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Communication, Mediation, and the Expectations of Data: Data Valences Across Health and Wellness Communities

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Communication technologies increasingly mediate data exchanges rather than human communication. We propose the term *data valences* to describe the differences in expectations that people have for data across different social settings. Building on two years of interviews, observations, and participation in the communities of technology designers, clinicians, advocates, and users for emerging mobile data in formal health care and consumer wellness, we observed the tensions among these groups in their varying expectations for data. This article identifies six data valences (self-evidence, actionability, connection, transparency, "truthiness," and discovery) and demonstrates how they are mediated and how they are distinct across different social domains. Data valences give researchers a tool for examining the discourses around, practices with, and challenges for data as they are mediated across social settings.

Keywords: big data, health communication, communication technology, qualitative methods, ethnography, theory

The excitement around big data has come with a lot of big promises about how information-intensive approaches to public policy can improve lives. This is particularly true in medicine, where many expect new types of data, data science, and predictive modeling to solve some of the biggest and most intractable problems. We would argue, though, the challenges for integrating the data from these emerging sources—including mobile communication devices and consumer electronics—into clinical health care settings are social, not technical (See Neff, 2013). Communication scholars can play a significant part in solving these challenges, and this article is, in part, an attempt to encourage others to join us in doing so.

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Two examples from our ethnography on the impact of pervasive mobile data on the institutions of health care presented us with contradictory perspectives on the same types of data and challenged our existing categories for talking about that data. In one of our first interviews, a researcher who was studying sensing technologies used for elder care said that he was surprised at doctors' resistance to accepting the enormous amount of data generated from "smart homes" for their aging-in-place patients. One of the doctors expressed her problem as, "I don't need more data; I need more resources." Data here were discussed not as the valuable resources that advocates for the use of big data in health care claim. From the point of view of this doctor, such data *require* extra interpretive, clerical, and managerial labor and provide little in clinical utility, presumably costing more in time and money per patient with increased liability risk exposure. Contrast this value of data to that expressed in a humorous advocacy video. In it, a band plays the American rockabilly tune "Blue Suede Shoes" while patient-rights activists sing in harmony, "Gimme my DaM [data about me] data" (Martin, 2012). The video features cameos from Todd Park, then the U.S. chief technology officer, and Jamie Heywood, the cofounder of the patient data and informatics start-up Patients Like Me. Both argue that data, in the hands of patients, is valuable and should be freed from the constraints and restrictions imposed in clinical settings and returned to the patients whose bodies and conditions generated it.

These are just two examples from our fieldwork in which people talk about the functions and expectations of data in distinctly different ways. One view holds that data are infused with individual meaning and are valuable because of that unique meaning. The other is that additional data may fail to be a resource for patient care, with little value compared to other clinical resources. The validity of data was not in question in either of these examples. Rather, both examples are evidence of people's varying expectations for data in social and institutional settings. They reflect a recurring tension that we found around how different people talk about what they want from data and how they expect that data to perform in interaction with others. In our field site, patients and doctors valued and expected different things of the same data. If people in the health and wellness field have such vastly different sets of values around the same data, what does this mean for the contexts of privacy, reuse, and functions of data generated from communication technologies and mobile devices more generally?

To answer these questions, we examined the gap between the contexts for and the practices with data. We theorize these as the social *valences* of data. We analyzed our qualitative observations of, participation with, and interviews of the designers and users of Internet-based health and wellness mobile and technological tracking, including the Quantified Self (QS) community. We studied the community of health and wellness technology innovators hoping to harness analytic power from online and mobile communication traces to improve health outcomes, and designers and users of mobile applications for self-tracking and pervasive sensing to improve health and wellness along with digitally empowered or e-patients looking for increased access to their own health data. Our research focused on how communication technology mediated the ability of data to cross the lines between health data and consumer wellness data. We found the gaps in communication of and about these data were particularly stark across the communities of practice of technology designers, e-health providers and advocates, and users of health and wellness data.

We have three aims in this article. First, we propose the term *data valences* to encompass the wide range of people's expectations of and values for data that emerge from their discourses and practices across different contexts for data. We define the term and use it to identify the multiple data valences that we found in our study, with the aim of generating a transportable typology that other scholars can apply. Second, we hope to provide a model for bringing communication theory and qualitative context to the study of data, especially at a moment when large-scale data sets are generated from the use of online and mobile communication technologies. Finally, we extend theories of mediation to data to show how communication scholarship can provide one way to understand this phenomenon.

Literature Review: Data as Mediated

Communication theories of mediation provide a useful lens for examining the social processes of data. The notion of contested or socially constructed data has long been examined by science and technology studies through making visible the performative agencies of metrics and measurement tools (Berg & Bowker, 1997; Mol & Law, 2004; Schubert, 2012). Many scholars have noted that tools of measurement are neither neutral nor objective, but rather assume a vantage point from which they participate and perform in the construction and definition of what counts, what is countable, and how to make them commensurate through social calibration (e.g., Espeland & Stevens, 1998; Latour, 1993; Mol & Law, 1994; Stark, 2009). Science and technology studies scholars often focus on the multiple interpretations of data across different social settings. This represents an important, but potentially limited, view of how data are constructed and how they function.

However, what is at stake in the field of mobile health and health information technology is not entirely focused on the validity or social meanings around data. Rather, the ubiquity and pervasiveness of information and communication technologies as tools of measurement and mediation, the increased availability of digital health records, and an emerging participatory culture around personal information blur the lines between health data and personal wellness data. Health data produced both inside and outside of the clinic challenge the norms around what counts in different contexts of health and wellness, including previously defined distinctions between patient and consumer, device and data, and health care and personal wellness.

The renegotiation of these definitions occurs at the intersection of social domains and highlights the specific kinds of communication and mediation work that must be done around such data. Increasingly, making data meaningful and interpretable within health care is mediated by particular communication technologies. For example, patient-gathered health data currently have few ways to cross into clinical settings for interpretation by a care provider. The "intermediary labor" involved in crossing these settings, essential for translation, becomes apparent in a mobile health and telehealth project (Fiore-Silfvast, 2014). Another challenge is that the algorithms and code that parse data into user-friendly visualizations are rarely transparent: "Users tend to see only the interface. . . . Hidden away inside computers and software are attitudes, values, and politics that actors write into the code" (Chow-White & Green, 2013, p. 578).

Communication theorists have begun to extend the concept of mediation to include how everyday objects play a role in communication processes, and in turn theories of mediation are being applied to a wider range of objects (Anderson & De Maeyer, 2014; Leonardi & Barley, 2008, Leonardi, Nardi, & Kallinikos, 2012; Neff, Fiore-Silfvast, & Dossick, 2014). For instance, Lievrouw defines mediation as the "ongoing, articulated, and mutually determining relationship" (2014, p. 45) among artifacts, practices and social arrangements of communication technology infrastructure and the processes of reconfiguration, remediation, and reformation. Such a view allows scholars to see data as emerging from communication media, shaped by and embedded into communication practices and materiality. The more widespread view frames data as a stable material object rather than as discursively and communicatively enacted by multiple stakeholders through various practices in ways that resist such stability. Gitelman and Jackson challenge the common discourse of data as "self-evident, the fundamental stuff of truth itself," (2013, p. 2) or existing a priori outside of a social context and without material intervention.

A mediation approach understands the production of data as requiring the extraction, interpretation, and interpolation of data. Increasingly, the online communication technologies, mobile communication devices, and metrics that parse the data collected act as tools of data mediation. Quantification methods then can be seen as "strategies of communication" (Porter, 1995). Others call similar digital technologies "*communication* made durable" (Gillespie, Boczkowski, & Foot, 2014, p. 11). Data and information then come to be seen as both products of technological infrastructure and facts about the world. The reality is the relationship between facts and infrastructures is far more complex (Latour, 1996; Star & Ruhleder, 1996). For example, glucose self-monitoring devices enabled more frequent measurements, which shifted the value of the information about glucose levels, challenging the numerical standards for "normalcy" (Mol & Law, 2004). The communication technology infrastructure of data not only supports people's particular practices and interpretations but provides the mediation that makes such data even possible.

The Problem of Data as a Boundary Object

Scholars employ boundary object theories to explain how objects help people translate and interpret across different communities of practice. Boundary objects work at the boundaries of communities to coordinate across them, and they inhabit "several intersecting social worlds and satisfy the information requirements of each of them" (Star & Griesemer, 1989, p. 393). In the existing theory, boundary objects require interpretive flexibility so that they can be read in different ways by different people to enable their different informational needs. In health, boundary objects describe how "different records and different practices of reading and writing are intertwined with the production of different patient bodies, bodies politic, and bodies of knowledge" (Berg & Bowker, 1997, p. 513). However, the boundary object approach foregrounds the objects that do indeed translate across boundaries, even as it tends to bracket both the wider contexts in which the translational work is carried out and the forces that motivate collaboration (Nicolini, Mengi, & Swan, 2012). In other words, some coordination and collaboration are necessary for the existence of boundary objects.

Yet in our research sites we found that coordination absent, and it certainly was not being fostered by data. Even though people at times discussed data that might cross between consumer and clinical settings, we found that what people considered data in each of these sites were different things entirely. Unlike the central emphasis of boundary objects' ability to coordinate across different communities or groups, data in digital health became different things socially and materially within a broader set of social relationships and in light of people's different expectations for its use. Boundary object theory, by definition, connotes a process of the social construction of the meaning of objects across groups. Although those meanings are contextual, the focus on boundary objects is more on the intersections of those contexts.

More communication scholars are taking up questions around the extent to which the context shapes and changes data. While science and technology studies scholars have focused on the extent to which the interpretation, validity, or social construction of data is in question by different social actors, communication scholars are beginning to ask how mediation and communicative processes make data sensible. As Markham (2013) notes, *data* is a term with "high ambiguity, which, when combined with the illusion of shared understanding, can function to make us all think we're looking at the same map when we're not" (para. 8). For example, Patterson and Nissenbaum (2013) note that the collapsing social contexts around health data generate paradoxes in people's mental models of their own data.

We argue that health and wellness data are, in large part, shaped by the expectations for how data will be collected, stored, used, and shared. Health data, compared to wellness data, is subject to a different set of relationships around it, including laws, regulations, norms, and values. As a result, people have different expectations for the ends of the data. These expectations shape the data differently so that it functions, in effect, as different kinds of data, changing it in practice to different data.

Defining Data Valences

We use the term *data valences* to reflect the multidimensional differences in the expectations for and values around data. *Valence* has the same Latin root as value, *valere,* which means to be strong or to be worth. We choose this term because of how expectations for data are enacted and emergent through social and technical mediation. As a word adopted by multiple fields, valence 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 behavioral goal (psychology). These definitions all refer to an anticipation of value or expectation for performance within a particular ecology or system. We define data valences as the multidimensional expectations and values that mediate the social and material 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, even when the interpretation of data is relatively stable or settled. Data valences, by contrast, are neither neutral nor stable, and instead can change across multiple contexts, stakeholders, and interactions. When multiple and potentially contentious data valences emerge in interaction, the differences among them help us to understand the tensions among stakeholders and institutions. 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 in a particular context. Our view places the communicative mediation work and relationships around data at the center of inquiry. Taken together, we suggest, data valences can map a multidimensional view of the social and material life of data.

Methods and Setting

We interviewed 43 clinicians, technology designers, and users to ascertain various stakeholder positions emerging around data technologies in health and wellness.[2] These interviews focused on how respondents used health and wellness data and the work that they did around this data, especially in relationship to other stakeholders. Our method allowed us to map different values for data evoked in different discourses of and contexts for data. Our fieldwork included participation and observation at many sites in formal health care institutions and in consumer health and wellness communities. In addition to interviewing nurses and physicians about their experience with and practices around patient-generated data, we spent five days observing a rural telehealth pilot project that used information gathered in the home to improve the clinical outcomes of chronically ill patients. We also participated for two years in the communities of practice around health and wellness technology design (e.g., business accelerator programs, meetings of start-up companies) and among e-health clinical providers, innovators, and advocates (e.g., conferences such as Health 2.0 and TedMed and health information technology conferences sponsored by publishers and universities in four U.S. cities). We observed how participants talked about and attempted to demonstrate with data.

We also participated in the group known as QS (Quantified Self) in two cities and at its national conference. At these meetings we participated in discussions, gave research talks, recruited interview and observation participants, and engaged in formal and informal discussions about this emerging area of health communication. As Nafus and Sherman (2014) note of QS, the boundaries among communities of technologists, users, and practitioners are fuzzy, and membership often overlapped. Still, these categories lent us a conceptual frame for tracking how the contexts, discourses, and practices of data varied across them.

Setting: Different Expectations for Health and Wellness Data

Our study was situated on the blurring line between health care data and personal wellness data in formal health care settings and more wellness-oriented settings. The rapidly shifting health landscape is a prime site for a deeper inquiry into the social values of different social settings and how various health and wellness communities expect these data to function and behave. We observed how health and wellness data functioned and moved across multiple contexts for health within which people had different expectations for these data. With different expectations for data come a range of approaches for extracting and producing value from data across different contexts. So-called big data approaches rely on algorithms and advances in computing as a means to generate insights and reveal patterns, relationships, and evidence within and across large and complex data sets. In the field of health and wellness, big data

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[2] We use the term *health and wellness* to capture the range of regulated health care data technologies used in the home such as glucometers and blood pressure cuffs and unregulated consumer devices such as fitness and activity trackers.

advocates claim that these approaches can result in predictive modeling of patients, populations, disease, wellness, and resources. So-called small data approaches refer to the effort to capture and aggregate digital traces, or "small data," to generate personalized health data profiles and conduct personal analytics (Estrin, 2013). Data can also provide a potential for greater patient involvement in health decisions and for behavior modification for personal wellness, when, say, activity tracker data are marshalled to help manage a chronic illness or new visualizations of medical device data make health data available to patients in real time on their smart phones. However, these kinds of data challenge the distinctions among expectations within clinical, laboratory, and consumer settings.

In formal health institutions, the goal of the interpretation of data by clinicians is to manage symptoms, diagnose, decide intervention or therapy, and 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 discussed in terms of "disruption" of health care—that is, of the power of data to transform existing institutional arrangements in health care (e.g., Topol, 2012, 2015). Such rhetoric exposes a 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.

In patient communities, data can be the starting points for conversations concerning interventions, recommendations, and taking action. Consumers and e-patients are increasingly seen as the consumers and producers of such data. Within QS there is a focus on "n of 1," generating self-knowledge through extensive data. Yet the values that people in the QS movement place on the ever-evolving uniqueness of these data mean they perform a "soft resistance" to the shuffling of their unique data into categories and through algorithms by outpacing them in complexity ever so slightly (Nafus & Sherman, 2014). This small data, or "n = me," is expected to generate personalized data-driven insights that operate as early warning signs, indicators of improvement, or a personalized "social pulse" (Estrin, 2013). Quickly apparent at QS meetings is another way of talking about data, through personal stories loosely wrapped around self-tracking data. This community of users talks about data to connect to one another and make sense of their experiences through sets 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? This narrative structure casts self-tracking and the data generated as central actors. This data-intensive strategy for communication adopted by a wide range of individuals reveals a huge diversity of perspectives, providing a view of different data valences.

Findings: Data Valences in Discourses, Practices, and Challenges

We identify six data valences that emerged in this setting through 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) connection, (4) transparency, (5) truthiness, and (6) discovery.

Self-Evidence

The self-evidence valence holds that data are premade, requiring neither work nor interpretation. In its strong form, this valence neglects a key premise of science and technology studies scholarship that data rely on people to control, arrange, massage, and structure to make data meaningful or intelligible. The valence of self-evidence is commonly evoked in technology design practices and discourses. An example comes from Larry Smarr, whom *The Atlantic* labeled "the measured man" because of his journey of discovery through a series of elaborate laboratory tests involving terabytes 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 him 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" (field notes and Smarr, 2012). In this context, self-evident expectations for the data generated through these tests challenge how data is typically used by doctors who rely more often on symptoms and experience.

This valence maintains that data can and should precede symptoms or experience and require little interpretation or expert diagnosis. It implies that the data generated by new consumer devices and apps renders some kinds of medical knowledge, work, and workflows obsolete. One user and technology designer we interviewed was confident that the segment of health care that is doing assessment and diagnosis will become obsolete in the near future due to advances and availability of sensing instruments. When he became aware that he was losing his hearing, he saw an audiologist who performed many tests taking up most of a day and costing thousands of dollars. Afterward, 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 for diagnosis, making medical interpretation and expertise unnecessary. Conversely, for many people using sleep tracking tools, an expectation of self-evidence must be negotiated when their internal experience of their own sleep is not supported by data processed by the tool.

The valence of self-evidence is evoked in different interactions, revealing the gap in expectations for how data may perform, not necessarily what it means. One provider explained that his patients "may not understand what some of the limitations of measurement" are, especially when they bring in data that are inaccurate or even misleading. According to this doctor, when patients bring 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 slip without pause from data to diagnosis, from description to (their own) interpretation, rather than presenting the data as one indicator, perhaps among many, of their health. This valence of self-evidence can disguise data as diagnosis, making it difficult for clinicians and patients to jointly interpret data. The many steps of choosing what data to collect, making sense of and interpreting the data, and drawing conclusions still require a model, frame, theory, insight, or hypothesis, even though a self-evident valence holds them irrelevant.

Actionability

The valence of actionability refers to the expectation that data drive or do something within a social setting or that data can be leveraged for action. Take, as an example, blood pressure monitoring data. Doctors prize the actionability of such data and rely on clinical guidelines for what constitutes increased risks and suggested treatments for particular data points. Multiple readings from new home technologies, therefore, may not necessarily result in "better" data for doctors because of their expectation for clinically actionable data. As one doctor explained in an interview, 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.

In this example, pervasive and ubiquitous tracking in the home poses a distinct challenge to the actionability valence of the same type of data collected in the clinic. The expectation of actionability requires a different granularity of data for clinicians, because they use the data for making a diagnosis or deciding on interventions. Outside the clinic setting, the expectations of what actions data might suggest also vary. A clinician explained that her diabetic patients were often more knowledgeable about their own bodies and could more accurately regulate their insulin around any given meal than the clinician could. Fine-grained data on insulin levels over the course of the day may not necessarily be actionable in the clinical realm, but the same data may yield enormous actionability in the everyday lives of people managing chronic conditions, calibrating insulin levels throughout their daily routines by their own contexts and experiences.

Many marketing taglines for health and wellness data tools promise to deliver actionability: "you can't manage what you don't measure,[3] "own your health . . . take control today,"[4] and "know yourself, live better."[5] As one technology designer we interviewed explained about her product's data, "We don't just want to make it meaningful, we want to make it actionable." However, for many users, simply knowing that a behavior 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." After hearing the strong form of the actionability valence from a speaker stated as "data leads to knowledge, which leads to change," a psychologist at Stanford's Medicine X conference responded that, if data indeed led simply to change, there would be no need for the entire field of psychology (field notes). Yet the actionability valence is prevalent and strong in the health and wellness field, and the discourse of actionability suggests that quantifying is the single most important step required to change people's behaviors.

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[3] See http://www.insidetracker.com.

[4] See http://www.wellnessfx.com.

[5] See https://jawbone.com/up.

Connection

We saw the data valence of connection evoked in communication about and interactions around data, when data are what Taylor and Van Every (2000) refer to as a "site for conversation." For the patients in the U.S. rural telehealth case, daily readings and numbers became a reason for case managers and patients to have a phone conversation. In other words, the data provided a structure and opportunity for conversation that both clinicians and patients relied on and used for adjudicating or interpreting the data together. Personal connections and relationships developed through dialogue around shared data and gave case managers insight into their patients' home lives and understanding of the trends in patients' moods, behaviors, and health. Conversations between patient and case manager were often full of patient stories, which, although at first appearing to fall outside medicine, provided the case manager with important information for making sense of patient data, motivating the patient, making personalized recommendations, and developing rapport. We observed the case managers making separate notes about these stories in less formal spaces for documenting, but not in the electronic notes of the program associated with tracking device. These stories and conversations were essential for doing the work of patient case management. The data triggered by the home monitoring device turned into opportunities for forging and reinforcing connections with patients as well as a resource for informing appropriate clinical interpretation and intervention. Data reflecting patient fatigue triggered an automated alert for the case manager, who understood it in context of knowing the patient's schedule for exercise classes.

Data provided an opportunity for the case manager to connect even as their conversation provided contextual information that could contribute to a more nuanced interpretation of the data. In another instance, a patient called her case manager to ask why the telemedicine device prompted her with a different set of questions that day. The case manager knew that the call was not important necessarily because the data gathered from it could help in diagnosing or managing her client's condition. Rather, the call was important because it was a chance for a conversation with her client. The set of prompts that day were generated by an algorithm to routinely assess medical conditions other than the primary diagnosis. In this particular case, the clinical interpretation of the answers to those questions mattered less than the conversation that they sparked. Note that the connection valence is not about joint sense-making or interpretation, which often happens around data. Rather, this valence reflects the expectation that data can be a starting point, an excuse, or a reason for making a connection.

Transparency

People evoke the data valence of transparency when they talk about the benefits of making data accessible, open, shareable, or comparable across cases or contexts. The valence of transparency can ignore the negotiations people make among different data valences. The transparency valence privileges the power of transparent data for individual and social change. The rhetoric around data-intensive approaches to health that focus on the seamless flows of data across the individual, laboratory, clinical, and administrative settings is evidence of the transparency valence. People often evoke an expectation of transparency in how they talk about sharing (or are mandated to share) data across these different contexts. Making data transparent across communities is one set of values or expectations. Consider a patient’s increased capacity to produce, curate, and interpret data. Although these new data may be shared across clinical and nonclinical contexts, such data raise questions of ownership, access, and confidentiality.

In patient advocacy communities, the expectation of transparency—“Gimme my DaM data”—highlights the different valences of different communities and the tensions among valences. For example, the transparency valence is also evoked in patient rights discourse that calls for open Electronic Medical Records (EMRs) and access to all their associated data. Transparency can be evoked within the expectations of what individuals’ access to their own data can achieve, as with the U.S. Health and Human Services’ Blue Button initiative to make personal health information downloadable. But another way to evoke transparency is to make self-tracking data available to a larger collective to improve knowledge and tools. The community practices of Patients Like Me, an online network of patients who share data about their health care experiences and outcomes, epitomize the transparency valence. As its “Openness Philosophy” states, “When you and thousands like you share your data, you open up the healthcare system . . . Will you add to our collective knowledge . . . and help change the course of healthcare?” (Patients Like Me, 2007). In this example, through this openness, data become a site for transparency across patients and diseases and potentially transform health care.

Truthiness

The truthiness valence illustrates how people expect data to comprise a single, direct, objective representation of a measurable reality. As Jones and Baym (2010) put it, “Truthiness is [U.S. comedian Stephen Colbert’s] term for the substitution of emotion for rational thinking, of the valuation and celebration of perception, certainty, and feeling irrespective of the facts” (p. 286). In journalism, truthiness is the “politically or economically motivated indifference to experiential inputs,” as opposed to *truthfulness*, which is the result of “judicious regard” for “correspondence *and* coherence, fact *and* story, truth *and* value” (Ettema, 2009, p. 125, emphasis in original).

The power of truthiness as a data valence is not necessarily based on the validity of data, but rather on an affective sense of truth ascribed to data in general, or a specific quantified indicator. The truthiness valence in health data holds that quantitative data are “more objective” and “truer” for health understanding than other types of experience, symptoms, or evidence. The truthiness data valence prioritizes quantification over a broader set of relationships and discourses that make up data. This valence shares with science and technology studies theories a focus on how data are socially constructed and how they function. For the truthiness valence, certain quantified data *feel* truer.

This valence is particularly important when there is contestation or inconclusiveness around issues that formal health care institutions are not yet able to understand fully. Data get marshaled for the truthiness valence because of their ability to bestow validity to a particular explanation. One woman struggling with her own undiagnosed condition, which she later attributed to metals toxicity, commented that, without accessible, recognized, 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 whom she saw for a different chronic condition. 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!" For her and others in similar positions, 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 an osteopath, whom she considered 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,

> For him it was not a real thing because it is fringe science and I couldn't give him a name like Crohn's disease and I couldn't prove to him what it was. 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, the truthiness emerged through the quantification of an individual through instrumentation and through a validating interpretation of the data as somehow "truer" than the reported narratives of experience.

Discovery

People use the discovery data valence when they talk about data as a site for hypothesis generating and theory testing. For social scientists, the idea that data can lead to discovery is far from new. But within the health care discourses we studied, discovery data valences represented data as a method for discovering new knowledge by design or serendipity. The discovery valence describes how people expect data to be the source or site of discovery of an otherwise obscured phenomenon, issue, relationship, or state. The valence of discovery follows the logic that to *find* patterns in data is the same as knowing or understanding patterns in life on cellular, individual, or population scales. Many self-tracking advocates, scientists, and technology designers expect data to provide a window into bodies, revealing the microlevel processes and patterns that would not otherwise be perceptible. In aggregate, these data provide a view across macrolevel processes and complex patterns, unlocking the possibilities for understanding the science of the individual and for individualizing science. Leroy Hood, president of the Institute for Systems Biology, uses the discovery valence to describe blood tests as having "made blood a window into health and disease" (Hood, 2013, para. 6).

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 days and found that his blood pressure increased to an unhealthy range after three cappuccinos. In framing the production of data as an experiment, data become the basis of personal discovery, regardless of what the data actually signify about the relationship between caffeine consumption and blood pressure. This mode of individual self-experimentation challenges the established norms and expectations for discovery within scientific institutions. This self-experimentation approach to data contrasts with approaches of other self-trackers. For instance, one self-tracker managing a chronic illness admitted that sometimes "I just want to live; I don't always want to know."

The six valences that we observed during our field research are not intended to comprise an exhaustive list. Table 1 provides short definitions and examples of each of the valences described above. For each valence, we provide an exemplar practice and challenge based on analysis of our qualitative data. These are not direct quotes; rather, they summarize (and collapse) interview and observation data into ideal types of positions to illustrate our main point: the expectations that people have about data greatly shape how those data function within social contexts. By outlining and defining the six distinct ways people in this field talked about data, we hope to expand researchers' concept of the social implications of the expectations for data and provide a set of terms and theories for identifying and describing these expectations.

Table 1. Data Valences in Discourses, Practices, and Challenges.

Data valence	Discourses	Practices	Challenges
Self-evidence	Be your own doctor; medical diagnosis cheapened	Data-driven, self-diagnosis	Risk of misinterpretation, lack of expertise
Actionability	Data→Knowledge→ Action	Established clinical decision making	"I don't care that this is bad for me."
Connection	Data as site for conversation	Narrative medicine	Requires labor, time
Transparency	Sharing data; right to access and own data	Patient rights, open EMRs, Patients Like Me	Data collection & access outpace sense-making
Truthiness	Data make objective, "real," and representative	Finding validation of illness through data	Data are insufficient to bridge contexts
Discovery	Self-experimentation, pattern detection	Quantified Self talks	Findings not connected to medical validation

Discussion: Tensions and Challenges Across Data Valences

The discourse of data-driven health care innovation 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. Yet the data valences that we identified present challenges for data sharing across these contexts and communities. The tensions we saw in the field involved the variation in expectations or valences but not the interpretations or meanings of those data. Valences address the uses, not values, of data and the social functions of numbers in social contexts.

For an example of data valences in conflict in a clinical setting, consider physicians' concerns over the growing demand for transparency in medical records. A recent Accenture (2013) survey found that 82% of U.S. doctors want patients to actively participate in their own health care by updating their electronic medical records, but only 31% believe patients should have full access to their own record. The U.S. national coordinator for health IT stated that patients have a "civil right to their records" (Versel, 2013, para. 9). Still, doctors must negotiate the creation of records in ways that balance the needs for sensitive, strategic management of information and actionability of that data while protecting for confidentiality, security, and potential liability risks. Yet the value of data from a patients-rights perspective is that the "data about me" are potentially actionable and meaningful within patients' lives outside of a clinical setting and a doctor's decision-making process. Topol (2015) notes that the impact of this conflict over data will be "medicine turned upside down" (p. 3). Discourses advocating blanket transparency and openness, although useful, do not capture how data valences vary across these different communities of patients and clinicians, nor do these terms capture the extent to which data are made by people's expectations. As the development of tools for sensing is outpacing support for the work of sense-making, more data is not always better, and data have the potential to obscure and even mislead. Thus, the more productive questions about data are "open to whom?" and "open for what purpose?".

Sense-making conversations around patient-gathered data between patient and clinician provided a site between social domains where tensions among data valences became apparent. We were told repeatedly in interviews 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. One doctor we interviewed said physicians do not "think in terms of data points"; rather, "it's about higher-level concepts." Thus, the patient-gathered data did not carry the same expectation of actionability in the clinical realm.

For clinicians, using such data in the clinical realm presents many challenges. Clinicians are concerned about data 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 valences of data around which very different kinds of conversations are structured and materialize. A huge concern is the liability for whatever the clinician *does* or *does not do* in response to having access to patient data. One physician explained that he might accept data from patients' pedometers because walking more was not risky, but he thought blood pressure or glucose readings, which could potentially demand more clinical action, were risky data. Thus, the risk for patient-generated data integration in clinics is not about the data per se, but what expectations for interventions the data might require and which responsibilities are associated with the 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.

From Data to Story to Change

Designers are under great pressure to create devices and interfaces that encode meaning and actionability in the mediation of data generated by consumer wellness devices and applications. Designers of consumer-facing mobile apps face a challenge because they are designing for consumers and everyday users, but they often also want these data to count in health care institutions or scientific research. These contexts imply differences for who monitors, maintains, and controls data. But the challenge is often articulated as actionability solely on the part of consumers as users, but not necessarily as patients. One technology designer explained, “the user shouldn’t have to work really hard to understand what’s going on.” However, this perspective forgets that the data need to be structured narratively in terms of users’ lives and that the data may need help getting to a medical setting. As one QS leader posed the problem, “We haven’t gotten from data visualization to story yet.”

The actionability encoded into many mobile health applications consists of lightweight actions, small behavior interventions that most people would not see as medical. The recommendations and action items are carefully distinguished from medical advice. This differentiation is legal and practical as companies try to engage people in behavior change through personalized, fun, “gamified,” everyday options. In this case, the use and user of data are proscribed and circumscribed as being for “general wellness,” not medicine. Regulation is slow to catch up. However, people look to these data-driven wellness initiatives to bring down the costs of the U.S. health care system and manage populations increasingly framed as struggling to fit normative standards for healthy.

Conclusion

With the identification of data valences we contribute to an emerging scholarly conversation about the nature of data. We extend these conversations by discussing the ways that data valences may be contested at the boundaries of institutions and communities. The valences of health and wellness data become apparent at the intersection of communities of practice or social domains through the way different people talk about what they want from data and how they expect data to perform socially, organizationally, and institutionally.

Data valences, we argue, are important to consider 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 valences allow scholars to identify the *mediation work* that is not simply about meaning or interpretation of data but about data’s function and performance in different social settings and for different communities. They bring back into the picture the practices, communities, and networks of data that are generated alongside data—sometimes as by-products. Data valences could be used to map the challenges of the use of data by multiple communities in multiple settings. One implication of our work could be a way to approach conflicts between how data are designed to function and how people expect data to function. In our case, data did not function as a relatively flexible and malleable object, nor was the interpretation, validity, or social construction of data in question by the social actors most of the time. In other words, data was not performing as a boundary object by crossing different realms; rather, people considered data as materially different things shaped in large part by data valences. Such differences are not restricted to health and wellness data. Federal Trade Commission chairwoman Edith Ramirez noted that one of the most significant challenges that needs to be solved for the Internet of Things is people’s differing expectations of data:

> Will the information flowing in from our smart cars, smart devices, and smart cities just swell the ocean of “big data,” which could allow information to be used in ways that are inconsistent with consumers’ expectations or relationship with a company? (2015, p. 3)

There are several recent examples of situations in which the different expectations around data may come into conflict. For example, many people have a different awareness of and expectation for the algorithm that parses their Facebook feed than the reality of the engineering (Eslami et al., 2015). Data valences may give researchers and practitioners alike a tool for understanding conflicts around data.

Communication scholars should be involved in the emerging conversations about data for several reasons. First, much of the object of study in big data approaches to social behavior is based on digital traces of the use of communication technology, something communication scholars are well positioned to analyze. Second, our discipline's existing theoretical and methodological tool kit can provide both context and critique about communication data alongside emerging empirical contributions to knowledge. This is the challenge we undertook in our research, and we think data valences could be applied to many different settings where social expectations vary about data, not just the health and wellness field. Our charge to communication scholars is to use the unique methodological, conceptual, and theoretical tools within our discipline for engaging with empirical and critical studies of data and for contributing to the urgent policy debates about the roles, functions, and potential dangers of such data.

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