of others; in addition, the speaker’s narrative authority cannot be challenged by the audience either. In this framework, even if a self tracker from a minority group articulates difference, they cannot use their self collected data as an example of what other people in a similar position might also be experiencing, since you can only own your personal story and your personal interpretations. As we noted in the second chapter, a woman’s account of self-tracking sexual harassment was subject to dismissal when other women’s personal experience, and interpretation of what constitutes harassment did not match that of the self tracker, undermining the significance of her experience and capacity to garner support.

In addition, QS organizers relegate analysis of larger social forces by limiting the Show & Tell stories to personal experience bounded by data — let’s take the marginality of white women in a white male space; one 62 year old woman was asked to leave out from her self-tracking story, her commentary on how society configures women’s aging as a problem to be fixed, medicalizing aging and subjecting aging women to “treatment” (Informal conversation, QS conference, Amsterdam, May, 2014). Her self-tracking story was inspired by a resistance to the cultural imperative that she must overcome aging. Although, in the QSXX meeting (women identified self-tracking meeting largely attended by white women) where I first encountered her talk, she found a receptive audience; as this talk traveled to the QS global conference in Europe, she was asked by the QS leaders to leave that section out while preparing her talk. It wasn’t clear why she was asked to omit her critical social analysis and instead focus on her fitness tracking, but the ideas espoused by Wolf that criticality of larger social forces be considered when one reaches the limits of data in solving a problem, offers some insight; suggesting also, an understanding of data as apolitical. His commentary on other people’s positions as something the QS audience does not need to engage also evidences the boundaries that are placed on political self expression in the QS cultural context.

Secondly, QS evades history through its grasp of human difference. QS self-tracking assumes the certainty of individual difference and celebrates its articulation without historicizing the difference self-trackers experience. Gender historian, Joan Scott (1993) argues that a project that describes difference but not how those differences came to be, is only partially effective in producing structural change. The QS mirrors the turn to the local in development discourse, and rests on a belief that the bounded unit — the self in QS, like the local community in international development — with unique and privileged knowledge exists in the first place (Massey, 1994). Scott (1993) highlights that experience as recounted by an individual is already an interpretation that needs to be subject to further interpretation. In this process, we need to ask how the very terms with which a self tracker articulates his experience and sense of self have come to be constructed by hegemonic discourses of which we are all a part. She emphasizes analyzing how



experience is mediated and how it comes to be legitimated as evidence in the first place. Even if the QS cultural context engages all stories equally, the uptake of a self-tracking story by critical stakeholders like doctors will be varied in ways that matter; in ways that may negate the equality that QS professes, rendering its platform irrelevant for some groups. In addition, such evasion of history I argue, serves to erase the relationality that configures how white bodies are represented and viewed by medical stakeholders, limiting the capacity of majority groups in the QS to deploy their self-collected data to garner better treatment themselves.

Take the case of pain management. Research on racial bias in pain management now point to how black patients are administered less pain medication than their white counterparts (Green & Bullough, 2010; Hoffman et al, 2016; Institute of Medicine, 2002). Even black children are vulnerable to such inadequate treatment of their pain (Sabine & Greenwald, 2002). This phenomena is attributed to miscognition about the resilience of black individuals (Waytz, Hoffman, & Trawalter, 2014), with this bias now documented in white children as young as seven years old (Dore et al, 2014). The social construction of race still underpins the biological understanding of black physiology. These studies suggest that the experiences of black patients as articulated by them are interpreted through a lens that misperceives black embodiment (Trawalter et al, 2012; Waytz et al, 2014) with false beliefs such as “black people have thicker skin”, among others (Hoffman et al, 2016). Waytz et al (2014) describe this phenomenon as a form of “superhumanization,” where black people are attributed qualities of strength and resilience that exceed what is perceived in the embodiment of white people and other racial groups. The authors state that although such ideas might sound complimentary, they work to justify and excuse violence, as they have in histories of slavery, and continue to persist in cases of police brutality against black men and women in this current moment. In addition, black patients are more likely to be dominated in conversations by doctors, who were also less patient centered in their communication (Johnson et al, 2004). The Institute of Medicine (2002) in a review of literature on racial bias in medicine states: “The study committee was struck by the consistency of research findings: even among the better-controlled studies, the vast majority indicated that minorities are less likely than whites to receive needed services, including clinically necessary procedures. These disparities exist in a number of disease areas, including cancer, cardiovascular disease, HIV/AIDS, diabetes, and mental illness, and are found across a range of procedures, including routine treatments for common health problems” (pp.2).

The misperception of pain experienced by black patients, their “superhumanization” is built on a racial relationality that rests on grasping white patients as more sensitive to pain. The effects include easier access to prescription opioids in white populations (Pletcher et al, 2008) resulting in prescription opioid abuse at higher rates in white populations than non-white populations (Han et al, 2015). Singhal et al (2016) found that such racial bias in opioid prescription is higher in conditions linked to drug abuse with non-hispanic blacks receiving fewer opioid prescriptions, likely due to the misperception that black patients are more likely to abuse such drugs, an unsubstantiated stereotype. In unpacking white racial ignorance, Hoagland (2007) brings into view the mechanism of “denying relationality.” White individuals falsely see themselves as autonomous and unmarked — only non-white people have race, and thus the problem of racism

is also only theirs. However, white sensitivity is mutually constituted by the alleged black insensitivity to pain. Racism against black patients is also instrumental in enabling prescription opioid abuse in white populations. The denial of relationality limits white populations from seeing racism against black populations as their problem too, shaping their representation as well.

To assume that the self collected data or self-tracking story of a black patient will operate outside the QS cultural context in a similar fashion to that of a white patient, is to assume falsely, that marginalized communities have the ability to precede their representations, when in fact it is those ideologically constructed representations that make them visible (Butler, 1990). And, further, to assume that the misrepresentation of minority groups has no effect on the well-being of white groups is to deny the relationality that configures how white bodies are also perceived in medical treatment. In their empirical analysis of multiculturalism and colorblind ideology, Ryan et al (2007:6) state that “whites are socialized to believe that it is simply wrong to acknowledge ethnic group differences.” Embracing individual difference without providing avenues to historicize and culturally situate difference in systems of racial inequity, however, replicates the ways in which color-blind ideologies further racism, harming all groups involved. In these several ways, QS maintains forms of ignorance that have been instrumental in maintaining dominance, racial and gendered, and is designed to continue to do so as it heeds the call to address its diversity problem, limiting its capacity for all races to effect change.

### **3.5 Conclusion**

In chapter 2, I described the socialization that helped me contour a QS ethos that I critically engage in this chapter. Here, I showed that quantification, broadly interpreted is subordinate to an episteme of personal experience and an exploration of tools. I surfaced how such priorities can be traced back to counterculture histories, its libertarian leanings and in particular, gnostic and cybergnostic epistemologies of experience. Such frameworks conceive of the individual as autonomous; social categories of race, class and gender among others are considered devoid of influence, thus the histories of oppression at the many different intersections of these categories are deemed unnecessary until the individual’s self-tracked data reaches its limits, offering no answer to the predicament of the individual who can now, and only now look at their social location. In structuring the QS primary platforms of knowledge exchange such as the Show & Tell to replicate this ethos, the QS leaders shape what kinds of knowledge has legitimacy in the QS social context. The emphasis they place on personal experience engenders some critical potential — in particular, it allows QS self-trackers to locate issues of data privacy and ownership in their personal experience, allowing discovery of how the personal is political. The dignity that the QS affords to individual bodily difference, and its “no explanation needed” approach, helps patients who have been disenfranchised by the medical system, who did not “fit” diagnostic categories find acceptance and community. In connecting self-tracking as a modality to such difference and its embrace, QS leaders hail patients into its practice. Perhaps, the most significant intervention is the rendering of personal experience in statistical lexicon, the sample

size of 1, suggesting that the individual stories shared by patients are not just anecdotes but patient expertise, the emergence of an alternate science.

I have argued, however, that these critical potentialities produced by the QS episteme are also limited by that very ethos. The individuality QS self trackers are encouraged to feel, does not carry over to the settings where their data will be read, settings whose frameworks are historically engaged. It will be read as x's data, as y's data, where x and y have already been represented by their location in the race, class, gender, orientation spectra, and their representation will precede them and shape how their data is seen. The data adopts the personhood of the self tracker, and different self-trackers are attributed varying levels of personhood in systems of oppression. If the goal of the *n of I* activism is to render self-expertise in the language of the dominant, it is not similarity of language that matters but the actor who generates it. In this way, white ignorance of racial relationality serves to limit the capacity of the dominant racial group in the QS to access self knowledge and challenge their representation as well. A de-historicized worldview cannot effectively challenge historically formed systems of power.

In the next chapter, I take two case studies of prototypical QS patients who perceive the medical system as having failed them, and examine the utility of the fixed components of the QS episteme in their private re-authoring of disempowerment and uncertainty. In this chapter, I showed how white ignorance is functional in maintaining dominance, but also limits the potential of QS aspirations to produce a radical alternate science. In the next chapter, I show how “temporal ignorance” or uncertainty is orchestrated in ways that render self-tracking as a coping mechanism in the face of debilitating disease. Through a strategic engagement with uncertainty, Smarr and Henry, the two protagonists of the following chapter, sustain hope even in the absence of health outcomes. The concept of self-tracking opens a space for creative re-interpretation of the aspects of illness that challenge the limits of individual agency. In showing how “self-tracking” as a concept has a capacity to meet highly personalized needs, I move in chapter 5 to showing how self-tracking becomes a “boundary object” in development, one that, despite the intentions of QSers themselves, can meet the needs of much larger actors such as state, corporate and medical stakeholders.

# 4 The Productive Uncertainty of the Feedback Loop

My name is Nancy Dougherty and I am going to talk to you a little bit about my detox from all things quantified and how much healthier I got, and how deeply disturbing that was to me. (Dougherty, 2013)

Nancy Dougherty is both a QS tool maker and a self-tracker, with several sensor-based personal projects she does for fun and exploration. Like many other QS health stories, Dougherty experienced a set of chronic symptoms with no definite diagnosis. The prototypical QS response to this situation, Dougherty notes, would be to initiate a self-tracking project to detect patterns and find culprits; appropriating the cybernetic construct of the “feedback loop” self-trackers alter their behavior in a sustained fashion in response to feedback from monitoring devices, slowly matching their current behavior to their desired future selves (Cameron and Leventhal, 2003); deploying a feedback loop intervention for behavior modification encourages independent learning, which in turn enhances the sense of self-efficacy (Kazdin, 2012) that QS self-trackers seek. Although, the feedback loop construct is fundamental to many self-tracking projects during illness, Dougherty says she abandoned that option, and submitted herself to extensive tests and medications prescribed by her doctors. In tandem, she adopted a set of widely recommended healthy habits — “doing all the things I knew I should do anyway” — and started feeling a lot better; “In fact I got healthier than I had ever been doing any of my QS experiments.” In her case, the revelation that self-tracking was unnecessary to create positive health outcomes had a rather destabilizing effect on her ardent belief in self-tracking practices. Like many self-trackers in the QS, Dougherty lies at the intersection of multiple positions — self-tracker, tool maker, patient — enabling critique of constructs embedded in the activities and pursuits of one role, from the experiences of another. Here, from her recent position as a patient, she contemplates the limits of the feedback loop concept that motivates her own work as a toolmaker, and one she rejected when signs of illness emerged:

The reason I quantify is I try and look into this feedback loop that a lot of us talk about, where you look at your health inputs, you view your health outputs and monitor your behavior, and then it all makes sense and you fix everything...But there is a huge problem with this and it is something I think we have all encountered. There are so many variables, inputs, we are not quite sure what to care about. Like [someone] said yesterday, a lot of the responses are time delayed. They are interdependent, they are non linear. It’s a really awful system to try and characterize. (Dougherty, 2013)

Dougherty, now skeptical of the “feedback loop” so central to the QS self-tracking enterprise, still recovers the ethos of the QS by reconsidering it in light of what Sharon and Zandbergen (2016) refer to as the other values at play in self-tracking discourse. They describe how self-tracked data can also function as prompts for personal narratives; as a way to reach out to others and share embarrassing details about oneself rendered in deceptively impersonal charts and spreadsheets; the act of collecting data can also help introduce a sort of “friction” into daily activities that foster a sense of mindfulness (Sharon and Zandbergen, 2016). Further, Sharon (2016) finds that self-tracking helps people negotiating adversity execute values of personal and communal importance such as autonomy, solidarity, and authenticity through a critical and informed engagement with data. The motivations that support self-tracking experiments are heterogenous and dynamic.

Dougherty describes such other values of the QS self-tracking ethos that supported her, even as the promise of feedback loop appeared unattainable: “but it still felt very much like a QS experiment to me. Not because of actually logging or taking data but because the QS mindset, the flexibility, the exploration, even just the idea that I was in control of my health and it wasn’t just antibiotics that would fix me.” The components of the QS worldview that are fixed and left uncomplicated, such as the inevitability of technological advancement, support an allied interpretive flexibility in all concepts and ideas that could destabilize that unwavering belief in technology. If the feedback loop fails, that’s okay because QS is actually about experimentation, and acknowledging a sense of personal control — in this case, the ability to do what she already knew she should be doing. In a similar spirit, Wolf quotes another self-tracker’s observation that regardless of how hard it might be to carry out a scientific self-tracking project, “you always learn something” through observation (Wolf, 2012). Not all self-tracking projects are motivated by scientific self-discovery, but in the many different assaults to the aspirations underpinning such technology-mediated self-experimentation, the QS rhetoric is still configured to rescue the self-tracking imaginary. In this chapter, I bring into view how against a backdrop of computational promise, the fluidity of such ontological play can help self-tracking persist, even in the absence of health outcomes. In this story, the relationship of two categories, hope and uncertainty, are central.

#### **4.1 Configuring uncertainty to engender hope**

Dougherty’s talk was featured by the organizers in a curated set of Show & Tells in the QS global conference held in San Francisco in 2013. The idealism that fell apart in her story, is one that QS has perpetuated through a specific QS archetype, a character that positions the story of QS as a movement of health reform, and self-tracking as a sandbox to test one’s agency in the face of an unknown and potentially dismal future of disease. This archetype is a person who has suffered for long with an intractable illness that the medical system has failed to diagnose or treat. This person, then takes matters into their own hands, and armed with data and evidence from self constructed experiments, speaks back to power in the doctor’s office, with an answer to their problems and a personalized treatment plan that’s been proven to work for their body, not the average body of public health. This rather triumphant and oft-repeated story furthers the QS

claim that self-tracking practices can subvert the paternalism of institutional medicine, and challenge what counts as legitimate knowledge in the reform of health care in the United States. Whether self-tracking and its technologies do in fact produce health is up for debate, but hope that the “feedback loop” once perfected will be deeply entrenched.

Hope has received little academic attention in the social and psychological sciences due to a pervasive understanding of hope as a “passive” orientation to the future, unlike notions of desire, understood as promoting striving (Crapanzano, 2003); its loose conceptual connection with “agency” has rendered it insignificant in analysis of social action. In Vincent Crapanzano’s (2003) view, the relegation of the hope category, speaks to larger American cultural values that prioritize action, which then infuse and direct the academic gaze. However, emergent empirical academic orientations suggest a shift towards examining how social practices engender hope (Good et al, 1990; Novas, 2006). In their work on oncology, Mary-Jo DelVecchio Good and colleagues (1990) introduce a “political economy of hope” that undergirds oncology practice; the “message of hope” in the “fight against cancer” is central, and the cultural imperative to instill hope directs how physicians interact with patients; choreographing a personalized and intentional process of disclosure that reveal and obscure health prospects to patients, throughout the life course of disease (Good et al, 1990). Physicians in this study claim they “sprinkle as much hope in a situation as we can” (p.71) as one informant put it, even when their understanding of its role in health outcomes remain diverse and often unclear. They effectively design how patients interact with information and uncertainty to create positive orientations to unknown futures.

In another strategic choreography of uncertainty, Tiffany Romain’s (2012) ethnography of oocyte preservation or egg freezing practices among women in northern California, reveals an active engagement with the hope concept — “Egg freezing women participated in discourses of hope as well as practices that create, cultivate, market, and sell that hope” (Romain, 2012:190). They saw egg freezing as an investment that expands their options both in the present and the future. For the women in Romain’s study, the ability to keep the future unknown and open to multiple possibilities through oocyte preservation, helped them “cultivate hope” and experience “pleasurable surrenderings” to an unknown future, as the company offering its services, Extended Fertility, suggests on its website’s welcome page — egg freezing helps you “preserve your options.” Romain points to the intentional production of uncertainty that such services support: “My informants could have chosen options that would end the uncertainty of the future: they could have decided to make a family with a less than ideal partner, to become a single mother by choice, not to have children, or not to pursue a promotion. But, my informants chose instead to live with the uncertainty of the future, for this uncertainty also contained all of the possibilities of the future that they desired” (Romain, 2012:190). This uncertainty is functional, it becomes a coping mechanism that helps Romain’s informants aspire towards heteronormative goals, and deploy technological innovation to align themselves to gendered social norms, while waiting for the components of that imagined and desired life (the ideal partner, an established career, and so on) to harmoniously manifest. In both oncology practice and oocyte preservation, “temporal ignorance” (Romain, 2012: 210) enlivens in multiple ways; uncertainty is not merely

an anxiety inducing feature of unknown futures, uncertainty is also deployed as a strategic mechanism that orients an individual towards that future in productive ways.

How do self-trackers engage uncertainty while negotiating the prospects of debilitating illness? In what follows, I use two cases of self-tracking illness to reveal the private re-authoring of disempowerment and uncertainty using technology, numbers, data, experiments, woven into a dynamic and functional narrative. In the first case characterized by data fetishism, I examine using two presentations spread over a three year period, Larry Smarr's investigation of his body in Crohn's disease, a diagnosis that he discovered via self-tracking even before symptoms began. In the QS cultural milieu, Smarr's story most clearly typifies the QS archetype described above; in fact, he has actively shaped the archetype. I show how Smarr destabilizes the felt experience of health, troubling its certainty in the absence of symptoms, and configures a state of perpetual uncertainty that only self-tracked data in a continuous feedback loop can effectively re-stabilize, thereby legitimating expansive and constant surveillance of bodies.

In the second case characterized by data skepticism, using interview data, I analyze how Henry, a self-tracker suffering from debilitating migraines, deploys self-tracking in a quest to manage his pain. In Dougherty's talk she problematizes the practicality of the feedback loop, but she does not question its basis, suggesting later, that it's important to keep persisting, because in the future, it may very well be less impractical. I surface how the inherent uncertainty of the feedback loop concept, its impractical but not impossible nature, nourishes hope for Henry that self-tracking is the answer for diagnostic closure and elusive treatment, by orienting him in a positive relationship to the unknown future of his illness.

Both oncology and oocyte preservation rely on faith that imminent technological and medical advances will offer a cure (Good et al, 1990) or more reliably access fertility in the future (Romain, 2012). In both cases that follow, I reveal how a similar faith in computational advancement is instrumental in extending temporal ignorance, creating a self-sustaining framework for engaging data. One 58 year old woman in my fieldwork, a former nurse and expert in personalized health care, wondered why self-tracking individuals don't track their resilience, given as she suggested, you can have resilience even with degradation, resilience is "replenishable" — it grows. In describing how different elements in a self-tracking practice are in fact choreographed to render the QS mindset as a form of resilience, which as resilience does, then persists, I add to the genre of QS research on the other values of data (Sharon and Zandbergen, 2016) by bringing into view how the experience of hope is made replenishable through self-tracking. In examining how uncertainty is manipulated, I add to the emergent body of work on functional forms of ignorance by showing how "temporal ignorance" maybe intentionally produced to help hope persist through self-tracking. In the concluding section, I add to the theory of ontological choreography; deriving from the two case studies, I argue that uncertainty deployed as a strategic temporal ignorance, maintains the synecdochal connection necessary to continue self-objectification in service to a healthy long-range self.

## 4.2 Visioning the “future patient”

The story of the QS archetype begins with the canonical self-tracking practice of Larry Smarr and his discovery that he had Crohn’s disease before he experienced any discernible symptoms. Smarr is a leading physicist and computer scientist, whose interest in self-tracking began when he moved to the fitness conscious culture at La Jolla, California, to head the supercomputer center at University of California, San Diego. Experiencing a renewed motivation to lose weight, he started tracking his weight, slowly adopting a range of QS tools and in a QS Show & Tell presentation, a little over a decade later, he said he tracked variables in the realm of “25 billion with microbial data” with a team of experts recruited into the analysis process (Smarr, 2013). This exponential expansion of his self-tracking pursuits is motivated by his initial personal experience of the power of self-tracked data in diagnosis; in the early 2000s, Smarr, diagnosed as pre-diabetic, wanted to reduce the levels of inflammation in his body; using a private biomarker testing service called yourfuturehealth.com to access lab work that his doctor said he could not order given there were no symptoms and consequently, no insurance codes, Smarr discovered that his inflammatory markers were skyrocketing, despite targeted self-care and medical interventions to keep them in check. In experimenting with other tests offered on the website, he found there was a specific protein, lactoferrin, at levels that indicated Irritable Bowel Disease (IBD) and eventually discerned that he had Crohn’s disease. Smarr made this connection through an extensive review of scientific literature, online sources like wikipedia and 23&Me genomic data to spot genetic propensity for Crohn’s disease. In this 2013 Show & Tell, he describes his doctor’s response and his own:

Now my doctor who had done the colonoscopy said, “you don’t have IBD, I would notice it, I did your colonoscopy. I have been inside, you don’t have it.” And I said, “like, you must be doing this all day long right?” He said, “oh yeah, I do dozens of these a day.” I said “that’s why you don’t have any time to read the scientific literature!” (audience laughter).

Smarr’s challenge to the capacity of physicians to accurately deduce the state of one’s body while constrained by the inefficiencies of the current health care system, is fundamental to his advocacy of self-tracking. His efforts are in response to the perceived failure of the medical system; a quest to find an antidote for its inadequacy, using his personal experience and his own body as an example. In the recent 2016 Human Data Exploration (HDE) conference in his home institute, CALIT2, Smarr gave an updated presentation on his tracking story titled the “Future Patient” with visualizations of 20 years of self-tracking data, charting his immune system and the progression of his Crohn’s disease. He says pointing to the visualizations projected onto an interactive display made of 32 screens, “There are no graphs like this longitudinally in the scientific literature for a human” just like there was nothing like Bay Area counterculturist Buckminster Fuller’s “45 tons” of paper containing his own diligently self-tracked data in the 1980s (Sanford, 2003). Underpinning Smarr’s monumental project is his most significant intervention: the idea that markers of disease states cannot be identified by individuals based on



how they feel or look. In constantly challenging the felt experience of health he produces an important form of uncertainty that fuels self-surveillance.

How can I have a chronic disease? I'm feeling, you know, look! (opens jacket) — do I look like I have a chronic disease? This idea that you can feel what is going on inside of you, that is so epistemologically false. You just can't do it...my end point that I have come to is that where there is data, when you can actually quantify your body and you get a sense of knowledge, a sense of, if not control, the ability to at least understand what is happening to you, there is hope. (Smarr, 2013)

In Smarr's ontological choreography, is first a reworking of the health concept — he creates the absence of symptoms as an entity which he then separates and removes from the concept of health, and supplants instead with self-tracked biomarker data. Although, it is true that one cannot always discern biological processes moving towards a disease state through feelings — the centrality of this separation in his narrative helps necessitate and authorize extensive self-tracking.

Smarr asserts both in the 2013 talk and his recent 2016 presentation that the ritual of the doctor asking you how you've been feeling should be replaced with a question about your quantitative biomarker data, the patterns therein and its relationship to population level data. This computational contingency that Smarr suggests and lives is nothing new; Bjorn Hofmann (2001) details in his paper 'The Technological Invention of Disease' how since the mid 19th century, medicine's engagement with technology has slowly separated the individual's self-reported bodily experience from the expertise that pinpoints their illness. This trivializing of self-reported symptoms or absence thereof, that Smarr refers to as "feeling" is predicated on notions of objectivity in medical sciences but also indicative of changes around which information warrants attention in diagnosis — in the case of Smarr and in contemporary techno medicine, this is typically data at the molecular level, where greater technological precision in observing variations, has led to a proliferation of new conditions. Hoffman writes, "the capacities of technological medicine have replaced the individual patient as the epistemological basis of the disease concept" (p.15). Although, doctors in my fieldwork vehemently denied that this was the case and described how symptoms are in fact the basis of diagnostic processes, in the technologically mediated framework of disease both held by Smarr and critiqued by Hoffman, both patient and doctor are rendered as impaired without technology, as bodily threats to health are far too often invisible and cannot be located with critical faculties and technically unmediated observation alone.

In most QS cases of health tracking chronic or mysterious illness, it is the presence of symptoms which remain unmatched with a specific condition that is the issue; doctors who do take self-reported symptoms as a basis for their investigation are then unable to find biological evidence to explain those symptoms. The quantitative quest that many self-trackers without diagnosis begin and sustain, is a response to this predicament. At the heart of Smarr's now 20 year tracking

project, however, is a critique of the United States health care system which he calls the “sick care system” (Informal discussion, Health Data Exploration, 2016) where treating diseases are prioritized over predictive medicine, which in his vision would require close and longitudinal monitoring of various biomarkers to detect and manage threats before their result in disease. In his presentation he imagines predictive medicine with an analogy of a car equipped with sensors continually keeping watch of its many components that can then be accessed to see if all is well when the car is taken in for service, predicting early signs of dysfunction:

Predictive medicine — this is like your car — you are going in and saying, yep, everything is okay. Everything is okay, everything is okay, oops, things are beginning to diverge and that might have been a good time to intervene but they (the doctors) didn't because they weren't doing this. I was doing this. The doctors weren't doing this methodologically. It wasn't having any impact on their diagnosis. It will in the future because they'll change the methodology. (Smarr, 2016, Presentation)

Unlike Wright, another self-tracking proponent who rejects the need to further pursue diagnostic closure when none is offered by medical science, questioning whether such categorization is really essential to well being (Wright, 2014), Smarr embraces a more amplified medical engagement, one that extends the reach of the medical system; he doesn't subvert or even reject it, he asks for more and more medicalized objectification in the name of more personalized care. In Thompson's (2005, 1996 as Charis Cussins) ethnography of infertility clinics, she shows how the objectification of medical fertility treatment can be willingly sought out when it promises to produce the long-range self envisioned by patients seeking care; in her informants' case, the future self as pregnant or parent. As long as the treatment has not definitively failed and its promise is still kept alive, the patient's subservience to an objectifying medical gaze is experienced as having agency, because the objectification is still synecdochally connected to the “parent” or “pregnant” ontological innovation. Only when treatment fail, does the connection rupture, and consequently, objectifying interventions become alienating (Cussins, 1996). Smarr's unwavering faith in technological advancements allow him to maintain the promise of medical science to discover a cure for Crohn's disease in his lifetime, and ontologically produce the disease-free self. In this way, he maintains the power position of medical science, which he is also connected to as a renowned scientist invested in creating his body as its own medical lab. In this work of maintenance under the guise of innovation, other QS values such as individual difference is also configured to reproduce norms.

In Smarr's 2016 Health Data Exploration presentation, he critiques the healthy ranges offered by many leading labs in the United States — “what is normal isn't necessarily normal” — stating that the data used to derive standardized healthy ranges include that of people with disease. He asks how many of us in the audience have Asthma, “your blood is in there” he says referring to the people who raised their hands, going on to list obesity, allergies, diabetes as deviations in the base data that inform healthy ranges used in diagnosis. In Smarr's analysis of the healthy range, he is critical of all deviations from the biomarker equivalent of what Rosemarie Garland-

Thompson (1997) terms the “normate” in disability studies. The normate is “the figure outlined by the array of deviant others whose marked bodies shore up the normate’s boundaries” (Garland-Thompson, 1997:8). The normate is a fantasy that only a few people (cisgendered, heteronormative, white, male, able-bodied, healthy, young, athletic) will ever embody, and even then for just a moment in their lives, but it is a figure through which the disabled, “deviant” other is mutually constituted. Although, the emphasis on difference in QS on the surface appears in service to a radical project, when Smarr says “what is normal isn’t necessarily normal” he means something other than what Garland-Thompson critiques with the normate figure; he means the normal is not normal enough, it does not attain the extraordinary norm that would be useful in his mission to combat disease.

In the Q&A section of his first QS Show & Tell in 2013, Wolf asks Smarr how his extensive tracking has made him feel. He responds:

It’s made a huge difference. I mean I have these things happening to my body that are called ‘symptoms’ that I didn’t used to have and I think I would be like what is going on with me? I would feel completely out of control, you know, what’s happening to me? It’s this race to figure out what is happening to me faster than it can deteriorate.

In Smarr’s engagement with the uncertainty of his illness, one entity — his sense of knowing his body, his feelings, is discounted (it recedes) and concepts, and frameworks from medical science are selectively deployed to produce a new entity: a subjective sense of control, new understanding and hope. The absence of felt symptoms during much of his investigative process is merely an absence of information, an error in self perception, a risky ignorance, as evidenced by the arrival of symptoms many years later. In Smarr’s description of his data analysis, are prominent renderings of parts of the self as objects, distanced and captured through immersive visualizations and 3D printing of organs such as his intestines. These objects absorb his personhood just as Thompson’s (2005) informants project their personhood onto objectifying components in their treatment process, maintaining the synecdochal connection — “So this is the 6 inches I found out that is inflamed, that is causing all of this trouble, all the inflammation and everything else, it is right here, I have it, in my hand.” This rendering of his illness in a 3D printed artifacts is empowering he says, “Because, this is what is wrong with me. Right here. This much. The rest is just fine. I have this sense that I can conquer this.” In order to engage this sense of empowerment, an artificial separation between the health of this piece of his intestine, and its entangled, symbiotic relationship with the rest of him has to be maintained, strategically suspending the more systems approach he takes in his scientific and personal interest in the microbiome.

The self and the disease emergent within it can also be separated temporally producing a “race” where Smarr’s knowing/understanding can be faster than the disease. Although, he doesn’t explicitly foreground aging, at play in this decade long story that he recounts in his 60s is also the separation of aging and illness (it is possible for me to age without illness) but also, perhaps

the merging of aging as illness (if aging is a “deterioration” then it can be cured, beaten). Smarr (2013) when asked about the implications of his extensive tracking practices on his everyday life, says:

Well, yeah it has made a huge difference in my life but then so has coming down with Crohn’s disease. Normally, you are in your 20s when you get it and it can be quite devastating. And what I have been wondering is, is that going to happen to me? And, one of the things that this has helped me do is understand that there are several kinds, one that is devastating at the end of smaller intestine .. and I am over on this side, and that’s worth knowing about.

Although, his disease remains untreatable, not knowing himself on a longitudinal molecular level is a critical form of ignorance not just for himself but for the larger social good, a justification that underpins public health engagement with the QS and its requests for “data donations” examined in chapter 5, as he says in his 2013 talk:

I think in the next five years there will be such changes that therapy will change in a way, that could actually, there is a million people who have this and 10% of the American population has an autoimmune disease. There are 80 autoimmune disease. This is one autoimmune disease. If we don’t get on top of this stuff, it’s going to be a terrible thing to the whole population.

In 2016, three years after that prediction, his biomarkers suggested that things were getting worse despite pharmaceutical intervention. One audience member asks him if he was worried about that emergent trend in his data. He responds with his usual wit “I don’t worry, I just measure. And then I think and research, but I don’t worry — that would drive up my cortisol (audience laughter).” Although, in the years following his self-diagnosis, symptoms of Crohn’s disease did emerge along with other signs of illness, his data has been helpful in generating various hypotheses about the immune system, including an intriguing relationship between one of his medications and his predisposition to diabetes. An audience member asks, examining his visualizations, whether he was disappointed that his subsequent intervention did not have a positive effect. He says he will be doing more research but pointed to her observation as an instance of the usefulness of *n of 1* studies and the layers of intent that underpin his self-tracking project, which he accesses in his shifting relationship to self-tracking.

See, you are already drawing hypotheses out of this. That is what  $n=1$  is for. It’s not that everybody is going to be like me, it’s that I see a relationship here which I can say is a hypothesis and then they can go and do a bunch of mouse experiments or something, they can test other humans and so forth...That is why I am really doing this for, to turn my body into an observatory that is publicly available; It’s like I donated my body to science but I did it on a rental agreement [audience laughter] so I get to take it back...I encourage you guys to keep doing what you are doing. Follow your nose, do what you think is important to do and

then take advantage of things like our n=1 journal that is getting funded, blog it, whatever, because people ultimately will listen to you. But it takes a while to get the data to you know, convince them that there is really something there that they have missed. (Smarr, 2016, Presentation)

This story of Larry Smarr, a key figure in the QS and evangelist of technology-enabled patient monitoring in many of its health focused conferences, is atypical given his status as a renowned and powerful scientist, his endless curiosity, his passion for the emergent science of the microbiome, his extensive access to advanced technologies and the financial and technical assistance he receives in gathering and analyzing his data. He himself states that he does not expect everyone to be like him. However, he makes several critical interventions in fashioning the “future patient.” First, he troubles the certainty and experience of health at any given moment, he produces a temporally extended uncertainty about latent disease lurking just under the surface that can only really be “known” and potentially controlled, through data and surveillance. This uncertainty serves to legitimize extended monitoring of not just patients but those who are seemingly well. The 25 billion variables (with microbial data) that his tracking project contains, speaks to his quest to perfect the feedback loop essential in his narrative to both monitor his disease and develop hypotheses that would be taken seriously by medical science. The uncertainty of the feedback loop drives the quest for more and more data and sustains self-tracking, bolstered by his sense of certainty in computational advancements that will help analyze such an extensive dataset. In these ways, Smarr maintains and produces multiple forms of uncertainty that help him easily submit to self-objectification in order to become disease-free or at the very least, contribute to the aspiration for a disease free society. His narrative forms part of the speculative imaginary of self-tracking and furthers the framing of self-tracking practices, technologies and services as critical in producing health, even when they are not producing relief. I move to the second case of self-tracking to find the source of one’s migraines, after the likelihood of medical and pharmaceutical science delivering a panacea for migraines feels increasingly dim for Henry. Unlike Smarr’s story, Henry’s is characterized by a sense of skepticism in data, which ironically, when placed in conversation with the computational promise Smarr supports, works to produce a similar quest to perfect the feedback loop.

### **4.3 A useful analysis paralysis**

Henry started self-tracking when the pain of migraines exceeded the anticipated difficulty of keeping track of all the variables that could be causing his pain; “It’s no fun you know. It’s just not like a nice QS project” he says, given his long standing hesitancy around tracking and collecting migraine data. Having suffered from migraines for over 20 years with no relief, tracking was suggested many years prior by his doctors as a way to capture contextual and situated knowledge, to be able to better identify triggers. Henry an African American man, lies at the periphery of the QS cultural context both racially and through his orientation to self-tracking. Although Henry was first hopeful that he may have found his community (as noted in chapter 3), over time, his sense of connection to the QS became more tenuous as his self-tracking story unfolded a more complex and intractable trajectory of pain and illness than typically witnessed in

QS Show & Tells. Henry's self-tracking response is motivated by his analysis of larger systemic issues. In our interview, he explained the factors that relegate his condition from being placed in the running to receive research funding necessary to find a cure; having examined the pharmaceutical pipeline for the next 25 years and finding little evidence of important innovation, he viewed self-tracking as his last resort. Unlike Wolf, who in chapter 3 suggested the failure of self-tracking as the starting point for critical analysis of systemic issues, Henry did not arrive at his political analysis after his data failed him — the combination of his doctor's long standing self-tracking prescription and his political analysis motivated his uptake of self-tracking as a modality. In these ways, although Henry deploys the chosen modality of the QS and shares some of its assumptions, he does not easily fit within the apolitical and dehistoricized contours configured by the QS leaders. However, his story offers important insight into the components of self-tracking that allow it to persist, even when it provides no answers.

Henry collects data on his health inputs and his health outputs in the tradition of the feedback loop, documenting approximately 85 different measures. He notes: "Almost every part of my day I am tracking something, so as I finish this tea, I am going to put down the time. It is something I always think about." He wears a Basis watch, a fitness tracker with the most number of sensors in the market: heart rate, galvanic skin response, activity and sleep monitoring, skin and air temperature. He wears it 24 hours a day. The array of sensors contained in this device help Henry in his quest to perfect the feedback loop and its absence, therefore, engenders some anxiety: "I rarely forget it. It kind of sucks when I do. There is that kind of attachment. Right now, it is on really low battery power and I hope this holds out until I get home. Because I am missing out on data during my day but then there is this other part of me that says, well, you know life is full of missing data." He is both dependent on and skeptical of this device. Apart from inaccurate data he sometimes receives from his Basis watch, he says: "It's just that I don't expect these companies to tell me something so deep and interesting about myself that I did not already know. If it does tell me something, it is more like it confirms it." The reason he uses it then is primarily archival; in case a variable in the dataset predicts a migraine outcome. The 24/7 monitoring that this technology affords, increases the chances that his feedback loop system will detect a culprit.

His process of self-tracking is fraught with the sense of incompleteness Dougherty captures in her critique of the feedback loop; in addition, it surfaces the inadequacy of common statistical methods of analysis, found in much of the scientific literature and appropriated in many self-tracking projects. "Some people have wondered why are you so vigilant about tracking and even about the model. Just try a simple correlation, or do a simple linear regression, you know." He says he is really picky about the statistical models he uses because he understands the assumptions they make and the ways in which data is spliced for easier handling. For example, he talks about how an action he takes at one moment could have an impact at a later time but data needs to be made amenable to analysis: "I kind of cut up [the data] in 24 hour blocks as if they are independent and identically distributed. That is just not real. People make all sorts of assumptions to put it into these nice fancy packages. And, I get it as a first step but I am very aware of the limitations. It is not a paper and it is not other people's problem." Henry requires a level of personalization that institutionally produced science does not necessarily have to meet

because the goals and stakes are different for a population-level researcher, for a doctor and for the person who needs the pain to stop. Though his measurements are derived from scientific methods, they also question their validity, and the feasibility of creating a scientific model, by making apparent the missing information and the impracticality of considering all that may be important. He reflects on the impracticality of the feedback loop, in the same vein as Dougherty who we met earlier: “But I am also realizing that life is so complicated, that it’s so complex, the weather is changing, there is different pollen levels. I ran when I was on my way here. I drank tea. It is just so much is going on that even trying to think about that I am sure. I could be right but I am probably wrong.”

In addition, the increasing quantification of this debilitation revealed a new reality. For the longest time, he conceived and self reported his pain as episodic, that is less than 15 days in a month with headache. However, through tracking he found that his condition was in fact chronic and far more debilitating than perceived, recording only 8-10 days of pain free living over a 180 day period. Tracking then, did not allow the experience of pain or disability to recede. (I see the re-examination of pain felt in other cases of tracking headaches in QS as well. Another person suffering from headaches, Kay Stoner (2014), says in a Show & Tell Q&A section, when asked how her data documentation has altered over time, “before I used to say I had 2 or 3 on ten days but it was hurting more than I let on. I started writing more 6 or 7 out of ten days.” Henry explains: “The thing with migraine is that you are in it but once you are out of it, you don’t think about it, so maybe it was always something that was more of a chronic condition but I had this convenient form of amnesia to not think about it.” “It kind of has me depressed, looking at the numbers.” Stoner mirrors this sentiment too: “tracking my headaches in exhaustive detail is not much fun and really depressing, wrecks my day.” For Henry, tracking dismantled a coping mechanism. In its place, is a new habit of meditation that’s also drawn into the experiment where the triggers of migraine seem intractable. “On one level, could this be another prophylactic for you know, migraine. But then there is another part that kind of comes through this practice, which is if the pain does not subside, how do you actually manage and live and deal with it? How can you suffer and not suffer?”

Over a year long period of extensive experimentation, tracking has not provided compelling answers for Henry, its methods are inconvenient and fraught with spurious assumption and most importantly, it’s dismantled a coping mechanisms, made pain an object that persists conceptually even when not experienced physically. Migraine triggers are also a moving target, as he says: “The factors that drive the phenomenon one time may be different from the factors that drive the phenomenon another time.” What then does tracking do? “I would say that tracking it, though it can be somewhat negative gives you a sense of control.” This sense of control, however, hinges on Henry’s embrace of a simplistic mechanistic metaphor of the body that makes his circumstance amenable to the promise of a feedback loop intervention, like Thompson’s informants’ reliance on mechanistic conceptualization of their bodies that helped them believe it could be “fixed.” In a similar fashion, he says he finds empowerment in this approach of “treating my body as a system and sort of investigating the system.” This manner of thinking about the body then alleviates suffering “because” he says, “it makes it interesting and because it

makes it understandable”; this move only creates a fantasy that the body can be understood, but this fantasy is nevertheless essential and productive in stabilizing hope:

I think part of the pain is, both the physical pain but then there is this worry that I would never get out of the pain. And if I am able to document myself, because living experiment, and actually understand oh, it is on these days, under these sets of conditions, etc. If that is something that is a robust finding, however I find it, then I have more control over migraine. Then it is not this random thing that happens. It is a thing that happens in response to some stimulus...It’s hope, it’s hope, that maybe if there is something that is measuring, that is connected to a lever, that could be important.

Evidently for Henry, his self-tracking practice and the devices that mediate his search for migraine triggers also produce hope as a constant, evoking comfort in the idea that there may be a solution just around the corner, even if there’s none apparent at the moment. As another informant, a 62 year old woman, suggested referring to biosensing devices she uses in her own self experiments: “These devices are like little crystal balls at times.. because they are about hope that you can change things .. as well as tools.”

I ask Henry how much agency he thinks he has to conquer his migraines and he says: “I struggle with it. I am on the left and right side of that everyday. I don’t really know, and I need to develop an infrastructure for data collection and analysis so that I can find out.” Whether it has increased a sense of agency is, he says:

Contingent on whether there is some mechanistic world that I could push the levers and change the migraine. But I think it is a good thing in the sense that if that mechanistic world exists, and I can change things to change migraines, then it has given me more agency and control, but if I got through that process and find out that that world does not exist, then I can kind of release and let go. And not live in expectation...I think at the end of it, it could be a freeing process. Like the way that I am imagining it. So whether I really have agency to use it, or if I don’t to let go. Both of those are viable options. Versus, I wasn’t there a year ago. A year ago, I was hell bent on, I have to find the answer. I will find the solution. And maybe the solution could be let it go.

Stoner (2014) also speaks to this distancing that tracking could produce between the physical pain and emotional suffering, “the thing that I learned the most, even if I do have a headache, even if this is always there, it doesn’t have to wreck my life. My internal state isn’t dependent on what is happening outside of me. I am actually a really happy person, pain and all.”

In Henry’s ontological choreography, numbers, data, sensors, surveillance, the body envisioned as an mechanistic object; all support the pursuit of a new thing, ‘pain free living’ or ‘relief.’ In the process, an older coping mechanism of ‘selective amnesia’ was dismantled. Tracking



however, sustains itself because an ontological innovation in this case of self-tracking, is not necessarily a cure or an answer but the inadvertent sustenance of hope as its own form of “pain relief” — an antidote to the possibility of an ongoing and debilitating future. Tracking foregrounded the physical pain of the headache as a constant while managing and receding the pain of future loss, of a fear of aging in pain, of passing on a genetic propensity, by also foregrounding for Henry, hope and a sense of control as a constant.

But, how sustainable is this sub-optimal form of pain relief? Quite sustainable, I argue, because the way in which data and analysis are woven into Henry’s practice creates two stable components. The first is an ‘unresolvable tension’ derived from both skepticism of statistics and dependence on statistics. I ask Henry what would end his tracking and he says: “I think what would definitively stop the tracking would be if I get to the type of statistics that I want and I see the findings and everything is really random. I mean, I really have robust findings that this kind of randomly happens. At which point, I think it would also be very freeing...there is no lever to push, it is part of life.” However, he also points out that he does not even know if the sophisticated statistical models he would find convincing even exist, and when he finds ones that are close, they take days or weeks to run. The second stable component is the rather useful analysis paralysis this creates. So, if tracking leads to finding a culprit for migraine episodes, then it produces relief. If tracking results in a finding that migraine cannot be controlled, then it produces freedom. If tracking is not delivering an answer, either way, then it produces and sustains hope. In every way Henry sees his practice, self-tracking becomes functional. The method of self-tracking deflects attention to the present imperfection of the feedback loop and the inadequacy of statistical models, both of which are then alleviated by the promise of more data and imminent statistical advancement.

Henry effectively deploys the tactic of uncertainty used by the tobacco industry (Proctor, 2008) and climate change deniers (Oreskes and Conway, 2008) described in chapter 1 to produce a functional uncertainty that helps self-tracking persist: Are the findings robust? How robust? Have all the variables necessary to arrive at robust findings been captured? Have I adequately addressed the assumptions of statistical models? Are the statistical models that I would find convincing even accessible yet? Like the oocyte preserving women in Romain’s (2012) study, who chose uncertainty over reproductive closure in order to keep the heteronormative possibilities of their future open, Henry keeps in place uncertainty to open his future to an array of statistical possibilities that could harness his comprehensive investment in data and end his pain. Like the egg freezing women, the oncologists and their patients, this choreography of uncertainty is only possible because of an uncomplicated belief that unfolding technological advancements will inevitably serve the causes that are important to us and act in our best interests.

#### **4.4 Conclusion**

In chapter 3, I showed how an episteme of personal experience is central to the QS ethos. Smarr’s personal experience self-diagnosing his Crohn’s disease is the anchoring story behind

the QS patient archetype, acting as a powerful marketing tool that hails new patients into the QS social context, just as the oocyte preserving founder of the Extended Fertility (n.d) service in Romain's (2012) study consistently deployed her personal experience in persuading women to choose egg freezing. The figure of Smarr, and his legendary story shapes the QS as a platform for people with intractable illness, and strengthens the idea that self tracking is the answer for diagnostic closure. Both Smarr and Henry used self tracking as a modality when they perceived the medical system as having failed them, and discovered the QS after they'd already initiated their self tracking projects. This pattern is common among patients who participate in QS activities as we saw in chapter 3.

In this chapter, I have shown how the emphasis on personal experience is functional in another way; it allows a certain intimacy with data and the components of self-tracking; this opens opportunities for private, flexible and creative ontological play. I make three contributions in this chapter. First, I show how uncertainty, rather than motivating closure, is instead effectively designed to cultivate hope, adding to the emergent ethnographic genre of research on how ignorance can be functional. Smarr and Henry deploy self-tracking as a coping mechanism in the face of debilitating disease with uncertain futures. Both Smarr and Henry's self-tracking projects re-configure and produce various forms of uncertainty to keep self-tracking ongoing. The feedback loop concept that underpins their self-tracking experiments renews the need for data in an iterative fashion, thereby also renewing hope constantly; through this mechanism, hope becomes replenishable. In this fashion, the temporal ignorance they create, and the bodily ignorance Smarr reinscribes is functional, just as uncertainty is functional in creating hope in oncology and oocyte preservation.

Second, in showing how hope motivates self-tracking and vice versa, I add to the genre of emergent research on the QS, that speak to the other values at play in self-tracking (Sharon and Zandbergen, 2016). However, unlike that trajectory of research that offers the other values of data as a counter to the data fetishism critique (Morozov, 2013), I bring into view in these case studies, how the other value of hope is activated in both data fetishism and data skepticism, through a strong impulse to collect more and more data, serving to reinforce the data fetishism that Morozov (2013) highlights, not challenge it. Finally, I add to the theory of ontological choreography by showing that uncertainty deployed as a strategic temporal ignorance through the feedback loop concept, renews the synecdochal connection necessary to continue self-objectification in service to a healthy long-range self by pushing diagnostic closure and treatment failure, further and further away. By replenishing hope while expanding data collection towards a likely impossible goal of the perfected feedback loop, patients perceive self objectification as an act of agency, which then strengthens self-tracking as a modality for self-empowerment even in the absence of desired patient outcomes and patient empowerment. However, this sophisticated ontological play is a response to medical and policy failure; but their self-sustaining quality might also prevent engagement with policy that would more effectively offer medical support in the future.

In this chapter, I have shown how “self-tracking” is flexible enough to meet the highly personalized narratives of individual patients. In the next chapter, I show how the concept of self-tracking undergoes negotiation to meet the needs of larger actors and divergent social worlds, unpacking its formation as a “boundary object” (Star and Griesemer, 1989). I examine how the surveillance imperative that Smarr sets up is supported by corporate, state and public health stakeholders, and expose the ontological shifts that obscures and subsumes the patient empowerment discourse of the QS into the medical science it contests. In chapter 3, I surfaced how the QS epistemic ethos limits its capacity to become a platform for minority groups to advocate for participatory medicine that meets their needs. In chapter 5, I show how QS proponents imagine such groups in a fashion that obscures them and challenges their ability to participate as equal epistemic partners, reinforcing once again, white privilege.

## 5 Obscuring Participation: Fashioning Self-Tracking as a Boundary Object.

Dr. Dave Albert, an inventor and “serial entrepreneur” from Oklahoma — a man whose father Carl Albert, the late Speaker of the US House of Representatives was instrumental in healthcare legislation and the medicare bill of 1965 — was scheduled for the Ignite session, a set of talks delivered over lunch break at the 2013 Quantified Self Global conference. Although it’s not uncommon, as we’ve seen, for Show & Tells to involve an application that the speaker himself produced, this one stood out in its blatant disregard for the rules of the Show & Tell and the nature of his plea. He spoke of the heart health of the masses not privileged to be in that room in the Presidio, a former military base — one of San Francisco’s most exclusive neighborhoods. He said this movement wouldn’t exist had it not been for advancements in science, and called upon the audience eating their lunch — it was time he said, for the individuals who had benefited from such progress to give back and take responsibility for people’s health all around the world. His smartphone electrocardiography (ECG) sensor, AliveCor, would detect if a patient was suffering from an adverse heart event anywhere in the world as long as they had a smartphone connected to the internet. He did not say what would happen once they sensed such an instance in the far off country his speech led us to imagine, but reports suggest the AliveCor has played a pivotal role in heart emergencies (Gaglani, 2013): for instance, cardiologist and leading digital health proponent, Eric Topol (2013), used his AliveCor to diagnose his fellow passenger as having a heart attack in a plane; the plane made an emergency landing and the man received critical care that saved his life.

That day in the 2013 QS conference, the individuals that were asked to submit to this cause were largely male, white, western, and affluent. Such a self-tracker would use the AliveCor device to submit to the longitudinal tracking and examination of their heart health along with “millions” of others, at a distance, in the cloud, as part of a research initiative from UCSF called the Health eHeart study. “God and truth are on the side of the biggest n” Dr. Dave urged the room and “connected sensors are integral to the internet of us.” As described in chapter 2 and 3, the QS has seen growing interest from the medical and research community interested in harnessing voluntary self-collected data over extended periods of time, outside the doctor’s office — “in the wild.” The reader might remember the rather tense discussion between professional researchers on these very topics of shaping self-tracking data for such data donations in the 2013 Global Conference described in chapter 2. Dr. Dave, who didn’t attend that breakout session that day, was the most evocative of all in his call to consider the “quantified us” and since 2014, the QS

leaders have actively engaged the idea of self-collected data for public good, mediating the relationship between public health research and the QS community.

I've noted several points of tension between medical authorities and self-tracking patients in my fieldwork; doctors often viewed self-tracked data as noise, an additional informational burden, especially when such data was hard to parse within the limited time they had with each patient; they frequently challenged its utility when collected without consideration of the information they needed to more effectively care for the patient, and sometimes, they viewed self-tracking as a sign of the patient's dismissal of their expertise. As mentioned in chapter 2, medical researchers were also concerned about whether self-tracking projects would evidence the scientific rigor they required to deploy self-collected data in their research pursuits. Thus, in order to produce QS self-tracking as a legitimate alternate science, these points of tension between QS self-trackers and medical authorities need resolution.

The QS Public Health Symposiums (QSPH) are the key meetings where medical stakeholders collaborate with QS leaders to share perspectives on self-tracked data, and negotiate the meaning and role of such data in advancing medical science. In the first section of this chapter, I examine self-tracked data as a boundary object (Star and Griesemer, 1989) to which such different actors attribute different meaning. In particular, I focus on how medical authorities and QS leaders conceive of the expertise that self-tracked data bestows on the individual or groups engaged in self-tracking. Drawing from work on the "politics of boundary objects" (Huvila, 2011), I argue that medical stakeholders enact dominance by subsuming the QS aspiration for self-trackers to be seen as equal partners in advancing medical science, by obscuring the meaning of participation that hinges on self-collection of data; we go from citizen science to "data donations", and back and forth. This production of ambiguity around the meaning of self-tracked data, and the participation it evokes is functional, as the QS framework is partially supported, and left able to engage the ontological shifts. In the second section, I consider "sample representativeness" as another boundary object; I show how speakers and participants in this conference, motivated by a new imperative to produce a more ethnically representative sample in aggregated self-tracked datasets, attempt to grasp the "other" they've been called to "value"; I argue that by obscuring the "other" through a deficit framework that serves to question the ability of minority groups to participate as equal epistemic partners, the actors in the Public Health Symposium enact positions of racialized power and reinscribe white privilege. In these two ways, I argue, the act of obscuring serves to maintain power.

The first section is organized in the following way: I briefly describe the concept of boundary objects; next, I unpack how self-tracked data is conceived in the different sites that intersected with the QS cultural milieu. In doing so, I point to how the interpretation of self-tracked data as a form of alternate science, as an act of agency and patient expertise, that we've seen in previous chapters is unique to the QS. For instance, patients diagnosed with chronic heart disease undergoing treatment tended to consider self-tracked data through a framework that is far more aligned with that of their doctors. It is in negotiations with medical science and actors invested in health reform, that the heterogenous array of ideas about self-tracked data become more apparent

for examinations of power; negotiations that take place in the two digital health sites described in the following section, but largely in the QSPH. Thus in the QSPH setting, I surface the different discourses surrounding “methods standardization” of self-tracked data, exploring how self-tracked data is shaped and legitimized at the intersection of the different communities present. I then discuss the subtle ontological shift from self-trackers as experts (citizen scientists) to self-trackers as merely data donors; this shift helps place self-trackers in a subordinate position, as aides in the generation of hypotheses, subsumed into traditional processes of scientific knowledge production, rather than actors of an alternate and counter-science.

## 5.1 Boundary objects

The different actors whose perspectives I examine in this chapter can be considered through the Arenas/Social Worlds framework developed by Anselm Strauss and colleagues (1964; Strauss, 1978). Social worlds are “universes of discourse” (Mead, 1972 as cited in Clarke and Star, 2007) where groups cohere around shared activities, mindsets, and resources; when actors from different social worlds, whose perspectives and needs may be in conflict with each other, convene around a common interest, they are configuring an “arena” (Clarke and Star, 2007) characterized by negotiation, rather than the imposition of a worldview. However, the focus on negotiation does not mean that the various rhetoric found in the arena don’t attempt to dominate each other, power is enacted by achieving interpretive dominance. The social worlds that convene in the QSPH arena have a common interest in self-tracked data, and the various actors representing these social worlds convey their intent to act on self-tracked data through their presence and participation in negotiating the meaning of self-tracked data.

In order to analyze this negotiation, I deploy an analytic concept called the ‘boundary object’ developed by a student of Anselm Strauss, Susan Leigh Star, and her colleague, James Griesemer (1989) — a boundary object is an entity that cuts across different social worlds that come together in cooperation either transiently or in a long-term collaboration towards scientific goals. A key characteristic of the boundary object is that the information it communicates is productive in each social world:

Boundary objects are objects which are both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. They may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is key in developing and maintaining coherence across intersecting social worlds. (p.393)

In the development of a boundary object, different actors contribute to a process of “methods standardization” that helps define an interface, a common contour, that sustains the utility of the boundary object in the different social worlds that it will travel. This standardization helps to

“discipline” the ways in which non-scientists and other actors contribute to the overarching scientific goals that underpin the cooperation. Central to the boundary object construct is the idea that scientific work is a collaborative activity involving heterogeneous actors that hinges not on consensus, but on a shared foci where their divergent social worlds and viewpoints contribute, while their varied local needs are reasonably addressed. In Star and Griesemer (1989) study of the establishment of the Berkeley Museum of Vertebrate Zoology, the state of California came to function as one anchoring and “loosely structured” boundary object; conserving the nature of California became a motivating and common goal, towards which multiple actors directed their efforts, regardless of what their local interests in conserving California may have been. In creating standardized forms and protocols that cut across the different social worlds, information necessary for the museum’s scientific enterprise was collected and prepared. In the complex negotiations that produce and sustain the museum, itself a boundary object, are numerous other boundary objects that anchor the work of the museum both internally and externally.

Like the boundary object California, in the domain of this dissertation, loosely structured boundary objects include “health”, “health reform”, “personalized medicine”, “precision medicine”, “alternate science”, “patient empowerment”— these boundary objects motivate heterogeneous actors to make contributions without necessarily needing to come to a consensus. However, as these different movements come into conversation with each other, and view self-tracked and surveillance derived health data as useful in furthering their goals, “self-tracked data” is fashioned as a subordinate boundary object. In what follows, I examine how two related settings that I discovered following Dr. Dave’s AliveCor, considered self-tracked data in relation to patient empowerment. Tools such as the AliveCor cut across the venues in digital health that I observed, along with an overlap of people and experts; as I detail the interpretations of self-tracked data in the two settings below, I also highlight the function of AliveCor as a boundary object that meets the informational needs of diverse actors in different social worlds.

I should note that I too submitted to the “quantified us” imperative Dr. Dave espoused in the opening section and volunteered for the UCSF Health eHeart study for which he requested participants. The FDA approved AliveCor device was free if you signed up. I filled out their online form, guessing the answers to an extensive list of detailed questions about the heart health of my family, with medical terms I had to search online; wondering all the while how many people would be able to answer its questions accurately. The sensor arrived in the mail and since 2014, I’ve offered an ECG recording sporadically, heeding its reminders at first before eventually turning off its notifications and prompts. Although, the UCSF study was actively recruiting people without a history of heart disease into its longitudinal study, the device through which it would gather heart data, the AliveCor, was not designed for me; my own position at the periphery of the AliveCor social worlds helped me discern its contours and the actors who have helped shape it.

Take the USC Body Computing Conference in 2014 and 2015, gatherings geared towards medical innovators, futurists, entrepreneurs and venture capitalists; the event was marked by numerous signifiers of wealth and power. There was no visible patient presence and the patients

discussed were all imagined as in the medical system, with insurance and doctors, even though as one speaker suggested, 50% of individuals in the United States do not have a primary care physician, and the rest, he said, could not name a doctor they have consulted in the last two years: “What patient engagement?” he challenged. Still, technological futures and entrepreneurship took center stage with many of the physicians and researchers there also leading digital health companies. I discovered that the man sitting next to me was the CTO of the company that owned eCardio, the remote analytics service that processed AliveCor ECG reports. He described a room full of cardiac technicians interpreting ECGs sent using AliveCor sensors and algorithms. Dr. Dave was a well respected figure at this venue, seated a few tables away from me, and AliveCor, was perceived as one of the stars of digital health innovation for its utility in crisis intervention.

Both doctors and entrepreneurs in this venue were most concerned with high-risk patients and how these new tracking technologies could help discern patterns and make predictions, allowing care teams to intervene at critical moments and help patients reach out to them for education and assistance through patient engagement platforms. Enabling the ability to “reach out” was seen as “empowering” patients. In addition, there was an emphasis on compliance; the rhetoric around biosensing and surveillance health data reinforced the view that patients often work against their own best interests, and such non-compliance must be managed through surveillance and control. The patient absent in this meeting, was by no means constructed as an expert or a potential citizen scientist; any self-tracking imagined was in collaboration with the doctor. As Sharon (2016) highlights, this view of “empowerment” where patients are only enabled to carry out the instructions the medical authorities have given them but not challenge these nor direct their own care — outside of making suggestions about how they might best implement the doctor’s instructions given their life circumstances — is symptomatic of more traditional ideas of patient empowerment and autonomy in medical rhetoric. The manner in which self-tracking and surveillance technologies were considered in this setting also signaled an ongoing paternalistic orientation, with no evidence of the anti-paternalistic aspirations found in the QS. The next setting was in many ways at the other end of the spectrum in its quest to involve patients in the co-design of medical research.

In this second venue — the UCSF Patient Powered Research Summit where distributed users of AliveCor and participants in the UCSF Heart eHealth study convened — I would meet the intended audience of AliveCor, patients suffering from cardiac arrhythmias. Here, unlike some QS self-trackers who received and used the AliveCor as just another sensor in their tool belt for self-tracking experiments, the cardiac patients saw the AliveCor as revolutionary. As one patient explained, it allowed him to know when he needed to go to the hospital and avert life-threatening disaster without depending on the occasional visits to his doctor, which were ineffective in helping him assess his day-to-day risks. It gave him autonomy and a sense of safety.

The central assumption of this summit was that patients and caregivers have important insight to offer about living with disease and must have a say in the directions institutional research programs pursue. The organizers, having noticed that they weren’t engaging participants as they



hoped through their online outreach (“millions” of people were not in fact signing up with the AliveCor) said that the “internet was not enough” and they didn’t want to get “just data” but also wanted to engage patients in research “co-design.” Jeff Olgin, a physician, said they quickly realized in reflecting on the Health eHeart data that it was the patient’s data and maybe they wanted something to do with it — they saw this event as the first step in a process of democratization with the goal of “prototyping a process for collaborative research design.” The doctors in both the Body Computing Conference and the UCSF summit tended to be invested in technology and data but saw these tools as fitting into the natural progression of their craft; the entrepreneurs (ones without a medical background) in the Body Computing Conference did display strong libertarian ideals and saw themselves and their technology as “disruptive.” In contrast, the medical authorities organizing the patient-powered research summit at one point called themselves “socialist researchers.”

People in this meeting expressed the view that the needs of a patient with cardiac diseases was especially well matched with the sensing technology that were emergent and considered sensors as a tool for greater patient involvement in disease management as one patient said: “With tech I can be accountable for my own heart health.” Technology was also seen as a tool for more personalized and predictive care by doctors: “we over treat people now, we could make it better for the patient with technology.” However, there were important distinctions between how QS self-trackers and participants in this setting viewed self-tracking data. People in this meeting were somewhat unenthusiastic about self-collected data, regardless of whether they were doctors or patients. One doctor talked about how walls go up when a patient brings self-collected data as the doctor is already overwhelmed with information and embedded in a system where they can only really allot a short amount of time to each patient, suggesting that such data should be built in a collaborative fashion with the doctor. Another participant, a tool maker, said that we need to develop new research models to work with tracked data. As noted earlier, a key step in the development of boundary objects is the standardization of methods (Star and Griesemer, 1989); the participants at this venue were seeking to “discipline” the ways in which non-scientists and other actors contribute to overarching medical goals that underpin their collaboration, gesturing to self-tracked data’s potential as a boundary object while noting the standardization required to legitimize it, as still nascent.

Unlike QS settings, the patients here suggested that you can’t always tell patients to consume information; they explained that both collection and sense-making are very hard, tedious and exhausting, and may not even meet their informational needs — what mattered to them when it came to self-tracked data was whether the data collected could provide them with enough “action points” increasing their capacity to act. However, the capacity to act, they qualified, waxes and wanes, noting that some people don’t have the capacity to act at all, suggesting that what most of them needed was a balance of autonomy and support, unlike QS settings where autonomy was given greater weight. A central and pervasive concern was getting timely and real time information to avoid disasters. There was a general acceptance of the inevitable in their relationship to their disease prognosis, but patients said they wanted assistance in making sure that those inevitable adverse events were not expedited because of a lack of information at a

critical moment. They wondered when quantifiable data about the patient is most useful in the continuum of care, but did not see quantified self-tracked data as inherently useful at all points in disease management, also noting that data sense-making needs are different for patients and doctors.

Patients and care teams were seen as intertwined; the patient's autonomy was understood as shaped by both themselves and their care teams; this entanglement was seen as necessary, given the shifting capacity of the patient to act during the trajectory of their illness. In general, they did not desire to further foreground their disease states in their lives or engage health constantly even though it was often necessary; and self-tracked data had the reputation of producing these effects. They were excited about technology in so far as it might assist in managing illness, but didn't show the same enthusiasm as evidenced in the QS social context, for tools in and of themselves. The patients in this workshop held the belief that research programs should act with reciprocity allowing the patient participants to direct research goals and access the results and findings. However, they did not express the same sense of data ownership that self-trackers in the QS assert while still believing that patients should have access to their data. I have no notes or memory of the term "citizen science" being mentioned in this setting — I want to highlight this absence and in particular the different ideas about data ownership, because in the section on QS Public Health discourse that follows shortly, we will see how the genre of patient participation — contributing to research directions — foregrounded in the UCSF summit gets rendered as a form of citizen science in the QS in order to engage the QS epistemic ethos. I return briefly to the AliveCor device and examine its characteristic as a boundary object, as this device, like the markedly different orientation to self-tracking in these settings from the QS social context, helps contrast the complexity of negotiations in the QS.

Multiple actors I encountered — entrepreneur and cardiologist Dr. Dave Albert, CTO of eCardio, the technicians and cardiologists who read ECGs sent in remotely at its offices, the patients at UCSF, invisible cardiac patients and more sporadically, the QS self-trackers from the global conference and I — all fed resources into the AliveCor, be it entrepreneurial, technical, medical or non-scientific, which in turn contributed to the research endeavors of various actors around their common goal of "heart health." Not only did the AliveCor coalesce resources like a boundary object but it directed un-intended actors through the different social worlds where it had utility. I encountered a set of intersecting social worlds for whom the AliveCor represented a common goal of heart health. However heterogenous the contributions to heart health through the device maybe, all intended actors shared a vocabulary, contributions were made through standardized methods to spot cardiac crisis: input of heart data, analysis and reports of heart status. It was even integrated into the economies of cardiac care and research programs of hospital and universities. In its introduction into the QS global conference, Dr. Dave was hailing a new social world and its own boundary object, self-tracking, into the collaboration anchored by the AliveCor. This device was considered the technological next step in treatment and management of cardiac disease. It was not counter-conduct, it was not alternate science, it was situated in the patient empowerment discourse that Sharon (2016) explicates where such devices allow patients to "reach out" in moments of crisis, and obtain some amount of autonomy and

empowerment during the life course of their disease. The various meaning that patients, entrepreneurs and doctors attributed to self-tracked data, collected by devices like the AliveCor, coexisted in a cooperative orientation in a network of intersecting social worlds.

Unlike these settings that revolved around cardiac health, a research program and medical practice, self-tracked data that comes out of the QS cultural context is even more heterogeneous, with varying intent and ambitions. The actors in the section on QSPH that follows, do not necessarily share common goals as the doctors and cardiac patients in the settings above. Self-tracked data in the following worlds is still unruly; and the devices that self-trackers deploy in their experiments suffer from interoperability issues that the AliveCor — designed with the healthcare infrastructure in mind — bridged more successfully. In what follows, I describe the emergent conversations around self-tracked data as a resource that can meet the needs of divergent players.

## **5.2 Negotiating the standardization of self-tracked data**

Given the heterogenous meaning attributed to self-tracking and self-tracked data, key players, including non-scientists, invested in advancing medical science are required to cooperate. In this section, I examine such cooperation in one arena where representatives from different social worlds convened, the QS Public Health Symposiums (QSPH). The impetus for this event was a call by the CTO of the U.S. Department for Health and Human Services (HHS) Brian Sivak, asking QS leaders to help public health researchers engage the QS self-trackers and tool makers. In enlisting the QS to mediate access to key non-scientific actors, QS leaders are established as obligatory points of passage (Callon, 1986; Star and Griesemer, 1989) and an authority in emergent forms of participatory science.

Upon the request of Sivak, the QSPH attendees were asked to consider how they could help align the goals of various social worlds, especially when, as Wolf suggested, they share “no common goals” (Wolf, 2016). That is, self-trackers were not necessarily as invested in considering their data for the greater good or public health as the participants in the Health eHeart Summit; individual difference and ownership are significant anchoring assertions in the QS ethos after all. Wolf suggested instead that the ambition for this dialogue was not necessarily an alignment of goals, but how different goals could exist and support each other. The attendees at the QSPH events were in the process of shaping a loosely structured boundary object —“advancing medical science” — like the first director of the Berkeley Museum of Vertebrate Zoology, Grinnell, conceived of “California” as a boundary object that would anchor heterogeneous motivations in co-existence while diverse players contributed to the goal of preserving California’s nature (Star and Griesemer, 1989). Huvila (2011) in his analysis of the politics of boundary objects such as archeological documents, argues that the intent to make “hegemonic interventions” by dominating interpretations, is inherent to every process of creating boundary objects even when it may not be explicit. In this section, I detail the points of antagonism (Huvila, 2011) between different social worlds; in the section that comes after, I surface the efforts of medical stakeholders to “achieve authority” in such negotiations.

A critical point of tension requiring resolution is the divergent perspectives on the scientific contribution of self-tracking. QS proponents present *n of 1* research practice as producing expertise about one's body that is on equal footing with that of doctors and researchers, warranting a place at the table; however, many medical stakeholders — even those who identify as allies of the QS — see in the *n of 1*, the ability to generate hypotheses, which can then be systematically tested on a larger scale, co-opting *n of 1* assertions into traditional epistemic priorities. In the QSPH arena, the alternate science proposed by QS seeks scientific legitimacy (should be noted that not all self-tracking projects in other QS contexts seek such institutional validation). The medical actors in this venue position their obtaining access to self-tracked data as the avenue through which such legitimacy may be garnered.

Wolf (2016) began his introduction critiquing the “explosion of research proposals with grand claims and little traction” that have failed to address the issue of access for various actors:

We have all heard of initiatives to engage thousands of participants, hundreds of thousands of participants. I've sat in rooms like this and heard people talking about instrumenting millions of participants in tracking biometric data for the purpose of discovery. I share whatever feelings of awe you may feel at these lofty goals. But in the meantime, data collected by millions of people already is both invisible to people working on public health and inaccessible to the very individuals who gather it, except through the very limited visualizations and summaries. So that was our problem. (Wolf, 2016)

Thus, the central theme of the QSPH'16 symposium was data access for self-trackers, for patients, and for public health researchers — how can these different players obtain the information they would find useful from the self-tracking phenomenon? As we saw in chapter 3, QS coalesced into a community conversation, an emergent trend of people appropriating surveillance and sensing technologies for their own personal goals; QS proponents even built their own tools or modified existing ones. These practices resulted in highly local and personalized adaptations with no intentions of cohering into a larger networks of diverse actors, further complicated by the siloed entrepreneurial development of tools for self-tracking described below.

In typical QS problem-solving style, Wolf asked: “What tools are missing?” The state representative, Susanna Fox, an anthropologist by training and the current CTO of HHS, pushed back to this pattern of thinking not just in the QS leaders but among many other attendees, later that day, when she asked: “why is it that we identify with culture and data flows so strongly and not policy?” Fox, who took over from the original QSPH convener, the prior CTO of HHS, Brian Sivak, is tasked with assisting various state actors in her home institution leverage data and computational innovation, and in the QSPH she offered a regulatory influence in shaping self-tracked data as a boundary object. However, the reliance on innovation is deeply entrenched in the social worlds represented in the QSPH. As patient advocate, Dave deBronkart suggested —

what Fox was noting was a learned helplessness; known online as “e-patient Dave”, deBronkart is a key figure in participatory medicine debates — “People don’t think about policy...that’s just a less productive path to go into rather than innovating.” Fox asserted “policy is here, there are people from the government, we are here to help.” However, the problem of data flow was not one easily solved, given as deBronkart suggested: “commercial entities are knowingly interfering with data flow.”

In the QSPH orientation to this issue, the corporations who build and maintain these tools play a pivotal role in producing the obstacles self-trackers and public health researchers face in harnessing self-tracked data for individual goals and the larger public good. The subject of “data flows” was a prominent issue in fashioning self-tracked data as a boundary object that could more efficiently meet the needs of diverse non-corporate actors. One attendee (2016) said that this notion of flow suggests that we think of data like “water” but really we should be thinking of “data travel” instead of “data flows” so that we acknowledge the “baggage” that also “moves with the data” and the work that is involved in attaining access to data (QSPH’16). Another engineer suggested that although the term “travel” does some important work in the present to help us acknowledge the problems with data integration, he said what we must aim for is flow. However, a QS leader pointed out that these sorts of demands tend to come from “people who are relatively well funded” and the startups in the domain, who typically have little money don’t see a business value in directing resources towards interoperability. In addition, the man suggested “the kind of structures that they are creating, there is nothing to transfer them to.”

Rachel Kalmar — the kind of archetypal counterculture figure who cuts across many subgroups of Silicon Valley: neuroscientist, data scientist, organizer of the San Francisco sensor hacking meetup group, also known for wearing twenty one tracking devices on her wrists and in a belt around her waist — in response to the assertions described above, called for QS to support startups in building more sustainable business models, prefacing her point saying what she had would be an “an unpopular perspective in this room.”

We built all these things, all these wearables and we’re realizing that we don’t really have business models for these..this is just because it is early days but it is important to understand what kinds of things will keep these companies afloat as well. It doesn’t do us any good if we have another Zeo which has cool data but we don’t get access to it and I just want to encourage people to think about not just who has access but how do we create these ecosystems to be sustainable not just for patients and end users but for the companies producing them. (Kalmar, QSPH discussions, 2016)

Only a few industry products are mentioned from the early days of the QS, and the ones that are, often have a cult like status. One way to spot a QS old timer is through their rather nostalgic account of the sleep tracking device, Zeo, that Kalmar strategically references — a startup that subsequently went out of business, but is still seen by many self-trackers as the gold standard in sleep tracking even if its form was rather unattractive as a sleep accessory. Her point about

supporting startup ecosystems is taken up begrudgingly during drinks when self-trackers reflect on their own personal experience losing all their data when Zeo could not find a sustainable business model and shut down, without giving its users the ability to download their data.

For the reasons described above, public health researchers do not and cannot understand what data exists in each system and how such distributed data may be integrated, rendering their interest in mass health surveillance somewhat in-actionable at this moment, given the logistical barriers in manifesting that vision in reality. But first, what specifically is attractive about self-tracking and self-tracked data for medical stakeholders?

Ignorance of individual variability is the primary motivation behind efforts to implement continued and extensive surveillance of both patients and healthy individuals. This knowledge has become especially pertinent as American medicine has been called to deliver more personalized and predictive care described in chapter 1, a cause that is taken up by all of the digital health venues in this dissertation. Individual variability not only refers to differences between bodies but also to variations within one individual. For instance, the question “What happens to biomarkers when the patient leaves our office?” is a frequent source of curiosity and concern for medical practitioners, public health researchers and patients; the inability to track changes as they occur across contexts prevent current health systems from efficiently intervening during critical periods, as we heard doctors and patients explain in the previous settings.

In addition, the focus on individual difference on the part of medical scientists reveals a self-critique of the modalities of inquiry and knowledge production deployed thus far in institutional research, as several attendees lamented at the QSPH 2016 event. One oncologist said of variance: “we ignore it, pretending it doesn’t exist.” Another man said that we need to return to the philosophy of science: “we need a place to talk about epistemology” as our current frameworks are not advancing the field, “our science has gotten incredibly lazy” he said. What we have on our hands is “not a replication problem” he suggested, but an “over-generalization problem.” In this discussion on epistemology in the medical sciences, the attendees were theorizing themselves why specific kinds of ignorance, of individual variability in this case, had come to be and what actions were necessary to remedy its neglect.

Smarr, a key figure at this venue, asserted that it was important to consider the most advanced technique to finally capture such individual variance — the *n of 1* longitudinal time series which he applied to himself in the case I described in chapter 4, requiring extensive tracking over long time periods of an expansive array of possible variables. Such ambitions for surveillance then have a dual purpose: continued tracking helps institutional medicine in delivering more personalized care and also, helps reform its frameworks for scientific knowledge production. In these ways, as mentioned in the introductory chapter, the self-tracking patient is positioned as the link between multiple interests, configured as the only entity that can effectively help advance modern medical science. In return, they are marketed a more personalized form of care and prompt assistance when their health takes a turn for the worse. Unlike the boundary objects of Grinnell’s museum, the boundary objects emergent in the discourses in these venues, such as the

self-tracking patient who can help accomplish the multiple objectives of scientists, have needs of their own. Therefore, the absence of discussion on whether contemporary medicine and the health care infrastructure are ready to treat problematic variations discovered through such surveillance, both here and in the precision medicine discourse, becomes critical to consider. Only the discovery of individual difference is certain, with individualized care an alluring promise. By leaving uncomplicated the processes through which treatments are generated and delivered, and instead foregrounding data as the solution in and of itself, bio-surveillance is legitimated by obscuring infrastructure. That is, in furthering a specific techno-utopian trajectory of data pursuits and solutions to remedy ignorance of individual variability, ignorance about the structures that will support them, are maintained.

Conrad (2007) in his work on the “medicalization of society” discusses the various technological, political, corporate and advocacy influences that create some bodily conditions as disease or disorders, while others are left understudied and untreated. Such selectivity of medical science and its willful ignorance remains obscured in debates in these settings. Still, self-collected data is constructed as the answer, never a redistribution of resources, or the reconsidering the reasons and processes by which some diseases receive attention and others do not. The individual must initiate and persist in self-tracking data to remedy this epistemological constraints of medical science; leaving surveillance and data relatively uncomplicated in the quest for better population and individual level health. If self-collected data is conceived as the answer to a myriad set of problems, then under what argument, can it be obtained while still supporting the QS ethos that demands ownership and epistemic equity?

The thorny concept of data ownership prominent in this venue raises an antagonistic tension (Huvila, 2011) that the processes of negotiating self-tracked data as a boundary object needs to resolve, particularly as attendees conceived of access to data and ownership of data generated from one’s body a human right. Larry Smarr, whose story and support was much appreciated throughout the QSPH and the HDE events asked, “who has the fundamental property rights to the data that you generate from your body?” claiming that, “you and only you have the right to data that is generated from your body.” On the other hand, Barbara Evans (2016), a professor of law stated: “we can have a strong sense of ownership to things we don’t own. Our feelings of data ownership is intense and strong, and legally we don’t own our data and if we did, it would be something other than owning a house. The issue is one of control and access, not ownership.” Given the siloed nature of the self-tracking infrastructure (or lack thereof) and the diverse goals and orientations of self-tracking communities obtaining data from the self-tracker individually maybe the most efficient step in the short term. In fact, a majority of the funding (\$130 million) behind the Precision Medicine Initiative (PMI) has been directed to creating a voluntary cohort of patients who will submit their data to medical research (The White House, Office of the Press Secretary, 2015); and this event was convened by such state actors. However, the strong sense of individual data ownership evidenced in the QS presents a significant obstacle: it is here that two conceptions of participation become pertinent in reconciling the antagonistic orientation of different actors, as a critical feature of boundary objects is their ability to support the “hegemonic ambitions” of all invested actors (Gal et al, 2004); the first notion of participation, is the self-

tracker as citizen scientist deploying *n of I* expertise put forth by QS, and the second is the self-tracker as data donors, an interpretation advanced by medical and state stakeholders. In the following section, I show how these two notions are enmeshed in ways that allow for the ambitions of both actors to co-exist.

### **5.3 Obscuring participation: citizen science or data donations**

In the 2015 QSPH symposium, there was murmur of an *n of I* journal, with suggestions that QS should perhaps start one, signaling its ambitions to alter and intervene in health science practice, and introduce new forms of citizen science as legitimate knowledge. In the 2016 QSPH symposium, several professors in the QS had negotiated a special issue in the journal, *Methods of Information in Medicine*, issuing a call for papers for *n of I* studies and Mark Drangsholt, a physician and professor, announced the funding of a QS journal on *n of I* research. Greenfield (2016) points to how Drangsholt's own *n of I* self-tracking in the QS, wherein he explains the relatively scientific method of the "single case crossover design" to non-scientific actors, signals *n of I*'s nature as a boundary object. One scholar asked of this development — did it not conflict with the QS philosophy of curiosity and personal meaning making given the rather systematic modes of self-tracking that such journals would advance? Drangsholt answered that perhaps there could be a section for that genre of QS style projects but *n of I* was not yet accepted by medical science and so the journal "has to do that work." In other words, the journal has to "methods standardize" (Star and Griesemer, 1989) the *n of I* alternate science in order for it to be legitimized by institutional science, and a separate section for more hobbyist self-experimentation would engage the diverse interests of QS members.

In talks and informal discussions later, there was a slight alteration of such citizen science and self-tracker participation in altering medical knowledge production; although as noted earlier, QS sees its *n of I* research practice as producing expertise about one's body that is on equal footing with that of their doctors and researchers, many medical stakeholders view such research as a resource to locate new hypotheses, which can then be systematically tested on a larger scale. In this view, *n of I* does not exist as an alternative science but is subsumed into exploratory early stage phases of traditional scientific inquiry. This turn brings the QS self-tracker into a similar position as the cardiac patients in the Health eHeart Summit, given some say in the direction of research programs, but not engaged as researchers on their own (which Health eHeart patients did not necessarily want either) and in fact, the barriers to having self-tracked data count through this new journal venue are significantly higher given the the standards of rigor projects need to meet to be published, as opposed to Health eHeart Summit where the personal experience with disease counted as legitimate grounds for influence and a redistribution of power in directing research projects. The Health eHeart Summit in this way furthered the QS episteme of personal experience in broader ways than evidenced thus far in QS negotiations with public health researchers.

Rendering citizen science as an act of *giving* institutional researchers hypotheses to test, supported considering such data and findings as "donations." Throughout the QS public health



symposium in 2016, there was a rhetoric of evangelizing citizen science, broadly interpreted overall, while also making subtle gestures to such science as acts of donation. A few other researchers studying QS over a period of years, noticed this trend as well. In a breakout session I participated in — facilitated by the CEO of a leading patient network where patients can connect with other patients creating a peer-to-peer knowledge sharing community, which researchers can also access to conduct studies — the goal was to consider what kinds of incentives would drive data donations. He said his platform’s users were mostly middle aged women of higher socioeconomic status managing chronic but not acute illness, and the user population leaned towards caucasian with prior technical training. In considering ways to incentivize data donations more generally, he spoke of marketing data donations as a “gift that keeps on giving” and one that “outlives you.”

One professor asked if donations was the right word. Having once signed up and explored this interface, receiving email requests to donate data, I explained that these donations occurred through “data drives” that the platform researchers organized. The CEO clarified, however, that they consider all data on the platform as donations and distinguished between two types as he saw them: A “passive data donation” is when a patient/user of a service responds to a data donation drive. An “active data donation” is information contained in online profiles, considered active because you can change this information as and when you wish. It was unclear whether the users of the service consider their profile information a “donation” in any sense, active or passive, but according to the service provider, all data filled in by users on their platform are considered donations.

These kinds of ontological shifts — moving from *n of 1* and citizen science to data donations to active and passive donations as it suits the interests of the authorities, make state, corporate and institutional stakeholders appear to integrate the QS counter culture and garner legitimacy among self-trackers by partially supporting the QS ethos. In Huvila’s (2011) analysis of the politics of archeological documents that function as boundary objects, he draws from Gramsci’s concept of cultural hegemony — “a condition of attaining and holding the power of imposing a definition of how things are discussed and understood” (Huvila, 2011:2530). I argue that in this QS setting, dominant social groups do not fix meaning; instead, in obscuring the participatory mechanism, this tactic creates a synecdochal connection between citizen science and data donations, both of which are connected to the goal of intervening in medical science. The act of obscuring maintains the synecdochal connection necessary for the QS framework to engage the ontological shift while maintaining its integrity and foregrounding its potentially critical role in manifesting advances in institutional medical science. In addition, in Star and Griesemer’s (1989) account of Grinnell’s negotiations, he reconciled the goals of non-scientists with those of scientists in a manner that did not disrupt the pleasure lay actors derived from the activities that generated the information used in the construction of the museum’s knowledge base, such as camping and personal hobbies. In a similar manner, the construction of “data donations” allows self-trackers to preserve the pleasure they get from self-tracking outside the confines of medical frameworks. Through such negotiations, QS is able to find legitimacy in its contestational, yet ambivalent orientation to establishment science while meeting the needs of medical authorities. In the

following section, I examine “sample representativeness” as a boundary object, the absence of which threatens to render QS data donations limited in utility for population level medical research.

#### **5.4 Obscuring the “other” and sample representativeness as boundary object**

Consider the dataset that aggregated self-tracked data will create. A common goal of the stakeholders in arena is the representativeness of the sample. In order for self-tracked data to most effectively advance medical knowledge production, the sample has to be representative of populations across the race, class, gender spectrums. One of Sivak’s primary challenges to QS, noted above, was the issue of equity. Wolf (2016) says of this challenge:

What the public health community saw as socio-economic bias in self collected data, we tended to think of as: how can the things we are learning be more broadly useful and how can we learn from others whose questions and life situations are different from our own. But both of those ways of looking at it are a kind of — they touch each other.

In this section, I argue that in valuing epistemic equity as fundamental to the QS ethos as we saw in chapter 3, while also rendering the “other” as deficient in the skills and resources required to attain equity as I show below, the QS reproduces and maintains its exclusivity and privileged status, by obscuring the “other” it seeks to value. It is important to highlight the analogy that was most often used for the people in the symposium both in 2015 and in 2016. We were on the “mountaintop” and others: traditional doctors, entrepreneurs and researchers, patients suffering from learned helplessness, the National Institute of Health (NIH), the “Washington D.C. establishment” were all down in the “valley” (not Silicon Valley, though it too was sometimes in the abject epistemic position of “down in the valley”) unable to see what “we are seeing.” It becomes evident that many of the medical authorities in the room also saw themselves as countercultural — they were different from other doctors, and other medical establishment in their desire for the democratization of medicine, and in their foresight and vision in understanding the significance of self collected data; one health care professional said of her experience with children: “What we have discovered is really powerful. There is an intersection between clinician collected data and self collected data that is magical.” She then went on to talk about the children who come to her center, and one 11-year-old girl in particular — diagnosed with Attention Deficit Disorder, living in an unstable family environment, the father in jail, a sister with Bipolar Disorder — whose discovery of a particular activity tracker, described below, was seen as pivotal by the health care professional in her empowerment, helping her manage her abundance of energy and reconfiguring her status among her peers:

I found this cool tracker, it tracks my steps, and the thing that I love most about it is that it’s from UNICEF and UNICEF donates food for children and...for every step I take, I earn food for other kids and I got to pick the kid and so I’m feeding a

little girl in Uganda and I got her this for breakfast this morning. (11-year-old self-tracker, as recounted by health care professional, QSPH, 2016)

At first, she wasn't allowed to use it at school, where she was seen as a problem student, but the health care professional used her "super powers" to "write a prescription" for the activity tracker and use her authority to require the school to allow the child to use it when she felt the need to burn off her energy. The health care professional explains:

She went from this child who was in this downward negative spiral — "you are moving too much, you have too much energy, you are not doing your work" — to the hero of this third grade class because when she leaves, they know that she is going to walk to feed this child, and now they see her in a completely different way. That's changed her life. So, that's the magic.

Although the 11-year-old child merely discovered a tracker and an app designed by UNICEF, the Ugandan child who this disadvantaged child living in the U.S. got to "pick" and feed through an activity she already does — walking— is indicative of a relationality to the "other" that surfaced throughout the symposium: The QS had excess and the other was deficient.

The keynote presentation at the 2016 QSPH symposium, was by a medical science professor, ally of QS and advocate of citizen science, who would soon move to a position of leadership in the U.S. government. Smarr and others were excited that "one of us" was going to enter the "establishment" and "change things" as an insider/outsider. Here the "establishment" was not an "other" but instead "down in the valley." Her presentation on citizen science, started with a automated scrolling display of selected pictures of people from across the world. She articulated her vision: "7.1 billions citizens in the world - engaging in data donation" going on to explain the array of faces moving behind her on the screen, "often we think citizens look like us but they look like them, they look like themselves" First, in her talk on citizen science I noted that citizens "donate" data. The next thing I noted was that her presentation slide titled: "But what if citizens are wrong?" — where she explained how the expert audience might consider citizen mistakes — featured a picture of two black people, evoking and reinforcing a long standing marginalization and stereotyping of black individuals in American medical science as incompetent and non compliant, unlikely to follow the rules of engagement whether in treatment or knowledge production, necessary to produce positive health outcomes (Hoberman, 2012). She continued her presentation, offering towards the end a long list of values that we must embody if we are to take this citizen science forward, with "valuing of the other" being one of them. Her presentation ended with thunderous applause and tweets about her exceptional vision.

Many others did not notice the choice of picture as problematic and I went back to my pictures of her slides to check, making sure of what I had seen. Mills (2008) suggests that such inattentiveness is one characteristic of the set of cognitive patterns that support "white ignorance" that do not even register gestures that are racially coded, whether intentional or not on the part of the speaker. In addition, the display of black bodies in the slide about the possible

deficits of citizen scientists further signals to the relationality to the “other” evidenced throughout the meeting: the “other” is deficient, the QS has excess: tools, knowledge, income, empowerment, data — in fact it revels in such data excess; Kelly (2016) suggests that given the plummeting costs of sensors and the relative ease with which large troves of data can be recorded without the individual’s input, we can, for example, afford an “extravagant use of computation” and many significant inventions stem from such “creative wasting” he says. The “other” however was wanting.

In the same breakout session where I heard about passive and active data donations, when I brought up race, one professor said that with white populations, you could just email them and recruit them into your study but given low levels of technological literacy and lack of resources in minority groups, to recruit hispanic populations for example, you would have to go knock on their door — “it’s just too much work” she said “it’s just too expensive” leaving any analysis of class and difference within groups that might be at work here unarticulated. Later, the CEO of the patient network said that he too felt that black populations, in his case, needed to be approached differently and cited an example when his colleague was soliciting participants for a clinical trial in Baltimore, and the black folks, he said, thought of the term “trial” in the legal sense, resisting the requests to participate. He speculated of his own users, who were mostly white, unsure about why that was so — is it access to technology, knowledge, worldview? This direction of speculation that locates the resistance of black populations to participate and submit to medical research, in issues of access and epistemological orientation is categorically ahistorical. In his book, *Black and Blue: The Origins and Consequences of Medical Racism*, Hoberman (2012) traces the history of American exploitation and abuse of black bodies in medical research; one that didn’t end with the atrocities of the Tuskegee syphilis study as commonly understood (Hoberman, 2016). Medical racism is pervasive and largely unexamined by bioethicists (Hoberman, 2016). The biased and abusive realities of medical research and care has not been forgotten in black communities, and has engendered a strong distrust. Although, the cultural transmission of distrust has been shown to harm the health outcomes of black communities, this resistance to medical intrusion is also self-protective (Hoberman, 2012) as the consequences of participation is different for different communities.

As evidenced in the different examples described above, “the other” was grasped through a deficit framework. Wolf (2016), in considering how the self-tracking discussions and practices in the QS could relate to the “other” continued to evoke this dynamic — “What we are doing here could help them.” This pattern of white benevolence creates and maintains the power position of QS practitioners, while also rendering them “different” in their generous consideration of the other; the racialized and deficient other mutually constitutes the privileged self. In addition, every other gesture to race was embedded in a concern about sample bias, serving to limit the significance of race to merely an issue of sample representativeness. Hoberman (2012) cites James Baldwin’s insight from the 1950s that this impulse towards “statistical depersonalization” of black communities has been functional in compromising health outcomes; white medical scientists have historically configured black communities in a state of perpetual abjection; and in considering black populations primarily through a statistical framework, they continue to

obscure: “the black individual remains invisible and unknown, and this too has its consequences” (Hoberman, 2012:5). This pattern of obscuring is continued in the QS setting, and as the professor and CEO recounted earlier, cannot be easily solved given their understanding of minority populations as compromised in knowledge and technical facility.

## 5.5 Conclusion

In the previous chapter, I described how the self-tracking and feedback loop concepts were able to support the highly personalized and functional narratives of patients suffering from intractable illness. Self-tracking as a boundary object met the needs of different kinds of patients, with varying levels of technical facility and access to resources. In this chapter, I have described two acts of obscuring evidenced in the emergent shaping of “self-tracking” and “self-tracked data” as boundary objects that can meet the needs of larger and heterogeneous set of privileged actors, with no common goals.

Huvila (2011:2536), drawing from Gramsci, states that “a specific characteristic of a boundary object is that it makes hegemonic interventions easier to accept for communities with antagonistic tendencies, even if the emerging norm would be... advantageous by default only from the point of view of the hegemonic position.” In this chapter, I have shown that in attempting to resolve and reconcile the antagonistic orientations of several social worlds, the subtle reworking of the concept of participation — the first act of obscuring by medical authorities — serves to meet the needs of medical stakeholders while only partially engaging the ambitions of the QS. Caught in the throes of its own ambivalence over whether QS research constitutes participatory science or an alternate science, and the cognitive dissonance engendered by the conflicting perspectives of data ownership and the libertarian idea that “information wants to be free” the QS is unable to assert interpretive dominance, and succumbs to the hegemony of establishment science.

In the second act of obscuring, I have shown how participants’ framing of minority groups absent in this discussion, reinforces the marginalization of minority groups in medical science and reenacts the mechanism through which American medicine has failed minority populations, and black communities in particular. The medical actors in this arena continue this trajectory of negligence by embracing QS as the wellspring of citizen expertise, that is, a dehistoricized epistemic framework structured by a color-blind style ideology (as shown in chapter 3) that does not have the capacity to correct racial injustice.

Through these two primacy acts of obscuring, representatives of different social worlds gathered at this arena, maintain multiple positions of power. The rhetoric of democratization of American medicine, of which QS is one instantiation, remains largely in service to the needs of dominant groups and the establishment science the individual is called to reform. In the concluding chapter, I bring together the different ways in which the new self-tracking culture persists and limits its potentiality for reform by producing and keeping in place various forms of ignorance accounted in the chapters thus far.

# 6 Conclusion

## 6.1 Intersecting social worlds

I began the work that led to this dissertation interested in the assumptions underpinning development discourses surrounding health and information technology in the United States. My curiosity was seeded when I started to observe the limits of ICTD and mHealth interventions conceived in U.S. research institutions and deployed in my home country of India during my early doctoral fieldwork. What I initially saw in the QS was a contrastingly grassroots appropriation of mobile and digital health technologies including wearable devices for well being and health. I was intrigued by the QS discourse because it positioned itself in contestation to the paternalism of the development discourses I had come understand and critique as problematic in India, but in the American context. It challenged the idea that the health of populations could be “managed” without any regard for individual difference. It offered the opportunity to observe and understand how individual American patients experienced the health care systems that many American ICTD researchers held as the standard by which they assessed health care in the Global South.

The QS meetings included doctors, patients, caregivers, researchers, artists, activists and technologists as described in chapter 2; this entanglement allowed access to the world-views and perspectives of different stakeholders on health reform from within one networked cultural space. Studying the QS was a useful grounding mechanism as its advocacy of digitally mediated self-care was presented both as a contestational move of independence from traditional institutions of medical knowledge production, and as an opportunity to reform that institutionalized medicine it found wanting. In these ways, I used QS as an anchoring context (Burrell, 2009) to conduct a cross-sectional analysis of the points of antagonism (Huvila, 2011) between individual expertise and institutional medical science, and to capture the nature of health activism, in particular, patient engagement and advocacy, emergent in centers of technological innovation like the Bay Area and its counter-cultural legacy.

My ethnographic immersion in these different social worlds brought into view the dynamic of two intersecting responses to perceived medical failure. The first is the emergence of an activist orientation in the QS. By taking an existing self-tracking phenomenon as its object of study, a practice that features in the everyday lives of many patients with chronic illness, the QS has drawn patient self-trackers into its cultural context and become a platform that advocates for the expertise of the individual patient, through the statistical translation of personal experience into “n of 1” science, as shown in chapter 3. In this way, patient autonomy and empowerment discourse pierce the QS self-tracking hobby club and personal meaning making activities. This turn to self experimentation is often the last resort for some patients as in the case of Henry in

chapter 4, but also indicative of a neoliberal worldview that locates both the source and solution to systemic problems manifesting in personal lives, as the responsibility of individuals (Rose, 2006). The second intersecting response is newly formed and structured American efforts to examine how medical researchers and practitioners can offer more personalized care to those patients, thus far marginalized from dominant and established frameworks of care.

Both these forces desire the same final outcome; they look to individual variance in shifting contexts as the object of their inquiry and technologies of surveillance as the answer to medicine's failures. Underpinning both world-views is an uncomplicated and idealistic connection between "information" and "empowerment" evidenced in the developmental gaze directed towards resource-constrained communities in the global south as well. Such similarities, and the voluntary in-situ data collection evidenced in the QS renders it a productive resource for medical authorities looking to aggregate and harness such data, especially when state authorities have tasked such actors to build a cohort of voluntary data donors towards the aspirations of precision medicine initiatives. In addition, as I show in chapter 5, in aspiring to build self-tracking as the dominant modality of an alternative science, the QS, while sometimes presenting as a resistance to conventional medicine, nevertheless seeks to gain from cooperating with the medical system that can offer such pursuits legitimacy.

The auto-ethnographic style orientation of self-tracking practice discussed in chapter 1 and 3, helps build some reflective capacities (Boesel, 2013a) around technologically mediated self-tracking as an epistemic instrument, allowing self-trackers to intercept contemporary debates on privacy, data rights and ownership, and participatory medicine using their personal experience as an anchoring point, in turn enabling self-trackers to grasp through this modality of inquiry how the political is also personal. In shaping such orientations towards self-surveillance, encouraging the explorations of its opportunities, and acting as an intermediary between medical authorities and individual self-trackers as shown in chapter 5, the QS is an "epistemic community" in development (Haas, 1992), and an obligatory point of passage (Callon, 1986). The epistemological priorities evidenced in the QS cultural context, then, is its own form of collective contouring (Marcus, 1995) as highlighted in chapter 3. The central concern of this dissertation emerged through observations of emerging activist positionality — in what ways is the QS ethos, its technologically mediated self-expertise and alternative science emancipatory, and in what ways does it reinforce the status quo? Throughout this dissertation, I deployed ignorance as an entry point to examine the dynamic of power and marginality.

## **6.2 The utility of ignorance as an analytical tool**

An oft ignored ethnographic imperative is the examination of ignorance in informant's accounts of knowledge (Clifford & Marcus, 1986; Mair, Kelly & High, 2012). As discussed in chapter 2, traditional ethnographers studying subaltern communities in remote settings have shown strong resistance to foregrounding ignorance, as the knowledge systems of those communities had already been configured through colonial hegemonic renderings as unworthy of scholarship — ethnographers worried that an account of ignorance would further entrench these biased and

oppressive positions (Mair, Kelly & High, 2012). However, the 1980s “crisis” of anthropology allowed an entry point; by dismantling the concept of culture as coherent and the knowledge frameworks that support it as complete — Clifford and Marcus (1986) called for an examination of ignorance that emerges as a byproduct of an “imperfect mode of knowledge” (p.8). In such calls to take ignorance as an ethnographic object, ignorance is no longer perceived as the “inverse of knowledge” (Chua, 2009) but an active entity with dynamic qualities of its own deeply intertwined with knowledge. In this framework, you cannot study knowledge production, without examining the production of ignorance that goes hand in hand with it.

Not only is the study of ignorance an ethnographic imperative, it is also an avenue to examine power, as Tuana (2008) states: “Ignorance is a complex phenomenon, which, like knowledge is interrelated with power. For example, ignorance is frequently constructed, and it is linked to issues of cognitive authority, trust, doubt, silencing and so forth...The study of ignorance can provide a lens for the values at work in our knowledge practices.” (p.140). Drawing inspiration from theories described in chapter 1 on the social construction of ignorance (Proctor and Schiebinger, 2008), and race and epistemologies of ignorance (Mills, 1997, 2008, 2013; Sullivan and Tuana, 2007; Bonilla-Silva, 2009), I began examining the activities and discussions in QS settings for absence, omissions, denial, selectivity, simplification, forgetfulness, selective scientism and selective attention, stereotyping, epistemological preference, and functional ignorance that help maintain the dominance of certain groups such as white ignorance (Mills, 1997; 2008) in chapter 3; and strategic uncertainty that helps replenish hope and reproduce the self-tracking imperative even in the absence of health outcomes in chapter 4; and hegemonic interventions that obscure notions of participation to achieve interpretive authority in chapter 5.

Given the recent emergence of ethnographic attention to ignorance, the tools to study ignorance empirically are limited and still experimental. Tuana (2008) warns: “We should not assume that the epistemic tools we have developed for the study of knowledge or the theories we have developed concerning knowledge practices will transfer to the study of ignorance” (p.140). In this dissertation, the notion of ontological choreography (Cussins, 1996; Thompson, 2005) offered a useful strategy by which to analyze how different forms of ignorance are woven into a self-tracker’s analysis of their practice, in the QS’s cultural design and in its activist rhetoric. Asking how ignorance is an ontological innovation helps us track how ignorance is produced and sustained, and what role it plays in sustaining such communities.

In noting and articulating such absences and their choreography, as a researcher, I am making several claims that I know things that the people I am studying do not, or I am consciously aware of things that they do not acknowledge (Smithson, 2008). In this way, the positionalities that I hold and my own expertise cannot be disentangled from the analysis in this dissertation. The difference produced through my racial identity, my postcolonial subjectivity, my immigrant status, my gender identity, my training in critical studies of information and technology all provide distance from the phenomenon I study. On the other hand, the similarities produced through my status as a patient during this dissertation research, my own self-tracking forays, my interest in design, visualization, data, technology and the body, and my immersion in the Bay



Area cultural milieu, all place me inside the phenomenon under study as well. My insider/outsider status as deployed in the analysis in this dissertation suggests a choreography of my own. As I've attempted to scrutinize its dynamic, I note that only another gaze, from outside of me, could effectively analyze my ontological play. In a similar dynamic, although it is useful to examine the practices of individual self-trackers, individuals by themselves cannot necessarily overcome the epistemological deficits and tactics that matter in their own practice, warranting an analysis of the cultural context and norms (chapter 3) through which their self-tracking practice is shaped, if we are to consider interventions that would most effectively remedy critical forms of ignorance. In what follows, I review the field findings that a focus on ignorance has helped highlight.

### **6.3 What has the focus on ignorance revealed?**

There are three primary engagements with ignorance examined in this dissertation: selective choice, the production of uncertainty and the act of obscuring. In chapter 3, I examined selective choice. At its origins, the QS was envisioned as a hobby club of self-tracking enthusiasts coming together to share their self-experiments, and learn new methods and tactics from others like them, akin, as I have suggested, to the Bay Area's legendary Homebrew Computing Club. The QS leaders did not introduce self-tracking or the co-option of surveillance technologies for self-exploration, rather they captured an emergent trend which they then coalesced into a community in the tradition of counter-cultural writers of the Bay Area. Activism was never a goal of this group of hobbyists, even if some self-trackers in the QS milieu pursued their own empowerment as patients via self-tracking. In focusing the self-tracking conversation on tools, the individual and their personal experience, QS leaders began contouring the foci of reflective capacities in the QS cultural context. The selectivity inherent in such contouring is not natural, but follows in the traditions of libertarian and countercultural epistemes discussed in chapter 3.

During my fieldwork, the QS and its form of self-tracking was frequently dismissed as the indulgence of wealthy white men. By historicizing the epistemic choices that shapes its possibilities, I was able to go beyond such dismissals, and access the specific aspects of the QS framework that furthers white privilege, not just state that it rests on white privilege. In chapter 1, I noted Linda Martin Alcoff's (2007) advice on epistemologies of ignorance and identity: "The problem is in the cognitive norm, not in the identity per se, and so we need to focus on isolating and identifying these dysfunctional norms and understanding how they operate" (p.50). In chapter 3, I show how the epistemic commitments the QS leaders repeatedly make in shaping and protecting the QS space works to replicate forms of racial dominance predicated on a color-blind style ideology; the specific cognitive norm is a de-historicized embrace of individual difference — the QS ethos renders all difference as equal, without unpacking the historical inequities that create them and continue to shape their capacity to effect change in the world, thereby limiting its capacity as a platform for minority groups to advance the same goals of participatory medicine. Epistemologies of ignorance, as I have shown in chapter 3, can help us interrogate why efforts to produce more inclusive cultures can so often fail.

The form of racial dominance that color-blind style ideology begets rests on shaky foundations. Here, theories of racial ignorance allowed me to see that the cognitive norm of “denying relationality” (Hoagland, 2007), a specific component of white epistemologies of ignorance, sabotages the capacity of white individuals to effect change as well. The cultural representations through which white embodiment is viewed outside the QS context is mutually constituted through the representation of black embodiment. In chapter 3, I used the case of racialized treatment of pain and prescription drug abuse to show how the denial of such relationality, harms white populations as well. Thus, the ongoing dehistoricized engagement with difference in the QS episteme serves to sabotage its capacity for members of its dominant racial groups as well. In this way, ignorance has provided an entry point to analysis of power and to an understanding that some forms of racial dominance can be short sighted for the group in power, not just the groups it marginalizes.

Next, I consider uncertainty. In chapter 4, I explored both the “production and productivity of ignorance” (Mair, Kelly & High, 2012:15) in the form of uncertainty. How do self-trackers engage uncertainty while negotiating the prospects of debilitating illness? I used two cases of self-tracking illness and the framework of ontological choreography to reveal how the episteme of personal experience described in chapter 3 creates opportunities for the private re-authoring of disempowerment using technology, numbers, data, experiments, woven into a dynamic and functional narrative. I began my analysis in this chapter with the case of Henry and his quest to discover the cause of his migraines. In deploying an ontological choreography style reading of his narrative, I was able to spot how his self-tracking functioned as a coping mechanism — his narrative strategically configured uncertainty about data and statistical methods and placed these tensions in a manner that created a functional analysis paralysis, which constantly replenished hope. Such strategic choreography of uncertainty is also found in oncology practice (Good et al, 1991) and in the personal narratives of egg-freezing women (Romain, 2012). The general concept of self-tracking is flexible and able to accommodate highly personalized narratives, anchored on the fixed uncertainty of its feedback loop mechanism.

In the case of Smarr, I show how his narrative destabilizes the felt experience of health, troubling the certainty of health in the absence of symptoms, and configures a state of perpetual uncertainty that only self-tracked data in a continuous feedback loop can effectively re-stabilize. The personal experience of Smarr and his achievement of diagnostic authority over his doctors through a self-tracking process that rested on his dismantling the felt experience of health, legitimizes expansive and constant surveillance of himself and, by extension, the bodies of others. Smarr’s story is significant as it forms the QS patient archetype through which the QS hails people disenfranchised by the medical system as well as the “worried well.” The two cases show how the production of ignorance in the form of perpetual uncertainty around epistemic closure, akin the tobacco lobbyists and climate change deniers, engenders hope but also markets self-tracking as essential even in the absence of immediate health outcomes. It allows self-tracking to persist as a modality of inquiry even when it may contain few material benefits.

In addition, the analysis in this chapter contributed to the scholarship I drew from: I added to the concept of ontological choreography by showing how uncertainty deployed as a strategic temporal ignorance through the feedback loop concept, renews the synecdochal connection necessary to continue self-objectification in service to a healthy long-range self by pushing diagnostic closure and treatment failure, further and further away. Strategic ignorance helps maintain the “referential power between different kinds of things” (Cussins, 1996) perpetually. In addition, in showing how the cybernetic concept of the feedback loop holds a productive uncertainty, I contributed to emergent ethnographic examination of ignorance by showing how ignorance can be functional in engendering hope. And, in showing how hope motivates self-tracking and vice versa, I add to the genre of practice based research on the QS, that speak to the other values at play in self-tracking (Sharon and Zandbergen, 2016) but also bring into view that the other value of hope is activated through a strong impulse to collect more and more data, serving to reinforce data fetishism not challenge it, as this strand of research has typically suggested.

Next, I locate medical and racial dominance in the act of obscuring. Chapter 5 focuses primarily on contradictions within the second intersecting strand of this dissertation, the pursuit of precision medicine and the call to democratize American medicine. I examine self-tracked data as a boundary object (Star and Griesemer, 1989) to which, heterogeneous set of actors assign multiple interpretation, meaning and relevance. In particular, I show how medical authorities and QS leaders conceive of the expertise that self-tracked data bestows on the individual or groups engaged in self-tracking. Drawing from work on the “politics of boundary objects” (Huvila, 2011), I argue that medical stakeholders enact dominance by subsuming the QS aspiration for self-trackers to be seen as equal partners in advancing medical science, by obscuring the meaning of participation that hinges on self-collection of data. Here, I add to Huvila’s (2011) work on the politics of boundary objects by showing how dominance can also occur by obscuring definitions and not just by fixing meaning. In this way, epistemologies of ignorance come into conversation with the concept of boundary objects.

In addition, there are entrepreneurial stakes in this ontological play, following in the traditions of Silicon Valley’s world saving innovation rhetoric (Turner, 2006) — as we saw in chapter 1 and 5 — the patient is now called to consume and adopt an array of biosensing technologies and health services; through such technological adoption, they come to experience the “right” to data and the right to their personal data being “counted” in health care decisions. In the reform of American medicine that hinges on “data donations”, the ability to participate is dependent on ongoing technological consumption and submissions of data generated, to create and maintain data rights to participate. In addition, another problem of equity arises: concerned about sample representativeness, public health authorities urge the QS to consider its diversity problem. I show how this imperative is constrained by the QS members grasp of the “other” both in the United States and globally as abject and deficient, obscuring and challenging their capacity for epistemic equity, pre-emptively foreclosing the inclusive culture it has been called to produce, and furthering the rhetoric of informational deficiency that has long colored the “development” gaze upon the Global South.

## 6.4 Conclusion

In this dissertation, I have examined two intersecting strands in contemporary computational approaches to wellness — the evolving self-tracking ethos found in the Quantified Self, and American medicines shift from the treatment of disease towards the prevention of disease. I have followed an oft-ignored ethnographic imperative to examine how knowledge systems are imperfect and contain various active forms of ignorance; the knowledge pursuits inherent in the two intersecting strands, I have shown, are substantiated by functional forms of ignorance. I have added to the emergent scholarship on ethnographic engagement of ignorance by configuring Thompson's notion of ontological choreography as a tool to study ignorance, by introducing ignorance as an object that exists, which can then be tracked in the ontological choreography of communities and individuals. Through the many ways described in this concluding chapter, I argue that the rhetoric of democratization of American medicine (Topol, 2013) and the Quantified Self ethos is largely in service to the perceived needs of dominant groups and the establishment science the individual is called to help reform. This dissertation shows how ignorance is a useful analytical and ethnographic tool to examine maintenance of practice and power in creative technological appropriation and the fashioning of new movements. The homogenous character of the demographic in the intersecting social worlds accessed in this ethnography precluded examination of how minority groups also deploy ignorance strategically to resist domination and enact power (Sullivan and Tuana, 2007). In future research, I hope to explore how the epistemic choreography of marginalized actors are also shaping contemporary data cultures.

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