

What We Talk About When We Talk Data: Metrics, Mobilization, and Materiality in Performing Health Online

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Abstract

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.

Keywords

Data; health; mediation; materiality; ethnography; quantified self

Why Talking Data Matters

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 behavioral change: In the words of one advocate, “data leads to knowledge and knowledge leads to change.” This data-behavior model forms the logic of technology development in health and wellness applications and digital health sites. 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-behavior 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.

We map the symbolic and material performances of data through a lens of mediation, defined as the “ongoing, articulated, and mutually determining relationship” among artifacts, 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, Boczowski, & Foot, Forthcoming). The infrastructure of data communication in this process is not simply “a web of objects” that support particular practices (Star and Ruhleder 1996), but also the *mediation work* that makes such data possible. Thus data across health and wellness sites functions differently from a boundary object in that the mediation work is not translating different interpretations of what data mean across groups (Star & Griesemer, 1989). 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.

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*. We define data valences as the multi-dimensional expectations and values that mediate the social performance of data, or what data can do and will do within a particular social system. It is through mediation that data valences are enacted and emergent. 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. 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.

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.

Data Valences in Institutional Interstices

We extend an emerging scholarly conversation about the nature of data by pointing to the ways that data valences may be contested or negotiated at the boundaries of institutions. Within institutions data valences come with more institutional authority and seemingly cohere and congeal within those institutional settings. What we see in our research is that at the intersections between institutions or, what we call interstices, the polyvalent nature of data is more apparent.

The diverging rhetoric around health and wellness data among clinicians, users, and designers interacting in these interstices 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. For designers and users, data are often defined outside of the healthcare setting but squarely in a (free) market for consumers. Among advocates for data-intensive innovation, data become the starting point for conversations concerning interventions, recommendations, and taking action.

Blood Pressure Monitoring: Data valences across context, discourse, and practice

For example, there are multiple data valences that emerge in the interstices of home, clinic, and lab around blood pressure monitoring data (Table 1). This is not simply a matter of having better, richer data from multiple home readings as promised by health tech innovators. Doctors need to know what

constitutes increased risk for the patient and what patterns they can act on and influence with their therapy or treatment. They need actionability. As one doctor explained, having two standard readings of blood pressure in the clinic is known “to predict that you are at a high risk of having a heart attack or a stroke down the road, and that by giving a specific therapy the doctor knows he/she might be lowering that risk.” Whereas, “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.

Table 1: Data valences across context, discourse, and practice for different stakeholders

Stakeholder	Context	Discourse	Practice	Data Valences
User	HOME: Blood pressure self-tracking	<ul style="list-style-type: none"> • More accurate and personalized data • Enable more control of and engagement in their own health 	<ul style="list-style-type: none"> • Sharing with doctor as story (data plus interpretation) • Searching for clinical interpretation • Self-diagnosis 	<ul style="list-style-type: none"> • Communication/ Connection • Transparency • Self-evidence • Actionability (low)
Care Providers/ Clinicians	CLINIC: Professional blood pressure monitoring	<ul style="list-style-type: none"> • Reliance on known predictors of risk • Interested in data that impacts intervention strategy 	<ul style="list-style-type: none"> • Actionable data is expressed clinically within known decision frameworks • Liability and reimbursement • “I don’t need more data; I need more resources” 	<ul style="list-style-type: none"> • Actionability (high)
Designers	LAB: Tools for tracking blood pressure	<ul style="list-style-type: none"> • Simple, beautiful, fun leads to engagement/ use • Richer data leads to knowledge leads to behavior change 	<ul style="list-style-type: none"> • Develop personalized recommendations and insights • Interfacing with other devices and networks for seamless feedback • Measuring tool usage, not behavior change 	<ul style="list-style-type: none"> • Actionability • Discovery

Conclusion

Data valences have incredible importance for the design and use of data-intensive technologies and in the visions behind creating and managing the resulting data streams. 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 byproducts—in the socio-technical assemblages we study. Further, health and wellness

data talk help us to frame notions of user and use differently, as relationships with data are inscribed, enacted, and discursively labeled as problematic or appropriate.

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