



# The Data Economy of Biosensors

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Biosensing does not take place in a void. It always has a social context of some kind, and that context has profound implications for the types of things that biosensors can and cannot do. The social context is, however, not as obvious as it might at first seem. There are some design considerations that must be tied to specific situations. For example, what one might build to enable professionals to care for an older person with chronic obstructive pulmonary disease (COPD) is very different from the monitor that tracks an athlete's activity levels or what a citizen science group might use to look for better assessments of local air quality. What works well in fully privatized healthcare systems may not find much demand in single-payer systems. Even within single-payer systems, what works in the Netherlands may not work well in the United Kingdom. There are also differences that need attending to, based on not just the population of end users but on a whole range of other actors involved. The way we represent data to professionals must be very different from the way it is represented to epidemiologists or civil society groups.

Not every design consideration, however, applies at the level of these specific contexts of interaction. Larger-scale social transformations are happening that change how people encounter biosensing in everyday life. This chapter discusses those changes, which have to do with who interprets data and to whom data circulates. The point of view from which I offer these reflections is as an anthropologist who contributes to the relevant scholarship and as a person working in the information and communication technology (ICT) industry whose job it is to distill and translate that scholarship into concrete design and strategy decisions. Although this may appear somewhat unusual in a technical volume such as this, anthropologists now frequently work in the technology industry and regularly inform decisions regarding technology design and market strategy (refer to Cefkin, 2010, for an overview). Given my anthropological background, this chapter will flow somewhat differently than the other chapters, and its subject matter will be different as well. I leave it to the other chapters to focus on the material affordances of various sensors and suggest possible uses based on those affordances. Instead, I will draw on the relevant social science to discuss the social arrangements that make some uses more valuable than other uses. I cannot parse every social situation in which biosensing occurs, but I do address some aspects of what it is these situations have in common.

There are patterns in how the industry and engineering research tends to approach biosensing, and these patterns have social as well as technical origins. The usages that at first seem to be the most likely usages seem that way because of a social history that ties sensing technologies to institutional use. These most obvious usages may not ultimately prove to be the most valuable to end users. I have confidence, however, that it is possible to see past the first port of call. Indeed, there is good reason to do so. The evidence shows that applications that at first seem most plausible are also the same applications that lead to biosensors falling into disuse and that have troubling societal effects. Some of that evidence is presented here. Once we can identify the commonalities in how today's biosensors are conceptualized, we can develop additional approaches. In this chapter, there are pointers to new kinds of use models and applications; however, these are intended to be suggestive of a broader underlying approach.

Biosensing for the purposes of this chapter includes both sensors that sense what is on or in the body and sensors that sense things in the environment that affect the body. Biosensors are already part of a larger data economy. By "data economy," I mean the everyday circulation of data between devices, people, and institutions. Regardless of device, use case, user group, or institution, data is most useful when it moves around. If it goes nowhere, the data can fall flat or fall into disuse. If it has an extended biography, either by moving between different kinds of people or as one data

stream providing context for another data stream for a single person, it can be said to have a life of sorts—an extended set of social and cultural meanings. As it moves around, it acquires different valences (Neff and Fiore-Silfvast, 2013). That is, we will not all agree on what the meaning of “5,000 steps” is or what kind of action the measurement calls for. For some, it is an indicator of good health, and for others it is considered medically useless. For some, it means that more steps should be taken, while for others, it is a low level of activity across a week. That we use “steps” at all is the result of previous circulations; for example, early product demos gave examples of fitness indicators calculated in “steps,” and through use, “steps” became adopted, understood, and accepted.

Whether through differences in perspective or through the way that standard metrics begin to emerge, when data is part of an exchange or circulation, that is where we see its value.<sup>1</sup> Whether that exchange looks like a market or, as in the exchange of open source code, a gift economy, or whether it takes yet another form, depends on particular circumstances. Indeed, when data moves between family members and a person being cared for, the economy of data is not at all like a market. But a circulation it nonetheless is, and circulation is one aspect of biosensor data that makes it so deeply social. Kenner (2013) provides a helpful classification of different kinds of data economies for mobile asthma technologies (see Table 7-1). These examples show clearly that when the participants change, so do the social effects of data.

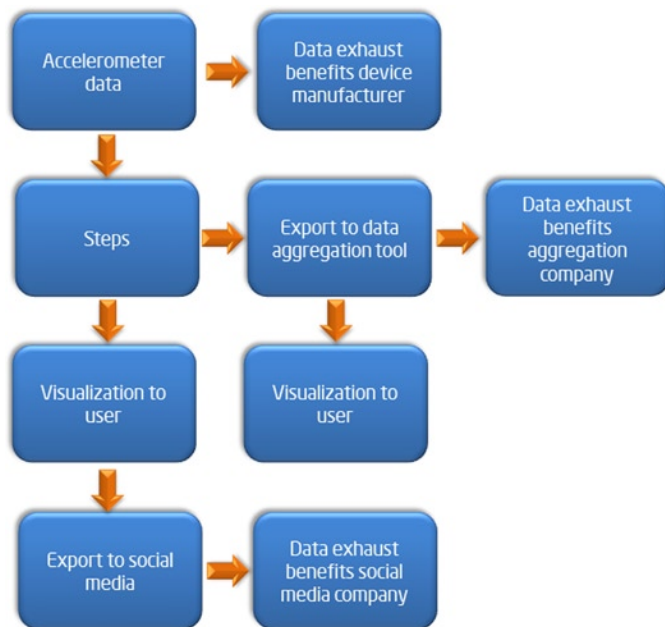
**Table 7-1.** *Data Economies for Mobile Asthma Technologies*

	Type	Examples	Economy Participants	Social Relationships and Data Flow
<b>Class I</b>	One-way information delivery	Asthma Signal	Patients	Patient receives alerts to take medicine based on action plan.
			Doctors	Doctors provide information about patient’s condition.
			App developer Environmental data providers	Patient receives health information from app developer.
<b>Class II</b>	Compliant care	My Asthma Asthma Check Asthma Tracker	Patients	Patient receives alerts based on action plan.
			Makers of national standards of asthma care	Patient enters observations of symptoms.
			App developer	Little information available about who looks at those observations.
<b>Class III</b>	Environmental health	AsthmaSense AsthmaWin	Patients	Patients record observations of symptoms.
			Makers of national standards of asthma care	Patient receives environmental data.
			App developer	Combination of health and environmental data makes it possible for patient to make sense of triggers.
			Environmental data providers	
<b>Class IV</b>	Participatory epidemiology	AsthmaMD Propeller Health (Formerly Asthmapolis) Breathe Easy	Patients	Patients record observations of symptoms.
			App developer	Patients generate location data for where symptoms occur.
			Third-party data collectors	Patients opt in to third-party data collectors to conduct research on sources of asthma triggers.

<sup>1</sup>Anthropologists will see that here I am drawing on notions of circulation and exchange derived from Tarde (Latour and Lépinay, 2009), not neoclassical economics.

Each system is designed to support asthma sufferers, and each takes a different approach. Class I apps treat data exchange as an extension of the current medical system; data moves out from that system and to the patient but not the other way. The patient is there to be managed by experts. In Class II apps, the patient has the opportunity to record observations about symptoms. Note that this recording is done largely by user input, but we might imagine that with an extended availability of biosensors on the market this might not be the case in the future. It is unclear whether this information is for the patient's own consumption or whether it is intended for medical practitioners to look at it. In my own research among Quantified Self participants (refer to the "Evidence Base" section for details), it is rare that a doctor has the patience or inclination to look at patient-generated data. It forces doctors to parse what is and is not medically relevant, as opposed to relevant for self-care. In the context of a busy clinic, that parsing is also not likely to take priority (Neff and Fiore-Silfvast, 2013). A connection between medical system and patient where the patient has the opportunity to speak to the medical professional may be intended, but it also may not succeed. In Class III apps, the addition of environmental data brings in additional data providers and also affords possibilities for patients to make sense of their condition, as opposed to simply being told when to take their medicine. In Class IV apps, the circulation of data is yet again different. The patient is both a consumer and generator of data, and epidemiological research is enabled. Because these apps are so new on the market, it is impossible to tell how the power relations between the actors work in practice, but the flow of data is designed to create relationships between participants and epidemiological research, not clinical care.

Declining costs mean that biosensing is no longer confined to medical institutions. Now that it is more popularly accessible, the exchanges in which biosensor data circulate are also diversifying in surprising ways. A generic example is provided in Figure 7-1 for an electronic pedometer. The chain of data exchange in Figure 7-1 demonstrates that who has access to what data, and who ultimately benefits from that data, is different in a consumer market than it is in the earlier asthma example. Note first the actors: social media companies are not traditionally considered actors in the healthcare space, nor are they subject to monitoring by health regulators. Then note the distributed nature of who or what makes sense of the data. The data is not sent to an expert who validates it or invalidates it. The beneficiaries of the data exhaust do not necessarily share institutional goals or incentives. They also do not benefit by creating connections with careers or relationships between careers and patients. They benefit by creating correlations that can be achieved only through large, complex datasets that may or may not have anything to do with health.



**Figure 7-1.** Example of a simple data economy for an electronic pedometer. “Data exhaust” refers to that which can be inferred from a dataset that the creator of that dataset did not originally intend to collect

Looking at sensor data in this way—in other words, tracing its movements across different actors—also allows us to ask questions of how data moves around: What social processes are really at stake in these arrows? Are all the actors involved equals, or are there power relationships that shape these relationships? Here I am drawing on a longstanding methodology within the social sciences to analyze the social meaning of objects by looking at their biographies as they are exchanged (Kopytoff, 1986). Although it would be foolish to expect data to do the same thing it once did in clinical or scientific environments, thinking in terms of a data economy helps us see that it is not a complete free-for-all either. Patterns form based on social arrangements and cultural assumptions that make some uses, designs, and business models more plausible than others.

The shift from expensive biosensors in labs to relatively inexpensive biosensors in the hands of many has consequences for the kinds of use models and designs that are appropriate for a consumer market. The first section of this chapter will examine how biosensors have been socially shaped through their origins as devices that institutions use. This institutional history has created a preoccupation with controlling the behavior of others, based upon population-based science from which beliefs about what is normal and healthy have been derived. This history gives rise to the use models that appear most obvious to technology designers: to set and track progress toward the goal of higher activity levels so that people lose weight, monitor someone’s blood pressure and deliver tips on reducing it when it is high, and so on. The history of biosensors is so rooted in institutional use, yet the devices are rapidly expanding into the consumer domain. The data economy of today’s biosensing has changed much more slowly and is underwritten by a set of assumptions that do not necessarily hold when developing a consumer product.

There is reason to believe that the limitations of this early ethos of “behavior modification” have been reached and that early adopters of biosensing at the consumer level have found a different set of preoccupations altogether. The second half of this chapter will document cases of early adopters, where a notion of biosensing is forming that is centered on the ways that biosensing can help people make sense of the world around them and rely on their own knowledge about personal context to make appropriate decisions. This shift is happening primarily among early

adopters, but others are well positioned to take part in this transformation. The underlying approach is that personal context is always, ultimately, a matter of human interpretation. These early adopters consider machine recording of certain phenomenon to be useful, but ultimately how people come to understand their own context will always take into account more than machines will ever be able to do. This perspective generates debates about how much automation is valuable in what circumstances. Whereas Chapter 9 addresses context as a type of data that people who are out of context would need in order to make sense of that data (for example, a healthcare provider trying to understand a patient), here context is something a person has and can draw on. Data can be contextual data to the extent each data stream sheds new light on the other; however, when the user is at the center of the sensemaking, there is no need to separate “contextual” data as a particular kind of data.

Let me be clear that I am not talking about “personalized medicine,” or “personalized health” as it is commonly understood. I am making an argument for changing our underlying reflexes about the kinds of problems we choose to solve. The shift is away from predefining problematic behavior and using technology in an attempt to control it remotely and toward supporting people and communities to make sense of data for themselves—and to act based on what is normal or appropriate for them. This requires designers to not only make clearer choices about what is and is not a design for healthcare, or will be subject to health regulation, but to innovate well beyond these frameworks. This shift also brings with it implications for the kinds of sensing capacities necessary to maximize the overall value that biosensors bring. That is, the sensors are hardly enough. Better analytics tools, data exploration tools, and innovations in the technical and social pathways through which data circulates are all necessary.

## The Evidence Base

I make this argument by drawing on longstanding and recent scholarship in anthropology, sociology, science, and technology studies (STS) and media studies. There are three components of that research I am drawing from:

- Longstanding social theories shared by all the previously mentioned disciplines. Although they will be new to many readers of this book, they form the underlying conceptual framework of much qualitative social scientific research today. In particular, I have used the following:
  - Approaches to government and social control derived from Foucault (1977)
  - Approaches to responsabilization derived from Giddens (1990)
  - Poststructural approaches to how societies perceive what is natural (Strathern, 1992; Haraway, 1991)
- My own scholarship on how people make sense of sensor data. There are three studies that have informed the present argument:
  - Ongoing research in the Quantified Self movement (Nafus and Sherman, forthcoming), which is a group of 20,000+ lead users and makers of sensing technologies. They meet monthly in major metropolitan areas to discuss their biosensor data and other data relevant to their mental and physical well-being.
  - Past research on users of home energy monitoring systems (Nafus and Beckwith, forthcoming).
  - Past research in the United States, Bulgaria, and Portugal in which researchers showed large, complex datasets of computer use to the people who generated those datasets (Rattenbury, Nafus, and Anderson 2008).
- Recent publications from Intel’s Biosensing in Everyday Life Program (see Table 7-1 for details)

The Biosensors in Everyday Life research program is sponsored by Intel’s University Research Office. This program involves projects at four universities over three years, ending in December 2013. I serve as the program’s technical manager. Table 7-2 contains details of these projects and principle investigators (PIs). While not all the researchers on this program will agree with every component of my argument, they have deeply informed my thinking. In this chapter, I have deliberately limited my comments about their work to what they have made public at the time of writing and do not draw on private communication or reports to Intel, unless the researcher has given me explicit permission, in which case I have noted it explicitly. Where I do draw on the research coming from that program, I corroborate it with other work in the social sciences more broadly.

**Table 7-2.** *Research Projects within the Biosensors in Everyday Life Program*

<b>Institute: Researchers</b>	<b>Focus Area and Goal</b>	<b>Case Studies</b>	<b>Methods</b>
Lancaster University: Celia Roberts, Maggie Mort, Adrian Mackenzie, Mette Kragh-Furbo, Joanne Wilkinson	Focus: Risk perception Understand the practices of using health information, relation to risk and anxiety, notions of personal/institutional responsibility, and uses of social networking and health advocacy groups	Pregnancy and conception practices Direct-to-consumer genomics practices	Ethnographic field research Citizen panels
Goldsmiths College: Nina Wakeford, Sophie Day, and Celia Lury (now Warwick University)	Focus: The new numeracy Understand how everyday, informal practices of numeracy and calculation are emerging	Weight Watchers Biobanks Fine-art practices	Ethnographic field research Theoretical enquiry Speculative design
University of Washington: Gina Neff and Brittany Fiore-Silvfast)	Focus: Institutional systems of healthcare Understand how healthcare systems might (not) adapt to patient-generated biosensor data	U.S. primary-care clinics Heath practitioners Biosensing Technology firms	Ethnographic field research
State University of New York at Buffalo: Marc Böhlen, Joe Atkinson and students	Focus: Challenging the scope of biosensing applications Explore additional uses of biosensing that are excluded from current market framing	Sites of public water use (swimming and drinking) in the United States and Indonesia	Designing, building and evaluating working prototypes

All scholarship reflects the epistemic cultures in which the researcher is embedded, and this work is no exception. I have largely not chosen to engage with the human-computer interaction (HCI) literature on the topic because on the whole it has not addressed the underlying social dynamics I address here; Leahu, Schwenk, and Sengers (2008) and Böhlen et al. (2012) are important exceptions. I also have not extensively examined the relevant psychological literature because this lies beyond my expertise.

## Why Building Technologies for “Should” Rarely Helps

Chapter 9 situates consumer-based biosensing within the broader transformations of healthcare delivery systems and links consumer-based biosensing to healthcare in an institutional context. In a similar vein, Chapter 10 is optimistic about the current trajectory of biosensor design for wellness: “Technology is now having a positive effect on individuals by helping them to manage their physical wellness. This trend will continue to grow in the future as sensing and supporting technologies are seamlessly integrated into our daily lives.” Indeed, as I have witnessed in both public talks and private conversations throughout the industry, there is an overwhelmingly common narrative surrounding biosensors’ role on the consumer market that coheres with this claim. The narrative is that preventable diseases such as obesity, diabetes, and high blood pressure are now overwhelming healthcare systems, and biosensors designed for consumer use are a low-cost way of monitoring patients. They are seen as a way of ensuring patient involvement in disease management and a way to shift to an emphasis on prevention. Chapter 9 lays out this approach more fully, though it is useful to note that this particular framework is in widespread circulation and thoroughly pervades industry conferences and workshops on mobile health.

Usually, however, this narrative rarely includes specific reference to how people actually use the devices that are already on the market. It is one thing to elucidate the affordances of biosensors that could contribute to solving certain problems in healthcare delivery and another thing to look at actual practice. If we look at how biosensors are used in practice, there are more reasons to be cautious than if we based our judgments on affordances alone. First, a seamless integration of technology is not something that is desirable in all cases (Ratto, 2007). Second, it would be fair to say that there is no comprehensive, authoritative impact assessment that assesses whether the effects have truly been positive and for whom. Usually with any technical change, there are both winners and losers, and those have not been exhaustively identified. Indeed, the research program I manage is but one attempt at filling in the picture. More work would be needed to dig deeply into both the kinds of technologies that do or do not successfully help people manage their physical wellness and also into cases where even if there were a medical consensus on what constituted physical improvement, what the long-term social consequences would be. Sometimes physical improvement is not the same thing as happiness or well-being, particularly if it creates power imbalances between people in the process.

In fact, the limited quantitative and qualitative data that we do have to support or refute the claim that technology is helping people manage their physical wellness suggests healthy skepticism is warranted. For instance, Mort, Roberts, and Callen (2012) show how telehealth technologies are not being used in the way their designers intended. They show how elderly people who are being monitored by telehealth technologies are not enjoying the “independent living” promised by the makers of telehealth technologies. Instead, they often creatively misuse the technology in order to access the kind of care they do want—the kind provided by a human. They also sometimes “fail” to use the technology in order to avoid suffering the indignity of living under surveillance. In other domains, quantitative work has shown extensive nonuse of biosensors or apps working in the space that biosensors are slated to occupy. Mobile health and wellness applications have a 67 percent user drop-out rate in the first six months if the app relies on manual entry and a surprising 74 percent drop-out if data entry is automated (EIU, 2012). If, as is often claimed, biosensors are to be used to alleviate diseases of industrialized living that play out over the long term (diabetes, obesity, hypertension, and so on), then a six-month usage cycle is not likely to solve the problem the industry is claiming to solve. My own ethnographic evidence from the Quantified Self community suggests many of those who stick it out do so only with significant adaptation. Steps, for example, stop serving as an indicator of whether one has successfully exercised for the day and become contextual data for making sense of other phenomenon such as sleep quality or stress levels. Such a high drop-out rate should serve as an occasion to question what design approaches have in common that contribute to it.

There are many conceivable reasons for nonuse. One contributing factor is the prevalence of a “problem-solution” approach to design. In this approach, user needs are framed in terms of problems that can be solved by technologies. While this is the most common approach, it is not by any stretch of the imagination the only way to conduct user-centered design (Dourish, 2006; Dunne and Raby 2001; DiSalvo, 2009). However, more importantly for the present argument, there is an implicit assumption that both the problem and the solution can be tidily contained within the frame of the technology. The result of this problem-solution approach is that today’s biosensing technologies are largely designed to recommend some sort of action or to facilitate achieving a goal in a narrow way. For example, a user might be shown growing flowers on a display or given points in a game if he or she is engaging in more exercise. Such design strategies seem obvious enough and are intended to help by identifying a discrete problem and creating



opportunities for discrete solutions. In practice, however, they create an overdeveloped confidence with which designers predefine a problem and an under-recognition of the complexity of solutions necessary in practice. These may involve key components well outside of the user's control.

This approach can be seen in many biosensor systems, including ones that address lifestyle diseases and beyond. The overall effect is a large number of devices on the market that too often facilitate feelings of failure and discourage people from developing their own expertise about the phenomenon being sensed. To demonstrate how this overall effect is created, I will offer examples from weight monitoring and ovulation monitoring. In the context of ovulation monitoring, Wilkinson (2012) shows how ovulation monitors are sold as tools to aid “natural” conception by pointing out likely fertile days. Ovulation monitoring can happen through either body temperature monitoring,<sup>2</sup> testing saliva, salts on the body, or hormones in urine. In the case of body temperature, the device reads body temperature either as a continuously worn sensor or as temperature taken intermittently throughout the day. Before it even gets to the user, there has already been an “exchange” in the data economy of ovulation: temperature is changed into the device's inference of fertile days. That inference is represented as the word *fertile* or even a smiley face. That ovulation merits a smiley face makes clear that its intended use is when people are trying to conceive children, rather than avoid them. The data economy here is between device manufacturer and user, between user and partner (if partnered), between users in online forums discussing fertility, and occasionally between doctors and patients. Interestingly, it is often in online forums, not doctors' offices, where interpretations of the meaning of the word *fertile*, or the actions that ought to happen, based on that reading are made.

In the exchange between device and user, the focus on inferred fertility days gives the false impression that there is a “normal” body that cycles in normal ways. While this is true across a population, when brought to the individual, it has the added effect of framing the deviations from “normal” that must occur by definition as problematic or even as failures. All bodies are different. In fact, more people are “abnormal” than “normal” in one way or another, and basal temperature varies individually. There can be basal temperatures that are normal for one person but not normal for others. By designing devices around notions of a normal range, designers give users the false impression that somehow theirs is the odd one out. Over time, device users do develop a sense of what is normal for them, but as much despite the interpretive frames offered by technology as because of them.

Abnormal readings do stoke users' anxieties, but the problem is more than just raised anxiety levels in an already anxious situation. By extension, the impression is given that outcomes other than conception through sexual intercourse are not normal and are undesirable (Wilkinson, 2012). In the vast repertoire of reproductive technologies, including ovulation monitoring technology, “natural” cannot plausibly describe a state of being devoid of technological mediation or assistance. There is no such thing. Humans have been building tools for thousands of years, and there is no body that remains free of any technology whatsoever. Indeed, earlier technologies such as pasteurization and improved agricultural production have all shaped what is today considered “natural” and “normal” fertility rates. The marketing of ovulation monitoring as “more” natural hides the basic fact that measurement is itself a technical intervention. Therefore, we should not understand claims to “naturalness” as a straightforward, naïve claim but a claim that stokes and manipulates fears, desires, and anxieties about what is “natural.”

While the point may seem theoretical, the consequences are very real. There is a long history of scholarship that shows how claims to “naturalness” both in terms of beliefs about “natural” conception (Strathern, 1992) and, more broadly, about what is and is not natural about the body (Haraway, 1991) carry cultural and moral weight about what is supposed to be desirable. There are many, many people who do not fit the mold of what is considered desirable. The framing of these devices as enabling “natural” conception creates culturally loaded distinctions between people who reproduce through sex and the people who do not. There are many people who start out using an ovulation monitor and end up adopting, using in vitro fertilization, miscarrying, co-parenting, or remaining childless. That's too many people to brush off as abnormal or as people who failed to act in “natural” ways.

As with many sensor system designs, the line between information and action is not made clear in the design. Designers want their devices to be useful, not merely informational, and therefore have every incentive to encourage their users to take action based on that information. In this case, as is true in many biosensing cases, this puts unfair burdens on device users when the ultimate outcome is not limited to the action related to that information. Here the sensor designs have created the illusion that the body is somehow “fixable” with enough knowledge about

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<sup>2</sup>The effectiveness of these various methods of ovulation monitoring is contested.



its workings when in reality conception comes down to phenomenon in the body the user does not control. The user cannot control whether sperm meets egg or whether that egg is implanted in the uterus, or any number of compounding factors that make conception a complex biological process. Ultimately, no amount of temperature sensing will change the vagaries of the body. While intended to surface a probability of conception, that probability is, in practice, vague (Guyer, 2012); it is not cleanly connected to the desired result of conception. In these ways, not only do ovulation monitors contribute to false norms, but they also contribute to a sense that simply “trying harder” could change a situation that it cannot.

When device manufacturers create frames that have negative social consequences, they also leave opportunities on the table in doing so. People who take alternative paths in reproduction may in fact abandon the importance of “naturalness” and seek other frames to understand their circumstances. The device manufacturers, however, remain wedded to notions of naturalness, and that in turn constrains the data economy they could actually be in. For example, “natural” flattens and hides the myriad social practices people in fact have around ovulation (Wilkinson, pers. comm.). It makes ovulation one thing—fertile or not—where in fact there is more diversity to how people are experiencing the process as a whole. As time goes on, the cycles of what people do with that data change. There is also an extended social media apparatus that helps people make meaning out of the data, and people’s roles in that social media change over time, too, as they become more expert in the topic. Companies could extend their markets by paying closer attention to these nuances and evolutions in how their customers use their devices. If they abandoned “natural conception” as their value proposition, they could also develop partnerships with other actors with whom their users ultimately engage. This would enable them to provide information about the full range of options could be tabled earlier in the process. In essence, the data economy of ovulation monitoring could be more nuanced than it already is, both in terms of the stakeholders to whom the data is shuttled and how the data is framed and reframed through time.

The consequences of ovulation monitoring might at first blush appear extreme, but there is a much longer history of biosensor data working in similar ways. For the overweight, scales, manually entered food diaries, and pedometers have been measuring devices used to lead an intensified war on fat (Greenhalgh, 2012). Berlant (2007) calls this war on fat a “cruel optimism,” in which “raising awareness” about fatness<sup>3</sup> is a cultural activity that does little to solve the actual problem at hand and in fact gets in the way of people leading meaningful and productive lives. According to the EIU data previously mentioned (2012), technologies designed for weight management are not being used in the ways that they were intended. At least in terms of obesity management, they have not secured prevention or ensured patient involvement in that management (although in the case of mobile health apps, the users are rarely patients). Here the current data economy in which data is trafficked between health professionals, insurers, device manufacturers, and device users sets a frame that forces inappropriate conclusions. If we hold on to the premise that biosensors are a way to enable people to manage their health independently, stay out of the healthcare system, and yet continue to think about users as essentially patients, then we would be forced to conclude that the high drop-out rate is a function of a lack of compliance or self-control. In reality, much more is going on.

*Compliance* is a tricky term if biosensors are truly consumerizing. It is notable that in most spheres of life within Western societies, and particularly in the United States, people who are not “compliant” are the ones who are celebrated. It is notable, too, that the expanding waistlines of industrialized countries correspond with major shifts in geographical arrangements, car reliance, food manufacture and distribution, changes in work types, and distribution of paid and unpaid labor. And yet in our enthusiasm for technical solutions, these factors are acknowledged only as other parts of the puzzle out of the control of the technologist. Personal fitness monitoring is often acknowledged as a contribution, not a total solution, but it is problematic to downplay the significant matters of social structure that cannot be managed through technology. The issue is not a lack of “compliance.” The issue is that people are compliant with other, more powerful forces. Put differently, if Westerners did not suddenly and consciously decide to put on massive amounts of weight as a series of individual decisions, then the plausibility that we can individually consciously decide to lose that weight as a matter of individual self-control, enhanced by technology, is thin at best. As with ovulation monitoring, the “problem-solution” design approach is at the root of the problem. It insufficiently acknowledges the factors that are outside the control of the technology or the user. The limitations of personal monitoring to solve these large problems need to be acknowledged more robustly if we are to build truly useful technologies.

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<sup>3</sup>Fatness is the term Greenhalgh (2012) uses in order to avoid using the medical terms (*obese*, *overweight*) that she convincingly argues *inflict* shame. This chapter follows her usage.

If fitness monitoring technologies are able to contribute only one piece of the puzzle, then when the rest of the puzzle starts to exert its power, these other social forces start to change the effects that the technology has on the user's practices, habits, and beliefs. Behind those high drop-out rates are cycles of initial enthusiasm followed by disappointment. Ultimately, the sheer amount of headwinds one has to fight in order to stay fit leads most people to give up. Through the course of this process, the valence of the information communicated by devices changes. Two thousand steps in a day starts as progress toward a goal and ends as a way to tell people with great authority and precision exactly how much they failed to exercise. There is even evidence that the cultural connection of these devices with institutionalized healthcare and healthcare experts is itself a significant source of the problem. Greenhalgh (2012) has shown that the framing of fatness as a health problem (that is, speaking in terms of "obesity") exacerbates the human suffering involved. Historically, fatness was not popularly thought of as an issue of health, but now we say that people should lose weight because it is healthy and that others should lose weight because we are concerned for their health. Politeness now dictates we keep our aesthetic concerns to ourselves. Greenhalgh's study documents the fact that this change has not softened the blow but made it worse. The notion that fat is unhealthy in all cases—and changeable with diet and exercise for anyone willing—is a topic of an ongoing debate in scientific communities. Little is known conclusively about how bodies metabolize, so even if were the case that it is in fact biologically changeable, what one person's body responds to is likely to be very different than another person's. The consequences of fatness vary individually, too. What is true in the aggregate—a correlation between widening waistlines and various health problems—may or may not be the case close-up, for an individual person.

This debate, however, is rarely discussed outside of research communities. Only the aggregate is presented, and it is presented as if all the relevant mechanisms were not just known but as if each factor were known to be of equal importance for each individual. This rounding up to the aggregate makes some intuitive sense, but the consequences for end users are enormous given the significant cultural baggage that fatness carries. Greenhalgh (2012) demonstrates that the medicalization of fatness results in people overidentifying with being "the fat person" because it has become a matter of authority figures saying so, not just because of impolite comments from peers. She shows how the shame only deepens the more it is connected to a "health" issue and how the sense of being the "fat person" becomes all-encompassing. Greenhalgh shows how people internalize the sense of fatness and make it the dominant part of their individual identity, rather than reaching out to social movements or seeking political change that would address the underlying structural issues. Many then take drastic measures, such as extended periods of near starvation and excessive exercise, that can do serious physical and psychological damage.

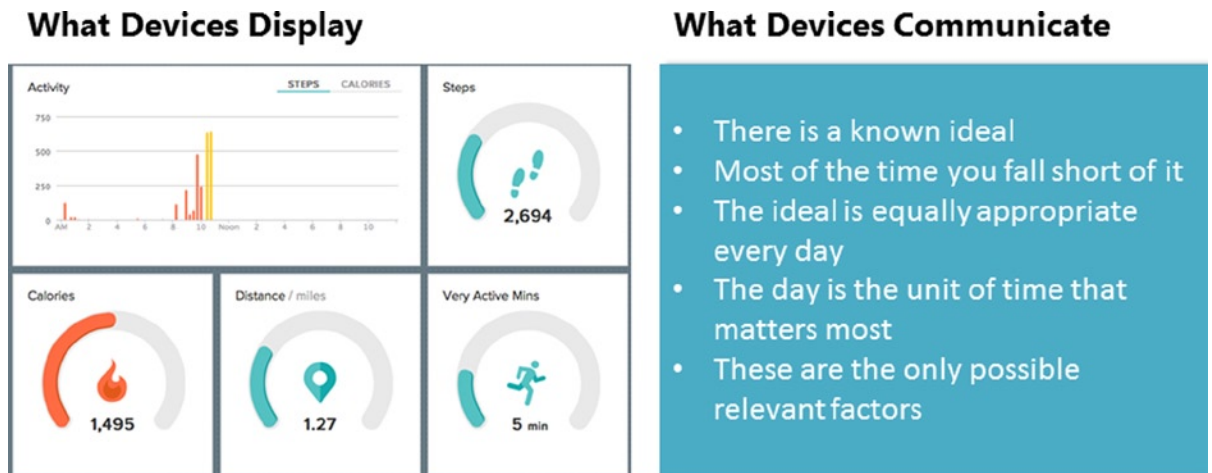
Indeed, this propensity to internalize negative feelings about the body, or to interpret negative information as a much more worrying indication of a deeper character flaw, is a propensity that expands beyond issues of body size. Much sociology has documented the ways that Western cultures have shifted to cultures of responsabilization (a voluminous literature that began with Giddens, 1990). In cultures of responsabilization, individual choice is seen to be both the only possible cause and the only possible solution to a problem, regardless of the broader social forces that may in fact be in play. In cultures of responsabilization, the preferred solutions to problems are framed as individual, but they are never really individually devised. They have been designed by experts and are implemented by individuals who are supposed to internalize the knowledge of experts (refer to Cheney-Lippold, 2010, for a discussion of how this social dynamic works in the context of big data). This means that the control supposedly offered to the individual as a newly active participant in their healthcare is often not in fact real empowerment. It is not an expansion of that person's agency but an expansion of the power of experts and institutions who defined and specified the problem to be solved. This cultural shift pervades the current biosensor market, but it is worth noting that it is also much larger than that market or even healthcare. For example, it was clearly at work in the 2008 Great Recession. The newly unemployed were perfectly aware of the larger economic forces happening and attributed other people's unemployment to be a function of those larger forces. Still, they attributed their own unemployment to their personal failings and not the wider social phenomenon. Predictably, books, blogs, and even new technologies claiming to help people make themselves more employable continued to flourish and prey upon self-doubts (Gregg, forthcoming).

The pervasiveness of the framework that claims biosensor technologies can solve a widespread social problem like lifestyle diseases through individual responsibility for management and monitoring (but without individual control over what to monitor) echoes the broader cultural shift toward responsabilization too strongly, and too consistently, to be mere coincidence. When our sense of personal responsibility goes so far that we can no longer see or address what else is at work, it becomes a hindrance rather than a help. While we must design for the cultural context we are in, when we can see its workings more clearly, we can choose to draw on other aspects of that culture that are more constructive.

Once we can see how cultures of responsabilization work, we can start to see that there is a world of difference between an athlete (or someone who is generally enthusiastic about technology using one of the myriad of devices that record bodily activity) and the fantasy that these devices will solve the obesity crisis. In the fantasy that obesity can be resolved with accelerometers and gamification, the technologies do find market demand, but it is demand that takes shape in the context of cycles of drastic measures and subsequent despair. That is not the same thing as meaningful support for making major changes to one's body. Instead, as with ovulation monitoring, technologies for fitness and weight loss are designed to create an awareness of something predefined as a possible problem, and that predefinition creates its own need for action regardless of whether the right problem has been identified.

There are examples of current fitness devices that show how, specifically, their design choices play into the wider culture of responsabilization I have been discussing. In Figure 7-1, which is an abstracted synthesis of how many accelerometer-based fitness devices work, note the reduction of data that takes place in the first three steps before it ever gets to the end user. Designers make decisions about what is and is not relevant data to their target user group. For example, some device manufacturers only show steps taken per day. But what if the user were attempting to cultivate the habit of taking walks in the morning? When those steps took place is relevant information. It could have been a high concentration of steps in the morning followed with a sedentary job or a day that had mild activity. For that purpose, some steps do count more than others. Even before the data is cleaned up and binned into “steps,” it is entirely possible that an end user could find the data as it comes from the accelerometer useful in ways that the designer cannot anticipate ahead of time. It is nearly impossible for end users to get access to data beyond “steps per day.” This suggests that designers of devices like these are doing more than just making choices about what to emphasize as a normal part of the design process. By not leaving the door open for other calculations and interpretations of that data to flourish, they have made a much stronger assumption that it is the designer who has the privilege of predefining both problem and solution. They leave very little room for their users to adapt these devices to their own situation.

Many fitness devices, including the JawboneUP, Fitbit, Fuel, and BodyMedia, emphasize daily targets. I have provided an example of one such device—BodyMedia—in Figure 7-2. The example is not intended to call out any one manufacturer but to illustrate a much broader approach shared by many systems designers.



**Figure 7-2.** What user interfaces (UIs) communicate

On the right side of Figure 7-2 there is a composite of how many people interpret numbers like this. There can in fact be many interpretations of these numbers, but these are the themes that commonly arise in the research. For example, it is possible in many systems for users to set their own goal number of steps or calorie deficit they want to create, but there are few systems that provide good resources to even figure out what these goals should be, given the wild variation from person to person in terms of physiology, enabling geography, and constraints in terms of

family and work commitments. The design choices made about what and how to measure already imply there is an ideal even before anyone has the faintest idea of what that ideal is. This can be motivating for a little while, but when the realities of life start to kick in, they stop becoming motivating and start becoming demoralizing. It becomes a reminder of just how much the user falls short. There is also a tremendous emphasis on the day in current designs, whereas people with heavy travel schedules will need to manage their exercise and calorie consumption across the course of a week or month. The emphasis on the day is almost entirely unworkable for many people, but it is what is cleanly imaginable from afar—the epitome of the ordered person (see also Gregg, forthcoming). When we see things close-up and in context, people make all sorts of temporal trade-offs, compositions, and rearrangements that are highly complex (Darrah et al., 2007).

What is most concerning about these designs is the way they act as a frame that implicitly makes claims about what is and is not relevant to fitness. There is a narrow repertoire of measures that have been deemed relevant. Most devices do not ask their users to take measures of the amount of time spent in sloth-inducing artificial lighting, assessments of microbiome, exposure to poor air quality, weather conditions, or responses to certain foods but not other foods. Some of these are technologically far more difficult, and indeed politically and scientifically controversial, but regardless of what we can or cannot scientifically say actually contributes to fatness, it would be hard to disagree with the proposition that fatness is likely to be more complicated than calories and exercise. As Chapter 10 observes, calorie expenditure is technologically difficult to sense and can deliver a false sense of accuracy. Calories consumed, on the other hand, is notoriously difficult to track according to the Quantified Self participants I have been studying. It is complex because portions are tedious to estimate, and specific nutritional contents are difficult to specify without significant labor. That labor is somewhat reduced if one is prepared to eat manufactured foods, but many find eating manufactured foods problematic from a dietary, environmental, and economic perspective. And yet, calories and activity levels are the main focus of devices currently on the market. By emphasizing the day, narrowing the choice of relevant information, and creating an impression of ideal states, these technologies fit squarely in the wider culture of responsibilization where controlling the behaviors of others is done remotely so as to appear as if it were an individual solution.

## The Consequences of Designing for “Should”

What do these examples have in common? They tell us that the first generation of biosensors took at face value the medical model of what sensing and measurement are for. This first generation too easily took for granted that the underlying science is well established in all cases and that it scales easily down to the individual level, such that whatever is good on the whole must be good for the individual person. They retained legacies from their origins in medical systems that privileged experts’ control over patients’ behavior, and experts’ control over what to measure, even though users are no longer patients. We can see it readily in the data economies currently in play: medical knowledge, device manufacturers, and end users are in a tight loop. The communication primarily happens between device manufacturer and user, possibly including a clinician or insurance company, depending on the business model. Medical knowledge frames what data ought to be collected, either directly to the extent medical practitioners design devices or indirectly in the sense that medical framings shape which problems are seen as appropriate problems to address. That data is sent to end users who are left with narrow ways of interpreting that data, but with the impression that the problem is theirs alone to solve and solvable only within the bounds given by the device. To the extent there are “social” components, such as the ability to share data with others either to compete against them or to motivate one another, these components primarily do not open new ways the data could be interpreted for end users. Possibilities do open for data brokers and advertisers, of course, but does not substantively change the user experience.

The consequence has been that sensor measurements appear more authoritative than they are, and technology designers have become empowered as a kind of extension of medical authority at discerning what is and is not beneficial. This comes at the expense of people actually learning about their own bodies. The problem with “should” is that it creates more guilt, shame, and dependence on experts than it does actual support. Current devices afford little opportunity for people to investigate for themselves what the significance of the measurement could be for them and afford limited opportunity for people to participate in the creation of new knowledge, scientific or otherwise. This is of major societal significance: the apparently authoritative answer to a problem either may be bogus to begin with or may become obsolete as new knowledge emerges. In a limited data economy, data-sharing practices are limited to motivational concerns, and users are not given the opportunity to learn from one another. If we all already know

what a “good number” is—more activity, low glucose, low weight—then there is little to be gained by sharing, beyond asking for encouragement or outright bragging. The data falls flat, quickly becoming uninteresting.

There are cases where sensors telling people what they should and should not do is absolutely appropriate. In fact, Böhlen et al. (2012) note an important tension between voluntary and involuntary biosensing and essential and nonessential biosensing practices. Similarly, athletes are not deeply shamed by negative feedback, and running or cycling coach technologies help people adjust their movements in ways that do not feed a broader cultural dynamic of shame and blame. While the social costs described earlier should be reason enough to change design strategies, there is a very real business cost for device manufacturers and service providers. The high churn in the user base might be an opportunity for more disruptive hardware innovators, but it should concern service providers who have costs associated with acquiring customers.

## Why Designing for “Could” Matters

There are clear areas where what a person “should” do cannot be defined *a priori*. Allergies are an example. Many people have allergies, and responses to allergens are deeply individual. Different people’s bodies respond differently not just to different allergens but to different combinations of allergens and circumstances. In my own research, one woman told me about how she thought that she was allergic to “Chinese food.” She had no idea which actual substance in Chinese food she was allergic to, but the precise chemical cause mattered less than the ability to avoid it being ingested. In her case, she had a strong weekly pattern of going to the gym on Fridays and eating Chinese food afterward. On the rare days when she did not go to the gym but did have the Chinese food, there was no reaction. Because she had a distinct, human-discernible pattern, the underlying issue became clear: her allergy had something to do with the combination of the gym and the food.

In cases like these, people do not need a system with predetermined goals for them to meet. They need a way of developing their own hypotheses about what could be going on. Most are not lucky enough to have such a distinct pattern that we would notice a combination like the gym and Chinese food. Machines, however, are remarkably good at picking up on patterns. If the daily pattern were not as distinct, machines could help spot the potential pattern amid the noise. A system does not necessarily have to provide a conclusive answer. It can suggest possible pathways—practices that are changeable or exposures that are avoidable. The researchers in the Biosensors in Everyday Life program found a range of human experiences along these lines: sleep, headaches, fatigue, mood, and asthma all share the characteristics of being rooted in patterns of everyday life that are complex enough to make human detection of the pattern hard. Health systems are largely not helpful in these circumstances, and the resolution is largely nonmedical. These problems also do not carry the cultural baggage and feelings of shame associated with traditional biosensor interaction design strategies. For one person, headaches may be related to air quality. Another might try sensing air quality, having heard of the first person’s experience; if it seems not to correlate, they may try sensing sleep or caffeine intake. Moving from one sensor to the next is a known practice. People involved in the Quantified Self movement rarely stick with one sensing practice. They move on to the next when they develop new areas they want to explore, sometimes for fun and sometimes for practical need. For example, one man I interviewed had been tracking his sleep using a Zeo and found that the data became boring and not useful after a few weeks. During that period, he also began tracking his mood. He found the Zeo data to be excellent contextual data to help him discern whether his mood indicated the beginnings of a mental health issue he had experienced in the past—or if he just needed a good night’s sleep. This suggests a much more productive role for churn in the marketplace. Instead of abandoning a sensor out of a sense of failure, long-term self-trackers evolve their understanding of how their particular bodies work by composing together different sensor technologies as necessary, effectively doing their own ad hoc sensor fusions.

Today, doing these evolving sensor fusions is tedious and laborious, but it need not be. Figure 7-3 shows how a data economy for biosensor data might work if the emphasis were more on exploration and sensemaking. While this is still hypothetical, mapping it in this way shows important differences from Figure 7-1. In this scenario, the end user begins suspecting that air quality or something in her diet might be triggering her allergies. She begins tracking these two but does not find a relationship to her allergies. Although the initial hypothesis that air quality might be related to an allergic response was proved wrong in this case, it inspires greater use of location tracking that then makes it possible for her to decide to adjust her jogging route to avoid other possible effects. In this hypothetical scenario, the location tracking becomes a basis on which to test her new suspicion that travel might have something to do with it.



This new hypothesis came because her data is better connected to a community forum that helps her make sense of it. Because she is continuing her practice of photographing what she eats, she can now see her diet in relation to location and can work out that her allergy is related to alcohol consumption, which she tends to do more of on trips.



**Figure 7-3.** Example of a possible data economy for exploring allergies

In this scenario, the end user benefits twice—she finds a better jogging route and works out the cause of her allergy problem. The ability for machines to find patterns and synthesize them supports end users in making their own decisions and developing their own hypothesis. It stops short of presuming to know what the answer is; instead, the problem the user is trying to resolve shifts over time, and her use of biosensors and other data shifts with that evolution. Within this scenario, different designers might make different decisions about how much automation is useful. Some end users will want to see more of the granular data, while other end users might want a system to alert them to what other people have also tried to collect. No air quality monitoring system manufacturer will be able to anticipate all the uses to which that data could be put, but the ability to compose data in ways designers cannot anticipate makes it possible for end users as well as companies to benefit from data exhaust—the flow does not go one way. With improved data security technologies that would allow people better control over their data exhaust, it is possible that the balance could be evened up even more. Another difference is that the institutional beneficiaries of the data are more heterogeneous, which opens up the possibility for additional solutions should it prove impossible to simply avoid poor air quality by changing one’s route through the city. It is entirely possible, of course, that the various actors involved in this scenario may have poor relations or conflicting incentives and might not want to see data exchanged in this way. But by emphasizing exploration, we open up the possibility to create alignment or otherwise manage conflicting incentives and decrease the probability of the data simply falling into disuse.

Once we shift from thinking of technologies as machines that tell us what we should do to machines that tell us what could be going on, the role of pleasure and fun changes. In the mobile health space, there are many attempts at “gamification,” also noted in the foreword and Chapters 10 and 11 of this book. In gamification, developers use Skinneresque reward systems to entice people into doing what has been pre-ordained to be good for them. Some

designers are having success with these techniques, but people are more than Pavlov's drooling dogs hoping for the next treat. Already in this space we see plenty of examples of people adapting the sensors currently on the market for fun and creative endeavors. Indeed, I interviewed a man who wore a continuous heart monitor out of sheer curiosity and happened to get into a car accident while wearing it. The data stream from that moment holds a particularly poignant memory for him. The monitor is hardly there for diagnostic or disease management reasons, and "pleasure" would not be the best word to describe his relationship to that data, but it nevertheless has personal significance for him. He sees it as an occasion to remember what it is he is thankful for and shares that with his family.

Similarly, genomics used to be only about establishing risks for disease. People often deem this information useless, inasmuch as there is often no action to take other than eating healthy and engaging in exercise, which we are all told we must do in any case (Bietz, 2013). That same "useless" data has another life as people turn to DNA to examine their heritage. There is nothing utilitarian about looking at one's heritage genetically, but some find it interesting to do nevertheless. In some domains, these more entertainment-oriented practices can once again get caught up in the cycle of shame and guilt. Ultrasound is a well-researched example (Roberts, 2013). Turning an ultrasound of a fetus into a three-dimensional picture might at first appear entertaining or endearing, and in fact it is so commonplace that it is possible to purchase such an image in shopping malls. The cultural politics of doing so are at best thorny. There are many people who would use those images to fuel the culture wars around abortion, or, in parts of the world experiencing high rates of female infanticide, they could be used to select the sex of the fetus either before or after birth. In this way, what at first appears to be a game becomes far too serious.

We know from the anthropology of numeracy (Lave, 1988; Verran, 2001; Guyer, 2004) that people are much better adapted to dealing with complex numbering systems than the technology industry usually gives them credit for. Gerlitz and Lury (2012), for example, have showed how people's enjoyment in measurements of their social media impact is rooted in its complexity, not simplicity. For people who pay attention to their social media presence, the game is one of ongoing recalibration. Metrics companies that do this well, given both highly impactful people and people who do more listening than talking, have a continued role to play. The role is one not rooted in their "failure" to be as influential as those more famous. Indeed, in a study on computers and time use (Rattenbury, Nafus, and Anderson, 2008) computer users in three countries were shown vastly complex multivariate datasets that showed their second-by-second computer usage—applications, keystroke frequency, location of computer, and so on—and had no trouble whatsoever parsing the information and telling stories about what else was happening in that time period and why the computer use data was the way it was. In the world of "should," the ethos is about making the sensor readings as simple as possible in order to get a specific message across. This fails to take advantage of the extraordinary levels of numerical complexity humans of all education levels and backgrounds are capable of.

Sometimes people do want sensors to "tell the truth" as straightforward empirical knowledge, and other times what is "real" is neither here nor there. Some other form of human creativity takes over. Leahu, Shwenk, and Sengers (2008), for example, see possibilities for how people might relate to machine-inferred states not in terms of whether the machine inferred correctly or incorrectly the emotional state of the user but in terms of a playful unfolding of the relationship between machine and person. Indeed, it is notable that the measurement of "fuel" used by the Nike FuelBand is entirely made up. There is no real meaning of "fuel." It has something to do with the accelerometer, of course, but the accelerometer is not measuring "fuel" per se because there is no such thing. This tells us that we need not constrain biosensor measurements to what is *a priori* understood. No one cared about "fuel" before Nike brought it into existence. Fuel users start to care in varying degrees, depending on how they are using the FuelBand. Sometimes they game it and shake it in full knowledge that they are increasing the number without any actual exercise, and sometimes the inadvertent gyrations from sitting in a vehicle on a bumpy ride can create disappointment in having accidentally stumbled into more points. In this way, there is more "could" in sensor numbers than we anticipated. Not only does this open up new physical paths to walk down, but it can enable new kinds of pleasurable fictions about how we can quantify our world.

The Quantified Self movement has been the most visible in terms of supporting practices and discourses around "could." In Quantified Self meetings, people share with one another the hypotheses they have about what is happening to their bodies, why they track what they track, and what they learn. They also suggest to each other what else could be going on, learn appropriate phenomenon to track, and come to understand the technologies available to track it. There is a social basis on which "could" could become much bigger than Quantified Self. Marc Böhlen and team (2012) are showing what "could" could look like from a design point of view (refer to [www.sirebi.org](http://www.sirebi.org) for an extensive portfolio of concepts and literature). For example, one of these concepts suggests taking environmental data



and wearable sensors of bodily response to that environment and suggesting different places to take a stroll (refer also to Chapter 11). These are recommendations to be sure, but it serves up new choices rather than scolds the user. It facilitates the enjoyment of new spaces and enables the serendipitous exploration of finding oneself in a new part of the city. With biosensors on a hike, combined with topological maps and the knowledge of how much water the person is carrying, a system could help a person assess which hikes are realistic for them. All of these things expand people's horizons in new and compelling ways.

## Requirements for a Data Economy of “Could”

When we start from a place of enabling exploration and pleasure rather than self-management and compliance, we help people create and capture value from their interactions with data. The usages of biosensors in the world of “could” require a better way for people to combine different kinds of data and use each other's data to collaborate, corroborate, and identify new pathways.

For data to be more useful to end users, there needs to be more heterogeneity in the actors who participate in the data economy of biosensors. The allergies example makes clear the need to combine different kinds of data and enable people to fold in new data sources as they explore. This in particular requires the ability to make connections between environmental sensing and bodily sensing. Consumer-level environmental sensors are only just getting off the ground, which makes folding into the environmental picture a hard if necessary job. Those data may at first not appear relevant to health or be provided by traditional healthcare stakeholders. Similarly, the beneficiaries of data aggregation also need to expand. That is, instead of sharing one's individual data with chosen friends, end users do in fact have interest in the aggregated data too. Indeed, the Asthmapolis project (now a commercial company called Propeller Health) creates a mapping system where a location-tracking asthma inhaler records the location of asthma attacks and enables people to make sense of potential irritants through the lens of geography. This suggests that sharing data when trying to discern the sources of one's asthma triggers becomes a valuable exercise in collaboration and mutual benefit.

Currently, wearable technologies are designed to make building a picture with multiple sensors difficult; making a Fitbit talk to a sleep sensor like the Zeo is at best heavy lifting, let alone making it talk to an Air Quality Egg. Exporting data into common formats is difficult for users without coding skills, and widespread awareness of what can and cannot be obtained from device providers is lacking. Even active participants in the Quantified Self movement sometimes do not know, for example, that it is impossible to export raw data from the FuelBand, unless they are developers with a business relationship to Nike. No single biosensor manufacturer can predict every possible use case, but we currently have a system of nominally open APIs whose characteristics in terms of the amount of data that can be obtained, and by whom, is at best patchy. At the time of writing, however, many start-up companies and projects, such as Singly, Quantify.io, and Human API, are filling this important gap in the market (refer to Franzen, 2013). In the medical devices space, the Continua Alliance has made significant progress in increasing medical device interoperability, but not every biosensor device is medical, and not every data stream relevant to what users want to understand comes directly from a biosensor (for example, lead users often use location data to understand their dietary habits). In the consumer space, the supply of data can be less stable than one would like as companies decide to turn on or off data services.

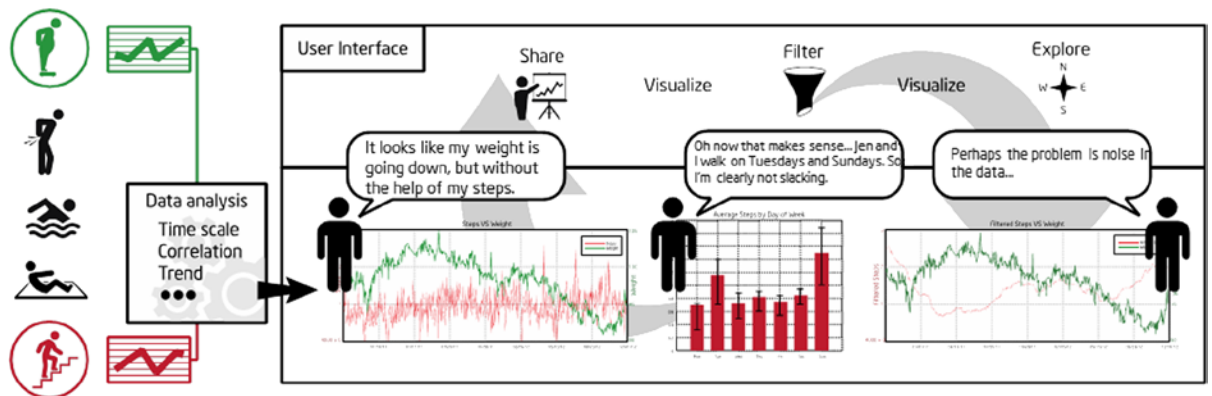
While there are trade-offs in terms of data sampling rates and aggregation in any technical system, it is also clear that better data granularity opens up new uses than any single designer can design for. Some subset of end users will find value in this data, provided they have access to it and provided they have robust ways of controlling where it goes and who else has access to that data. Data use controls (DUCs) (Maniatis et al., 2011) are likely to be an important technology that allows users to travel these waters more securely. DUCs wrap data in user-controlled permissions, such that even if a Facebook user uploads a photograph onto Facebook, they can control who sees its contents—including whether Facebook itself can conduct facial recognition in it. This makes it possible to benefit from data aggregation in a secure way, without giving up one's raw data.

We will also need forms of analytics and machine learning that place a greater emphasis on helping people develop hypotheses and take advantage of what they know about their own context, while also taking advantage of a machine's ability to recognize the patterns difficult for humans to detect. It might be that no single sensor or product will be able to help my research participant discern whether it is the gym or the Chinese food causing her

allergic reaction. However, the ability to easily compose data sources in a human-interpretable way so that she can develop the hypothesis that it might be a combination of the two is an important capability. Early indications from the Quantified Self research suggest that simply categorizing data according to simple temporal cycles (i.e., good sleep quality tends to happen on Thursdays) and being able to visualize data in ways that make cumulative effects more visible (i.e., a stacked graph showing sleep quality and weight might not surface the relationship if it takes two weeks of poor sleep to have an effect on weight) are two simple ways to take advantage of machines' pattern recognition advantages over human perception. These are often processing steps taken on the way toward building more sophisticated machine learning capabilities. But if the goal is to have humans do the sensemaking rather than the machines make the inference, knowing when to stop predicting is often just as important as knowing what to predict.

Thinking differently about analytics tools and data processing will go a significant way toward supporting more widespread data literacy. Data literacy is not simply the ability to perform mathematics. Data literacy is the ability to answer questions with data and critically interpret those answers. This may or may not involve mathematical skills. Not everybody wants to have, or can have, the statistical skills that would be required to use data to answer the questions they have, given the tools available to us. People with high levels of mathematical skill can also be data illiterate and either ask the wrong questions or fail to critically interpret the answers they receive from data. Indeed, a public scandal erupted in 2012 that involved Target, a large U.S. retailer sending advertisements to a pregnant person based on inferences from her shopping patterns when that person had not told other members of her household about her pregnancy. In this instance, sophisticated mathematical skills were required to put her in the “pregnant person” box, however, and poor data literacy skills were also at work in the failure to critically interpret the meaning of that box.

There is currently a large gap between the limited functionality that device manufacturers currently provide for the sake of ease of use and generic statistical packages such as R or Matlab, which require full statistical fluency. Most people are perfectly capable of asking quantitative questions in lay ways or asking about recurring patterns, but today's tools do not occupy an appropriate middle ground that would enable them to do so. At the time of writing, Intel Labs is building a tool to support data literacy in order to test some of the ideas developed in the course of the research within the Quantified Self community. Figure 7-4 shows how this tool works to support people trying to make sense of their data. This is but one tool that can fill a large gap in only a small way.



**Figure 7-4.** Schematic diagram of Intel Labs data processing tool for the Quantified Self community. (Image courtesy of Pete Denman)

Improved APIs needs to be supplemented by other ways of bringing data together for nontechnical people. This is crucial to creating a vibrant economy of biosensor data. A vibrant data economy is one that enables people to calibrate and contextualize their data, as well as build new hypotheses together rather than just individually. Without sharing data, people have few ways of discerning whether it is their body that works differently or if, as so many of our research participants are inclined to believe, they “just aren’t doing it right.” Again, we can do this incrementally.

Even comparing two people's Fitbit data streams would enable them to understand whether the devices are working. There are some cases in the research in which people confidently use sensors to buck the norm of what they are told they should do. One person told us, "I don't get migraines like most diabetics. Most diabetics get migraines when their glucose is really high; I get the opposite." Although people who can do this on their own are still the exception rather than the rule, with better ways of sharing data, more people will be able to come to similar conclusions with confidence. They will know what to try, and why.

This means, however, that "sharing" in a data economy of "could" requires some retooling. Appropriate sharing here is one that preserves the context that each person is grappling with. For example, it is not useful to see an aggregate statistic on the prevalence of migraines or whether an individual's migraines are more severe than on average. What is useful to see, and what must be done in a privacy-preserving manner, is more about the context of another person's experience so that the user can assess whether it is an appropriate comparison and to learn from that person's experience. A user will want to know, did that person also have sleep disturbances? Did that person have the same dietary issues that I do? To the extent that there are clusters of similar people, that is helpful and even comforting to know, but on the whole what matters is what people are capable of imagining, not the abstractions that can be derived. There can be overlap, but they are not the same thing. This must be done in a way that reveals the main components of that person's data such that another person can make sense of it but does not share the raw data or other identifying data.

Finally, in cases where something like a recommendation is in order, we need these recommendations to be designed in ways that lay out surprising and pleasurable options beyond gamified points. Such combinations and associations between data must be incremental from a user's point of view. They must enable people to move along a path of A to B to C in their own way. Sensor systems can show them roads they may not choose to take, but what developers should not do is wait for data to pile up into a single, central system with all the conclusive answers. It needs to deliver immediate, personal value. Even enabling simple comparisons across two data streams would do that, yet that is surprisingly difficult from an end user's point of view.

## Summary

This chapter has shown how the industry's current thinking about the uses of biosensors has been shaped by their legacy as objects for institutional use. Their movement into the consumer space has been accompanied by design choices that make biosensors extensions of institutional or expert control over people. This choice has constrained adoption and has negative societal effects. However, the ethnographic record shows plenty of examples where end users are perfectly capable of making meaning from biosensor data and benefit from an expanded ability to pick and choose what to keep track of and how. This modality involves a more exploratory ethos—a sense of what "could" be at stake rather than what one "should" do. It also creates more value for data within the ecosystem.

This does not suggest that any particular sensor is more crucial than the other but that people will want to create an ensemble of them so that each sheds light on the other as new hypotheses emerge. It does suggest the need for improving, and making available for alternative uses, higher levels of data granularity. There are also additional requirements beyond sensor design itself that are likely to support a thriving biosensor ecosystem organized in this way. They are more stable, expanded APIs, end-user facing security technologies that enable people to manage their data exhaust more meaningfully, applications of machine-learning capabilities that refrain from putting people into machine-inferred boxes, interfaces that support greater data literacy, and design strategies that support experiences of pleasure beyond Pavlovian responses to gamification.

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