

What we talk about when we talk data: Valences and the social performance of multiple metrics in digital health

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Data as a discursive concept in and around data-intensive health and wellness communities evokes multiple social values and social lives for data. Drawing on two years of qualitative, ethnographic observations, participation, and interviews in these communities, our work explores the gap between discourses of data, the practices with and around data, and the contexts in which data “live.” Across the communities of technology designers, “e-health” providers and advocates, and users of health and wellness data, we find that tensions emerge not around the meaning or legitimacy of particular data points, but rather around how data is expected to perform socially, organizationally and institutionally, what we term data valences. Our paper identifies data valences in health and wellness data, shows how these valences are mediated, and demonstrates that distinct data valences are more apparent in the interstitial interactions occurring in the spaces between institutions or among powerful stakeholder groups.

INTRODUCTION

Data as a discursive concept in and around data-intensive health and wellness communities evokes multiple social values and social lives for data. Drawing on two years of qualitative, ethnographic observations, participation, and interviews in these communities this paper examines the gap between *discourses* of data, the *practices* with and around data, and the *contexts* in which data “live.” Our ethnography has found these gaps are particularly stark across the communities of technology designers, “e-health” providers and advocates, and so-called users of health and wellness data.

In discourses of health care technology designers and advocates, data comes to represent a notion of actionability, the potential of data to be used for social and material performances. In these discourses, possessing data serves as a catalyst for behavioural change: In the words of one advocate, “data leads to knowledge and knowledge leads to change.” This data-behaviour model forms the logic of technology development in health and wellness applications. For technologists, this framework means they try to solve the seemingly inextricable problems of healthcare within the United States with what they see as well-designed, personalized, and beautifully visualized interfaces for this data. However, these data-behaviour models do not account for the conversations with, about, and through data that occur in online and face-to-face communities of health and wellness data practice. The models frame data as a stable material object, rather than as discursively enacted in multiple emergent ways that resist such stability.

DATA AS DISCOURSE AND MEDIATION

We map the symbolic and material performances of data through a lens of mediation, defined as the “*on-going, articulated, and mutually determining relationship*” among artefacts, practices and social arrangements of communication technology infrastructure and the processes of reconfiguration, remediation, and reformation (Lievrouw, Forthcoming). Mediation allows us to think about data as emerging from communication media, and therefore always contextually shaped and embedded into practices and materiality. Data as mediated draws on the contested or socially constructed nature of data, highlighting the performative agencies of metrics along with measurement technologies (e.g., Berg & Bowker, 1997; Gitelman & Jackson, 2013; Mol & Law, 2004; Schubert, 2012), and the emergence of data through communication processes, in which methods of quantification can be seen as “strategies of communication” (Porter, 1995) and the multifaceted complexity of technology is “communication made durable” (Gillespie, Boczkowski, and Foot, Forthcoming). The infrastructure of data intensive communication in this process is not simply “a web of objects” that supports particular meanings (Star and Ruhleder 1996), but also the *mediation work* that makes such data possible.

Data multiplicities

The concept of boundary object has been helpful in explaining the coordination of work and interests across multiple communities (Star and Griesemer 1989). The boundary object approach, although fruitful for many studies of technology, fails to capture the complexity of the interactions around data across sites of digital health and wellness. First, as Nicolini et al. (2012) argue, the boundary object approach foregrounds the objects that translate across boundaries, but tends to bracket the wider context in which the translational work is carried out and the forces that motivate collaboration (p. 625). These contexts inform how people can use data and what expectations they may have of that data. Second, boundary objects, in the literature, rely on their interpretive flexibility across the boundaries of multiple groups. This means that boundary objects can be read in different ways by different people. But it may be that the interpretation, validity or social construction of data is not in question (although these are all valid exercises routinely done in science and technology studies (STS)). Rather, people may expect data to do multiple things in part because data are mediated through communicative infrastructures, requiring translation work that is not simply about meaning or interpretation but also about function and performance in different settings.

Defining data valences

Across stakeholders and contexts of digital health and wellness, these differences are not explained through different perspectives on the meaning of data points, rather they reflect the multi-dimensional expectations for and values around data operating within different data ecologies, what we term *data valences*. *Valence* has the same Latin root as value, *valere*, which means to be strong or to be worth. As a word adopted by multiple fields,

it is used to refer to the combining power of an element (chemistry) or the relative capacity to unite, react, or interact (immunology) or the degree of attractiveness an individual, activity, or thing possesses as a behavioural goal (psychology). These definitions have very specific meanings within their respective disciplines, yet they all reference a particular expectation for or relative value associated emerging within and mediating something's performance in a larger ecology or system. Thus, we define data valence as an expectation or social value that mediates the social performance of data, or what data can do and will do within a particular social system.

As a concept, data valence allows us to examine how data are rhetorically evoked, and how the conversations, discourses, practices and contexts of data diverge and multiply. Data valences are neither neutral nor stable, and are instead polyvalent across multiple contexts, stakeholders and interactions. When multiple, potentially contentious data valences emerge in interaction, the differences among them help us to understand the tensions among stakeholders and institutions. Particular data valences are not necessarily consistently evoked by an individual, rather in different interactions, conversations, and contexts. Further, how people talk about data may not be consistent with what they do with data, which still might be different from what the data themselves do. Our view places the communicative mediation work around data at the center of inquiry. Taken together, we suggest, data valences can map a multi-dimensional view of the social and material life of data.

APPLYING DATA VALENCES IN HEALTH & WELLNESS COMMUNITIES OF PRACTICE

We interviewed 43 clinicians, technology designers, and users to ascertain various stakeholder positions emerging around data technologies in health and wellness.¹ These interviews allowed us to map different values for data evoked in different discourses of and contexts for data. Our fieldwork included participation and observation within multiple sites of the emerging health and wellness data ecology, both within formal healthcare institutions and within consumer health and wellness communities. In addition to interviewing nurses and physicians working within formal healthcare institutions about their perspectives on and practices around patient-generated data, we observed a Medicare demonstration of a tele-health project in rural Washington State that was using information gathered in the home in an attempt to improve clinical outcomes of chronically ill patients. In the realm of consumer health and wellness, we participated for two years in the communities of practice around health and wellness technology design (e.g. business accelerator programs, meetups of start-up companies); “e-health” clinical providers, innovators and advocates (e.g. conferences such as Health 2.0, TedMed, and Medicine X); and so-called “users” of health and wellness data including a Quantified Self (QS) national conference and many local meetings in several cities. As Nafus (Forthcoming) notes of QS, the boundaries of these communities are fuzzy

¹ We use the term “health and wellness” to capture the line in the United States between regulated health care technologies used in the home (e.g., glucometers and blood pressure cuffs) and unregulated consumer wellness devices such as the Fitbit and Nike FuelBand, among other devices.

and members often overlap. Still, these communities lent us a conceptual frame for tracking how the contexts, discourses, and practices of data varied across them and bounded who and what we observed in this data-intensive field.

DEFINING DATA VALENCES AMONG USERS, CLINICIANS & TECHNOLOGY DESIGNERS

Within formal health institutions, the goal of the interpretation of data by clinicians is to manage symptoms, to diagnose, to decide intervention or therapy or to encourage patient compliance. Health care providers work within proscribed contexts for data and with a set of values around patient data shaped by legal, ethical, and medical concerns. Currently, though, innovation in data technologies is talked about in terms of “disruption” of healthcare—that is, of the power of data to transform existing institutional arrangements in healthcare. Such rhetoric exposes an acute gap between the challenges for data across the formal, organized, and regulated approaches to health data and those approaches that privilege the potentially unregulated consumer health and wellness space. In the former, design considers patients; in the latter, consumers.

Among advocates for data-intensive innovation, data become the starting point for conversations concerning interventions, recommendations, and taking action. This discourse presents data as if they are expected to drive health, wellness, and behaviour change, collapsing these functions of mediation into a single, linear process. At the heart of attempts at data-driven health and wellness is a seductive, but perhaps flawed, model of the relationship of data to knowledge, sense-making and action. This model collapses multiple identities into a patient/consumer/user placed at the center of care integration and data management, responsible for negotiating the implications for data.

The QS movement provides another way of talking data. Quickly apparent at QS Meetups is the ubiquity of personal stories loosely wrapped around self-tracking data. This community of users literally uses talk about data to connect to one another and sense make around their experience through a set of narratives. Three questions structure QS show and tell presentations:

1. What did you do?
2. How did you do it?
3. What did you learn?

In essence, the first question structures how to communicate about what was tracked and measured; the second is the methodology, the tools, calibrations, and representations involved; and the third is the value of the information gathered for the presenter, or the knowledge or insights produced intentionally or accidentally. Providing a dramatic narrative of beginning, middle, and end, this structure casts self-tracking and the data generated as central actors. This data-intensive strategy for communication reveals a huge diversity of perspectives, and provided one key lens onto different data valences.

Data valences in institutional interstices

Distinct data valences are more apparent in what we think of as interstitial interactions that occur in the spaces between institutions or sites of power or among powerful stakeholder groups. While data valences are less open to contestation or negotiation within the central spaces of any one institution, they become more apparent as the arrangements around that data change and people interact across them. The norms and regulations of clinical practice support certain data performances more than others. Yet in the interactions at the interstices between clinic and home, there is more flexibility and permeability among data valences. For instance, mobile health applications tracking diet and fitness are situated at the interstices and blur categories of health and wellness, data and device, patient and consumer. Without clear institutional norms and regulations around this health and wellness data, multiple, overlapping, and many times contested data valences emerge as different expectations for how this data will perform clinically versus how it will perform for consumers outside the clinic must be negotiated.

FINDINGS: DATA VALENCES IN CONTEXT, DISCOURSE, AND PRACTICE

Below, we identify six data valences that emerged from our research and map their emergent symbolic and material performances across the discourses, practices, and contexts of health and wellness communities of practice. These valences are:

1. Self-evidence;
2. Actionability;
3. Communication/connection;
4. Transparency;
5. Truthiness; and
6. Discovery.

Self-evidence

The self-evidence valence holds that data are pre-made, requiring neither work nor interpretation. In its strong form, this valence neglects a key premise of STS that data rely on people to control, arrange, massage, and provide infrastructure to make data meaningful and sensible. However, it is a valence that is commonly evoked within technology design practices and discourses. An example of the self-evidence valence comes from Larry Smarr, a Computer Science professor and strong proponent of QS who *The Atlantic* called, “the measured man” (Bowden, 2012) because of his journey of discovery through a series of elaborate laboratory tests involving terrabytes of genetic data and stool samples. One test indicating his lactoferrin levels were higher than normal, led to further research that associated this measure with Inflammatory Bowel Disease. Even though he felt fine and could not report any symptoms to his doctor, his data told a different story. At the 2012 QS Conference he argued “*This idea that you can just feel what is going on inside of you, that is just*

so epistemologically false. You just can't do it." He talks about data as functioning very differently from clinical practice, in which patient-reported symptoms or experience lead to a physician's decision to order laboratory tests.

The self-evidence valence holds that data require little interpretation or expert diagnosis, so that data from new consumer-level devices renders some kinds of medical knowledge and work obsolete. One user and technology designer we spoke to was confident that the segment of healthcare that is doing assessment and diagnosis will become obsolete in the near future due to advances and availability of sensing instruments. For example, when he became aware that he was losing his hearing, he went in to see an audiologist who performed many tests taking up most of a day and costing thousands of dollars. Afterwards he found an app that could test his hearing and delivered exactly the same results as he received from the audiologist. He concluded, "So that audiologist is out of business very soon, because of these devices and these sensors." His perspective privileged the self-evidence of the data produced by the app and its algorithms, making medical diagnosis a kind of data redundancy.

Actionability

The valence of actionability emerges when data are called upon to drive or do something, when data are talked about or expected to be leveraged as the basis for action. For example, there are multiple data valences that emerge in the interstices of home, clinic, and lab around blood pressure monitoring data. This is not simply a matter of having better, richer data from multiple home readings as promised by health tech innovators. Doctors, prizing actionability for data, need clinical guidelines for what constitutes increased risk for the patient and what patterns they can act on and influence with their therapy or treatment. As one doctor explained, having two standard readings of blood pressure in the clinic is known to predict high risk for heart disease, for which there is a specific intervention to reduce risk, but *"if I have 1,000 readings, and some of them are high, I don't know what that means. I don't know what the risk of that is, and I don't know whether I can meaningfully influence whatever outcome that might bring."* Here, pervasive and ubiquitous tracking in the home by a user conceptualized as a consumer/patient poses a distinct challenge to the actionability valence within the clinic.

Many marketing taglines for health and wellness self-tracking tools promise to deliver actionability, *"you can't manage what you don't measure,"*² *"own your health...take control today,"* and *"know yourself, live better."*⁴ As one technology designer explained, *"we don't just want to make it meaningful, we want to make it actionable."* However, for many users simply knowing that a behaviour is healthy or unhealthy is not enough to change it. For example, a user tracking his food consumption explained that *"It can recognize that there are carbs there...I still might eat it because that is what humans do."*

² <http://www.insidetrapper.com>

³ <http://www.wellnessfx.com/>

⁴ <https://jawbone.com/up>

Communication/Connection

The data valence of communication and connection is apparent in interactions around and through shared data. For the patients in the U.S. rural tele-health case, adjudicating or interpreting their data often meant using data to connect with their case managers. In other words, the data provided the structure and opportunity for conversation, which both sides counted on. Personal connections and relationships developed through dialogue around shared data, providing case managers insight into their patient's home lives and the trends in their mood, behaviour, and health. Conversations between patient and case manager were often full of patient stories, which while at first, appearing to fall outside the medical realm, provide important information for the case manager as they make sense of the patient's health data and engage with this patient in the future. While many of these stories are chock full of patient data, this is not the kind of data that is put in medical records. We observed the case managers making separate notes about these stories in less formalized documenting spaces, not in the electronic notes of the program associated with tracking device. These stories and connections were essential for doing case management work and helped in interpreting the data.

Transparency

The data valence of transparency is apparent when data are the site of "making visible", and function as an instrument of vision rendering an issue, relationship, or state transparent. The valence of transparency operates on many different scales, from individual to population level data, and relies on linked data to "unlock" this vision. Many self-tracking advocates, scientists, and technology designers expect self-tracking data to provide a transparent gaze into the body revealing the micro-level processes and patterns that would not otherwise be perceptible. In aggregate this data provides a view across macro-level processes and complex patterns. This data opens or "unlocks" the possibilities for understanding the science of the individual and for individualizing science; as Kevin Kelly, co-founder of QS, puts it "total personalization requires total transparency"⁵. For scientists and other researchers this data drives the development of the macroscope⁶, an instrument for viewing with the human eye what is too large and too complex to perceive otherwise. In linking massive amounts of distributed data, the macroscope enables the viewing of larger patterns through advances in computing and bio data analytics. The valence of transparency follows the logic that to *see* patterns in data is to *know* patterns in life at whatever scale.

For some individuals, self-tracking data becomes associated with the value of making that data transparent and available to a larger collective with the expectation of developing better knowledge and tools. The community Patients Like Me, an online network of patients that share data about their healthcare experiences and outcomes, epitomizes this data

⁵ Kelly, Kevin (2007) "The Next 5,000 Days of the Web" TED talk

⁶ Described in Mundie, Craig (2007) The way forward. In T. Hey, S. Tansley & K. Toll (Eds.), *The Fourth Paradigm: Data-intensive scientific discovery* (pp. 223-226).

valence. The Patients Like Me website highlights their “Openness Philosophy”⁷: “When you and thousands like you share your data, you open up the healthcare system.” The website then asks: “Will you add to our collective knowledge, and help change the course of healthcare?” Sharing health data within this community is framed as a way of seeing deeper into and across a range of health conditions and fundamentally transforming healthcare.

Truthiness

The data valence of “truthiness” is related to the notion of raw data as comprising a direct, objective representation of measurable reality. It holds that sensing technologies are technologies of representation. As one technology designer explained “*if we instrument you, we can sense you accurately.*” A QS member explained how “tracking doesn’t allow any self-delusions,” helping him get closer to “*what’s really happening and what’s really going on.*” This perspective taps into the truthiness valence and implies there is something more objective and “true” about the self-tracking data in understanding his health. “*Once I track, then I can change my behaviour to potentially alter whatever that outcome is...the tracking itself continues my behaviour and I can gain understanding about the condition. There is a feeling of power. I realized I was able to take my health in my own hands, I was able to enhance my health.*”

These health and wellness data are particularly important in the interstitial interactions where there is contestation or inconclusiveness around issues that formal institutions are not yet able to handle effectively. Here, data get marshalled for their ability to lend truth and validity to a particular explanation. One woman struggling with her own undiagnosed condition, that she later attributed to metals toxicity, commented that if you can’t produce accessible and legible data “*in a pre-established or set methodology to the conventional medical profession, you are actually, to them, not sick; you’re imagining your illness.*” After having an alternative practitioner discover high levels of metals through specialized tests of the blood and urine, she was hopeful that this data—proof of her illness—would demand validation from a medical doctor. Instead the doctor responded, “*I don’t even know what that is, I don’t know what that means, therefore this test is not real to me, this is not real data!*” The challenge was in “trying to establish valid data and establish the data’s validity with the people who they want to be paying attention to their illness”. Two years later she found a different alternative practitioner, who she saw as more data-driven and scientifically minded, to make sense of the data with her, helping to establish a “truth” from the data that made sense to her. As she explained, “*It was not a real thing until he saw the level of oxidative stress and all of the different indicators that are way, way off in my blood. So now I could theoretically, like now I’m real to him, my story is real, it’s real through data.*”

In this case we see that the truthiness said to emerge by the technology designers through the quantification of an individual through instrumentation is in tension with the truthiness that does not automatically emerge through quantification of metals toxicity, but rather emerges through a validating interpretation of the data as truth.

⁷ <http://www.patientslikeme.com/about/openness>

Discovery

The valence of discovery is apparent when data become a site for hypothesis generating and theory testing. Engaging data in this way represents a method for discovering intentionally or accidentally knowledge one did not have before. A common story among the QS community is that self-tracking helps discover previously unseen patterns or truths, sometimes before theory or clinical data can support their conclusions. For instance, one member of QS wanted to discover the relationship between his caffeine consumption and his blood pressure. He designed an experiment in which he took his blood pressure upon waking up and then again after each cappuccino over 10 different days and found that his blood pressure got up into an unhealthy range after three cappuccinos. In contrast, another self-tracker managing a chronic illness admitted that sometimes “*I just want to live; I don’t always want to know*”.

A doctor who was also part of the QS community commented that “*the gimmicky aspect of quantified self on some level is that tracking for the sake of tracking doesn’t necessarily actually give you useful information.*” He notes that while there are many QS presentations that are very thought out, “*there are other presentations where it’s almost a curiosity project to kind of derive meaning out of things you’re tracking that honestly may not have any biologic or medical significance.*” In these cases in which there are biomedical consequences, “*one has to be very careful what conclusion one can make from those things*” because “*without having an underlying kind of relationship, whether it’s scientific or what have you, but something that really can be understood - I don’t know how useful that is.*” Still, the valence of discovery motivated many of the QS presentation narratives, even if the data discovered were not actionable or connected to medical validation. The Table below outlines a summary of data valences:

TABLE 1. Summary of data valences

Data Valences	Discourses	Practices	Challenges
Self-evidence	Be your own doctor; medical diagnosis cheapened	Data-driven, self-diagnosis	Risk of misinterpretation, drawing causal links without consulting expertise
Actionability	Data→Knowledge→Action	Established clinical decision making	"I don't care that this is bad for me"
Communication/Connection	Data as site for conversation	Narrative medicine	Requires labor and time
Transparency	Sharing data and the right to access and own data	Patient advocacy around open EMRs, Patients Like Me	Data collection outpaces sense making

Truthiness	Data make objective, “real” and representative	Finding validation of illness through data	Data is insufficient to bridge contexts
Discovery	Self-experimentation, pattern detection	Quantified Self	Findings not connected to medical validation

This is nowhere near an exhaustive list of possible data valences (see Table 1). These, however, emerged through our research in the field and help expand the concept of data valence. Identifying data valences in the interstices exposes the tensions that emerge among different data valences as well as along a single data valence that manifests differently across discourses, practices, and contexts.

TENSIONS AND CHALLENGES

The rhetoric of data-driven institutional change in healthcare envisions a tightly coupled relationship between total transparency and total personalization, in which a seamless flow of data connects the clinic and lab with patients/consumers. However, there are many contexts that present barriers to sharing health information and communities that don’t want data to be transparent for a variety of reasons. For example, while a recent Accenture survey⁸ showed that 82% of U.S. doctors want patients to actively participate in their own healthcare by updating their electronic health records, only 31% believe patients should have access to their full health record. Further as one doctor noted, “*I don’t need more data; I need more resources.*” Data here are not the valuable resources that advocates for big data in health claim them to be. From the point of view of this doctor, data require, and do not save, extra interpretive, clerical and managerial labour. Yet the value of data from a patients-rights activist perspective advocating for access to their data, is that *data* is infused with individual meaning and is valuable because of that meaning. In addition, the more data collected may not make patterns and underlying mechanisms more transparent. As the development of tools for sensing is outpacing the development of approaches for sense making, then more data is not always better, and has the potential to obscure, and even mislead. Discourses of “transparency” and “openness” make it possible to dodge the conversation about “open to whom” and “for what purpose”.

Sense making conversations around patient-generated data between patient and clinician provided an interstice in which tensions among data valences became apparent. We were told repeatedly that doctors like to solve problems, and managing conditions is intellectually less interesting work and not feasible given time constraints and reimbursement policies for doctors. For a diabetic patient we spoke with the insulin pump provides a major benefit in that “*it really is an on-going, every day, every hour, sort of issue and the doctor isn’t there all the time. You*

⁸ See Patient Access to Electronic Health Records: What does the doctor order? (2013) <http://www.accenture.com/SiteCollectionDocuments/PDF/Accenture-Patient-Access-to-Electronic-Health-Records-What-Does-the-Doctor-Order.pdf>, accessed 3 April 2013

see him every three months and so it is about management.” Being a motivated and educated diabetic patient, this respondent wanted *“to have alarms that tell you when things are going wrong and to have such a tight feedback loop, you can make adjustments and changes much faster and that has an impact on your overall health which I’ve seen in my own results.”* But the doctor doesn’t “think in terms of data points”, rather *“it’s about higher level concepts.”* Thus the patient-generated data did not carry the same expectation of actionability in the clinical realm.

For clinicians, using such data in the clinical realm present many challenges. One clinician explains that his patients *“may not understand what some of the limitations of measurement”* are, especially when they bring in data that is inaccurate or even misleading. It is common that when patients bring in their data to the clinic they *“want to interpret it, and they don’t want to just describe, they want to tell you what they have.”* Patients can slip without pause from data to diagnosis, from description to (their own) interpretation, rather than presenting the data as one description of their health status. This valence of self-evidence can disguise data as diagnosis, making it difficult for clinicians and patients to jointly interpret data. Noting this common slippage between data collection and interpretation, the clinician continued *“sometimes people are right but a lot of times they are trying to diagnose things themselves and it can just cause problems.”*

Clinicians are concerned about data potentially decoupled from clinical actionability. They need to know what constitutes increased risk for the patient and what patterns they can act on and influence with their therapy or treatment. The work of management for the patient requires attention to a different granularity and different valences of data around which very different kinds of conversations are structured and materialize. Another concern is liability for whatever the clinician *does* or *doesn’t* do in response to having access to patient data. One physician explained that he would accept patient-generated data from some wellness behaviour interventions such as pedometers because there was very low risk involved in having a patient walk more or start taking the stairs, but he perceived a greater risk in accepting data on blood pressure or glucose readings, which could potentially demand more clinical action. Thus the risk for patient-generated data integration in clinics is not about the data *per se*, but what interventions data require, and which responsibilities are associated with that data. The data in the clinical realm evoke a valence of actionability that may refer to the interventions demanded by the data and the *expectations* for actionability associated with the data. Both mediate the performance of this data in this realm.

There is also great pressure on designers to create devices and interfaces that encode meaning and actionability in the mediation of consumer generated data. Designers of consumer-facing mobile-based apps face a challenge in trying to develop an interface for interaction in the interstices because they are designing for consumers and everyday users, but they may also want these data to count elsewhere, either in healthcare institutions or scientific research. Technology reflecting this approach to behaviour change encodes actionability into the product as lightweight actions, small behaviour interventions that most people would not associate with a clinical interaction or anything in the medical realm.

The product offers *“them stuff they can do that’s kind of low-touch, frequent interactions rather than like a very high-touch, heavy clinical interaction.”* The recommendations and action items are completely separate from the medical arena, not only legally, with disclaimers that specifically note that information for use is “not medical advice”, but also practically, as the company

tries to engage people in behaviour change in a personal, fun, gamified, everyday living space, outside of the clinic, beyond the reach of the medical community. This “user” and “usage” is prescribed in a non-medical, but health and wellness oriented space. This approach does not attend to multiple expectations for the performance of data at the interstices and within the formal healthcare system.

The rural tele-health case demonstrated how communication and data could be structured and designed in order to account for the multiple data valences at the interstices between home and clinic. The tele-health device enabled data to flow from home to clinic, but this data on its own fell short of generating value across stakeholders and contexts. This required very particular kinds of work in interpreting and communicating patient data for doctors that would actually create value to them by presenting data that was actionable instead of creating more work with vague kinds of patient data that require they follow up. One doctor working with the program explained that the worst for him as a physician would be the 1-800-dial-a-nurse scenario, in which he would get a call from a nurse saying, *“We just wanted to let you know that Mrs. Johnson isn’t feeling well today.” What the hell am I supposed to do with that? All you’ve done now is, thank you, you’ve increased my work.*” The work of interpretation, translation, and articulation of the data was integrated into the design of the program. Case managers figured out how to communicate data to doctors in a way that dovetailed with the doctors’ existing data practices, rather than adding a time draining step or increasing clinics’ workloads. Integrating the data from the patient tracking device and their conversations with the patient, case managers structured their communication with doctors so the data came to doctors already integrated with a health interpretation in a trusted information network.

The aim of the tele-health project was to reduce costs for Medicare and improve health outcomes for high risk and high cost patients. The program, despite its successes with patient outcomes and despite other research that treatments based on such monitoring lead to a 75% improvement in congestive heart failure (CHF) patients, Medicare stopped the program. As it turned out, the case management program made institutional sense-making of the data collected by patients in their homes possible as health/medical data and effective in the institutions of health care. Yet, Medicare deemed the team of trained case managers needed for the program as too expensive. These case managers provided the tight coupling of communication and connection with chronic disease data management, while simultaneously translating data generated outside the clinic into actionable data for physicians. The financial compensation routines of formalized medicine doomed the project, even though the data were enormously beneficial to patients and to physicians.

CONCLUSION

We contribute to an emerging scholarly conversation about the nature of data. We extend these conversations by pointing to the ways that data valences may be contested at the boundaries of institutions. The polyvalence of health and wellness data becomes apparent in the interstices of institutions through the way different people talk about what they want from data and how they expect data to perform socially, organizationally and institutionally. These conversations point to tensions between institutions and stakeholders and complicate our understanding of the production and consumption of data-intensive

technologies by bringing back into the picture the practices, communities, and networks of data that are generated—sometimes as by products—in the socio-technical assemblages we study.

Data valences, we argue, have incredible importance in the design and use of data-intensive technologies and in the visions behind creating and managing the resulting data streams. As a concept, data valence allows us to identify the *mediation work* that is not simply about meaning or interpretation but also about the function and performance of data in different settings and for different communities.

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REFERENCES CITED

- Berg, Marc, and Geoffrey Bowker
1997 "The Multiple Bodies of the Medical Record: Towards a Sociology of an Artifact." *Sociological Quarterly* 38 (3).
- Bowden, Marc
2012 "The Measured Man." *The Atlantic*, 13 June. Accessed 14 July 2013.
<http://www.theatlantic.com/magazine/archive/2012/07/the-measured-man/309018/>
- Gillespie, Tarleton, Boczkowski, Pablo, and Kirsten Foot
Forthcoming. Introduction. In *Media technologies: Essays on Communication, Materiality, and Society*. T. Gillespie, P. Boczkowski and K. A. Foot, eds. Cambridge, Mass.: MIT Press.
- Gitelman, Lisa and Virginia Jackson
2013 Introduction. "*Raw Data*" is an *Oxymoron*. L. Gitelman, ed. Cambridge, Mass: MIT Press.
- Lievrouw, Leah
Forthcoming "Materiality and Media in Communication and Technology Studies: An Unfinished Project." In *Media technologies: Essays on Communication, Materiality, and Society*. T. Gillespie, P. Boczkowski and K. A. Foot, eds. Cambridge, Mass.: MIT Press.
- Mol, Annmarie and John Law
2004 "Embodied Action, Enacted Bodies: the Example of Hypoglycaemia." *Body & Society*, 10 (2-3): 2-3.

Nafus, Dawn

Forthcoming "This One Does Not Go Up To Eleven: The Quantified Self Movement as an Alternative Big Data Practice." *International Journal of Communication*.

Nicolini Davide, Mengis Jeanne and Swan Jacky

2012 "Understanding the Role of Objects in Cross-Disciplinary Collaboration." *Organization Science* 23: 612-629.

Porter, Theodore

1995 *Trust in numbers : the pursuit of objectivity in science and public life*. Princeton, N.J.: Princeton University Press.

Schubert, Cornelius

2012 "The agency of means in medical work." In *Agency without Actors*. J.H. Passoth, B. Peuker and M. Schillmeier, eds.

Star, Susan Leigh and James Griesemer

1989 "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology 1907-39." *Social Studies of Science* 19: 387-420.

Star, Susan Leigh and Karen Ruhleder

1996 "Steps toward an ecology of infrastructure: Design and access for large information spaces." *Information Systems Research* 7 (1): 111-134.

WEB RESOURCES

Kelly, Kevin.

2007 "The Next 5,000 Days of the Web." TED video. Posted Jul 2008.
http://www.ted.com/talks/kevin_kelly_on_the_next_5_000_days_of_the_web.html

InsideTracker.

Accessed 14 July 2013. <http://www.insidetrapper.com>.

Jawbone.

Accessed 14 July 2013. <https://jawbone.com/up>.

PatientsLikeMe.

Accessed 14 July 2013. <http://www.patientslikeme.com/about/openness>.

WellnessFX.

Accessed 14 July 2013. <http://www.wellnessfx.com/>.