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Homo experimentus: digital selves and digital health in the age of innovation

Author

Greenfield, Dana Emily

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Homo experimentus: Digital selves and digital health in the age of innovation

by

Dana Emily Greenfield

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[redacted]

To the memory of my mother Linda Brodsky, MD, who dedicated herself to continuous improvement and innovation, before it was fashionable.

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Homo experimentus: Digital selves and digital health in the age of innovation
Dana Emily Greenfield

Abstract

This dissertation is an ethnographic investigation into the uses and meanings of emerging quantified-self and digital health technologies, which enable the collection of personal and biometric data. As self-quantification tools proliferate – from step counters to wearable heart monitoring devices to wireless scales and blood pressure cuffs – I ask what are the implications for how we experience and understand health, illness, and the experience of daily life. In particular, digital health devices that mobilize tools once restricted to the doctor's office or hospital alter the location, mode and dynamics of care. How is medical expertise and practice remade when clinical metrics are in the hands of patients or lay people? How is the role of the patient altered with the reflexive use of the clinical gaze, when self-care occurs through self-quantification?

This investigation is based on over a year of fieldwork in the digital health industry, the movement for participatory medicine, and the Quantified Self movement. The latter is a community of individuals who utilize self-tracking and digital health technologies to measure, understand, improve, and care for themselves. The QS movement began in the San Francisco Bay area with small meetings of individuals sharing their data and has now grown to over 100 groups around the world, including two annual international conferences. The data was gathered via participant observation and interviews across these various sites where new health technologies are being developed and used.

Through techniques of self-quantification, self-reflection and self-care, "trackers" challenge traditional clinical practice and cultivate new forms of knowledge production, medical and others. The very terms of health and illness are in flux, I argue, as the ability to collect almost continuous data on oneself and one’s body makes daily life available to continuous innovation and optimization. I explore the meanings of living in experiment, where digitized life provides almost limitless experimental horizons for the cultivation of new (and often improved) selves. *Homo experimentus* is the name of an emergent subject and set of practices that come out of life and health rendered digitally.

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Chapter 1. Introduction

I. Health is Data

On April 1, 2015 a tiny storm brewed in a corner of Twitter when Mark Cuban—business mogul, owner of the Dallas Mavericks, entrepreneur and author of *How to Win at the Sport of Business*: *If I can do it, you can do it*—posted to his 2.83 million followers: "if you can afford to have your blood tested for everything available, do it quarterly so you have a baseline of your own personal health." A follow up tweet read: "create your own personal health profile and history. It will help you and create a base of knowledge for your children, their children, etc." These seemingly innocuous suggestions from a celebrity businessman (in addition to his high profile holdings, he is also one of the investors on *Shark Tank*, a show where small-time entrepreneurs pitch their ideas to investors and negotiate business deals—where the American dream meets reality television) caused a little bit of turbulence in the twitter-sphere. Physicians and medical journalists, most notably *Pro Publica* writer Charles Ornstein, jumped to challenge Mr. Cuban on the necessity and scientific validity of such frequent testing, arguing that prevention can actually be a form of over-treatment. Debate erupted between those who worried that Cuban's vast reach (millions of followers) would mislead and confuse "the public" and those, like Mr. Cuban, who would prefer to take health matters into their own hands. Some painted the reactions of physicians and journalists as paternalistic towards both patients and physicians. Some health data startups joined the virtual brawl too, taking advantage of the exposure and Cuban's maverick position. Inside Tracker, "a personalized health analytics company," which offers a "science-driven nutrition and lifestyle interventions that empower people to optimize their markers," chimed in, offering its services to help people make sense of this data: "Quest

[Diagnostics] is a good place to start, but that will still rely on ‘normal’ ranges. We’d love to help!”

It did not take long for news pieces to spin out of the social media maelstrom. In the LA times, journalist Michael Hiltzik wrote[1]:

> In one tweet, Cuban writes: "a big failing of medicine = we wait till we are sick to have our blood tested and compare the results to 'comparable demographics.'"
>
> No, that's not a "failing" - that's the right approach. As an element of public health policy, having our blood tested for nothing in particular or everything under the sun would be unimaginably wasteful and costly and invite billions of dollars in unnecessary treatment. You want to know why Americans spend so much more of its gross domestic product on healthcare than most other developed nations? It's because we already have too many tests and too aggressive a response to the results they deliver.
>
> In short, the Mark Cuban method is one that would make sense only to a billionaire, and a billionaire with no understanding of health and healthcare. As a public intellectual, moreover, Cuban isn't especially open to professional advice or hard information. His attitude is that he didn't get where he is today by

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[1] Accessed here: http://www.latimes.com/business/hiltzik/la-fi-mh-mark-cuban-vs-the-facts-20150403-column.html

> listening to criticism. But then again, he's a businessman and billionaire entrepreneur, not a doctor.

One reason that physicians active on social media and health journalists pounced on Cuban’s tweets was the worry that his reach might drive people to follow his advice, demanding more testing from their doctors. These are worries that stem from past social media effects of celebrities sparking, for example, the spread of anti-vaccination sentiment. Cuban’s critics urged him to educate himself on the clinical and health policy evidence that point to the dangers of over-testing and potential over-treatment. In spite of expert opinion, Cuban dug his heals in and challenged the journalists to trust doctors to be able to handle the data. He asserted that the data was not for “diagnosis” or even “treatment” but to make sure he had a baseline for the future. To some people reading this debate, this argument revealed a kind of obsession with collecting personal health information. However, quarterly testing is tame compared the continuous monitoring to which some medical futurists and digital health entrepreneurs aspire. For them, health data will lead to predictive analytics and lead to prevention, not over treatment.

There is clearly a large gap in how people with various stakes in the game read this sort of behavior and the purpose of data. Is the proliferation of personal health data symptomatic of American excesses or symbol of personal efficacy and responsible medical citizenship? On the side of those who advocate for the collection of personal health data, some monitor the body far more often than quarterly measures—even continuously on some measures. Transformed into a data-rich resource, the body becomes another frontier on which to develop a new kind of medicine and self-care. Consider (albeit extreme) the case of computer scientist and digital health luminary Larry Smarr:

> I spent 25 years doing relativistic astrophysics, so what I'm thinking about is this is a complex dynamic system, my body. I'm trying to read the base variables and understand what's going on. When you begin to [collect this data], particularly with the microbiome, which is 90% of all the cells in your body and 99% of all the genes in your body, it's entirely outside of medicine. You begin to see how your body works.
>
> We're going to turn the whole medical world upside down, by staying healthy instead of developing chronic diseases, by actually feeding back as you begin to get variables that begin to move away [from a baseline]. But the problem is I'm just an n of 1.

Smarr is a physicist turned computer scientist who founded and directs the California Institute for Telecommunications and Information Technology at UC San Diego and UC Irvine. He has become well known in the media for his efforts to quantify and capture everything about his body. He made the above declaration at an invite-only symposium called Quantified Self-Public Health (QSPH) in the spring of 2014. There, he shared a story of self-tracking and quantification that led to self-diagnosis of pre-diabetes and Crohn’s disease. His data collection far exceeded quarterly blood tests. At the conference, for example, he shared years worth of data, including a 64-million pixel wall, displaying 150 variables of data tracked over the last 5 years. He even brought a 3D printout of his colon for show and tell, made by processing his MRI data through virtual reality software. This exploration was jump-started from his move from “the heart of the obesity epidemic” at University of Illinois at Urbana Champaign to take create CalIT2 in La

Jolla, California. He tracked his activity and sleep, and he began to lose weight. Finding he was prediabetic through his data, he began to follow C-reactive protein (CRP), an inflammatory marker. He explains:

> Starting from about 2005, I thought I was getting better. My CRP was five instead of less than one. Then it was 10. Then it was 15 and there was something crazy going on inside my body.
>
> Doctors were not interested when I brought in my charts.
>
> They'd say, "What's your symptom?"
>
> I'd say, "I don't have a symptom."
>
> They'd say, "Why are you here?"
>
> "I've got data."
>
> "Well, that's not useful. I'm a doctor."

This small exchange was told as a bit of joke, and it circulated quickly amongst the tweeps (people on twitter) following the conference from afar. That this information, or data, that patients bring to the clinic is not legible or given its due resonated as a problem amongst the followers and audience. More than pointing to the power differential involved in a clinical encounter—whose testimony and whose knowledge is sanctioned—this face-off between data and symptoms points to a deeper epistemic rift that is taking shape within (and outside of) medicine. On the one side of the divide is traditional clinical assessments and decision-making, centered around the patient’s report of symptoms and the physician eliciting signs. Symptoms have a particular ontological and epistemic place in this encounter, as part of patient’s subjective testimony. On the other, is the concept of data, testimony that is in the idiom of information and computation. Traditional medical decision making sees the patient as potentially filled with subjective experiences and stories, or illness scripts or narratives, which the physician must decipher and translate into their own language. Data, however, interrupts this rendering of the patient: whereas the former is a subject made legible through ineffable experience and narrative to be rendered into signs and symptoms, the former is a subject saturated with information. The patient hopes pixels of data points will collapse the gap between symptom and diagnosis, making the body legible, finally, transparent. This dissertation is about how this kind of computational body and subject is unfolding around the edges of medicine, sidling up to clinical practice with tools and techniques that bring personally generated data into the diagnostic field.

The debates over how to use new technologies to monitor health have been carved upon two competing visions. On the one hand, medical journalists feel obligated to communicate sound medical science to the public, quelling epidemics of hype and paranoia. They worry that a frenzy of self-monitoring will produce such epidemics. On the other hand, these exchanges and the experts' censure of Mark Cuban misses something important: by focusing on utility of data and "misinformation" the critics miss the cultural and epistemic shifts proffered. That is, Cuban's opinions represent more than just potentially virulent misinformation about best medical practice. His cavalier and perhaps careless tweets and the reactions they elicited also contain within them (at least) two different visions of health and care. One, echoed by Hiltzik above, understands health and healthcare as the province of experts. Physicians deal with illness in ways that are supported by an evidence base garnered from and applying to populations. The other vision treats health as a project under continuous achievement by patients and the public. In this vision, patients and the publics imagine using personally collected health data to determine "baselines" and monitor modulations in their own health. In this second vision, there is a subtle critique of medical expertise. Here, medicine fails to take on the role of not just prevention, but other terms of care: monitoring, maintenance, optimization, and personalization. People monitoring their own health, some self-trackers argue, will be able to do a better job at prevention. These competing visions of not just how to achieve optimal health, but also where expertise lies in this domain, form a key debate that has been spawned by the rise of the Quantified Self (QS) movement.

In this dissertation, I examine the possibility and contours of both credibility and culture in the practices and experiments that come along with this second vision of health and care. Following my interlocutors in the QS world, I explore how the journalist's claim that this practice of frequent gathering of health data "would only make sense to a billionaire" is, in fact, a woefully inadequate response if not simply wrong. In fact, the more one learns about the QS movement, the more one learns that the method of tracking, or what is called "sousveillance" by those in the Quantified Self movement, is being put to purposes that are not just more complicated than these journalistic accounts claim, but are also far more widespread than they realize. The use of digital and mobile health technologies is creating a world where self-tracking of biometrics and health behaviors, and the sharing of stories, experiences, and insights gained from personal data in meet-ups[2] and conferences or online, are becoming commonplace activities. These are just some of the new realities made possible by the Quantified Self movement and the practices and techniques it enables.

In what follows I explore how people are making sense of the things they are doing with new technologies for quantifying themselves. This includes the collection of personal data, exploring how these techniques of self-tracking are changing the meanings of health and illness,

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[2] QS meetings are arranged through Meet-up.com, a website that allows users to organize mutual interest groups. Meetings from here on will be called "meet-ups."

reshaping the notion of valid knowledge and how it is produced, or epistemology, and altering how the body, understood as data, ushers in forms of experience that characterize life *lived digitally*.

Along with the rise of digital health technologies and services that enable the tracking and collection of health data outside of (or even circumventing) the clinic, new experiences of health and care are emerging. The politics of health data collection—including debates over validity, access, proliferation, and ownership—are coming to the fore as information technologies make big data a personal matter. Beyond the question of whether or not data is good for you, this dissertation attempts to look at what this question elides, to get a handle on the implications of experiencing the body in bits and bytes, managing health as data, and participating in self-care and self-experimentation as a challenge to traditional medical authority and epistemology. In order to study something so emergent—phenomena just now appearing at the margins or frontiers (depending on how you see it) of medicine and technology—I moved in and out of various spaces and settings from the Quantified Self movement, to mobile and digital health forums, to patient advocacy groups. These touch points were nodes in a network of overlapping interests and people. I made connections across these communities and followed people who rotated between these overlapping worlds. As something emergent, my objective in this ethnography is less to stabilize an understanding of a singular phenomenon than to write an "ethnography of possibility", where my travels in these diverse communities created more openings than final determinations about what might be happening and could be imagined *vis a vis*, bodies, health, and bytes of data.

As an anchor for this work, I start with the Quantified Self movement, its short history and socio-historical context to help us make sense of this new convergence of health and its appearance in everyday forms of data.

II. QS: Community and Self In-Formation

A. QS Folk Histories

> The story of quantified self is the story of personal computing coming all the way in. But that's not just a change of scale. There are a new phenomena at different scales.
>
> - Gary Wolf, Founder, Quantified Self

The folk history of QS—written by former WIRED Magazine editors and movement founders Kevin Kelly and Gary Wolf—is punctuated with inaugural events: a blog launch (2007); a first meeting at Kelly's home in San Francisco (2008); Wolf's New York Times Magazine debut "The Data Driven Life" (2010b), followed by an influential TED talk (2010a); and the first international conference held in Mountain View, CA (2011). This history of QS, articulated and rearticulated as the decentralized network continues to grow offers the beginning of the history of QS as a history of personal computing. But, what are the cultural and political histories of personal computing and how might they give us even more insight into what QS is and what it might become?

When Gary Wolf informally polls audiences at Quantified Self meet-ups, he finds that many—often most—of the attendees are new to the scene. So he has taken the time to introduce new attendees to the Quantified Self as a phenomenon and a "cultural and technological movement"[3]. In a talk he gave at a meet-up at the design firm Autodesk in San Francisco in early 2014, Wolf frames the emergence of Quantified Self in a world where computing transformed from a tool for industry, management, and science to one of personal communication, connection and expression. As a forum for exploring the personal part of personal computing, QS also provides a platform and community for those exploring how to answer personal questions with tools that were not necessarily designed for those means. The work of the community, he explains, has not only expanded from 2008 from Kevin Kelly's studio to 100s of groups across the globe, but it has also turned its focus to helping people use, build, and repurpose personal computing technologies—from 'the spreadsheet' to a FitBit step counter—to answer questions not anticipated by those machines. QS Labs (the organizational form of QS that hosts the website and conferences)then, has expanded their efforts from creating a forum to advocating for data access, inter operability, and setting standards for the ease of use and connection across multiple apps, devices, and services.

Talks like Wolf's in 2014 are given to check in with an ever-evolving community made up of people who are all, in some sense, exemplary of 'the quantified self.' The Quantified Self is an introspective undertaking, continuously engaging in asking questions of meaning around personal data. Just before his first ever Global Conference in 2011, Wolf offered a brief history on the blog, the main hub of the growing QS network and community. Founded with Kevin Kelly, the founding executive director of *Wired* magazine, where Wolf was an early writer, QS grew out of the publication's creation of and reporting on emerging technoculture:

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[3] Description on the webiste:http://quantifiedself.com/2014/02/introduction-to-the-quantified-self/

> In 2007 we began looking at some new practices that seemed, loosely, to belong together: life logging, personal genomics, location tracking, biometrics. These new tools were being developed for many different reasons, but all of them had something in common: they added a computational dimension to ordinary existence. Some of this was coming from “outside,” as marketers and planners tried to find new ways to understand and influence us. But some of it was coming from “inside” as our friends and acquaintances tried to learn new things about themselves. We saw a parallel to the way computers, originally developed to serve military and corporate requirements, became a tool of communication. Could something similar happen with personal data? We hoped so.

As journalists and cultural entrepreneurs, Kelly and Wolf created the QS community to both reflect on, articulate, and nurture emerging computing practices. In the era of Big Data and post-911 surveillance, issues of data and tracking provided a backdrop for new conversations around the ownership and use of data, big and small. Their 2008 “Inaugural Show&Tell” at Kevin Kelly’s studio in Pacifica grew to be modeled after the user groups of the Bay Area, such as the Homebrew Computer Club a group of computer hobbyists that began in Menlo Park and met from mid 1970s to 1980s. “Users groups, when they succeed, are wonderful things; informal but deeply engaged learning communities operating outside the normal channels of academic and commercial authority. Here at the Quantified Self, we want to know what these new tools of self-tracking are good for, and we want to create an environment where this question can be explored on a human level.” Staged in this way, QS embodies a hacker ethos, which values an approach that tinkers, uses tools as they go, experimenting in an ad hoc fashion to problem solve, often with a spirit of play and a sense of curiosity of what is possible. By placing itself alongside these user groups, QS borrows not just from the ethos of creative tinkering, but also with an anti-authoritarian streak that welcomes and supports the non-expert and non-academic. Commercial motives are similarly suspect, though relied upon for devices and data. QS has continued to walk this line, bringing together users in a "learning community", careful to balance local expertise with formal expertise, welcoming tool makers and entrepreneurs but wary of mere consumerism.

As Gary Wolf described in his 2014 talk, this community grapples with how to get meaning from data and devices that are often not built with our questions in mind. Commodities in a fast growing market, such as the FitBit or the highly anticipated iWatch by Apple, have built in to them assumptions and technological scripts of how the user ought to use them (walk more, lose weight, sit less, etc.). In the QS community, users and toolmakers are sometimes hoping to repurpose pre-fabricated technologies to novel uses, personal experiments, as well as push for changes in protocols and access in how commercial products are developed. Personal stories intermingle with discussion of how to create open data infrastructures and open APIs (Application Program Interface), so that devices and services can more easily connect, allowing the freer interaction and flows of data.

B. Capturing QS Origin Stories and Creation Myths

> What started as a small group of people, 20 people maybe, meeting in my friend and partner, Kevin Kelly's studio in Pacifica in 2008, has grown into a real global community of tool makers, users, artists, engineers, designers asking the question, 'What have we learned from our own data?' Actually, my daughter, asked me to correct that and said 'It's really what are we *learning* from our data,' since

> nothing has been finally learned' and if you say, 'What have I learned?' it sounds like you're done and we are not done.
>
> -Gary Wolf, Co-Founder, Quantified Self

In the spirit of personal archiving, the late psychologist Seth Roberts documented his notes on the very first QS meeting at Kevin Kelly's home in Pacifica in 2008 on his blog—a blog that is mostly dedicated to self-experimentation, his own and others. He listed all attendees and their 5-word (or fewer) introduction, a protocol that has since been routinized at many Quantified Self meetings. This is a selection of some of thosenotable taglines*:*

> Now Future Earth People Children
> Machine Learning Applications
> Athletic Performance Language Acquisition Cognition
> Machine Learning Life Extension
> Writer Radio Experimental Man
> Reporter Utopian
> Visualization Democracy Lambda Graphics Usability
> Social Constitution of Self Online
> Systems Accumulating Evidence Reflexively
> Python Family Jazz Piano
> Open Source Health Research

Seth's words were *Sleep Mood Self-Experimentation Flaxseed*. He has since become famous in the QS community for discovering that he could optimize his sleep by standing on one leg for 8 hours a day, improve his math skills with a diet extremely high in butter, and elevate his mood by looking at pictures of faces first thing upon waking in the morning. Seth's notes from the meeting listed out the products of a collective brainstorming around what people might be interested in learning, tracking or talking about, from "gadgets" to "measuring the effects of measuring." Unlike future QS meet-ups, where speakers are scheduled and prepared before hand, this first meeting unfolded on its own, with participants sharing what they had, in stories and on their computers.

Aaron[4], one attendee, tried to capture for me how open ended that first meeting was: "Who knows if Gary and Kevin actually had a plan for the meeting, but it started off with, 'Well does anybody have anything to talk about?'…[they]made a list on the whiteboard, and started talking, and the talks really sparked interest much, much further as we saw the diversity of views." Julie, also in attendance, recalled: "It was highly geeky. I mean, it was very ad hoc, it was basically, 'Hey, who's here, why we are here, who's got something they would like to share?"…it was fun." They recalled how all of a sudden the outpourings of ideas, stories and data—people shared intimately held spreadsheets—started to become magical. Aaron and others remembered big personalities like Tim Ferris—who was working on his second book *The 4-Hour Body: An uncommon guide to rapid fat-loss, incredible sex, and becoming superhuman*—and Ka-Ping Yee, (called Ping) who was a graduate student in engineering at UC Berkeley at the time. He spoke first about time tracking, because he "felt like [the] problem was not making good use of time," Seth had noted. Aaron remembered that Ping had tracked his life down to about 5 minute increments for three years:

> The only breaks were Burning Man because, he said, 'You're not supposed to record what happens at Burning Man.' So he had done this in such a detailed way,

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[4] This is a pseudonym. All names of those who are not already public figures have been changed to pseudonyms.

> and then he had gone through the trouble of coming up with a way of graphing it, and different colors for different kinds of activities….He showed us his three years, and what floored us was that after he showed us all of that he sort of snaps at us with, 'What do you think I can learn from all of this?' And we're just like, 'Well, holy shit you've been putting all this work into it, why have you been bothering, if you didn't have a sense of that?' …It really opened up this issue of what can we learn and so forth.

Seth's notes go on to detail all the speakers that followed: "Tim Ferriss: Athletes…Gary Wolf: Learning/Knowing…Rajiv Mehta: Ways this Helps…Peter Mortensen: Motivating Running…Seth Roberts: Sleep." The topics covered planted some of the seeds for the diversity of concerns of the QS community that would later develop. However, what was more evident in hazy recollections of that evening from interviews with some of those first in attendance, was that there was some spark to that meeting. Luke, who shared his extreme calorie restriction experiments at the time remembered very little of the meeting in detail—he had it tape recorded and archived somewhere, something he does a lot, augmenting his own faulty memory—did remember something about Kevin Kelly's space:

> There's a whole wall that's floor to ceiling books. Custom made bookshelves that completely, exactly fit to the house. It's a pretty big wall, and he has this workbench with just lots of cool stuff all over it. There are some interesting three-dimensional properties to the house. I got the idea, like, 'Okay. This guy thinks about interesting stuff.'

The space, he recalled, in addition to the people gave a sense that this is the vanguard. Brad, a British expatriate, found QS pretty early on meeting Alex Carmichael one of its early directors at a hackerspace in San Francisco called Noisebridge. He shared his own tracking work—which grew to encompass caffeine, meditation, and mood tracking—with her and she urged him join QS. His first meeting, the 5th one ever, impressed him: “It was interesting. There were all these luminaries, like Matt Cutts from Google. He’s like Google [employee] number 7, the search quality guru. And Esther Dyson. It was funny. I was walking around and everyone there was either the VP of some major company you’ve known or, like, ‘I founded something that was legendary.’ It was a very interestingly high-powered group of people, like ‘I’m the leader of this track at Singularity University.’ I was way out of my league.”

For his part, Brad felt like he had found what originally drew him to Silicon Valley: a utopian vision of creative and technological frontiers embodied in institutions like Xerox Palo Alto Research Center (PARC), Xerox’s west coast innovation lab, where engineers made formative advances both personal computing and workplace technologies, such as a graphical user interface and the ethernet. Xerox PARC along with Apple “shaped my imagination of what the Bay Area might be like…the really cool stuff that people do here.” He reached the Bay Area from Great Britain as an adult with his own start up, but he sought out Silicon Valley since an adolescent, teaching himself programming and finding his way into computer labs by any means necessary. Coming from an unhappy childhood with difficulties at home, Brad found solace in the hope, optimism, and possibility that seemed to thrive here. I turn to the cultural history of this place later in this introduction. For now, my aim is to characterize broadly the kinds of people and desires that animated QS as a place of newness, possibility, with an ad-hoc startup sensibility. The “coolness” that Robin talked about was described to me by Luke also as something that was radical, *avant garde*, maybe even marginal or extreme, yet something that was going to somehow translate to the rest of the world in a revolutionary way.

The presence of these Silicon Valley celebrities stoked this charge of promise and cultural import. Kelly and Wolf are cultural entrepreneurs themselves, assembling networks of technologists, moguls, and tinkerers who live to create and contribute to the affect of innovation and the avant-garde. Brad explained to me how this felt to part of such a network and moment: "I think they were drawn to the honey. There was this thing like, 'There's something happening here." There's a spark of some new coolness happening here, and maybe this is the epicenter of it. There was sort of a vibe. Also, Kevin and Gary had gravitas. Kevin himself is like a cultural instigator, and so that was probably enough." As WIRED magazine editors, Kelly and Wolf participated in crafting this vibe out of the magic of Silicon Valley. These luminaries—from hackers and entrepreneurs to journalists and engineers— continue to cycle in and out of the Quantified Self movement, at user meetings and conferences, or as investors and entrepreneurs in the industries that QS has seeded and encouraged. Of course, QS as an organization and meet-up group was not the sole origin point for the technologies it uses, such as step counters or biometric devices. The company that created FitBit, for example, was founded in 2007. Rather, QS emerged in the same milieu, where technology companies, devices and apps, turned their attention towards activity, behavior change, and habit formation. One influential point in this constellation of technologies and people is BJ Fogg's Persuasive Technology Lab[5] at Stanford Univeristy, founded in 1998, out of Professor Fog's work in computer science on how to use computers to influence people's behavior. He has since become a habit design guru. Some of the same individuals with shared interests in technology and behavior circulated amongst various overlapping networks in the Bay Area, from hackerspaces to Stanford computer science labs to

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[5] http://captology.stanford.edu/about/about-the-lab-1.html

Google. Quantified Self become yet another site where these digerati circulated and created a new foment around uses of personal data.

Back at Kelly's home, the whiteboard held too many ideas to fill just one evening. So the second meeting was scheduled right away: it took place at the Institute For The Future (IFTF), a research organization based in Silicon Valley that is "committed to building the future by understanding it deeply."[6] The IFTF was to become the first of many innovative, high-tech, entrepreneurial or design-oriented sites to host QS meet-ups. During my year in the field, I attended QS meet-ups at technology business incubators, Evernote headquarters, the design firm Autodesk, and digital health startup offices. These spaces, like Kelly's home, orient everyone towards not just technology and tools, but towards the future itself. QS meet-ups sometimes seem to draw on the power of the settings in which they happen, spaces that are built for building things, futures and futurism.

The current organizers of QS try to maintain this ethos of open sharing of personal stories as the community and their practices grow into a mainstream phenomenon and a growing industry, replete with market potential, investment, and hype. Startups and entrepreneurs are ambivalently embraced by Wolf, given space in demo booths, yet kept, as much as possible, out of the core story-telling function of QS meet-ups and conferences. This separation, as we will see, is sometimes hard to maintain as many of the toolmakers and tinkerers are entrepreneurs themselves. Moreover, the forms of subjectivity and practice that QS engenders are intimately entwined with an entrepreneurial mode of self-governance.

My encounter with QS begins six years into this experiment, where the leading edges of QS's many frontiers are meeting the industries of digital and mobile health (also called "dhealth"

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[6] http://www.iftf.org/what-we-do/history-of-the-future/

and “mhealth”) and precision medicine, leading QS, for example, to partner with scientists and physicians to put on QS Public Health, mentioned above. It is those exchanges between the communities of trackers, biohackers, patient advocates and activists, and dhealth and mhealth entrepreneurs that interest me.

C. QS Community: continuous becoming

At these early meanings, the community grew and began to take its multidimensional shape as a morphing, self-organizing network. Some of those at the inaugural meeting became leaders in the community, creating new meet-ups to reach farther corners of the Bay Area, which is now home to 3 to 4 QS groups (QS Bay Area, QS San Francisco, QS Silicon Valley, QSXX for women, and QS Berkeley which is now dormant). Beyond the Bay Area, there are now over 100 QS meet-ups worldwide, from Australia to Spain. Two Global conferences take place each year, one in the San Francisco Bay Area, one in Amsterdam. The meet-ups that I have attended in the Bay Area usually follow a familiar format. To begin, attendees socialize over food and drink while also circulating amongst demonstration tables where toolmakers, entrepreneurs, or representatives from digital health companies share their wares—from the latest activity tracker on the market to at-home blood test kits in beta testing to new tracking and life-logging apps.

After networking and demos, but prior to the talks, the meeting hosts—such as Evernote (tagline “Remember Everything”)— make an appearance, connecting with the community, offering its services or products as a means of self-quantification or business incubation. The hosts usually gather everyone into the presentation area, where speakers give short 7 minute “show and tell” talks in an “ignite” format, where automatically advancing slides keep the message on pace and concise, with Q&A to follow. If the group is small enough, the hosts carry on the QS tradition of (now) 3 word intros. At even smaller meet-ups, like QSXX for women, the presentations range from formal slide talks to casual roundtable discussions to informal socializing over drinks and snacks. Conferences take this format, scale it over a few days, add breakout discussion session on topics that range from technological challenges of aggregating data across platforms to the meaning of life-logging.

Participating in QS as a tracker and contributor also means participating in crafting a kind of "community." Social scientists like me enveloped into the community, not as observers, but as participants in the project of trying to understand what is possible with personal data. It is not always clear who or what constitutes the QS "community", or if it is a community at all. At informal polls, Gary Wolf finds that over half of the attendees at a given QS meet-up are new to the scene. As Brad, an early member of QS, described it to me: "There's this thing about what is the community….It's not just the people doing stuff. It's people that are interested in this stuff in some way, beyond just doing it." When people come to QS to share their stories of self-tracking or experimentation with personal data, they often come and participate in conversations not just about best practices, new techniques, new tools, or unexpected findings; they sometimes participate in the larger, reflective conversations about the possibilities and meanings of tracking and personal data. "People bring their whole selves" to QS, Brad explained. In that way, QS provides a "big tent"(Nafus and Sherman 2014) and general forum where a diversity of people—from engineers and entrepreneurs to non-expert users and social scientists—come together to see what can be done and learned from personal data. Nafus and Sherman(2014), anthropologists at Intel, a sponsor of Quantified Self, who have spent time in the Quantified Self movement offer that while the "community" brings together large health care companies with entrepreneurs, the focus on the self, and marginalization of commercial interests has a particular effect that carves out what they call "soft resistance," critiquing larger corporations and using technologies for unscripted means. This “soft resistance” is something that I, too, chart in particular relation to self-quantifying techniques, bodies and healthcare, and is highlighted through showcasing and inviting stories of personal meaning, sometimes it is triumph, sometimes it is failure. The issue of meaning is built into these settings—a welcoming poster at the last QS conference reads: “Self Knowledge Through Numbers.”

Keeping the community relatively dynamic and diverse is difficult as an entire industry of “wearables” (from “smart” watches to “smart” clothing), tracking applications, digital health gadgets, direct-to-consumer health data services (from genomics to blood work), and personal data analytic and aggregation tools mushroom. The organizers of QS are very conscientious about the place and role of startups and commercial interests in QS. While the lines between self-trackers and entrepreneurs blur—they are often the same people, sharing a similar ethos—the demo booths and tables are meant to separate out what is commercial from what is a user group of individuals sharing insights and personal stories. At early QS meet-ups, Brad told me, entrepreneurs who attempted to hide a pitch inside a personal story were heckled off stage. This separation is not always achieved as personal stories and challenges are often the impetus or seed for the entrepreneurial pitch and venture.

One patient-advocate, Kate, who works at a digital health startup and circulates between quantified self and health technology communities, described her experience this way:

> Everyone’s really friendly and seems approachable….It’s not very corporate. It’s just like a spirit of experimentation and everyone’s just kind of trying things and everyone talks about not only their successes but [also] their failures. And there aren’t lot of people just trying to sell and pitch. I think there is some of that but I

> think they try to minimize it on purpose. It's just kind of people who have a curiosity about this stuff, a really good group.

I heard this repeated amongst others in QS, that the directors of QS—currently Gary Wolf and Ernesto Ramirez—make an effort to keep it feeling like a community of users. Without that active management, it would be just another technology conference, of which there are many, especially in the health space. Even more than tempering the commercial bent of QS, Gary and Ernesto actively try to keep the "culture" of QS pretty open, going out of their way to recruit speakers who break out of the mold, challenge the themes of optimization, athleticism and performance that can so easily overwhelm the scene, with exercise trackers and athletic performance at the center of many wearable design. The talks that kick off the conferences often set the tone for opening up the edges of what might be considered QS. Brad was asked to speak about meditation and mindfulness two years ago. At the top of the Amsterdam conference in 2014, I was asked to speak about life logging project I was doing around grief and memory.

Other more radical examples of tracking closed out the 2013 San Francisco conference, such as Mark Carranza who has logged every thought and idea since 1984, calling himself the "Social Memex." On stage Mark spoke, typed, logged and mined his memex, live and almost all at the same time. It was a strange and intriguing performance of digitized thought, memory, and experience. Sitting in the back of the ballroom, startup guys sitting to my right snickered and dismissed him: "this isn't quantified self.""Memex" is a portmanteau of "memory" and "index," a term coined by Vannevar Bush (1945) in an essay in *The Atlantic Monthly* that detailed a vision of personal computers as "a device in which an individual stores all his books, records, and communications, and which is mechanized so that it may be consulted with exceeding speed and flexibility. It is an enlarged intimate supplement to his memory." As I will discuss below, the origins of quantified self reach far beyond the first meeting in 2008, or the rise of smart phones and small sensors. Rather, QS owes its rise to the very beginnings of computing, and those, like Bush, who imagined computers as extensions of our selves. Personal computing developed from cybernetic visions of expanding and liberating our cognitive capacities, a vision developed at the heart of post-war scientific frontiers. Unbeknownst to those skeptical gentlemen at the back of the conference hall, the performance of the memex, as an origin point for computing as a personally expansive enterprise, was as close to a *quantified self* as one could get. Given this expansive idea of tracking, my goal is to understand what kind of subject these techniques and technologies produced.

III. Cybernetic Counter-histories of Personal Computing

The folk history of QS reinforces the Silicon Valley story of innovation, creativity and radical The roots of QS can be even better understood by probing the larger cultural context of the rise of information technologies, "personal computing" and cyberculture. More than depending on the technological development of further miniaturization of mobile, ubiquitous computing, the cultural origins of QS and a "community" or network of users, tool-makers, and experimenters makes more sense by looking at the social and political roots of such "personalization." More than providing the climate for personal computing, an ethos for hacking, and technological wherewithal, this history links the very charismatic figures that helped develop Silicon Valley cyberculture to the networks of luminaries that were present at that very first meeting. Kevin Kelly, co-founder of QS with Gary Wolf, is a direct link between the shapers of 1990s cyberculture, as an editor of Wired magazine, then emergent from networks of thinkers and technologists that had participated in the counterculture of the 1960s, held together by figures such as Stewart Brand who anchored this world in cybernetic visions of better worlds. In other words, the practices and ethos of QS share some resonances with older cybercultures, and the networks that created QS are the very same networks that participated and shaped these former networks of entrepreneurs and engineers, and the values, politics, and working cultures they created in the region of Silicon Valley.

I take my reading of this history primarily from analyses on digital media and Silicon Valley culture[7], in particular Fred Turner's *From Counterculture to Cyberculture* (2006) which traces the rise of personal computing and what has come to be seen as the liberating networks, channels, and platforms of the internet. This history, which is often told in the folk history of Silicon Valley as emanating from the counterculture of the 1960s, drawing a straight line from the free thinking, acid-tripping hippies that flocked to the Bay Area in the 1960s and 70s to democratizing, decentralized, experience-expanding virtual life. Relatedly, the rise of the internet is also explained as resulting from the technological advances—networked computing, minitiarization, domestication—in computing itself.

Qualifying these accounts, Turner shows how the meaning of information technology is not so self-evident. Rather, activists in the New Left, particularly those in the Free Speech Movement, saw the computer as instruments of oppression, bureaucratization, and alienation. Mario Savio had said in an interview: "At Cal you're little more than an IBM card." For the New Left branch of the counterculture—steeped in political struggles and demonstrations from the Civil Rights movement to ending the war in Vietnam—information technologies carry a very different meaning. Turner shows how the other branch of the counterculture, what he calls the

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[7] See also *Cultures@SiliconValley* (English-Lueck 2002) for an ethnographic analysis of life and work in Silicon Valley at the end of the millennium.

communalists, the back-to-the-landers who embraced social change not through agonistic politics, but through constructing new models (either anarchic or religious) of sociality outside of the mainstream, using LSD, creating radical experiences through art, re-appropriating tools and technologies for small scale personal use, all in the service of global harmony.

At the center of Turner's story of how information technologies became the internet, embodying connectivity and liberation, are two crucial figures: the countercultural and social entrepreneur, Stewart Brand, and cybernetics. Brand is most notable for creating *The Whole Earth Catalog: Access to Tools* and its related networks. Through its pages , the catalog presented the tools, technologies, and tips that would aid the communalist, counterrevolution on various intentional communities and back-to-the-land living experiments that Brand visited throughout the late 1960s and 70s. He simultaneously circulated among the disparate worlds of the San Francisco (as a member of the Merry Pranksters) and New York bohemian and avant garde art scene, as well as amongst technology researchers who were steps away in Menlo Park, CA. Cybernetics, its vision of cross-disciplinary collaboration, global connectivity, and ecological views of human sociality and information laid the ground for much of his networking.

In the pages of the *Whole Earth Catalog (WEC)* he explicitly wrote on the counterculture and the role of small, scale, personal technologies in it. Brand also published the letters of readers as contributions; the pages became a collage of a community, haphazardly edited and compiled, embodying its DIY ethos and that of its readers/contributors. Before the internet, this catalog became a site for exchanging ideas, technologies, and an imagined community of sorts, where far-flung communities could draw on one another in revolutionary and techno-utopian discourse. Brand propagated his readings of cybernetics and technology—in particular the views of Buckminster Fuller and Lewis Mumford—through his vast networks, the military-industrial research culture found its way into the communalist countercultures of the 60s and 70s, finally flourishing in cybernetic visions of personal computing and information technologies.

> Together, the creators and readers of the Whole Earth Catalog helped to synthesize a vision of technology as a countercultural force that would shape public understandings of computing and other machines long after the social movements of the 1960s had faded from view. In the 1980s and 1990s, as computers became ever smaller and more interconnected, and as corporations began to employ increasingly flexible modes of production, Brand and his colleagues repeated this process at the WELL, in the Global Business Network, through Wired, and in a series of meetings and organizations associated with all three (Turner 2006, 6).

Brand traveled between the *WEC* offices in Menlo Park and his neighbors: the Augmentation Research Center (ARC) at the Stanford Research Institute (SRI), Xerox's Palo Alto Research Center (PARC), and computer hobbyist groups such as the People's Computer Company and, later, the Homebrew Computer Club. Cybernetics and visions of human-computer interaction and collaboration connected these communities to the countercultural mission of the back-to-landers. While these experiments in communal living began to fail in the 1970s, the pioneers of networked computing took their place in advancing their vision. Additionally, this vision also included the idea of tools as personal. The early engineers at ARC and Xerox PARC read the *WEC* and were involved in making computing personal. For example, Alan Kay at Xerox PARC, wrote his PhD dissertation on a desktop computer that would be interactive; he envisioned computers as tools for creative and individual expression. He read *WEC* and thought:

> The same way it should be easier to do your own composting, you should have the ability to deal with complicated ideas by making models of them on the computer.' For Kay, and for others at Xerox PARC, the Catalog embodied a do-it-yourself attitude, a vision of technology as a source of individual and collective transformation, and a media format-all of which could be applied to the computers on which they were working (Turner 2006, 112).

Out of this kind of everyday networking between the research parks and the *WEC* office and events that intentionally brought the countercultural and high-technology worlds together. QS draws both explicitly and implicitly on this lineage and tradition of cross-pollination between mainstream technology brands and developers and a countercultural ethos Brand continued to evolve these networks: the *WEC* served as a model for WELL (the Whole Earth 'Lectronic Link)—a teleconferencing system that maintained these networks that Brand created: technologists, journalists, and counterculturists—and the Global Business Network, a small consulting firm. These are just a few of the ventures that Brand launched out of his travels and networks. One of the fruits of these networks was WIRED magazine, which emerged in early 1990s and became a prominent voice of the culture of personal computing as a tool for personal liberation, communication technologies, entrepreneurship and innovation, the computation metaphor for life and the market. Aligning themselves, sometimes with the libertarian zeitgeist of the 1990s (all hallmarks of the New Economy). This mix of personal computing to achieve the goals of counter-culture, coupled with the use of free-market logics to develop these technologies, spawned some surprising bedfellows and some interesting politics. One particularly interesting moment of agonistic convergence occurred when Esther Dyson interviewed Newt Gingrich for the cover story of WIRED magazine (1995). This interview stemmed from an invitation to Dyson to join a conference called "Cyberspace and the American Dream," sponsored by the Progress and Freedom Foundation with the goal to draft a "manifesto" on decentralization and deregulation in relation to the Net. In her preamble to the fascinating interview, Dyson expresses her own surprise at the invitation and the conservative agenda attached to information technologies. Reaching across a seeming political divide, through cybercultural values of freedom and decentralization, Dyson found Gingrich to be both "Friend and Foe."

The libertarian founders of WIRED, Louis Rosetto and Jane Metcalfe, drew from the *Whole Earth* network of thinkers, inventors and writers including Kevin Kelly, who became executive editor. With Kelly, WIRED knit together the libertarian bent of the founders with cybernetic visions computing. According to Turner:

> Kelly turned Wired into a network forum. Within it, writers utilized the computational metaphors and universal rhetoric of cybernetics to depict New Right politicians, telecommunications CEOs, information pundits, and members of GBN, the WELL, and other Whole Earth-connected organizations as a single, leading edge of countercultural revolution. Together, Wired suggested, this digital generation would do what the New Communalists had failed to accomplish: they would tear down hierarchies, undermine the sorts of corporations and

> governments that had spawned them, and, in the hierarchies' place, create a peer-to-peer, collaborative society, interlinked by invisible currents of energy and information (Turner 2006, 209).

WIRED furthered and spread the computational metaphor for life, communication and economy to a wider audience. However, this metaphor was hatched in the post-war government-academic research efforts, seized on by the counterculture by luminaries and social entrepreneurs like Stewart Brand, and disseminated and flourished in the pages of *WIRED* and with the expansion of the internet and communication technologies themselves.

This multi-pronged genealogy of personal computing, cybernetics, and the *Whole Earth Network* is important for our story of the Quantified Self and digital health technologies. First, techniques to make meaning out of personal data (including using it to alter behavior) and the rise of mobile computing (and with it mobile health) are the fruits of cybernetic logics that underpin personal computing, maybe even their apotheosis. Second, QS as a DIY user community was explicitly modeled after the computer hobbyist groups (e.g. the Homebrew Computer Club) that ran with Brand, the *WEC* world, and other Silicon Valley innovators mentioned above. Lastly, Kelly and Gary Wolf, a subsequent writer and editor of *WIRED,* founded Quantified Self, holding the inaugural meeting at Kevin Kelly's studio in Pacifica, CA. Following Brand's moves, Kelly and Wolf wove together (intentionally or not) their own entrepreneurial networking to bring together a part users group and part network of luminaries, some of whom were mentioned above. Kelly has also published a contemporary version of the *Catalog*, called Cool Tools (Kelly 2015)—based off a mailing list and growing website of the same name—that he describes as "things that are helpful and practical for doing things yourself, for learning things yourself or as a small group. They are self-empowerment tools. While there are more than a thousand tools in the book, I'm not suggesting that you buy any of them. I think you should just know about them. This is a book of ideas. It's a book of possibilities (Bilton 2013)." Like the original *WEC*, this book is crowd-sourced and accommodates a wide array of media "tools" including books. Categories include "Homestead", "Autonomous Motion," and "Somatics"— where some self-quantifying gadgets live.

Quantified Self and digital health technologies emerged from these tangled networks of cybernetic and libertarian visions where personalized and mobile computing can, in part, find their socio-technical roots. Again, the folk history of QS points to the rise of personal computing, as Gary Wolf explains, we now think of computers as part of our daily lives rather than as tools for the management of work and science. What this partial explanation leaves out are the historical and social contexts—the mingling of cybernatic visions with countercultural revolution, later resonating with libertarian promises of technology—that have given us the idea of personal computing in the first place. These preconditions do not simply determine the fate or future of personal computing, like a fixed technological script (Akrich 1992; Childerhose and Macdonald 2013), rather they do allow us to understand the some of the constellations of meanings of QS as "personal computing brought all the way in." Those who self quantify draw on and reimagine some of these scripts. Furthermore, Turner showed how seemingly contradictory cultural tropes—cybernetic war-time research and the countercultural revolution—can synergize (to use a term coined by Buckminster Fuller) and find overlapping resonances to alter the trajectory of how information technologies are given social and cultural meaning and use in everyday life. Similarly, QS—by bringing health technologies into its orbit—rescripts technologies of medical expertise, even alienation, into ones that serve cybernetic visions of personal liberation and expansion. Moreover, this engagement with personal data is occurring in a context in which "Big Data" and surveillance politics (in the wake of government surveillance or wire-tapping revelations by whistleblowers like Edward Snowden) are shaping our engagement with networked technologies. As Nafus and Sherman argue, QS can be understood as "soft resistance" to Big Data. Thus, while these sociotechnical legacies inform these technologies, their meanings are extended and put to knew uses in emergent sociopolitical contexts. As I will elaborate further below, personal computing brought all the way in, to the *n of 1*, also renders, through a cybernetic and computational metaphor, the human body and human health as part of an information system. Understanding the cybernetic roots of personal computing as well as its countercultural resonances helps us to understand a parallel appropriation and attempt to redirect the meaning and means of seemingly disciplining technologies of medicine to other, liberatory and somewhat revolutionary ends.

IV. Setting and Methods

> It's nice to hear your story, after we've shared ours.
>
> -Aaron, after my talk at the QS conference, Amsterdam 2014

I *thought* I had entered the field only when I started visiting a mobile health startup in Silicon Valley, or when I interviewed one of the founders of uBiome, a citizen science and microbiome company, or when I downloaded my first tracking app, Moves, or when I walked up to the registration desk at my first QS Conference next to Chris Dancy wearing Google Glass and host of the Mindful Cyborg podcast. Really, the field began and followed me back to my hometown, Buffalo, NY, where my mother was in the Intensive Care Unit in a rundown county hospital, the trauma center for the region. At the beginning of fieldwork, she had an accident, hit her head. No amount of tracking and good "health behavior" could have saved her. Bad luck cannot be optimized away. So, I started fieldwork, spending a month "at home" in the Bay Area, and another month "at home," in the hospital, a place familiar as a medical student but strange as a patient. Anthropologists talk about doing fieldwork "at home" as if home is a straightforward concept. This back and forth, between hospital and Silicon Valley complicated that idea of home and its ethnography. Buffalo is chronically gray, and when the wind is blowing east at the right time off Lake Erie, the city smells of toasting bread—Cheerios toasting at the General Mills factory that is still there.

Buffalo used to be "The Queen City," a boom-town at the turn of the 19th Century. After the steel mills left and the factories moved overseas from the 1970s on, it became another forgotten casualty of American post-industrial, millennial prosperity. Once, a beacon of American industry, art and architecture, Buffalo has at times been one of the poorest cities in the nation. Now, the biggest industry is healthcare. Disease, it seems, is an unlimited national and natural resource. . Silicon Valley[8] is chronically sunny, and can smell like jasmine. Home became a confusing word over those six months of sleeping in childhood rooms, spending days staring at ICU screens or waiting in hospice. In one place, medical technologies were instruments of high-tech and heroic medicine; in another, they were sometimes recreational tools or even toys. In the ICU, the cognitive self that was not there (my comatose mother) was replaced or maybe supplemented with enumerable biometrics. In QS, biometrics seemed to be used in service of a self. Amidst these confusing displacements, I ask: What kinds of subjects and selves

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[8] While "Silicon Valley" used to refer to the South Bay cities, from San Jose to Palo Alto, now you hear it used throughout the wider San Francisco Bay Area as encompassing San Francisco, or where the tech industry has expanded. Now, it refers as much to an imagined space as much as a geographic place.

are produced by domesticating[9] modes of medical (a)ccounting? What kinds of worlds, bodies and versions of health and healthcare—utopian or otherwise—are contained therein? What are the implications of self-quantification—and attendant appeals to self-care—for the experience of health and wellness? What does it mean to take the "digital" in digital health, seriously? That is, what is the digital experience of health and illness? What kind of knowledge and modes of knowledge production (i.e. epistemology) are produced through QS and its particular engagement with expertise?

This dissertation, in many ways, is about American frontiers and horizons. The foil to these horizons of hope and prosperity became, for me, the other "home" that constituted my field site: a depressed county hospital in the depressed post-industrial town of Buffalo, NY. Outside the hospital, houses crumbled, ever other one boarded up—Buffalo has always suffered from an epidemic of eyesore buildings—former homes and corporate headquarters that could not be missed if you took Main street downtown. Inside, a shell of a shabby building contained the latest in medical technology, a high-technology ICU with digital monitors, digital health records, and digital medicine machines. The contrasts were haunting and dystopic. I did not appreciate it at the time, but this place was as much part of my field site as the utopian frontier visions of health and hype that animate the Quantified Self movement and digital health technology scenes in Silicon Valley. Like in Buffalo, the dystopian threats (or constant surveillance, perfectionism, technocracy) that haunted the utopian fields of digital optimization and personal transcendence through technology. The Rust Belt and Silicon Valley, probably for the first time, share ethnographic space in my travels and experiences of them. Strangely, both of these place and imaginaries make up America. The remainder of this dissertation will take place on the utopian

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[9] I take the idea of domesticated medical technologies from both .

horizons, but my impressions of them remain anchored by a different experience of medicine, health, death, and dystopian alongside utopian technoscapes (Escobar 1994; Suchman 2011).

Against this backdrop, my time in the field was focused around three area of empirical and analytical interest: 1) the Quantified Self movement, 2) the Digital and Mobile Health industry and ecosystem, and 3) the Participatory Medicine and e-Patient movements, where the "e" stands for engaged or empowered or electronic. Across these sites, I asked: How do people relate to their data, gained meaning from it? How is the generation of personal data altering the way we understand and experience health and illness? How is self-quantification challenging and shaping medical and clinical epistemology, or ways of determining what is true about disease and its treatment? How does personally generated data enable relationships to medical knowledge and power that are both new and challenging to medical authority, on the one hand, but also extensions of that knowledge and authority as well? What kinds of subjects emerge from self-quantification and self-care?

By locating my research across these diverse sites, I was able to discover the connections between these worlds—both in terms of their values and visions of the future of medicine and the actual networks of people that traveled between them. For example, while the Quantified Self movement first seemed and presents itself as a user group, often on the fringes, or the vanguard, I was surprised to find that the practices—like life-logging or self-experimentation—that seemed extreme, were being translated from that community into clinic through scalable digital health technologies, for example. Similarly, self-tracking technologies and techniques—around, say exercise or mood—were becoming incorporated into the academic research enterprise, through studies like the Health eHeart, called the "digital Framingham." Further, self-tracking as self care cuts across this research effort, the QS community and the movement for "Participatory

Medicine," which demands that patients have an active role in their healthcare, including meaningfully contributing to and having access to their data. "Give me my damn data!" is a clarion heard across these sites. Drawing on observations and the interconnections, I found that a new kind of experimental- and patient-subject are emerging--*Homo experimentus*—embodying the drives for continuous innovation, experimentation, and even personal transcendence through data.

A. Quantified Self Movement

During my time in the field, I regularly attended the meet-ups in the San Francisco Bay Area: QS Silicon Valley, QS San Francisco, QS Bay Area, and QS XX (for women). I also attended the QS Global Conference in San Francisco in October 2013 and Quantified Self European Union (QSEU) in May 2014. In addition to observing and attending, I also was an active participant in the community. I began my own self-tracking project that resulted in three presentations, or "show and tell talks" the first as the opening plenary at QSEU in Amsterdam, and two others at local meet-ups (QS Silicon Valley and QSXX). Additionally, I led a breakout session in Amsterdam on grief, death and self-tracking. I also conducted interviews with individuals currently and formerly associated with the QS community, including some who were at the original meet-up and subsequently went on to start their own meet-ups.

Entrée into the Field

The question of just what kind of subject is produced by self-tracking and self-quantifying was given a radically different meaning when, at the start of my fieldwork, my mother experienced a devastating and, ultimately, fatal accident, that had me tacking between the Intensive Care Unit and Quantified Self, a strange juxtaposition that I touch on in later chapters. I experienced QS while in grief and I experienced grief through QS. On one level, I began to experience my mother through her embodiment through numbers—the continuous streams of biometrics that tracked her in the ICU. On another, I learned from those in QS who track unusual to see my experiences in grief through the techniques of tracking and logging life and memories. After 6 months in hospital and then in hospice she passed, I had started to track my memories of my mother in my daily life: I logged in a spreadsheet on my iPhone where she showed up in my writing, my work, and my daily life. You could say it was memorializing or grief, tracked in "real time."

When I shared this experiment with Ernesto, he asked me to present it at the Amsterdam conference in May of 2014. It may seem strange that this kind of logging—or micro-journaling, as I sometimes experienced it—would fall under the activities of QS. However, as I alluded to above, the QS community is filled with all kinds of people, including artists and social scientists, who are sparking a conversation around what is possible with "personal computing all the way in" (Wolf). I was reluctant at first to present; the log is hardly quantitative. I was also worried that my efforts would be misconstrued as "optimizing" grief. Most mood tracking is focused, eventually, on maximizing happiness, after all. From my vantage point, happiness looked foolish, even absurd. Rather than tracking the grief away, I logged it to invite my mother into my daily life, however painful it was. In some ways, the tracking, however small, enabled me to move forward with a project that worked with people who were charting hope- and hype-filled horizons just as my own personal tragedy created a personal life-world where those same frontiers seemed to implode. My mother did not suffer an illness that invited experimentation or therapy. Instead, she had been exceedingly healthy, as avid exerciser and health nut, not dissimilar from many people I encountered in QS. There, data is the gateway to forms of self-understanding and often, self-control. Rather, her fall and subsequent complicated hospital stay was a constant, bitter reminder of the random precarity of life.

With this ambivalence, I decided to give one of the open plenary talks in the Amsterdam conference, followed by a breakout session on death and digital life. Some at the conference were puzzled by my project—was it really QS? Others suggested that I turn this into an app for other people grieving, or that I become a grief activist. Most touching were those in the audience who shared with me their stories of loss. My talk reminded them of their experience of grief, some long ago, some ongoing. I was asked to present on this project at least three more times at local, Bay Area QS meet-up groups.

I was coached on the story and the presentation by Karen Herzog, an organizer of QS Silicon Valley and someone who became a "key informant" but more importantly a friend. She came to QS and the e-patient movement (more on this below) through caring for and losing her daughter, Sophia, as a toddler to a devastating genetic disease, Niemann Pick Type A. She cared for daughter at home creating what she later termed "healing in community."[10] I tracked just to find something to get me through, somehow connect what felt like two disparate worlds: quantified self and devastating, unexplainable loss. We both tracked out of grief. Between coaching and interviewing, we shared meals, time, and memories at and near her Palo Alto home, which was filled with or traces of her daughter. Karen was also an avid collector of artifacts and antiques, in addition to data. We also spent time together collecting and reflecting on collecting.

Thus, we both came to self-quantification and what it meant to "show and tell" from a place of deep vulnerability. We began to help develop my talk in our almost weekly meetings at

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[10] Sophia's Garden Foundation came out of her life. www.sophiasgarden.org

a café in Palo Alto, our "office hours." Through her coaching, I learned that Karen's unique talents, as a QS leader and an e-Patient, were in her ability to tell a story. As a QS talk coach, she would take the mess of slides and data and information overload that QS speakers had, and helped them strip it down, simplify it, and craft a narrative. When looking at that data and that person as a coach, she was always asking, "what's this about?" For me, she gave me the courage to talk about something so personal, helping me find the ways to deliver the story in a way that enabled connected with the audience. The "data" was almost beside the point. She spent time listening to me practice, getting through the tough parts without breaking down, on the one hand, or dissociating completely, on the other. Her coaching of me also involved choosing just the right images, for example of the small Hungarian, Herend porcelain figurines my mother collected for me. Karen taught me that tracking and self-quantification was like collecting objects, heirlooms, tokens or fetish objects of our selves or loved ones.

I gave this presentation eight months into my fieldwork (from August 2013 to September 2014), and it opened up the community of QS in ways that I could not experience before. As cliché as it seems, the talk was an initiation into a kind and corner of QS where tracking means exposing the underbelly of the everyday, offering granularity to experience, turning the stuff of life into something that can shared and reflected, that is, in the QS idiom, into data. Or, as Brad put it, Gary and Ernesto brought my talk in to demonstrate "how this stuff touches on the drama of human life.…If you don't get primed with the personal part, it's easy for the conference to become just another tech conference." My presentation along with others were encouraged and highlighted by design, to set continually frame QS—as a community and conference—as about personal stories, tempered against the growing technology piece. Again, though, this distinction gets muddled, as the technologies themselves—from life-loggers to direct-to-consumer diagnostics—traffic in this attachment to the personal and personalizable as part of what they sell.

My own tracking was, in a way, bringing the technology and my smart phone (the most personal of computers) to bear on a very human experience of loss and grief, augmenting it, expanding it, rendering it into my own kind of maternal memex. However, I engaged with QS and loss in very ambivalent ways, from the ICU as a place where extreme quantification felt alienating to my own tracking of a person who was not there. In other words, I participated in QS to intervene on it, as well, to describe a kind of tracking with an expanded, or perhaps more anthropological "dividualistic" understanding of the self (Smith 2012). This was welcomed in the big tent, as part of cultivating the sense of new frontiers for tracking as well as the DIY nature that tracking can take. My personal experiences of grief through tracking and fieldwork run in the background of this dissertation. At various points in this dissertation, I engage with that experience directly, when it serves the argument I am making about numbers, data and selves.

At one of the last QS meet-ups I attended, I had been asked to present my talk. I declined, a bit fatigued from sharing too much—I had presented the talk at QS Silicon Valley and less formally at QS XX. After the talks, Gary lamented that they had been culturally one-note, tending towards the optimization side of QS, and were presented by all men who were striving to be better, stronger, faster through numbers. One presentation was about improving memory through flashcard technique. Another was about figuring out a benign bowel problem. Keeping the group interesting, for them, means expanding the boundaries of what can be learned and done to make computing personal and personally meaningful. There seems to be a desire to capture that magic, that elusive coolness and potential energy that charged the air at those early meetings. As self-tracking devices and their ethos of quantification become more ubiquitous—I met many people in my everyday life who wore a FitBit but had never heard of the Quantified Self movement—the QS movement as a users community, driven by its directors, strives to stay on that leading edge, generating possibility, wonder, and sometimes weirdness.

The QS community is both about understanding the marginal and the mainstream: what can be learned about a group that is seen as exceptional, out of the ordinary, as it pertains to general health or even medicine? To begin, the Quantified Self—as movement or community of interlocutors—is a place, though, for self-proclaimed "weirdos." However, their tools and techniques articulate with other networks and toolmakers who aim to change general health and healthcare through digital health technologies and patient advocacy. I follow those articulations, connections across communities, and I take the marginal, vanguard and innovation as objects for anthropological analysis themselves.

B. The Digital and Mobile Health "Ecosystem"

One of the mainstream counterparts or counterpoints to QS is the emerging industry of digital and mobile health technologies, where information technologies (especially using mobile, networked devices such as a smartphone) are leveraged to change the way illnesses are tracked and cared for. My fieldwork involved experiencing and observing very diverse sites where digital health technologies are being created, discussed, and implemented. During my time in the field (and still) digital health technologies—especially those that encourage people to collect their own data for later clinical use—are in very early stages of development. Beyond the ubiquitous activity trackers—bracelets such as the FitBit or the Jawbone—digital health and personal data techniques place in the clinic is yet to be determined. To study this emergent phenomenon, I went to the sites where these technologies are in early phases of development, such as startups, digital health incubators, and digital health conferences (of which there are many). During my year in the field, I spent significant time in: a) a small mobile health startup; b) a coaching practice, where coaches reflected on personally collected data with people tracking illness or fitness; c) a user group for a digital health device (a breath and stress tracker) that spun out of a prominent digital health business incubator, coming to market during my time in the field; d) the following digital health conferences that blended discussion of research with a trade show: Health Datapalooza, Stanford Medicine X, and the Robert Wood Johnson Foundation listening tour "Data for Health". In addition to observing at these sites, I interviewed entrepreneurs who are creating these new technologies, services, and websites to help people gather, access, and make sense of their personal data.

C. Participatory Medicine and Participatory Research

Additionally, I was a participant observer in aspects of the movements for "Participatory Medicine" and "Participatory Research." The former, led by people who call themselves "e-patients," where the "e" is expansive and flexible: it can stand for empowered, engaged, or electronic, since part of the movement is about using the tools of the internet and information technologies to empower patients. I joined the Society for Participatory Medicine (SPM), which hosts active and lively discussions on their listserv and website. The community of e-patients is also integral Stanford Medicine X (MedX), which focuses on the use of health technology to drive patient-centered care. E-patients are part inspirational speakers, social entrepreneurs, and patient advocates and activist. They host seminars and give TED-like talks at MedX as "E-Patient Scholars." Through SPM and MedX, I met and interviewed e-patients, some of whom also participated in Quantified Self and Digital Health communities as entrepreneurs. Lastly, I actively participated in an innovative effort to redesign health research so that it is participatory as well, involving patients in asking and answering research questions that come from their own concerns and experiences. The Health eHeart Study—a digital health cohort study that aims to collect personal health data through participants wearable and digital devices—is funded by the Patient Centered Outcomes Research Institute (PCORI) to create a model for doing such "Patient-Powered Research." To begin, I enrolled in Health eHeart, filling out surveys online and connecting my digital health device data to their research servers via the internet: my FitBit activity tracker, iHealth wireless scale, Qardio digital blood pressure cuff, mood tracking applications on my smartphone such as Ginger.io, and my AliveCor, a single-lead EKG that is built into an iPhone case. During my fieldwork, I observed this design committee made up of mostly patients with heart conditions (from congenial heart disease to atrial fibrillation), a Health eHeart Principle Investigator, and partners from the American Heart Association. Their goal is to creat the Health eHeart Alliance, which will facilitate the patient-driven arm of Health eHeart. Beyond observation, I participated in research design sessions with patients and continue to sit on a research team led by patients.I did field work by spending most of my time in the Quantified Self movement—attending and participating in the Bay Area meet-ups, which met from Berkeley to San Francisco to Silicon Valley; mining the extensive show and tell talk video archive online; attending and participating in the global conferences in San Francisco, in October 2013, and Amsterdam in May 2014; interviewing and spending time with self-trackers and organizers in QS. I explored the emerging mobile and digital health industries by observing a mobile health startup for a short period of time; participating and observing a digital health study at UCSF in the process of designing a PCORI (Patient Centered Outcomes Research Institute)-funded participatory research network that brought patients into the research process; attending three major health technology and innovation conferences—the Mobile Health Summit (December 2013), Health Datapalooza (June 2014), and Stanford MedicineX (September 2014)—; and interviewing entrepreneurs creating mobile and digital health companies that engage with personal health data. These conferences are crucial sites where research and policy on digital health sit side by side with startup pitches. Hype and hope abound. Lastly, I observed and participated in communities of patient advocates, including the Society for Participatory Medicine and the "e-Patient" movement, anchored at Stanford Medicine X. The internet was also a fruitful space for exploration, where patient advocates and digital health innovators gather on blogs, webcasts and for social media gatherings, from virtual conferences and class to twitter chats.

V. Situating the work:

Arturo Escobar, in his article "Welcome to Cyberia" (1994), outlines an anthropology of cyberculture that accounts for rise of new information technologies and biotechnologies. At that time of articulating an approach to cyberculture, the concept of biotechnology was largely limited to molecular biology, genetics and genomics as sites for imagining biology in the mode of information and open to reengineering. With quantified self and the rise of digital technologies, we can imagine biotechnology as expanding to encompass other ways of rendering biology into instrumentalized information. Although not generally used in this way—digital health and biotech are considered different industries, the former related to computers and health IT, the latter to molecular biology—I think its useful to think of digital health technologies and self-quantification alongside biotechnologies for the purpose of seeing how they share a computational metaphor for life. My approach the quantified self and digital health technologies is grounded in three general areas of analytical interest: 1) biomedicine and technologies of the self, 2) anthropology of science and technology, and 3) anthropology of innovation, computation and the future. Out of this work, I take up Lucy Suchman's appeal for an "anthropology of innovation" (Suchman 2011; Suchman and Bishop 2000). I'm interested in not just innovations in technology as subject matter, but what it's like to *live* innovation. *Homo experimentus* is my attempt to name QS as entrepreneurial life "all the way in."

A. Towards a Micro (Bio)economics: or, high-definition biopolitics

I use the term *Homo experimentus* to name a form of subjectivity and practices that come out of changes in epistemics of biomedical care and self-care. *Homo experimentus* elaborates on and plays with *Homo economicus*, the idea that humans are essentially self-maximizing rational actors, and in the neoliberal context, endlessly flexible (C. Gordon 1991; Martin 1995; Sahlins 1977). *Homo experimentus* recalls Natasha Schull's (2006) *Homo addictus*, which is a similarly networked subject, tethered to technologies and systems that invite self-modulation from within and without in the mode or idiom of addiction. "Habits", "habit design", and "behavior change" are often invoked with digital and mobile health technologies. Using cell phones or tracking technologies to reinforce habits through information "feedback loops," to retrain the mind and body indeed conjures a cybernetic *Homo addictus.* I use *Homo experimentus* to describe a kin species to both *H. addictus* and *H. economicus* where these kinds of feedback loops occur in the context of personal data collection and along what I later call experimental horizons. Lastly*,* the term points to the ways QS and personal data are read as more "human" forms of computing.

While the individual body is the locus of biopolitical practice, regimes of calculation render the individual legible insofar as they contribute to a larger *n*, the population. While the drive to self-care through self-tracking may promote biopolitical (Foucault 2004; Foucault 1978) values of enacting healthy citizenship, the epistemological apparatus takes a slightly different form. Rather, in QS, I will argue, the regime of self-numeration (where quantifying, tracking, and making data relevant occurs at a different scale), the individual is statistically legible in her own right, resetting the source of expertise. The *n of 1* is a rallying cry for a new political epistemology of the body that recasts traditional biopolitical values of healthy consumption, citizenship and belonging (Rabinow 1996; Rose and Novas 2006), with the neoliberal values of self-care, enterprise, and introspection on the other (Rose 1998; Rose 2007). Following, Deleuze (1992) and others (Poster 1990), I observe shifts from discipline to modulation and control as the subject is refracted through digital technologies and the ongoing tracking they enable. Further, these technologies participate in emerging forms of biosociality (Rabinow 1996), where novel social affiliations take shape as individuals associate as a "user group", seeking "self-knowledge through numbers." Finally, my analysis Quantified Self draws on and extends Foucaultian analytics of "care of the self" and "technologies of the self," where knowledge is gained through mutated form of medical authority (Foucault 2001). Paying close attention to logics of self-care (Mol 2008), we observe how well known neoliberal biopolitical subjects are making new forms of expertise, health and care.

I also situate my work in relation to the study of authority and power in medicine (Conrad 1992; D. Gordon 1988; Illich 2010; Taussig 1980a) and biomedicalization (Clarke et al. 2003). To begin, self-caring and self-quantifying subjects challenge may provide an instance of the ultimate biomedicalization of everyday life, or the extension of the clinical gaze into even more aspects of life. However, these technologies and techniques offer, I argue, a more complicated relationship to medical knowledge, attempting to short-circuit it, remaking epistemologies and the affective politics of epistemology (Murphy 2012). Secondly, the change of scale entails a change in epistemologies and medical values. The digitally engaged patient-activist demands legibility as a producer of valid knowledge through personally generated data. Like Murphy and Epstein on activists in science, my work similarly understands QS as intervening on the politics of science and medicine, a phenomenon that goes beyond an analysis that considers biomedicalization alone.

Studies of medical subjectivity as they relate to developing science and technology also provide an important reference point for my analysis. The quantified self, as introduced above, provides another instantiation of the cybernetic subject, a subject described and analyzed in varying, late 20th and early 21st century contexts, such as immunological discourse (Martin 1995), addiction (Schüll 2012; Schüll 2006). In particular, this subject resonates with economic formations of the time, providing, in Emily Martin's work, the flexible body. Like Martin, I take the technoscientific engagements with body as a starting point for understanding wider socio-cultural and economic contexts. My work takes a similar approach: describing a subject—*Homo experimentus*—and set of reflexive orientations that emerge across domains, technologies of the self, practices of work, care, and emergent epistemologies of science and medicine.

B. Anthropology of Science, Technology, Biomedicine:

As an anthropological study of techno-scientific things and practice, this dissertation follows anthropologists of science and technology who extend the study of technoscience beyond the lab (Martin 1998; Latour 1999; Callon 1986). I am interested in how science works—its social conditions, and epistemology. My work understands technoscience as an enterprise that happens outside the traditional bounds of a research lab or formal research program, or outside the "citadel" (Martin 1998). My work is also informed by feminist science studies and anthropology of the cyborg, which challenge the traditional divisions between the human and the technological and insist that knowledge is “situated” and produce out of particularity and that marginal other create alternative epistemologies (Murphy 2012; Haraway 1991a). This dissertation is also grounded in science and technology studies of experimentation and experimental lives . Again, I follow experiment and experimental lives as they exceed the bounds of the laboratory or a community of scientists, understood in the traditional sense.

My understanding of *Homo experimentus*, is aided by those who analyze new practices of technomedicine as altering definitions and experiences of health and illness. Specifically Joseph Dumit (2012a) and Jeremy Greene (2008) examine how thresholds and understandings of health and illness shift with new pharmaceutical technologies. In the former, the normal is redefined as medicated, or “drugs for life.” Similarly, I am interested in the ways that by privileging data and the granularity human health and experience, the normal and the pathological are reoriented and redefined, through shifts in scale and epistemologies. Following Michelle Murphy (2012) and Steven Epstein (1996; 2007), I am interested in the ways that this epistemic innovation comes from a combination of activists, patient advocates, and an emerging digital health industry which seeks to redefine healthcare and the role of big, personal data in defining the norm.

Finally, my work also builds on our growing understanding of the impacts of health information technologies on clinical practice and clinical norms (Forsythe 1996; Mol 2008; Pine 2011), which are also given new, unscripted meaning through use (Childerhose and Macdonald 2013). As health information technologies are getting personal and mobile, they need to be understood also as an extension and innovation on personal computation, joining other work on computers in daily life (Rushkoff 2013; Boyd 2014; Turkle 2011).

C. Anthropologies of Innovation

Lastly, as an emergent and emerging phenomenon, to get a handle on self-quantification and the promise of precision "high-definition" medicine, I look to anthropological studies of utopian imaginaries, temporalities, and various "scapes"—techno-, media-, and otherwise(Escobar 1994). The Quantified Self movement self-consciously unfolds along a frontier—technological, epistemological, and social—framing its goals and practices as experimenting and tinkering with the seemingly infinite ways data can get personal and plentiful. The digital and mobile health industries are indulging in the kinds of hope and hype around data that also have animated genomics enterprises (Sunder Rajan 2006; Sunder Rajan 2005). The frontier, argues Anna Tsing (2005) remakes objects as well as subjects: "It is a space of desire: it calls; it appears to create its own demands; once it is glimpsed, one cannot but explore and exploit it further" (p.32). Like the ecological or geographic frontier, startups and individuals alike organize personal health data (infinitely divisible) as a natural resource. For some, it is a resource to be kept private, unexploited, for others it is to be shared and mined.

QS's origin point of Silicon Valley and the Bay Area requires that we contend with the regions self-told story of innovation, futurism, and counterculture (touched on above). In my field site, innovation and newness are actively cultivated in the affective curation of conferences and QS social gatherings. The new and "innovative" are held up as unequivocally good. Following Suchman, I want to understand "what insights we might gain by shifting questions of innovation, creativity, and the new from their status as unexamined qualities, to constitutive moments in the reproduction of familiar modes of identification and action within particular locales and imaginaries" (2011). Silicon Valley and cyberspace are very particular where QS and digital health technologies take particular shape. Built into digital health is an insistence on personal innovation—behavior change, personal optimization—and sometimes it is continuous. An ideal towards continuous improvement in health and healthcare, serves a view of the subject as particularly amenable to personal innovation—akin to Martin's flexibility—and modulation through data. Here, the valorization of innovation tells us about more than just the neoliberalization of biopolitics (it is partly that); it also tells about the demands of living life in the computational metaphor, legible and amenable through data, as a flexible and discoverable *Homo experimentus*.

VI. Layout of Chapters

In the first chapter, *Deep Data*, I begin with a discussion of a central tent of the QS community, the idea of the *n of 1*. The *n of 1*, which refers to a sample size of one (the self-experiment) offers a view into the kinds of selves produced by personal data. Second, I turn to one of the strong manifestations of tracking, what I call the well role, the corner of QS preoccupied with habit design and behavior change for optimized life, work and health.

In Chapter three, I discuss the intersection of QS wellness, with participatory medicine and emerging forms of patient activism around data. In Chapter four, I talk about a kind of subjectivity immanent throughout these articulations of self in quantification, *Homo experimentus*. Finally, in the epilogue, I return to Karen's story to contemplate tracking and QS in relation to futurism, affect, and temporality in an age of innovation.

Chapter 2. Deep Data: Notes on the *n of 1*

I. Intro: Enter Intensive Surveillance Unit

This chapter addresses the implications of self-quantification in its relation to clinical quantification. By self-quantification, I mean those practices of keeping track of aspects of ones life, activity, or body. Some track actively, using a pen and paper, others with a custom made spreadsheet. Other devices such as digital scales or home blood pressure cuffs connect actively tracked data to a cloud server. Wearable devices, such as the Fitbit® or a BodyMedia® armband, or even smart phone applications such as Moves, enable continuous, ambient data collection (e.g. step count or heart rate). The complex and entangled relationship between medical and QS modes of accounting[11] are not yet well understood. In what follows, I explore these trends in conversation with more traditional biomedical modes of accounting and quantification. I will then turn to the *n of 1*, a central tenet and practice of Quantified Self (QS). The *n of 1* is where QS begins. While this chapter will introduce the *n of 1*, this concept will emerge in further chapters, too. Borrowing from scientific discourse, where the *n* signifies the number of participants in an experimental study, the *n of 1* suggests that knowledge can be gained at the scale of the individual. The *n of 1* rejects the requirements of large numbers of subjects for statistical validity and expert credentials, forging a new epistemology of health and being where the single case or person collecting data over a lifetime displace the population as locus for knowledge and intervention. The *n of 1* unites the diverse QS community and collective,

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[11] Whitney Erin Boesel has made a useful distinction between "little" qs and "big" QS - the former being the tracking that people engage in (by buying a fitness tracker or being tracked by their phone, for example) without explicitly claiming ties to the Quantified Self community or movement. "Big" QS is the latter. I mostly deal with the latter, although reference tools that are used in a "little" qs way.

including the mood and productivity trackers, the bio-and health-hackers, and the life loggers and personal data artists.

Diverse practices and goals all start with the idea that the *n of 1* can and (maybe) must be asserted as the starting point for self-understanding, -expression or -improvement. Providing a common ground for practice, the *n of 1* does different things for different people. Exploring the heterogeneity of *n of 1*, we can begin to understand how self-quantification entails a complex relationship to biomedical representation - from one that mimics and extends the gaze to another that undermines. In other words, the *n of 1* asserts itself as having legitimate access to self-knowledge and self-care, presumably unmediated by claims to expertise. How might the *n of 1* reproduce, undermine, or relate to critiques of disciplining and displacing practices of biomedical technologies (Foucault 2004)? What are the convergences and departures between the fog of data produced around my mother in the ICU and the instruments that enliven QS?

In what follows, I address the implications of QS as forming what I call *paraclinical* practice to describe what happens when clinical tools are redefined through their domestication. I take the *n of 1* as an experimental system[12] where new possibilities for the meaning and experience of health and illness ramify in surprising ways. Next, I describe extant and overlapping practices of medical knowledge production, against which the *n of 1* both wittingly and unwittingly casts itself. Last, I consider the poly-vocal nature of the *n of 1* and what we might learn from it, as a space to rethink care and the clinical.

My analysis is based on fieldwork that was not restricted to QS as a community. I spent time at health technology conferences, with entrepreneurs, an mhealth start up, a clinical tracking

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[12] Throughout this essay, I often draw on the analytical lenses of the epistemologist and historian of science Hans-Jörg Rheinberger (1997). His work analyzes the iterative processes of experimentation and experimental systems, how new questions are formulated, discoveries revealed.

practice, and I continue to observe a large-scale dhealth research project in its attempt to innovate participatory research. What connects these diverse spaces and initiatives is that they are assorted experiments in health and care. Here the stakes of a healthcare crisis (rising costs, chronic disease) are affixed to the ongoing management of wellness through behavior change. Health and care are not fixed concepts or achievements - rather, they are contested. The people and projects I encountered are in part a *response* to crises in health care. They participate in aspirational projects for what health and care might look like. Accordingly, they are also utopian projects, where, for example, health behaviors can be changed, medical mysteries can be solved, and self-knowledge, -mindfulness and -awareness can be achieved.

II. Medicine Inside-Out

> You can't stop it. You can complain all you want, but you can't stop people from trying to make decisions and from trying to engage. … So, I have an AliveCor[13] and I told [the doctors] that. I ask for every copy of every interrogation of my implantable device and put that stuff up online and I ask for the insights and points of view of others who are laymen, a lot of times, and we're all sharing this stuff and talking about it, even though we may not be qualified to speak about this stuff. We're collecting [data].… It's like the Aikido effect - when you use the energy of your enemy. … The idea is that you can't stop progress. Digital health devices will continue to appear. Will continue to create and figure out health platforms. We're going to continue to take [medicine] apart and decentralize control.

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[13] A single lead electrocardiogram (EKG) built into a portable iphone case. See http://www.alivecor.com/home

e-Patient Jaime Campos, on a recent trip to a cardiology conference (Interview, 2014)

Jaime is famous in the e-Patient movement for his ongoing quest for direct access to the data from his implanted cardio-defibrillator (ICD), a device that shocks his heart when it gets into a dangerous rhythm. For now, he has to visit his physician for any of the data collected by his implant. In addition to taking medications to keep his heart from jumping gears, he has tried to collect as much data as he can, using spreadsheets, an AliveCor® phone case, and a sleep tracker to get a handle on general health as well as dietary or behavioral triggers that send him into atrial fibrillation, for example. His own experiments and data gathering have led him to give up his occasional scotch or wine with dinner and question his caffeine intake, for instance. Showing me some of this data on his phone - in spreadsheets and EKG graphs - he lamented that these simple consumer devices were mere workarounds: “I have the ultimate class 3 implant medical device with high-fidelity data that is of clinical quality in me. It's ridiculous that I can't tap it, that I have to rely on these stupid little things that I have to move to my arm! The device knows when I go to sleep. The device knows my heart rate at every moment.” MedTronic has little yielded in his effort to secure the data. Jaime wages smaller battles now: refusing to allow remote monitoring by his physicians if he cannot access the data, asserting his participation in all clinical encounters, sharing his message on social media and at conferences as a patient-advocate, and seeking out electrophysiologists whose views are in line with his values of engagement and transparency.

Jaime’s ongoing collection of data from quasi-clinical tools is just one example of paraclinical practice: the self-tracking of biometrics, behaviors, symptoms to borrow the tools or metrics of medicine, working alongside and even in opposition to formal medical practice.

Paraclinical processes reproduce the clinic and its optics with a difference, as a departure. The *para* use of clinical techniques (an EKG, here) opens an adjacent space for producing new engagements with self-care and access to medical knowledge and data. The paraclinical sets the ground for the *n of 1*, operationalizing everyday experiences as sites for exploration and experimentation.

The paraclinical[14] is slightly distinct from the concept of biomedicalization, which is an extension of medicine to other human affairs (Clarke et al. 2003). Self-tracking can be a grafting of medical tools for personal means. Clinical techniques - from direct-to-consumer laboratory tests or "recreational" genomics[15], to domesticated[16] EKGs or heart rate monitors - open to varied possibilities, from supplementation to subversion of medical authority. Instead of seeing the use of digital health technologies as the biomedicalization of everyday life, understanding them as part of paraclinical practice we see how recreating, appropriating, or grafting[17] tools of the clinical space enables continuities and ruptures in epistemologies. More than the domestication of clinical technologies, the creation of spreadsheets or graphs overlap with clinical renderings of personal and bodily experience.[18] These traces (Rheinberger 1997),

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[14] The paraclinical also borrows by the "para-ethnographic." Developed by anthropologists Douglas Holmes and George Marcus (2008), the para-ethnographic addresses contemporary ethnography of expert communities.

[15] Analysts of DTC genomics examine how glossing these products as "recreational" distracts from and elides their complex clinical and personal medical meanings for users (Bolnick et al. 2007).

[16] On the domestication of on particular clinical technology, the pregnancy test, see (Childerhose and Macdonald 2013).

[17] I take this term from Rheinberger (1997) who uses Derrida's use of this term to understand how experimental systems generate new knowledge through repetition, differences and displacement. I think of the paraclinical and QS *n of 1* as a kind of experimental system.

[18] Earliest uses of graphs in American clinical medicine, began appearing in early 20th century, and accompanied not availability of technology but a change in practice where tests were transformed into monitoring devices, and encouraged by the proliferation of the earliest forms of health information technology: standardized forms.

potentially extend the logics of the clinic (e.g. remote monitoring). However, they also make an opening - as personal data for personal use - for reframing clinical questions and goals. The paraclinical, then, does not indicate that the clinic has necessarily or merely taken over the home, invaded it with its techniques or logics of pathology and risk.

What difference does the *para* make? The paraclinical hails a different kind of subject. Similar to a medical injunction to compliance (Whitmarsh 2013; Dumit 2010), QS as a paraclinical activity invites the subject to turn inward, becoming both subject and object of their own data-driven inquiry. This process where the tools of subjectivation (Foucault 1986) (e.g. blood pressure cuffs, blood assays), are extrapolated from the clinic and are used for purposes outside of it. By taking up its tools, but not its claims to expertise, this is medicine turned inside out. Part self-help community, part user and maker group, part data politics agitators (Boesel 2013), QS creates a community where members can reformulate the epistemic cultures of medicine and care.

III. Getting the Numbers

Gathering quantified information has long been part of good clinical practice. “Getting the numbers,” as it is called on the wards, in a contemporary clinical setting is part of using what Michel Foucault famously called “the clinical gaze” (1973). The clinic, he argued, enabled medical modes of perception and assessment to isolate disease in the depths of a individual body, apart from the context of familial and social life. Initially, a new science of pathological anatomy provided the gaze with its perceptive depth, revealing disease below the surface. The need to probe deeper, to isolate the seat of pathology, has manifested in the further development of diagnostic tools and devices from the x-ray to the blood pressure cuff (Ostherr 2013; Saunders 2010; Dumit 2003). Monitoring and quantifying in the hospital extend this gaze. In the hands of self-quantifiers - some non-patients - these tools borrow but also depart from biomedical modes of quantified care, to which I now turn.

Self-quantification usually entails personal monitoring of symptoms or biometrics in ways the recall continuous or serial monitoring in the hospital. However, it was not until the early 20th Century when clinical tools were used to monitor, rather than diagnose. This shift in the use of data began with the rise of the patient-centric chart and the laboratory (Howell 1995; Berg 2004). The chart centralized clinical communication in an increasingly complex hospital, encasing the patient as an individual, data-intensive subject as well as an object of standardized documentation and treatment (S. Timmermans and Berg 1997; Berg 2004). Embodying the patient through diagnostic results and systematic notes, the chart and its data manifested Foucualt's deep structure in actual clinical practice (Howell 1995). The patient's record and the graphs that began to pepper it, were early modes of health data as "epistemic things" (Rheinberger 1997), vehicles for making new medical knowledge. More than an epistemic tool, the organization of the patient data into Subjective and Objective categories served to disavow the patient's claim to authority. Michael Taussig (1980b) famously argued that such splicing alienated a patient from their own experience of illness, rendering them under clinical control. The politics of epistemic things matter for those who self-quantify, whose self-collected data flout such divisions.

Like clinical quantification, self-quantification may be viewed as an extension of risk and surveillance-based medicine, biomedicalizing daily life (Clarke et al. 2003). Though, as I understand it and argue here, emerging forms of personal data and self-quantification are exceeding our understandings of biomedicalization, requiring that we reformulate our analytical tools to understand the intersections of (para)clinical optics and every day life. Getting ones own numbers - managing a daily blood pressure or activity level - means experiencing and minding individualized notions of risk (Castel 1991; Beck 1992; Gifford 1986; Armstrong 1995), rendering ostensibly health people into patients-in-waiting (Greene 2008; Dumit 2012a; Sunder Rajan 2006; Dumit 2012b). No longer a binary, disease becomes distributed in a prodromal way, throughout the life course. This experience of vigilant risk is reinforced by pharmaceutical treatment practices where shifting thresholds for treatment - “prescribing by numbers” (Greene 2008) - further cloud wellness with risk. Many QS tools mobilize a risk-y gaze, keeping an eye on the horizon for disease. This can be part of a biopolitics where the individual is enjoined in self-care and discipline according to biomedical standards (Rose 2007; Petersen and Lupton 1996). However, self-tracking might be better understood not as classically disciplinary, but as forms of modulation and control (G Deleuze 1992). As an ongoing, unfolding project of monitoring, data becomes an epistemic thing (Rheinberger 1997), where through its accumulation and repetition, differences and deviations can be recognized and managed. These tactics are not a straightforward internalization of subjective possibilities given in discourse. Rather, they are unfolding of creating the self in relation to recordable, quantifiable data about the self. Perhaps what is internalized as a normative subject, though, is the need for modulation and continuous reflection.

Finally, the *n of 1* casts itself against Evidence Based Medicine (EBM) as another aspect of contemporary biomedicine. Having formally emerged in the 1990s, EBM spawned from the desire to reign in costs,, hospital standardization movements, and a deeper paradigm shift from practicing medicine as an art to a clinical science (Stefan Timmermans and Berg 2003; Berg 1995). The hierarchy of evidence in EBM prioritizes large, experimental studies, while individual and non-experimental knowledge recedes to the background. Guidelines are then developed from meta-analyses to apply the evidence to patients and populations. For proponents of EBM, this “gold standard” steers medicine away from a woefully irrational tradition of following judgment and experience. For opponents, it represents “cook-book medicine”, blind to the nuance of individual experience, placing cost or statistical abstraction over care[19]. The hierarchy of evidence is both an epistemic and political tool, dividing sound fact from quackery.

The gaze of EBM is almost diplopic, with one eye on the patient and the other on the evidence (Sinclair 2004). As EBM privileges population based-data, the gaze moves laterally, panoramically, and probabilistically. Precision and personalized medicine is a response to this history of standardization and science-driven practice. The *n of 1* draws on the desires for precision, non-standard medicine to assert a different mode of knowledge production altogether - the subjectively gathered objective data. As I explore below, the *n of 1* disrupts these dominant modes of clinical perception and care. For some, it is a gaze with heightened acuity. For others it instantiates a transition from experimental to an exploratory, big-data driven paradigm of medical knowledge production (Boyd and Crawford 2012; Hey, Tansley, and Tolle 2009).

The *n of 1* grafts onto this varied history of medical accounting and perception, drawing on, interfering and colluding with the clinical gaze, itself multiple (Mol 2002). Now, I turn to the paraclinical gaze and various *n*s *of 1* I find there.

III. From n of 1 to n-of-a-billion-1s

> The n-of-1/n-of-billions idea will be vital to the program of Wikimedicine. Massive pooling of the granular but 'pixelated' data from individuals creates a positive feedback loop, such that the overabundant granular data becomes more

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[19] For an account of the impact of EBM on other realms of health care, such as global health and development projects see(Adams 2010; Adams 2002).

> valuable and defined - transforming the extensive data to real information and knowledge that can ultimately be used to improve the health of individuals. The enhancement of health in a large number of individuals is the precursor to an upgrade in population health. This is how to connect the dots from the science of individuality to improving health on a large scale - a bottom-up approach that could not have been previously contemplated.
>
> Eric Topol, MD (2012, 231)

> Imagine that you've got a gravitational field.…It's flat and a planet will be a big dip, and it takes a lot of energy to get out of the gravity well. These sorts of stories, the calorie in/calorie out story, the 10,000 steps story - are these energy wells. Good places to start. But how hard is it to get out of it? Quantified Self is a rescue ladder…. to get out of the deep imposed frameworks that are being dug out under them and enables them to go to the higher flatter spaces where you could adopt or craft something that doesn't detract from [your] goals or identity.
>
> Anne, QS Organizer

These different, yet related, views of the *n of 1* tell us that there is a lot more going on with the *n of 1* than biomedicalization (Clarke et al. 2003). For Topol and others, personal big data is a big promise to transforming medical science and public health, finally delivering on precision medicine. For others, QS is a practice that serves a different purpose: finding personal answers to personal questions. Here, self-tracking and experimentation conflates reflection and revelation, on the one hand, and a data set as a natural resource to be mined, on the other. In this section, I discuss some of the many valences of the *n of 1* in QS as a nexus for the many stakes of self-quantification - from the epistemology to the politics of medicine.

Taxonomy of the *n of 1* would belie the fact that these meanings draw on each other, but I offer it as an exercise in outlining where experiences and practices overlap in a network of partially shared meanings:

kinds of *n of 1*	**Some practices, movements that relate**
n of 1 as aspirational self	*Homo experimentus* Mindfulness tracking Self help Optimization
n of 1 as new public health	Anatamopolitics Neoliberal self-governance Compliance Consumer health
n of 1 as counter conduct	DIY health Alternative epistemology Participatory Medicine Data liberation
n of 1 as care	Precision medicine Self and family-centered care Participatory medicine
n of 1 as collecting	Self-awareness Mindfulness
n of 1 as portrait	Narrative medicine Data as mirror Data as communication tool
n of 1 as new science	Big Data *Homo experimentus* Citizen Science

Table 1: *n of 1* taxonomy.

These are some of the varied meanings and practices I found associated with the *n of 1*. We find self-care as public health surveillance alongside DIY health and open data politics. Or, self-experimentation might be scientific democratization (citizen science or participatory research) or the vehicle for personal, life-long optimization[20]: "rather than looking for illness and then treating illness, you look for how does the body function and then maximize function" (Miri). The *n of 1* can also carry a moral valence: "with the *n of 1* we're putting it against ourselves as responsible. If I lie about my tracking I'm just lying to myself" ("Quantified Bob"). This responsibility can cut both ways—empowering some (those with resources, time, wherewithal to collect data) and potentially enjoining others (for better self-care)[21]. Below, I visit just some nodes in this semantic network, addressing those with particular implications for the practice and optics of medicine.

Who and what is served by personal data is a healthy debate in the QS community. What is at stake is partly captured by the distinctions between "surveillance" and "sousveillance"[22] or "self-tracking" and "other-tracking."[23] These concern power, privacy and control, but there is more, too. The *n of 1* is the starting point for thinking outside of given frameworks, or what Anne describes as 'gravity wells'. Put it another way, when faced with a problem, the *n of 1* seeks out a different kind of knowledge - insight that may not exist in a textbook or a diagnostic manual. Or in the case of the late self-experimentalist and psychologist Seth Roberts, the self is a

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[20] Represented publicly as the life-hacking work of Tim Ferris (2010) and Dave Asprey (2015).

[21] In the field, I encountered companies or products that were aimed at the disenfranchised, the poor, the marginalized. The question of the impact of a culture of active self-monitoring on these communities is an extremely important one, it is not the focus of this dissertation. While neoliberal self-management that on the surface appears to individualize (and thereby depoliticize) social-structural causes of suffering are certainly built into many self-quantfiying tools and companies, the broader impact of this socio-technical practice is to be determined by future investigation. While some trackers in QS aim their data at social and structural variables, such as air pollution, and broaden the scale of quantification from the self to a community, these perspectives remain marginal. For example, one woman at a QS meetup presented data she collected on her daily street harassments.

[22] These issues were discussed at a session at the 2013 Quantified Self Global Conference

[23] Formulated by QS organizer Anne Wright.

fertile source for research idea generation[24], seeing outside of the silos of given research. Starting from personal experience, QS enables a science of a different quality, not just a higher-resolution version of biomedicine. As a social, technical, and epistemic forum, the shared space of QS generates a kind of friction[25] where practices of care and inquiry co-mingle and potentially produce something unexpected and new.

A. n of 1 as precision medicine:

As a medical futurist, Dr. Eric Topol (quoted above) forecasts that scaling up the *n of 1* - plugging the big data of personal informatics into the even bigger data[26] effort of EBM - will catapult us into the age of truly personalized, precision medicine. This "high-definition human" as Topol calls him, recalls a digitized upgrade of Foucault's anatamopolitics, where the political desires and drivers for better population management are operationalized at the individual level, just finer grained. In comparison, Foucault's anatomopolitics appear low-fi and modest. For precision medicine, the *n of 1* is an untapped natural resource[27], which, once aggregated and deciphered, will unlock optimal health. As a departure from genomic personalized medicine of latter decades, where the genome was an inner truth to be known and disclosed, precision medicine indicates the need for ongoing interrogation and optimization of continuous flows of hyper-particular individual information. Throughout the Quantified Self Global Conference in 2013, some called for the need to upgrade the "quantified *self*" to the "quantified *universe*."

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[24] A practice quite resonant with Anthropological inquiry, in which ethnography uses the self as a starting point and tool itself toward understanding. See Ortner (1995) for one particular articulation of this. Thanks to Dawn Nafus for pointing this out explicitly here.

[25] Inspired here by the work of Anna Tsing (2005) on the productive capacities of frontiers.

[26] On promises, pitfalls of big data medicine see (Neff 2013; Boyd and Crawford 2012).

[27] The genome has also been characterized this way, an information rich, natural and collective resource. For example of deCODE in Iceland, see Winickoff (2006). Also, (Hayden 2003)

Those with concerns over privacy or those who use QS as a set of techniques for personal growth did not necessarily share this sentiment.[28]

What exactly is the *n of 1* in this version of precision medicine? What kind of individual is posited here? Asking for a far more granular view of individual health through personal informatics, precision medicine asks not what is generally true of a disease or an intervention, but what is particular and provisionally true in a given moment for a given intervention for a given person. Precision medicine entails a tailoring of diagnosis, treatment and prognosis given the *ongoing* and *continual* collection of personal data, mined at the *n of 1*, but also given meaning in aggregate. Unlike the aggregating technologies of EBM or the clinic, QS precision medicine does a different kind of work. Here - the crowdsourcing of personal health data - when the *n of 1* scales, it does not merely become the large *n* of a highly powered randomized controlled trial. Rather, the *"n of billions"* heard at QS and health technology conferences alike, is more like what I call *n of a billion 1s*. The return to large numbers is a return with a difference. The new crowd of *n of a billion 1s* differs from the "study population". For one, it is potentially ever-expanding, not delimited, encompassing individuals without subsuming them to a group or average type. The open-ended nature of crowd-sourced health data reflects the nature of the knowledge and subject produced - open to continual revision, improvement, and optimization. Relatedly, a new epistemic paradigm is embodied by the *n of a billion 1s*, where big data rather than experimental design produces insights[29] from ongoing data sets, where truth is an emergent property of information (Hey, Tansley, and Tolle 2009).

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[28] For example, a presentation by a "Quant-friendly Doctor" tracks with patients, yet resolutely keeps their data out of their electronic health record.

[29] Of note: "Insight" is the name of a data analytics tool created and sold by the electronic medical record company, Practice Fusion. In data science, insights perhaps reflect the provisional nature of results from this kind of research. Unlike truth, the object of experimental

A different kind of subject emerges from the *n of 1* as a "high-def human" and the *n of a billion 1s*, one perhaps related to Deleuze's *dividual* (1992). The pixelated *n of 1* is a subject ever divided into finer granularity, but also whose partial data sets can be joined with others, in network, dividuated in data. The individual is no longer cast against and molded along side the mass; rather the *crowd* and the *n of 1* melt into each other. In other words, the crowd or open data set[30] anticipates an *n of 1* that is already pixelated, made of similar stuff of the crowd, "interoperable" data points to be seamlessly joined to the *n of billions/billion 1s*. The ease with which personal data enters the cloud, fashions the "public" (RWJF, 2014) into an "operable" or "bioavailable" crowd of untapped value (Cohen 2004). Kaushik Sunder-Rajan (2005) described genomic research participants as "subjects of speculation", where multiple speculative processes (capitalism, experimental science, and predictive medicine) secured future market values. The *n of 1* scaled to *n of billions/billion 1s* adds to this guarantee to surplus value, where not only is future risk of illness a guarantor of future value, but where moment for modulation - real time - transposes the future into the present, over and over.

Topol's particular formulation of a 'pixelated' human is just one of the strong views of how the *n of 1* enters into medicine. In concert with EBM, his *n of billions* searches for clinical truth from the aggregate. But are they both referring to the same thing? I argue that EBMs target and unit is the population, while that of precision medicine is the crowd, an aggregate of a *billion*

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science, "insight" is the kind of knowledge produced in a modulating system, where information is gathered and processed in "real time" https://insight.practicefusion.com/.

[30] Exemplified by dhealth tools and studies such as the Health eHeart Study, dubbed the digital Framingham Study, where participants' dhealth devices (pedometers, scales, blood pressure cuffs, AliveCors) are synced to the study's cloud servers, so that you may take care of yourself through self-tracking while simultaneously merging your numbers to a larger data set. The Framingham Study was a prospective cohort study. 'Cohort' may be obsolete now as *n of 1* data streams flow into the open-ended set.

1s. The individual is articulated differently here. In EBM, the individual is considered in *context* of the evidence, whereas, in precision medicine the individual *is* the context. Is the pixelated individual a more complete understanding of the human? It might be the next best resolution or just a partial view, again.

Grasping for a pixelated human, something not lost to the crowd, is another such attempt to remediate this aspect of the clinical gaze. In the following sections, I will explore how the practices of *n of 1* amongst those in the QS community relate to the optics and epistemic values of medicine as well as attempts to pixelate the human in the service of the crowd.

Stanford systems biologist, Mike Snyder, is starting to build the evidence base to support a medicine of the future in which populations are conceived of as *n of a billion 1s*. Starting with himself and, now, 16 participants he is gathering huge amounts of "baseline" data, doing "omics"—the analysis of the information contained in metabolic and genomic aspects of our bodies. For example, his dataset includes analyzing his, proteome (the entire set of proteins produced by a biologic system) or his microbiome (the genetic profile of microbes living in his gut or mucosa. He has over a *petabyte* of data on himself, alone. A petabyte is 1,000,000 gigabytes, or 10^{15} bytes, of data. He showed me, what his body looked like as it experienced a year's worth of ups and downs, with notable perturbations around times that he had a cold. Through the sequencing efforts, he knew the exact microorganism that infected him—respiratory syncytial virus (RSv)—and how it affected key biomarkers. "We do dense sampling when I get sick and then every two to three months when I'm healthy and so with those RSV, these are all common colds…. See that day, next day, two days, two days, three days, four days….The idea is that I want to follow in detail the physiological change, well in this case the biochemical changes that are occurring during this disease and recovery times." All this is to figure out what is really going on in the body, to get a view of high-def disease if you will: "You know, when you get hit with a viral infection it probably is one bug that's triggering it, but is it one thing happening or are there ten bugs all kind of going berserk in you? As soon as they figure out, 'Well you have strep throat or the flu or something like that,' they're done, they don't measure anymore, but maybe you have 10 things going on with you and you don't, nobody even knows that." Disease in high-def, like traditional research efforts requires large quantities of data, almost unimaginable volumes of data (petabytes). This means not just getting a more granular view of what is going on, but this view is more personal, as well, where the person is made visible through data saturation.

At the beginning of this project, Prof. Snyder chose himself as a guinea pig, assuming he was a "healthy" baseline, but by carefully watching the numbers, he caught diabetes in the data. That is, he watched his glucose creep up, even as he appeared healthy and very thin. Combined with his viral data, he might even have a picture of a virally induced diabetes (goes one hypothesis). He explains: "It is personalized. It's *n of 1*, and the goal is to treat people individually according to what they're at risk for or what they are getting and not lump everyone together. I mean, this is a classic disease, Diabetes I probably a hundred diseases but all lumped together because of high glucse. But it's a classic case where you see 80% of people respond to metformin, 20% respond to salicylates (high dose aspirins)…It's a very heterogeneous disease, you know. 10% of people like me, thin diabetics…So it's probably going to be a lot of different diseases, all leading to high glucose." Tracking and collecting personal data tends to lead to a new nosology: high-def diagnosis. This attention to the individual, their own environment and baseline metrics harkens back to the late 19th Century medical philosophy, during which the specificity of the patient and their illness guided treatment (Warner 1997). Medicine transformed with the rise of the physiology laboratory and hospital monitoring that developed standards of health on the "normal" (vis a vis a population or lab-derived value) versus the "natural" (for a given person, place or season). The *n of 1*, both as it is practiced in QS by non-experts, and as it is taking shaping in these corners of academia—systems biology and precision medicine—combines the modes of clinical or biometric accounting, with an orientation to the specific and particular. Biomarkers, then, transform from "labwork" ordered by a doctor to screen or diagnose to data, collected to shed light on an individual, intricate process. Below, I describe the extraclinical uses of medical data collection as "paraclinical," and this transformation can also be understood as part of the makeup of *Homo experimentus*.

The high-def human is available to not just those who have access to incredibly sophisticated tools (such as Larry Smarr, discussed in the introduction). Extreme specificity is also built into the idea of the *n of 1* and many self-tracking tools and techniques. As the founder of a new breath-sensing wearable, explained: "So what we do is, your goals are about you, your average. So we let you know when you're near your average, you're past your average, or you're less than you're average. It's about you." This device, which you wear clipped to your waistband, will measure your breath and steps, purportedly providing a view in to your current levels of concentration or relaxation. It grew out of the "Calming Technologies Lab" at Stanford, also established by the founder. Breath is just the latest biometric that quantified self companies are going after. At the time of fieldwork, the hype around wearables was beginning to flag. However, as the co-founder of Flux[31], insisted "We are just at the beginning. Open up your Anatomy 101 textbook. Activity is a tiny fraction of our health and our body. We are finally moving past this signal and forcing the industry to explore the rest of the human body with new

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[31] This is a pseudonym.

sensors, new deep technology and new experiences." This idea of "deep technology" also contributes to the ideal of the high-def human, generating data that is specific to the individual, uncovering new horizons of the person and their body.

This is one highly diligent self-tracker's description of his weekly and daily regimen of data collection:

> Wake up. After sleep track…I go ahead and put the kettle on, because I'm going to have coffee in the morning. I go back to the bathroom and have my first movement of the day, and that first movement, I usually will take 15 minutes for, I like the data that I take after that, I like to have an apples to apples number. I clear myself and then take the data. That way I can watch things over time. So I step on the Withings[32] scale and then I pull out the Withings blood pressure monitor and I take the blood pressure. The only difference is on Sundays, I also pull out my tape measure and I breathe out, take my waist, again to have the same thing…So that's the data that I take first off. And then I make my coffee and coffee is something I never touched for the first 49 years of my life, Again, I read some stuff saying it had multi-modality of health, so I added it to my diet.

Adrian adds to this routine regular glucose testing and other direct to consumer services. These measurements are just a small sense of the kinds of information he both consumes and produces to manage his health. Minding his health responsibly, means taking what he learns and reads about diet and health and crossing that with his own experimentation: "I don't just want to try anything, because a lot of people, to me, don't know what they're talking about. But then I can

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[32] Digital, cloud-connected scale that also measures body fat percentage in addition to weight. As with other digital and networked quantified self devices, the data is stored and aggregated online, where you can monitor trends, or compare to other data for correlations.

try it and then see if it works for me through my data." This experimentation, like the work of prof. Snyder, enables a kind of specificity that trackers like Adrian and others find lacking or failing in the medical system. For Alan, a longtime type-2 diabetic, he came to QS at a particular low point in his illness: he had been obese since he was in college, and had his first heart attacks and stent placement in his coronary arteries before he was 40 years old. Despite following the guidelines and his doctors' prescription of glyburide and other anti-glycemic medications, his disease was out of control. "My experience with the medical system is that it's a lot of policies and procedures....It's like, 'Okay, he sort of fits in that [category] so we'll follow this policy.' I was on a high dose of glyburide and I would be hypoglycemic a lot….I would feel terrible all the time and wonder why. I tried to get the doctor to help. 'Eh, this is what we do.' 'But it's not working.' 'Eh, this is what we do.'" Eventually, Alan acquired a continuous glucose monitor, shed the weight, and reduced his medications to a fraction of the original dose. "Doing the [finger] stick, it's just a data point. There's no slope to that line. That is the fundamental difference that changed my health, right there. Just that feedback." The difference between one point and the slope, in many ways, captures the *n of 1*, in that the slope is about movement, causes and effects, and a story.

While Adrian's frustration with medicine has relatively benign consequences—he tracks for health optimization and prevention—Alan found himself at an impasse with his medical care. Both demonstrate a reason to track and self-quantify commonly found in QS: to capture and address a kind of specificity they find or missing from their clinical encounters. The next chapter, the Well Role, I will go into greater detail the kind of forms of wellness and health are produced by these technologies of self-monitoring and care. However, for now, my goal is to point out how the *n of 1,* as a practice of self-tracking or experimentation, addresses or even creates a different standard for medical knowledge production and scientific clinical practice, a kind of accounting on which one can count.

B. n of 1 as Counter Conduct

It's not about big data or small data, it's about our data.

Gary Wolf, Founder, Quantified Self

In the late 1960s and early 1970s, feminist activists gathered in homes and community centers to teach each other how to a wield a speculum and mirror to do their own vaginal exams and to share personal stories. The latter served "consciousness raising", where connected across their personal experiences. The former aimed to wrest control of women's health from the medical establishment, by teaching self-care. The "self-help clinic" was also a space of epistemic innovation, where both women's stories and intimate protocols started with the self as a partly oppositional, partly medical way of knowing. In *Seizing the Means of Reproduction*, Michelle Murphy (2012) describes such practices as *counter conduct*. These women did not renounce the tools of the clinic, rather they reappropriated them and forged their own technomedicine. As epistemic pioneers, they crafted new modes of objectivity (Lorraine Daston and Galison 2010), exposing the "affective economies of technoscience," or "how capacities to feel, to sense, and to be embodied are valued within political economies of technoscience" (p. 72). Put simply, feminist self-help placed affect - sharing narratives, examining bodies in an emotionally saturated space - at the center of credible knowledge making.

Quantified Self (unwittingly) recalls feminist epistemology by grounding the self as the starting point for knowledge. Self-tracking also qualifies as counter conduct when paraclinical practices open a space for challenging hegemonic medicine. This *n of 1* also shares with feminists the reformulating of affective economies science, where narrative and subjectivity (often on display at "show and tell talks") are similarly centered as epistemic virtues. Unlike feminist self-help, the *n of 1* is not overtly political.[33] Nevertheless, I use counter conduct as a frame for understanding paraclinical practices*,* where the *n of 1* is a vehicle for reassembling the hierarchy of evidence. Neither big, nor small, Gary's "our" data gestures at this move, sidestepping questions of scale to grounding epistemic legitimacy in the self by engaging narrative, affect, and politics of ownership, access and control.

Jaime, mentioned above, acquired his own ICD interrogation machine off the internet during a brief period without medical coverage. Without disclosing his status as a patient, he took technical courses in how to operate the machine. He keeps it at home as a matter of principle and comfort:"It's like having a gun at home." The machine is there for peace of mind and a symbol of his battles to gain access to the information produced by a device that he owns and is inside of his own body. His form of counter conduct speaks to access to health information and self-determination. Others, though, see counter conduct epistemically, asserting knowledge at the level of the individual as valid. As Quantified Bob explained to me:

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[33] Some QS projects connect to civic projects such as using citizen scientists to gather data on local pollution, for example Carnegie Mellon University's CREATE Lab's water quality project: http://www.cmucreatelab.org/projects/Water_Quality_Monitoring. However, the status of politics (small p) is a point of contention. There was an attempt to address social structures and politics at one panel at the 2014 European Conference. Instead, the conversation became tense when a few members of the audience felt condescended to, and claimed that QS was about them working on themselves.

> *N of 1* to me means a few things. First it's an experiment that's constructed around me and my own special circumstances. It also means that you can't tell me my results are necessarily wrong because we are all different, and *n of 1* of me means what will happen to me: these are results that relate to me. …I've always told people that I'll share results or insights [but] I can't promise that you're going to get the same results. It doesn't mean that one of us is wrong or one of us is right. There are always other variables in play…That's my *n of 1* to me.

As I asked almost everyone what the "*n of 1*" means to them, I got many different answers. Most though, gestured towards a form of knowledge that was qualitatively different, yet borrowing from, scientific discourse and practice. Harkening to Nafus and Sherman's (2014) characterization of QS as "soft resistance" or "alternative big data" to ascending forms of big data surveillance, the *n of 1*is a similar form of resistance, that I understand as closer to feminist counter conduct. Just as Murphy describes the feminists as participating in technoscience and biopolitics, even as they were in an agonistic relationship to science, QS is agonistically participating in emerging forms of biomedicine and technoscience. Individuals who track make themselves further "bioavailable" (Cohen 2004) to the optics of medicine and data. Importantly, the counter conduct of QS, like that of 1970s feminist self-helpers, is a particular practice and discourse that reinforces a universalized, unraced, even unsexed (the in the case of QS) subject. The meanings and costs of self-surveillance are uneven across racial and class lines, as self-care for some may be coercion and unwanted surveillance for others[34]. This epistemic innovation is

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[34] Critics of "the new public health" warn of this use of digital health technologies for "patient engagement." See (Lupton 2013b; Lupton 2013a; Petersen and Lupton 1996).

both part of the counter conduct and may be seeding new forms of medical science. For now, however it remains marginalized.

In addition to upsetting the pyramid of evidence, the *n of 1* insists on a kind of specificity of biologies and life. Take Vivienne Ming, a computational neuroscientist, entrepreneur and mom of a son with type I diabetes. She and her partner have shared their efforts to model their son's diabetes, against the warnings of the their doctors to not even try. It is futile, they warn, "forget about it. It's Diabetestown!" She explained to me:

> I've had many interactions…I love the medical profession. But, my interpretation…is there's one thing. It is a patient. Given current data, it is treated this way. There is no digging in to why it is true of you. I'm sure there are doctors that do …Buts, as a profession, almost every doctor I've interacted with, they have a lot of patients coming through. It's Crohn's disease. Doesn't matter. The person doesn't matter. This is how we treat it.

In opposition to this vision of medical treatment, Vivienne and her partner demanded early ongoing monitoring, and have strapped all sorts of wearable devices to their son, to crack his diabetes code, so to speak. For example, by having him wear the Body Media armband, they can correlate his activity with his glucose and insulin usage. He is just 6 years old, and they are getting a better picture of their son's disease, in real time.

The QS tagline promises "Self-Knowledge through Numbers". Not better medicine through numbers. Not better public health through numbers. Not lower health care costs through numbers. Mostly, QS leaders attempt to defend the space - conferences, website and meet-ups - from a takeover by the growing app and wearable industry. The presentation formula - "What did you do? How did you do it? What did you learn?" - reflects this mission. Here, logging weight by pen and paper or food by spreadsheet are techniques of self-tracking as much as a wearable biosensor. Tracking accommodates many goals, from passive, long-term data collection to active logging for mindfulness and behavior change. Centering the self serves more than personal needs. Self-experimentation can reframe epistemic values and politics: reintroducing affective attachments to scientific inquiry and seizing the means of (knowledge) production.

C. "N=1, Loved by All"

In August 2014, friends of Seth Roberts, PhD - experimental psychologist, QS founding-member and pioneering self-experimentalist - gathered to honor his life and legacy. Seated in a biology lecture hall at UC Berkeley, fellow scientists (both citizen and academic) spoke about their shared experimental lives. "He had skin in the game" went a refrain that echoed throughout. Epistemic debate - around big data and the *n of 1* - mingled with tears. Seth often talked about using self-experimentation to generate ideas for further research. Sometimes it was the only way to test out certain hypotheses or ask questions of personal relevance. His experiments, collaborations, and his prolific and loyally followed blog also spoke to his passion for curiosity. He elevated the smallest, most personal observations into data. Unlike "blind sight" objectivity (L. Daston 1992), where the subject is a hindrance to truth, Seth's "skin in the game" made him more trustworthy and marked him as anti-establishment. He was memorialized by others who lived life experimentally, making the everyday amenable to scientific inquiry, examples of *Homo experimentus*.

Others in QS push for self-experimentation as normative science. Mark Drangsholt, DDS, PhD has made the case for single case research design - EBM-speak for *n of 1*. This *n of 1* spans the EBM hierarchy, elevating the case report into a quasi-controlled study. The legibility of “single case crossover design” to traditional EBM remains to be determined. The difficulty in translating *n of 1* to EBM perhaps reflects its history, where standardization, reproducibility, scale, and cost-containment underpinned its development. While Mark presents his *n of 1* arrhythmia tracking at QS meetings, the “single case crossover design” is presented in scientific settings, fitting into the hierarchy. Mark began his research career at what is now the top of the pyramid, working on meta-analyses. At the time in the late 1980s, however, meta-analyses were methodologically suspect, making his work a bit “risky,”

> because it was too new at the time and a lot statisticians felt like it was unproven. They joked about ‘garbage in garbage out’ saying that it was just rehashing old data. There was really quite a bit of opposition to it. It was interesting. Now it's well accepted and felt to be a big step forward. I guess that's one of the nice things of some experience—that you can see these things with a 20 to 30 year view. I think a lot of single subject research is probably not accepted but it’s because that’s just how the scientific community feels about it but they’ll change with some pioneering efforts.

Mark is leading, among a few other clinicians and researchers, to elevate single-subject research up to a higher post on the evidence pyramid, maybe even redefining it, too. In presenting his work deciphering his own complex set of heart arrhythmias, he explained how the *n of 1* combined elements of the controlled trial with the case report, collapsing the hierarchy, somewhat. This *n of 1* appears as a boundary object (Star and Griesemer 1989), translating across multiple forms of objectivity and moral economies of science, allowing contested truths to sit side by side. Mark believes, that just like meta-analyses, the *n of 1*, will find its place in mainstream medicine soon enough:

> With personalized medicine coming, it's hard…. You've got to have personalized data. Otherwise it's not going to work. I mean it's such a huge need then to have. This whole single subject work—I mean if I'm not going to do it and you're not going to do it and Gary’s not going to do it, somebody's going to do it.…I'm surprised when I talk in academic circles, other people haven't come to this same conclusion.

In addition to trying to elevate the single case design, Mark has also tried to bring a bit more scientific rigor to the QS community. So far, his efforts to bring a methodology to QS remain just an *n of 1*. The leaders of the community keep the field open to almost any presentations and methods, refusing any kinds of standards[35]. Rather, his methodologies circulate on the same plane as the countless other talks that populate the QS website and blog.

Self-tracking for self-care can also lead to a way out of the silos - the “gravity wells” - that limit medical categorization. For some, medical mysteries lead to diagnostic odysseys, for others self-tracking trouble shoots symptoms beyond simplistic pharmacological regimens. Both use the *n of 1* for self-efficacy. QS organizer Anne Wright makes a strong case for the distinction between self- and other-tracking; the former is a way of reclaiming a sense of dignity in the search for answers to personal suffering. Having control over who and what is tracked, for whose ends and on whose terms are all crucial elements to self-tracking, leading towards hope and control in the face of chronic illness. Tracking this way is a technology of the self that operationalizes some of what Annemarie Mol called “the logic of care”, which leaves medical

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[35] The place of science and scientists is contentious, as heated debate broke out at the QS Global Conference in 2013, with some scientists in a breakout discussion demanding standards, with others defending the non-expert nature of the community.

measurement open-ended to inquiry and the needs of the situation, opposed to logics of (consumer) choice and cure.

Some models of tracking for clinical problem solving utilize a coach (rather than a physician) to guide self-discovery. The coach and the self - mirrored in data - provide the relational foundation to this logic of care. Unlike popular considerations of QS, this *n of 1* is not (only) rooted in consuming dhealth technologies (Mol's "logic of choice"). Enabling a different form of medical knowledge production, it refuses the logics of scale, aggregation and standardization. Like feminist self-helpers, this *n of 1* "diagnosed and redirected the exercise of power as it moved through technical practices that invested…health with new political dispositions" (p.32). Tracking ones own biometrics and symptoms with devices or simple spreadsheets, reflecting on them with coaches and data visualization tools[36] redirect the clinical gaze, and invest it in self-determination.

This paraclinical work - asserting the ability to derive valid and useful knowledge from personally collected data - dovetails with participatory medicine's (DeBronkart 2013) clarion call "give me my damn data!" Agitation over health data - who collects it, how and when it is used and accessed, where it is stored - -points to the both epistemic, affective, and political stakes contained in this *n of 1*.

The *n of 1* as diversely practiced in QS (a small sampling of which is presented here) consists of a social field where the moral economies of science and medicine are at play. To start, it enables a reassertion of subjectivity and affective attachments in knowledge production, and performs a political operation by relocating the site and terms of clinical tracking. The *n of 1* can also make space for what remains outside of or exceeds the narrow clinical frame, where

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[36] Like the CREATE lab's Fluxtream tool https://fluxtream.org/

diagnostic categories, paradigms, and hierarchies of evidence (from the SOAP note to EBM) reign. Here, I think of chronic disease patients I have met who tracked to “hack” their fatigue or seemingly idiosyncratic flares - concerns that barely make the cut in a short office visit with their doctor. Their data rounds out the portrait.[37] Next, I consider how *n of 1* operates as narrative, reframing the challenges of humanistic medicine.

D. Living the Data Stream: n of 1 as Deep Data

> After a long walk where Karen detailed the second part of her long saga caring for her sick child, reorienting her entire world, and the worlds of the hospital around her and her home, we sat to dinner. There was never a strict separation of our formal oral history interviews from the informal time we spent together in and around their home, where traces of their medical home and their lost daughter remain. “This was her hospital, sanctuary, and a home!”, she told me late one evening. They are there in the remaining prayer flags that adorn the walls, the logs that tracked her daughters life and health (from symptoms to diaper changes), and herbal remedies like “Liver Failure Tea” that still fill the cabinets. “It’s all data, to me.”
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> (Field Note, August 2014)

In the 1990s, physician-humanists like Rita Charon MD, PhD promoted the use of the medical humanities and narrative medicine in medical schools (2001). Both patient and doctor

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[37] Data as portrait is explored in QS by the artists that present their work at QS, translating data into artistic artifacts or portraits. See the work of Laurie Frick, for example, who just completed a Kickstarter campaign to make a phone application to help people turn their data into art: https://www.kickstarter.com/projects/lauriefrick/frickbits-your-data-is-now-art-on-your-iphone

narratives - in the form of writing exercises - are used to palliate the rough training, long hours, emotional and physical burnout, and desensitization that was seen to dehumanizing patient and doctor alike. The turn to narrative was also a response to ascendant techno-medicine, which can center care on diagnostics and machines, instead of people. Competent scientific management, Charon argues, cannot enable a physician to help patients make meaning out of suffering. Narrative medicine encourages trainees to understand why stories and life-worlds matter to healing. Relatedly, medical anthropologists have also asserted the importance of narrative to the experience of suffering and healing, aspects that are left out by biomedicine's technological, pharmaceutical or surgical interventions. Narrative is part of therapeutic practices, woven into the delivery of a prescription, prognostication, or medical education.[38]

These forms of rehabilitating clinical relationships and care sometimes oppose what is human (narrative as experience) to what is techno-scientific (probing, fragmenting data). However, when we pay close attention to the *n of 1*, we hear how data and narrative are sutured together, recuperating aspects of human and patient experience. When a tracker projected a graph of her symptoms on the big screen she implored us to remember, "It's personal!" In a twist of the clinical gaze that uses technologies to ostensibly fragment, reduce and alienate patients from their own illness experiences (cf. Taussig 1980b), self-quantifying domesticates clinical perception and potentially recuperates narrative, time, and experience. This depends, of course, on the kind of engagement, context and respect for the affective entanglements of science.

In QS, personal data may function to extend the narrative, as a scaffolding or medium for narrativizing experience. "It's all data to me" expresses the notion that the *n of 1* can be used to gather personal experience, remnants of the past, memorializations of space and time as worthy

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[38] For a selection see: (Del Vecchio Good et al. 1994; Mattingly 1994; Kohn 2000; Mattingly and Garro 2000; Good and Good 2000)

of being counted. Karen is not trying to aggregate or calculate for the purpose of scientific argument, or for "presenting" to the doctor a "good history."[39] Her tracking was at home, where she created an in-home care space for her terminally ill daughter, displacing the locus of care from the hospital, pulling together a huge community of caregivers - from nurses to neighbors - into their orbit. The few times they felt they had go to the hospital - acute crises - they snuck in their own food for her feeding tube (contraband in the hospital, the staff were not allowed to administer it), with the staff sometimes in collusion with these small acts of resistance. While not all aspects of their paraclinical care entailed data collection, self- (or kin- in this case) tracking of symptoms, medicines, and diaper changes was a constituent part of their home as both clinic and sanctuary. The data logs, she explained, were also entry point for those who wanted to join and help out - it gave them something to do, marking and tracing not just the numbers, but their attentiveness, presence and care. Nurses visited the home, lingering longer than they should. A neighbor, a trained scientist, managed the tracking logs. Others planted a garden of therapeutic herbs alongside the house. Their cosmopolitan therapeutics also included experimental pharmaceuticals, which they tracked alongside other masses of their daughter's data.

I call the way they lived the data stream *deep data*. Partly a subtype of big data (Nafus and Sherman 2014), the *n of 1* enables a proliferation of personal data, aided by technologies of the clinic, charting, imaging, or biometrics. The bigness of the data is both probing and fine-grained - the "high-def human." The data is extended and deepened by social stakes hinged to it and its collection. Data is collected, recollected, and marks time, presence, and events on the scale of the everyday. As the fruit of the paraclinical, deep data knits together in productive

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[39] In the clinical context, and told to us in training, patients are often praised or admonished (no in front of them) as being either 'good or reliable historians' or 'bad historians' of their own illness experiences.

tension what is often mistakenly opposed: objectifying calculation of clinical gazes and navigating personal and social meaning.[40]

As part of paraclinical care, the *n of 1* situates oneself in ones own life, attending to its specificity. For self-trackers of chronic disease this function is especially important for participating in a medical system that only has so much bandwidth to take in the complexities of living with chronic disease, let alone the context of family or community. The *n of 1* might provide a way to stare back at a clinical gaze whose surveillance probes much but actually sees very little.[41] While the clinical gaze is accused of being panoptic or omnipresent (biomedicalization), the *n of 1* points to its blind spots, to what is unseen or distorted.

IV. Conclusion: Caring in Real Time

In another auto-ethnographic account, Janelle Taylor (2008) describes caring for her mother with dementia, and the nagging question asked by many around her: "Does she recognize you?" This question frustrated Taylor because it made her mother's loss of herself as tantamount to the inability to have a caring relationship. It assumed that caring for and about someone requires selves that are stable, coherent, and cognitively situated in the world. She describes, instead, care that is immanent in her mother's seemingly idiosyncratic gestures, habits, and detours into memory - a logic that does not require an idea of personhood that requires recognition. Rather, she urges us to "start looking more at how 'selfhood' is distributed among networks, sustained by supportive environments, emergent within practices of care." This self recalls the *dividual* (Smith 2012), a distributed subject, held together by relationships and attachments of care.

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[40] This can also be read as the convergence of Foucualtian idea that modern power operates by using expertise to know ourselves intimiately. However, in QS and the use of the *n of 1* offers a different relationship to expertise, one where it is undermined in the course of creating new epistemologies of medicine and the self.

[41] Thanks to Dawn Nafus for helping to articulate this.

My mother's death didn't have this potential. The permanently comatose - the total absence of recognition - lacks biomedical definitions of selfhood. Strangely, she may have qualified for quantified self-hood, not only because of her pixilation and saturation with data, but because of the ways that data tethered her to us. When gathered in an ICU pod, we were not 'getting the numbers' in the same way as the medical team. Instead, we rode every single up and down; five minutes sometimes felt like an eternity. As she entered a persistent vegetative state the numbers seem duplicitous: they were taking her away from us, they were all that was left. Those experimenting with QS technique reinvest data with new kinds of meaning and forms of subjectivity, where life is not excluded from the data, but breathed into and with it. Perhaps, tending to my mothers numbers was a form of care in real time. Dismissing a grimace or movement as merely, neurologically involuntary, short-circuited our caring practices. Her personhood was felt in the presence of family and friends, tethered by invisible strands of kinship and vectors of care. Perhaps we just surfed the data stream to hang on.

I came to understand and participate in QS and understand personal tracking, logging and quantifying through these strange displacements and the affective muddle of grief that I carried with me into the field. This situation shaped the way that I came to understand the realities and potential of QS practices. I have attempted in this chapter to understand the potential of the *n of 1*, including the proposition that quantification can do more than reduce experience to a number; rather, they can seed connectivity and new forms of knowledge and self. One of these forms is explored in the following chapter on the *well role*, which refers to the vigorous pursuit of wellness and fitness that are more often associated with QS. Digging a bit deeper, though, the well role looks to the forms of subjectivity, values, and connectivity enabled through digital health.

Chapter 3. The Well Role

I. Digitizing Health

I began my exploration with the *n of 1* because it is a central rallying and meeting point for QS, where the diverse stakeholders in digital health and personal computing gather to make sense of their personal data. Moreover, I chose to foreground this dissertation with an understanding of self-tracking techniques through the kinds of knowledge and selves made possible through "personal computing going all the way in" (Gary Wolf's formulation). This chapter picks up one of those threads, where the *n of 1* serves a particular vision of health and wellness, what I call the *well role*. In many ways, critiques of QS can be overdetermined by its pursuit of a kind of robotic pursuit of bodily perfection[42] or by the more well-known examples of fitness tracking bracelets, like the Fitbit[43]. My goal is to get beyond the surface and take the "digital" in digital health seriously: what does it mean to live and practice digital health? What form of health is *digital* health? I use the well role to talk about the entrepreneurial kinds of practices, habits, and dispositions encouraged by the technologies and pursued by many in QS. The well role exists in a web of both enduring and innovating ideas of health that stem from a deep American obsession with wellness, healthism and fitness [citations], connected to new forms of living and working in health. I begin with time I spent, as part of a user-testing group for a new health and fitness tracker incubating in San Francisco's premier digital health incubator. In addition to placing us at

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[42] See Evgeny Morozov (2014) for a particularly scathing critique of QS and "technological solutionism."

[43] Fitness and health wearables are chronicled exhaustively by tech journalism (I receive at least one Google Alert per day about the latest blog post or news article on QS). For a clever take on our new digital health overlords, see humorist David Sedaris's essay on his Fitbit in *The New Yorker* magazine (2014), about a relationship that is built on equal parts adoration and angst.

the forefront of the "wearable," this episode also takes us into the heart of a growing startup sector, where entrepreneurship ethos meets health reimagined digitally.

A. Training our Algorithms

On Friday in early 2014, I first visited Rock Health, a digital health business incubator that skirts the edge of the new UCSF Mission Bay campus. This home to small digital health start-ups joins other healthcare innovation centers, such as Bayer and Nektar Pharmaceuticals, in the growing biotechnology corridor. Unlike the biotechnology labs and incubators embedded in and around the university, Rock Health exposes itself and its small companies to passerby on the street. Large glass windows provide a view into an open-planned office space and hacker space, especially of the digital variety. Small posters with company names, such as "Augmedix" and "Mango Health". These startups range from making tools to help physicians with managing data and patients to creating apps to help patients manage chronic illness or purchase health insurance. The range of companies in their portfolio (they provide funding, resources, office space) represent the interventions that digital health technologies are making into health care, helping them deal with felt challenges and needs. That day I met Flux[44], a digital health company focused on maintaining wellness, to help them test the prototype of their breath sensor.

After checking in at the front desk, I settled in the waiting area (a couch alongside the wall facing the open work area) and watched the incubation. There were a few rows of tables with mostly young people at computers, some at standing desks, working intently. After a minute or two, a small group of us, 10 or so people—mostly women—were led past what looked like garage doors into an open area with a small kitchenette, lounge chairs, and rows of seats in front of a large screen. After awkwardly snacking with the other strangers, Peter, one the founders of

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[44] A pseudonym. Most names throughout are pseudonyms unless the real names were requested.

Flux, asked us to take a seat. He welcomed us with an abbreviated introduction—he did not want a full pitch to affect our impressions of the prototype. Only, he offered that Flux was a “next generation wearable,” that “expanded the notion of health” beyond just fitness. Their goal was to incorporate more data about overall wellness, like breath and (we were to discover later) posture. While the “space” (the term this set uses to talk about market niche) was admittedly crowded with step and fitness trackers, Peter offered that they only paid lip-service to holistic wellness. Flux would change that.

With that brief preamble, we affixed the prototype—which consisted of a cushioned cube fixed to a clip—to our waistbands, so that the padding was flush with our abdomens. In order for it to sense our breath, the device needed to sense subtle pressure changes from our diaphragm expanding. We were told only that the following two hours with them would involve performing some exercises to help train their algorithms to more accurately track various movements and activities. The first exercise was coordinated breathing. Seated in rows facing the screen, Flux’s data scientist conducted the group’s respirations. With one hand holding a laptop to which the data streamed, he lifted the other up and down to synchronize our collective inhales and exhales. Peter joined us on the side, seated with his hands on his knees, eyes closed, breathing with us for ten minutes. But it felt like an eternity. A seasoned meditator himself, he counseled us to concentrate on breathing in through our noses and out through pursed lips. The pace was very fast to start and made me anxious at first, but as we went on the pace slowed and varied. It was a challenge to consciously control our breath for so long. Peter encouraged us through the discomfort: “do it for the DATA!" After the data scientist released us from his control, Peter asked how it felt. Some raised felt it was relaxing. I disagreed. Nodding and taking in our feedback with wide eyes, he went on to explain that by manipulating our breath, increasing the lengths of exhales we could manipulate the output of the vagus nerve, inducing relaxation and calm.

Flux was also working on learning the nuances of human movement throughout the day, culling more signal from the noise. So together and on cue, we jumped up and down, slouched, hunched over, got up, leaned from side to side, walked in place, and just sat – all to teach their algorithms. We must have looked like a gym class from the street. The organizers explained that it was hard to measure these slight changes, but being able to capture such data would provide valuable information about healthy seating and activities beyond active fitness. Say you are slouching at your desk, engrossed in computer work, and unaware of your poor posture and strained muscles and breathing. Flux could interrupt you, nudge you to correct your position to a healthier and more ergonomic state.

Our next set of breath-altering exercises involved reading. We read silently, read aloud and read in anticipation of a test on the material, and all in unison. We chanted a passage on mindful eating, an exercise about a raisin, written by John Kabat Zinn, the physician and Mindfulness-Based Stress Reduction practitioner, someone who popularized mindfulness apart from Buddhist practice and, arguably, makes Flux possible. Then, we studied a text about Bit Coins, inducing a heightened sense of anxiety and attention. After admitting that we would *not* have to take a test on bit coins, Peter explained that they were trying to capture breathing data on “screen apnea" – holding our breath while concentrating at our computers, a syndrome of the knowledge economy. Last, they wanted to help to the algorithms understand laughter. We were mercilessly subjected to the best of YouTube. Initial self-consciousness unraveled into uncontrollable, synchronized chuckles.

After an hour of moving and speaking together as a crowd, we gathered in a circle, arranged ourselves as a focus group, passing around and sharing our impressions of models of the device, its packaging, and interface. They wanted our immediate impressions of the colors, textures, sizes, and shapes. Unlike the prototypes were wore, the product models were packaged in soothing, neutral tones, suggestive of pebbles, sand, and wood. Later in our interview, Peter explained that Flux came out of a mission to create calming technologies, also the name of the lab he created as a graduate student in human-computer interaction at Stanford University.

Speaking afterward with Peter's co-founder, he believed that the obsession with tons of data was misguided or at least not useful or interesting for the average person. Their goal at Flux was to provide actionable information, crunching the data for the user, providing them with informed and guided feedback based on their data. The actual device—which I finally received the following fall—maintained this Zen mood. It looks like a soft pebble from a stream and its iPhone application depicts mountains and sky. The data, though, the ins, the outs, the laughter, the slouches, all disappear behind a few key metrics: minutes of calm, tension and activity, and, of course, steps. Every so often, as I write, I become tense and the app nudges me to take a minute to breathe with their built-in exercises, narrated by the soft voice of a woman. Digital holism could be achieved by actually capturing the data of daily living. Just sitting still and breathing had a wealth of data points (a deep *n of 1* fount), legible to sensors and apps if only we trained them properly. Like Topol's high-def human, life becomes machine readable once it is translated into digital data, discrete packets of information, pixilating what was an analog flow of living and breathing. In pixilation, life is rendered into discrete bits of information that lend a quality of transparency and operability for intervention, alteration or modulation.[45] Pixilation

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[45] As discussed previously in a Deleuzean mode of subjectivation (1992).

also provides a way to understand how the flow of time, the present, is fixed, collected and captured, or made operable, translatable and available for manipulation. In pixilation, life (either experience or biometrics) is actively created into an archive—a past that counts for something. This digitization of activities in time fixes life into the kind of time that media theorist Douglas Rushkoff attributes to the Greek concept of *chronos* (time as ordered, discrete, digital), opposed to *kairos* (time as experienced, relative, sensed as "timing"). In an odd transposition, Flux brings *chronos* to mindfulness through data tracking, where the present stress level is archived in real-time to serve an infinite future in the present, something close to what Rushkoff calls "the short forever."

Moving, breathing, reading together as one body or mass of data points, we trained the algorithms so that, some day, when the algorithms were ready, they could train us. Flux is just one of many wearables or apps that have been developed to help course-correct, or rewire our circuitry to wellness (Schüll 2006). Quantified Self tools and practices, while enabling the collection of large sums of data at the level of the *n of 1 (*for self-experimentation, personalized medicine, etc. discussed above), users and my informants also talk about how its the logging, the tracking itself that produces the desired effects. This is what is referred to a quasi-mindfulness function of self-tracking, an idea and practice that circulates in Quantified Self meet ups and conferences. This quality of personal data takes many forms: logging, keeping track, staying connected, increasing awareness, placing oneself, or checking in. Taking a picture of a plate of food marks that meal and heightens awareness of what you eat. Checking your 'step counter' alerts you to your actual activity level, keeping you honest, keeping you on track. Trackers talk about these short feedback loops (in contrast to a long experiment or long term data collection), where information is taken in, a reflection is made, and a behavior is changed or reinforced.

In this chapter, I address a kind of tracking that serves what I call the *well role*: forms of self-tracking and self-care that entail modulation, optimization, control, productivity, self-reflection, and health maintenance. In quantified self I observed people who tracked their moods, their 'upsets' and anxieties, their bad nights of sleep, their distractions, addictions, etc, with the desire to find and then return to a baseline. Become more in sync with—if not with the 'normal' defined by a population—themselves, as an *n of 1*. These modes of the well role overlap and intersect, with people engaging in some or all of them. They reflect a tendency towards embracing a kind holistic health, where work habits are as much of a concern as diet and exercise. The recurring themes of performance, productivity and optimization form what I am calling *the well role* in ways that speak to a special relationship between the working body and the healthy body that I will explore below.

B. Taking the "worried well" seriously

When speaking with physicians about my time spent in quantified self (even those who work in digital health), I am frequently met with a version of the question: "But aren't they all just healthy? The worried well?" This assumption is often mixed in with accusations (half hyperbole, half joke) that these practices reflect Obsessive-Compulsive Disorder, or general neuroses. Even some of my informants joked nervously that what they were doing might be "OCD."

I am not interested in deciding whether or not quantified selves are truly the worried well or diagnosable as having OCD. Rather, I take their nervous laughter and suspicion seriously—they are perhaps symptoms of shifting ideas or practices of proper health behavior. They may index a kind of double-bind, where a subject is challenged to take care by paying attention to themselves, but not too well.

In my fieldwork, I spoke with those who tracked for chronic and acute illness as well as those who tracked for wellness. However, what these technologies and their implicit logics of risk mitigation and prevention suggest is a blurring of wellness and sickness. This phenomenon has been documented by those scholars who address the rise of risk-based medicine (Gifford 1986; Beck 1992; Greene 2008; Petersen and Lupton 1996) as bringing future morbidity into present health, or the conception of people as "patients in waiting" (Stefan Timmermans and Buchbinder 2010; sunder 2005; Dumit 2012a) or wellness that can only be attained through pharmaceutical intervention (we have never been healthy) [Dumit]. The well role builds off of these emerging experiences and blurring of health and illness. Risk mitigation and the experience of living with and treating risk (as not quite health but not quite illness) is at odds with the notion of the "worried well"—a term coined by Dr. Sidney Garfield of Kaiser Permanente. In a 1970 Scientific American article, he argued for a "rational medical care delivery system" that explicitly separated the sick and near-sick from the well and the worried well. He described a system of health testing and surveillance, organized around a computer center, that triaged patients amongst the Health-Care Center staffed with paramedical staff, Preventive-Maintenance Service, and Sick Care—all to keep the well and worried well from overwhelming over-taxed doctors offices. Since its first use in the context of health care reform (really a call to provide more health care in supplement to sick care), the term "worried well" has since taken on a negative connotation—at once a figure of irrational use of medical resources and a pathological state.

Here, I do not take the quantified self or users of self-tracking technologies as the worried well. Rather, I note it as a figure that emerges in the shadow of the well role that I see enacted by and through tracking practices. The worried well represents concerns by those who see these practices as self-medicalization (Fainzang 2013). Again, the worried well could be understood as the achievement of biomedicalization and responsible self-government and care (Clarke et al. 2003). However, I maintain there is something else going on here. Labeling self-trackers as overly worried dismisses the care and knowledge they produce for and by themselves. We could read this labeling as symptomatic of the shifting locus and source of authority, a nervous response to the transformation of health and care. The anxiety about there being a proliferation of the "worried well" speaks to this indecipherability around where appropriate wellness and self-care begins and ends. Like the debates around appropriate serial testing, accusations of OCD or problematic worry demonstrate that the terms of debate are not shared. For trackers with chronic disease, many do not want to track unless they are actively engaged in fixing a specific problem. For the well role, tracking is seen as necessary and rational maintenance of health, not a hypochondriacal pursuit of symptoms. Here, again, we see a gap between an epistemology of symptoms that map to a nosology of diagnoses, on the one hand, and an epistemology of data and computational health, on the other. A rebuttal to those that charge that QS is the worried well taken to obsessive proportions might say: "It's the data, stupid."

Technologies such as Spire are in good company at a typical QS meet-up in the Bay Area (and the conferences as well), where there are a variety of technologies and programs on display. At the various meet-ups and conferences I have attended over a year, I have encountered and tried multiple tools. Some include: athletic or activity trackers for logging steps or distance cycled, life-logging applications for tracking daily activities and encounters, data aggregation tools for comparing data streams, mood tracking apps and card games, posture improving tools like smart fabrics for office chairs, wearable devices for tracking brain waves or heart electrical activity, at-home diagnostic kits for measuring lipid or inflammatory markers, genome or microbiome kits, and personalized genomics, nutrition and functional medicine services. Tools for managing your health and fitness sit alongside those that make you more productive at work or more attentive to your meditation practice. Data, whether actively logged or ambiently collected, here serve to provide ongoing or intermittent feedback, an outside and presumably objective source of information about internal and external states. For some, the data serves the supporting or developing of habits. Lift is a popular social habit app. You can find them at Lift.do where they help you "succeed at everything." You can succeed at your achieving your step quota, eating right, meditating everyday or even at achieving healthy posture most of the day. There are even tools for helping you use your technologies less, ironically.

Seemingly recreational tools such as consumer genomics products (23andMe or uBiome) skirt the divisions between the supposed worried well and the chronically ill. For one, those who use uBiome for example, are doing paraclinical self-care for problems that are both acute and chronic in nature. However, here I would like to focus specifically on the overlap between the well and the unwell where habits and behavior change are concerned. In other words, tools that self-quantifiers (presumably worried well) use for 'merely' optimizing or monitoring blend into those that enjoin patients with chronic disease to self-care. Some in public health turn to tracking and self-quantifying practices to create "patient engagement" tools. Quantified selves look to chronic carers, most notably type-1 diabetics, as pioneers in self-tracking and quantification, proclaimed as "the original quantified self". At QS meet ups where the well and the unwell mix, devices and implants are shown off as conversation starters. Talks are given with continuous glucose readings displayed on screens. Insulin pumps are no longer hidden.

II. Well Role 1: High-Def Health

At the beginning of this century, a team led by Gordon Bell at the Microsoft Bay Area Research Center in San Francisco initiated MyLifeBits, a project to develop a database for personal information collected on personal computers. These computer scientists were inspired by Vannevar Bush's "memex", an idea for "an all inclusive, personal information system" (1945) Drawing from Bush's 1945 Atlantic Monthly article "As We May Think" that grappled with the dual problem of expanding information in the wake of war-driven Big Science. The article imagines what is possible once our "gadgetry" catches up with our desires to record automatically and almost continuously. For example, he describes the walnut-sized camera worn on the scientist's forehead that takes photos at short time intervals. (The Narrative camera, often found at quantified self events, now fulfills this function.) He describes the *memex* as a system of organizing information and memories along the lines of association, creating trails of thought and connections, presumably mirroring the processes of the human mind, rather than the organizational schema of libraries. Invoking future scenarios, he anticipates contemporary uses of personal computing, including electronic health records that augments the physician's learned judgment and experience:

> Presumably man's spirit should be elevated if he can better review his shady past and analyze more completely and objectively his present problems. He has built a civilization so complex that he needs to mechanize his record more fully if he is to push his experiment to its logical conclusion and not merely become bogged down part way there by overtaxing his limited memory. His excursion may be more enjoyable if he can reacquire the privilege of forgetting the manifold things

> he does not need to have immediately at hand, with some assurance that he can find them again if they prove important.

Computer mind interactions are explored explicitly by life-loggers and life-hackers in QS — where one begins and the other ends is unclear. Evidenced by presentations on memory enhancement projects or the striking thought logging project of Mark Carranza (dubbed the "human memex", who types why he thinks and thinks with what he types in his vast log of conversations and thoughts and memories. Recollection for him is a search function. The metaphoric relationship doesn't really provide us with a linear projection of an idea onto a reality, and then realities conformity to the computer metaphor. Rather, they're enmeshed and complexly implicated, what Katherine Hayles calls "intermediation", which she describes as "mediating interfaces connecting humans with the intelligent machines that are our collaborators in making, storing, and transmitting informational processes and objects." Out of these processes emerge ways of inhabiting the world and bodies that, in the current moment, include computational means and metaphors. The cultural roots of MyLifeBits demonstrates another way in which the means, and desires of Big Science (or, now, Big Data) are being extrapolated to the personal (the *n of 1*), enabling or encouraging a kind of engagement with one's data as a *Homo experimentus*, or for whom life is logged, catalogued, accounted for to be understood and assessed computationally.

In 2010, Gordon Bell presented his own memex at a Quantified Self meet up. The video, preserved on the Quantified Self website, shows him wearing his SenseCam (which takes a photo every 20 seconds) and standing alongside a screen displaying a quickly moving slide set. Photos—from sepia toned portraits to scanned documents—flash by without explanation or context at a rate of an image or two per second. Streaming images of his baby photos and magazine cover shots backgrounded a short explanation of the project: “I’ve tried to get rid of everything physical…this is just some of the stuff that’s in there” presenting just a handful of the over 100,000 images he had had in there at the time. Pausing at a full length portrait of himself, duplicated in transparency, with the caption: “I am Data” he explained how he worked with Jim Gray, the computer scientist at Microsoft who helped invent SQL, a database programming language they used to create “a transaction processing system for life.” “I tend to think of it as tending to capture everything…we’ve don’t lots of experiments to capture different kinds of everything.” He continues: “I regard my hard drive as the ultimate ground truth, that’s e-memory. I regard this [pointing to his head] as my url to my e-memory and metadata. My physical memory is the accessor for my ememory….one has a bunch of different lives here…and then we have a personal state of an individual which is location, heart rate, blood pressure, stress, GSR[46], all of the things you want plus the physical stuff.”

While MyLifeBits and the memex circulate in a social space that imagines the personal computer as a life-log, Bell focuses on the biological data: “the killer app is health!” His own health record goes back to 1941 and includes X-rays, genomics reports, cholesterol levels, operative reports from his two heart attacks and two bypass surgeries. He has scanned all of his pacemaker data, the granularity of which is ignored by his doctor. “No one cares until I get sick,” he complains. Alluding to the idea that slight changes or shifts in the large data set could be useful and tracked more closely. Displaying more charts and “squiggly lines” he walked us through hospital stays and infections. With time short, he frenetically gave us a tour of his data-driven medical history continued apace through audiograms depicting hearing loss and polysomnograms for sleep apnea. However, with all his problems “I think the key thing is

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[46] Galvanic Skin Response measures sweat on the surface of the skin and presumably can monitor the sympathetic nervous system.

wellness monitoring. You want to monitor what's your ambient there….I tend to settle on this pedometer…I weigh everyday." He showed a satellite image of his walks, a birds-eye view of the GPS coordinates in Sydney Australia where he spends much time. Anticipating how people track these exact same metrics now, he says: "But I think this where we want to be, which is essentially the cellphone is a healthcare platform, where you want to know your GSR and stress as a function of where you were."

Marching through the rest of his talk, he shows more data, more charts—lines and bars—giving us a data dump of his health, which he estimates might amount to a ten terabyte life. But there is more here in the MyLifeBits project than just a data deluge. This more general version of the high-definition human (Bell uses the metaphor of high resolution), aided and augmented by the memex points to the way in which the well role function of the quantified self partakes of computational thought, and a model of the mind and body as a computer system, to be tracked, monitored, and optimized. Optimization—recalling the debugging of a software coding or a computational system—can refer to efficiency of time used, tasks accomplished, mood elevated, but also to a higher state of wellness, defined by the user. It is a key function of the well role and appears a great deal in Quantified Self.

Informants—many of whom are engineers— use the language of computation. When asked how he relates to his database, Bell describes how his mind is the "URL" to his memex—meaning, whatever he wants to search for in his bio-brain directs his mind *in silico* to specific places, data points in time. For example, he described how at one point he was feeling wheezy, that his lung capacity was waning. He wanted to test his intuition, the validity and objectivity of which he doubted, so using his bio-mind as URL he called up past spirometry results, obtained current ones and confirmed his suspicion. "That confers in fact that I have this problem." This moment of utilizing an archive of personal data to either shore up or refute intuitions one might have about one's body is a common theme in quantified self practices, where hunches become hypotheses and data collection establishes baselines, encourages feedback loops, and fosters system optimization.

The idea of QS as big data, or as I previously described as deep data, is expressed in biology as the emerging fields of multiple kinds of -omics, such as genomics, methylomics, proteomics, etc. I spoke with Bell's biomedical analog, scientist Michael Snyder, who has similarly made himself the subject of his own research on deep biological data as a path to create personalized medicine. In media reports, he has been dubbed another "ultimate quantified self" for the amount of biometric, genomic, proteomic, metabolomic and other -omic data that he has collected on himself through his lab. Snyder is a pioneer in studying biological systems as systems, investigating thousands of genes at once for patterns, instead of studying one gene at a time. A decade or two ago, this work was considered basic science, however in a move from Yale to Stanford Medical School, Snyder actively started to put his frame his work as potentially clinical and applied. In an interview in his office at Stanford he told me:

> I always thought it was kind of crazy when you go to a doctor's office they give you back a report with 15 acolytes that are measured and knowing they can analyze thousands of things at once, this seemed a little primitive to me….Really that's what launched in 2009 when we moved here: Let's bring in genomics and other omics into healthcare and start shifting. There was a motivation at that point to think too, how do we *really* transform things? Where medicine right now is very reactive. You get sick, you go to a doctor, here's what we think you have,

> here's now we treat you. To this, genome sequencing's coming…. We could measure 1,000 molecules. Let's make this all a proactive thing where you can predict risks or catch things early, long before they show up symptomatically.

Dr. Snyder showed me visualization after visualization of his massive data sets (billions of measurements) of him alone—though he has now enrolled 60 more subjects into a similar ongoing -omics project. He was the pilot for what a "so-called healthy individual" might look like, to get what is often called in QS as a "baseline." All this data about his body—including specific micro-biomes from his gut, urine, nose, tongue and skin—make what they call "the Personal Omics Profile….Initially we were following about 40,000 molecules now with the macrobiotic and epigenome, it's literally billions of measurements we make on me, okay?" Life here, one's life course is an *n of 1* spread out over time is the platform, the experimental system:

> It's a lot of sampling over these four and a quarter years. Here's the first time, four days later, each of these is a day, so nine months after this initial infection I got a second one. I have a little kid so I was getting sick at a pretty high frequency. Not so much lately, but we do very dense sampling…when I get sick and then every two to three months when I'm healthy…The idea is I want to follow in detail the physiological change, well in this case the biochemical changes that are occurring during this disease and recovery times, if you will….You know, when you get hit with a viral infection it probably is one bug that's triggering it, but is it one thing happening or are there ten bugs all kind of going berserk in you? As soon as they [the doctors] figure out, 'Well you have

> street throat or the flu or something like that,' they're done, they don't measure anymore, but maybe you have 10 things going on with you and you don't…, nobody even knows that. These are some of the questions we're getting at.

I discussed Dr. Snyder's work and story in the previous chapter as an example of the "high-def human" where the depth and density of data has the potential to create further diagnostic differentiation. Here, I focus on how the depth of time and data leads to a computational mode of health where ongoing collection of data, the saturation of a life course by data points—of time and biometrics, all infinitely divisible—may lead to feedback loops of information, insight, and prevention ahead of the illness curve. This kind of deep data differs from his genomic data, which has told him that he is at risk for developing aplastic anemia in the future, in that it captures the body's processes in *real time*. In the mode of the well role, data is collected to monitor and understand baseline processes, tweaking and course correcting continuously. A data-driven well role places the emphasis on data profiles, or in the case of Professor Snyder, Personal Omics, where perturbations in the data drive action. Snyder's own data story garnered some press for using big data and continuous surveillance of multiple biometrics (from his micro biome to activity to blood glucose levels) diagnosing himself with type II diabetes, predicted by his genome scan and confirmed by self-surveillance:

> We'd been doing all these other omics profiles including my metabolomics so we had been following my glucose and I had been marching along perfectly normal but ironically I went in for a very fancy glucose metabolism test with the experts here and even before we started my test we measured my fasting glucose it came

> out 127, which is high. It should be about 90….Anyway we repeated a week later. We measured it again, it went up higher so we're both surprised by this…I didn't know much about diabetes so I went to my general practitioner. They don't give you a lot of information and you know, she was skeptical, said "What are you talking about?"… I I don't look the normal phenotype people expect for diabetics which is generally overweight. We went there, we measured again and sure enough the glucose was even higher and hemoglobin A1Cs cross the threshold and, you know, basically she says, "you're diabetic!" I could tell you when that was. That was April 11, 2011 because on that day I basically completely changed my diet and I changed my exercise regime, so I had been eating a lot of sweets and things because I didn't know I had a problem or anything, right? I basically completely cut out all exogenous sugars like cakes and sodas and all that. I've had one bite of wedding cake since and I still have fruits but otherwise I don't. Then I also, I had been biking but I doubled my biking and I started running and it didn't happen right away, but gradually I brought it down to normal. Took about six months.

It is unclear here and to Dr. Snyder if he is considered ill or well. According to physicians, he now is diabetic, based on his glucose, which is usually used as a screening tool. However, in the mode of computational health, ongoing monitoring of data introduces real-time response to a perturbation in the system. He returned his numbers to normal through an aggressive behavior change program, documenting his personal risk, watching it evolve in his numbers, and take action.

> That is the goal of personalized medicine. To get information back to you based on what your profile is, in this case my genome sequence or my glucose and act upon that, that is what personalized medicine is all about. That is the goal…The reason this is such a big deal and got a lot of attention, is it's the first time that anyone used the genome sequence to predict a disease in a healthy person and they got the disease and in my case the information was *actual*.

Dr. Snyder moves between what *might* happen, as foretold by his genome, and what is happening or might continue to happen, as told by glucose trending upward. In the well role, where metrics is continuously monitored and tracked, data approaches into the realm of the "actual" or what is real, current or now. This is partly the function of pixilation: it is an attempt to approach life as experienced, as what Henri Bergson (2010) described as *duration*. In later chapters I will revisit some implications of life lived in experiment and through data. For now, I want to point out the well role that emerges in feedback loops between bodies (both virtual and actual) in-formation[47].

At the level of the *n of 1*, the high-def human defies or challenges diagnostic categories, where patients are traditionally 'lumped'. When we focus on the data and -omics a strict division between the normal and pathological breaks down, or at least recedes. A normal state becomes pixelated by billions (or more) data points, oscillating around baselines. The task becomes not just one of diagnosis but one of differentiating the signal from the noise, monitoring, feedback and course correction.

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[47] I feel there is more to say here on virtuality and actuality in the quantified self, but left to later chapters.

> According to the medical profession, you never become un-diabetic. You become managed. So, once I got my glucose back down, technically I'm managed. I don't spend much time losing sleep about it, because it is what it is. When my glucose is high it's not a good thing. I get on it, control it, that's a better thing.

The line between the well role and a managed chronic managed condition is increasingly blurred, here. Dr. Snyder does not necessarily feel that a label of diagnosis is relevant. What is relevant is the metric that must be managed, as he feels well. This is similar to the kind of management introduced by the correction of asymptomatic disease risk factors, like hypertension. The well role captures both the increasing measurement and monitoring of more and more biometrics and the kind of active engagement that focuses on the continuous production of information. Maintaining wellness is about self-responsibilization read through a new ontology of health, illness, and epistemology of risk. Moreover, it overwhelms "risk" as a category of experience and understanding as a future threat in the present (Gifford 1986). The feedback loops of going from virtual risk, to actual information and then real-time response (for now) repackages this equation of temporality, to a new kind of relation to the understanding of the evolution of disease in time. This form of subjectivity and experience is part of what I will describe later as *Homo experimentus*. For now, I focus on the difference that wellness in data in action makes.

Finally, the merging of a personal and a scientific project resonates with the growing movement of self-quantifiers who engage in (albeit lower-resolution versions of) self-experimentation. He is elevated in this community as a model *Homo experimentus*—perhaps more so amongst bio-hackers and self-quantifiers. In our conversation, he admits that his epistemic approach—letting the data speak to him, as he says—goes against traditional hypothesis-driven controlled experimentation. Instead, he exemplifies a new big-data driven paradigm (Hey, Tansley, and Tolle 2009) that is more in line with understanding the body, or experimental system as an open ended data set, where data and continuously collected information provides feedback for continuous prediction, intervention, modulation and optimization. In fine and even dizzying detail, Snyder is able to perform the well role at a very high level of granularity. There is no end, though, to his experimentation or even optimization as he continues to add more sources of data—devices and services that roll out to the consumer market. While his resources and research power outstrip the average, lay *Homo experimentus*, he shares with other self-quantifiers an aspect of the well role that experiences data, life and the body as information system optimization. Next I turn to more examples of this lived metaphor, where the personal data technologies intermediate our experiences with personal data, facilitating new kinds of networked ways of placing and understanding our bodies and lives.

III. Well Role 2: Body Computing

When Gordon Bell proclaimed that the "killer app is health!" it was unclear what he meant. Did he mean that the most useful, profitable, transformative innovation to come out of MyLifeBits or any other big personal data project will improve our health, by consolidating all of our information in one place enabling referencing and better monitoring and diagnosis? Or did he mean—taking his words more at face value—that health itself would be an application, an algorithm and computer program? Or did he mean both? The former possibility is obviously his main point. However, the latter, which I take from the way he phrased his wish, I think points to a deeper or perhaps another parallel meaning of personal databases: that is, the ways in which we become interpolated into computation and computational modes of rendering information, action, thought and experience. In this section, I dwell on a few more the ways in which some ways of enacting the well role enacts metaphors of computing and systems engineering, drawing on studies that take the metaphors that we use for bodies and illness seriously as signaling cultural social shifts, linking how we live, ail, and even work (Martin 1995). My analysis builds on analyses of the shift of the biological sciences to an information science, with the emergence of the genetic code. With the emergence of code and information as the pervasive metaphors for molecular biology, Evelyn Fox Keller (1990) argues:

> It is not so much [a shift] from representation to intervention, but rather from intervention in the larger and indirect sense of the term appropriate to the aspirations of most late nineteenth-century and early twentieth-century biological science, to the particular conception of intervention or control that promises effective mastery over the processes of making and remaking life.

The making and remaking is a key element here. With QS and the big data approaches to health and illness, the information model has extended well beyond the genome, with Dr. Snyder as an exemplary case. Additionally, data-science shifting the notions of “the experiment” (from controlled trials to big data analysis) there is a merging of representing and intervening. Fox argues that the root of the information-as-code metaphor for molecular biology lies in the quantification of life, or the divisibility of life into quanta as genes or mutations. This operation is extended through health divided, ever-finely into data. Code, in the case of health data, continues the metaphor of puzzle, and expands it to continuously growing puzzle. Unlike the genome, a person's individual health-as-dataset is virtually and potentially infinite. Body computing metaphors, therefore, necessitate a rethinking what life as code means.

The computing and systems engineering metaphor of the body appeared in many places in the field and was drawn on in different ways—from optimization and habit design to mindfulness. To begin, the terms "life-hacking" and "bio-hacking" circulate in and out of the quantified self space, signaling an approach to the body or life that is not just oriented to problem solving or "solutionism" (Morozov 2014) but as a project and a system to be tweaked and improved as an engineer would approach it. Self-tracking and hacking offers a form of data-intensive, non-pharmaceutical self-fashioning (Dumit and Greenslit 2006; Schüll 2012). Following Dumit and Greenslit, self-tracking offers a new kind of "informated health" that relies on monitoring of metrics. Notably, a recent conference on digital health at UCSF in the Spring of 2015 was called "Informed Health," which envisioned a future where we ceased to call these tools "digital health" and just called it "health." This aspiration implies a future in which normal health and health care are defined by forms of informing and information—an aspect of what I call the well role.

In one striking example of computing talk, one quantified self presenter and tool maker (he makes a tracking app that pairs data collection and reflection with coaching), talks about "debugging" his allergies:

> I've been using Mymee [the tracking application] since the beginning of May. I've made more than 9,400 observations of myself, my condition and my daily life…Something that used to be I was subjected to symptoms. Now its empowering data and now I'm more feeling like a hunter following the trail.

> Every time I sneeze now, it's the symptom. This is my system revealing something about itself. That's where I get empowering data for making new experiments."

Self-trackers sometimes defend what they are doing as *not-science*, but rather engineering a problem at the level of the *n of 1*:

> Coming from process improvement, I'm using the scientific method but I'm not trying to prove anything for you. I had a problem and I'm using the scientific method to improve something about my own processes. That's a kind of iterative learning process.

Iterative processes and feedback loops are recurrent themes in quantified self, where data collection of outside, presumably objective data about one's behavior or body offer an opportunity to reflect and change accordingly. Another engineer that I spoke with similarly invoked systems design and optimization driving his self-quantification:

> For me it was really about…I'm a systems guy. That's more or less if I was to describe my career, it's about taking a complex system, and making it more efficient, making it more effective, making it work. That's a lot of my motivation, was just looking at myself as a system, and trying to take apart all the variables, and understand how exercise actually affected weight, how activity actually

> effected mood. Once I started orienting my perspective in that way everything was a question.

Here, computing systems and processes melt into the body as a particular kind of system, that can be modulated and modified. Importantly, confronting and altering the mechanisms of the body, habits and behaviors that result in sub-optimal wellness, is enabled by an orientation toward life and the body that externalizes and objectifies it as a system. As another tracker put it to me, having a system for workflow and tracking it, externalizes it and removes some of the self-judgment and shame potentially involved in attempting to examine and remediate one's failings (in work and in life). First, the experimental mode—as *homo experimentus*—also shores up an objective orientation, also one that involves semi-detached concern to play, "debug", optimize, and hack. Second, here, this engineer and tracker speaks of the "actual", in terms of a kind of real truth of how his body works and reacts, at the level of the *n of 1*, where problems and solutions are personal and personalized. The actual—seeing cause and effect in the data, in real time—grounds and lends coherence to dis-ease.

The externalization of the system is a repeated trope in QS and amongst my informants, who like to talk data as objective, free of the kind of shame that surrounds less than ideal behaviors (tackled elsewhere in discussion of *Homo experimentus*). For now, I want to flag the systems aspects of this kind of objectivity—the enabling of reflection, or feedback loops. In an influential paper on "personal informatics systems", human-computer interaction designers map out how "one way to obtain self-knowledge is to collect information about oneself—one's behaviors, habits, and thoughts—and reflect on them." This could be understood as objectivisation of the subjective. Reflection, or feedback loops as they are often called, is the awareness function of much tracking, that many in QS point to as foundational to behavior modification. Also, referred to as “write now, read never”, this kind of data collection is appreciated in QS for establishing short term feedback loops to cultivate awareness of habits or bodily states, such as logging food, time meditated or weight on a scale. Even without a goal, feedback loops are described as cultivating an honest awareness, checking in with a kind of reality. For example, the maker of a meditation app explained seeing the need for nonjudgmental feedback on actual meditation practice, noticing that he would unwittingly lie to himself, or really misremember, how often he practiced meditation. He felt that by documenting the meditation, no matter how seldom, would lead to a more reasoned approach, rather than a shame-based approach to practice. Memories when they are “false” accounts are rejected as subjective here, so are some of the emotions or aspirational desires of meditators. Feeling like a good meditator, feeling like you do it often, or feeling connected to a community of practice, are false when not documented as resulting in real minutes sitting, actualized in data. This self is optimizing towards a kind of transparency. Documenting actions or tasks or time via data seems to contribute to transparency of self and life

Flux, the breath-tracker, began as an experiment in the founders’ “Calming Technologies Lab”, where he “did a series of studies where I had my colleagues hack together sensors to measure peoples’ breathing, and measure it when they’re at the computer, and see if we could change their breathing with feedback on the computer, and later feedback on the phone.” I learned from the founders that their goals included wanting to provide user actionable information, telling them when they are tense or focused, providing informed and guided feedback on their data. Reflection and awareness, as shorter-term feedback loops towards behavior change, recur in QS. The overriding of breath—usually under autonomic control—in a way typifies the management and optimization of mind, body and life, through data that, through phone or application interfaces, lines on a graph, externalizes a manipulable copy. The algorithm that we helped create through our coordinated actions participates in that mirroring of self and normalcy. The self in this kind of self-reflection, then, when using such a tool, mingles selves when your data meets that of the algorithm. The well role involves a kind of self-reflection, with wearables or devices that nudge the user to take more steps or breaths offer "reflection" in the mirror of an algorithm.

For one self-optimizer, following the data, tracing the line, is daily or weekly feedback: "After that day and I got back on *ogbono* [a seed that's considered a "superfood"], I'm telling you the story of like a line, a curve because my weight and my waist went *du du du*, and then plummeted, like within two weeks like eight pounds or something and like two inches off my waist, my belly. And that got my attention. It got me also very interested in data and also tools and modalities that would control this line, whatever the line is, the line of data. So it could be my weight. It could be my waist." Unlike long term experiments, following a line on a day-to-day (if not hour-by-hour or minute-by-minute) basis enables a kind of control and grounding in a daily data diet, whether that is stepping on the scale, clocking meditative minutes or logging a glucose level. There is more to the line or the data point than just the external objectification that it enables—it also simplifies, distills, and condenses a sticky problem (perhaps a socially or emotionally burdened one, such as sleep or weight) to a number or a pixel. The mess of life in analog—in duration—is rendered legible and changeable as digital data or a line on a graph.[48]

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[48] I return to this digital and data-driven form of life in later chapters.

IV. “Behavior change for the bottom line”: The Well Role, Productivity, and Performance

Field notes, Bay Area Quantified Self Meetup #34, California College of the Arts, San Francisco, August 2014:

Walking past the modular white-walled gallery space of CCA, I found the usual group of demo tables, arranged along the perimeter of the square space. At first I skipped the familiar companies—the existing and up-and-coming wearables and activity trackers—to the new companies or devices that came to eagerly offer their technologies to the room of early adopters. After visiting with a woman who had created swimming goggles that could log heart rate, pool laps and distance, I floated over to an older, formal looking woman, slightly out of place in this setting dominated by the young, the casual, and the male. Her table displayed cars for something called “The 21 Day Club”. “We measure things that are hard to measure,” she explained, rather proud. I learned that her company, ESSI systems (she found the company in 1983) worked for many years as an employee wellness program where they would help gauge EQ (emotional intelligence), resiliency and stress, and develop behavioral tools for workforce wellness and leadership development. She handed me a brochure and business card that read: “Behavior change for the bottom line.”

Speaking of their strange name, she boasted that they were the ones who figured out that it took 21 days of practicing a habit for it to stick. I recognized this as a truism that circulated in habit and behavior change circles. “Yep that’s us!” she confirmed. When I asked her more about what they did, she began to flip through a complicated, color-coded info-graphic that presented a mosaic of wellness metrics. I was confused by both her complex tools and her presence at a Quantified Self meet up. She lamented “companies don’t spend money on their employees anymore" so they were modifying their tools—statistically validated and evidence-based—to individuals, incorporating the latest trends using sensors and biofeedback. I found later that she was not the only corporate wellness program there that reaching out to the quantified self community to cross over into the emerging self-tracking as self help industry.

Sensors would enable her to merge her tools for measuring emotional intelligence (EQ) and resiliency with biofeedback strategies, that is, close feedback loop between sensing, measuring, reflecting, and acting. Pointing to the start-up Flux's booth across the room, she brought me closer, speaking in a low tone: "what they do is child's play", nowhere near the complexity and scientific precision of her program, based on the latest neuroscience, statistically validated tools, and educational psychology. Emerging from the corporate wellness world, where the bottom line had to drive results, she looked askance at the many of the apparent toys around the room.

One such toy was a 3-electrode EEG (electro-encephalogram) that recorded brain waves. This company, too, was looking to translate from the research arena—notably "neuro-marketing research"—where they sell their full-lead EEG, to the consumer side. I sat down in front of their tablet and let them fix their simplified version to my head, careful not to spill too much conductance gel down my face. Then, using my powers of attention, I moved blocks on a screen. The EEG leads translated the electrical signals emanating from my concentrating brain to the game, giving the illusion of telekinesis. Their pitch also included attempts to induce and then capture the data produced by frustration. The system didn't always work as designed and it was awkward to try. Frustration waves flowed on the screen, turning my thoughts into traceable images the revealed the truth of my sentiments to everyone in the screen's range.

My attention was then broken by a familiar face—Gustavo, the budding productivity guru. After visiting the other "toys" in the room—activity trackers, life logging apps, etc.—I joined him and his friend, a woman whom I met a few meet ups ago who works for a Korean life-logging company. Gustavo looked less buttoned than when we had met a few weeks earlier. He was no longer wearing his smart Pebble watch, an accessory that tethered his smartphone to his wrist, where he could check text messages, the weather, control the stereo volume, and, of course, the time. He had just returned from a 10 day silent meditation retreat, doubling as a "digital detox." He spoke with his usual excitement and intensity about the transformational silence and isolation. Eye contact is forbidden during and after the 11 hours of meditation per day. "I have never felt so alone." Wide-eyed, he described his heightened sense perceptions, too. "I could hear my heart beat."

Standing amidst all those tools for making just such invisible physiologies and mechanisms visible—from heart beats to calories burned—it was strange to talk about tech-free modes of intuiting and perceiving ones body and surroundings. Yet, our conversation was entirely consistent with the QS desires to be attuned, in a way, to the resonances of the body. Meditation and mindfulness talk reverberate throughout QS partly because of the resonance with seeking self-knowledge and control. But there is this other element of getting out of the way, circling a true self, an inner core, or an objective unmediated grasping of ones behaviors or physiology. Creating data out of ones daily life—minutes meditating, or steps taken—mirrors the move of the perceiving mind of meditation.

Both the quantified self and the meditator—at least in this context—become the ones who notice, who point out, become the outsider to the thoughts on the one hand, and the data on the other. As one QS meditator put it to me: "either the coffee experiment or the meditation apps both function quite similar—where there are false beliefs and thoughts that are going around and the experiment or process works by proving that there is another self. It proves that it's not the person that believes. I can be thinking one thing but can be doing another thing…There is this notion of all of these things pointing to a deeper idea of the self." Gustavo similarly describes his approach to productivity hacks—that self-tracking of time used or tasks completed creates a relationship within oneself where you become your own internal manager. The workflow, as he calls it, is a way to externalize a process, to make work, like data, outside of your self, free from shame or judgment, just something to be worked upon and optimized. Before he quit his job at a branding agency to become a full-time productivity consultant, he complained "I got tired of having an actual manager that did not do that job as well as my manager side…I would request reviews every month, like that personal review that people hate and dread all year long." His self-designed productivity experiments did not go over well with his managers, he had explained in our interview: "the workplace is not built for that, it's not built for workers to care about and conduct experiments on themselves." He had a similar experiment with his physician who even referred him to a psychiatrist for tracking and collecting data on a voice problem. He was finding himself getting more hoarse than what felt normal to him, so he tracked the data, even acquired a scope to look at his vocal cords. According the physician, Gustavo was more than the "worried well," he needed psychiatric help.

I thought back to our interview weeks ago, when he described his turn to meditation, tracking it and its effects, to really objectively see the results. Using a customizable tracking application called Reporter, he created 20 questions that had had to answer every day he missed his self-assigned 30 minutes of meditation. "Some of them were like, did I have breakfast? Did I sleep well? And others were like, how mindful do you feel?" After a month, he figured out his most common “trigger factors”, risk factors that were most associated with not meditating. He’s incorporated this and other experiments into something he is calling Habit Loop 2.0 and teaching it in his online course for designing habits for optimizing work productivity.

His course augments David Allen’s “Getting Things Done” (a well-worn manual of productivity hacks) with quantified self tracking and BJ Fogg’s habit insights. Gustavo is a budding and aspiring productivity guru. His work integrates many of inter-related dimensions of the well role, where optimizing performance in body and mind converge. He offers his strategies of optimizing productivity with tracking, habit building and mindfulness with individuals in online courses as well with large corporate clients. In the framework of Habit loops and workflows, success comes not from cultivating a truer self, one that is a better more responsible, moral person. Rather, habits and a habitual self are emergent out of an environment that is designed and structured to nudge our behaviors this way or that. There is no center, no better self at the center, just better protocols. The self implicated in the emerging field of habit design, built into behavior change applications and tools, is the “healthier” or perhaps more well adjusted chronically addicted subject described by Natasha Schüll (2012; 2006). In other words, the discourse and practice of habit design—where a desired repetitive behavior is mediated and modulated through data—invoke a subject that is legible through its addictive (positive or negative) attachments. The well role relies on this habitual self, one that is almost evacuated of a will, or a central subject of depth, replaced by protocols.

When it came time for the talks of the evening to begin, the three of us, engrossed in the other-worldly place of Gustavo’s mountain meditation retreat had been describing, reentered the lecture hall, where we were greeted with the familiar site of a stage, a podium and a screen. However, there was one mysterious, unmentioned tablet screen displaying a single, digital number, left unexplained through many of the talks. After the host (CCA) introduction, which included a invitation to join a designing for wearables course, and Gary's welcoming remarks, the talks began with Michael Kerr revisiting his work productivity and movement efficiency data after initiating a new boxing program for people with Parkinson's disease.

His lightning talk was followed by Jon Cousins the creator of several mood tracking apps, and now, a card set for assessing mood and overall wellness called WellBee, to "give a quick objective way of rating ourselves in three dimensions…with regards to making our well-being. So that's mental health and physical health and on the matter of social health you're connected with some other people around you." There are 12 hexagonal cards total—6 for positive traits, such as "understood" and 6 for negative traits, such as "lonely"—with ratings of zero ("not at all") to five ("extremely) on each side. To develop a WellBee score, you measure yourself on each of the 12 traits and then use the scoring grid to come up with an overall number, which you plot on a graph that comes folded up in the small hexagonal tin. Jon used the cards with his partner Alex and her daughters to check in every morning, before the day can affect you.

> The biggest benefit of all is in being able to share stories because WellBee becomes a safe way to know how you're feeling. It's a kind of objective, non-judgmental way. You can explain why you're feeling good or more importantly bad. What we are then able to do is devise some kind of strategy for when things go wrong.

For John's high anxiety score one morning, Alex prescribed making a list of worries to externalize and work on together. Unusual for this forum, they were exploring self-quantification together: “I think it feels as to us we’re closer when our WellBee scores are in sync with one another and it’s been really helpful to have this kind of objective data.” They had even calculated correlation coefficients to see if they were ‘actually’ in sync, since they lived and reflected on those lives together. John did not want or assume that syncing their data streams was useful—it probably came in handy some times and hindered at others—but achieving balance through course correcting instant feedback was definitely the aim. Here, the objective is achieved not just by translating feelings into numbers, but also by performing the measure in the morning, when it is assumed that there is a baseline of feeling, before the days events intervene. This belief that the morning provides a more raw or actual assessment of mood or wellbeing implies that mood and wellbeing is based in the individuated self, some core that is at a baseline, unperturbed or ameliorated by the world in which they are embedded.

One question from the audience wondered about the “danger” of using the cars as a communication tool rather than a measuring tool. Laughter from the audience at this point may have signaled some ambivalence towards that distinction, measuring and communicating. Clearly, the cards worked because they enabled communication, provided a standard with which to convey distress. Much of QS data, especially presented in public forums, does fulfill this function of communication of a narrative and story through numbers and data. From a previous talk on the cards: “It’s a terrific great way for our family to stay in touch with one another, to communicate better and to find new ways or better ways of helping each other thrive.” With these cards, they track their ups and downs over their morning coffee, and start their day knowing where they sit. As for not dwelling in the downs:

> Alex: I actually like to track ups and downs and see... if you're tracking the downs you can see that you're kind of fucked up but it's not a permanent thing. But he doesn't like to track when he's down. So I know it's a really bad day when he comes out of the garage and I say, "What's your score?" And he'll say, "I can't do it today." I'm like, "You're going to go do it now. I want to know what it is. We're going to fix it."
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> John: I mean you are right. I was very reluctant one day to do the score, but, yeah

Living in the data stream, there is movement to life, progress to be gained but also to be lost. It helps them to locate and ground themselves on a shifting line, rather than settle in the chaos of their angst and depression.

The WellBee presentation was followed by Paul, who tracked every time he got upset at work and set up an alarm system using a heart rate variability monitor. He described methods like this:

> I used the HeartMath EMWave2 that measures heart rate variability and indicates when you’re in and out of coherence. When I was out of coherence I captured that as an upset. I would stop what I was doing and use an audio recorder to keep track of the time, how long I was upset, the reason, and what method I used to recover. I tracked 71 sessions (each session was 25-45 minutes) totaling 42 hours of tracking time. I logged 1292 upsets during this period. And overall, by tracking and intervening he succeeded in reducing his time being “physiologically upset” by 12-15%. I actually discovered a way that I should reduce the upset, it did work

> but I approached this entire thing, as an athlete, I approach this as a training technique with the way so that I can actually do specific technique that actually make it work in confidence that I found.

Athleticism is, unsurprisingly, a prominent theme, where many trackers who look to optimize their health, improve what is already healthy (or at least not pathological) understand their goal as better performance, achieved through the athletic discipline of self-care through tracking[49]. Paul continued:

> I started to think of it like skiing a mogul course. The moguls didn't move, it was about how effective I could move through them. And, dealing with upsets is like playing whack-a-mole. They come fast and furious and every second counts. For recovery I was able to find that my most effective technique was breathing. By returning to six breaths per minute routine I was able to improve recovery time from 33 seconds to 17.8 seconds. It was the primary way I could remove myself from being upset and make myself calmer.

Paul likened his emotional work to a navigation strategy on his blog, where he writes about these and other self-quantifying experiments:

> Looking at the frequency of the Upsets and their regularity, I could not imagine why I was getting upset every two minutes. It was oddly regular. So much so, that

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[49] Foucault's (2001) discussion of care of the self invokes the athlete as a moral paragon of ancient Greece.

> it reminded me of my experiences doing open water swimming. The most efficient swim stroke is having your head in the water and keeping a horizontal position, but with open water swimming you have to break stride periodically and look up. It is inefficient because you disrupt your horizontal position but as a whole far more efficient than swimming smoothly and off the course. Are my "Upsets" really just a version of this navigation to ensure I am steering correctly?
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> I found that using work plans to focus on one thing for 25 minutes at a time removed a lot of Upsets. With that focus I did not have to question whether I was doing the most efficient activity or not. I was "in the right place" for that 25 minutes. I still was triggering based on elements of what I was doing but the entire set of questions regarding how I was using my time disappeared. I created a mental space of focus, and those navigational triggers around whether my activities were the best ones to be done at the time dropped.

Here, Paul is not talking about recovery after a work out or a race; he is talking about his emotional states at his daily work, where being upset came from "feeling lost" or "being in the wrong place." He achieved physiological "coherence" (when the variability is patterned and seen in states of calm), with his breath and with structuring his work in ways that emplaced him and his work. The tacking back and forth between work tasks and emotional/physiological states had become a sort of microtuning of performance. For him, that meant breaking his work into small 25-minute chunks. Figuring out what led to coherence required an incredible workflow and process: the heart monitor going off, audio recordings of the circumstances, and recording the intervention. Every other minute, he had to engage in the feedback loop and process that he had created: “It was actually a training point, you have to learn how to deal with feedback. It's really, really difficult during the beginning because you want to try to fix it and that actually makes it worse.” Paul entered a feedback loop to optimize his work as well as the tiny moments of suboptimal psycho-physiological health, where stress is conceived not as an affective or emotional state, but imperceptive to our own hearts and minds, requiring the right sensors.

Mood can take the form of complex reflective processes such as WellBee or as invisible data streams generated by our bodies. In both cases, the phenomenon is externalized made an object, not totally separate from the self, but implicated in a feedback loop. Paul and John, in a way, are tethered like an umbilical cord to their data, impacted by its recording, reflection, and reactions, by participating in what they describe as a communication system between bodies, data, and action. The development of hyperconsciousness was taken as not only possible, but optimal for living and staying well in and through this technology. Paul’s presentation was on the extreme end of how much data people collect—and it was criticized by some I spoke to afterwards who felt it to be unlikely and even absurd—however I share it here as one endpoint for more everyday or less frenetic forms of self-modulation and control, such as habit or mood tracking tools.

The urgency to fix these upsets comes from the belief that it is the daily exposures to stress and stresses on the heart—imbalances between sympathetic and parasympathetic nervous systems—that take a toll on the body, slowly chipping away at a slow death. This is also desire to stay balanced in the face of life’s turbulence or unmooring, to know where you are in space, work and on a graph. In these examples, the idea of the well role is tied to a mapping practice that presupposes a healthy state that is in a constant state of disruption or perfectability—slight alterations of mood, heart rate, and performance can be calibrated so that an optimization of health can be restored. Here, being ‘well’ becomes a constant focus of attention. It is hard to tell, in this sense, where wellness ends and unwellness begins, as they seamlessly drift into one another. Both of these men engage in a well role that enjoins them to measure, collect, and capture fleeting states—ones that might otherwise be described or seen as subjective—make them objective, placed in scientific relation—correlation—with other variables (partnerships, work activities, time).

These daily measures and interventions on wellness sometimes reflect the need to correct what medicine would consider a pathological state, an upset every 2 minutes may be understood as generalized anxiety. However, this was below the surface—Paul did not *feel* chronically anxious. He had to measure it. When asked this by an audience member, he replied:“It was far less chronic. I had reached a point in my life where my son was going to college, everything was great and I just remembered talking to my wife saying, "I thought at this point I have achieved what I want to achieve but, could I be happier?" Not everyone who engages in QS is happy and up for the challenge of being happier. Problems are being solved, especially for the chronically ill. The creators of WellBee and many informants who track mood and general wellness have struggled with depression and anxiety and turn to the tools of trackers and mindfulness.

However, what I am calling the well role, is not so much about those who are well engaging in extreme self-quantification and self-help regimes; rather, the well role points to the mode of continuous engagement in the process of data- and metric-driven feedback loops for improvement. When the body is continuously deteriorating or on the verge of collapse, broken or healing day-by-day or minute-by-minute, the line between the normal and pathological is not just blurred. It becomes irrelevant. The self is under constant modulation, not just care. This role helps to beat back the persistent tides of unwinding, or it gives us a place to stand—on a graph, a matrix, or a timestamp. This kind of experimental life, says "let's try and see!" and the hiccups of daily life can be elevated to questions and discoveries. The well role is engaged, open and always ready to detect imbalances or threats and course correct, in real time. The technologies become passage points through which self-reflexivity about being well or ill is constantly pushed.

After an intensive life-logger presented his personal annual report—FYI he drank 5 gallons of soda, walked 32 miles to the drugstore, and completed 1800 tasks—the final speaker of the evening took the stage, and revealed the source of the oscillating number on the iPad screen as someone's continuous glucose readings—a type 1 diabetic in the room. He was speaking about a crowdsourced project that hacked continuous glucose monitors (CGMs) to enable the raw number to be displayed on a device (watch, tablet, phone) in real time. Type 1 diabetics are treated with reverence, as the "original quantified self" in this community: they engage in daily, life-long (and life-dependent) data-driven feedback loops with their own bodies, activities and consumption. At QS meet ups, wearable monitors and pumps are objects of curiosity and desire, rather than medical devices to cover up. The regular misrecognition of one my informant's CGM as a recreational or fitness device speaks to collapse or confusion that is taking place between what is normal considered healthy. A symbol of dysfunction can easily be one of high function and optimization.

A. Working Well

> It's been a lot of: there's a problem in here somewhere. We don't know which of the hundreds of pieces is broken. Let's break it down and try to find which of

> those pieces is broken, or which of those pieces need to be optimized. Then make the choices around optimizing it. I look at most problems in that way, are these problems that aren't, obviously, simple things, right? The human existence from not just what's going on inside my body. My body is a complex system in and of itself, but it extends into the environment, and what I'm existing in, as well, and those have huge impacts on the system.
>
> - Ben, 37, Texas

The way we work has a remarkable way of insinuating itself into the way we experience our bodies. Emily Martin demonstrated how the pervasive discourse of complex systems theory informs and invades people's understandings and experiences of their bodies. The aspect of flexibility, in particular, took root at the end of the 20th century, in spaces as disparate as immunology to human resource management. Flexibility is lauded as essential to success and life itself. In this concept of flexibility, she notes, there is a collusion between what is normative in changing (increasingly precarious) workplaces and what is taken to be natural, biological. What she shows is that the demand to conform to new corporate strategies become a natural order, experienced through our own bodies and immunologies. Martin pointed to the ways that experiencing the world as such brought the body into view as a "complex regulatory mechanism."

> [T]his bundle of ideas about flexibility has become central to a substantial movement in contemporary human resource management and, through this route, has had an enormous impact on the way in which many manufacturing and

> service industries are reorganizing themselves. This school of thought (which often goes under the unwieldy name of total quality management) recommends that organizations become ‘continuously improving’ organization or ‘learning organization.’ Very much on the model of a loosely coupled system, such a flexible organization can respond quickly to changes in its environment and can initiate changes in innovative ways. (1995, 118–19)

The body takes its cue from the flexible organization and imagines the immune system and health in a carefully balanced, flexible flux. The worker, made himself pliable and compliant to this regime, which made flexibility the cost of participation in the work force. The body follows suit, mirroring flexibility as normative and essential to (immunological) survival.

The well role enjoins the body in similar kinds of work. The well role evokes complex systems theory, through systems engineering, with health hacking, data-driven optimization and feedback loops. Specifically, QS produces a digitally networked body, emitting and acting on data streams, where the analog experiences of pain or affect translate into discrete data points, manifesting “actual” causes and effects.

> I’m a systems guy. That's more or less if I was to describe my career, it's about taking a complex system, and making it more efficient, making it more effective, making it work. That's a lot of my motivation— just looking at myself as a system, and trying to take apart all the variables, and understand how exercise actually affected weight, how activity actually affected mood. Once I started orienting my perspective in that way everything was a question about okay, well,

> I know that I'm listening to a particular music. Does that make me more or less productive versus another kind of music? Could I do something as simple as just listen to the right kind of music, and suddenly get 10% more productive at work, or 20% more relaxed at home, or whatever it may be? (Ben)

Ben, the systems guy at a large corporation in Texas, describes himself as one of those self-quantifiers who collects data voraciously, leaving the analysis and questions for later (often described as "write now, read never"). His projects range from productivity hacking to tinkering with his diet to address his familial hypercholesterolemia; tracking electricity usage to step tracking on a FitBit with his kids. Like many who spend time in quantified self he draws on life-hacking personalities such Dave Asprey, author of *Bulletproof Diet* (2014) and promoter of Bullet Proof Coffee, a mix of butter, coffee, and a high medium chain triglycerides supplement. Ben, like others I encountered in QS, drinks this concoction every morning, a habit he keeps from his cardiologist. Optimizing body, mind and life are strongly linked for those who engage in this kind of well role. *"*A lot of the attractiveness of Quantified Self is how do I discover I can get the same amount of work done in less time," Ben explained. The *Bulletproof Exec* (Asprey 2015) website ("knowledge for high performance") offers a lifestyle and promises a kind of freedom in high performance: "Discover how to upgrade your body and your mind using the proven Bulletproof® blueprint to enter your state of high performance every single day. And it's easier than it sounds. Simple tricks like upgrading your cup of coffee, sleeping smarter, all the way to consciously controlling your brainwaves, are possible with the right information. You can think faster, have limitless focus, laugh at food cravings" The website features a silhouette of a man seated in lotus position, hands resting on his knees, meditating alongside a mountain climber at the top of summit. Featured articles include: “50 shades of Zen: How to meditate for more results in less time.” The bulletproof approach typifies one prominent and maybe extreme version of the well role: active, aggressive, results oriented, holistic wellness that sees body, mind, and life as a flexible system to be highly attuned and efficient.

Ben explained that his life and work—in the middle of a management and hierarchy structure—drove him to streamline his life, getting his body in line as well. Juggling a young family puts a premium on his time, which is up to him to maximize in his work at a large technology firm. Self-quantification, self-tracking and experimentation export the flexibility and continuous improvement demanded by the working world into personal life and wellness. Life-work is a project to be engineered, tailored, and tinkered with into a chaotic, but finer tuned system. Productivity hackers and habit gurus refer to externalizing one’s tasks and processes into, and breaking down time and procrastination through a workflow—personal and self-tracked data channels what remains (activities, physiologies, sleep, diet) into a life-flow, made separate and manipulable through devices, spreadsheets and graphs. The workflow, Gustavo explained to me, removes the judgment by making it outside of ourselves, but it allows manipulation and ostensibly shame-free judgment of another kind, where one doubles and becomes a manager to oneself, oscillating between worker mode and manager mode.

Such holistic optimization is also found in the work of Tim Ferriss, attendee to the very first quantified self meet up, self-experimenter and life hacker, and efficiency guru who wrote *The 4-Hour Body: An Uncommon Guide to Rapid Fat Loss, Incredible Sex and Becoming Superhuman* (2010) and *The 4-Hour Work Week: Escape 9-5, Live Anywhere, and Join the Super Rich* (2007). The titles alone communicate the kind of liberation that is desired and the utopian dreams that come with it. These books are giant handbooks, describing Ferriss’s experiments, many outlandish and comical, others quite extreme—he goes to almost any length to hack his body and his life. Constant experimentation conveys his relentless striving for something that is not quite perfection, but just better. His life hacking and that of the *Homo experimentus* in general shows the restiveness and striving of the well role, creating a space of possibility in experiment.

In my fieldwork and field sites engineers abounded, so it was no surprise when the way they approached problems at work percolated into their self-quantification or experimentation (or perhaps drove it to start). However, the terms of systems engineering and computation exceeded just the bounds of just the circles of engineers. It overflowed, in much the same way flexibility and immunological discourse seeps through the porous boundaries around science (Martin 1998). My aim here is not just how this disciplines workers and changes the nature of work (which is indeed happening)—I leave that task to someone else—but rather that performance and optimization, as they travel in and out of the workplace as either personal or corporate projects, are conjoined in the well role, where the body and life in general is considered not just a complex system, but one rendered open to re-engineering. The biological systems sciences analyzed by Martin to understand immune systems discourse and its saturation into many aspects of public and academic life here merge with systems engineering, specifically from computer sciences, to render biological and personal life legible and manipulable through data. As tools such as the "21 day club" start sharing the same spaces as breath tracking devices and life-logging apps at quantified self events, the well worker and the (worried) well role commingle, making the difference between the two difficult to discern.

B. Resisting Optimization: Ambivalence in a Complex System

When I first described my own memory and grief-tracking project to Ernesto, a QS director and organizer of the global conferences, he especially liked that it was not about optimization, placing it at the top of the program, the opening talk. Gary and Ernesto, I later learned, are constantly trying to balance the QS community, keep it from being taken over by mere efficiency-maximizing optimization or start-up pitches. They see themselves as caretakers of a diverse and dynamic community that brings together a lot of different 'cultures.' I was asked again in the fall to help balance out a program of mostly young men, talking about hacking their bodies or lives. From the beginning, Gary protected the space from monoculture as well as rampant selling. Speakers who are clearly just promoting an app or a tool have been challenged or outright dismissed. So there are tensions in this diverse community which make it interesting to watch how people "get meaning from their own data." The kind and content of that meaning varies, as does the very meaning of meaning, here too. Even optimization, which is clearly built into much of self-quantification, is engaged with ambivalently.

Tracking as attentiveness, awareness and mindfulness practice sits at this intersection of wanting observe oneself and wanting to change. William, a long-time QS member lives in that tension and pushes back against the optimization tide. First, I will offer some background. Maker of a meditation tracking app, William has spent a long time struggling with depression and anxiety, engaging in deep meditation practices. He also tracks aspects of his mood, experimenting with tracking and creating mood diaries with friends, tracking together. His ups and downs came with an incredibly stressful career in technology startups, including as a founder. Drawn to Silicon Valley from abroad with a vision of a better, freer, creative community:

So back then, um, first of all, there was like the obvious background of Apple., like that first generation of personal computer kind of success. Um, but also Xerox PARC was a thing, you know. It shaped my imagination of, you know, what the Bay area might be like, of really cool stuff that people do here. And also the kind of culture. Um, because there was evidence that there was kind of a lot more appreciation of creativity in tech than was apparent to me in [Europe, where] it was kind of industrial, much more short term focused. Um, so I was kind of coming for cultural reasons…So my image of it was entirely fictitious, basically. You know, it was based on a documentary I had seen … focused around the Allen Kay computer era, which was before Macintosh. I was 8 years old, watching this documentary. And it was a place where computers represented freedom, and a kind of freedom of creativity. Like the world was going to change from this place. And, that that's what it kind of represented.

That's what it kind of grows into for me. And you know, the BBC documentary was going on about how amazing it was [in Silicon Valley]. I remember specifically, a guy who was writing software to produce architecture… And there are these beautiful high resolution images being displayed. And there’s software behind it that kind of understood the structure of the architecture. The documentary was making the point that it was radical that someone is being encouraged to do this kind of crazy sounding thing. As opposed to automate the payroll of a bank.

> My childhood didn't go very well. School was extremely painful for me. College was a struggle, and that made places like that Utopian vision of a spot even more attractive, 'cause it seemed like a place where people were nice to each other, and in some way, it was, in a way, that I haven't really experienced growing up. So I had to fight to get to make these things happen pretty hard. My programming was self-taught... I had to learn how to pick locks to break into this computer school to teach myself. That kind of stuff for me was not an easy path.

Emerging out of a particularly dark time, after he left his start up, struggled to find his place in the industry, broke up with his long time partner, and found his way to a quantified self meet up. At this point, perhaps 5 years ago, the meet ups were organized more loosely, where people showed up and signed up on the spot to informally share whatever projects or data they had. A spot was open, so he discussed data he collected, trying to figure out if needed coffee to be productive. It was received well, he was asked to write a blog post about it and became drawn into this community of like-minded folks, finally what he had been looking for:

> W: That was quite a good boost. I kind of felt like I achieved [that] I would be able to detect the community of people who were doing the kind of stuff that I was interested in at that time. Like I felt okay, I have successfully found the people who are interested in this stuff
>
> D: Did that click right away for you? Or was it just sort of enough to keep you going back?

> W: It was pretty, pretty soon. I'm going like, ‘Yes, this is the thing that I imagined existed.’ … There are people who were aware of this shift that's happened in technology..So I had a bunch of thoughts. I'm still looking for a community of people for the desire that had been there right since Xerox PARC thing. I kind of know that doesn't really exist in the way it does, but that doesn't mean there aren't other people like me … I had a much more sophisticated view by this point, but it's like, there have got to be people who are really into using technology to make human life better. Actually it turns out there are a lot of us who are hurting and directly going for that may be the way to do it, as opposed to trying for a [utopia]. We've actually got to recognize that maybe technology can be helpful in helping people heal in some way, and there was this thing [picks up phone]. The iPhone existed and it suddenly became possible to make personal software that hadn't been possible before, because what was called a PC was really a desk computer, and we're not at our desks all the time, and we don't identify desks as the place where we do personal reflection, necessarily.

William also connected with the non-optimization non-wellness oriented tracking project that I presented at the QS conference in Amsterdam in the Spring. He appreciated any challenge to the stronger currents of efficiency and solutionist (Morozov 2014) minded talks on sleep hygiene or happiness habits, and found any discussion that we generated around loss and reflection as a useful antidote. Even with his struggles with anxiety, he tries to track without a goal in mind. We talked about why he disliked the framework of “optimization”:

W: The reason is that if I choose to optimize something the activity of optimization takes place in the future so right now I could say that something I want to optimize that's going to happen in the future, the optimization, the feedback is all in the future. The person who is making the decision to do the optimization is now me. It's me in the present: that is the least well-qualified version of myself that would ever exist again.

D: Okay, interesting. So then what would you call figuring out your sleeping pattern?

W: Right. It was more just like learning something about myself. It's not optimizing. It is what I think is happening. It's really just casting my eye in a direction that it otherwise wouldn't be.

D: Well, what would cause that to go over from just paying attention to optimizing?

W: So I effectively learned a statement, what became in my mind is the statement of fact. You know, like I am sleeping much less than I thought I was and it is because I have been woken up by the snoring, so then I did something about that. So there was no closed loop, there was just a thing that's happening and now I know some more about it, and now I am going to change something and now I'm going move to forget about that and move on with my life now that thing is gone. Instead I could of said, "Okay, I am going to buy the Zeo[50], the Zeo is going to give me a score," it's better for me to keep that score up in some range, I'm going

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[50] An EEG-based sleep-tracker that is now out of business.

> be constantly looking away to keep that score in some range so my attention would be focused on the score, and when does that end? There is not end point.

Being stuck in the QS optimization feedback loop is undesirable to him—"some part of my attention is captured by it", a complaint echoed by others in QS who prefer DIY tracking to prefab products and systems, like the FitBit or other activity trackers. This ambivalence gets at some of the nuance that those in the QS community bring to the goals and consequences of different kinds of tracking. Further, in

In his narrative, William draws on some of the deeper cultural (and folk) histories of Silicon Valley, as a countercultural mecca that seized on emerging technological innovations to serve personal and creative liberation. As described in the introductory chapter, this idea of the technological counterculture draws from even deeper roots of post-war cybernetic discourse. William's story is illustrative of both this history and the ambivalence it contains: combining on the one hand Cold War cybernetic visions of systems theory, flexibility and optimization, and the desire for creative personal and social liberation on the other. Stewart Brand bridged these worlds, and the inheritors of his legacy—WIRED magazine and the Quantified Self movement—still wrestle with these frictions. For William, that results in ambivalence towards a world of systems optimization—where the kinds of feedback-loops matter. Depending on the device, and the wellness scripts it embodies, the movements of data collection, reflection and feedback will have different destinations.

Conclusion: Behavior Change and Care of the (non?)-Self

> There's no such thing as will-power, there's only habits.

- Adam, a digital health start-up founder

Ethnographic data in *real-time*: at the very moment of writing, a message landed in my email inbox—"AddApp 2.4 is here!"—alerting me to the redesign of a data aggregation app, for which I signed up at a QS meetup while in the field. The new version promises: "Better understanding of you and your data, so we can serve you better insights," and "Action points for insights, like scheduling reminders to drink more water or go to the gym." This datum encapsulates many aspects of the well role: data collection, monitoring, reflection, and (here, automated) feedback to the user to change a behavior towards better health. In this chapter, I have described the well role, as a self-disciplinary regime that draws on particular ideas of optimization and systems theory. Depending on how those feedback loops are set up—if endpoints are served or not, for example—a cycle of endless optimization could lead to subjects that are not just patient-in-waiting, but also (in addition or maybe instead of?) always already *unwell*. With the explosion of the digital health industry,[51] the never-ending feedback loops towards optimization is a perfect frontier, an unlimited natural resource for capital investment and expropriation. Moreover, and for my purposes here, the unwell at the center of the feedback loops raises interesting questions about the kind of self produced through and for this regime of never-ending care[52].

Following up from the last chapter, where I described the *n of 1* and the kind of subject that is in formation in QS. The well role expands on one of the modes served by data collection and the *n of 1*, one that is oriented to a particular form of self-care through self-knowledge. By

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[51] http://rockhealth.com/2015/01/digital-health-funding-tops-4-1b-2014-year-review/.

[52] I would add here, that in response to Mol's logic of care that is open-ended, attendant to the situation can serve a capitalist logic of choice. In other words, I do not think a logic of care, as she describes it, ultimately offers an alternative to the commodification of medicine and a market orientation towards health. Logic of self-care in the well role easily slides into flexible consumption of data and "data insights" as health commodities.

way of concluding this chapter, however, I would like to suggest that the kind of self produced by the cybernetic well role or the *n of 1* needs to be interrogated a little further. Above, I introduced William's use of mindfulness, meditation, and data collection to reveal a deeper self who is naming and tracking thoughts, feelings, and actions, rather than stuck doing them.[53] However, for those digital health apps and devices that are geared towards habit design and behavior change, I argue, that there is a curious non-self self that emerges amidst the circuitry of information-reflection-action.

Adam, quoted at the beginning of this section is a self-tracker and entrepreneur who is creating a self-care tool for those with chronic disease, helping patients manage their care, their medications, and their data. We talked about both his venture and his own approach to wellness and how he uses various apps and approaches to designing his life to make sure he stays, and behaves, well:

> So there was this interesting study a long time ago: each 'no' decision you make uses glucose in your pre-frontal cortex and makes it difficult to say 'no' the next time. Every time you say no to temptation, you're more likely to indulge in the next temptation you see because you've used up the glucose resources in that part of the brain that inhibits. You're tempted by sinful things 300 times a day, things you want to do. It's impossible to say no that many times. So my philosophy is try to minimize the 'no' decisions you have to make, so you have resources to say no

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[53] I think there is a curious confusion here, as William is a long time student of Buddhism, not just a practitioner of western interpretations of mindfulness. And in Buddhist meditation practice, there is a goal of finding non-self, so for him to find a deeper self amidst the tracking of minding it confusing to me, but points to the complex ways that disparate practices and philosophies are mixing in QS and personal computing.

> when you want to. And just make habits because are easy to maintain but having to make a decision about whether or not you go to the gym everyday is really, really hard. So the way I do it, is everyday, or every week day at 4 o'clock I'm at the gym and I take the 4 o'clock class so I don't have to think about whether or not I'm going to the gym. I've scheduled it in to my day so that I'm just there.

Adam also moved closer to the gym, a small "life hack" (as its called) that sets him up for success. Making behavior change is a core tenet of habit design, so are "nudges," reminders or cues in the world (or from your phone) that get you to do a desired task. These design principles are part of his health app as well as the countless others I encountered in QS and digital health conferences. Though so many apps and devices are created to address what has traditionally been called "compliance" or "adherence," list latest generation of digital health tools, built on the foundation of habit design and systems ideas of the human, completely eliminate the burden of moral or personal will or responsibility. Although the well role may imply a self-responsibilization to stay well, it has a strangely negative notion of the will built into it. The cybernetic, data-diet mode of evaluating, engaging with and reflecting with life tends to evacuate the self of a willful subject. Or, at least, it is a split subject, on the one side automatic and algorithmic, and on the other, reflective and willful.

I cast the well role against Talcott Parson's "sick role," (1952) which is the idea that a sick person occupies a special social category, enabling "sanctioned deviance," where sickness essentially removes a person from society and their social obligations. The role of the physician is to resolve the deviance, and return the patient to society. In turn, the patient is expected to seek out wellness. Many critiques of the sick role have pointed out its limitations to acute illnesses, or well-resourced patients, to accepted illnesses, for example. Rather than read the well role as a normative category, I observe it emerging out of new technologies and practices. Unlike the sick role, the well role describes a chronic state of seeking out information for improvement. The matter of deviance is almost made moot, as chronic self-care is desired as the norm. However, as we have seen, the division between the chronically well and chronically ill is blurred, if not collapsed altogether in the well role. Moreover, as more technologies enjoin otherwise healthy individuals in self-monitoring for self-care, the category of the "worried well" (the unsanctioned deviant) seems to unravel.

However, there are different stakes for those grappling with the day to day challenges of a specific diagnosis. In the next chapter I turn to these patients' uses for data and new relationships to medical care they produce.

Chapter 4. Participatory Medicine: “The Patient Will See You Now”[54]

> In terms of the conversation we’ve had and the conclusions that I’ve come up with, forget it, forget about it. That’s not what they’re built to do. They are built to—if you have a disease—they have a tool kit that can *maybe* ameliorate the disease, and maybe not, but that’s all they do. It’s not about lifestyle, doctoring. Daily habit choice is all these things that we’re talking about. That’s not what American medicine is about. I’m just saying health is like love. Love isn’t taking your date out for a dinner on Valentine’s Day. It’s every freaking moment of the day of consideration. That’s love, right?
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> Adrien, avid self-tracker

When I asked him if he ever shared his data and the conclusions he gained from them with his physician, the above passage was his answer. He became slightly upset and frustrated when describing his interactions with physicians, a complaint somewhat common among self-trackers both well and unwell that I return to below. To begin, Adrien’s data collection, he feels, is not given the attention or space in the clinical encounter that he feels is due. More than speaking to a lack of time, he argues, medicine is misguided and limited in its vision and practice of health. This complaint—that medicine is not health care but sick care—is common, and has spawned a niche specialty called “functional medicine,” where what matters is functioning rather than outright pathology. In other words, functional medicine takes the well role to the clinic, helping

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[54] The title of a new book by physician and self-proclaimed “medical futurist” Eric Topol

patients optimize their function, rather than manage pathology. This chapter is about people and movements that are bridging that gap between functional and regular medicine with patient-generated data. I will begin with the story of Randy, a patient and his quest to manage himself through data. Then I turn to the emergence of a new kind of patient-advocate the "e-patient," and those who are trying to bring their data into the clinic. I finish with how the *n of 1* may be entering the clinic, upgrading participatory medicine with participatory research.

I. "In this corner, hope": The well role meets chronic illness

Coach Kim turned the volume up on the hip hop, set the clock to two minutes and called out "ready to go!" Randy, the boxing student, responded, "Ready!" "Starting in three two one. Begin!" —with that and the buzzer Randy started throwing jabs and uppercuts to one of the many large Everlast bags hanging from the gym ceiling. Between blows, Randy hopped from side to side, practicing staying low, stepping light and moving his head this way and that. "That's it!" Kim encouraged him "Keeping that jab nice and active! You've got an entire two minute round so don't expend it all in the first 30. Pacing. Those undercuts take a lot more energy." She circled him, coming in and out of the view of my camera. I had accompanied Randy to help him take some video footage of his training and progress. He tells me he has a habit for recording a lot of his and his family's life. His proclivity for life logging only intensified and expanded to his voice, gait, finger tapping, and typing speed since he turned his data capturing habits to his newly diagnosed Parkinson's disease (PD). He has presented some of these gait videos to the QS community, where he has started a QS group specifically for people with PD. Today, he wanted me to record his movements during one his sessions with a program called Rock Steady Boxing (RSB), a program specifically for individuals with PD.

Randy wrapped his hands in preparation for today's drills focusing on his agility, movement, and precision, stepping through ladders, tossing frisbees, punching bags, sparring with Kim, throwing medicine balls.

> It's all the boxing training, like jump rope, hula hoop, you know. All these exercises. Stretching before and after and then punching the bags and stuff. It's getting rhythm down and getting response time down so when they call the shots, you got to be doing the shots right away. That relieves stress, too. Punching the bag is always good.

He finds that the exercises help him with his walking and precision. He records himself walking in a circle and he thinks he is getting better, or at least not getting worse. The boxing, too has has given him a bit of power back: "I've always been kind of like a softie, you know? …But then this is helping me have more of a fighting spirit. Both to fight my disease and even just, in general."

Unlike the muscled shirtless local champions, whose autographed photos papered the walls of this gym, Randy wore a t-shirt that said "Fight Back" and was considerably older, though young for a Parkinson's patient. The Rock Steady brochure, which features Randy as one of the founding members of the SF branch of the Indianapolis-based organization, explains that it helps people in "fighting back against Parkinson's." Kim explained that since boxing offers high intensity exercise and focuses on moving the bodies in all planes that it help stave off the progression of symptoms of PD, offering neuro-protective or even neuro-restorative effects as well. Actively fighting—figuratively and literally—PD, they offer, " improves quality-of-life and sense of efficacy and self-worth." Kim runs him through drills that are constantly changing, keeping him, his body and his Parkinson's disease on their toes.

Randy is part of the QS community here in the Bay Area and is spearheading an effort with a patient-colleague, Emma, to involve other Parkis (as Randy called himself) in self-quantifying projects. They have started a fledgling QSPD group. I met Emma through QS friends, and saw her again and again at QS and health innovation conferences, like the patient-centered conference Stanford Medicine X. In addition to acquiring the latest gadgets for measuring her movements, she is also an engineer working on a program for helping PD patients to quantify their neurological function—through finger tap tests, for example—aiding them in self-monitoring and self-care. Also diagnosed at a very young age, Emma faces her PD head, trying anything she can to care for herself. She is a paragon of an engaged empowered patient, or an e-patient (as the movement is called and I will discuss below). Her condition is more advanced than Randy's, and her current concern is a freezing gait and the risk of a fall. When we saw each other in the summer, she had just come back from a "PD Bootcamp" in Portugal, where she ran through drills to help her improve her shuffling and freezing gait. She writes on her blog, "Not Patient, Im-patient":

> There has been Nordic walking gait training, balance exercises, home training program, walking and even running on a treadmill, multi-tasking training, Ronnie Gardiner Rhythm Music Therapy, hydrotherapy, and combinations like walking on treadmill while doing brain training or walking in the pool wearing flippers while calling out words beginning with "L". I have improved my posture, as

> shown on the photos here and I have a lot of self-tracking data to analyse. During my time here, I have been measuring my heart rate, made notes about activities and observations and I have been wearing sensors to track my movements on my feet.

She practiced what she learned as a group of us walked around the campus to the sculpture garden. While Stanford Medicine X is the major patient-centered medical innovation conference, where patient-scholars are speakers and sessions teach about patient-centered design, Emma admitted to me that she still loved her Quantified Self conferences the best, where she can forget she has Parkinson's. We reminisced about the meeting in May, where she led a breakout session on tracking for neurological conditions, and where she attended with a friend who created motion sensors that he used to create art with dancers as well as work with Emma on her own tracking projects. At the QS conference, it was normal to be self-monitoring and self-experimenting. The distinction between the well and the not-so-well melts when all (out of necessity or desire) monitor their movements, physiologies, moods, intakes and output. She writes:

> Because at QS, no-one evaluates or assesses you, no-one judges, no-one looks at you and wonders what Hoehn & Yahr stage you are or what your UPDRS score is. At QS everybody measures something about themselves but they also respect your efforts to improve your life and your health without judgment. That is a very empowering feeling!

Digital health and self-tracking is enabling new forms of patient hood, that resemble the active self-management of the well role, blurring the lines between illness and wellness self-care through practices of ongoing data collection. The kind of patienthood—on which I will continue to elaborate on below—has kinship with the quantified self in its search for specificity (*n of 1*); an active pursuit of self-knowledge (*Homo experimentus*), self-care and improvement (the well role); the expansiveness of control or hope in data collection; and the mark of chronicity.

In forums for patient-empowerment that participated, such as Stanford Medicine X or the Society for Participatory Medicine (that hosts an active and lively email listserv), what is appropriate attention to ones body or condition is unclear, or at least it may be in flux. As chronic diseases eclipse acute in the American medical landscape and imagination, the model of the chronically, essentially ill body that must modify its risk factors via adherence to therapeutics, behavior modification, and continuous monitoring draw in conditions that previously were seen as incurable or ultimately degenerative, like Parkinson's disease. As one self-quantifier—and Crohn's disease sufferer-turned-Ironman competitor—explained:

> [Ironman] was something that I never could have done a year earlier or three years earlier because I was just so weak and so sick. Having that constant pain kind of every day really pushed me to keep at it and track all these things that I could. In the end, it's an incurable disease, but my doctor, the last time I saw him he ended up sending me a letter saying, "We can no longer find any trace of the disease in your system," so, I've kind of cured myself of Crohn's disease.
> I learned what didn't work and what did and I've actually been able to help some people with similar conditions and Crohn's disease since then. Because of the

> data, this is the best thing honestly, because of the data I was able to share this. … We need to share this kind of information and I wish that somebody else had done these experiments on themselves to share that information with me, but what I found was it's actually replicable so it's applicable to other people and other diseases. There's all sorts of diseases where there's always debate about what exactly causes them or what helps them, but it does seem that if you gather enough data and you really drill down you can find the things that work and don't work for more people than yourself.

Another Parkinson’s patient, featured on a radio feature about the utility of tracking technologies for actual medical practice, echoed this struggle against fatalism:

> My feeling was, don’t worry about things that you can’t control and that aren’t affecting you,” he said. “I’d rather just live my life and not think about it.’ But as the disease progressed, Parker found himself forced to think about it more. He came out publicly, with a blog he wrote for Forbes.com[55]. And, reluctantly, he come to realize that he needs to pay closer attention to his Parkinson’s — for instance, to the granular details of how his symptoms fluctuate. “It’s become more important to get into the details of, ok, is my medication wearing off or not? Is eating something with it (the medication) or not eating something with it affecting it?’ And that’s where the technology could come in. It might provide a detailed recording of the severity of his tremors, while saving Parker from having to jot

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[55] Becoming an engaged patient, or an e-patient, often means getting active on social media, blogging about your condition, tweeting on health care social media (#hcsm)

> down notes all day. “This disease is going to creep up on me,” says Parker. “As it advances, I need to be smarter about my role in it.

Like Randy and the Rock Steady team, these patients are “fighting back.” Like the well role, with active self-tracking and data collection, the patient can reframe the experience of some chronic illnesses or diseases. As Parker says, his need to have an active role in its progression came from the realization that such a role might be possible or even desirable. By transforming the minutia of daily life into data, it makes it operable to self-care and even more clinical care. Continuous monitoring alters the experience of having a chronic disease. Similarly, envisioning life and illness as a data-rich *n of 1*, as I argue, can externalize a problem through data, relating to a double of the self, reflected in graphic inscriptions like graphs or spreadsheets. In this context, the meaning of personal data or health data changes along with the meaning of chronic illness. Whereas clinical chronicity (Garcia 2008) might imply a trap of unending suffering or decline, self-tracking offers an experience of chronic disease as the continual remaking of identity (Becker 1997). This chapter builds on these and other anthropologies of the chronicity of illness (Kaufman 1988) to show how new techniques and technologies offer a cybernetic chronicity (Bateson 2000), one that offers not an endless trap to decline but a self-fashioning that is information driven. Moreover, the response of patients to their chronic conditions with data also highlights the cultural and structural limitations (or “impingements” as Kaufman calls them) of clinical responses to illness.

Our digital exhaust[56], the traces of ourselves that we leave across the internet, data of our activities tracked by our networked companion devices[57] from our computers to our smartphones

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[56] Again, Chris Dancy’s (of “The Mindful Cyborg”) term.

to our fitness trackers, automatically leave digital simulacra. Collecting and cataloguing our own data—with these devices or on our own, with a private spreadsheet—sets the stage for a small battle over the control over our digital copies. In the case of patient hood, self-collected data is arming those in the fight for participatory medicine with new epistemological tools. Participatory medicine, in part, is about what a patient can and should do with this personal data. One of the rallying cries of e-patients, after all, is "Gimme my damn data!"[58]

II. What is an "E-Patient"?

> When I think of an e-patient, I think about it in two different ways: the people who are really on top of their own personal health. They have all of their records, and they know their legal rights, and maybe actually are smarter about their illness than their doctor is, because they're reading the journals articles and all that kind of stuff. Then on the other hand, I think about a lot of people that are like, "Oh, I have this illness, and I started this foundation, and I wrote this book. I go around and speak and I educate large groups of people about the condition. I am a community organizer or community builder or something like that." I fall in the medium range on both of those things, and I want to try to get better and do more. But again, it's always hitting up against that hard constraint that you can only do so much. You only have so much time; you only have so much energy.
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> Marie, 33, e-patient scholar with Crohn's Disease

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[57] A phrase I borrow from Meena Natarajan.

[58] E-patient Handbook *Let Patients Help!* (DeBrokart 2013)

In a moment of desperation—between jobs and out of health insurance—Jaime bought his own medical equipment to read the data stored by an implanted device in his chest. He has yet to use it. This machine is insurance, in a way, in case of emergency, as well as a part and symbol of his struggle to gain unmediated access to his data. "Sick and tired of hearing patient engagement. What I want is #autonomy." He shared this demand on Twitter, accompanied by a picture of his face in the monitor of one of these ICD programmers. His ICD (Implantable Cardiac Defibrillator) was placed there a few years ago when he was diagnosed with a genetic heart condition called Hypertrophic Cardio Myopathy, which alters the shape and size of his heart and increases his risk for arrhythmias and sudden death. As part of his care, his physician, a cardiac electrophysiologist, "interrogates" the device, reprogramming if necessary, to pick up on any abnormal or risky heart behavior in time between visits. Usually patients are remotely monitored, too, with a device at home that gathers information from the ICD and transmits it to a physician dashboard. That way, healthcare professionals can see cardiac events in real time. Some practices require it. Jaime refuses, though. On principle, he firmly believes that if he cannot access his data with the intermediation of the physician, then neither should they. For years, he has fought an informal battle (it has not escalated, yet, to a law suit) with MedTronic to liberate his data, but to not avail. He continues to forgo remote surveillance, even if it increases his risks. Speaking as a patient activist, or an e-patient, he explains:

> It's a matter of life and death. Access to data about my own body is a matter of life and death. It's a matter of living a better life. A way of having information. A way of managing my health! And how dare they collect it and not share it with me! It's just not right. It's not right. When I think about the core of it. It really

> irritates me. It propels me….It's an irritant that's always there. Data from implanted devices is collected remotely and the manufacturer benefits from this data and patients do not.

As an engaged patient, or an e-patient, Jaime does more than advocate for access to his data and passively resisting medical surveillance, he also participates in the e-patient community in the Society for Participatory Medicine, attending Medicine X as an e-patient scholar, and collaborating regularly with researchers around the country on issues related to HCM research. He sometimes has a hard time finding physicians, and particularly cardiac electrophysiologists who are willing to work with him and forgo remote monitoring. He vetted a few physicians before he found a staff that would understand his cause.

At the first visit, he hands his physicians the "patient engagement" handbook: *Let Patients Help!* Written by an influential and e-patient pioneer "e-Patient Dave" deBrokart. He asks for printouts of his data every time he leaves, and even bring his own data to the visit: readings from his AliveCor device, a single-lead EKG iPhone case. A tracker and self-quantifier, Jaime tracks triggers and actual cardiac events with consumer-grade wearables and applications to identify his triggers and take better care of himself. Pointing at his wrist: "I have the ultimate class 3 implant, medical device with high fidelity data that is of clinical quality in me. It's ridiculous that I can't tap it that I have to rely on these stupid little things that I have to move to my arm. The device knows when I go to sleep. The device knows my heart rate at every moment."

Jaime is part of a larger conversation in health about the access to data, or how he calls it "data liberation." "Gimme my Damn Data" is just one of the rallying cries of the growing e-patient movement, founded by Dr. Tom Ferguson, a non-practicing physician who advocated for self-care and patient access to tools and information. Notably, Ferguson was the medical editor for Stewart Brand's *Whole Earth Catalog*, the compendium of personal tools published throughout the 1960s and 1970s. He also established and edited a magazine entitle *Medical Self Care* from 1975 to 1989. His work turned to the internet and networked information technologies with the publication of *Health Online: How To Find Health Information, Support Groups, And Self Help Communities In Cyberspace* (1996) and "The Ferguson Report: The Newsletter of Consumer Health Informatics and Online Health" starting in 1998.[59]

The "e" in e-patient stands for many things, including electronic, engaged, empowered, educated, expert, and growing. Before his untimely death in 2006, he launched a blog—e-patients.net—and spurred on a movement, most led by the Society for Participatory Medicine. One notable e-patient, Dave deBrokart (aka "e-Patient Dave") chaired this society for a time, and wrote "Let Patients Help!" a concise handbook for patients and doctors to practice participatory medicine. Jaime hands this book to his physicians to prepare them for the kind of relationship he would like to have with them. E-Patient dave is a luminary for other e-patients like Jaime, and has provided a model for others' e-patient activism. Written out of his experience beating the odds against an aggressive kidney cancer, and in partnership with his primary care physician, this handbook speaks in clear-eyed language about how truly engaged and participatory medicine ought to look. It offers definitions, such as "An empowered person knows what she wants and speaks up. A disempowered person, faced with a challenge, will say, 'There's nothin' I can do about it.' Thats the hallmark of being powerless. Facing the same challenge, an empowered person thinks 'What *can* I do?…no matter what the odds." Or, "to be engaged is to be involved, active, responding….A disengaged patient treats healthcare like a carwash: rolls up the windows,

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[59] He died in 2006, his obituary: http://www.nytimes.com/2006/04/24/us/24ferguson.html?_r=0

sits back and gets things sprayed on him." However, he also acknowledges the murky space of definitions and the changing vocabulary around the shifting roles of the patient to consumers: "some find it empowering, others belittling." Similarly, he distinguishes the e-Patient understanding of engagement from the health care industry's—taking more drugs or consuming more—and expands it. The rest of the hand book lays out "Ten Fundamental Truths about Health and Care" and then "Ten Ways to Let Patients Help" such as "give us our data!" and "let patients help set research priorities." Patients are the only targets of the book; he offers doctors ways that they can open the relationship to one of engagement. While "engagement" has exploded as a buzz word in the mobile health industry and emerging behavioral sciences, as a more palatable version of treatment compliance or adherence, the e-Patient message contributes to the expanded meanings of "engagement" and represents another iteration of patient advocacy and activism.

The e-Patient movement, grounded in e-Patients.net and the Society for Participatory Medicine, is also firmly anchored in Stanford Medicine X, patient-centered conference and "a catalyst for new ideas about the future of medicine and health care." MedX, as it is called, convenes design classes and workshops throughout the year at Stanford, such as "Engage me! Empower me!" co-led by the e-Patient Scholars, a cohort of e-Patients that apply to be patient leaders at MedX and Stanford for one year. Amidst numerous and competing health innovation conferences (I attended Health Datapalooza and the Mobile Health Summit during the year of my fieldwork), MedX distinguishes itself by combining emerging digital health technologies, patient-centered design and a heavy e-Patient leadership and presence. As the website[60] explains: "The initiative explores how *emerging technologies* will advance the practice of medicine, improve health, and empower patients to be active participants in their own care. The "X" is

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[60] http://medicinex.stanford.edu/about/

meant to encourage thinking beyond numbers and trends—it represents the infinite possibilities for current and future information technologies to improve health."

Part Ted-talk conference, part weekend retreat, part "summer camp", as one e-Patient described it to me, MedX takes place in the center of Stanford University's campus, and consists of a highly produced MainStage, where lighting and music are cued for every entrance and exit. At MedX, the class of e-Patient scholars performs several roles. In addition to taking center stage as panel moderators, giving "ignite talks" where they share their stories, in well-packaged narratives accompanied with self-advancing slides, similar to Ted Talks or the other highly produced health tech conferences I attended. The stories are sometimes hopeful, sometimes angry, sometimes energizing. Unlike other conferences, the first third of the room were reserved for e-Patients who supportively gave a standing ovation after every patient testimony. Tears were not a rare sight, even from where I stood by the productions tables in the back of the room. People were more quiet and attentive to the stage. The e-patients sit up front in a reserved section and rise to standing ovation after every ignite talk. Needless to say, MedX may be the most affectively saturated technology conference I attended.

MedX continues to operate programs, courses and workshops throughout the year. Through the live video stream and the parallel tweet chat, I attended and participated in many of these courses, which are based out of Stanford. The in-person classes were made up of medical and design students. Each "MedX Live!" course, for example, began with a patient story and testimony, and was followed up by a panel of experts on a topic or another talk by an expert. For example, I attended one remote panel called "Engage me, Empower me" on patient engagemenet and empowerment tools. This course was often well attended by an audience on twitter, where it was widely promoted via #hcsm, or "health care social media".

A large part of being an e-patient is this social media presence. In my fieldwork, I participated in these MedX tweetchats as well as other organized discussions around health and technology. E-patients that I met and interviewed in the field often got involved in advocacy or this movement via social media or the internet, blogging about their illness experiences. Some twitter communities organize around specific illnesses (e.g. #spoonies for those with chronic pain). Gina, a past e-patient scholar turned entrepreneur told me that she felt pressured to tweet at MedX, to produce a continuous buzz, suggesting that MedX relies on these e-patient scholars to produce or crowdsource their content.[61] Most e-patients, however, rely on social media for both personal and political goals. For example, Marie who has Crohn's disease jump-started her journey to becoming an e-patient online:

> Twitter has been a way for me to connect with people that just exploded by worldview … And especially because my own disease organization is limited in their funding and their vision for what they want to accomplish and what they want to offer to people and how they want to use their money. I had always been into narrative journaling. So I would start new blogs, and I would go on Twitter, …You would see people talking and say, "I know so and so. She has Crohn's, or she has a friend who has diabetes." So your social circles expand without you thinking about it too much. Once you get a smartphone it's all over, I think. It makes everything happen.

Her smartphone made hospital visits a different experience, too,

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[61] One flip side of "engagement." Others include the demand to be engaged, self-responsible patient-consumer.

> So I'm in the ER and just in pain but you're using the smartphone as a distraction because what else are you going to do. I also feel a lot of empathy and support from Twitter even if it is a bunch of strangers, or it used to be a bunch of strangers. Maybe now it's not. So I'm in there Tweeting, "Oh, God, the Wi-Fi is not working, don't let me die this way." And the hospital... I'm kind of a jerk. So the hospital had had an account, a social media account and I guess I had tagged them. And they wrote me back. So it's not a person, it's just their logo. Obviously a person's writing it. They write me back, and they're like, "Is there anything we can do? What's wrong?" And tech support whatever. Turns out the person writing that account is Nick Dawson.
>
> …
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> At one point - I don't know if it was the same visit or another visit - he had one of the people from the back office come out and say, "Oh, hi Carly. Nick says to tell you hi." And my mom who's sitting there is like, "How did that even happen? What's Twitter? What's going on? How do you make a real live person do something based on something you've done online?" Meanwhile, my mom had known that I had met people from all over the world based on this message board I had been affiliated with. She was just shocked, because she was like, "You're in a hospital."

Nick Dawson is the current director of the Society for Participatory Medicine and active with e-patients and MedicineX. This social media connection helped build a relationship and connect to a media group Dawson worked with, where she was invited to talk about the use of twitter for business. There, Gina connected with other patient advocates who use twitter, notably a woman Deb who is known for posting her glucose readings (she is a type 1 diabetic) and a DIY, automated pancreas she designed and built.

Marie's story tells us about the networked and mobile computing as an important vehicle and mode of the new e-patient movement. These tools enable more than biosociality—in fact disease categories are preferably transcended in wider #hcsm and e-patient communities. Marie's story and the surprise of her mother conveys the desires of participatory medicine to flatten hierarchies between patient and doctor or hospital. One physician, Dr. Bryan Vartabedian, who is blogs, tweets and is active at MedX, teaches a course on social media to medical students, hoping to encourage future physicians to engage with each other and patient communities in more direct and open ways.

If social media achieves actual participatory medicine or the illusion of an audience, remains to be seen. However, participatory medicine and e-patients seize on the internet and information technologies as the key to changing the way healthcare is practiced. Twitter helps individual e-patients launch personal brands, based on their illness experiences, sharing their stories and critiques. At MedX, they launch as "scholars" and sometimes budding gurus, the faces of an emerging and growing industry[62].

The first time I met Jaime, he signed his consent form, "if it helps the cause of data liberation." He is on a quest to gain access to his device data without the gatekeeper of the

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[62] I want to note that the relationship between the industry of health IT and participatory medicine is fraught. The SPM almost runs as a consumer rights organization. The listserv teems with heated debates on healthcare IT, some embracing a consumerist model of health, others rejecting it. Active discussants represent a range of stakeholders, from patients and physicians to professional patient advocates and digital health entrepreneurs. Sometimes these identities co-localize in a single person.

physician. Before he launched on this campaign, though, he was on a diagnostic journey, trying to make sense of fainting episodes. It took him a few years, a few dead-ends and misdiagnoses to get the care he needed. After a few years of visiting various specialists and obtaining tests like echocardiograms, he was finally diagnosed with a genetic condition called Hypertrophic Cardiomyopathy (HCM), where the heart becomes enlarged and results in abnormal heart rhythms. The biggest worry is sudden death from cardiac arrest, which can be prevented with an implanted cardiac defibrillator (ICD) that shocks the heart back into rhythm. In addition to doing extensive research on various ICD brands (Jaime had a past life in advertising), he eventually linked up with an HCM advocacy group:

> J: [My partner] found the HCM association online, which is a group out of New Jersey, headed by this woman Lisa who does amazing work for patients with HCM. Her sister died of a sudden cardiac arrest. Her father died of a sudden cardiac arrest. HCM runs in her family. It's usually genetically transmitted, passed on. And if there's a sudden death in the family, and you know what you're looking for, it's a serious concern. People in the family should be checked. None of this information was passed on by the doctors who were treating me. Three years down the road, I got this information from other patients. This woke me up to the fact that patients knew a lot more than doctors knew, in my experience. It might be true, it might not be true, but in my experience, patients were at least willing to share knowledge with me, with other patients, through patient networks.
>
> D: did you take that information back to your doctor?

> J: I immediately became an e-patient, I suppose. I didn't know I was an e-patient at that point
>
> D: what were you doing that made you an e-patient?
>
> J: Well it made me realize first of all, that I need to take charge. I had been trusting that things were being taken care of for three years, and clearly they weren't. I was still having issues and I felt like I wasn't on top of it. And I realized at that moment I had to be in charge. So I asked for copies of all my records. I read everything with a highlighter. What I did not understand, I highlighted and looked it up. And I sent all my records to Lisa.
>
> …
>
> My last appointment with Dr. K was 5 hours long because I told him I would not leave until I had all my questions answered. And he was willing…he would walk out and come back in. …At that point I was sick of not getting answers.....They did a lot of tests that are not recommended with patients with HCM. I asked him about those....and then I fired Dr. K. I said I'm clearly not getting the care not I need here, and I'm not satisfied. And so at this time I had been talking to Lisa who said you have a classic case of Hypertrophic cardiomyopathy, your case is textbook, it's amazing that they would miss is for three years.

Thus launched Jaime's career as an e-patient. He later became involved in both QS and the movements for participatory medicine. He continues to advocate for access to his ICD data and demands to work with physicians who share his approach. He brings copies of the e-patient handbook in addition to his self-tracked atrial fibrillation events to his physician—litmus tests of engagement.

III. Doctors and Data

> Doctor: "What are your symptoms?"
> Larry Smarr: "I don't have any symptoms, I have data"
> [Joke told at Quantified Self Public Health Symposium, April 2014]
>
> "The question is: will you blow me off when I have my spreadsheets? Because that has happened."
> [Patient at the Health eHeart Patient-Powered Research Summit, November 2014]

A. From Gimme my Damn Data to Take my Damn Data

What is the role of self-tracked data, or patient-generated data in the clinic? Across observations and interviews in the field, informants talked about how personal data, data for self-care and self-knowledge, sits awkwardly in the doctor's office. An illness narrative in the form of personally generated data, an info-graphic, a spreadsheet, or a chart unsettles and reformats the traditional 'History of the Present Illness.' According to Pew Research report *Tracking for Health*, led by Susannah Fox, a leader in the movement for participatory medicine, 69% of patients track a health indicator for themselves or a loved one. According to the poll, which defined tracking rather broadly, 34% use pen and paper while 21% use a digital technology, such as a device or a smartphone application. These data on self-tracking practices or paraclinical care (as I have called it above) indicate not just the expansion of a practice, but also introduce a change in the epistemic grounds of medical care. These numbers are quoted in the Quantified Self movement or at health innovation conferences such as Medicine X to naturalize tracking, make it visible as existing outside of what may be considered fringe spaces of QS. It is this border zone between QS (perhaps thought of as the "worried well") and medicine (the "legitimately" unwell) that interests me. When personally collected data enters the clinic is one particular moment of convergence or perhaps articulation between these worlds. What I am trying to argue is that the implications of technological innovation (the rise of personal and ubiquitous computing, sensors, the smartphone) become far less exotic and futuristic, when placed alongside epistemic shifts occurring within medicine and the clinic. As digital tools enable the ongoing collection of data, passively and actively, the separation of patient testimony into the "Subjective" domain of the doctor's SOAP note, becomes increasingly untenable. The separation of a patient's visit into "Subjective", "Objective", "Assessment" and "Plan" becomes even more fraught. Where does data from a self-tracked spreadsheet fit? Output from a symptom tracking app? The epistemological, ontological, ethical and procedural status of personally- or patient-generated data is uncertain, evidenced as debates around access, interoperability, privacy, ownership, and legitimacy of data flourish. The joke that introduces this section reveals some of the uncomfortable tensions that arise when data not only enters the clinic, but as health, wellness *and* illness come to be redefined on digital terms.

What are the implications of replacing symptoms with data? That is a question I want to pose and start to think through later on. For now, I want to turn to the difference that data brings up. At the time of my fieldwork, I observed and learned about the coaching model, where a non-clinician, a “coach” helps you look at your data and interpret it, helping you be accountable to its collection. In 2013 and 2014, I observed many debates about the role of all this data. Should it be included? How to make meaning of it? What is the physician’s role? In 2015, as of this writing, pilots that put continuously generated, patient-generated data into the doctor’s office have begun.[63] For now, I will present some of those conversations, concerns, and reactions that patients have had with doctors and data. My time in the field captured a difficult and fraught moment for doctors and data—this may just completely resolve over time, as self-quantifying becomes more legitimate and part of sanctioned medical practice, with more devices seeking validation from the FDA, crossing from recreational to medical (as many believe and hope).

B. Signal and Noise

The encounters between those practicing the well role, or the “worried well,” self-trackers and physicians could result in dismissive attitudes toward patients on the part of caregivers (“the worried well”) or it could result in pathologization. Gustavo, the budding productivity guru, brought “very sensible, very rigorous” self tracked data about voice problems he was having to his physician. Instead of leaving the office with a referral to the laryngologist whose expertise he sought, he left with a referral to a psychiatrist “who thought I had mind-body issues.” The specter of hypochondria continues to haunt interactions between doctors and patient-generated data. At best, there just is no space for the data; it becomes illegible in clinical workflows and algorithms. Adrien, the relatively well, self-tracker quoted above, explained:

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[63] I will be conducting observations in the clinic with Tidepool, a diabetes nonprofit dedicated to the liberation of data from diabetes devices for type 1 diabetics. Another pilot is from Open mHealth, in a pain clinic by Ida Sim, using self tracking and their n of 1 tool, to foster physician patient collaboration around data.

> So I do have a doctor and I did bring him like a spreadsheet of seven years of this data. They were curious and puzzled or whatever, but they stuck it in their file, they didn't have enough time to think about it…That whole business is not meant to be curious…It's like that's all noise. That's all noise and because it's noise to them, they'll never get to it.
>
> Adrian, lawyer late 50s

Adrian's frustration points to the realities of practicing medicine, short on time, as well to his perception that medicine not oriented enough towards this kind of curiosity, a sentiment echoed by others in quantified self. Further, he later bemoans the sickness care that medicine provides, rather than prevention and bolstering of wellness—where functional medicine has taken off. He wants to be able to talk to his doctor about his low cholesterol, his habit of eating raw eggs, walking barefoot, taking his glucose every week, his experiments with the latest "super foods", troubleshooting his sleep and other issues of his daily life. These subtleties between being well, being sick, being dismissed as crazy (OCD and the worried well) hinge in large part on the problem of having new technologies that extend the clinic outward, on the one hand, and impinge on the clinic with new data on the other. Such paraclinical data collection and care challenges the clinic in interesting ways, to reconsider its own epistemologies and modes of care. For those with diagnosed conditions, though, making personal data part of the clinical encounter can be just as difficult. Experiences, though, vary of course, depending on the kind of physician, form of the data, and the clinical issue at hand.

For some, it place of data in the clinic is just a matter of limited time and relevance:

> [My doctor said:] “All that’s great, keep doing it,” but I could sense though, that feeling of “That’s great that you’re doing it, but it’s not controlling all the variables. And it’s not scientific. Be cautious.” I mentioned I’m tracking so many different things from sleep to activity and things I’m trying to see what helps me the most, to reduce my symptoms. Again, it was like their time was short and even I could tell they would love to talk more, but they had their next appointment to go to. [Randy, Parkinson’s Disease Patient]

> So, within [my doctor’s] workflow, she doesn't have time to deal with you know, god, each time I go in there there's probably like 25,000 blood sugar readings in a CGM [continuous glucose monitor]. The systems aren't built for that. It's not the problem that she's there to solve.…I think this is one of the issues that came up at the last QS, that they wanted to highlight, was that my goals as a patient don't necessarily match the goals of my doctor in treating me.
>
> [Doug Kanter, Type 1 Diabetic, creator of Databetes project]

For others, reception of personal data or data summaries, in form of DIY info graphics, varied. Jaime, who makes a summary of his cardiac events, fired one of his doctors partially because of his dismissal of the data. His other cardiologist, on the other hand expressed enthusiasm and curiosity. “It was a conversation starter.” “I had 2 events in the life of my ICD that were treated, which dates they happened and we can talk about it, what was relevant about it,” Jaime explains.

Jess, a human-computer interaction (HCI) designer, created her own illness summary in a graph, annotated with diagnosis, events, treatments, symptoms. Later, she would arrive at office visits with a pictographic representation of her mercurial symptoms drawn on a body figure:

> It was just me and six pages of white blank paper. I just put them down in my living room and just drew two big lines and then I just marked them like years and then I basically just wanted to capture a few key things like diagnosis, when I first started prednisone, when things had been bad enough to remember over the years.Other than that, it was just sort of like wishy-washy wavy line, meaning . . . I don't know. It was not too bad, not too good. It was all from memory and I didn't have my medical records at the time but I did request my full medical records from University of Michigan, who has my neurological history from when I was 13 until 21. After that fact, probably about a year later, I went back and added how I was diagnosed, so that if I took it to a doctor, they would know how the diagnosis happened. Because I don't want to have all those tests done again.

Her physician's reactions varied, from enthusiastic to lukewarm. One doctor:

> He was a little bit of an abrupt person anyway. He was sort of like, "Okay. Okay. Mm-hmm," and kind of moved on. I asked him if he thought it was helpful and he was like, "Yeah." I don't know. I think people bring things to doctors a lot and I think when—from my later subsequent conversations with doctors—when a patient pulls out their own tracking data or graphs, I think it can be scary because it might be too much information.

She has since moved between New York City and Vermont, visited doctors there as well as made special trips to the Cleveland Clinic, to address her complexifying disease. Some physicians welcomed her hand out, perhaps pointing them sooner to widen their diagnosis from her original Myesthenia Gravis[64].

> I moved to Vermont and that was another big change. I went in. I had a new, a first meeting with a bunch of different doctors. That was another time when I kind of brought in the timeline. I laid it down and walked through it. I had to do that quite a bit when I first came back here. I also had like a body that I drew with my symptoms just kind of drawn on it, which I took to my primary care doctor, because I still was very unsure of what was going on with my sensations. I hadn't really had a good answer.
>
> I did that and then fall of 2012, I also went to Cleveland Clinic and I saw I think five doctors. I saw a rheumatologist who finally diagnosed me with Sjogrens[65]. I took [my data] to Cleveland Clinic and I showed it to my primary care doctor here. I think that all the information helped point to the rheumatologist toward Sjogren's [Syndrome] and they did all the blood testing and an eye test, things like that, so I mean I think it's definitely been helpful. I think doctors have their own systems but for me it's been like a story telling aid and when I brought like my body, my symptoms on the body to my primary care doctor, I noticed that she kept referring back to it as she was kind of thinking. It's like a way to help remember everything.

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[64] Autoimmune disorder leading to muscle weakness and fatigue.
[65] Another chronic autoimmune disorder.

Jaime, our data liberator, has fired physicians for the way that they treat his data, putting his summary aside, not even making an attempt to incorporate it into his chart. His summary is one page,

> The way I look at it. It's an easy way for the doctor to see the health of my heart and device for last seven years. It's an info graphic, a bar chart, where each bar corresponds to a month, going all the way back to November of 2007 which is the month of implantation of my ICD. Each bar shows the number of non-sustained ventricular tachycardia events that were faster than 171 beats per minute." These data are collected, he emphasizes, not from access to the data, but from print out summaries from interrogations of the device when he goes to the clinic. Even though he has owned his own reader for a long time, and even took a course meant for technicians to learn how they work, he still avoids using it. The electrophysiologist—a cardiac specialist who cares for patients with electrical abnormalities of the heart and their implanted devices—he fired did not want to see it. He "didn't bother, didn't care. He picked it up and said 'Uh, ok?' He didn't even bother to read what it was. He left it for me. He had a plan and the plan for him was to do the visit as he normally does clinic visits and he didn't want to go out of the norm and he wanted to get it done as quickly as possible and be done with it and move it on to the next room."

This slight, in addition to his less than warm reaction to Jaime's standard mantra—"It's very important for me to be a part of my care. I am very interested in learning about the latest stuff about HCM. I know it's a challenging condition to adage, so count on me to help you do your job"—and presentation of the e-Patient Handbook, led to his firing. Jaime's cardiologist, on the other hand, welcomed the data excitedly. They then worked together to find Jaime a better electrophysiologist, one who looked up from the interrogator screen.

C. “Forget about it, it’s Diabetes Town”

The varied reactions of doctors to patient generated data partly reflect the time-pressured and information overload realities of clinical care. Clinical workflow and information management are usually controlled by the physician, who manages both time and data. Some physicians either choose to invite this data into their interactions or are more flexible in their workflows or with their time in general. Time and workflow aside, some patients encountered an attitude towards their data and self-tracking that might be described as defeatist. In other words, the value of self-tracking or quantifying in great detail is not apparent to physicians, whose clinical outcomes are based on interventions and levels of information that are vetted in clinical studies. Moreover, the desire to track or gather even more, even continuous, data on one’s condition was seen as a futile exercise in the face of the limited ability to control disease.

Feelings of control—often called empowerment—indeed, is one of the byproducts of a quantified life. This is especially so for those chronic illness. While the medical approach to chronic disease does emphasize patient management, compliance, adherence or (an allied term) “engagement”, the level of fine-tuned control by *n of 1* experimentation and granular quantification often goes beyond what physicians expect or even believe to be helpful. Ron, a type 2 diabetic, with a long history of struggling with his weight and the disease and its complications—he had cardiovascular disease and stent placement already before he was 50—had to advocate strongly with his physician to allow him to purchase a continuous glucose monitor (CGM), devices usually reserved for type 1 diabetics. Continuous glucose, data, is increasingly coveted in the quantified self space, for people with both normal and abnormal pancreases.

Many look forward to the watch or contact lens that achieves this for the consumer. Ron—who was frustrated with the lack of control he had over his diabetes, and the suboptimal dosing of his medications that kept him on a roller coaster of blood sugar levels—found that the continuous glucose data, instead of intermittent finger sticks (standard type 2 diabetes treatment), gave him the “feedback loops” he needed for change, in “real time:” “it's all about feedback loops. The reason why quantified self works is that it's a feedback loop. And the shorter the loop, the more real-time that feedback loop is. Human memory being what it is, the closer to the event you can get the feedback, the more effective it is.” The Dexcom device also enabled Ron to externalize and offload some of the active management his diabetes to a device:

> I don't know if you've read the book, "Thinking Fast, Thinking Slow" by Kahneman. Basically it's a model of system 1 and system 2. System 1 is your habits and your unconscious execution of things without having to think about. System 2 is like, "Oh I've gotta stop and think about it." Your conscious thinking process. So finding the system 1 thing, or training system 1 habits... The way you want to do it, it's called cognitive offloading, or cognitive easing. Basically these small habits are basically me finding ways to cognitively ease a change into existence. Essentially you can say that that's what the Dexcom was. It was a cognitive easing, because I didn't have to think about, "Oh I'm gonna prick my finger." There's resistance to that because it's a little bit of pain and it's annoying.

Without setting goals, which would add more to his “system 1”, the continuous monitor allowed him to watch, observe, and gain awareness of the glucose consequences of his actions. He describes how by just noticing, following the feedback of the data, he naturally just stopped eating bread. Following the numbers, the data, over time he began (without consciously setting an intention) to avoid thing that made his sugar spike and learned to do activities that brought it back down, like take long walks after meals. Prior to getting the Dexcom and finding Quantified Self, Ron felt more complacent with his condition:

> “Oh this is just the way it is.” Now I know that that’s not true at all. It’s like the trick of someone who’s depressed to track it through the day, to then graphing and realize, ‘I’m not that depressed all the time.’ It’s just the cognitive bias all the time, where it’s the depression talking and not the truth. Data is the truth, whereas a whiny voice inside is making stuff up.

Other self-quantifiers have expressed the benefit of just focusing on the data, the small feedback, keeping their heads down, so to speak, following the numbers reduces larger seemingly insurmountable goals to points on a line, baby steps:

> A side effect of me getting control of my diabetes is my depression that I had my whole adult life was far, far less. And totally controllable. Whereas if I'm feeling down or whatever, go for a walk. I always feel better. I think it was [sugar fluctuations]. I think a large part of it is. That or just feeling defeatist about my body and not able to change it totally changed everything. And now I know that there's something I can do. Going for a walk totally changes everything. It's simple. It's a small, small thing to do for a big change. And it's easy. But then

> there are people who say, "No, I don't have time." No, that's not true. That's the whiny voice lying to you again, and you're buying it. I don't know. It's small, little hacks like that that make a big difference. And it's cool. Because if you just say, “I’m just gonna do this one thing for three weeks until it becomes ingrained.”

His physicians were surprised at the results, his tight sugar control, shedding the pounds (he lost 40 pounds within the first six months of wearing the Dexcom) and the medications:

> It was not easily that I could have discovered it. I think I could have if I was really hardcore about testing my blood sugar with the sticks, but this was much more accurate and a much better feedback loop. And so by the time I was down to such a small dose, a dose that my doctor said, "That can't possibly work." "I have to disagree with you, because I have data that proves that it works." I would go a week without glyburide and show the uptick. And then I'd go the next week with that glyburide. "I can continue that experiment as long as it takes to convince you of it." She was like, "Well, your A1C is for the first time below six, so who am I to argue with.

His new physicians are equally surprised and impressed by his results. Ron no longer does continuous monitoring because he learned and modified his behaviors with that one period of tracking. However, he sees his condition in remission, not cured. The damage to his heart vessels is done. All he can do maintain his current habits, prevent atherosclerosis, hold off the need for more stents. “I can keep it in remission consistently and persistently, as long as I do what I’m doing.”

Patients have been leading the movement to gain access, meaning, and clinical legibility for their data. Even for Type 1 patients, where continuous monitoring and management are the norm and essential, the role of patient generated data—access and utility—is contested. In the QS community, where type 1 diabetics are revered as "the original quantified self", individuals and organizations have emerged to lead the charge in gaining access to the streams of data that are collected and trapped by the devices they wear (CGMs and insulin pumps, mainly). Three notable projects point to the ferment in this space: 1) Tidepool, 2) Nightscout, and 3) Databetes. Tidepool is a nonprofit organization whose mission is to help type 1 diabetics and their families get access to their continuous data streams and make sense of it with programs that translate it into approachable visualizations that allow annotations and comparison to other data sources (activity, food). They are also working on a clinician-facing interface to help coordinate care and bring more meaningful patient data into each visit. Nightscout is a crowd-sourced software that takes advantage of a simple hack of the CGM: an engineer and parent of a type 1 diabetic figured out how to get real time glucose readings to project from a CGM to almost any kind of screen (a tablet, a phone, a smart watch), wirelessly. Families can now just glance at the iPad on the wall instead of having to ask their child what their number is, sometimes a point of tension. Or, the real time number can alert parents of sleeping children's number remotely.

Lastly, Databetes, is a project created by Doug Kanter, a type 1 diabetic himself who wanted to help diabetics more fine-tune their insulin control. He is also well known in QS and ePatient communities for tracking and creating visualizations of an entire year of his diabetes data.

> I mean, another reason that I started this whole thing was just that it's frustrating that you see your doctor three or four times a year. In theory you get a half hour

> each time, but in reality you get like seven to 12 minutes with them. And then the amount of time that you actually talk about how you're doing in terms of managing one thing versus the other is so little that it's like there should be better systems for dealing with your own data. And asking other patients for answers, and help, and support…. I mean just because the studies have shown A1C under seven is best, well it's like, what if I want to get an A1C closer to six? You know, what if I think that's going to improve my chances? Just those types of questions.

Databetes, like other QS and personal data projects, sees the purpose of data as generating more personal and relevant, rather than universal knowledge, about a disease. Cast against traditional evidence-based medicine ("the studies," above), self-tracking data creates a new kind of clinical science. While self-quantifying patients or parents—often engineers or scientists—may represent the extremely engaged patient, not at all the average, their interactions with clinicians and medical system reveal the limits and assumptions of medical care. For Vivienne, the neuroscientist, data held so much promise for cracking her son's diabetes. She gave the following talk at a QS conference:

> My son felix. Needless to say I love him...he's so full of life and so amazing and 2 years ago he was diagnosed with type 1 diabetes…He's also fortunate because 2 of his parents are scientists. We thought, we're gonna go crazy on this. We recorded everything. We built these spreadsheets. We recorded everything he ate, every moment of the day, how his activity went up and down during the day. We were so proud. The month after we got out of the hospital, we went to the checkup with his doctor and we brought this spreadsheet in to her--and I like her, we just saw her yesterday, not knocking my doctor--but my goodness, they were not

> happy…This is not what they wanted. ‘What are we supposed to do with this?’ So we were flummoxed. We felt like parents and adult sufferers get told this story--it's Jack Nicholson[66], ‘Forget about it parents, it's diabetes town. You can't understand it.’ There's nothing you can do. It's endocrinology. Well, I hope I don't come across as too arrogant but if you think diabetes is too complicated, try the brain. So we thought, alright, we're going to build our own model.
>
> QS Talk Vivienne, 2013QS Global Conference

We spoke more in depth about her experiences with physicians and the incredible amount of data collects and the systems engineering she does to try to understand and model his own personal disease patterns.

> I feel like in diabetes treatment, and I can't imagine it's unique that what parents hear a lot is, "Forget about it parents, its diabetes." You can't understand it, you can't control it beyond the most basic level. It's something we've been to diabetes camp with my son, which he loved and we loved but it becomes a mantra there, it becomes a mantra with doctors, it becomes a mantra at conferences. And I thought that's crazy, you know, I think I said this in the talk online. I modeled the brain. You think diabetes is complicated? This is nuts. What's missing is something that's dealing elegantly with the really mechanistic underpinnings of diabetes.”
>
> Interview, VM

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[66] In the movie *Chinatown* the classic line is “Forget about it, Jake. It’s Chinatown,” referring to a set of circumstances you cannot fix, no matter how hard you try. Give in and move on.

When she brought her data into the clinic, nurses looked at her askance, almost worried. The tendency to tell parents to "forget about it," stems from a concern that parents will beat themselves up for trying to control a notoriously idiosyncratic disease. This refrain is meant to release parents from any guilt or shame around their care. Vivienne's story and diabetes modeling project, though, resonates with other QS and digital health tools and projects that aim to make signal from the noise of life and the body.

With self-tracking, we see patients with chronic disease wanting to collect more data, make their daily experiences more available or visible to the clinic. Additionally, for those conditions like diabetes, where self-tracking (via continuous glucose monitoring and insulin pumps) is the clinical norm, some patient advocates are working to make that data more operable for a personal science. The status of the good, adherent patient, here, is also in flux. Again, what is perceived as normal self-care and attentiveness is in flux. Patients are caught between wanting to self-track, carefully minding the numbers and their health, on the one hand, and being told that too much attention is a problem too. The latter notion is contained in "Forget about it; it's diabetestown," where parents are encouraged to relinquish control to the uncontrollable. But the ability to collect more and more data is providing the opportunity or at least the appearance that measurement can lead to better management. In a flip of the oft-heard QS adage "what cannot be measured, cannot be improved," the bounty of data now available—through new devices or application—reframes the task to: "what can be measured, *must* be improved." In a world where continuous reflection and improvement (embodied by the well role) is lauded, the bizarro, helter-skelter logics of diabetestown start to look more like Levittown.[67]

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[67] Levittown was the ur-suburb, developed in post-war World War II America. For more, on this and American utopia landscapes, see (Hales 2014). "Diabetestown" represents, the

IV. The *n of 1* enters the Clinic: Participatory Medicine Meets Participatory Research

The Health eHeart Patient-Powered research summit in November 2014 was the summation of nearly a year of work by a steering committee working of heart patients—mostly experienced advocates and organizers of support groups—to figure how to redesign the way medical research is done. Most of the day included design work (I will discuss more below on "Participatory Research" below) in small groups on actual research projects. This intense, collaborative work was framed with and punctuated by panels on the changing face of patients roles in research and self-care, enabled by new online communities and technologies that connect patients to each other in support *and* knowledge-making communities. On one panel, a young heart patient advocate joined a UCSF faculty member, Ida Sim a physician and informaticist, and "Patient-PI" Sean Ahrens, the founder of Crohnology, a website for the sharing of self-tracking, self-care insights and self experimentation for people with Crohn's and Ulcerative Colitis. Katie, the patient, and the UCSF Health eHeart PI were present to discuss their journey figuring out what their version of patient-powered research will look like. Ida and Sean, though, firmly anchored this new kind of research specifically to growing self-quantification and tracking— where *Homo experimentus* meets participatory medicine. While Crohnology started out as more grassroots and fringe, as he came from entrepreneurial programming and DIY—"I was just thinking i can build

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unwieldy chaos that cannot be completely understood or tamed (according to physicians). Levitttown represents the harnessing of American utopia, at the edge of the rural frontier, the buffer between the unruly city (New York, in this case) and the wild untamed landscape. My point is that with new technologies that remake the uncontrollable disease appear to be manageable through data, that leading edge of the tamed utopia on the edge of the frontier (requiring it and feeding off of it, of course) is shifting.

software tools for people to track their health and track the treatments they do. that's the world that I operate in"—his next venture, patientpowered.us is in partnership with PCORI and widens the scope beyond his own patient community. Ida Sim, founder of *Open mHealth*, an organization dedicated to building open-source mhealth infrastructure, similarly comes from the world personal data for self care. She framed the challenge patient-powered research as starting in the clinic, at the border zone between doctors and (certain kinds of) data:

> I'll start with a story. As part of open mhealth, we're trying to figure out how to get data that people have tracked. And we're really struggling with how to make value out of that data, and I was at Medicine X conference last year and I was sitting down with a patient and she has a son who has cystic fibrosis and she was just meticulous in tracking his clinical status and some of you may in this room as well. We were just talking about why it's so difficult to get value out of this data and she says, 'you know I spend all of this time, I have deep insight into my son's disease and I went to my son's doctor and walls went up.' [lots of hmhhmm in audience] I'm seeing lots of heads nodding. I was sitting there thinking 'yes, why wasn't that data looked at? That's wrong. There's a lot of insight there.' The other half of me, with my doctor hat on said, 'well yeah, I'm 15 minutes behind, I didn't ask for that data, It's going to take me a long time to make sense of that data, I've got all these other things to do that I think is my professional responsibility to do and there's a mismatch of agenda. What I took away from that is both sides have a legitimate response to a challenging issue. Out of that session came the idea that the data was not collected collaboratively. They were facing off over the data.

> They were not sitting on the same side of the data. Out of that came a project we're building called Linq in Open mHealth that allows doctors and patients to collect data together. I think it's important to recognize the emotional response of both sides and validate and come up with a different solution. [IS, HeH Patient-Powered Research Summit, November 2014]

Over lunch, Sim unveiled her *n of 1* tracking tool for physicians and their patients to an enthusiastic room of heart patients and researchers who circulated amongst a few innovators including a science crowd-funding platform, called experiment.com. "You personally have that control and that's huge", said one patient. "People are already doing it. But it's being lost. This tool is to make people more scientific, not to make them into scientists," Dr. Sim said. "The role of the clinician is to do it in a setting in a way that's safe, to have clinician oversight," she clarified. One of the atrial fibrillation patients chimed in: "I'm so ready to do it with a-fib triggers. I'm ready to be done with the trigger wars!," alluding to the murky medical guidance on what foods, exposures, behaviors actually trigger an episode for a given person. Melissa, a middle school educator from New Hampshire who also has a-fib, later told me that her doctor did not even warn her about triggers, guiding her to better manage her condition. She shared with me an extensive months-long calendar she had made with excel to track precisely that. She had not yet taken the data to her doctor; she worried what they might say.

QS has been a space where self-tracking pioneers and *n*s *of 1* have charted out their own paraclinical as epistemic pioneers, sharing their data and their experiences as a kind of expert technique (how to track, how to parse your own data, how to gather it all on your own or at home). For those who track out of necessity, their personal data have existed in a murky epistemic zone—not mere subjective illness narrative, but not yet ‘objective’ clinical data, legible to their doctor or their medical record. However, tools such as Ida Sim’s Linq and Tidepool, which will bring diabetes data—from devices and self-generated—into the clinic, may change this. The QS pioneers, tracking, diagnosing and hacking themselves, may just be a footnote in a potential future where there is real-time, remote monitoring of patients from a physician dashboard. Whether or not their experiments were generalizable or effective or true, self-tracking created its own kind of epistemology and logic care, demanding new capacities and capabilities of medicine. Through their own data patients participate in a new logic of care; they are also attempting to shift the locus and mode of expertise through data. Patients assert expertise of their own illness not just through their subjective experience of their illness—often conceded by physicians—but also through the crafting an objective stake on their condition that appeals to the authority of data and numbers. At this juncture, a new kind of medicine may be emerging, or perhaps is being forced to emerge, where new patient demands, practices and technologies require remaking (some kinds of) patient-doctor encounters. Part of this new encounter might mean embracing a logic of care(Mol 2008) that is experimental in the fullest sense of the word. It also might mean continuing to evolve medical relationships to uncertainty (S. M. Holmes and Ponte 2011; Fox 1957; S Timmermans and Angell 2001), where new forms of patient data in the clinic adds to the management of uncertainty, already imminent in medical practice. This remains to be seen, as these practices are as yet still marginal. For now, I am interested in the kinds of epistemologies we do see in this moment, as they are emerging with new kinds of experimental practices and subjects, to which I now turn.

Chapter 5. *Homo experimentus*: The digital subjects of digital health

So far, I have presented some of the interlocking and proliferating implications of self-quantification and digital health techniques and technologies. To understand these implications I have developed the concepts and analytical devices of the *n of 1*, the *well role* and *participatory medicine*. These have been places to stand, vantage points to understand the varied practices of self-quantification. As functions of self-quantfication these constructs relate to one another as less between parts of a whole. To borrow a chemical versus a biological metaphor, self-quantification—in tools and in community—exists in more of a resonance structure, where varied practices and tools (from active to passive tracking) circulate and generate overlapping and diverse meanings. Here, I try to name what emerges out of that structure as a kind of subject that I call *Homo experimentus*.

Quantified Self is, as founder Gary Wolf has described, a community and network where people share their techniques. Throughout this dissertation, I have followed some of the actors that circulate between the worlds of QS and digital health, and I have tried to develop arguments about the kinds of worlds and forms of life that they help to create. From software applications to data aggregation, visualization and analysis platforms, tools proliferate amongst communities of practice like the bio-hackers, optimizers or the e-patients. For the former, tracking serves a well role, whereas, for the latter, paraclinical practices serve an *n of 1* that challenge medical epistemologies and care. QS practices have partially shared meanings for different kinds of users, from the chronically well to the chronically ill. For example, the chronicity of diabetic life and self-care serve as a model for measuring, reflection, experimentation, and even granular control. The good patient and the good well person resonate and blur together, perhaps a circumstance that is symptomatic of obsessions with adherence, compliance and resistance to medical orders (Whitmarsh 2009)..

As a modality or subject, *Homo experimentus* runs throughout previous chapters and has helped me to elaborate other implications of self-quantification in the pursuit of self-knowledge, struggles with illness/wellness, and medical authority. In the following, I draw on *Homo experimentus* to deepen my understanding of stories from quantified selves navigating their data, digital lives. Whereas quantification may imply a flattening or reduction of selves and bodies to 'mere' numbers, by understanding these practices as partaking in the mode of *Homo experimentus*, we can see these techniques and practices in a different, less simplistic light. I will argue that *H. Experimentus* emerges in the traction between, life in digital experiment—captured in discrete, linear data—and life as narrative possibility—where data serves proliferating stories and future selves. As I explore below, the mode of *Homo experimentus* begins with not *just* living in experiment or embracing experimentalism. I draw on other analyses of subjects of experiment (Petryna 2009; Sunder Rajan 2010; Sunder Rajan 2005), subjectivity and science (Shapin and Schaffer 1985; Shapin 2008; Haraway 1991b) to ask similar questions on the kind of lives and ways of knowing that built out of particular practices and particular moments. Experimentalism, as I use it, in addition to fostering a tinkering *bricoleur,* invites quantified selves to engage in particular kinds of epistemic innovation, self-reflection, and the grasping for novelty and maybe a kind of freedom.

I. Coached back to health: *Homo experimentus* in the clinic

To begin, I start with tracking in the clinic, where trackers work with "coaches" to help make sense of their data. The coaching model is percolating throughout medicine to help bridge the gap between costly health care professionals (physicians and nurses) the care or behavior change that needs to happen at home. For example, one successful digital health company, Omada health, uses coaches, data and a digital platform to guide diabetics and pre-diabetics through weight loss and exercise regimens At the time of fieldwork the potential of personal health data in the clinic was largely unknown. I also encountered digital health startups that were looking to operationalize data and wellness scores in mainstream healthcare. They traffic in the patient "engagement" discourse, billing themselves as ways to save money by getting patients more involved in their health. One company that I observed briefly utilized text messaging to target wider, lower-tech audiences. The impact of these products will be left to another investigation and others who are critiquing the "digitally engaged patient" (Lupton 2013b; Lupton 2014) . Here, I explore coaching that is used for *n of 1* self-experimentation and explore the growth of a kind of subject emerging across these diverse sites of practicing personal informatics. I return to some of the stories we heard about in previous chapters, and to concepts of participatory medicine and the *n of 1* in order to demonstrate how they form a *Homo experimentus*.

I begin with a two scenes on quantified self and coaching, one from a physician, an early pioneer in bringing self-tracking into the clinic, and another of a coaching session. These two takes on supervised digital self-care gives us a view into what tracking and digital heath data does and does not do for those collaborating around and through it. Coaching involves sitting down with a coach or peer who helps review data, propose experiments and elements to track, and offers hypotheses. Coaching is emerging outside of QS, too, as a support role outside of the clinic to help individuals and patients stick to treatment, diet, or tracking regimens with a non-hierarchical or non-authoritative support. While these two scenes are about self-tracking with coaches, one in a clinical setting, the other in a peer, non-clinical setting, my use of them is not solely to show

how the *n of 1* could change medical practices. It is about that, in part. But more so, when placed in coaching context—that is, where a tracker necessarily reflects on their data and their meaning with another person—features of *Homo experimentus* appear throughout the QS community and QS practices. These perspectives from coaching and against a clinical backdrop introduce my interest in the relationship between data and narrative, experiment and hope, truth and evidence.

A. Family Doctor 2.0

> It's not about the data! It's about people. Anyone who says they can make an app to solve these problems is either a moron or a huckster.
>
> Dr. Berger , the "Quant Doc"

Dr. Berger is a primary care physician in private practice who has been advocating for self-tracking in medical practice. He sees himself as a necessary link between two worlds, the Quantified Self community and old-fashioned "high touch" medicine. After becoming disillusioned with practicing in large hospital systems, including running an acute care setting, he set off on his own to create a private practice, unfettered by the demands of large payors or insurance companies. He bills for time, of which he gives much. A typical office visit could be 30 minutes to an hour, or more. His inclusion of quant coaching into his medical practice has drawn some attention in the media and in the QS and Medicine X communities as a "Quant friendly doc". His background in computer science is clear. He left a PhD program in electrical engineering to pursue medicine. These educational starting points obscure his much more traditional medical commitments to small scale, one-on-one, "high-touch" medicine, where home visits and 1 hour consultations are the norm.

Dr. Berger's offices are located in a well-appointed Art-Deco building in downtown San Francisco, a building that is home to many high-end medical practices. His offices look more like a technology or a design firm, with modern, clean lines, spotless white walls and tables. The aesthesis is more in keeping, with the cool purity of an Apple store than the sterility of a clinic. The white walls of the waiting room have little artwork, but they host a small shelf books that includes integrative medicine leader Dr. Andrew Weil's *Why Health Matters* and *Healthy Aging.* Completing the deliberate aesthetic intentions of the space, there is a large monogrammed black leather doctor bag, at least a half century old, propped in the corner. I learned that it belonged to Dr. Berger's grandfather, a country doctor in the South. His father's and grandfather's medical diplomas hang on the sparse walls, too. After many encounters with him, I noticed that he wore the same outfit every day: no whitecoat, black pants, button up shirt, with a sporty black utility vest on top. His vest, I realized, functioned as the new doctor bag. Each pocket, which he zipped and unzipped in rhythmic lock-step revealed some key tools, like his smartphone and a digital, portable pulse-oximeter.

I first met Dr. Berger in his personal office where he met with patients who sat in black leather chairs across a wide, shiny white adjustable desk, ordered from Denmark. He has virtually no papers or medical charts, just a wireless keyboard and mouse, and a screen that he positions perpendicular to his gaze. Patients share the same view, if not access, to the chart, seeing almost everything he enters, if they can keep up. He is an early adopter of a small, family run Electronic Medical Record (EMR) that was designed in partnership with IDEO. When I accompanied him to a demonstration night at IDEO offices, he walked other doctors through his own way of using it. "It's starting to feel like *my* notes." (A common complaint of EMRs is that, as instruments of audit, they were never built for doctors, patients, or the way clinical care actually happens). I have observed him maneuver around this digital tool with such ease and speed. As patients talk, he types what they say, often quoting them verbatim, sometimes repeating what they say as he enters their descriptions of their pains or malaise. The record is classically oriented around a problem list, dividing patients ailments into discrete, often interconnecting issues or diagnoses. Patients bring their messy narratives. He translates them into the neat digital space of his chart. Notably, his chart includes virtually no patient generated data from the quant coaching. This is data of daily logs—taken with a smartphone application that syncs to the cloud—of meals, exercise, symptoms, drugs taken, mood, and any other variable that patients believe may affect their conditions.

When pressed about this at the Quantified Self Global Conference at a session he chaired on "Quant Friendly Docs", he was determined that this kind of data should be owned and kept only by the patient. While many in the digital and mobile health industry dream about the big data possibilities of patient-generated data, Dr. Berger refuses to aggregate or do research on his patients through their data. Jaded by the possibility of learning from big health data, he only wants to treat one *patient* at a time. Feeling a bit pressed on this point by audience members committed to aggregation of big health data and evidence-based practice, he answers somewhat defensively:

> Even people with similar diagnoses are highly different, highly individualized and different from each other. There is no way to create any sort of population study using this model. About this as an effectiveness as an intervention—the coaching is not—it's nothing! The coaching with each patient is completely different. And what we're tracking with each patient is completely different and changes week to

> week. It's a constantly changing experiment based on the individual response. Can we say it's been successful? Yes. How do you define success? Because it's different for every patient. This is not an RCT [Randomized Controlled Trial]. This is not a population-based approach. This is an individually-based approach. And we will not waver from that. [chuckles]. We will not allow to be put into 'let's study this' because it would detract from the value of it, to try to standardize it.

Dr. Berger's urging that "It's not about the data!" is partly about his belief that an *n of 1* approach to even common diseases, like diabetes is incommensurable with models of evidence based medicine that make conclusions based on aggregates of data and recommend interventions on individuals based on populations. His admonition is also about a commitment to active tracking and a coaching model where the data serves as a reflection device. He and the founder of the tracking app MyMee (the tool his Quant Coach uses), echo each other: the data is just a way to reflect, to engage with someone outside yourself.

> We don't WANT to have their data for a variety of reasons. Mostly the data is not very interesting; it's the discussion around the data, asking 'what do you think will be meaningful?'….Sometimes it's food, alcohol intake, location (where they were, the context of their life). We have an app called MyMee that just lets you define the buttons based on what we decide. Those could be changed on the fly. Active tracking. Sometimes we will use apps from data collection devices, like activity …We find the passive tracking much less interesting. It's more when people have

> to reflect and be more aware of what they're feeling…They're more engaged and then they have accountability. They know they're going to have to talk to [the Quant Coach] about it. She's watching. When they don't collect data. It's always interesting

This “Quant Friendly Docs” break out session at the conference seemed to divide between those who urged a population based approach to capitalizing on the big data generated via self-tracking, what some at the QS conference called “Quantified Us” or “Quantified Universe” and those that were very wary of aggregation, surveillance versus sousveillance, and scaling the *n of 1*. Other users of MyMee, including its founder, and practiced coaches chimed in:

> Anne (developer of the Body Track project) : I also work with people outside the medical setting in a quant coach way. A huge part of this is the stories the person is telling themselves and their actual experience. When there's a discrepancy. How are you going to test the story? How do you refine your users manual for yourself? That's what comes out of this process. That's going to be very individual. That's essentially the trajectory of practice and evolution for that individual. Even if I've got the same label as you've got, we're going to have a different trajectory of our narrative and experience.
>
> Mette (founder of MyMee): It's important and general in this process. Session 1 [you realize]: 'Oh my god I don't do what I thought I did!’ One of our programmers said, ‘I’m the kind of guy who runs 4 times a week. Or at least I was.’ That's how he feels—that's the kind of guy he is. I think all of us have these

> ideas of how we live. Once you see that data, black and white. Whatever it might be. Realizing it and seeing it makes it your story. The difference is—it's not that we don't know that it's good for us. We all know it, but do we do it? Very different thing. Once it's your data, it becomes your own.

The data becomes a mirror, in a sense, for verification and identification. People learn to think that their data will not lie to them, even if their own perceptions are fallible. Moreover, the data is about remaking stories, challenging and testing narratives, and therefore selves. As described in the well role, rendering a life in data makes it a systems engineering problem—“ a users manual” needs to be rewritten and reread as trackers become second order observers of themselves. Dr. Berger describes how this is subtly different from having self insight or a solid foundation in medical knowledge:

> Of people that I see in my medical practice, they actually have a lot of insight into themselves. But what they're actually doing moment to moment and day to day is wildly different from their insight and self-knowledge. There's a behavioral aspect to all this. Coaching by the framework, the structure, accountability and a feedback loop that allows people to get closer in their insight and their experience and their actual behavior. Then they start to go 'Wow! This is good.’ Because when you're discrepant between what you're doing and what you know, it's very uncomfortable on a deep level…We teach people technique of observing themselves, making changes one at a time, not impulsively changing everything, and paying attention and learning how to learn about themselves in a semi-structured way and sometimes they finish their three months, they achieve some

> goals and then they continue on their own! They come back and say, 'Wow! This is a totally new way of approaching my life. I feel totally empowered.’ So they don't need the doctor. But maybe they hit a bump in the road and they have a Crohn's flair and they reinitiate coaching.’

This description of tracking recalls what I described in the well role as using data as a mirror, an externalized version of the self as a system of data. Again, data and tracking offer a window into some kind of self. As a practice, it needs to be taught, he explains. The coaches impart the explicit lessons of how to collect the data, account for medicines, symptoms, or behaviors. There are also tacit lessons to be learned about encountering another self in a way that is non-judgmental—in “black and white”—somewhat detached, an affect they model in coaching sessions.

Dr. Berger surprised me. Where I expected to find a digitized doctor, alienated from hands-on patient care, I found someone who was seemingly an anachronism. He wore Google Glass, had the latest gadgets and tools, yet carried himself as a country doctor, a once paternalistic figure amidst a community of hackers, do-it-yourselfers and people generally wary of the clinical status quo. He explained to me his approach to care, that it was a relationship, a give and take, with a necessary power differential. He also advocated “high-touch medicine,” sitting with patients for up to an hour, making house calls, and all in the midst of wielding the latest gadgets and digital tools. What I now realize, though, is that Dr. Berger’s spirit harnessed an aspect of the quantified self movement. We see in his approach, and in his relation to his patients, the beginnings of what we might call *Homo experimentus*, emergent in a set of practices that replicated older forms of individualistic and paternalistic care, reread through the technoscientific and utopian visions of mobile and personal computing. For Dr. Berger, this approach contrasted with guidelines and population based evidence-based medicine, in its opennes to experimentation in a relation of care. The support of the physician as well as the coach provide, for him, a necessary relationship of relinquishing complete control. The coach allows insight to emerge from the context of a relationship where data and care are held up as mirrors of the self. In our first meeting he described effective care as a relationship. But what does data *do* as a "mirror"? Is it simple truth? Externalized reality? To understand that, I turn first to a coaching scene, then to stories of other trackers and their search for meaning, new futures in the mode of *Homo experimentus*.

B. "I'm sick of my story"

As part of my fieldwork, I observed coaches review weekly data collection with a simple app that trackers use to log relevant activities, symptoms, moods, observations, medications, or whatever else seems relevant to the problems at hand, in real-time: from depression to chronic pain to addiction. Built into the coaching model is the desire to have the tracker cultivate their own motivation and desire for tracking and change. Because self monitoring can be so onerous and intrusive, it is important that self-surveillance comes from within. The coach is part of the data mirror. The coach tows this fine line, there for accountability and structure, not shame or coercion. The following observations are from tracker is a tackling chronic illness, anxiety and depression, in the context of a life that feels stifled and stifling.

Tina is the longest tracker in the practice, a woman working on her Crohn's disease, depression, anxiety, and general wellness and fitness. I finally met her in person. All previous encounters have been over the phone--I got to know her voice and her and her general malaise in the face of even the smallest of life's daily challenges. The coach begins with an overview of the week in general, then just dives into the data, the daily log. Entries serve as outlets into smaller stories, concerns. A high rating of anxiety might spin off into sidebars about coping with life. She talked about how she's sick of rehashing her life in therapy, that in therapy this "story" gets created and she implied it takes a life of its own, shaping her actions and pre-occupations. The discussion becomes too much about the story and not what she can do about it. So she tracks.

After going over one day of food data of candy and cheesecake and cookies, the coach jokes, “well that days awash.” He says this often with trackers not to punish but to note and move on. In coaching, there's little judgment shown in the negative, or at least that's the stated goal. While marking every moment and noting the past is important, and fastidious care in recording is important, dwelling or beating oneself up is not.

Driving home from Fresno she tracked that she felt really tired. Without much prodding into why, Tina quickly added that her exhaustion here had emotional components. She reminded us about her vacation a few weeks ago, when things got emotional with her boyfriend, how she put it away so she could move on and get on with her vacation. But sometimes it comes up. “You put all this stuff away to get on and then it gets dug up.” She feels like there's this story that gets dug up and rehashed over and over again, and she just wants to move on.

“Fear cripples me" she says. Going to an exercise class or mustering up the courage to ask if something is gluten free at a restaurant is a battle. More serious challenges—like ending her emotionally draining and painful relationship—seem impossible. She does have some small victories, though, like mustering the smallest amount of courage to ask about the gluten content of foods at restaurants.

The coach interjects here a bit excited: "I'm thinking about what you track. We can get rid of heat, creativity and then we can add meditation and victory”

“It’s a breakthrough!" She adds.

“It's great, it's way more important than if broccoli makes you gassy," the coach adds.

They decide to give her a goal of 30 minutes of meditation per day. Tina emphasizes how she really has faith that meditation can do great things for her. That for her it's about "finding the breath…I don't always make the connection…but I have faith in it that it'll work."

Having noted that as a new goal, the coach redirects us back to the data, reading one of her notes: "Spin. I felt good to be alive, challenged." Tina added further, speaking with a residual high from the class: "something about that physical activity that made me feel really good.” I could see her reliving that, as her mood perked up for just that moment seeing it reflected in her data. The coach keeps us moving along: "So next day, Friday…" and they launch into food talk, the meals that were logged. There's much discussion about protein. She likes to have mostly non animal based proteins but it's difficult and the coach offers that it's not optimal to get your protein only from plant sources. She pushes back a bit: “does my life have to be optimal? No. Just acceptable to me." The tensions with tracking are revealed, here, where one tracker meets her limits with the drive to “optimization.”

At the end of their session, the coach leaves her with her assignments: to track 30 minutes of meditation per day, her victories, and for next week to look into getting a sleeping "appliance" (a substitute for a CPAP machine for sleep apnea). Finally he says, "let's leave the big protein discussion for next time" as well as doing the luminosity base-line cognitive test, so she can get "baseline on her brain." With assignments and smartphone in hand, she leaves.

The quant coach told me some time later that he aims to be like “a therapist in their phone”, serving that function of accountability and reflection. Unlike a therapist, the quant coach, they told me, was meant to remain quite neutral, a mere reflective surface, where trackers bring their problems, their data, and their hypotheses. The coach can share interpretations, encouragement, but the exploration, motivation and problem identification should come from the tracker. Or, so that is the goal. In practice, this is hard to maintain. Regardless, there was an odd kinship between therapy and coaching that I found curious. I am interested in the gap between the coach’s “I want to be a therapist in her phone” and the tracker’s “I’m sick of my story”, where her story, she believes, is the object of her psychotherapy. Other than the function of generic support, I wondered how the self in coaching—the self of *Homo experimentus*—related to a self sought out, explored, or generated in psychotherapeutic setting. In the *n of 1* and the *well role*, I portrayed this cared-for self as “high-definition”, pixelated, cybernetic, computational. Here, I use *Homo experimentus* to get us a little farther, or a little more specific. When not a vocation (Shapin 2008), what is the experimental life or experimental self?

From the QS community and self-trackers, I learned, at least, what it can be. During and after fieldwork, I encountered many wearers of activity trackers (like a fitbit or a jawbone) or users of tracking or habit apps who had never heard of the Quantified Self movement. Whitney Erin Boesel has made a distinction between “Big QS” those who participate in the QS community (attend meet ups, conferences, see themselves as the *n of 1*) and "little qs" those who track or count with tools unaffiliated or unaware of any sort of "movement," where individuals are sharing data and self-experiments as well as their lay-expertise.[68] Both users were interested in using the technologies to change health habits, among other things, but how they did so mattered differently to each type of user, depending on their perception of being part of a 'movement.' Both however, revealed the extraordinary extent to which using these technologies entailed becoming hyper aware of the self and its infinite capacity for improvement.

Those in "Big QS" may no longer apply as QS tools and techniques expand, disappearing in the everyday fabric of our lives (as automatic GPS tracking and internet tracking already does), offering seamless insights to be and stay well from our data exhaust. As "little qs" grows, as medical futurists envision, the QS movement may become a quaint and curious moment in the history of discovering ourselves digitally. I focus not solely on the "early adopters", considered unrepresentative of the general population, nor solely on the medical futurists who imagine that this is the future of medicine. Instead, I have explored both groups to gain insights on what I would call an anthropology of possibility; I want to show that what emerged here at this point with self-tracking and quantification are key ingredients of any effort to trace the very concept and zeitgeist involved in the idea of possibility itself, where experiment, as Hans Jorg Rheinberger shows, is the engine or for generating surprises (Rheinberger 1997).

When Tina sits with her coach, she fills in the blanks, patching together her life in a week. The data are anchors to past moments, sometimes of significance, requiring longer explanations or diversions to deeper stories. Other data require little elaboration, more noise than

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[68] A distinction first made by Whitney Erin Boesel to note the difference between the movement and those that are incorporating the tools and even ethos without self-subscription to a "movement."

signal. Her week's map is not in a neat, linear story; these data can require work to re-stitch together her experience. The data may be plotted along digital time, discrete units where minute to minute, day to day pass one after the hour in simple sequence. She takes us on little detours, asides, and tributaries. Some data are not as important as others. Some food glossed over as mere noise, others a signal of significance, where a new story or association can be made: discovering a trigger of her bowels, a way out of her anxiety and depression, breakthroughs in what works to make things better. This is practical, "real" stuff, as the quant doc has said. Reflection with the data facilitate a telling of small stories, "little narratives", along the linear moving plot of digital time, where certain days and events gather more energy or momentum for the week and its experiments.

In her book *Healing Dramas and Clinical Plots*, Cheryl Mattingly (1998) argues, using the case of occupational therapists, that stories and narrative transform time or amorphous experience, into "an experience." Something similar is happening with data and the sense people make out of it. With tracking and quantifying technologies, time and events are captured and marked at an unprecedented level of detail, thus transforming what it means to experience and remember. Daily experience, in other words, has new ontological potential. Does its status as data cause the experiences of life to cross into "an experience," to play a role in a human plot? Dr. Berger's assertion that "it's not about the data!" perhaps captures what it takes for self-quantification and self-experimentation to enter into human time, that is narrative time. In reflection—with a coach or on ones own—data become something else, the recalling and recounting of life as events, as part of a larger, unfolding story of transformation. In other words, digital "impartial time becomes human time" (Mattingly 1998). This time keeping through data brings together *chronos* and *kairos*—digital time and human timing, respectively—where the "impartial" time of the clock meets the human time of experience, event, plot, and narrative. However, in the experimental mode, the teleological nature of plot and narrative (for the therapists, movement towards rehabilitation) is loosened up, moving towards innovation and new possibilities itself. When Tina says, "I'm sick of my story," she looks towards data collection and self-experimentation as a way to write a new one, or maybe even break free of "stories" (that is, closed-ended ones) altogether.

Likewise, the narrative quality of experience, Cheryl Mattingly argues, does not rely on any kind of linear or narrated plot where the end is known and actors (in her case, rehabilitation patients and their occupational therapists) act out scripted roles towards a given end. Rather, the use of story and narrative to move things along, tie small actions to possible futures of rehabilitation, in the therapeutic process ("therapeutic emplotment") involves provisional and precarious trajectories, "an unreliable guide to experience, projecting future shapes which falter and need continual modification as therapists and patients move toward that future" (Mattingly 1998, 156). Similarly, the little narratives that emerge from a data point or a series of data points—mood and relationship trouble, activity tracking and stories about courage and fear of the unknown—are little tributaries or perhaps small eddies along the linear path of digital time. Upon reflection or hypothesizing—will tracking victories bring up your mood? Will eliminating corn calm your colitis? Could these symptoms indicate an underlying syndrome?—to craft or call out the signal from the noise, little stories offer potential, malleable, fragile futures that may come to be. Tracking, Anne explains, "does give you new ideas to kind of modify your hypothesis set and how does it kind of cause to reorder you amount of faith in the various possibilities. If you look at the story, it's like, there were all sorts of hypotheses that came along and things that happened to see: how much traction do you get by looking through this lens, how much traction you get by looking through that lens." For Anne, tracking offers an experimental machinery to try out different stories – stories with hypotheses that may be proven correct or incorrect – of what is going on with a mysterious illness (in her case) or suboptimal functioning. Patterns and stories, it seems, can even emerge with passive tracking, where devices collect data without much active reflection:

> My dream I think eventually is…you can dump all that data somewhere and rent some analytics engine that would look for anomalies and things to discover like…what's your optimal sleep? What seems to be your optimal diet? What seems to be your optimal exercise? After Yoga are you better off than you are after you play basketball? Find some basic patterns. …That's my dream to help guide us to know what to really focus our experiments on. To really see if that's true or not. (Michael, parkinson's disease patient)

This is a common dream, to have a way to efficiently aggregate personal data and design algorithms to generate insight from them. Although such a system does not yet or may not ever exist, some self-quantifiers see these personal analytics companies as augmenting their ability to understand themselves in the present as well as their future risks. Risk, after all is a narratively structured story about the body and life course, one that places various futures in the present.

All of this emplotment and narration, the anticipation and monitoring of the effects of engagement before they have occurred create one sense of the experimental life. Narrative exploration, searching for possibilities and ways out of problems, are techniques of living that pass through the epistemic lens of self-tracking and self-experiment –self monitoring as if, with a little adjustment based on the evidence, one could know the perfect formula for a healthy life. More than in-depth personal exploration of, say, therapy, or high touch primary care, tracking and reflecting the self and the body through high-definition data—the granularity of life and the experience of disease—enables a path to such understanding of presents and charting possible futures through the rubric of data and experiment. This is a self of breadth as well as new kinds of depth[69], where new horizons unfold along streams and tracks of data.

In tracking and in reflecting on daa (alone, with a coach, to an audience in an "ignite" talk), I argue, the quality of experiment creates the idea and the experience of new habits, new futures, and new selves. Even, perhaps, eschewing the self, or the self's "story" as oppressive, scripted, and stale. Like the mindfulness trackers previously described, the tracking and data provide an alternative self in a mirror of data. Data is not an alternative to narrative self, or a self of narrative depth. Rather, data and digitization of life participates in new kinds of narrative experiences of self where the horizon of possibility are mediated in the experimental mode. Here, I draw together Cheryl Mattingly's work on the essential narrative quality of experience and action with Hans Jorg Rheinberger's insights and analyses of experiment systems and "epistemic things." Rheinberger's epistemic things are the objects under investigation that require understanding, probing, or elucidation; they are any objects that need to be materially defined. In self-experimentation or self-tracking, questions about ones life or body, materialized in data, might be epistemic things. Despite the finality of the word "thing," these epistemic objects are constantly under the process of unfolding or shifting. An object of inquiry, in other words, is never quite done in its process of becoming; it is a moving target. Or, as Karen Knorr Cetina explains: "I want to characterize objects of knowledge ('epistemic objects') in terms of a lack in completeness of being that takes away much of the wholeness, solidity, and the thing-like character they have in our everyday conception."

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[69] Recall the high-def human here. However, the kind of depth that I describe here and in Chapter 2 is not necessarily that of an inner subject, necessarily.

When we try to understand the epistemology of self-tracking or self-quantification, then, we are necessarily talking about the ontologies of selves, disease or data as things or objects in formation[70]. Both the Mattingly's understanding of care of Rheinberger's understanding of experiments seem to converge on the epistemic nature of narrative or the narrative nature of epistemology, where how we know what we know is grounded in movement, action, or plot. But it is a form of storytelling and emplotment that is enlivened by the scientific episteme where truth, facts, and believable stories are made available through technologies of tracking. Plot and movement are become known through the machineries of scientific epistemology, or the objectification made possible through capturing elusive life in data. When life is lived experimentally, it is emplotted in experiment and it unfurls as something to be known and altered in the movements of a personal science.

II. Signal and Noise: Self-knowledge and Self-making

> [A]n experimental system is full of stories, of which the experimenter at any given moment is trying to tell only one…[They] contain remnants of older narratives as well as shreds and traces of narratives that have not yet been related. Grasping at the unknown is a process of tinkering; it never proceeds by completely doing away with old elements or introducing new ones *ex nihilo*, but rather by removing and reorienting given elements by a preceded concatenation of the possible(s). (Rheinberger 1997, 185–6)

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[70] Can also be thought of through Knorr Cetina's (1981) "tinkering" or Pickering's (1993; 2002) "tuning", mutually, of self and data.

The creator MyMee, a tracking app used in a coaching platform in the clinic with the quant doc, gave a presentation at a QS meeting called "Debugging my Allergies," where he discusses the more than "9,400 observations of myself, my condition, and my daily life." He hypothesized: "If I kept my body in an overall good state during the grass pollen season, perhaps I could reprogram my system not to be afraid of grass pollen." He approached the experience of his environment as a system to optimized, "reprogrammed," so that it might relearn how to respond to pollen. In experimentation, there is hope, a path forward:

> Used to be that I was subjected to symptoms, now it's empowering data and now I'm more feeling like a hunter following the trail. Every time I sneeze now, it's the symptom. This is my system revealing something about itself. That's where I get empowering data for making new experiments.

Tracking platforms—whether a wearable device or a tracking app—become experimental systems where the collection of data and its a reflection (with or without a coach) becomes a "machine to make the future." Data collection, following the scent of the trail, sets one up to recognize repetitions and differences, the seeds of innovation and possibility. New symptoms, new triggers, new associations, new data provide the fodder for continuous innovation and discovery in debugging the body's system.

After a problem is solved, a system debugged, the tools and techniques remain to pursue new questions and new challenges. *Homo experimentus* can be drawn on any time. "Our threads that bind us here are that we are curious people. We are curious people who live in the information age," explained Gustavo, the budding productivity guru and all around wellness tracker. He continues:

> It's a way of life, I'd say. I think it's a more adult way of looking at personal development….I think that when we're young, say…we see personal growth and personal development as this ocean. This vast ocean of possibilities. We're going to sail the seas. And we're going to have adventures. Or we're going to accomplish everything. But then something happens in your mid to late 20s where reality sets in. And you realize that work is hard. And being an adult is hard. Keeping an apartment is hard. And then you start families. And the dreams kind of die in some way. Not completely die. But you realize that you don't have all the free time in the world just to go on adventures. And so instead of seeing just this wide open ocean of possibility, it's much more just sober and realistic to just see one month at a time. See each year as a series of 30-day personal experiments.

Gustavo speaks from the experience of a young (late 20s), single male, with some sense of impending loss or innocence overcome. Oceans of possibilities, perhaps grand narratives of what a life will be like, rescale to possibility in experiment. We joked that this scale might be more like a pond of possibility. The image is melancholic in a way. But it also represents a turn away from grander narratives of transcendence to what could be seen as a sacralization of the everyday. As Karen, organizer of QS Silicon Valley told me of tracking: "it's spiritual!" The every day is an opportunity to uncover mystery and meaning, create the new and the future. Another tracked explained his way of life as instinctive: "I found myself researching stuff. So this is what I would do. This is what I will do when I'm 90, what I've done when I was 10. I like to get underneath stuff and figure stuff out. So that's a prime motive as a human being." Quantified Bob expressed a similar sentiment: "Whereas some people might say I want to do this experiment to fix something or whatever, for me it's almost more like self enlightenment and self knowledge, what makes me tick. Like, this works for me, this doesn't work for me and maybe that's over and I don't need to track that every day."

Homo experimentus is a mode, or habitus (Bourdieu 1997), that emerges variously in quantified self. For some, it is a way to both disenchant and enchant the everyday. It may seem paradoxical that parascientific practices of quantification and objectification of life—classically modes of disenchantment—would enchant the everyday, injecting possibility and even mystery into the mundane. In some odd twist of logic, the experimentalization of the everyday, the search for meaning, possibility, and even new "little" narratives in self-tracking data, injects the possibility of enchantment or the encounter of some kind of previously obscured self. How can something be simultaneously spiritual and data-driven, engaged in optimization and meaning making? I argue that understanding *Homo experimentus* gets at that juncture and perhaps causes us to reconsider the boundaries we draw between the sacred and the secular and perhaps revisit the moment of disenchantment where the everyday becomes the site and then the disappearance of the sacred famously described by Weber. I continue to explore that below in further considering the kind of self that is cultivated and immanent in *Homo experimentus*.

A. New and Old Sources of the Self

> For us, the subject is a self in a way he or she couldn't be for the ancients. Ancient moralists frequently formulated the injunction 'Take care of yourself,' as Foucault has recently reminded us….They can sometimes sound like our contemporaries. But in reality, there is a gulf between us and them. The reason is that the reflexivity that is essential to us is radical….Disengagement requires the first-person stance. This is what distinguishes the classical writers from followers of

> Descartes, Locke, Kant, or just about anyone in the modern world. The turn to oneself is now also and inescapably a turn to oneself in the first-person perspective—a turn to the self as a self. That is what I mean by radical reflexivity. Because we are so deeply embedded in it, we cannot but reach for reflexive language.
>
> -*Sources of the Self: The Making of the Modern Identity*, Charles Taylor (1992)

In his survey of western self-hood, philosopher Charles Taylor describes our contemporary situation of selfhood as propped up by three legs of a triangle, described as scientistic disengagement (or Enlightenment's Reason), Romantic ideals of sensuous self-discovery through nature and art, and an aspiration to wholeness "towards a fullness of joy where desire is fused with our sense of the deepest significance" (409). These three stems of selfhood and moral authority fill the vacuum left by the dissolution of grace and grand narratives, such as Christian salvation or predetermination. Taylor describes how some philosophies can capitalize on two of these legs of contemporary selfhood. He offers the example of Marxism, which combines materialism (a version of scientific disengagement) with aspirations to wholeness. Similarly, we can understand *Homo experimentus* as resonating between these three roots of selfhood, drawing on scientism and holism, and maybe even a romantic ideal that locates the self in nature (as understood as human biology) and elevates the intensity of experience of the everyday, like in life logging or mood tracking, and the kind of expressive micro-journaling that those practices mimic. Or, it follows his description of the modernists as "the interweaving of the subjective and the transcendent" (493)

I introduced the question of self-hood in the *n of 1*, where I quoted Brad, a core member of the Quantified Self community, who engages deeply with tracking, mood and meditation, including developing his own mobile applications. He reflected with me on the synergies between tracking his meditation practice, where tracking and quantifying called the stable self into question. He began his self-experimentation with coffee, mood and meditation experiments:

> There are false beliefs and thoughts that are going around and the experiment works by proving that there is another self. I can be thinking one thing but can be doing another thing. … There is this notion of all of these things [tracking tools] pointing to it, kind of a deeper idea of the self. There's something behind there. The things that we think are not really who we are, the things that we feel are not really who we are. The things that we do are not really our identity. So you can use actions of any sort to amplify and strengthen who you are,…. Or you can kind of go in the opposite direction, which is recognizing that the things that you think and the things that you do aren't really who you are. They are just things that you've done and you didn't even really do them because where do you get the idea from? So wherever you look for the true self, it kind of melts away. I think that [tracking] is just another way of doing that.

Brad offers flexibility through what Taylor call "radical reflexivity," or a turn towards inwardness that invites us to be "aware of our awareness, try to experience our experiencing" (C. Taylor 1992, 130). The turn towards inwardness and the sacralization of the everyday are common to QS and modern identity formation, through Christian theological (Augustinian to Protestant) reformations through to Descartes that is still with us today. Though self-tracking and quantification offers a disengaged reason, to gain a sense of the self that is set apart from our experience of it, there is still a strange appeal to individual, particular knowledge, like that of unmediated belief. Creating a mirror through data, both is in search and a destabilization of a self, for Brad at least. It makes the copied self, the quantified version of the self into something workable, malleable, or merely traces that can change. Not everyone in QS practices meditation, but I do believe that this apprehension of the "real self" is what is pointed at when data is externalized and a self is made operable. That is, the quantifying of life's events and the externalizing of data that facilitates experiment or change or optimization calls "the self" into a question, where the data that is meant to be changed can be a false or old self, which the experimenting one wishes to transcend. At first, Brad feels that tracking reveals a second self, one revealed in the numbers and the other revealed as the one who tracks. For him, this circular search for a true self is futile, as he knows from his years of Buddhist practice. However, he still talks about the tracking and the data as extending some of self, now in unified form:

> We can represent parts of ourselves outside of us and you can use that to say, "Well, I am my blood pressure, my heart rate variability, and I need to optimize those things," or you can look at it and say, "Oh, wow it's kind of interesting, there is this machine-like thing that is making measurements of this biological thing and we are all kind of similar in that way." I think it's just a matter of perspective how you look at it. I think that the power is that we can do slightly more powerful things with our individual selves. I think I can do more. I can amplify. I was able to do that thing over a distance. I was able to have an accurate record even though I didn't intend to have one in the first place. I was able to do that data-mining thing where I looked at the frequency of the postings and I was able to the same thing for meditation. You know, there's all of these new kinds of

> things that we can do, a kind of give us "how to" ask questions about ourselves
> but we've always been able to do that we just have less power to do it.

His malleable understanding of self, extended by technology and data, projecting his self across time and space, as he describes, might be aided by his mindfulness practice. He also attempts tracking projects with others, thinking about data beyond the individual self. He sympathized with my own tracking project that insisted on tracking someone else, or my relation to someone else, and not just myself. My point was to demonstrate quantified "dividual" (in the Strathern sense). He similarly experiments with pushing the boundaries of tracking. Nevertheless he slips from language and conceptualizations that break down the self to ones that amplify it. The melting of the self away, at the same time of its amplification, through techniques and technological systems is another way to express *Homo experimentus*. These techniques, rationalizing as they are, extend the self that are latent in human capacities (as Brad believes) as well as about deconstructing and reconstructing presents and future behaviors and capabilities The tracking and the freezing of moments in time are also experiments in memory and memorialization, where QS seems to spatialize time in a hyper-rational or hyper-objective way, obliterating the epiphanic nature of memory, prone to error, full of revisions and different kinds of truths.

In my own tracking project, I logged memories of another, logging the relationship. The data was used to extend the self in the moment by transforming and augmenting the act of remembering. I was reading Proust's *In Search of Lost Time* (2013) and Barthes's *Mourning Diary* (2010) in the field, and thought of the data not as a negation of self through its capacity to externalize or objectify, but as an enhancement of memories by enabling reflection (what QS folks might call awareness or "mindfulness") in the moment. Time expanded and looped back on itself when I tracked a memory and marked its time and place in real time. This was an experiment to see if self-tracking and quantification, as I learned from QS, necessarily led to a linear rationalization of time. I wanted to work with memories themselves, to challenge the ways that life-logging or tracking tends to flatten memory, as mere recording. The act of remembering itself—recalling time spent with someone, their lessons, what is now lost—is part of the self-making process. Traditional tracking or life-logging assumes that memory is fallible and less true, providing (like in the Memex) the subject with a supposedly more true, accurate or objective rendering of the past. However, this denies the dynamic, imperfect, active and embodied functions of memory and remembering as part of self-making practice. By tracking the things, places or events that elicit the memory of a person allowed me to use tracking for the continual rewriting of a self and others through the fog my own memory. Now that she is gone, she can only live distributed in my interactions with people and the world. This is a truth of her existence that cannot be captured by her own digital exhaust (a remaining facebook page, her website, or blogs). I tracked what was true in the moment, what my environment elicited in me to remember at the moment of my mother.

B. Dignity and the search for meaning:

In her talk “Breaking Free of the Tyranny of the Norm”, Anne Wright describes the difference between self-tracking and other tracking, sharing two juxtaposed figures: a lab rat and the television character MacGyver. Her talks come after suffering through a diagnostic odyssey in the medical system for years. After self-exploration and self-tracking to get out of the “flow charts” of traditional medical thought, she figured out that a confusing set of crippling symptoms were due to an intolerance to plants in the nightshade family. It took extensive self-tracking of food and biometrics (such as heart rate), and collaboration with an Ayurvedic practitioner to unravel her symptoms and triggers. She briefly describes this journey below:

> Starting in 1998, I was lead systems engineer for prototype Mars rovers at NASA AMES research center. That was great and I loved it. Then I got too sick to keep doing it. It was all the sort of vague stuff that screws stuff up, make it hard to do your work, to do what you care about in life but comes up negative on all the tests. In parallel to going to the doctor and getting sent to the next specialist and getting the next test, they gave up on me, I started taking pictures of what I was eating, logging what I was eating, playing with heart straps, stuff like that. This was years before I heard about QS, so you can imagine when I heard of QS, I was like 'My Family!' [laughter in crowd]. So I did come to the point, the bottom of the barrel, I had gone through all the flow charts of all the specialists and came out the bottom and I went back to my general practitioner, [and said] 'This is gonna sound weird but in Ayurveda this is called Vada imbalance, it's like 4000 year old Indian science." I gave him a thumbnail sketch of what that involved—so go study Ayurveda and go figure out what to do with Vada imbalance. So I worked with a practitioner and I was getting better. I was really strict, I would only use an ingredient if it was on the Vada balancing list. So I would take this over constrained set of principles and would try to apply it to a menu and almost all of them failed. There were three that didn't and they didn't seem to have anything in common. Then I noticed on a trip that I seemed to have trouble with very simple meals that I knew worked plus one ingredient. So I got suspicious of

> bell pepper, tomatoes and eggplant and it turns out when I got home to google that…it turns out they're in the same family. It's called nightshade. It has neurotoxins in it. They inhibit cholinesterase. What does cholinesterase inhibition do? Oh my lord! This kind of looks like what's been happening. So I started to avoid nightshade and there are a couple of books that people have written…but it let me know that there were people out there who had similar sorts of experiences and what there experiences were. That was incredibly valuable. At this point I could have gone back to do doing the rovers, but I felt there was something here. There was a kernel of salience that I needed to pursue, this experience that I went through. Suddenly I'm doing ok again, but everything that I know says that I shouldn't. What's the deal? So I started to look for other situations when people figured out that they have to run themselves differently than society has told them. Where what they always believed about inputs and results didn't match. Everyone knows about food allergies and seasonal allergies and everyone's aware of celiac disease and gluten sensitivity. But those turn out to be the tip of the iceberg. There are all sorts of ways that people have figured out that has triggered something…and they have to have this sort of custom user's manual to be ok.

In conversation, Anne went into great detail about the frustration, humiliation, and disempowerment she felt going from doctor to doctor, and not finding an answer. Her current work on Fluxtream—an open source application that enables users to aggregate data from multiple sources—and her own foray into coaching are fueled by a desire to bring what she calls more dignity to other’s journeys of healing and self-exploration. At the time of one of our conversations, she had been reading Victor Frankl’s *Man’s Search For Meaning*. Her own story was a search for health and dignity. Helping others to understand their data will provide them, she hopes, with a dignified response to their struggles, personal and corporeal, “to become their own investigator.” According to Anne, readymade devices and applications that track steps or programmatically hold you to a goal, such as a Fitbit, are just as confining as the diagnostic norms and flow charts of mainstream medicine. Open ended, agnostic self-tracking allows the user to figure out their own “user manual”:

> If you look at the story, it's like, you know, there were all sorts of hypothesis that came along…The nightshade thing is like; okay this is another candidate hypothesis. If I adopt that candidate hypothesis and I stop eating the nightshade, what happens? And the answer was, wow! This stuff really works. So that's great, and being able to do this sort of exploration and as your ideas adapt be able to kind of road-test those ideas…Even for the somebody who has previous straight forward diagnose mainstream kind of thing and then if you look at people who have something going where you know the strategies that are going to work for them are never ever, ever, ever going to be on flow chart. You have extra level of you got to go off the flow chart and but the process is very similar. Figuring out what to record, leveling up on perceptivity

For Anne, perceptivity had to be achieved in partnership with another person, a coach:

> When I was sitting there in 2010 and early 2011 trying to work on the designed model, how you take somebody from random initial state they are in, clubbed in the head to be the passive recipient of care. How do you have a website or an app or whatever that help them evolves into this sort of self- perception, self-management kind of thing and I don't think it can be done. I think the only way to

> do it to have to some human who gets it, to have some sort of interaction with and I think it's just like learning to cook. Cooking is a very complex cultural activity with a lot of feedback and customization and process involve in it and nobody expects, realistically, that you can take somebody whose never been in the kitchen before and it can go out to buy of pan and knife and read the instruction manual and suddenly don't know how to cook."

The kind of process that Anne describes draws on the kind of feedback loops and continuous learning and modulation described above. It also involves an experience and understanding of health and wellness that is dynamic, experimental, radically reflexive and open to new possibilities of cure or care. This is an experience, unlike being "the passive recipient of care," that gives her dignity. Experiment, then, as a state of existential innovation and self expansion, was described by another tracker:

> I think that the act of tracking and the act of tweaking and the act of being in an experiment gives a sense of possibility and hope. Even if this isn't working right now, I could change something and I could learn from it and I could make it different next time, that, therefore, could... so I think that's got to be a contributive factor to feeling better, this idea that, 'Oh, maybe there's some possibility, even if it's not exact right now, okay, I still have other things I could try, or other…' you know.

We might understand this kind of generation of hope occurs along what Charles Taylor calls a "fractured horizon," where external meaning is no longer—in a modern "disenchanted" world—generated from sources outside of the self. Here, experiment intervenes and provides the quantified self with a forward-looking horizon of possibility. For those e-patients who are trying to gain access to their data, like Jaime, demanding data also means demanding that their chronic conditions be considered as alterable, discoverable. At one cardiology conference, he found himself challenging a physician who did not understand his quest for what he saw as actionable information:

> He said, ‘why do you want access to [your ICD]? I said, ‘why do people with diabetes need access to their blood glucose levels?’ He said, ‘well I have diabetes, but it's different.’ I said ‘it's funny that you are somebody who needs data to manage your healthcare and you think I should be any different?’ And his point was that perhaps heart disease is not like diabetes in that heart disease or somebody with an implanted device, therapeutic device to treat tachycardia, there isn't anything you can do to prevent non-sustained ventricular tachycardia or onset of atrial fibrillation. But you know, we don't even know! There might be. And I know that there can be! Like I know that alcohol is a trigger in my case for A-fib, and so, there are clearly things that I can do, one of them to refrain from alcohol. So it's funny that he would say that…So he said, ‘you know when I have my oil changed in my car, I don't ask for the old filter because what can I learn from the old filter? I said ‘this is a terrible analogy—It's not the kind of information I’m after. So you're sure there's nothing to be learned from the old filter. There might arguably be something you can learn from your old filter about the health of the engine, but it's not about that. It's about the data in the GPS of your car, that would be a more accurate comparison.”

Here, we see how tracking and *Homo experimentus* helps to not only expand what can be self-treated and managed, but also tries to stretch the experience of chronicity of a condition—its unfolding over time, as something that can be managed, modulated, and controlled—to more corners of medicine and medical care. Or, even with a condition characterized by constant monitoring and modulation, Type I diabetes, real time glucose data transforms management into investigation. As the creator of Nightscout—a system for displaying realtime blood glucose levels on tablets, smartphones or smart watches—explained at a quantified self meeting: "The second major benefit is it makes you smarter about your Diabetes because you're now looking at the cause and effect from multiple peaceful mornings every day. So it helps to transform Diabetes from a mystery to cause" and optimization. *Homo experimentus* also points us to the horizons of the future—the GPS or the dashboard of the car—providing "real time" feedback about how things are going now, and maybe into the future, that can be alterable. As e-patient Sara spins it, "No longer patient, but *im*patient." In the next section, I describe some efforts to bring this new orientation into the practice of medicine and medical research itself, inviting *Homo experimentus* into the evidence-based medicine model.

III. *Homo experimentus,* Participatory Research and the Patient, or "The doctor will see your data now."

This section is about another way that *Homo experimentus* is forming within the clinical sciences themselves. In the clinical setting, we saw patients generating their own data, sometimes demanding that it have a place in clinical assessments (as in participatory medicine). In parallel, there are moves to alter the art of medical practice through the *n of 1* in the context of coached tracking, for example (as we saw with Dr. Berger). Now, I turn to other, similarly alternative and albeit marginal (so far), ways that investigators, patients, and clinicians are trying to use digital health data to alter the way clinical science is designed and practiced.

As part of my fieldwork, I participated in and observed a digital health study that has the ambition of conducting a Framingham for the 21st century, where digital tracking devices and smartphone applications enable the monitoring and surveillance of cohorts of participants not limited by geography. When I enrolled in Health eHeart[71] online, after I signed a digital consent, I was directed to fill out surveys about my health and family histories and encouraged to "connect" my digital health devices and apps so that the data could stream to their research servers. Since joining the study in late 2013, I have connected my Alivecor (single lead EKG in an iPhone case), a digital scale that logs my weight, water and fat percentages, a wireless blood pressure cuff, a step-counting application, and most recently, Ginger.io, an application that passively tracks your mental health through your cell phone habits. In partnership with the Health eHeart study, Ginger.io now sends me biweekly mental health surveys that take about 2 minutes and a few swipes on the screen. Ginger.io has been making a big impression in the digital health world with its big-data approach of passively collecting data on phone use patterns to better understand depression. This study, encourages participants and their donation of data as participating in heart health prevention. In addition to inviting you to contribute your data, the Health eHeart study also invites its participants to take part in the research itself, forming the Health eHeart Alliance (the Alliance) from a PCORI grant (Patient-Centered Outcomes Research Institute)[72].

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[71] https://www.health-eheartstudy.org/

[72] PCORI was established as a private, non-profit organization by the Affordable Care Act. It was originally dedicated to comparative effectiveness research. Political considerations took any reference to cost-effectiveness out of its title, and reoriented (in branding at least) their mission towards patient-centered outcomes. Part of this effort was to fund about a dozen "Patient-Powered Research Networks" (PPRNs) to engage patients in research, often tied to a clinical data-base. The Health eHeart Alliance grant is to form a new cardiovascular-focused PPRN tied to the growing Health eHeart database.

Participatory medicine, as I have tried to show, can use the *n of 1* and self-tracking and self care to give voice to personal histories and life between office visits. Further, these stories may be made more clinically legible through the quantification into data from experience. Participatory research is a movement that extends these capabilities and what is seen as the democratizing connectivity of the internet to invite patients into the research process itself. The Alliance is currently being designed by an interim steering committee made up of a heart patients and one of the Health eHeart Principle Investigators. As part of the design process—which is hoping to craft principles and processes by which patients and research subjects can meaningfully shape research questions and agendas—the committee hosted a two-day summit where it widened its participation to more patients and researchers from the community. As a participant observer of both the steering committee and this summit, I watched patient advocates and researchers come together to try to find a way forward for "patient-powered research." Unlike, say, the efforts of AIDS activists to break into the world of scientists and clinical trials (Epstein 1996, 1995) heart patient advocates have been invited to contribute both their data *and* their research questions to an ongoing cohort study that aims to revolutionize research, both through digital recruitment and big data. As possessors of digital health data, patients are encouraged to be both an *n of 1* and part of *n of a billion ones* as this study aims to scale digital health data and insights.

Between intensive design sessions where groups of patients and researchers clustered around patient-generated research questions (my group addressed a patients concern about statin drugs), panels were convened of patients, researchers and innovators creating new ways for patient-centered research to happens. Notables included Sean Ahrens, quantified-self, entrepreneur and creator of Crohnology[73], a website for crowdsourcing the experience and personal experiments of people with Crohn's Disease from all over the world. Ida Sim, a family medicine physician and informaticist and founder of Open mHealth, an open source platform for organizing and analyzing personal health data from various devices, was there, too. Together, with other heart patients and the UCSF PIs, they set a tone of collaboration, curiosity, hope and experimentation with the process of research itself. "We could fundamentally change the way we do research," said Dr. Jeffrey Olgin, UCSF cardiologist and HeH PI. One of the patients on the Steering Committee, Maya described her experience and perspective

> I'm celebrating 30+ years of being a UCSF cardiology project. Had a rare arrhythmia and an early ablation patient. Kept living my life--never felt like a victim, then in 2006 I had heart failure. I was always an athlete and I was no longer being me. The idea of Health eHeart—I work in tech and was used to using sensors for performing [in sports]. I want to change perceptions of heart disease. A patient learns is that it's the #1 killer of everyone, then we leave them. Where was the hype? That there's a future? How come the cancer patients get the cool campaigns? There are many who want to not be a victim.

A similar sentiment was expressed in the steering committee during one of the many monthly meetings held: "I don't want to be a guinea pig anymore." There was a pervasive sense that being a passive recipient of care was not acceptable, including being a passive subject of research. Being a guinea pig means being someone else's subject of experiment, rather than one's own.

Dr. Olgin again:

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[73] https://crohnology.com/

> We started this process to mix up the way we do research--remove bricks and mortar--you are all data, you're providing the data. it was a nice experiment to go to he next level --this is the participants data--surely they'd wanna do something with it. ...the democratization that you have with the internet...I think of the alliance as an amorphous, socialist researcher that has [laughter] same resources, data. I see the Alliance as a republic of resources.

> We believe in this mission. We’re funded for a grand mission. Nobody knows how to do [participatory research] right, to do this in ways that are meaningful. This is really a grand experiment. In the past, patients have participated but never got anything back, feel used. One goal is to prevent that.

> Maya: This is the first time I feel that I have a voice…A place to provide the wisdom in my history and help others

> JO: What comes out of this two-day summit could really transform how we do research. I want everyone to understand that bigness of this and we have no idea how this is going to work.

While the panelists and participants reflected on how we were trying something new in research—contributing to the experimentalist affect—there was also a related focus on how the medical practice changes with this democratizing of research, inviting *Homo experimentus* into the clinical encounter. The same digital health technologies that invite subjects to seamlessly connect their data to the research servers in the cloud, are making daily experiences amenable to research for themselves (*H. experimentus*) and their physicians (participatory medicine).

> The doctor patient relationship is kind of flipped on its head. If you think about it, normally patients come in with a problem and they're looking to the doctor to fix it for them, and the doctor does the best he can. Here, the researchers are asking the patients for their help: what are the research questions? What is the best way to conduct this research? This is brand new territory. We need to figure out what that process is. But I think that's one of the more interesting, revolutionary, transformative things.

This slippage between care and research was evident with the conversations in our working groups where patients research questions or topics – Who should take statins?' was ours – often stemmed more from gaps in care, understanding and trust between patient and physician, and was not really aimed at gaps in the literature or the science. What is true versus what is right for me was at the heart of our group discussions and designs, where the patient leaders wanted to know why they personally should be on statins. After the physicians in our group did our best to describe (often not in agreement) the current guidelines and science behind the management of dyslipidemia and cardiovascular risk mitigation, our research design turned towards medication adherence. These slippages between research and care were furthered by patient testimonies where the meaning of the word research itself became expansive to include understanding ones own disorder from the internet, peers, physicians. Research also translated into care for others, beyond getting to know ones own diagnosis:

> Initially when I was going through diagnosis, I came to a realization many people going through trials to help me be healthy. I joined a trial. I was scared. How will this help me? I didn't get much. I gave data. I didn't know what happened. In this

> group I felt listened to. It wasn't about [myself] anymore—it was about being citizens of the world. It's not just about me--it's a bigger scale.

Research and care blended into each other as both Sean and Ida discussed their contribution to this changing field of research paradigms. Dr. Sim has worked on Linq make data more legible in the clinical encounter. However, the idea is to disrupt the traditional hierarchy of Evidence Based Medicine, with this new methodology (the Single Case Crossover Design) that spans the pyramid, combining elements of controlled trials and case studies.

> Unfortunately for most patients, their data is considered trivial in the clinic. It remains illegible as its status as relevant clinical or scientific in formation is either unwelcome, dismissed or just invisible. Ida Sim, a primary care physician and informaticist is trying to change that. She is the founder of a digital health platform called Open mHeath. One of their projects is a tool that will help patients design *n of 1* trials—or self-experimentations—in partnership with their physicians. These are "Patient PIs," where QS and participatory medicine meet.

At a participatory research workshop I attended, she explained her motivation:

> At a Stanford Medicine X conference I was sitting down with a patient who has a son with cystic fibrosis. She was just meticulous in tracking his clinical status, like some of you in this room. And we were just talking about why it's so difficult to get value out of this data. And she says, "you know I spend all of this time, I have deep insight into my son's disease and I went to my son's doctor and walls went up.

> I'm seeing lots of heads nodding. Why wasn't that data looked at? That's wrong. There's a lot of insight there. The other half of me, with my doctor hat on thought, “well yeah, I’m 15 minutes behind, I didn't ask for that data, it's going to take me a long time to make sense of it, and I’ve got all these other things to do … There's a mismatch of agenda and the data was something they were facing off over.

Later, she demonstrated the tool called Linq. With patients and researchers huddled around her, Dr. Sim shared the process and why it makes clinical and scientific sense—since the single case crossover design can make individual clinical treatment into a rigorous scientific practice.

> People are already doing it. It’s just getting lost. This is to make people more scientific, **not** to make them scientists.

A patient chimed in,

> I’m so ready to do it with Afib, I can’t wait to be done with the trigger wars!

Others added, excitedly, that having that kind of control and input was key. Later, at the conference one of the other A-fib patients, a retired middle-school principle, shared her data with me. She had kept track of all of her episodes and triggers in a spreadsheet and displayed it on a calendar, all color-coded. When I asked her what made her do it, she said “I’m an educator!” by which I think she meant that she is trained teach, learn and handle measures of success, from teachers and students. The data is just for her, so far: she has yet to share it with her doctor, worried about their reaction. Dr. Sim's tool got her excited, too, to finally be part of the process of discovery and care as a partner not just a patient.

Dr. Sim bridges the worlds of DIY (do-it-yourself) experimentation and evidence-based medicine:

> One way to characterize the research is typically done, is to ask the question and find the answer on a population level. ... you find on average whether its better not to drink alcohol. We run a long trial for years and we publish it and we get one answer for the population. Um… we need to change that model. Number 1 it takes too long; number 2, we're looking for far more personal answers than what's right for a population—it's what's right for me.

Online communities already exist, such as Patients Like Me where patients are sharing their insights, data, and experimentation. Sean Ahrens, from Crohnology, was at this workshop, too. His mission is also to transform the role of patients in research, creating what are called "Patient-PIs."

Mark Drangsholt, DDS PhD a dental health and epidemiology expert is part of QS and has self-tracked his own arrhythmias. Like Sim, he is trying to translate the QS *n of 1* into the EBM hierarchy, presenting his work to scientific audiences. His EBM training was initially in meta-analyses, which were also once considered suspect a few years ago, he believes that "single case crossover designs" will be accepted in time. "With personalized medicine coming, you've got to have personalized data."

IV. Personal is political / Alt. Science:

Anne, discussed above, has talked about this experience as going through a plinko machine. She felt abandoned by medicine and it had failed her. Her meticulous tracking led her to discover intolerance to nightshades, which are natural cholinesterase inhibitors. Anne, and others in QS like her, use self-tracking and personal data collection to practice their own forms of inquiry and self-care. For Anne, the collection of data gets at her raw and everyday experiences in ways that medical diagnostics cannot. She help coach others, too, through their data to help them define their own "custom users manual." Now, as a some-time data coach and Fluxtream engineer, she is helping others learn about themselves through data, to help you "make sense of your life and compare hypotheses about what affects your well-being." The figure of the McGyver, featured in her talk, above, is a call for self-sufficiency, reliance, and even a maverick sense of rebellion. Julie, another QS organizer, echoes Anne's desires for autonomy:

> I see myself as someone who believes in designing your own life outside the mainstream. To have agency. To cure yourself…. And I use this word, **disintermediation**. For example, I home school my kids because the typical idea is that there's supposed to be this expert mediator who's going to facilitate. I like the idea that there's an option and the awareness to take away the intermediaries between ourselves and our life experience.

More important than appealing to scientific validity, for her, is the assertion of self-efficacy and the challenge to expertise. Others (as I will describe shortly) are redefining expertise outright by challenging the gap between patient's testimony and doctor's data.

> We can take away the intermediary, take away the expert in between. And then so QS fits that sort of political or personalized politics, I guess, which is I don't really care if so-and-so says, "Your experiment isn't valid because it's just you. You really need to have a thousand people in your study group, in a control group." Well, I say, screw that, I don't really care because I do think there's valid information for stepping outside of sort of this systemic authoritarian kind of culture.… for me there's certainly something about the N 1 that is about re-empowering and taking agency over how we interpret and experience our lives that has to do with us as individuals and puts us in the driver seat… puts us on both sides, to be the evaluator and the evaluated… Again, not to say that there are times when I want to go to somebody else for an opinion or whatever. But the fact is that our culture is so steeped in the idea that we're just pawns of other people's experience and belief systems around how they're evaluating our health, our experience, our life, our education, the way we live.

As another tracker put it similarly:

> I'm using the scientific method but I'm not trying to prove anything for you. I had a problem and I'm using the scientific method to improve something about my own processes. I might come back next year and say "Well it wasn't my diet" but I have already had the benefits this summer. That's a kind of iterative learning process."

This passage returns us to the optimization and systems of the well role and tracking as counter conduct (Murphy 2012) in the *n of 1* chapter. What I want to emphasize here is the way that the subject *Homo experimentus* incorporates alternative epistemologies, that draw on dominant tools (quantification, monitoring) to attempt to subvert them. The subject that emerges is one that is not necessarily free from the powers of medical authority, but redirects it, iteratively.

What is the *Homo experimentus*? I'm choosing this term to get at a mode of living in the world, or engaging in life and meaning making that uses data, tracking, and/or self-experimentation. Not all tracking is experimental in the sense that it would hypothesis driven or with a control, or even designed, even if sometimes it does entail use of these tactics. My use of the term *Homo experimentus* or *H. experimentus* encompasses those who use self-tracking tools for open ended data collection or those that develop experiments in the traditional sense. Data collection itself is enough, I believe, to participate in a mode of engagement with the self—the quantified self—that prepares for experimentalism, by way of using of using forms of objectivity to negotiate subjectivity. That is, collecting experience as information or data renders such experiences, sentiments, encounters, sensations, or invisible and insensible biological processes as accountable. As paradigms of science grow, expand or even shift from hypothesis-driven, controlled experimentation to Big Data driven science—what has been called "the end of theory" (Anderson 2008) or "the 4th paradigm" (Hey, Tansley, and Tolle 2009)—data presupposes hidden patterns, knowledge or insights. Then, if life can be rendered as a database, then it can be lived through the prism of experiment, expansively defined.

Homo experimentus gives us an idea of what it looks like for personal computing to go all the way in. The creation of personal databases, seemingly unending and inexhaustible, creates a kind of externalized internal frontier, to be explored and mined. Or perhaps is a technoscape and cyberscape (Suchman 2011; Escobar 1994) that is internalized, too. In creating a putative double, *Homo experimentus* may make false promises: that the self can infinitely transparent, malleable, optimized or flexible.[74] Those in QS and those that take up these technologies to gain "self-knowledge through numbers" are also experimenting with these new frontiers, what they can do. *Homo experimentus* is a practical practice, tinkering and figuring things out as she goes. This kind of living in iterative innovation, means that the relation to the future is more complicated that promissory. Trackers keep their eyes on one data point at a time, staying in the present, yet, with the hope of generating a different outcome, a personal innovation or change. This is a hyper-present mode, what Douglas Rushkoff calls "present shock" (2013), where the present is overtaxed with our attention. In the mode of *Homo experimentus*, present shock is managed by directing attention to a specific goal or project. *H. experimentus*, can be both a diagnosis and response to the ways that data can overwhelm and exhaust us.

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[74] In Martin's (1995) sense.

Chapter 6. Epilogue: Living 2.0 or “The House that Never Sleeps”

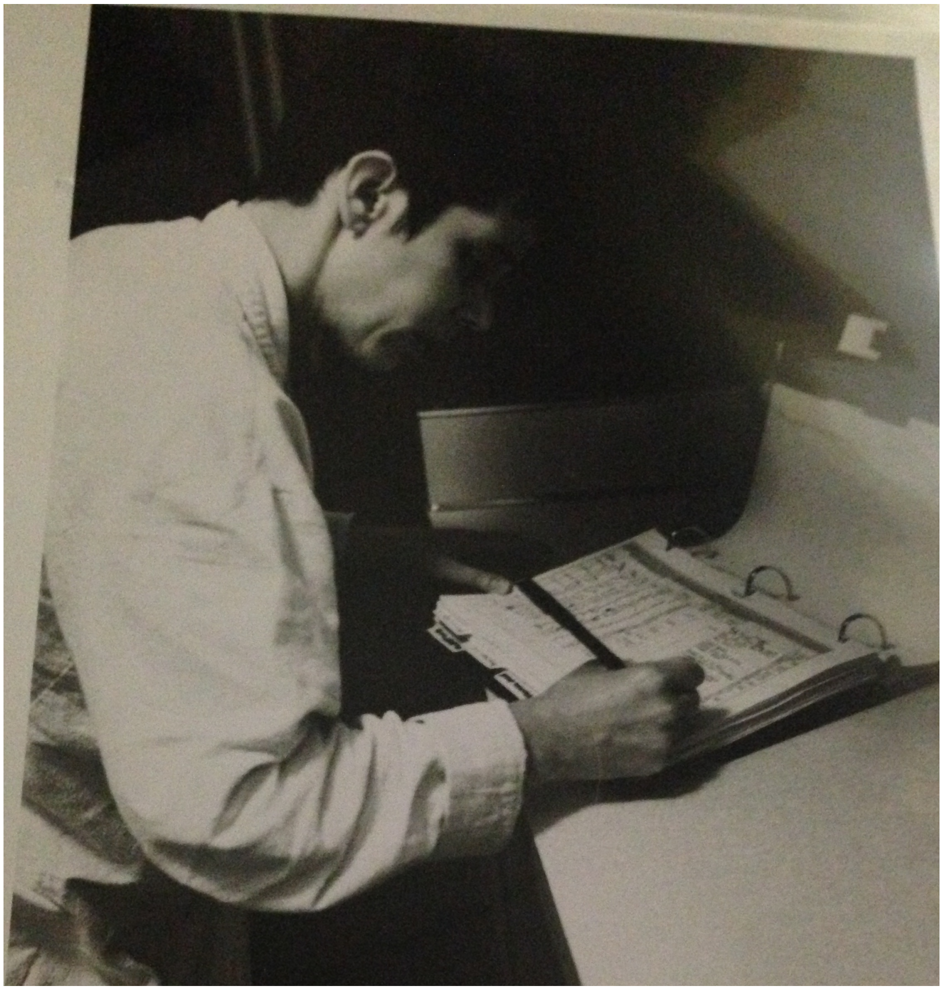

Figure 1: Karen tracking her daughter.

At the end of one of our long afternoons together, Karen summarized her experience, exasperated: “I was experimental. The hospital isn’t experimental. There, it’s just right and wrong.” Karen is one of the organizers for the Silicon Valley QS group, where I first met her. She coached me my talk while she also shared her story of caring for and losing her daughter, 13 years ago. We have since become close, adopting each other. I have interviewed her for several hours spread over the last year, but we have put off the last interview—the one where we leaf through her daughter’s data—for months. The records are too painful revisit.

She came to QS through the tracking and home care she provided for her daughter, who suffered and died of Niemann-Pick Disease, a rare genetic metabolic condition. Children rarely make it past a year or two of age. Parents are usually screened for carrier status, but they fell through the cracks. When Sophia was born it wasn't long—just weeks—before she was "dying and growing at the same time." The first sign of trouble was the newborn's inability to latch on strong enough to breast feed. Many children with this condition go straight to a feeding tube. Undeterred, Karen sought out a nursing coach and trained sophia. This is just one of the small examples of Karen's relentless search for solutions, from shamans to traditional chinese medicine. She brought her home and created she called "caring in community" out of her home.

"Democratic" caregiving distinguished Sophia's healing community (later called "Sophi's Garden") from the hospital. It was "not evidence based medicine; [it was] really the wisdom of the crowd." Whoever was around made decisions together, sometimes even voting on napkins around the kitchen table. She called her home "a mini medical center, a sanctuary, our family residence. It was many things to us and to other people."

Information technologies, as basic as they were in the early 2000s, were crucial:

> We did tracking. We were democratic. We were empowered. We were the ones making decisions. We were trying to do things in community and have a way of communicating that was not just on email, it was all in a group. Also we wanted to go after distinct information, meaning the long tail. And there are ways now that you can get that information more quickly. We were sending video messages

> to different [practitioners]. We'd be sending them through email. We lived the principles of Web 2.0.

At the time, caregiving platforms were just coming out. Smart phones and apps for tracking symptoms or biometrics didn’t exist. So they kept elaborate record system at home, tracking symptoms, experimental therapies, medications, meals, dirty diapers, people. Keeping those records was another bit of glue that held the healing community together: “Some people didn't want to track, like Richard hated it at first. Then after a while, he realized that every time he put a little checkmark by something he did, or put his initial and the time, he felt empowered. ‘I did my job. This is helpful to Sophia.’ It was low-tech, but it was enormously powerful. Some of the people that came in for therapies, saw us tracking and would say, "I want to do that. I want to do my own thing." I said, "Okay, here's the book. This is how you fill it out.” So many came to her wanting to get involved and wanting to help, from off-duty nurses and to neighbors. Just as tracking was a tether to Sophia, Karen invited visitors to make prayer flags, many of which were burned when she passed. Both activities were ways to dwell in a space that was difficult and sometimes filled with grief. When Sophia passed, the community disappeared and left a vacuum. However, Karen and Richard felt they had created something novel and important: “We wanted to honor her and the learnings from her life. We were involved with this growing community and this distinct way of caring for her, we thought that there would be some value in that.” So they created a foundation called “Sophia’s Garden” named after the actual garden planted with food and medicinal herbs at their home. She came to view her home as a “think tank” for “caring in community:” “an immersive, very human, very patient-centered environment where everyone worked together." The organization morphed into a virtual rendering online of what they lived and how they created care in a network, giving their lives as "the future of medicine."

Sophia's Garden never took off. They entered health innovation contests, but funding, with the recession, dried up. But this work launched Karen and Richard into the growing world of e-patients and health 2.0, where she became a coach for e-patients, and the Quantified Self Movement.

Since then she's been part of other fledgling digital health startups and one in the "wisdom 2.0 space." While Richard has returned to his career as a designer, Karen is a bit stuck. After we attended the last Stanford Medicine X conference together, she didn't feel there was anything new anymore. It felt stale, too. When I ask what's next for her and for the dormant website and foundation, she's unsure. One idea is to redesign their home as another think tank, this time to model Aging 2.0. That means remodeling parts of their Eichler bungalow to their own eventual caregiving needs to age in place. That hasn't yet happened. It's just an idea, and they still have time.

Every time I visit them in Palo Alto, the house always looks different—new vintage estate sale finds, new art on the walls, a new garden. Traces of Sophia are slowly fading, too. Her old room, now the office, no longer has her little shrine in the corner. "It's time" Karen told me on mothers day. Other items and collections remain. Sitting at their kitchen table after dinner, Karen pointed to the last remaining prayer flags and said, "It's all data to me."

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