Chapter 5
From the Shrink in Your Pocket to the Quantified Self: Self-tracking and Self-care

Jody Ranck

Back in 2006, the editor of this volume (Jody Ranck) was co-directing the health practice at the Institute for the Future, a Silicon Valley think tank that studies technology trends, and we were holding one of our regular conferences on emerging technologies and business models in health care and trying to come up with some scenarios on where mobile health and personal heath technologies might lead in the coming years. Our conferences typically had a number of health executives, techies, and cutting edge thinkers from Silicon Valley. In one of our typical brainstorming sessions some of the personalities that tend to be on the cusp of emerging technology trends kept telling the audience that we needed to pay attention to some of the extreme athletes, typically cyclists and triathletes, who were tracking data on their workouts and diets. This was the future of health care some of them advised. Many in the audience shrugged. What does this have to do with health care? The explanation we heard was that more and more devices would be coming to market that enable us to track more and more vital signs and this would become mainstream in the health care sector within years.

The Quantified Self (QS) is described on the QS blog as "self knowledge through numbers" or "Quantified Self is a collaboration of users and tool makers who share an interest in self knowledge through self-tracking. We exchange information about our personal projects, the tools we use, tips we've gleaned, and lessons we've learned. We blog, meet face to face, and collaborate online."[1] If one

[1] http://quantifiedself.com/about/.

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explores the QS blog and the forums on LinkedIn where practitioners meet and share their self-tracking insights one is greeted with a very impressive range of narratives and insights of individuals who have been tracking sleep, diet, food, exercise, mood, supplements, sex, menstrual cycles, vital signs, and cognitive abilities—and sharing this data in many cases. From organized research efforts to n-of-one accounts of self-experiments and studies, the movement is beginning to make itself known in popular culture. Author Tim Ferriss and the popularity of his books on work, diet, and exercise is one indication of the early mainstreaming of self-tracking and "body hacking" as popular trends.

By 2007 Gary Wolf and Kevin Kelly, journalists and editor/founder of Wired Magazine had coined the term Quantified Self and started writing a blog about their own self-tracking efforts which soon led to a community of writers chronicling their self-tracking efforts. Within a year or two meetups of the QS movement began and we now see QS groups in over 50 cities worldwide. A number of Silicon Valley venture capital firms have their eyes on innovative technologies and companies that could push the trend farther into the mainstream and become the next big thing in health care and health technology. In June 2015, Fitbit had an IPO, one of the first for a wearable device or self-tracking maker and one that has become synonymous with the QS movement. In 2010, Wolf wrote an important essay on the QS in the New York Times Magazine entitled, "The Data-Driven Life"[2] in which he highlighted the efforts of a number of individuals to solve specific behavioral or health problems through data collection about their lives and conditions. He notes that data or numbers are changing the way government and businesses work, so why not individuals:

> Numbers make problems less resonant emotionally but more tractable intellectually. In science, in business, and in the more reasonable sectors of government, numbers have won fair and square. (ibid)

He highlighted how this practice was actually quite widespread if we looked across the Health 2.0 ecosystem, we could find large numbers of self-trackers. One popular Health 2.0 site, MedHelp (http://www.medhelp.org/), had over 30,000 new personal tracking experiments launched per month by 2010. What was driving this was a number of important new trends. First, sensors got better—that is, cheaper and smaller. Second, more people began carrying smartphones. Third, the social media revolution had made sharing an important cultural phenomenon. Fourth, cloud computing was enabling more computing power to become even more ubiquitous.

One of the first areas to feel the impact of the QS movement is fitness. The impact of these technologies was already playing out in the athletics arena as the tools used to improve the performance of elite athletes had traditionally used video and analysis of footage to improve technique. Now, with the growing availability of sensors and accelerometers, we could use these at a much lower cost. The adoption of accelerometers by the auto industry for use in airbags had driven the price

[2]Gary Wolf, "The Data Driven Life", New York Times, April 28, 2010. http://www.nytimes.com/2010/05/02/magazine/02self-measurement-t.html?pagewanted=all.

down such that they could be used in a wider number of devices. Combine sensors and accelerometers with data analytics and you have something quite valuable to the average person. Athletes had been self-trackers for years already but now the tools were becoming far more sophisticated, on one hand, and cheaper, on the other. You no longer needed to train with the US Olympic Team to have access to tools once used only by elite teams.

About this time, some of the tools for data analysis began to become cheaper and more user friendly as well. IBM released and open-source data visualization site called "Many Eyes" and for several years, we had a platform called Swivel that allowed anyone with a spreadsheet to upload their data and choose the data visualization format they preferred. This used to take a fair amount of training, typically a PhD or graduate degree in design to accomplish readily. The cloud, one of the fundamental technologies behind most social media sites that had begun to take off, was adding further momentum.

Wolf speculated that quantifying the self could offer advantages over traditional cognitive therapies in areas such as personal development because we now have the tools to understand many of the small things that could make a big difference in our well-being. Tracking tools enable us to conduct self-experiments in more empirical ways. Furthermore, even athletes are prone to bouts of self-deception—I'll round off my run or swim today to impress my training partners when they're not looking or fall off the diet for a few days. We may intentionally ignore what we don't want to face, but machines, he argues, don't have that option. ***The cold, hard data could speak the truth***. This smacks of a hard-nosed empiricism that will undoubtedly rub many social scientists and psychologists who understand the interpretive dimensions of life rather differently. Improving the self is more than a data-driven empirical exercise. In reality, many of the practitioners of the QS movement don't inhabit a binary world of numbers versus context, but actively look for ways to integrate qualitative and quantitative approaches. There may be some shortcomings to neglecting the *Qualitative Self* that is more challenging to quantify. Nevertheless, the movement of self-trackers is taking off. There will likely be a point of reckoning where the limits of numbers become apparent, but there are substantial benefits to the way we think about medicine and norms. Wolf sees how the fetishization of numbers can sometimes lead medicine astray when he discusses an example of the use of "standards" for care and when you find out that your own situation does not fit the norm or the standard. Statistics deal in populations, physicians, and patients focus on individuals. Reality often lies in the movement back and forth between the two and quantitative methods will need to grasp this better in the age of population health management that concurs with patient-centric health and medicine. This is when the data one collects on oneself can potentially be life-saving or transformative in finding more personalized modes of care. This tension between the standard or evidence base and the individual, more personalized treatment is about to get interesting with the tools we have today and in the next few years. Digital health and analytics meet the reality of clinical workflows and patients' contextual lives and experience of disease. We won't win the battle by just throwing technology and numbers at physicians and patients. It is a far more complicated matter.

We're writing several years after the IFTF conference and Wolf's seminal piece in the *New York Times* and the self-tracking movement has moved beyond meetup groups and Silicon Valley. The Pew Internet and American Life Project conducted a survey during the summer of 2012 and found some interesting trends regarding the use of mobiles for health care issues[3]:

- 19 % of smartphone owners have downloaded a health app.
- Most of those downloading a health app are women who is better educated with a household income of $75,000 or over.
- One in three cellphone users have used their phone for health issues.
- 60 % of Americans track their weight, diet, or exercise routines.
- One-third of the survey respondents track a health indicator or symptom such as blood pressure, blood sugar, headaches, or sleep.
- One-third of caregivers track health issues of a loved one.
- 50 % of the trackers are tracking indicators in their heads and not on phones.
- Only one-fifth of the trackers use an app, cellphone, or online tool.

These data indicate both the promise and challenge of tracking applications in health care. On one hand, why isn't this number higher given the number of apps in the app store and the ubiquity of cellphones. Outreach and better apps that can sustain engagement of patients and those who are healthy in order to help them maintain their health status are needed. The science behind mobile apps needs to improve in order to justify the investment. We'll talk about gamification and gaming dynamics, often treated as the cure all for the challenge of patient engagement, but there is more to adoption than gamifying incentives. This also represents a potentially growing market opportunity for companies smart enough to marry the right behavioral change methodologies to mobile applications and creative uses of data for changing health outcomes. What the QS movement is creating is an important test bed for concepts and communities that may very likely hold one of the keys to the future of design and the entry of diverse other markets such as consumer electronics into the medical device and wireless health space.

The Quantified Self: From Silicon Valley Geeks to Mainstream Movement?

In the years since our Institute for the Future conference, this small band of trackers has emerged as a self-proclaimed 'movement'. They even have their own conferences well beyond the confines and 'bubble' of San Francisco with Wired Magazine even launching a new health platform around health data, tracking, and connected health technologies in early October 2012. Numerous Health 2.0 platforms emerged over the past several years that have leveraged the many-to-many

[3] http://pewinternet.org/Reports/2012/Mobile-Health.aspx.

sharing capabilities of Web 2.0 technologies to enable the scaling up of data sharing efforts of self-trackers to enable scientific research as an outcome of self-tracking practices. According to the Quantified Self blog's annual report, the number of Quantified Self groups grew by sixfold in 2011 alone.

Source Quantified Self Blog

One needs to be careful in always assuming that big in Silicon Valley will become a global trend and all we need to do is wait a few years and early adopters will become the harbingers of mainstream trends. In this case, the term "Quantified Self" may end up not being the most scalable name for a trend and can actually be off-putting to many mainstream users of tracking devices, but there are a number of trends and figures within the movement that are worthwhile following to see where we may be headed in the self-tracking space. Employee wellness programs fueled by incentives in the Affordable Care Act (ACA) and employers' concerns for rising health care costs have been driving adoption rates of tracking devices for the past several years. There are now platforms such as Jiff that enable BYOD approaches so that employees can choose whatever tracking device they prefer.

Many readers may utilize popular fitness apps such as Runkeeper and MapMyFitness. Globally, these two apps alone have nearly 20 million users, many of them quite passionate and active users. In early 2015, the clothing manufacturer Under Armour acquired Endomondo and MyFitnessPal for over $500 million and acquired communities of over 120 million users worldwide. Popular dieting and food tracking apps such as Livestrong, LoseIt!, and the Weight Watchers apps also have impressive numbers of active users. Wearable technologies used for fitness and sports are exploding in popularity as well with devices such as FitBit, BodyMedia, Striiv's fitness monitors, Withings (body scale, smart watch, and blood pressure cuff), and Adidas Mi Coach, to name a few, have become very popular tracking devices that also connect to apps or platforms where users can share

data and details on workouts with people in their social networks. At the end of European soccer games, we can see how far each athlete ran during the course of the match due to sensors in their athletic footwear. NFL spring training now sees rookies having their velocity and acceleration measured by wearables (wearable computing technologies) containing sensors that enabled coaching staff to follow their vitals remotely. In the next several years, the availability of these tools is likely to be given a boost by the entry of major consumer electronics companies into the broader eHealth space.

Fitness devices and the basic economics of health care are making mainstreaming of the Quantified Self look very attractive to a growing number of hardware manufacturers looking at the next big thing. With one-fifth of the economy going to health care, there is no wonder that devices equipped with sensors to monitor health indicators could be a possible opportunity. The QS movement taps into some broader trends that preceded the self-tracking for healthcare phenomenon.

Lifestreaming, or capturing data about one's everyday life, began to take off early on in the whole social media revolution that has shaped the contours of digital life and the internet since the early 2000s. Flickr was one of the early success stories in the history of social media and used by lifestreamers to provide a photographic documentary accounting of one's experiences. The term "lifestreaming" was coined by Yale computer scientists Eric Freeman and David Gelernter in the early 1990s to describe "a time ordered stream of documents that functions as a diary of your electronic life; every document you create and every document other people send you are stored in your lifestream. The tail of your stream contains documents from the past (starting with your electronic birth certificate). Moving away from the tail and toward the present, your stream contains more recent documents—papers in progress or new electronic mail; other documents (pictures, correspondence, bills, movies, voice mail, software) are stored in between. Moving beyond the present and into the future, the stream contains documents you will need: reminders, calendar items, and to-do lists."[4] If this looks familiar, it is because the concept became a central part of the Web as we know it today through the likes of Facebook, Myspace, and other social media sites.

Even prior to the lifestreaming movement, wearable computing pioneer Steve Mann (considered by many to be the first cyborg) had created a cyborg-like computer to capture all of his daily activities. Famously assaulted in the summer of 2012 in a Paris McDonald's by an employee of the fast-food chain who was annoyed by the wearable computing device Mann was porting to livestream, he has recently advanced the technology to the point where it now is attached to a brain–computer interface (BCI) and has now entered in the "mediated reality" space of thought-controlled computing.[5]

Lifestreaming meets data analytics in the area called "reality mining." Alex Pentland, a data scientist at MIT, has coined the term reality mining to capture the notion of the process of mining the "bread crumbs" of our digital lives. Email,

[4]https://en.wikipedia.org/wiki/Lifestreaming.

[5]His company Interaxon has a demo: http://interaxon.ca/.

phone calls, and social media "check-ins"—all of these leave a digital trace that may offer clues into how we are feeling on any given day. Given enough of these data points and mathematics, it is possible to create algorithms that are predictive of our moods and other aspects of our emotional and physical well-being. Most of the data points currently come from our mobile phones that have become passive sensors constantly collecting data that most of us are completely unaware of as we go about our daily activities. As we go through our daily lives, telecommunication companies can see our geographical location and when or for how long we call or use our smartphones. In aggregate, this data can be interpreted to reveal insights on our face-to-face interactions, social roles, and even the dynamics of social interactions at the level of an entire city. Albert-Laszlo Barabasi, founding director of the Center for Network Science at Northeastern University, has used data from mobile phones to develop predictive models that can predict a person's location, within a square mile, with up to 93 % accuracy.[6] The science of social network analysis that extends from human biology to social systems is going to become a powerful analytical tool when combined with the self-tracking data of many Quantified Self aficionados who can combine everything from genetic data to behavioral and environmental data to shed light on the complexity of the drivers for health outcomes. But reality mining has one important difference from your Facebook timeline—Facebook captures what you would like to share with others and reality mining comes closer to what you actually do.[7] Shades of big brother? Perhaps. There will likely be a great deal of discussion about privacy and the trade-offs as self-tracking technologies begin bleeding into the social tracking side as well. There are certainly trade-offs around individual privacy but if we can see benefits in smarter, healthier cities built upon these analytics, there may be ways forward on the policy front to engage individuals and communities. If data become merely the domain of private sector gain, we should expect organizations to demand more control over what data are collected by whom.

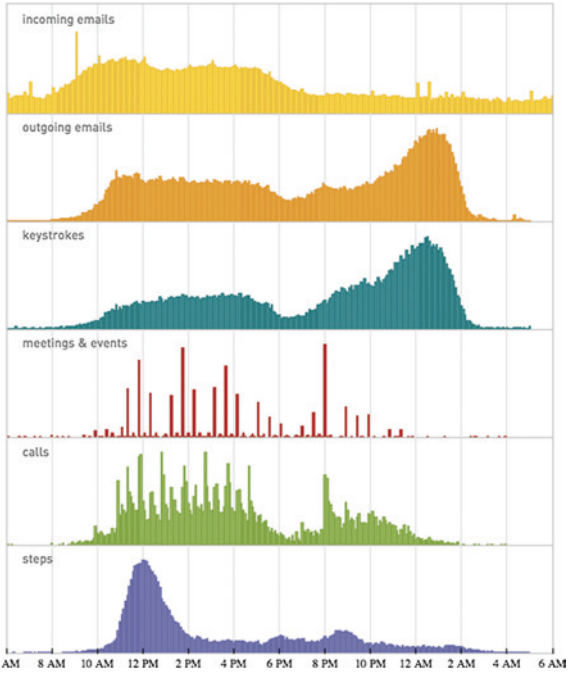
Some of the data points that can be collected include types of data from a person's voice that can indicate things such as depression or other dimensions of a person's emotional and physical status. Cogito Health (http://www.cogitocorp.com/) is a startup that is working in the area of detection of emotional status based on signals from an individual's voice. Their current applications include applications to analyze the voices of veterans returning from war for signs of PTSD. Another spin-off from MIT and Sandy Pentland's laboratory is Ginger.io whose focus has been on the development of diabetes applications that include machine learning algorithms that learn from one's cellphone usage patterns and will hopefully detect early signs of depression in a diabetic that can be an early indication of falling off the bandwagon for self-care. Once the early signs of depression are recognized an intervention can be prompted to provide the patient with social supports or other forms of support to keep that patient in compliance with their self-care regimen.

[6]Gregory Mone, 2011. This Man Could Rule the World. Popular Science, November 2011.

[7]Reinventing Society in the Wake of Big Data. A Conversation wth (Sandy) Pentland. The Edge. http://www.edge.org/conversation.php?cid=reinventing-society-in-the-wake-of-big-data. August 30, 2012 (accessed November 11, 2012).

Influential Data Scientist Dr. Stephen Wolfram added fuel to the QS movement after he released his personal data on his work behaviors and trends over the past twenty plus years in the spring of 2012. Wolfram, the founder of the computational software, Mathematica and the computational knowledge engine, Wolfram|Alpha, unveiled his "personal analytics" of his work life and productivity since 1989. The data included analytics of his email activity, keystrokes typed on his computer, daily number of meetings, phone calls, call duration, and pedometer activity. All of the data assembled and analyzed through his various products, created a picture of Wolfram's daily the day.[8]

What does this have to do with health? The act of lifestreaming and self-tracking is catching on and could become an important dimension of the personalized



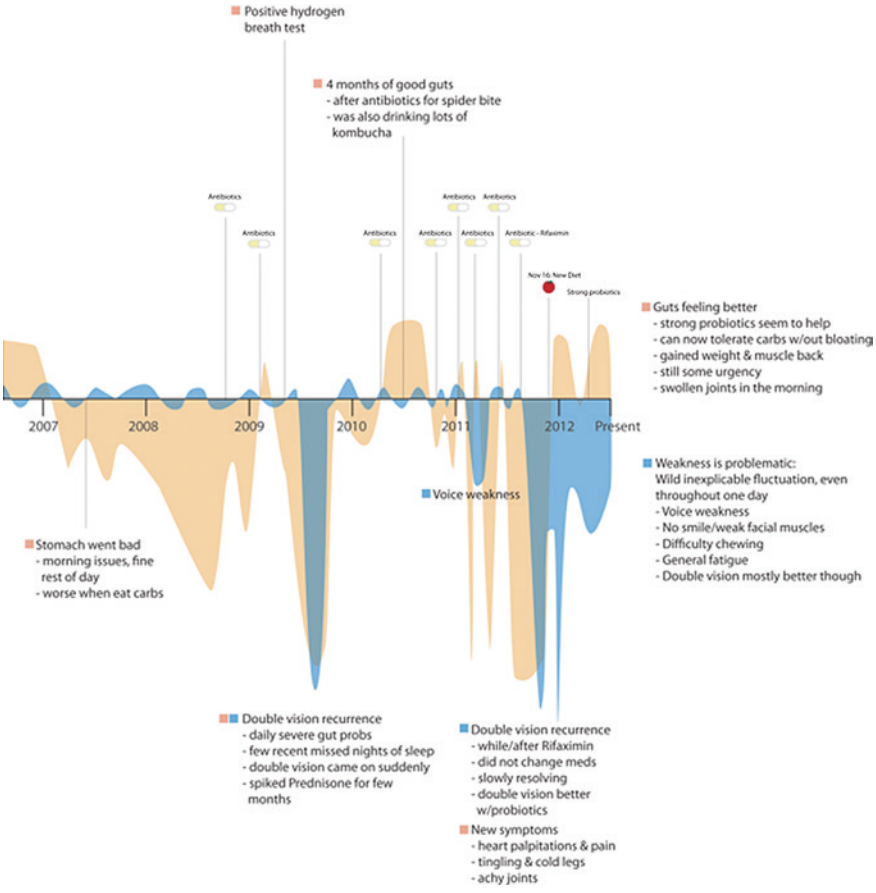
Wolfram's "Average Daily Rhythms"

or precision medicine of tomorrow.

We've already explored how expert patients or epatients are starting to drive change in health technology and a nascent movement in participatory health and medicine. An interesting health and medicine example that lines up nicely with Stephen Wolfram's self-tracking and personal data analytics is the experiments that Katie McCurdy, a designer suffering from myasthenia gravis, an autoimmune

[8]http://blog.stephenwolfram.com/2012/03/the-personal-analytics-of-my-life/.

disease. McCurdy has been taking prednisone for the past 20 years to suppress her immune system. Myasthenia gravis is a disease where one's antibodies attack the neurotransmitter receptors on muscles and cause fatigue, particularly with the muscles associated with the eyelids, facial expressions, chewing, swallowing, and even breathing. The disease can cause everything from impaired gait and difficulty breathing to changes in facial expressions. Prednisone, when taken for long periods can have numerous side effects including gastrointestinal problems. McCurdy had struggled with the side effects of Prednisone for years without much help in addressing these symptoms from a number of medical specialists. She eventually utilized her design skills to create a medical timeline that captured key data on the progression of her illness, side effects, medication usage, and dietary changes and created a "medical timeline" of her experience that could be shared with clinicians.



Katie McCurdy's Medical Timeline (http://sensical.wordpress.com/2012/01/03/medical-history-timeline-a-tool-for-doctor-visit-storytelling/)

The first time she took a copy of her medical timeline to the first clinical encounter with a new physician she reported that the data visualization gave her a stronger sense of empowerment when telling her medical narrative to the clinician. She felt that this form of self-tracking and data-driven story telling could prove very effective in jointly developing better treatment approaches.

The QS movement taps into another trend in the sciences that rises out of the nexus of the do-it-yourself, or DIY movement, and citizen science. Over the past few years, a movement around DIY genetics, often referred to as DIY bio or biopunk, has been growing. The biohacking or biopunk movement includes both scientists and artists who are using the tools of genetics to raise awareness of how genetic information is being used while working to democratize access to the tools and technologies of biotech. Scientists and amateur or citizen scientists are hacking their way around IP-protected technologies to make more affordable means to do genetics outside of formal laboratories. Not without its critics and risks in areas such as biosecurity, biohackers have a number of new "hack spaces" to practice their craft including Genspace, a community laboratory in New York City, BioCurious in Silicon Valley. In these laboratories, hackers work on everything from microfluidics to diagnostics on open-source hardware sets. Some efforts even focus on collective research for cures via open communities and open-source approaches that focus on cures for breast cancer as we find in the work of the Pink Army Cooperative. Biopunk and DIY biohacking are helping to expand the realm of possibilities for the Quantified Self movement.

Another open-source science and technology effort is the open-source medical hardware community that builds on the open-source hardware of Arduino. This is a Radio Shack-like set of components that can be ordered online from outlets such as Amazon.com but also has a community of interest on medical Arduino applications.[9] LittleBits (littlebits.cc) is another that makes it easy to develop sensors and robots. In these communities, hackers are developing open-source heart rate monitors, pulse oximeters, biofeedback control technologies, and other medical devices. Why does this matter to the Quantified Self? It is an interesting signal of how medical knowledge and expertise are continually being democratized by communities of passionate activists and practitioners. While open-source medical devices may never become the norm, they are part of a broader hacking ethos that is changing the way we think about medical knowledge and devices. Hackers are also at work on filling in some of the gaps around interoperability of devices. Kyle Machulis, a self-proclaimed hacker, has set up a wiki and GitHub site (a platform for sharing open-source software) that is a forum for sharing open-source solutions or hacks that make it easier for users of devices to share and aggregate data

[9]Medicarduino.net.

across different fitness and tracking devices. His site, OpenYou.org has a number of hacks currently developed for FitBit, Nike Fuelband, and Emotive EEG devices.

Self-tracking and the Shrink in Your Pocket

The QS movement is not just about physical symptoms and fitness but also takes advantage of the mobile platform to track data that can be of use in the mental health arena. Mental health is probably one of the most neglected areas in our healthcare system. Stigma and excessive cultural baggage create tremendous barriers for many people to even considering accessing the mental health system, and often, it is a challenge to have health insurance that covers mental health services. Yet we know that mental health issues play a major role in everything from obesity to compliance with therapeutic regimens and all of these systemic failures have tremendous costs. There are some estimates that by 2030, mental health issues like depression could become some of the most costly in terms of overall economic burden on societies. While we don't expect mobile phones and telehealth to solve the overall challenge of mental health, we do see a lot of room for improvement and there are aspects of the QS movement that will be worth following in the coming years to see how they can provide inspiration for new ways of expanding access to mental health services as well as even improving our understandings of the connections between mental health and chronic diseases.

The failings of the mental health system are brought home when we look at the plight of returning veterans from wars in Iraq and Afghanistan and the challenges they face from war trauma. Mobiles and some of the tracking technologies we've been exploring here are quite relevant. The Veterans Administration has taken the lead with their work on the PTSD Coach app. One of the gaps in the system is the length of time it takes from when a veteran feels that he or she needs mental health assistance and the time they actually receive it. PTSD Coach was developed to help veterans to recognize the signs of distress, access strategies to manage their symptoms, and find the closest mental health providers. The early trials of the app were conducted in collaboration with the Open mHealth Project, an open-source architecture project that we explore elsewhere in this book that focuses on creating the backend architecture so that apps and data collection efforts can be integrated and interoperable. The VA and Open mHealth Project have also collaborated to develop PTSD Explorer that offers data visualization capabilities for clinicians and patients to have better ways of seeing what is going on with symptoms and care and eventually improve outcomes. This example illustrates some of the potential for mobiles for more acute mental health issues.

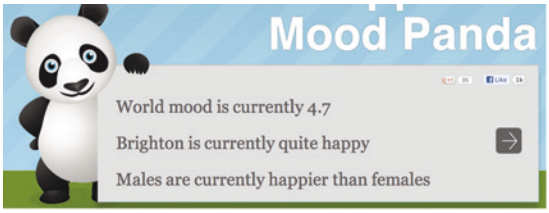
One of the most popular tracking items for QS followers is mood and emotional status. From athletes to those suffering from chronic diseases, mood can be an important factor in the overall equation determining outcomes. A number of popular mood tracking apps exist on the market and include Mood Panda, Buddy, Moody Me, My Mood Tracker, Mobiliyze, Viary.Se, and iCouchCBT. Many of these apps are simple tracking devices that act as "smart diaries" recording one's general emotional status alongside other indicators such as exercise, diet, and sleep so that the user can see how other factors may correlate with mood or emotional status. Viary is one of the first mental health applications to have undergone a clinical trial for use in treating depression.[10] In the first trial of this nature, over 80 subjects participated for over 8 weeks in a trial to assess the role of the Viary app in treating depression. The Viary app was compared to a mindfulness app not specifically designed for depression. Viary offers coaching and suggestions for activities and behaviors that can help a depressed person self-manage depressive episodes. At the end of the study, over 73 % of the users of the Viary app were no longer reporting the original depressive symptoms.[11] The makers of Viary are tar-

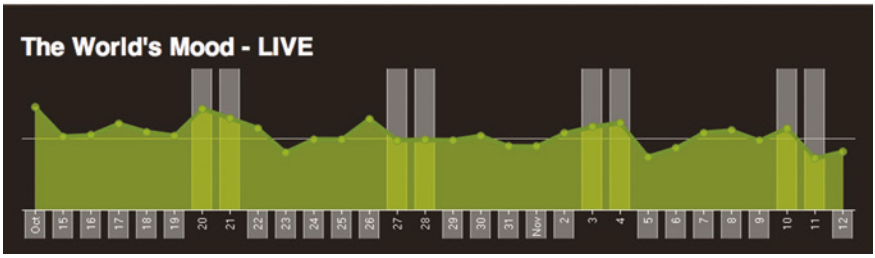
[10]Kien Hoa Ly et al. 2012, 13:62, *Trials*, Behavioral activation-based guided self-help treatment administered through a smartphone application: study protocol for a randomized control trial. http://www.trialsjournal.com/content/pdf/1745-6215-13-62.pdf.

[11]http://venturebeat.com/2012/05/30/app-cure-depression/.

geting the app for therapists, human resource managers, and lifestyle coaches because it enables the collection of data that can help both therapist and client monitor progress and behavior in between visits.

Many self-trackers are quite passionate about exploring the factors that can impact their moods. Mobiliyze resembles some of the reality mining apps mentioned earlier that track your location, level of physical activity and social interactions to detect whether the user could be feeling isolated. Billed as a "therapist in your pocket," the app will then send the user advice on activities that could help improve one's mood. Mood Panda is a similar app popular among QS practitioners that is a mood journal or diary and offers data visualization tools to display your aggregate data. It even allows one to compare one's mood with others, a popular activity in some quarters of the QS movement where data sharing is a central element of the self-tracking experience.





The app is marketed beyond those diagnosed with clinical mental health issues but for the general public merely interested in tracking moods and gaining insights into what potential influencing factors could be.

The valuable feature with the mood trackers is the ability to track changes in moods throughout the day and the contexts in which these moods change. The hardcore practitioners of the movement also have at their disposal a number of other tracking devices that can measure everything from sleep to food and alcohol consumption to build a rather comprehensive "health graph." Zeo was a device company that focused on sleep. Users wear a headband at night that can track your deep and REM sleep quantitatively. The MyZeo app then offers an analysis of your sleep with suggestions on how to improve your sleep outcomes. The company offered a great deal of suggestions and insights about the science of sleep and how to "hack one's sleep," in other words, they offered ideas for self-experiments that one can do in conjunction with using their device that could help you to improve the quality and quantity of sleep. One interesting note is that Zeo had

become the largest database on sleep data in the world from all of the user data they have collected. Given the role that sleep plays in overall health outcomes, Zeo could have potentially been sitting on a major data goldmine in the coming years if they could have combined other streams of data with their sleep data. But Zeo became a case study of the difficulty in building viable business models in this space when it went out of business in 2013. Newer companies such as the Finnish-based Beddit have learned from the mistakes of Zeo and offering new sleep monitoring technologies that are not worn on the body and less intrusive to sleep while offering more accurate monitoring of sleep without being medical diagnostic-level quality. Professional sports teams such as the Los Angeles Lakers are using the devices to avoid over-training and burnout of their athletes.

If you're having trouble sleeping perhaps, it is too much coffee late in the day. Well, there's an app for that too. Caffeine Tracker developed by scientists at Penn State University helps you optimize caffeine intake to stay alert when you need to and not to overdo it when you need to sleep. Based on peer-reviewed research studies on the metabolic rates for caffeine, the app allows the user to input the amount of caffeine consumed in milligrams and then offers a visualization of the metabolic rate or pharmacokinetics of caffeine based on some norms from the research literature.

The technology for monitoring emotions is improving as well. Galvanic skin response, respiration, heart rate, and speech tone are all indicators that QSers have begun monitoring to enhance their quantitative repertoire.[12] This area is now heading into the area of cognitive tracking. An interesting platform that emerged is the Quantified Mind (http://www.quantified-mind.com/) that helps you and a growing community of trackers explore what factors influence your mental performance. These "mind hackers" can join a number of experiments that explore everything from how eating breakfast impacts performance to the role of sex, coffee, or meditation on your mental acuity. And before we forget, there are trackers to monitor your sex life as well! The Quantified Mind has developed a number of tests to help one analyze and quantify various aspects of one's cognitive abilities including reaction time, verbal learning, context switching, short-term memory, visual perception, motor skills, and high-level processing abilities.[13] One can enter a number of academic studies sponsored on the site by registering and taking a given test. However, the selling point of the Quantified Mind is that they offer a platform that will actually let one empirically test the impact of different behaviors on cognitive outcomes through the use of psychometrics.

Lumosity (http://www.lumosity.com/) is similar to the Quantified Mind but it ascribes to the "brain hacking" point of view by offering tools and games that use research from the areas of neuroplasticity and fluid intelligence to improve your memory, problem-solving ability, and other cognitive functions.[14] Quite a few QS

[12] http://quantifiedself.com/2012/11/matt-dobson-on-quantifying-emotions/.

[13] http://www.quantified-mind.com/science.

[14] http://blogs.hbr.org/cs/2012/10/four_new_tools_for_brain_worko.html.

thought leaders do a bit of experimentation in this space and frequently present at the meetups. One notable example is Tim Lundeen who did a simple experiment on cognitive ability to see whether DHA (from fish oil) could improve his ability to do math problems over time. He gradually increased the dosage of DHA over 130 days. By day 80, he reached double his normal dosage and the time required to complete a math problem decreased.[15]

Food is an another important driver of health outcomes that is a natural area for QS practitioners to direct their attention. Several mainstream applications such as LoseIt! and Livestrong have become popular with the public at large as apps that can help you manage your diet and eating behaviors as well as fitness. Apps like these, along with the Weight Watchers mobile app, have extensive databases that allow users to input their meals and receive data on the number of calories as well as a brief snapshot of the nutritional content of the meal. One of the challenges with these types of apps is that the data input is only as accurate as the user input. Estimating the serving size of an average dish is going to carry a range of error with it unless you're eating at home and have a set of scales or the eating establishment has a precise measure on the package. Humans are notoriously bad at tracking their own meals in self-reported studies. This has been one of the big problems with a very popular eating and diet app created by Massive Health and later acquired by Jawbone. The Eatery was the first app released by Massive Health, who received over $10 million in venture funding. The app allowed the user to take a photograph of a meal, rate it in terms of how healthy it is, and then post the photograph on the app. Other users of the app then get to "crowdsource" their own rating of the relative healthiness of the meal. The problem with this app is the validity and reliability of data. As any health professional or QS practitioner knows, context matters. If I have a food allergy that meal that looks healthy could be toxic but the crowd might rate it as extremely healthy. Massive Health was known for their beautiful infographics but many in the healthcare world question the usefulness of the app as it now stands. And this is one of the questions that is going to continually arise in the coming years is when to jump on the bandwagon of an edgy trend like crowdsourcing and when is it actually producing useful new knowledge. Massive Health was eventually acquired by Jawbone to join the team building the Jawbone UP software and integration tools for users to track multiple biometric indicators and the company now competes head on with Fitbit for the lead in the domination of the tracking market.

A big part of the QS conferences and meetups is the sharing of insights and data. One can visit the LinkedIn group for the Quantified Self and at any given time come across surveys asking participants to share their own experiences and insights on everything from nutritional supplement usage to the calibration and accuracy of fitness devices. It is quite surprising sometimes just how passionate the QS community is. At one point, there was a very interesting discussion taking place over which fitness trackers provide the most accurate readings of exercise

[15] http://hplusmagazine.com/2010/02/08/self-tracking-quantified-life-worth-living.

and distance completed. It is impressive to see actually how many contributors to the discussion had already been using multiple devices at a time and had uncovered rather large discrepancies between devices such as FitBit, Nike Fuel+, Striiv, and other devices. Rachel Kalmar is a data scientist at Misfit Wearables who wears over 20 wearable tracking devices per day as an experiment to see how devices differ, the usability of platforms and any other insights she can gather from the data. A major interest of hers is how to break the devices out of the data silos so that more can be done with the data and ultimately lead to better applications and data services that render the devices more useful.[16] The future of many of these devices lies in the ways they will communicate with one another and tack back and forth between the body and contexts as well as other people.

Health 2.0 Meets the Quantified Self

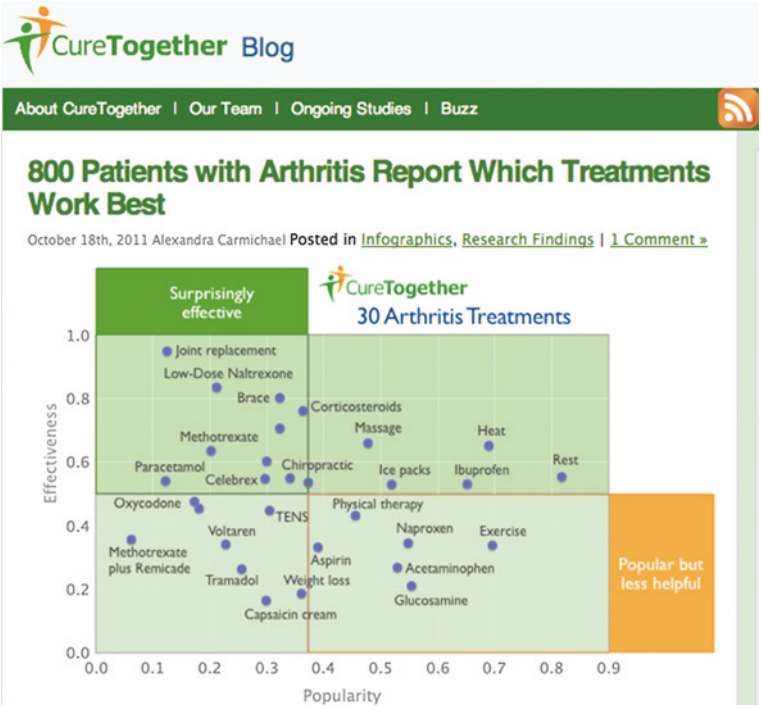
Earlier, we mentioned online communities such as MedHelp that have users in the tens of thousands and many are engaged in some form of self-tracking and sharing of data. In the first few years of the QS movement, a number of these platforms became important catalysts for scaling up efforts and actually changing the way research was being conducted. One of the first was the platform called "CureTogether." CureTogether was launched in 2008 by Alexandra Carmichael, who had been suffering from a chronic pain issue that defied adequate diagnosis from mainstream medical practitioners. She founded CureTogether with her partners to offer a community for trackers to explore their conditions collectively. By the summer of 2012, the online personal genomics platform 23andMe had acquired CureTogether in order to scale up research efforts that bridged genomic data with phenotype data that had been collected by over 25,000 member of CureTogether's community. By 2012, CureTogether's platform had over 300 medical conditions that they were collectively sharing data and researching. The CureTogether community had reached a level of proficiency in tracking and research that a number of major academic and pharmaceutical company collaborations were under way.

What accounted for the popularity and research potential of CureTogether? The story of the founder is quite illustrative in this regard. Trained as a molecular biologist, Alexandra Carmichael had witnessed the challenge of chronic pain both personally and through a parent.[17] Her mother had experienced migraines throughout

[16] http://www.fastcolabs.com/3036433/elasticity/misfit-engineer-rachel-kalmar-wants-you-to-be-an-intelligent-node.

[17] http://www.thefifthconference.com/topic/health/how-curetogether-enables-patients-drive-medical-innovation.

Carmichael's childhood and she had herself experienced vulvodyna, chronic pain of the vulva. Physicians had failed to find a causal mechanism for her vulvodyna so she commenced upon her own research to figure out what could be causing the pain. She found disease support groups but felt that what was lacking was quantitative, evidence-based knowledge. Being in the midst of Silicon Valley during the social media revolution that was well underway, she launched CureTogether to help conduct research on vulvodyna, migraines, and endometriosis. As the community grew, so did the number of conditions and this actually contribute to the value of the platform. The healthcare system is not that good at dealing with comorbidities. CureTogether's research that is patient and experience-driven developed a strong emphasis on these comorbidities. It also added a bit of transparency to the research and medical practice space by allowing patients to plot data around treatments and outcomes. What came out of this frequently was the fact that the most popular treatments were often not the best.



While not conforming to the strict rules of standard clinical trials, the surveys and research conducted by CureTogether are valuable in that they are a good indicator of the actual patient population for a typical disorder. Companies and academic researchers find these more participatory trials useful.

CureTogether has some additional unique aspects from the sheer volume of data collected by their members. With well over a million data points, the site has become the largest comparative effectiveness database accessible to patients in the

world.[18] The acquisition by 23andMe opens up many new possibilities that can link health outcomes to not only genetic data, but behavioral and environmental data for more realistic models that come closer to real-world drivers of health outcomes. Big data analytics are making it cheaper to do this kind of research and integrate a vastly wider set of sensor data into the analytics. From the data that CureTogether already collects they have the capacity to build data visualizations and infographics that could shed light on the preferred methods that patients have for making sense of data. Sense-making and patient engagement are going to be critical to the success of wired technologies, and sustaining engagement has been a difficult challenge across the field. Mere participation in a project that is larger than oneself or one's tracking device can be a life-changing experience if you've been suffering in isolation with a difficult chronic condition or rare disease.

When one mentions patient-driven research, one of the first things that comes out of health researchers mouths is the issue of privacy. Platforms such as CureTogether and PatientsLikeMe do enable strict control for patients to determine what data get shared with whom. There may be some trade-offs around selection bias and rigor of trials on the CureTogether platform, but the research is performed for a much lower cost than traditional methods, Melanie Swan notes.[19] She also notes that the rewards of the research accrue more directly to the research participants themselves. Another important difference she has observed is the funding sources for this type of research are often different from the traditional sources and include academia, patient groups, social venture capital, and crowdfunding. The crowdfunding phenomenon is beginning to enter into the health and medical arenas in recent years after the success of Kickstarter. Kickstarter is a site where entrepreneurs can post a technology or project that needs funding and the crowd can donate funds to the project in exchange for early dibs on the project when it is released. One medical device, the Pebble, a tracking device worn as a wristwatch, broke records when the developers posted it on Kickstarter with a goal of raising $100,000. In several weeks, they raised over $10 million for the device and then had the challenge of producing enough to keep up with demand. The success of the Pebble project inspired others to create a health- and medicine-specific crowdfunding sites such as Medstartr where entrepreneurs or social entrepreneurs can crowdfund campaigns and technologies. Kickstarter, due to the more complex regulatory environment for medical devices, shies away from medical devices, so there was an obvious opportunity to create a health- and medicine-specific platform given the success of the Pebble.

Overall, CureTogether has helped to set into motion a number of new trends that are going to be useful to watch in the QS space. First, some diseases are found in such small numbers that the market has little interest in pursuing

[18] http://blog.makezine.com/2010/09/17/curetogether-crowdsourced-health/.

[19] Melanie Swan (2012). Crowdsourced Health Research Studies: An Important Emerging Complement to Clinical Trials in the Public Health Research Ecosystem. J Med Internet Res 14(2):e46.

cures. Otherwise known as the orphan drug problem, there are policy measures around orphan drugs that can help create funding incentives to get companies to do research in these areas but platforms like CureTogether offer an alternative approach that also offers sufferers of rare disorders to become part of a community that is actively engaged in self-care and research. This can help overcome some of the challenges such as isolation and lack of information about their conditions. Another feature is that CureTogether actively works on improving the quality of health information that people have access to. This is one of the big concerns around Health 2.0 and the Web for doctors. There is a lot of unverified, inaccurate health information on the Web. The larger Health 2.0 sites have communities that can act as filters and help sort dis/misinformation from the information that is relevant and medically verified. Of course, there will be gray areas where the medical literature does not have a firm answer, but even these areas can become focal points for the communities to focus on research, often in collaboration with clinical researchers to fill in the gaps faster. As mentioned earlier, some of the disease groups have actually conducted research that has proven that standard therapies used for ALS, such as lithium, were not as medically effective as health professionals had thought. This came about through patients sharing data and analyzing health outcomes.

As the citizen science and QS trends take hold one of the challenges has been the aggregation of data and making is easier to make sense of all of the data collected. We'll talk more about big data and data analytics in the overall wireless health space in our chapter on data, but the experience of using these devices could be made more patient-centric if we moved beyond the data silos that many devices create. If you used a Nike Fuelband, you might have found that it is a challenge to integrate the data with data collected from another device. Many companies are using APIs to integrate data from different devices and then build apps that allow you to create charts and other data visualizations. Withings, glucose monitors, Runkeeper, etc. all have APIs and we are beginning to see a new generation of API-driven innovation through the aggregation of data that can then analyze multiple data streams. Once one has access to the analytics tools running on top of a data warehouse or application then the possibility for coaching engines and approaches to behavioral modification can become more personalized and even delivered in real time during a workout or based on a prompt from a given data point, an alert for getting up and moving, for example.

Gamification of the Quantified Self and Crowdsourcing

Sustaining engagement with tracking often takes incentives and social community to keep people engaged with tracking for longer periods of time. Crowdsourcing of scientific research can also leverage incentives and games to increase data collection and even optimize problem solving on various platforms. In our introduction, we introduced the bioinformatics game Foldit that used crowdsourcing and

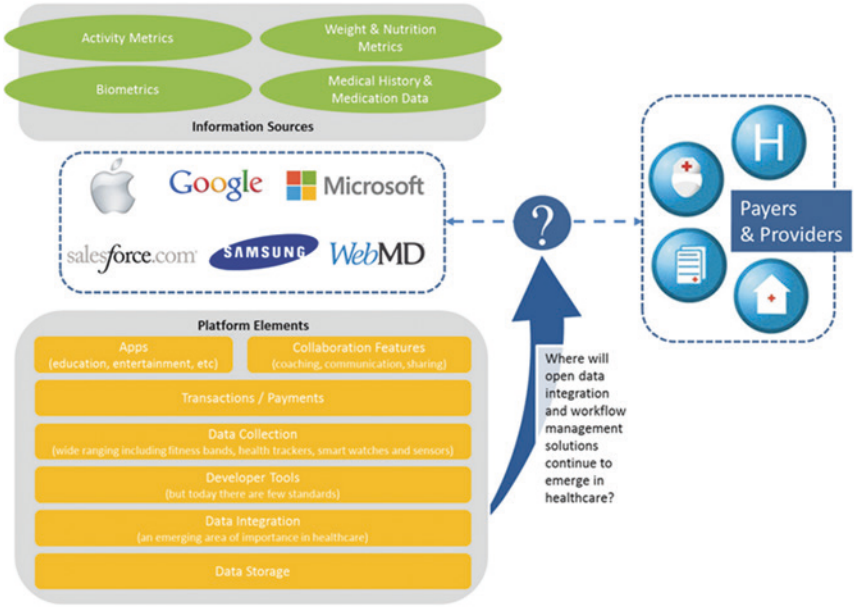
game dynamics to engage laypersons in helping to unravel the folding dynamics of proteins necessary for new HIV therapeutics. Over the past year, a number of new startups have entered the market at the nexus of the QS movement and data visualization. TicTrac is a platform that is targeting the tracking market segment and makes it easy for self-trackers to upload data and generate data visualizations of their data. We should expect a convergence before long where data visualization and information design come together with mobiles, crowdsourcing and gaming dynamics not only to make tracking fun but also to enhance the esthetics and ability to make sense of the growing amount of data we'll be collecting.

Fitness has already entered the gamification of tracking and motivational behavior space with examples like Striiv, the pedometer/fitness tracking company. They've developed a small digital pedometer that tracks your steps and gives badges to users for achieving a goal for distances traversed. This is not that remarkable in itself until they offer the opportunity to donate "steps" to one's favorite charities like GlobalGiving.org. A play on this has been to have users of fitness devices choose the causes they actually despise, for example, a Democrat could choose a Republican cause, and wager a set amount of funds per month or week that will go the chosen cause if one fails to comply with a fitness or diet regimen. GymPact uses this type of incentive scheme to ensure compliance with a weekly fitness regimen.

We can see how the QS trend is beginning to feed into a number of the major themes of this book. From mobile devices to big data and gaming, the QS has become an important practice area to follow if you want to gain insights into the future of health and medicine. The infographic below highlights the convergence of these trends.

The Five Pillars of the Quantified Self

As the field continues to grow, we will likely see a shift in language from the geek terminology of the "Quantified Self" to more mainstream self-tracking terminology that also reflects the fact that self-tracking has a very long history that goes back many years. In 2014, we also saw many of the large technology platform players such as Google, Apple, Samsung, and WebMD enter the fray. Everyone appears to agree that health data could become big business in the coming years. This raises questions of who benefits, what is the business model and how the ecosystem of digital health devices itself may change as the adoption rates scale.



Betting on 'Switzerland' in Connected Health. *Source* Triple Tree

The boundaries between fitness and health care will blur in some respects. Since the passing of the Affordable Care Act and the rise of value-based care emphasize outcomes, lower costs, and population health improvements, we have seen the traditional way of thinking about health care as divided into payers, providers, and patients begin to shift. Providers are acting more like payers with a focus on lower cost care and outcomes; payers are buying providers. The front door of the health care may someday not be the front door of the clinic but one's house, the street or on your wrist or elsewhere on the body. As the QS phenomenon goes mainstream, whether self-tracking becomes focus actually misses the point. The rise of wearables, telehealth, and data analytics will enable new business models for real-time, real-world, anytime, and anyplace healthcare delivery models. While the idea that doctors will be replaced by computers seems a bit farfetched, the way that doctors and systems deliver care at arm's length is becoming a reality. There will be many planks built into the platforms illustrated above that

provide new healthcare services and will aim to do a better job of providing more patient-centric care. This “platformification” of health care is already visible in the early days of some of the first steps that platforms such as Apple have initiated. In early 2015, Apple released Research Kit, an app that collects data from apps on your phone and can share this data with clinical researchers. In the first two days of the app’s existence, more people enrolled in clinical research studies than would have been enrolled in one year through 50 different medical centers! This addresses one of the major obstacles for clinical research and clinical trials where very few people are aware of studies or trials that they could be eligible for, and it has been difficult to keep patients registered in the trials. The result is that the cost of new medicines continues to grow. In the new app economy and era of self-tracking devices and apps, there are many opportunities to bring down the costs of trials. We will be turning to this subject later in this book but we can see how these tools help facilitate cooperation and collaboration between patients and researchers in novel ways.