Reflections on the BodyTrack Project
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Abstract

This article explores the author's experiences and vision for how the practice of self-tracking can empower individuals to explore and address issues in their lives. This work is inspired by examples of people who have reclaimed their wellness through an iterative process of noticing patterns of ups and downs, trying out new ideas and strategies, and observing the results. In some cases, individuals have realized that certain foods, environmental exposures, or practices have unexpected effects for them, and that adopting custom strategies can greatly improve quality of life, overcoming chronic problems. Importantly, adopting the role of investigator of their own situation appears to be transformative: people who embarked on this path changed their relationship to their health situation even before making discoveries that helped lead to symptom improvement. The author co-founded the BodyTrack project in 2010 with the goal of empowering a broader set of people to embrace this investigator role in their own lives and better address their health and wellness concerns, particularly those with complex environmental or behavioral components. The core of the BodyTrack system is an open source web service called Fluxtream (https://fluxtream.org) that allows users to aggregate, visualize, and reflect on data from a myriad of sources on a common timeline. The project is also working to develop and spread peer coaching practices to help transfer the culture and skills of self‑tracking while mentoring individuals in how to self-assess their own situation and guide the process for themselves.

Backstory

I did not originally intend to become involved in health empowerment. I intended instead to work on improving the state of autonomous robotics for space exploration. In 1998, I joined the Intelligent Mechanisms Group at NASA Ames Research Center as lead systems engineer for their terrestrial analog rover test-bed program. I put all I had into working on the Marsokhod and K9 robotic rovers. Then, around 2004, I had to admit that I was no longer able to continue that work.

Originally, my focus was on quickly recovering enough to get back to the rovers. I did the usual round of doctors, tests, diagnoses, and medications. However, nothing really fit well or helped much.

Eventually, I realized that I needed to shift focus to instead work on understanding my own situation better. I started paying more attention to how I was feeling, and how that changed over time and in different circumstances. I sought out and worked with care providers who were willing to engage more deeply. I read widely about how the human body and mind work. I played with various ideas and strategies and observed how they worked out. These various threads of inquiry, observation, and engagement fed back into each other. Some ideas and strategies would bubble up in hopefulness and utility, while others fell away, in an ongoing process.

In 2007, after exhausting the tree of referrals and tests within the Western medical system, my primary care doctor referred me to Ayurveda. Following the Ayurvedic approach to Vata balancing helped significantly. While I was eating strictly according to those principles at home, I was doing better. Eating out often led to bad results. Paying attention to what worked and what didn't over the course of several months led me to suspect ingredients that, upon further investigation, turned out to be members of the Nightshade family – tomato, potato, peppers, eggplant, etc. in the family Solanaceae.

Once I found the right search terms, I was able to find accounts of other people who have found through experience that they do better when strictly avoiding Nightshade. A couple of them even wrote books on the topic[1]. These materials were very helpful to me in exploring the idea that sensitivity to Nightshade may be playing a role in the issues I'd been struggling with.

The Nightshade sensitivity hypothesis, though outside of any mainstream system of belief, was consistent with my existing observations and was useful in building strategies for moving forward. I realized that the Ayurvedic cooking practices that I had been following at home had the unrecognized side effect of strict Nightshade avoidance: all of the Nightshade foods were on the list of items I avoided as Vata aggravating. Now I had a potential explanation for why that practice helped so much, and why eating out so seldom worked. Happily, after adopting the explicit strategy of Nightshade avoidance, I improved at predicting what additional foods I could eat without provoking a negative reaction and experienced further quality of life improvement.

At this point, I was doing well enough that I could have gone back to working with the rovers. However, I felt like I had stumbled into something important that I needed to pursue. The discrepancies between these experiences and my going-in assumptions about the way the world worked were just too compelling to ignore. So I let go of the dream of returning to the rovers and started exploring a new realm.

Reframing and Retooling

As I reflected on the experiences described above, I realized that the overall process resembled the type of one-off system debugging we did with the rovers. Marsokhod and K9 were each unique, complex, and constantly in flux. When something went wrong, there was no flow chart of diagnostics leading to categories of malfunction and repair instructions, such as you would expect with standardized products like cars or refrigerators. Instead, we had to compare expectations against observations, hypothesize on potential causes, experiment to see if a given hypothesis holds up, and craft a solution on a case-by-case basis as issues arose.

In recognition of this parallel, and lacking knowledge of any existing term, I initially called the process I'd used in exploring my own situation "Human System Debugging."

I recognized that this sort of approach was counter to mainstream messages about health. However, I also recognized that the models and strategies that ultimately made the difference for me would not have come about through continued adherence to the standard path. Also, despite having a great deal of experience of one-off system debugging in my professional life, it took many years before I began to apply similar approaches to my own health situation.

I felt that the transition from passive recipient of care to active investigator was critical, but was made more difficult than it needed to be by the lack of role models, community, or support. In the spirit of being the change you want to see, I made a first attempt at distilling and presenting the materials and methods I had found to be useful[2].

During this period, I began to both to seek out accounts from other individuals and affinity groups whose journeys of self-exploration led to custom self-management strategies, and to try to understand potentially relevant biological mechanisms. Initially I focused primarily on Nightshade sensitivity. Over time, my

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[1] Examples include Norman Childers, *Arthritis-Childers' Diet That Stops It!: The Nightshades, Ill Health, Aging, and Shorter Life* (self-published), and Michael Fowler, *Nightshade Free Pain Free* (Grass Fire Media, 2007)

[2] *Human System Debugging* breakout session, Coca-Cola Scholars Leadership Summit, Omni Hotel at CNN Center, Atlanta, GA, October 3, 2008. Slides at http://bit.ly/hsd-slides-2008

focus broadened to a cover a wider category of experiences, such as other food intolerances and allergies, asthma, migraines, etc.

These people's stories were unique in the details, and covered a broad range of symptoms, labels, and eventual strategies. However, I felt that they also hinted at common themes, trajectories, and approaches that could potentially be leveraged to help others. I approached this effort from the point of view of an engineer attempting to understand the landscape well enough to inform attempts to engage with and improve the situation, rather from the point of view of a scientific or academic endeavor[3].

In rough outline, the common elements in a Human System Debugging trajectory, from the point of view of the individual involved, look something like this:

1. Become aware of and concerned about some set of repeated or ongoing sensations (such as pain, fatigue, digestive issues, sleep issues, mood issues, etc. etc.).
2. Engage the medical system with the hope and expectation of a diagnosis that will lead to treatment which alleviates the concerning sensations.
3. Iterate on medical appointments, potential diagnoses, testing, referrals, medication trials, etc. over a period of time without achieving acceptable, sustainable relief of the concerning sensations.
4. Experience a shift of perspective from accepting the role of a passive recipient of care to taking a more active role.
5. Seek out and iterate on a combination of medical engagement and other potential methods and models while developing and refining an internal sense of evaluation (Is this helping or not? Do I feel different? How? What do the concerning sensations mean in this new context?).
6. Adopt a set of custom practices and narratives that lead to some combination of alleviating the sensations, providing a satisfying way of reacting to them, and/or reframing the meaning of the sensations in a satisfying way.
7. Tell the story, seek community, try to help others.

In reality, individual journeys are rarely a linear progression through these phases. It is common, for instance, for people to go through on multiple rounds through stages 1-3 and 5-7. The critical watershed seems to be stage 4: a shift from a more passive role, accepting external categorization and evaluation, to a more active role, developing an internal sense of discernment and agency in guiding the process and widening the scope of potential approaches.

In the current default environment in the US, the jump from stage 3 to stage 4 requires going off script and rebelling against a great deal of cultural conditioning about the importance of compliance to expert authority. It requires abandoning comforting myths and procedural hand holding for the uncharted, and generally solitary, unknown. This is not easy, and in the stories I encountered it was generally not undertaken lightly.

Each person who made it through stage 4 seemed to go through some moment of crisis paired with an encounter that hinted at both the implausibility of finding an adequate solution within the default system and some kernel of hope that a better solution might be possible. It might be talking to someone who describes a similar experience, or seeing a promising forum post or book description, after having been treated disdainfully at a medical appointment or receiving a dead end diagnosis (e.g., "somatoform disorder").

I spent about ten years, 1994 to 2004, going through bouts of stages 1-3 and garnering a collection of diagnostic labels and medications that I tried to believe in, but which did not lead to sustainable improvement, before experiencing such a perspective shift. In my case it was precipitated by becoming too

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[3] Such an effort, if approached as a scientific or academic endeavor, would have had a different sort of purpose and used different techniques and evaluation criteria that I explicitly do not attempt to subscribe to in this work.

incapacitated to work in a way that both shook my faith in earlier explanations and hinted at a larger pattern: the medication that I thought made the critical difference during a previous bout of incapacitation in the summer to fall of 2003 clearly failed to help a recurrence during the summer of 2004.

I wish that there had been a clear pattern for how to identify people who might be at the cusp of such a perspective shift, or how to aid in precipitating such a shift in those who were ready for it. Sadly, I didn't see any, other than the general measure of increasing the visibility of cultural messages that this is possible[4].

I believe that this is an important issue: for each success story I encountered of someone who made it through to stage 7, I saw many more examples of people languishing in stage 3 until becoming overcome by hopelessness and giving up. My heart goes out to the people heading in that direction: that easily could have been me. However, other than telling my story and supporting efforts that help other people tell theirs, I don't see a way for me to help people avoid ending up in that situation.

The part of the process where I felt like there was scope for constructive intervention was in improving the set of options available to people who had made it through stage 4, who were ready to take on a more active role, but who too often were trying to do so alone, in a cultural vacuum, and with inadequate tools. This seemed like an area where I could contribute.

The Dawn of BodyTrack

My husband Randy Sargent and I moved to Pittsburgh in 2009 to work more closely with Illah Nourbakhsh at the CMU CREATE Lab.

We knew from our work at NASA that tools to make high fidelity data explorable while preserving its context were a potential game changer in supporting people to develop situational understanding[5]. We had already applied this technique across diverse domains including supporting scientists in understanding Mars science data, supporting disaster response planners in the aftermath of hurricanes Katrina and Rita and the Pakistan earthquake of 2005 (Nourbakhsh 2006), and supporting the public to explore the world through geolocated National Geographic stories, panoramas, images, and tracking data using Google Earth.

Creating better data exploration tools also seemed like a potentially promising approach for supporting individuals to explore their own situation. The main differences were that the primary axis of exploration would need to be through time rather than through space, and we would need to find different types of data sources suited to individual self-reflection.

Around this time, various companies started producing commercially available devices that generated data of potential use for individuals to understand their situation, activities, physiological parameters, and context. Examples include the Zeo sleep monitor, that used an EEG head band to infer an individual's sleep states over time (awake, light sleep, deep sleep, or REM); the BodyMedia armband, that used accelerometers, temperature, and skin conductance sensors to infer activity level, steps, lying vs standing,

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[4] Later on I did encounter efforts that are engaged in increasing the visibility of such messages. These include the Quantified Self movement (http://quantifiedself.com/), the Society for Participatory Medicine (http://participatorymedicine.org/), the Medicine X conference (http://medicinex.stanford.edu/), and efforts to produce a movie on the topic of Medical Refugees (http://www.undiagnosedfilm.com/).
[5] *Health Empowerment through Self-Tracking*, Anne Wright, Strata Conference, New York Hilton, New York, New York, September 23, 2011 (http://bit.ly/aw-strata-2011)

and sleep; the Fitbit activity monitor, that also used accelerometers to infer activity, steps, and sleep; and the Withings body scale, that measured body weight and inferred body fat mass[6].

Each of these devices provided a method for their data to be uploaded to the matching vendor's servers, and each had a web site that allowed the user to interact with their own data in certain ways. This was sufficient to try out the devices and confirm that the data seemed potentially valuable for self-reflection. However, viewing different aspects of the data in separate and not particularly interactive vendor-oriented web sites did not provide what we considered to be a sufficiently explorable experience.

None of the vendors initially provided a way to access the data for use in other systems, but this slowly began to improve. BodyMedia, Zeo, Withings, and Fitbit all created ways for users to access their own data starting around 2009-2010[7].

At this point we had an idea of what we needed to build, a story for why it was needed, and access to some compelling data sources to start pulling it together and making it explorable. We christened the project BodyTrack, and were very fortunate to find support from the Heinz Endowments.

In June 2010, BodyTrack became an official funded project within the CMU CREATE Lab. This allowed us to hire some interns, get help from other CREATE Lab engineers, invest in equipment, and start building the tools we envisioned.

During the first year we created an initial implementation of a BodyTrack web site which allowed users to store data from a variety of sources and explore them interactively in time. The aspects we struggled with most were user interaction design and how to capture self-report data, such as subjective measures of how the person was feeling at various points in time. The turning point in making satisfying progress on these challenges involved finally finding a community.

BodyTrack meets the Quantified Self movement

We discovered the Quantified Self (QS) movement in 2011 and presented at the first QS conference[8].

I was very happy to find that the range of endeavors generally known as "self-tracking" within the QS community included what I had been calling Human System Debugging. This was the first indication I had seen of other people coming together into community around this sort of self-directed open-ended self exploration. It was exciting to find that we would not have to try to bootstrap community around such practices in a complete vacuum.

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[6] The weight measurement of these devices tends to be good, but the inferred body fat mass readings are very sensitive to confounders such as hydration. Vendors like Withings know this (see https://withings.zendesk.com/hc/en-us/articles/201489157-I-get-inconsistent-fat-mass-readings). The ongoing challenge is communicating such nuances in a culture that tends, in my opinion, to take labels too literally. The culture of self-tracking can play a valuable role in helping people to develop a more sophisticated understanding of the distinctions between the name of a metric and the reality of its behavior and to share such understandings with others.

[7] Other vendors have followed suit since, though not as many nor as fast as we would wish. Convincing device and app companies to do the right thing with respect to user-directed data access remains an ongoing mission.

[8] First Quantified Self Conference, Computer Museum, Mountain View, CA, May 28-29, 2011 (http://quantifiedself.com/conference/Mountain-View-2011/). Our poster and slides are available at http://bit.ly/aw-qs-110528.

Self-tracking is a broader concept than what I had in mind in founding BodyTrack, covering a broad range of potential motivations and areas of inquiry. The conference included self-trackers with a diversity of different areas of interests. Among these, we met two others, Thomas Christiansen and Allan Bailey, whose personal self-tracking efforts fit squarely within the scope of the type of health-oriented exploration I hoped to support. Both later collaborated with us and made valuable contributions to BodyTrack.

New collaborations, new directions

Mymee

For BodyTrack to meet the needs of self-trackers interested in exploring health concerns, we needed convenient and flexible ways for people to capture subjective sensations in the moment. We encountered and looked into quite a few tools at the QS conference geared towards this self-report domain. Unfortunately, most of them were either too specialized, too inflexible, or failed to adequately support the type of data flows we would need for incorporating into BodyTrack.

Mymee, an app developed and used by Thomas Christiansen in his own self-tracking, was the one self-report tool we found that took a promisingly flexible and compatible approach.

The fundamental concepts in Mymee are *topics*, each of which represents an aspect of life that the user wants to capture information about, and *observations,* which represent a particular sensation or action relating to a given topic at a particular point in time. Each topic has a name that the user can choose (such as "headache" or "coffee") and options for what type value may be entered -- either a range (1-5, 0-10, etc.), free numeric entry, or no value.

The topics and value options are flexible and are custom configured for each individual. When a user wants to make an observation, he or she brings up the Mymee app, taps on the desired topic button, optionally enters a value, comment, and/or photo, and hits save. There is also a time field which is automatically pre-filled with the time when the user hits the topic button to make the observation, but which the user may modify if he or she wants to record an observation that happened at a different time.

We added support to the BodyTrack web site to be able to pull in data from a given user's Mymee account. This allowed us to fill in a major missing piece for supporting the kind of self-tracking we wanted to support.[9]

Dr. Paul Abramson

Dr. Paul Abramson is a doctor in private practice in San Francisco[10]. He had been involved with the San Francisco QS Meetups for quite a while before the conference. He tended to work with and get referrals of patients with complex, nebulous, hard to diagnose conditions, and suspected that some of these patients could benefit from self-tracking.

He had made some initial attempts at encouraging patients in the direction of self-tracking, such as handing out donated Zeo sleep tracking devices to patients with sleep issues. However, none of the patients he had tried it with had managed to follow through with such suggestions and typically returned the box unopened.

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[9] We have since created a free app called Fluxtream Capture that can do self-report, as well as capture heart rate and upload photos. It is available on the iOS app store (https://itunes.apple.com/gb/app/fluxtream-capture/id989182896?mt=8) and Google Play store (https://play.google.com/store/apps/details?id=org.fluxtream.capture&hl=en).

[10] See Dr. Paul's medical practice web site at http://mydoctorsf.com/ or his blog at http://quantdoctor.com/ for more information.

He had been actively seeking tools to help his patients get past these hurdles, but had not so far met success. He had significant insights about the ways in which previous attempts to identify existing systems for his use case had fallen short, but was not equipped to try to construct a system from scratch. He contacted me as part of his ongoing effort to find a system that would meet his needs.

I was thrilled to find a doctor who recognized and respected that there were people who were not well served by the standard diagnostic model, but who may be able to make progress through self-tracking. I had tried to identify and contact such a doctor in Pittsburgh, but had failed to find a good candidate.

The fact that we both cared about helping people in the same type of situation and held complementary pieces of the puzzle meant that we were well suited to join forces.

Throughout our discussions, we struggled with the question of how to support people who could potentially benefit from self-tracking but who were not at the point of being able to go it alone, as Thomas, Allan, and I had.

Dr. Paul already knew that handing out equipment and advice within the context of a medical appointment didn't work. I already knew that trying to design a technological artifact like BodyTrack for people to use in isolation was not sufficient. Together we realized that there needed to be an additional human involved who could mentor the new self-tracker in the culture and tools of self-tracking within the context of the self-tracker's own situation. In keeping with Dr. Paul's existing branding of his role as a "Quant Friendly Doctor", he called this new role "Quant Coach."

Together with Thomas and his business partner Mette Dyhrberg from Mymee, we began to develop some initial ideas about the proper scope, tone, and activities for the quant coach role. For example, we agreed that the quant coach should support the agency and skill development of the self-tracker in learning to refine and pursue their own ideas, self-assessments, and judgments. This is quite different than the typical role of a doctor or coach in our society, where the patient/client[11] is expected to follow the orders of and bow to the judgments of the professional doctor/coach.

We feel that this distinction is crucial, though it turns out to be surprisingly challenging to communicate and maintain. We hypothesize that careful framing of the quant coach/self-tracker relationship and being consistent in not succumbing to doctor/patient type power dynamics are important in making it work. For this reason, as well as the prohibitive hourly rates he would have to charge, we realized that Dr. Paul could not fill the role of quant coach himself. The open questions were who would fill the quant coach role and what the logistics and framing would look like for engaging with people who could potentially benefit from self-tracking.

BodyTrack Deployments

San Francisco, August-September 2011

Through Dr. Paul, we connected with Dr. Larry Chu, organizer of the Medicine 2.0 conference to be held at Stanford in September 2011.

Larry was enthusiastic about self-tracking. He had arranged for some device donations from Zeo and BodyMedia and reserved some time on September 19, 2011, the last day of the Medicine 2.0 conference, for self-tracking related events. Larry offered us time to present plus ten Zeo sleep trackers and ten BodyMedia armbands if we could do something compelling with them.

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[11] The lack of a non-domain-specific term in the English language to be used here, and the fact that existing terms like "patient" or "client" imply a different power relationship than we seek to promote within the quant coach/self-tracker relationship, is a persistent problem in trying to communicate these points.

We decided to use this as an opportunity to field test our ideas about coached self-tracking with ten participants. We teamed up with Thomas and Mette, who contributed Mymee installs and technical support for the participants, and brainstormed with us about how the pilot would work.

Dr. Paul and I reached out to our network of likely contacts in the Bay Area to play the role of self-tracking participants. I played the role of quant coach. Dr. Paul played the role of quant friendly doctor. We equipped each participant with an instance of Mymee, a Zeo sleep monitor, a BodyMedia armband, a BodyTrack account, a quant coach appointment with me each week, and the opportunity to meet with Dr. Paul if they wanted.

We started meeting with participants on August 21, 2011, giving us roughly three weeks of active operation before the September 19th Medicine 2.0 presentation.

I have told excerpts from the experiences of three of the participants, Alan, Paul, and Marcy, at various talks, most recently at the June 2014 London QS Meetup[12], in more detail than I could here. I encourage the reader to check out those talks if they want to learn more. Here, instead, I will try to describe more about the general process and lessons learned.

Quant Coaching For Beginners

Overall, the experience of working with the participants in San Francisco greatly reinforced in my mind the importance of the role of the quant coach meetings and the need for participants to have a compelling and convenient way to capture self-assessment data in the moment for later reflection. The participants who were able to attend coaching meetings every week typically got a lot more out of the process than those who weren't. The participants who were able to capture relevant aspects of their situation in the moment to reflect on about how they were doing over time typically had a more productive and satisfying experience than those who weren't.

The need to generate a custom Mymee configuration for each participant provided an unexpectedly helpful structure for the first quant coach meeting. I would typically start out by asking each person what they wanted to investigate and why. While they told their story, I would listen and take notes of potential feedback variables, meaning what parameters they are concerned about (headaches, sleep quality, etc.), and what factors they are suspicious might have an impact on how well or poorly they are doing on those axes (caffeine, exercise, bedtime, etc.). Then we would brainstorm ideas for how they might want to capture the top few candidates, with particular emphasis on the feedback variables.

In the case of sleep or activity related concerns, this would involve a discussion of how the Zeo sleep monitor and/or BodyMedia armband works, what it can capture, and how that compared to what they felt mattered for them. In other cases, or in the case of sleep or activity related parameters which could not reasonably be captured by the devices, we discussed options for capturing via self-report.

The process of discussing a potential self-report topic involves three pieces: refinement, topic naming, and value type selection. Refinement involves helping the person explore what exactly it is that they want to capture. We discuss specific examples and try to peel back the layers of interpretation and judgment to get at the kernel of sensation, thought, or action. Topic naming involves brainstorming possibilities to find personally relevant language. Value type selection involves considering whether this topic is best treated as a range of discrete values (1-5, 0-10, etc), a continuous value (like weight or temperature), or an event which needs no value.

I am grateful to Thomas and Mette for teaching me that the personal impact of tapping on choices with a particular label and value configuration really matters. Their input is what led me to be mindful how this refinement process is conducted. If these are parameters are well and freely chosen, the process of making

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[12] Video: https://vimeo.com/channels/londonqs/102604323 from 9:38 to 17:32. Slides: http://bit.ly/aw-qslondon-140619

observations can be an affirmation and positively reinforcing. If poorly chosen or imposed in a way that grates against a person's sense of self, the same process can be punishing.

I feel that this is a very important point that in most contexts is either ignored or trampled under the feet of process standardization and "clinical validation". Valuing such considerations above the impact on an individual's sense of self may make sense in the setting of a study or the type of official diagnostic setting which stresses the need to make individuals comparable against each other. However, I feel like forcing the use of standardized terminology and value structures is over applied, such as in the design of most self-report type self-tracking apps, and the impact that this has on the individual self-trackers is underappreciated.

At the first meeting, I would generally also help people learn how to use the BodyMedia and Zeo devices. This included things like setting up accounts, how to adjust the tension on the bands, how to keep the devices charged, how to upload data, and how to use the vendor supplied web interfaces.

Follow-up coaching meetings were more varied in structure in response to the needs and priorities of different people at different times. They would typically start with an open-ended question like "How are you doing?" followed by an opportunity for freeform exposition. Then we would focus in on whatever set of activities best served the participant's needs, priorities, and interests. The potential activities included:

- Process debugging
- Technical debugging
- Cultural sharing
- Looking at and reflecting on data together
- Considering how the concrete experiences, as reflected in the data, related to existing hypotheses or if they inspired new ones

Throughout, the focus was on supporting the skill development and discernment of the participant themselves, and on helping them reflect on recent, concrete experiences relevant to their areas of inquiry. This often included asking questions like:

- What happened?
- What did you expect?
- How do you think that might have worked out better? (In regards to process debugging.)
- Does that seem consistent with your hypothesis that <fill in the blank> affects your <fill in the blank>?
- Does this give you any new ideas you'd like to try to pursue?
- How would you like to try to capture that?
- Would you like to add a new self-report topic?

I would typically use part of the second meeting to help them set up a BodyTrack account, pull in their data from BodyMedia, Mymee, and Zeo, and learn how to use the BodyTrack web interface to explore their data.

Ideally, the motivation to set up their BodyTrack account would naturally arise from the trajectory of the conversation. The motivation generated by trying to remember what had happened or the relative ordering of events as part of telling their own story is very helpful in learning to explore their data within BodyTrack.

This approach typically starts by the person mentioning some recent standout event that is salient to their inquiry process, like a particularly bad headache. This provides a natural lead-in to them wanting to tell the story of that event. Pursuing details, particularly places where there are gaps in the narrative, can then be used as a springboard for learning to use BodyTrack as part of the event reconstruction and storytelling process. I call this "data assisted recall." Also, reflecting on a particular salient moment is very helpful in helping them learn to tie their subjective experiences to various data representations.

In the headache example, we would start by looking at the matching observation in their Mymee headache channel using the BodyTrack web interface. That would pinpoint a particular date and time of special interest and make it visible on the timeline[13]. This can provide a good opportunity to bring up other channels like BodyMedia mets, which reflects metabolic activity levels at each minute, or Zeo Sleep_Graph, which shows sleep states through each night, and tie them into the conversation. I might ask questions like "I see there's a big spike in BodyMedia mets that day a couple hours before the headache, what was going on there?" or "All this orange in the Zeo graph shows that it thinks you were lying in bed awake since 3am, does that seem accurate?"

Later on, during subsequent quant coach meetings, that same type of process motivates logging into BodyTrack and exploring data together. As the person's fluency with the tools and data understanding improves, they become able to increasingly focus on exploring their concrete experiences through the lens of their evolving set of hypotheses.

In some cases, initially promising hypotheses fail to perform, and fall away. In others, formerly unconsidered ideas emerge from the process of exploring the data and noticing something unexpected. For example, Paul was interested in exploring what was leading to his recurrent headaches. He was initially suspicious of things like caffeine and processed carbs. After a couple weeks of recording in Mymee when he consumed such items and reflecting on it, he became increasingly convinced that caffeine and processed carb consumption wasn't lining up with the timing and severity of his headaches. Paul did not initially think sleep quality was relevant. However, after noticing clusters of headaches following gaps in his sleep data, he started paying more attention to sleep behavior. He decided to start recording when he experienced the feeling that he needed to sleep, a topic he called "Eyes Close." His eventual model was that the headaches would likely hit him when he ignored the "Eyes Close" sensation and did not at that time go to bed, but would likely not hit when he respected the sensation and went to bed.

By the time September 19 rolled around, we felt that we had learned many things we wanted to share at Medicine 2.0. Paul and I described our experiences in a joint presentation called "Implementing Self-Tracking in the Wild[14]."

Quant Coaching in Pittsburgh, Spring 2012

Back at CMU, we leveraged the experience we gained working with self-trackers in San Francisco as part of our efforts to redesign the BodyTrack web site.

In the original design, all of the channels existed together in a common graphing area (Figure A). This design was great for being able to overlay different channels on top of each other to look at relative timing. However, each time a new channel was added, all of the existing ones would typically need to be adjusted and rescaled to make room. This turned out to be unexpectedly disruptive to the flow of the participants' exploration experiences.

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[13] If, instead, it turns out they remember that such an event happened but find that they didn't actually make an observation, that's useful too. The disappointment that they're missing data that they would have wanted to have acts as feedback for reinforcing the habit of recording such events in the future. It also provides an opportunity to brainstorm and seek out what other data traces might be available to reconstruct when the missing event happened, which is a valuable skill.

[14] Slides at http://www.slideshare.net/annerwright/self-tracking-medicine-20-presentation-91811
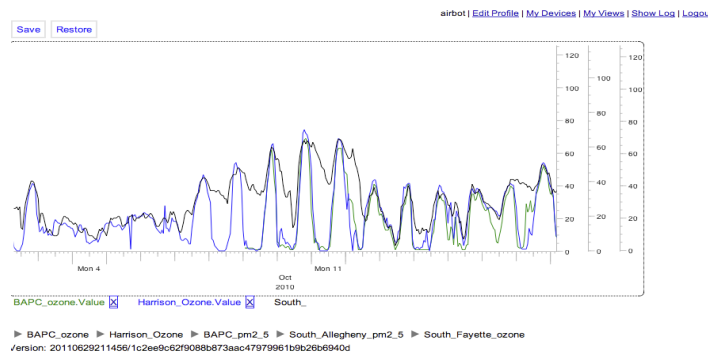
Figure A

In the new version, each channel had its own track with a tab at the end showing the name of the channel and allowing it to be manipulated (Figure B). Channels could be reordered by dragging their channel tab up and down, restyled by clicking on a gear-shaped channel settings icon, made taller or shorter by dragging the border between channels, or removed by clicking the X at the left edge.
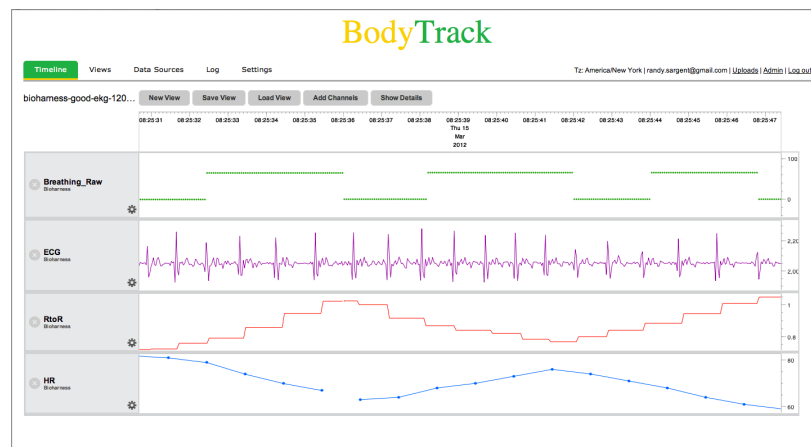

Figure B

As soon as the new version was minimally usable, I started doing weekly quant coaching sessions with people at the CREATE Lab who had something going on in their life that they wanted to investigate. As the technology matured, I started to include participants from outside the lab.

Instead of explicitly recruiting a participant group to all start and end at the same time, as had happened in San Francisco, I allowed this group to grow organically by word of mouth. For example, a number of participants came from those who expressed interest after seeing current participants give presentations using BodyTrack at QS Pittsburgh Meetups.

I ended up working with ten people as quant coaching participants using the second generation BodyTrack web site. I negotiated with Thomas and Mette to supply and support Mymee installs for each of them. I also supplied additional equipment, such as a BodyMedia armband or a Zeo sleep monitor, for each participant if it made sense for them given their interests. The pattern of the coaching meetings with each individual remained similar to what I described above: a one-and-half hour initial meeting structured around discussing data capture options and setting up their Mymee configuration followed by a series of one hour weekly follow-up meetings.

Some people came to a satisfying conclusion quickly and stopped after just a few weeks, others continued longer. Some would disappear for a while when other obligations became overwhelming, then reappear later on when whatever concern they wanted to track re-emerged as a priority.

Dawn of Fluxtream/BodyTrack

The next phase of technical development for the BodyTrack project started when I stumbled on a web site called Fluxtream (Figure C) in February 2012. I created an account, played with it a while, and was struck by the similarities between what I saw in Fluxtream and many of our as-yet unrealized aspirations for the BodyTrack web site.

Figure C

Fluxtream had a lot of nice user interface features and an excitingly diverse set of data services it could connect to and pull data from including various tracking devices, such as Fitbit, Zeo, and Withings, and web based services, such as Twitter, LastFM, Google Calendar, and Google Latitude.

When a given connector was added, it would begin pulling in the full set of historical data from your account. Afterwards, it would incrementally pull in new data automatically each night and when you logged in.

These features of Fluxtream were exciting to us. We had struggled with how to incorporate contextual data, such as maps and weather, as Fluxtream did, and we very much wanted to be able to be able to connect to more diverse data sources.

I contacted Candide Kemmler, the creator of Fluxtream. He had been working on Fluxtream as a commercial startup project from his home in Brussels for two years. He had recently decided to change direction, convert his existing code base into an open source project, and return to the work force.

BodyTrack too was an open source project, and I was excited by the potential for integration. Our approaches were different but complementary, and we could envision something great out of combining the strengths of BodyTrack and Fluxtream.

Candide joined the BodyTrack team and we worked together to realize this vision. We decided to keep the Fluxtream name for the combined web-based data exploration system, now relocated to fluxtream.org in recognition of its new non-profit identity, and keep the BodyTrack name for the CMU-based health empowerment project.

The combined system, like the original Fluxtream site, allows the user to add and manage a set of connectors linking to a range of services. It also, like the original BodyTrack site, supports an upload API to allow users to import data from other sources.

The user interface contains two main applications: the Calendar app (Figure D), and the BodyTrack app (Figure E).
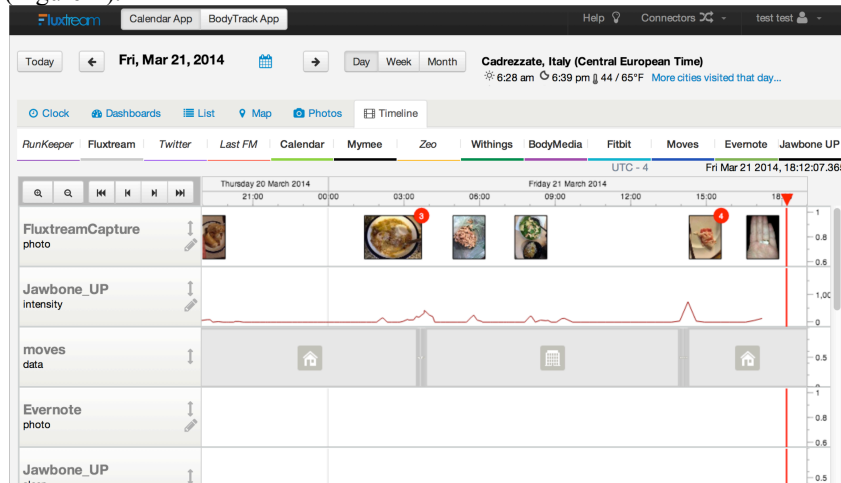
Figure D
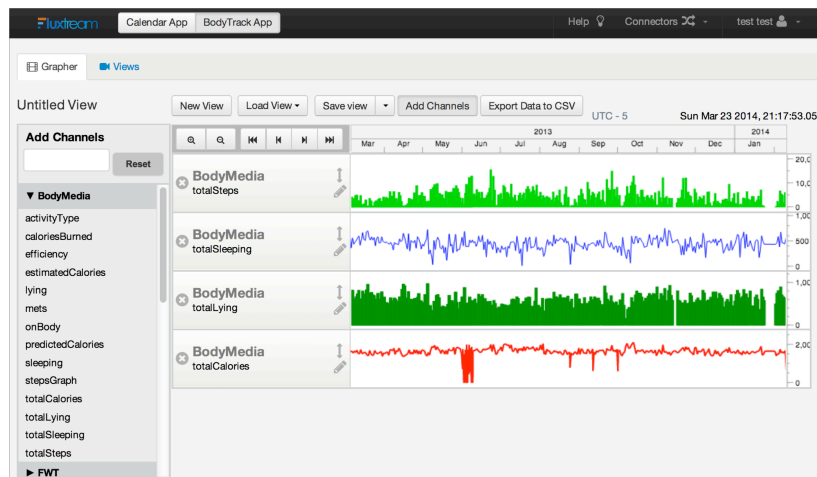
Figure E

The Calendar app is geared towards supporting a user to casually peruse the context of a particular day, week, or month. It preserves the calendar-based navigation, mapping, connector-based selection of what data to show or hide, and, at the day level, a circular Clock view from the original Fluxtream, and adds a BodyTrack-style Timeline. The channels shown on the Calendar app's Timeline are configured on a per-connector basis, with reasonable defaults when a connector is initially added. These channel selection choices persist until the user decides to change a given connector's settings.

The BodyTrack app is geared towards supporting the type of deep interactive inquiry described in the section on quant coaching. Like the original BodyTrack interface, time is treated as continuous, channels

are selected individually, and a particular set of channels and time range can be saved as a View, linked to, and reloaded later.

We launched the first publicly accessible instance of the new Fluxtream in September at the 2012 QS Conference at Stanford[15]. As of early 2015, fluxtream.org has over 3000 registered user accounts.

Fluxtream/BodyTrack in Dr. Paul's practice

In the summer of 2012, Dr. Paul hired Lauren DeDecker to act as an in-house quant coach within his practice. Paul recruited me and the folks from Mymee, who had set up their own Data Driving Coaching practice in New York, to help in training Lauren.

Thomas and Mette of Mymee had earlier teamed up with Josh Manley to act in the role of coach for their program in New York. I met Josh briefly in September 2011, but we had otherwise been evolving our approaches to coaching independently of one another.

I started working with Lauren remotely in July. My approach was to have her start out by experiencing the process from the point of view of a self-tracker, with me playing the role of quant coach. I met with her weekly over Google Hangout starting in July and kept as close as I could to the way I did normal in-person quant coaching sessions. I also mixed in technical training and conversations about the philosophy and practice of quant coaching, often motivated by experiences from her own self-tracking process.

Dr. Paul selected an initial set of people for Lauren to work with from among his patients. They were all people who he had been working with long term, who he thought were sufficiently flexible to try something new, and who had the sort of complex, multi-faceted, chronic issues that could potentially benefit most from self-tracking.

Lauren and Paul worked with Thomas, Mette, Josh, and me in person in September, 2012 while we were all in San Francisco for the Medicine X conference to flesh out their plans for how their in-practice quant coaching would work. On the technical side, they used Mymee for self-report, Fluxtream for visualization and reflection, and a web-based EMR for capturing notes about each visit and sharing them with Dr. Paul. On the quant coach training side, Josh and I had developed fairly different styles of coaching, and we wanted Lauren to have the chance to benefit from both sets of experience in synthesizing her own style.

Lauren started meeting with the self-tracking patients on September 25, 2012. Either I or one of the folks from Mymee sat in on each of her initial quant coaching meetings, and we debriefed together with Dr. Paul afterwards. I was also able to sit in with her at two of the second meetings a week later before leaving for Pittsburgh. Then she continued on her own.

Paul and Lauren shared their experiences and lessons learned in working together on this at the 2013 Quantified Self Conference in San Francisco in a breakout session called "Quant-Friendly Doctors and Doctor-Friendly Quants[16]". The session was positive, well attended and lively. I was very happy to see them doing so well and spreading their message to others.

Towards Community Based Self-tracking Programs

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[15] Third Quantified Self Conference, Stanford University, Palo Alto, CA, September 15-16, 2012 (http://quantifiedself.com/conference/Palo-Alto-2012/)

[16] "Quant-Friendly Doctors and Doctor-Friendly Quants" breakout session, Quantified Self 213 Global Conference, Presidio Golden Gate Club (Chapel Hill room), San Francisco, CA, October 10, 2013, 10:30 am. For details see http://mydoctorsf.com/the-quant-friendly-doctor-at-the-quantified-self-conference-2013.html

I want to help move us to a place where approachable, affordable, and properly framed opportunities for people to engage in self-tracking are available when and where people need them. In the framework of the "Reframing and Retooling" section above, the people I'm thinking about have spent some time languishing unsatisfyingly in stage 3 (spinning as a passive object of the medical system), passed through stage 4 (role shift to active investigator), are currently in stage 5 (active seeking), and have not yet either given up or reached a satisfying conclusion.

People in this situation do exist. Most of the people I meet and talk about BodyTrack with one-on-one, particularly those over the age of 30 or so, have either been in that situation themselves or watched friends or loved ones struggle through it.

However, at the aggregate, societal level, people in this situation are invisible. They aren't any statically defined *type* of person. They do not map to any demographic categories. They don't appear in any set of statistics.

In fact, a defining characteristic of this type of situation is that the person's concerns and presentation either do not fit well into or are not adequately served by classification into the standardized diagnostic systems used in western medicine (such as ICD-10 or DSM-V). There are various syndromes and diagnoses of last resort that may end up being assigned to people in such situations, but even gathering together people who have been given such diagnoses would not, I expect, map cleanly to people in the situation I'm talking about. Therefore, the common practice of talking about, studying, and computing population based statistics for groups of people based on diagnostic categories (such as "people with diabetes," or "people with heart disease") is unhelpful here.

Also, these types of situations are dynamic. A given person may go through this sort of situation during some part or parts of their life, and each time there is a limited window of opportunity: Too early, before a person passes through stage 4, or too late, after they have given up hope, and such self-tracking opportunities are not interesting. However, if the opportunity appears at the right time, when they're actively seeking in phase 5, it can be transformative.

The big questions are:

1. How do we create situations where active stage 5 seekers could engage with appropriate and accessible self-tracking programs?
2. How do we spread the knowledge of such programs' existence in such a way that people have a hope to learn about and engage with them during the window of opportunity where it would be helpful for them?

We so far have three examples of how this has worked in different contexts and types of framing:

1. The BodyTrack deployments, with the framing of participants co-creating with us the understanding how to best apply and refine the technology and techniques described in this article
2. Dr. Paul and Lauren's in-practice quant coaching in San Francisco, with the framing of existing patients engaging in a different type of practice within the context of their doctor's office[17]
3. Thomas, Mette, and Josh's Mymee based Data Driven Coaching service in New York, with the framing of a for-pay service analogous to other life coaching type offerings[18]

I have faith that quant coaching practices such as Dr. Paul and the Mymee folks have set up could be replicated in other locations. Over time, more doctors and coaches will come along who recognize and appreciate the need for such services and work in an area with sufficiently connected and motivated populations to sustain such practices. This is a good thing, and we all have our feelers out for candidates who are up for creating such services in their own local areas.

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[17] See http://mydoctorsf.com/quant-coach-program.html
[18] See http://www.mymee.com/whatwedo/

However, I am concerned about the social justice and access issues if those are the only types of contexts in which quant coaching becomes available. I dream of a future where there are additionally community based self-tracking support programs which can connect stage 5 seekers with quant coaches who operate in ways that preserve a sense of fair value exchange, but do not involve the payment of hourly rates in a cash-based economy.

Inspirations that hint at this possibility include:

- Rachel Naomi Reman's book "Kitchen Table Wisdom", where she discusses how we have historically supported each other's processes of self reflection and self re-creation through mutually supportive conversation. While this practice, as well as many others, has been weakened by the culture of professionalization (the outsourcing of things we used to do for each other to professional entities operating on a cash basis), her writings give hope that we can reclaim that heritage.
- Discussions about *gift culture* and the *gift economy* by writers like Dan Ariely and Charles Eisenstein19. The idea here is that there are many things work well when we do them for each other on a social basis as part of a culture of gift exchange, but break down when money becomes involved. Their writings give hope that quant coaching could potentially be pursued as part of a gift economy.

Gardening is an aspect of culture where such practices seem to have survived fairly intact. For example, when I became involved in Frazier Farms, a local community garden in my neighborhood, I did not know how to grow vegetables. Others with more experience helped me to decide what and how to plant, and helped me gain the skills needed to keep the plants alive. I watched for opportunities to reciprocate, such as watching after their plots while they were away, or sharing veggies as they matured enough to eat. When I, in turn, had more experience than new arrivals, I helped them get started as I had been helped. No money was exchanged, nor would it have been appropriate to do so.

The paying forward of startup help received from others earlier and the ongoing balancing of value on a social rather than a financial basis are integral for how these sorts of gift economies work. Much of what we do, such as church work, volunteer work, hobby related organizations, etc. operate similarly.

Self-tracking and quant coaching are fairly new practices, but I think there is the potential to make these opportunities available as part of gift economies. The Quantified Self Meetups themselves already operate this way: organizers and presenters are unpaid and there is a culture of helping each other, particularly those new to self-tracking. The quant coaching I have done is more intensive than the usual course of QS interactions, but I have seen other examples of similarly intensive, one-on-one self-tracking support partnerships. I am hopeful that such practices will grow in QS culture over time, and I do what I can to encourage that outcome. However, there tends to be little social interconnection of people involved in QS outside of QS Meetups, and few stage 5 seekers are likely to know about QS, so that mechanism alone is not sufficient.

What I think is needed is for self-tracking coaching opportunities to be linked to existing community sites which:

1. Already operate as part of a gift economy
2. Already exist as part of a deeply interconnected group of people that have a tradition of caring about each other
3. Have at least one person with deep connections to the community to act as a coordinator between seekers and those willing to act in the role of coaches

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19 See Dan Ariely's book *The Upside of Irrationality* or Charles Eisenstein's *Sacred Economics* (http://sacred-economics.com/).

4. Have a way to bootstrap the creation and customization of a program to operate within the specific milieu of that site, ideally involving both the site coordinator and an initial corps of coaches
5. Have a way to recruit an initial set of seekers, and sufficient ongoing interest in the community for word of the program to have a good chance of reaching additional seekers

The best parable I have seen for this last point, connecting seekers to opportunities for a better outcome when categorization fails, comes from the short animated film The Lost Thing[20]. A boy finds a Lost Thing on the beach and comes to care about it. He tries and fails to categorize it in hopes of getting it back where it belongs. Then he sees an advertisement for the Department of Odds and Ends and takes the Lost Thing there for processing. While filling out the paperwork, he's approached by a creature pushing a broom who tells him that if he really cares about the Lost Thing he should leave the building and follow a trail of arrows. At the end of that trail he finds a door leading to another land where the Lost Thing can thrive.

For a community based self-tracking support program to work, the community needs to have enough interconnected people who know and care about each other that those in the stage 5 seeker phase can, like the boy and the Lost Thing, encounter the right trail of cues to find and engage with the program. At least initially, when these things are new and obscure and don't permeate mass culture, this requires finding and working with more highly connected and caring groups of people than generic, disconnected, uprooted, city-dwelling Americans like me.

In May 2013, while we were struggling with how to approach catalyzing such an effort in Pittsburgh, Dr. Augustus Brown contacted Illah Nourbahksh, Director of the CREATE Lab at CMU, regarding a study he was working on related to heart disease in the Pittsburgh African American community. Part of the study design involved engaging with health ministries in local African American churches in recruiting, supporting, and monitoring the study participants. Illah explained that we didn't have anything designed to help with such studies, but asked if he might be interested in learning about our BodyTrack project.

Augustus met with us and was very supportive about the idea of working together on figuring out how to set up a BodyTrack style community self-tracking support program in Pittsburgh. He brought in others involved in the study and the churches to brainstorm about possibilities and began seeking out potential grant opportunities. He also introduced me to his daughter Renna who, it turns out, has had her own experiences in struggling with health mysteries and has become a powerful advocate for what we're trying to do. Augustus and Renna have been very helpful in working with us to refine these ideas about community based self-tracking programs, and are collaborating with us to identify potential communities, sites, and coordinators around Pittsburgh.

I have also identified a couple of potential options in Europe. We proposed to work with a network of female breast cancer survivors in Italy in collaboration with Instituto Tumori as part of a joint funding proposal to the European Commission. Unfortunately that proposal was unsuccessful, but hope remains that other opportunities may arise to work with them in the future. I have also been talking to Katherine May and her colleagues at the NHS Community Mental Health unit in Guildford, UK about coordinating a program there. I visited them in August 2014 to meet and set up the initial groundwork, and am hopeful about prospects for continued collaboration.

Conclusion

The journey I have tried to capture in this article started with pulling on one thread, personal paradoxes related to Nightshade and Ayurveda, and ended up with wide swaths of the fabric of how I thought the world worked unraveling. However, that process has also led to many fantastic partnerships and tantalizing glimpses of how those threads can be rewoven into a better world – a world that is more conducive to those of us who fail to fit comfortably in the available pigeonholes to seek our own custom solutions.

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[20] http://www.thelostthing.com/

As a culture, we want very badly to believe that we can apply industrial economies of scale to everything, including health care. We want to believe that we can develop a master diagnostic algorithm that sorts people into pigeonholes, have the best experts determine once and for all what the right treatment is for each pigeonhole, and add automation where possible to minimize the labor costs of processing patients through the machine.

However, the truth is both messier and more hopeful than that. The industrial approach appears to work only if we're willing to marginalize those who do not fit cleanly into the pigeonholes. However, there are other options, such as the type of self-tracking approaches I describe here, that do not depend on categorization and have other benefits, such as building a sense of self-efficacy.

Instead of applying the industrial model in a totalizing way that pretends to cover everything, we can learn to recognize and accept the landscape of its limitations and improve at helping people connect to and engage with other positive options.

It is my deepest hope that the approaches, experiences, and technologies I have described here help catalyze this transition.

Acknowledgements

References

Nourbakhsh, I., Sargent, R., Wright, A., et al. (2006). Mapping disaster zones. Nature 439(7078), 787-788.