

The Frictions and Flows of Data-Intensive Transformations: A Comparative Study of
Discourses, Practices, and Structures of Digital Health in the U.S. and India

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Abstract

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This dissertation examined the social and organizational implications of data-intensive transformations in healthcare through studying digital health and processes of informationalization in the U.S. and India. These transformations bring challenges of how to mobilize digital health data across different contexts of use and make data valuable for multiple stakeholders. To study these challenges I employed a combination of discourse analysis, ethnographic methods, and a comparative case study analysis to investigate digital health innovation across rural healthcare and urban consumer health and wellness settings in the U.S. and India. Through a communication lens this research examines sociotechnical interoperability for data across domains on three levels: discourses, communicative practices, and organizational structures and labor.

Across the discourses and practices of different communities, I found communication gaps around health and wellness data. To explain these gaps I propose the concept of *data*

valence to represent the different expectations and social values that mediate the social performance of data. Analysis through a data valence lens generated the following typology: actionability, connection, self-evidence, truthiness, discovery, accountability, and transparency. Mapping the multiple, and sometimes conflicting valences across contexts accounts for the multiple social and material lives of data and highlights tensions across stakeholder groups. I argue that this typology is portable to other fields of data-intensive work.

In comparing cases of digital health pilot projects, the differences between reinforcing and redrawing professional boundary relations, and in the role of intermediary labor in translation of digital health data for clinical and administrative sensemaking, patient engagement, and algorithmic calibration, at one time support polyvalent data in the U.S. Telehealth case and hinder it in India mHealth. Further, in the aftermath of the terminated U.S. Telehealth project, aspects of the technology continued to materialize within organizational practices and structures, such that organizational changes became the *technological residue* of the pilot projects. This suggests digital health's emphasis on technological innovation overlooks essential organizational and communicative dimensions of informationalizing healthcare and needs to be expanded beyond measures of success and failure to account for how technological innovation extends into and co-evolves with a wider network of organizational practice.

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Chapter 1

Introduction

By putting our physical bodies inside our extended nervous system, by means of electric media, we set up a dynamic by which all previous technologies that are mere extensions of hands and feet and teeth and bodily heat-controls—all such extensions of our bodies including our cities—will be translated into information systems.

—McLuhan (2003, p. 86)

The choices for the future cannot be deduced from economic data or from abstract measures of organizational functioning. They are embedded in the living detail of daily life at work as ordinary people confront the dilemmas raised by the transformational qualities of new information technology.

—Zuboff (1988, p. 12)

At the 2013 TEDMED conference, the “smartphone physical” was celebrated as “a disruptive innovator” and a “glimpse” of the future of the exam room, challenging the need for expensive standalone medical devices, the need to get a physical within the walls of the clinic, the level of expertise necessary to provide standard medical procedures. At the demonstration station I stood in line with other TEDMED conference goers to get such tests as blood pressure, weight, heart rate, oxygen saturation, inner ear, lung function, ultrasound, and ECG, all using smartphone applications and accessories. Thousands of miles away in a village in rural India something very similar to the concept of “smartphone physical,” though not as extensive or high tech, was in use by midwives during postnatal care (PNC) visits in patient homes. Midwives and other frontline health workers are using smartphone medical applications, some relying on integrated sensors and accessories, to conduct some of the same tests of basic vitals and a host of point-of-care diagnostics. In India, the smartphone PNC aimed to fill the gap in postnatal care for women and children in this region by enabling the visit to take place in patient homes, outside of the clinic, using an affordable, easy-to-use device, and without a highly trained medical professional. While the smartphone postnatal care visit represents a considerably lower tech

variation on TEDMED's smartphone physical, they both embody a similar imagination of technological convergence across strikingly disparate contexts. What does it mean that these so-called technological solutions can span such distinct contexts? And what can we learn from thinking about them in relation to each other, through communication lenses? The "smartphone physical" offers an emblematic example of a new category of data instrument that challenges institutions of healthcare and raises questions about the shape of data-intensive transformations in health. These are the questions I take up in this dissertation.

Introduction of the Problem

"The more data you have the clearer you see." This slogan from the IBM Smart Planet commercial epitomizes an information-idealizing logic driving many important data-intensive transformations across almost all arenas of human activity. But this logic reflects oversimplified assumptions about the nature of data as self-evident and fantasizes about a world computable and controllable, one disembodied from human experience. My dissertation considers healthcare as an arena in which informationalization, the process in which "information generation, processing, and transmission become the fundamental resources of productivity and power" (Castells, 2000, p. 21), is increasingly central in policy making and market decisions. Through the informationalization process, bodies, patients, and populations are made computable, and healthcare work is articulated as information-processing activities algorithmically coded into software operating through information and communication technologies (ICTs). The social and economic problems facing healthcare are transcoded into information problems, and ICTs are positioned at the center of proposed solutions. As processes of informationalization redefine health and healthcare in technological terms, reframing patients as users and technological devices as solutions to institutional problems, this shifts the locus of healthcare policy and design

to technical realms. Yet the logics underlying the processes of design, use, and evaluation within data-intensive transformations are not fully understood; nor are their diverse and heterogeneous implications for the future of healthcare institutions, organizational arrangements, and care practices across different contexts. This dissertation investigates these logics and their social and organizational implications across communities and contexts of digital health in the U.S. and India.

Defining Digital Health

There is already a plethora of consumer oriented health-related mobile apps (over 50,000 available on iTunes by one count¹) along with an abundance of other self-tracking devices and wearables, tracking a range of states such as heart rate, diet, physical activity, ovulation cycle, stress levels, and mood. The explosion of affordable, accessible instrumentation and data streams represents a convergence of diagnostic and therapeutic tools targeted toward health professionals with ICTs in the consumer realm, and devices formerly reserved for clinical use are now available to consumers (for example, consumer-grade pulse oximeters are available in sporting goods stores). *Digital health*, defined as “applying the most advanced information and communication technologies to the collection, sharing and use of information that can improve health and healthcare” (World Economic Forum, 2012b) is an umbrella term used to describe a range of data-intensive efforts in the health arena. Digital health includes efforts such as electronic medical records (EMRs), mobile health and wellness applications, clinical decision support or direct-to-consumer self-diagnosis software, and self-tracking and biosensing devices to monitor various aspects of health and wellness (for example, blood pressure, diet, and fitness).

¹ App Store Metrics <http://148apps.biz/app-store-metrics/?mpage=catcount> (accessed April 30, 2014)

The convergence of ICTs with an array of medical devices, biosensors, and medical applications represents a category of data-intensive technology that I refer to as *digital health technology*.

Digital health has subsumed the next generation of data instruments and technologies being introduced through mobile health, telehealth, and ehealth, around which new types of data, data science, and predictive modeling are being promoted as vehicles toward data-driven and personalized medicine. The telehealth model is now extended “to include cell phones and Internet-based telecommunications tools for remote and home health management with video assessment, remote bedside monitoring, and patient-specific care tools with event logs, patient electronic profile, and physician note-writing” (Ackerman, Filart, Burgess, Lee, & Poropatich, 2010). Mobile health (mHealth), a term coined in 2005, which evolved out of “ehealth,” now represents its own domain, and can be defined as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, tablets, personal digital assistants (PDAs), and other wireless devices” (mHealth Alliance, n.d.). For many mHealth advocates, the ubiquity of mobile devices in both developed and developing countries presents opportunity for the mobile to become the platform for delivery of health services and information and health- and wellness-related applications (e.g. Price Waterhouse Cooper, 2012; Vital Wave Consulting, 2009). Mobile health and pervasive sensing also create a data-intensive environment generating digital traces, in which so-called “small data” and “big data” approaches to health in these communities rely on “virtuous circle of data and computing technology” (Mundie, 2007, p. 223; cf. Estrin, 2014). The production and circulation of knowledge about bodies, patients, and population is reconfiguring across distributed sociotechnical networks. This presents opportunities for shifts in expertise, patient identities, and definitions of health and wellness (Eysenbach, 2008; Lupton, 2013a; Webster, 2002). The ubiquity and pervasiveness of ICTs as

tools of measurement and mediation, the increased availability of digital health records, and an emerging participatory culture around personal information challenge previous distinctions among social domains of healthcare and medicine. Yet these transformations in healthcare are not determined or uniform; rather they are contingent and materialize heterogeneously across different groups, in different places, and at different times.

While the focus of this dissertation is on the data-intensive transformations occurring across the field of health and wellness, this research is situated within and in conversation with literature theorizing broader trends of informationalization and investigating the complexities of data-intensive transformations occurring in other arenas, such as political organizing (Howard, 2006), biology (Chow-White & Garcia-Sancho, 2011), design and construction management (Dossick & Neff, 2010; Neff, Fiore-Silfvast, & Dossick, 2010), journalism (C. W. Anderson, 2011), and warfare (Cronin & Crawford, 1999; Fiore-Silfvast, 2012). The following section will conceptualize and situate the problem of data-intensive transformation in health and wellness within a broader set of approaches to informationalization.

The Problem of Data-Intensive Transformation

Just as the “information society” has many proximate terms, such as post-industrial society (Bell, 1974), mode of information (Poster, 1991), the information economy (Porat, 1977), and the network society (Castells, 2000), the process of informationalization can be understood in association with terms such as informatization (De Mul, 1999; Webster, 2002) and informing (Zuboff, 1988), all oriented around a cultural, economic, and technological imperative to render a growing network of people, things, processes, practices, and ultimately our “worldview” (De Mul, 1999) into interoperable and computable digital information. The term informationalization, as used in this dissertation, encompasses and builds across these

concepts, focusing in particular on informationalization as a sociotechnical process that operates and heterogeneously materializes on multiple interlaced scales and which underlies data-intensive transformations. In other words, my approach brings together the macro perspective of the informational “mode of development” (Castells, 2000), with the embodied, transformational qualities and forms of informationalizing within the interactions and configurations of daily life and work (Zuboff, 1988).

From a macro-oriented perspective, informationalization marks a transformation from the industrial mode of production, which relies on the production and circulation of energy, to the informational “mode of development,” which relies on “the technology of knowledge generation, information processing, and symbol communication” (Castells, 2000, pp. 16–17). For Castells (2001), this heralds a new economy based on “informational capitalism” and a new society configured through networks constituting a “space of flows.” This notion of a “space of flows,” linking locations at a distance “around shared functions and meanings on the basis of electronic circuits and fast transportation corridors, while isolating and subduing the logic of experience embodied in the space of places” (Castells, 2001, p. 171), represents a guiding logic for the technological imaginations evoked in discourses of digital health, in which networks of digital health information flows seamlessly link individual, clinical, administrative, and scientific domains through a series of information feedback loops.² Two common assumptions pervade this technological imagination for digital health and shape expectations for data-intensive transformation of healthcare: (a) digital health technology supports new, faster digital health data mobilities and interoperability, linking the contexts and communities of digital health; and (b)

² Also akin to the “end to end” design principle evident in discourses of the internet, see Gillespie (2006)

the digitally interconnected and networked production and flows of digital health data among contexts and communities will lead to better and more efficient health and wellness.

These technology-driven assumptions are challenged in the embodied experiences of informationalization across the field of health and wellness when data are insufficient to bridge contexts and domains of digital health. This argument echoes and builds on others' work that has challenged assumptions that ICTs will necessarily make data more mobile and that the networked mobility of health data will mean improved health or mobility of care (Coopmans, 2006; Mort & Smith, 2009). The value generation around digital health information relies on the processes of disassembly and reassembly across multiple utilization contexts, which in turn require new sociotechnical configurations, organizational arrangements and forms of labor. Emerging from observations about the contextual nature of medical information, a law of medical information proposed by Berg and Goorman (1999) states that "the further information has to be able to circulate (i.e. the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production" (p. 7). With a similar recognition of the work of translation, Mol (2002a) observes that in healthcare "most facts come as comparative facts" (p. 218) which require nuanced interpretation and analysis to be made meaningful. For example, in order for health information to be made meaningful for an individual patient, it requires an interpretation within or disentangling from comparative structures embedded in databases that are often centered on normalized statistics of a given population.

The work of meaningful translation or "disentanglement" is often underestimated in health information technology policy and development discourse as a result of assumptions that technologically defined links are enough to bridge the gap between different contexts of

information utilization (Berg & Goorman, 1999, p. 7). As succinctly stated by Berg and Bowker (1997), “The ever unattainable ideal of pure quantifiable knowledge remains a driving organizing force, even when it is patently absurd“ (p. 531). Information here is neither a coded transmission nor an isolated entity as envisioned by Norbert Wiener’s cybernetics and Claude Shannon’s mathematical theory of communication (Gleick, 2011); rather it is “entangled in the context of its production” (Berg & Goorman, 1999, p. 7). What makes information meaningful to a particular community is the way that particular information is generated and what people do with the it. This is the work that is problematically overlooked in the development and implementation of healthcare technology solutions, and it is that translation work that will be taken up in this project.

Digital health technology affords new possibilities for convergence and generativity through data recombination and reuse, thus multiplying the contexts of use for health and wellness data. This research addresses what I argue is one of the greatest challenges for data intensive transformation in healthcare. That is: how to mobilize digital health data across different contexts of use and reuse and make data valuable for multiple stakeholders. To discover what is required to support sociotechnical interoperability across multiple domains of health and wellness, we need to investigate the data frictions—or the ways in which data are sticky within discourses, practices, and organizational structures.

Drawing on Jensen and Winthereik’s (2013) use of Anna Tsing’s concept of “friction,” defined as “the awkward, unequal, unstable, and creative qualities of interconnection across difference,” (Tsing, 2005, p. 4) I analyze the embodied interactions and encounters of information infrastructures across digital health domains. As Jensen and Winthereik (2013) observe,

Information doesn't suddenly flow out of the categories and classification it is contained in, nor does it jump from one technological platform to another all by itself. At the same time, no infrastructure boundary is entirely static. And the fact that information is constrained in various ways doesn't mean that it is easy to control, or that it is always effective (Loc. 142)

These authors describe a stickiness of categories and platforms that makes it difficult for information to flow and generates friction in its encounters, while also noting the relational, emergent nature of infrastructure boundaries. In conceptualizing digital health infrastructures and their interstitial interactions this way, we understand that beyond simply facilitating the technological interoperability of data, the questions of *sociotechnical* interoperability are of even greater importance for understanding how digital health data moves across boundaries, how it can be made valuable for different stakeholders, and how data-intensive transformations can be supported within and across the communities of digital health and wellness.

It is important to occupy the everyday encounters and interactions around producing, communicating, and sharing digital health data within and across multiple domains digital health. Studying processes of informationalization from the perspective of daily work experience and interaction, Shoshanna Zuboff, in her 1988 book *In the Age of the Smart Machine: The Future of Work and Power*, suggests that *informating* is distinct from other processes of *automation* in that as information technology functions to accomplish work it simultaneously generates new streams of information about its underlying activities. She shows how the *reflexive* nature of the informating process within organizational contexts is both deeply imbricated within local organizational structures and relationships of power and generative as information that can be shared and appropriated by others in multiple contexts of use. Zuboff (1988) argues that the process of informating also has the potential to reconfigure the nature of work and the relationships that constitute organizational activity, but that it cannot do so without new social and organizational orders that shift configurations of power shift (p. 10-11). This helps us

understand the *frictions* co-produced through data-intensive interactions across digital health domains as both potentially destabilizing and generative. Thus data-intensive transformations in digital health must grapple with the “stickiness” of discourses, practices, organizational structures for data moving across contexts and with the expanded possibilities for data recombination and data reuse, multiplying contexts of use for data.

Description of Study

In order to understand the complex social and organizational implications for data-intensive transformations in healthcare, this study examines digital health innovation as it is mediated and negotiated across diverse social and institutional contexts in the U.S. and India. My research approaches digital health innovation on three levels: (a) discourses of and in the field of digital health, (b) communicative practices across communities, and (c) organizational structures and labor. Drawing on two years of qualitative, ethnographic observations, participation, and interviews across the emerging digital health ecology, I study how different groups and communities of practice, including digital health technology designers, innovators, and advocates, clinicians and ehealth providers³, and a wide range of users of digital health technology and health and wellness data, are adapting to data-intensive transformations in healthcare. Our capacity to adapt to heterogeneous contexts for healthcare is essential for solving the great challenges of healthcare, whether it is a midwife in rural India using a smartphone to monitor the heart rate of a newborn or a fitness enthusiast and Quantified Self (QS) participant in

³ Ehealth has been defined as an “emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” (Eysenbach, 2001)

the Bay Area using a smartphone to monitor his heart rate as a metric of wellness. I engage with these communities focused around digital health innovation in rural low-resource settings and in consumer health and wellness settings in both countries to ascertain differently situated stakeholder positions around digital health. The comparative view elicits potentially unexpected shared sociotechnical configurations as well as previously overlooked multiplicity and heterogeneity across multiple contexts. Thus this project looks far beyond questions of health outcomes, cost-effectiveness, and technical optimization to consider through a communication lens (a) the ways data is interpreted and valued, (b) the communication practices around, with, and through data, and (c) the different contexts shaping people's practices with data.

Across the two national contexts that are the focus of this study, the United States and India, digital health is heralded by policy and industry leaders as “a technological fix” (Gillespie, 2007) for the seemingly entrenched and intractable problems in healthcare. Yet within each national context we can recognize the specific institutional domains that address these problems by their historically specific ensembles of knowledge, skills, traditions and practices (Kallinikos & Hasselbladh, 2009). Together, India and the U.S. provide settings across, between, and within which different and overlapping dimensions of digital health can be productively analyzed and compared. India is a BRIC country⁴, at once rapidly growing but still not as wealthy as Europe and North America, and as such represents both a center for global health oriented Information Communication Technologies for Development (ICTD) efforts⁵ and an important emerging

⁴ Brazil Russia India and China (BRIC) was first coined in a 2003 Goldman Sachs investment report and now refers to the emerging developing states and economies with significant growth potential.

⁵ ICTD has multiple variants and is referred to as ICT4D. There are also more specific strains of ICTD focused on health, such as IC4H or ICTH, but for the purposes of this project I situate

consumer health and wellness market. The U.S. is an OECD country⁶ with both a national agenda to informationalize healthcare and an expanding, vibrant consumer health and wellness market that advocates project will “disrupt” formal healthcare institutions. In both national contexts, communities of practice emerging around buzzwords such as “Health 2.0”, “mHealth”, “telehealth”, “ehealth” and “Quantified Self” bring together healthcare institutions, users/consumers/patients, patient groups, scientists, technologists, and private industry into conversations about how ubiquitous and pervasive sensing from networked consumer mobile devices can translate into better health and wellness outcomes. However, in practice more complex and somewhat incongruous stories and experiences take shape and materialize around the processes of co-configuration in digital health innovation and the multiple performances of digital health technology across different contexts and communities.

Theoretical Framework

As I have described, the transformations associated with digital health can be understood within a broader class of data-intensive transformations occurring across many industries and facets of social and organizational life (Castells, 2000). I argue that informationalization is a key foundational process underlying these transformations that ties together a range of discursive, social, organizational, and technological arrangements, and thus provides a rich lens for conceptualizing the entangled multi-modal, multi-scalar, and multi-valenced phenomena of digital health. The previous section outlined my approach to conceptualizing the problem of

these sub disciplines within the larger community of practice of ICTD. This distinction isn't critical to the project at hand.

⁶ Organization for Economic Co-operation and Development (OECD) is used to refer to a set of higher income, economically advanced nations that are members of a cooperative alliance. <http://www.oecd.org/about/>

data-intensive transformation in health and wellness through engaging processes of informationalization on multiple scales across discourses, practices, and structures, and by relating macro-level dynamics and embodied practices across different contexts for digital health. In the following sections I explain the theoretical framework that underpins my study of data-intensive transformations of digital health throughout the dissertation.

Understanding Data-Intensive Transformation through Communication and Technology Theory

Theories of Informationalization

As growing arenas of human activity are mediated through ICTs, social scientists need to adapt and generate theory to articulate the emerging challenges and opportunities this scale of informationalization presents. Across many fields studying and developing information technology, informationalization represents a technical accomplishment, a process by which an operation or object is modeled as information in an effort to re-engineer or optimize for greater efficiency and accuracy. This technology-driven and productivist perspective at its worst forgets that information systems are social systems (Heeks, 2008) and frames ICTs as neutral and passive means for delivering and transmitting information. What emerges with this perspective is an understanding of information processing as independent from social life, separable from social interaction and communication within which information exchange and processing traditionally took place (Kittler, 1997). This is how many data-intensive technologies become divorced from communication processes as they informationalize human activity. In this section I articulate a gap between information systems and communication and technology theories of informationalization and make the case that communication scholars are in a particularly good place to advance theory for the study of data-intensive transformations.

Historically, informationalization has been associated with projects of rationalization and modernization and studied in relation to a diffusion of innovations model that reveals how particular communities or groups are adopting and adapting to the ICT occasioned informationalization (Rogers, 2000, 2003). Communication studies have also approached informationalization as the process of modifying the structure and function of communication networks and transforming the logic shaping media and underlying new modes of production (Castells, 1996; Manovich, 2001). Thus, the study of informationalization has been dominated by macro-level perspectives in the social sciences that mostly blackbox the process and study it as a formative context for or characteristic of organizational, social, or economic change (see, for example Castells, 2000; Rogers, 2000).

Informationalization has been studied within Science and Technology Studies (STS) scholarship as a sociotechnical process with a sharp eye to how information and technology are constructed, mediated, and micro-processed within particular cultural contexts and discourses (see, for example Bijker, 1995; Orlikowski, 2000; Pinch & Bijker, 1984). These scholars have thoroughly demonstrated the ways in which technology centric perspectives often construct information as neutral, disembodied, and decontextualized, rather than value-infused, socially constructed, and inextricable from its context of production (see, for example Berg & Goorman, 1999). Similarly scholars demonstrate how information infrastructures are far from neutral. Instead, they represent particular politics and values, embodying a series of social and political negotiations that shape, what counts as information, what gets organized and categorized, and what gets excluded or rendered invisible in the process (Bowker & Star, 1999; Star & Strauss, 1999; Star, 1999). From this view, data highlight the performative agencies of metrics along with

measurement technologies in the mediation of information and data (see, for example Berg & Bowker, 1997; Gitelman & Jackson, 2013; Mol & Law, 2004; Schubert, 2012).

Between the general theories of information society and the rich contextual accounts of information technologies, a gap for middle range theory for the transformations associated with informationalization emerges in the literature. From an information systems perspective, Kallinikos, Aaltonen, and Marton (2010) call for theories that focus on “particular practices or contexts without losing sight of those generic processes that recur across context as the result of the diffusion of information technologies” (para 1). These middle range theories would focus beyond the functional and structural processes occasioned by informationalization and the technical mediation of human activity and organizational processes towards considering “the blackboxed mechanisms through which technologically driven information processes reassemble reality and, in doing so, reframe the premises upon which individual and collective subjects perceive and act upon that reality” (Kallinikos, 2009, p. 184) This process of informationalization, what Kallinikos (2009) calls the “computational rendition of reality,” refers to when the bases, the very substrata for modes of action and communication, are configured as technological information through analytic reduction and decomposition of their “character and complexion” (p. 185). As I see it, Kallinikos is calling for theory that accounts for the *sociomaterial agencies of computation* as integrated across perspectives of technical mediation and for the co-configuration of organizational processes and structures.

Data-Intensive Technology as Media Technology

I argue that advances at the intersection of STS and communication and technology theory can begin to fill this articulated gap for middle range theories. Theories of media technology have conceptualized their “double articulation” as objects or artifacts situated within

particular contexts and as media or texts infused with symbolic content (Livingstone, 2003; Silverstone, 1994). Scholars have brought together an STS focus on the social and material co-configuration of artifacts and a communication theory focus on the symbolic and material co-configuration of media and text.⁷ Moving beyond the conceptualization of these co-configuration processes as separate, scholars have called for further foregrounding the intertwined nature of technical or material mediation and interpretive practice (Siles & Boczkowski, 2012). Media technology embodies this interpenetration, as they inscribe the information they process, both mediating and memorializing their content (B. Clarke, 2010, p. 134). I agree with scholars that have advocated a practice-based perspective as necessary to make visible the interpenetration of sociomaterial agencies of both content and artifact in the use of media technologies (Boczkowski & Orlikowski, 2004; Couldry, 2004; Orlikowski, 2000). From this perspective we recognize that symbolic and material agencies for both content and artifact are interpenetrated and activated through processes of co-configuration of information and technology in communicative practice. I conceptualize data-intensive technology as media technology and apply this view of co-configuration that takes into account the interpenetrated nature of artifact and content as situated within material and interpretive practices.

Recent work at the intersection of STS and Communication Technology studies has begun to engage more deeply with the underlying material and symbolic logics mediating data-intensive environments that shape how we communicate, what we know, and what we can do. In particular, work on the sociology of algorithms has begun to interrogate the algorithm as a “fragile accomplishment” that is constituted through an entanglement of human and nonhuman

⁷ See Lievrouw (2014) for a review of STS and Communication theoretical approaches to media technology.

agencies (Gillespie, 2014). This work has demonstrated the presumptions built into algorithms (Ananny, 2011), the power of algorithms in governing flows of information (C. W. Anderson, 2011), their role in producing publics (boyd, 2010) and identities (Cheney-Lippold, 2011), and their entanglement in practice (Gillespie, 2014). Gillespie (2014) and others advocate for deconstructing algorithms in order to discover what relationships they encode and for conceptualizing algorithms as a type of communication technology.

A theory of mediation advanced by Leah Lievrouw (2014) aims to encompass the multiple levels and processes of interpenetration and mutual determination. This analytical framework for *mediation* examines the “ongoing, articulated, and mutually determining relationship” among the reconfiguration of artifacts, the remediation of expression and interaction, and the reformation of patterned social and institutional arrangements (p. 45).

Applied to data-intensive technology, we can conceptualize data as emerging from communication media and therefore always contextually shaped and embedded into processes of communication and materiality. This takes into account sociomaterial agencies of computation as they are entangled in processes of communication. This can begin to shape how we understand the ways in which computational logic mediates and redefines the activity it informationalizes and thus reshapes the material affordances for computation and communication.

What may be distinct about this moment of informationalization is that computational tools have become not only our primary information storage and processing tools, but also our “primary media of expression” (Gillespie, 2014, p. 168). Indeed, not all computation is media, nor is all communication and media indexed computationally, yet these processes are increasingly entangled through our use of data-intensive media technology. Not only do computational logics underlie our mode of communication, which subjects “human discourse

and knowledge to these procedural logics that undergird all computation” (Gillespie, 2014, p. 168), but computation also co-produces new data out of data that affords a range of social and material interactions.

Digital Health Technology as Media Technology

Across the technology-driven field of digital health, the appropriate uses for digital health technology are configured as technological fixes for solving problems of data access or processing efficiency without attending fully to the problems of data as mediated communication. Thus the complexities of care, organizing, and communicative practice tend to get separated from information processing and exchange (Kallinikos, 2009). My conceptualization of digital health technologies as media technologies helps rectify some of the myopic tendencies of other perspectives. Thus it is able to more appropriately characterize its symbolic and material multivalent, multidimensional performances across institutional and individual domains. In attending to digital health technology as media technology, or a sociomaterial assemblage of artifacts, practices, and social and institutional arrangements, this perspective helps to maintain a view of digital health data as mediated communication as socially and materially imbricated in a communication process. Filling the gap that Kallinikos points to and engaging with communication technology theory allows us to develop a lens that accounts for data as mediated communication.

Digital health technologies mediate the sharing and communication of health and wellness information across occupational and organizational boundaries, but they also mediate and co-produce digital health data that then becomes sites for multiple material and interpretive practices. To conceptualize digital health data as mediated communication, I draw on Lievrouw’s (2014) mutually constituted processes of mediation. The first process is the making of or

reconfiguring of data, translating experience, body functioning, and talk into data. For example, mobile-based glucometers prompt users to draw blood to test their glucose levels, submitting that blood into a biosensor that produces a glucose level reading that automatically uploads to smartphones. Blood is transcoded into data that is understood as representative of body functioning. The second is sensemaking around and with data, or *remediating* data, such that it becomes a site for interpretation, diagnosis, and connection. Examples could include algorithms that categorize glucose level data based on encoded standards of care, sharing glucometer data with a case manager to make sense of patterns over time and relate it to other lifestyle patterns, or using the glucometer data for self-diagnosis or self-management. The third function is *reformation* of the social and institutional arrangements around data that organize and structure its meanings and power. Where arrangements are defined as “patterns of relations, organizing, and institutional structure,” this includes any changing or remaking of these patterns around the self or for others in society. Using the example of the diabetic patient, reformation could be an intervention from a case manager or self-directed behavior change based on knowledge developed around patterns in the individual’s glucometer data. Separating these three functions of mediation allows us to disaggregate multiple practices with data and the processes of co-configuration of data performances across different settings.

Digital Innovation in Organizing

In my approach to conceptualizing data-intensive transformations across different contexts of digital health, I focus on the processes of innovation emerging across the digital health ecology and the implications for social and organizational arrangements. This requires a theoretical framework that helps articulate the changing fabric of innovation, as processes of digital health innovation intertwine digital and physical materialities (Yoo, Henfridsson, &

Lyytinen, 2010). Processes of digital health innovation most often center around an expectation of pervasive digital technology across multiple domains and contexts. Of course, this pervasive digital technology across domains of healthcare is not a reality around the globe or even in many areas of the U.S. That said, as many digital health advocates have noted, the mobile phone's pervasiveness increases the reach of digital technology, and therefore digital health, to a previously unimaginable extent. This is the impetus fueling the excitement over mobile health across consumer, government, and global development contexts. However, this pervasiveness of digital technology does not mean that its affordances are accessible, realizable, or even desirable for everyone for a host of reasons. Nor are digital health technologies separable from a web of other social and material relationships of power, including unevenly distributed resources and infrastructures.

Nonetheless, there are key properties of digital technology and affordances for organizational innovation that span the wide swath of digital health contexts. These are important to consider as a framework for conceptualizing and comparing processes of digital health innovation. Yoo, Boland, Lyytinen, and Majchrzak's (2012) work on digital innovation and organizing offers such a framework. First, they argue that when digital technology is pervasive, its unique properties of reprogrammable functionality and data homogenization lead to digital environments that afford particular types of organizational innovation. They argue that these digital environments afford organizational innovation through digital technologies characterized by convergence and generativity. The concepts of convergence and generativity are not new to theories of digital media and the internet (see, for example Jenkins, 2006; Zittrain, 2008). However, Yoo et al. (2012) offer a framework for conceptualizing multiple aspects and

dimensions of convergence and generativity associated with digital innovation. In the following paragraphs, I adapt this framework to conceptualizing the processes of digital health innovation.

Convergence in Digital Health Innovation

First, digital health innovations can be characterized by the convergence of user experiences, in which the affordances of digital health technologies as media technologies bring together media content, storage, and distribution (Yoo et al., 2012). This user experience convergence is evident in a mobile app for diabetics that tracks glucose levels over time, provides recommendations and educational content, and sends the information to a clinician. As Castells (2000) observes, “the convergence of experience in the same medium blurs somewhat the institutional separation of domains of activity and confuses codes of behavior” (p. 391). Second, digital health innovations may be characterized by the convergence of technology, bringing together physical and digital technology (Yoo et al., 2012). This is evident across all the smart health devices and mobile apps that bring together sensors and software with devices, things, and wearables. Third, digital health innovations afford the bringing together of previously separate industries (Pool, 1983; Yoo et al., 2012), such as with the growing ties between medical and telecommunications industries. However, even the industrial-level convergence may not live up to what Jenkins (2006) argues represents convergence. For Jenkins, convergence is nothing short of a “paradigm shift” (p. 15) in which relationships between institutional actors, related enterprises, and cultural logics shift. This ongoing process unfolds over time and space.

Generativity in Digital Health Innovation

Pervasive digital health technology affords generativity in three ways (Yoo et al., 2012). First, digital health innovation may be characterized by the delayed binding of form and function such that new capabilities may be added after a product or a tool has been designed and

produced, in what Zitttrain (2008) calls “procrastinated binding” (Yoo et al., 2012, p. 1399). For instance, the fact that smartphones have the capability of accommodating different health and wellness apps and medical accessories makes that platform amenable to a range of medical or health-related functionalities. The second dimension of generativity afforded through digital technology is what Boland (2007) calls “the wakes of innovation,” the ways digital health innovation may transform how we work and produce knowledge across the field of health and wellness. For example, as more digital health data is captured and aggregated from individuals outside the clinic, the work of data production and sensemaking shift to individuals and other emergent intermediary roles (Cartwright, 2000; Mort, Finch, & May, 2009; Oudshoorn, 2008). Insights based on aggregated data may in turn reshape health and wellness standards and what is considered normal. The third dimension of generativity is the anticipated and unanticipated uses of digital traces left as by-products, what Yoo et al. (2012) call “derivative innovations.” I have also discussed this affordance in relation to Zuboff’s (1988) definition of the informing that characterizes the reflexive nature of information technologies. Digital health innovation may capture and aggregate digital traces, or what Deborah Estrin calls “small data,” to generate personalized health data profiles or population level health trends through personal analytics and “big data” approaches (Estrin, 2014). These data may also be leveraged in a process of “dataveillance,” in which the descriptive, predictive, and prescriptive practice of monitoring, aggregating, and sorting data may be used as control and compliance measures (Raley, 2013, p. 124). Thus, as digital health and wellness technology increasingly mediate our day-to-day lives, “our acts of participation or self-communication themselves become data, the entirety of our everyday life practices subject to, and constituted by, perpetual calculation” (Raley, 2013, p. 126).

Materiality as Performed Relations

Key considerations for this project are the social and organizational implications for digital health innovation of the dimensions of convergence and generativity materializing across the digital health ecology are key considerations for this project. These implications are considered through conceptualizing the relationships among various communities and the networks of digital health across which data production and sharing is distributed, and by examining the processes of design, implementation, and evaluation of digital health technology within particular institutional and organizational contexts. Researchers have noted that implementation does not occur as a simple diffusion process that can be evaluated in terms of whether communities adopted the innovation or not, as is suggested in the diffusion of innovations model (Rogers, 2003). Because this model takes a more productivist approach to innovation, it tends to configure the agency of prospective users as limited to the decision to adopt or not adopt technology, thus categorizing users as innovative based on how quickly they adopt a new technology (Burrell, 2012a; Sey, 2011). Instead, the process may be better understood as a series of “translations” (Latour, 2007) that reconfigure the innovation as well as the broader networks through which it is constituted. This is particularly true with digital innovation processes that often center around a platform, are distributed across heterogeneous groups and knowledges, and afford what Yoo et al. (2012) term *combinatorial innovation*, referring to the recombining and modularity of different aspects and layers of digital innovation.

This calls for a definition of materiality that can attend to the intertwined physical and digital agencies and analytically activate the ongoing reconfigurations of the innovation and broader networks. It must also attend to the multiplicity, “that which takes different shapes in different places” (Law & Urry, 2004, p. 403) and with its associated processes of translation. For

this I adopt a definition of materiality, not as “pre-formed substances,” but rather as “performed relations. “ This strategy allows for attending to the “recursive intertwining of the social and material as these emerge in ongoing, situated practice” (Latour, 2007; Orlikowski, 2007, p. 1438; Pickering, 1995). This definition is similar to one adopted by Burrell (2012b) who conceptualized the materiality of the oral form, rumor, as seemingly without matter, yet with great material consequence. Burrell prioritizes the processes of materialization rather than the work of categorizing material and non-material. This stance establishes the “interdependency and inextricability of material and non-material in an ontological and practical sense” (p. 316), and affords the conceptualization of the materiality of rumor, undetectable as a physical thing, in the same way that it affords the conceptualization of the materiality of the dimensions of the digital realm.

Digital Health Ecologies

I situate the processes of digital health innovation within emerging digital health ecologies. Digital health ecology refers to the emergent, heterogeneous assemblage of artifacts, discourse and practice, and social arrangements across the multiple social domains of digital health. In this section I present a framework for conceptualizing and mapping the convergence of different domains of practice and knowledge production and the data-intensive transformations emerging across the digital health ecology. I identify three domains of practice and knowledge production across the digital health ecology: (a) science and technology development situated in the “Lab;” (b) medical practice and healthcare situated in the “Clinic” and (c) consumers/patients and participatory cultures situated in every day social life, referred to as “Home.” These domains are not clearly delineated in practice; nor are they mutually exclusive. However, they provide a way to analytically engage with the emergent interstitial interactions that are challenging the

boundaries of institutionalized discourses and practices. As shown in this diagram (Figure 1), there are “spaces of convergence” (Chow-White & Garcia-Sancho, 2011) among the domains that are reshaping the emergent ecology of digital health. Central to each of these transformative processes is a shift in the practices of production and aggregation of digital health data that contributes to reshaping boundaries between categories of patient and consumer, clinical and non-clinical, health and wellness, and citizen and scientist. The relationships that emerge across domains and interactions within the spaces of convergence between Clinic and Home, Clinic and Lab, and Lab and Home frame how I approach the studying the digital health ecology.

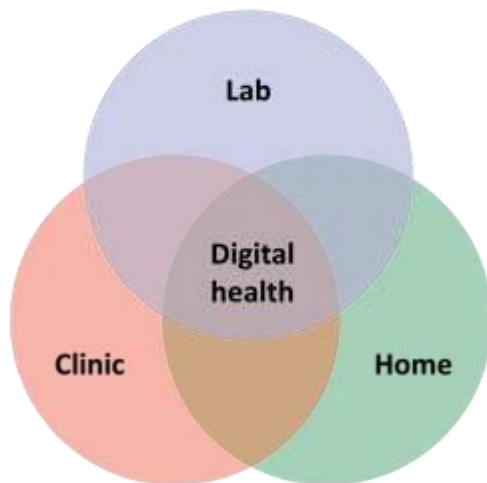


Figure 1. Illustrates the domains of practice and knowledge production that constitute the digital health ecology and the spaces of convergence emergent through the data-intensive transformations of digital health.

The processes of change emerging in the convergence of the Clinic and Home include the biomedicalization of society⁸, which reflects the increasing biomedicalization of everyday life; here, the increasing medical jurisdiction over everyday behaviors and lifestyle decisions recasts a

⁸ Biomedicalization is defined as the “the increasingly complex, multisited, multidirectional processes of medicalization, both extended and reconstituted through the new social forms of highly technoscientific biomedicine.” (A. E. Clarke, Mamo, Fishman, Shim, & Fosket, 2003, p. 162)

growing number of aspects of life as medical problems (Burri & Dumit, 2007). Simultaneously, trends of consumerization of healthcare and individualization of medicine function to reframe the once “passive” patient as an active, reflexive, and responsible health consumer and participant in their own health care and wellness. One can see this framing exhibited in terms such as “health 2.0” or “patient 2.0” (Eysenbach, 2008; Lupton, 2013a; Topol, 2012). One transformation emerging in the convergence of the Lab and the Clinic is the twinned scientification of biomedicine and the technologization of healthcare, where technoscientific innovations are increasingly applied in medicine, shaping how medical knowledge is produced. These processes transform medicine and biological sciences into information sciences and medical problems into problems of information. The processes of transformation emerging through the convergence of Lab and Home include the biotechnologization of society (Burri & Dumit, 2007), the datafication of everyday life, and the digitization of humans. Together these forces generate big and small data that fuel personal health and wellness analytics, a science of the individual, and a vision of personalized medicine (see, for example Flores, Glusman, Brogaard, Price, & Hood, 2013; Topol, 2012). There is also a shift towards engaging participatory and consumer cultures in citizen science, producing and diffusing biomedical knowledge, along with a do-it-yourself consumer movement (Swan, 2009).

Informationalization of Bodies, Patients, and Populations

Questions about the emerging processes and implications of informationalizing bodies, patients, and populations are at the center of understanding data-intensive transformations across the digital health ecology. Over the last few decades, many social theorists have pointed to shifts towards more information oriented medicine and approaches to care. Thus the growing role and status of information in medicine and healthcare is not new. As such, several researchers propose

that information-oriented medicine represents a new medical cosmology⁹, referring to it as “e-scaped medicine” (Nettleton, 2004), “informationalistic medicine” (De Mul, 1999), “information age health care system” (Eysenbach, 2000), and “surveillance medicine” (Armstrong, 1995). As part of an expanding ecology of information oriented medicine, the coupling of ICTs and medical technologies in digital health engenders new forms of representing and embodying the patient and has the potential to transform the “medical repertoire” to redefine health, medicine, and the body (Webster, 2002). As the body, the patient, and the population are increasingly being defined in terms of measurable and available data, knowledge about these entities is also being shaped, in turn, through the ongoing reconfiguration of informational infrastructures. Information infrastructures “provide the tools—words, categories, information processing procedures—with which we can generate and manipulate knowledge” (Star & Bowker, 1995, p. 41) and need to be examined as part of a sociotechnical assemblage that is continually remaking and reforming through relational interactions across networks of humans, information, and technology (Latour, 2007).

Informationalized bodies

Digital health technologies can be seen as part of a longer history of monitoring and recording devices that have been employed to make bodies visible, calculable, and governable (Armstrong, 1995; Foucault, 1980; Rose, 1999). Rose (2007) suggests that contemporary medical technologies are technologies of optimization seeking to “control the vital processes of

⁹ “Medical cosmologies” refer to guiding conceptual structures, such as those in orientations, tools, environments, and knowledge. How these shift, for example, from “person-oriented medicine” to “object-oriented medicine,” reveal the way to conceptualize the re-assemblage of a medical network of relationships and interactions within broader sociotechnical changes (Jewson, 1976).

the body and mind” (p. 16), revealing the invisible pathologies that define the body in terms of risk. This makes the potential future of the body a subject of calculation, and an object of preventative and pre-emptive intervention as the “existentially healthy” are reconfigured as “asymptomatically or pre-symptomatically ill” (Rose, 2007, p. 19). Data-intensive practices of monitoring and recording represent the body as information, but in the process, they also reshape the body as they function to configure and reconfigure complex bodily experience, knowing, and concepts of selfhood (see, for example Mol & Law, 2004; Nicolini, 2011; Oudshoorn, 2008).

Prior scholarship demonstrates the growing use of information as a metaphor for biology and its implications for the construction of subjectivities and the ontology of the body itself (Chow-White & Garcia-Sancho, 2011; Haraway, 1991; Hayles, 1999; Keller, 1995; Martin, 1994). This metaphor can most easily be recognized in the convergence of genomics and information technologies (Chow-White & Garcia-Sancho, 2011), in which bodies are conceptualized as genetically coded information. Haraway’s (1991) notion of the “cyborg” articulates the blurring of boundaries between technology, information, and organism as the body evolves into a flesh-information-amalgam. Similarly, Haggerty and Ericson (2000) describe the emergence of a new type of body, one that can be disassembled, broken down into informational flows, and then reassembled and combined in ways that are useful for institutions. The authors tie this informational body to the rise of surveillance technologies that produce what the authors term a “data double” (Haggerty & Ericson, 2000). This view sees the data double as “disembodied” from the flesh and thus devoid of meaning.

Yet it may be more productive to think about the ways in which the data double reduces or transforms different bodily subjectivities in qualitatively different ways (Bauer, 2007). New ways of visualizing and commodifying the body transform how we perceive bodies, personhood,

and ourselves (Cartwright, 1995; Dumit, 2004; J. S. Taylor, 2008). As Taylor (2005) suggests, biomedical technosciences may be providing new ways of giving the body surface. In this view, bodies are not something we have, but something we do; they “take shape and take place through social practices” (J. S. Taylor, 2008, p. 12). Thus the expanding practices of self-tracking, as explored in the Quantified Self (QS) movement, and patient monitoring, enacted through telehealth and mobile health models, are new ways of shaping and doing bodies. These data-intensive processes of informationalization afford to an even greater extent what Mol (2002b) describes as the body multiple, where the multiple practices of enactment now linked in to other flows and networks continually remake the body as multiple sites for knowing and intervention and for reconfiguring topologies of care and embodiment.

Informationalized patients

The transcoding of individual experience and bodily states into information and its subsequent translations across different realms of healthcare work is an increasingly central activity of healthcare. As the information is reassembled and interpreted as a “patient” in different healthcare settings, the healthcare organization’s informational infrastructure needs frame and configure what information makes up a patient. The physical individual patient body becomes an “icon” for what Verghese (2008) terms the “iPatient,” a situation in which the streams of data about the patient often attract more attention than the patient who is sitting physically in the office or remotely at home. In fact, the iPatient can be fully formed from the practitioner’s perspective before that practitioner has actually confronted the physical body of the patient, and it often forms the basis for driving clinicians to act, make decisions, and to *do* the actions that comprise their jobs, whether that is ordering a test, prescribing a drug, or recommending an operation.

The informationalized patient is also what is exchanged through organizational interactions among the primary care team, performing as an “immutable mobile” (Latour, 1987) across contexts. Yet Berg and Bowker (1997) demonstrate the multiplicity of a patient medical record as artifact that mediates the bodies it configures and as infrastructure that serves different organizational, clinical, and institutional needs. The “*different* records and different practices of reading and writing are intertwined with the production of different patient bodies, bodies politic, and bodies of knowledge” and are therefore at the center of coordinating different meanings and uses (p. 515). Additionally, the circulation of patient information can happen outside of clinical settings and in unanticipated ways, as with ultrasound images that were reappropriated across different contexts to perform different cultural meanings, whether it was as a first “baby picture” to share with friends or as part of anti-abortion activist materials (J. S. Taylor, 2008). These examples draw our attention to the multiple potential lives of digital medical images and information as they circulate not only within healthcare organizations, but also within broader social, political, and economic networks. Furthermore, as medical knowledge networks become more diffuse and distributed and digital health technologies become more widespread throughout the public, the role of patients as participants and knowledge producers in their own right becomes increasingly salient in conceptualizing the Informationalized patient (Epstein, 1995, 2008). The notion of patient as medical information producer potentially reconfigures previously established relationships between patients and clinical expertise and raises questions about how clinicians and health organizations may adapt to patient-generated data

Informationalized populations

The expanded practices of informationalizing bodies and patients across domains of digital health are part of larger visions and practices of representing, monitoring, and now

predicting the health and wellness of populations. A rich history of the role of quantification in medicine has been traced by scholars to reveal how bodies could be understood at a distance, commensurable with others, aggregated in ways that could be used to govern populations (Foucault, 1998; Hogle, 1995; Rose, 1999) Making differentiations, then, within aggregated population data becomes a “form of pragmatics” to facilitate the institutional monitoring populations (Haggerty & Ericson, 2000, p. 614) as the information infrastructures, in turn, shape the individual and collective subjectivities across populations.

Databases are a central fixture within healthcare information infrastructure and are a central innovation of the information economy (Chow-White, 2008; Suchman, 2005, 2007). The database “structures our personal and institutional experiences both symbolically and materially” (Chow-White, 2008, p. 1172) . Loro’s concept of a “networked multilogue” (1995, p. 55) is used to describe the interfaces that databases enable “between producers and consumers through the process of sorting and storing data, networking information, and constructing knowledge” (Chow-White, 2008, p. 1172). In this way the database can be conceptualized as a discursive, organizational practice that constitutes its objects and produces subjectivities (Poster, 1996, p. 182). Thus knowledge and particular subjectivities are produced through databases only through algorithms manipulating relationships between bits of information—relationships formed within its system but that don’t exist as such outside the algorithm and its associated database. This raises questions about the implications for a data-driven way of analyzing relationships across massive datasets that could escape our capacity to make sense of or explain these relationships (boyd & Crawford, 2012).

The informationalization of bodies, patients, and populations fuels a vision for personalized, predictive medicine. Proponents of a data-intensive approach to discovery, referred to as the fourth paradigm, aim to leverage this approach to advance medicine and healthcare.

The ability to compute genomics and proteomics will become feasible on a personal scale, fundamentally changing how medicine is practiced. Medical data will be readily available in real time—tracked, benchmarked, and analyzed against our unique characteristics, ensuring that treatments are as personal as we are individual. Massive-scale data analytics will enable real-time tracking of disease and targeted responses to potential pandemics. Our virtual “macroscopic” can now be used on ourselves, as well as on our planet. And all of these advances will help medicine scale to meet the needs of the more than 4 billion people who today lack even basic care (Mundie, 2007, p. 224).

This vision of personalized medicine relies on the informationalization of bodies, patients, and populations such that they can be computed, analyzed, and monitored. Through the process of data-mining, a way to search, filter, and generate knowledge out of digital databases (Chow-White, 2008), advocates foresee the capacity to both provide more personalized medicine and to monitor larger populations. For instance, in the pharmaceutical industry, pharmacogenomics is the technological platform on which visions of personalized medicine rest, in which companies can match pharmaceuticals to the appropriate human genetic profile (Lakoff, 2008, p. 753). Thus by directly linking illness populations to market segments, these healthcare outcomes interests dovetail with commercial interests in the potential for more personalized drug treatments, consumer marketing and interactions, and the ability to reach larger segments of consumers. The trend towards personalized medicine relies on constructing an individual through aggregated data in order to bring the power of “big data” analytics to bear on individuals, through a macroscopic view. The development of the macroscopic, the lens with which we are able to view what is too large and too complex to see otherwise, has become a central goal of informationalization.

In the previous section I have outlined the overarching theoretical frameworks that inform my research approach. The following section develops my theoretical stances in relation to three primary research questions focused at the levels of discourse, practice, and organizational structures.

Digital Health Discourses and Practices

The Doing of Digital Health Discourses

Discourse is a central analytical concept for this dissertation project, forming the backbone of my approach to studying the data-intensive transformations of digital health across multiple contexts. There are many ways to conceptualize and leverage the term “discourse” (for an overview, see Gee, 2013; Van Dijk, 1997), but, in brief, I concur with Potter and Wetherell (1987) that discourses “do not just describe things; they do things” (p. 6). This implies a need to approach discourse as language-in-use and to attend to the ways in which discursive structures are translated into heterogeneous sets of practices, social organization, and physical artifacts (Hedgecoe & Martin, 2003). While it is arguable that not all discourse materializes in the sense that it does things, I focus here on discourses that materialize both through their performativity (Barad, 2003, 2007), and through the potentially ongoing and multiple material effects of their performances. For the purposes of this dissertation I am interested in how discourses of and about digital health and the discursive practices and language-in-use within communities of digital health “do things.”

Technology-in-Practice

With this approach I take the relationships among discourse, structure, and action to be mutually constituted (Fairhurst & Putnam, 2004; Giddens, 1984; Phillips, Lawrence, & Hardy, 2004). To conceptualize the role of technology within these mutually constituted relationships, I

adopt an interpretive and practice-oriented approach drawing on a technology-in-practice approach (Orlikowski, 2000). Unlike approaches associated with social determinist or technological determinist perspectives, the technology-in-practice approach, along with a host of other middle range mutual shaping approaches, locates agency across emergent configurations of social and technical elements or sociomaterial assemblages throughout different periods of time in the unfolding of their constitutively entangled relationship (Boczkowski, 1999; Orlikowski, 2007; Suchman, 2007). This view does not assign agency to either the social or the material. Rather, it reframes agency as sociomaterial, in which the social and material are “inextricably related—there is no social that is not also material, and no material that is not also social,” and all practices are sociomaterial, shaping the possibilities of everyday organizing (Orlikowski, 2007, p. 1438). In adapting a model of structuration theory and adopting a practice-oriented lens, we can perceive the situated use of these technologies and means of communication as part of the greater structuring of sociotechnical systems. In focusing on the emergent technology structures enacted in situated practice rather than embodied structures fixed in technologies, scholars have demonstrated how different groups enact different structures of technology use or “technology-in-practice” with the same type of technology across various contexts and practices (Barley, 1986; Orlikowski, 2000, 2007). Thus digital health technology in practice is shaped within particular contexts of use and situated within a network of sociomaterial relationships and configurations of power. From this view, data-intensive transformation embodies the complex processes of sociotechnical change, in which new structures mediate and emerge from entangled social and material practice (Orlikowski, 2007).

I draw on Hutchby’s (2001, 2003) elaboration of affordances as a language for conceptualizing the relational quality of material and symbolic agencies and their entanglement

within broader networks of artifacts, practices, and arrangements. They are “opportunities for or invitations to action that things present to actors” (Lievrouw, 2014) that offer a way to occupy a middle ground between technological determinism and social constructivism. As Hutchby (2001) describes, affordances are “*ecological*, in the sense that they are properties of the environment *relative to an animal*” (p. 404). This relational and ecological view allows us to attend to the “embodied human practices in real time situated interaction involving technologies” (Hutchby, 2003, p. 582), and for studying the interactions that emerge from the material and technological affordances and constraints within particular contexts. This lens allows us to account for the affordances and constraints of both digital health artifacts and discourse in practice across multiple contexts.

Framing the Relationship of Technology and Social Change

Digital health technology, like any other technology, is accompanied by discourses about what the technology is, what it will do, how it should be used, and how it will change the state of things, in this case, healthcare (Yates, Orlikowski, & Okamura, 1999). These discourses frame the relationship of technological and social change by defining each and articulating a link between them. We can then ask *how digital health technology discourses are framing the relationships of technological and social change across different contexts of health?* In other words, *what sets of values, politics, and expectations are implicated in technological imaginations advanced through discourses about what digital health technology is and what it will accomplish across different contexts?* Yet as the approach I have detailed demonstrates, the relationship of technological and social change is indeterminate and emergent in practice within particular contexts. As Borup, Brown, Konrad, and Van Lente (2006) demonstrate, the experience of disappointment around science and technology is most often tied to the specific

structure of expectations and their operation. They point out that especially in the early stages of technology, the organizational and social factors may be downplayed. Thus “expectations of technology are also seen to foster a kind of historical amnesia—hype is about the future and the new—rarely about the past—so the disjunctive aspects of technological change are often emphasized and continuities with the past are erased from promissory memory” (Borup et al., 2006). As Leonardi (2008) demonstrates, the rhetoric of technological determinism accompanying the implementation of technology made the fundamentally indeterminate relationship of technology and organizational culture appear determinate, shaping users’ perceptions of the technology and the processes of socially constructing technology. Thus the rhetoric and discourse about and around technology matters for how it is perceived by designers, users, and non-users, and for the processes through which technology is configured and reconfigured in practice (Leonardi & Jackson, 2004). In this way, it becomes essential to identify the technological imaginations projected for digital health technologies in different discursive contexts and understand how they are implicated in the varying approaches to design, implementation, and evaluation in the field.

Themes Characterizing Technology and Social Change

In the rapidly changing field of digital health the discourses around technology and social change remains under-theorized, especially in terms of their roles in shaping how the relationships of technology and social change are negotiated within different health contexts. Across various contexts of digital health, prior literature reveals that dominant discourses orient around technology-driven social changes in health and healthcare, whether this is in the context of development (Chakravartty, 2009; Gomez, 2013; Warschauer, 2004), U.S. government (A. E. Clarke, Mamo, Fishman, Shim, & Fosket, 2003), or the technology-industry-driven consumer

health contexts in the U.S. and India (Lupton, 2012). These observations are reinforced through examining the rhetoric across the gray literature and digital health efforts, along with the ventures that emerge from these contexts. Indeed, the term *digital* health (even *mobile* health or *telehealth*, for that matter) draws attention to the change in technology even as health remains the same. While researchers have articulated and critiqued the problematic technology-driven trends, not enough has been done to parse out more precisely what relationships and expectations for technology, or technological imaginations, are being articulated within technology-driven social change discourses in health. Even more, these more nuanced technological imaginations have not been compared across different contexts to elicit the distinct and similar ways in which they may be situated in relation to different contexts. To fill this gap in understanding how the discourses of digital health frame the relationships of technology and social change across different contexts, I identify three mainstream themes characterizing technology-driven social change in digital health discourses across different contexts. The themes are technology-driven institutional change, democratization of power, and redistribution of labor. These themes around digital health technology are, of course, situated within broader discourses about technology and social change, and in particular, within the social transformations associated with digital media and the Internet. The connection across discourses of digital media technology as applied more broadly to society and more specifically to different industries should not be surprising. Yet around each shared theme there are differently positioned technological imaginations emerging from the multiple discursive contexts of the digital health field that are of great interest. In this next section I briefly review each theme as it is articulated in the dominant discourses surrounding the social transformations associated with digital media technology.

Discursive Theme 1: Institutional Change

Dominant discourses around the social consequences of ICTs have emphasized the shift to networked forms of communication and organization (W. Bennett, 2003; Castells, 2000), purportedly disrupting institutionalized hierarchies of power across industries. The digital revolution is often likened to previous technology-driven revolutions in predicting “a radical discontinuity from history and the present human condition” (Carey & Quirk, 1992). Imagined this way, the “digital revolution” expands individual autonomy and the potential for decentralized, distributed, collaborative, peer-to-peer forms of production and innovation outside or apart from the jurisdiction of formal institutions (Benkler, 2006; Christensen, 2013; Tapscott & Williams, 2006).

As such, the focus for many writing about the “digital revolution” has been the disruptive potential of digital media, where the Web “is really an internetworked constellation of disruptive technologies—is the most robust platform yet for facilitating and accelerating new creative disruptions” (Tapscott & Williams, 2006, p. 31). As such, it effectively redraws boundaries between formal institutions and individuals, professional control and open participation, centralized and decentralized production. For instance, in the case of journalism, Lewis (2012) describes how the discourse around open participation linked to digital technologies directly challenges the professionalism of journalism. For Lewis (2012) this represents a tension between open participation and professional control, and more broadly a tension between users and producers across creative industries. Popular discourses characterizing the digital revolution across journalism and other industries often frame digital technologies as “disruptive technologies” and often refer to their associated transformation as “disruptive innovation.” Healthcare is often noted as one of the last industries to be disrupted by the digital revolution (Vaitheeswaran, 2010). The same characterizations of disruption apply in healthcare, in which

digital health technologies are framed as disruptive technologies and terms such as the “creative destruction of medicine” and “disruptive innovation” are used to describe the transformations associated with when the digital revolution meets the institutions of healthcare.

The logic that accompanies the frame of disruption has roots in Clayton Christensen’s much-popularized theory of disruptive innovation (Christensen, Bohmer, & Kenagy, 2000; Christensen, Hwang, & Grossman, 2008; Topol, 2012). When a disruptive innovation occurs in an established field, what it offers has less to do with improving the original product or service and more to do with offering simplicity, affordability, and accessibility, thus generating a whole new plane of competition. Central to this process is medicine’s codification of knowledge, whereby experts are considered to hold intuitive knowledge, which is rendered explicit and precise so that it can be acted on by technicians. Codified knowledge becomes a product that can disrupt institutions, which is how algorithms can be framed as the cheaper, more accessible, simpler, and only slightly less skilled doctors of the future (see, for example Khosla, 2012). This theory as applied to healthcare positions the healthcare systems as healthcare industry incumbents that should be challenged and competed with in market-driven and technology-enabled ways. Disruption becomes a “natural process” that if allowed to flourish can build a cheaper, better, and more convenient system than the current status quo. This view frames technological innovations as driving the disruption of the status quo from outside of the system and frames the status quo as an inefficient and ineffective healthcare system that is fundamentally broken and unsustainable.

Discursive Theme 2: Democratization of Power

The second theme of democratization of power is pervasive across digital revolution discourses. In this theme, ICTs are imagined as tools for the democratization of information and

use, and in which individuals have an ICT-expanded capacity to act in the world (see, for example Bruns, 2008; Castells, 2009; Howard, 2010; Jenkins, 2006; Tapscott & Williams, 2006; Von Hippel, 2006). This theme emerges through claims around convergence culture (Jenkins, 2006), participatory culture (Jenkins, 1992), democratizing innovation (Von Hippel, 2006), and produsage (Bruns, 2008), terms that share the idea that digital media and the internet create opportunities for the empowerment of those who interact and participate (Rheingold, 2003). Across discourses of development, ICTs are often linked to notions of individual empowerment (Asiedu, 2012; Avgerou, 2010) and are seen as providing the infrastructural conditions that facilitate democratization in the political sphere (Howard, 2010). The rhetoric around democratization of ICTs, information, and power that characterized much of the excitement around “Web 2.0,” where “everyone becomes a content producer” (O’Reilly, 2005), is evident across digital health discourses, as seen in the popularity of terms such as “medicine 2.0” and “health 2.0” across scholarship and gray literature (Eysenbach, 2008; Van De Belt, Engelen, Berben, & Schoonhoven, 2010). Many policy-makers and scholars have portrayed the Internet as technology that changes the balance of power in the medical world in favor of the patient (Hardey, 1999; Mittman & Cain, 2001), and increasingly, the health consumer (Hardey, 2001). Take, for instance, a Silicon Valley health technology company called Scanadu, who is developing a tricorder, of the Star Trek variety, a tool “to scan and track health in real time” that would be enable consumers to diagnosis and monitor their health outside of the clinic. In their words, “Our vision is to put Tricorders into the hands of millions of people all around the world, enabling the individual to be a stakeholder in health, and bringing about a citizen-driven revolution in medicine worldwide” (Scanadu, n.d.). This vision epitomizes much of the rhetoric

espoused by digital health advocates; it is the same sales pitch given for transformations across countless other industries and institutions, including politics, journalism, and business.

Discursive Theme 3: Redistribution of Labor

The third theme around the social consequences of technological change is the redistribution of labor. In relation to labor, technology has a long history of being linked to projects of rationalization, in the service of the reduction of reliance on skilled human labor and management's control revolution (Beniger, 1986; Braverman, 1998; Lilley, Lightfoot, & Amaral, 2004). ICTs are often configured as tools of efficiency, reengineering or optimizing work processes (Castells, 2000; Yates & Van Maanen, 2001). While this industrial-era logic of automation is still alive and well, the new forms of labor are associated with data-intensive and networked digital technology are decentralized, individualized, and networked (Castells, 2000). Digital technology is often linked to distributed work and co-productive arrangements of labor (Benkler, 2006; DeSanctis & Monge, 1998; Fulk & DeSanctis, 1995) and seen as an important agent of a change that moves production away from hierarchical control and creates a comprehensive platform upon which new ways of accomplishing work develop (Barley & Kunda, 2004). In particular, scholars associate algorithms with replacing and automating forms of expertise and judgment (Gillespie, 2014). Increasingly, information algorithms present the appearance of automation and objectivity, obfuscating the labor, values, and politics upon which their functioning relies (Downey, 2014; Gillespie, 2014). Labor, in particular, has been pushed increasingly outside formal institutions into the distributed, aggregated networks Shirky (2008) calls the "wisdom of the crowds." By the same token, the same terms that referenced empowering the user, such as "produsage" and "participatory culture," provide the "free labor" (Terranova, 2000) and "digital labor" (Scholz, 2012) of cultural production. This theme is

evident across dominant digital health discourses that link ICTs to efficiency in organizations, portray algorithms as replacing clinical expertise and judgment, and shift digital health information production outside of formal healthcare institutions to individuals and “networked publics” (boyd, 2010).

Taken together and applied to studying the emergence and implications of digital health across different communities and contexts, these themes provide grounding for situating the range of technological imaginations for digital health across different contexts. These dominant themes are problematic for a host of reasons that will be discussed in more detail in Chapter Three. In the health arena, the discussions about the democratic potential of the Internet, the technology-driven empowerment of patients and consumers, and the shifts in institutionalized relationships between patients and medical professionals make a significant omission: They largely underestimate or entirely overlook, the work, resources, and competencies necessary for developing and implementing such changes (Henwood, Wyatt, Hart, & Smith, 2003a; Oudshoorn & Somers, 2006; Rice & Katz, 2001). Not only are the relationships of technology and social change infinitely more complex and messy than the simplified relationships advanced across the mainstream themes, but the emergence of these relationships are situated within different institutional arrangements of power, culture, and infrastructure. Across different discursive contexts of digital health, the political and social accomplishments of digital health are still being negotiated through a range of technological imaginations in relation to the three themes characterizing the relationship of technology and social change.

This study, then, seeks to articulate and compare the different “technological imaginations” enacted across the different discursive contexts of our research sites. Of course, these imaginations and implicated expectations around the themes of digital health technology

and social change materialize in practice in heterogeneous ways as they are adapted, negotiated, or resisted within different contexts and communities of digital health. This leads us to ask: *How do different technological imaginations around these key themes frame how digital health innovation is approached in design, implementation, and evaluation in the field?*

Challenges for Data Use and Reuse Across Domains of Digital Health

As I have described in the previous section, discourses of how technology will transform health and healthcare often fall short of expectations in practice. The technological imagination of digital health technology that provides an infrastructure for the seamless flow of data across the domains of digital health relies on technically defined interoperability. Yet in practice there are many challenges for data as it moves across social domains. On the one hand, standardization represents the foundation of interoperability as the promised technical solution for integrating heterogeneity across disciplines (Ribes & Bowker, 2009), medical practice (Hogle, 1995; Timmermans & Berg, 2003), operating procedures in cancer research (Fujimura, 1992); medical protocols (Timmermans & Berg, 1997) and data conventions (Millerand & Bowker, 2009). On the other hand, standardization as a method and a goal is always a social and political process with material and symbolic dimensions (Bowker & Star, 1999). In Bowker and Star's (1999) words, "systems of classification (and of standardization) form a juncture of social organization, moral order, and layers of technical integration" (p. 33). However, social studies of technology literature have demonstrated that this translation works across multiple contexts of use, frequently in informal spaces and adaptive non-standard interactions, and often in spite of the more formalized information systems in place (Berg & Goorman, 1999; Hogle, 1995; Latour, 2007; Suchman, 2007). As Larkin (2008) reminds us, "Flows for all their seemingly disembodied

nature, require material conduits. They appear because a place is embedded in precise networks of social relations built over time” (p. 251).

Taken together, the anticipated flows of digital health data across communities and contexts are in fact embodied and embedded within practices and materiality. As this technical interoperability falls short, scholars should engage with the ways digital health data is being produced, negotiated, and shared within and across different communities at the practice level. By doing so, we can answer some important questions: *What are the challenges for data use and reuse across different social domains of digital health? Why do so many digital health efforts fall short of expectations?*

Co-configuration of Technology and (Re)Use

Understanding how digital health efforts fall short of expectations in practice requires examining the processes of design and use across different communities to identify the gaps, tensions, and frictions in the performance of digital health data across multiple contexts of use. To do this, I draw on theories of co-configuration of technology and use, theories which have established how anticipated scripts of appropriate use and configurations of users get baked into technology design and how users, through their use and non-use, reconfigure technology-in-practice (Akrich & Latour, 1992; Akrich, 1992; Oudshoorn & Pinch, 2003b; Woolgar, 1991). Scripted programs of action that anticipate competencies and subject positions of users may shape user identity, invite or afford some interactions and uses over others, and delegate competencies and responsibility across people and things (Oudshoorn & Pinch, 2003b; Suchman, 2007). Of course, users can challenge and resist such scripts, reconfigure technologies, and socially calibrate the relationships between people and things (Akrich, 1992; Latour, 1987).

Increasingly, with the responsiveness between technological features and user behavior encoded in computationally-based media technologies, processes of design and use are overlapping, mutually shaping one another iteratively, in a process of design-in-use (Neff & Stark, 2004). This suggests that agencies become more difficult to pinpoint in time as they shift across designer and user groups, their roles and identities beginning to blur together, calling attention to the shifting and expanding role of the user in technology development. As Suchman (2007) suggests, “Rather than holding stable and separate the identities of “designer” and “user,” the latter work as categories describing persons differently positioned, at different moments, and/or with different histories and future investments in projects of technology development” (pp. 278-9). Furthermore, the processes of production, sharing, using and reusing of digital health data generate a multiplicity of uses, , potential users, and contexts of use over time that may be anticipated and unanticipated. Thus the many different subject positions and the dynamism over time pose challenges for designers anticipating the scripts relating user, use, and context of use.

To conceptualize the processes of design, use, and evaluation of technology across the complex, multi-valenced communities and contexts of digital health, I draw on an already well-established critique and iteration of these frameworks of co-configuration. As such, scholars have suggested other taxonomies to account for the diversity of users, with differently implicated participation in a broader category of use beyond the direct human and technology interaction (Burrell, 2012a; Casper & Clarke, 1998; Mackay, Carne, Beynon-Davies, & Tudhope, 2000). For instance, Burrell’s (2012a) study of Internet cafes in Ghana found an entirely unanticipated category of users developers could not have imagined: youth so disconnected from processes of design and development that the language of conformity and resistance were meaningless. In the

face of this, Burrell advocates a broader set of proximate roles more distanced from the human technology interaction yet still important in materializing the technology-in-practice.

Emerging from the feminist sociologist critique is an expanding framework that captures power relations in technological development, the heterogeneity of actors, and, in particular, previously ignored women's voices (Oudshoorn & Pinch, 2003b, p. 6). Work in this vein advocates differentiating between end users, lay end users, and implicated actors. *End user* refers to individuals and groups who may be affected downstream by technological development (Casper & Clarke, 1998), while *lay end users* are those end users who may be excluded from expert discourse (Oudshoorn & Pinch, 2003b, p. 6). *Implicated actors* are those “who are either not actually present and/or denied agency in the situation, but for whom the action in the situation is or likely will be consequential” (A. E. Clarke, 2005, p. 189). For instance, the role of implicated actors helps us understand Forsythe's (1996) study of the design of a migraine patient education system in which nurse and patient voices were muted, signaling the power differential between doctors on the one hand and nurses and patients on the other and the privileging of expert knowledge over experiential knowledge (p. 558).

Entangled Social and Material Lives of Data

The processes of digital health technology design and use present unique challenges as the multiple uses and contexts for use span different communities situated in different domains of digital health. First, conceptualized as media technology, we must understand the processes of co-configuration of digital health technology and use/non-use, user, and context of use in relation to the intersection of materiality and content, as media and artifact. Thus we need to consider the symbolic and material logics not solely of data as mediated, but also of data as mediated communication. This suggests that frameworks of co-configuration may need to be adapted to

take into account the increasingly networked, diverse, and multiple enactments of digital health technology. This includes the ways in which the entangled social and material lives of data extend across multiplying contexts of use. Pre-existing frameworks are in need of expansion and extension to account for entangled social and material lives of data. Expanding these frameworks can also help explain the gaps between anticipated and actual use, and they could do so across different networks, communities, and practices around data.

Second, the work of translation is most often not considered when conceptualizing the use of digital health technology. Core to this challenge of translation are the multiple expectations and values for how data will perform in particular institutional contexts or social domains. For these different expectations and values for data, I use the term *data valence*, a theoretical concept I develop further in Chapter Four. This leads to the following question: *What are the primary valences evoked by digital health communities and stakeholders?*

Data valences are multiple across social domains, and demand is increasing for digital health innovations to support polyvalent data. For example, in digital health, a clinician may value data for its ability to suggest clinical actions, at the same time that some patients may value data more for simply representing them or their disease condition (Fiore-Silfvast & Neff, 2013). While it is relatively easy to see the different relationships and practices with data—different data cultures—within well-defined disciplines, these data cultures are much harder to uncover in interactions among multiple disciplinary, professional, and social perspectives in the imagining and interpreting of data. This is the case in healthcare. In part this is because, as Gitelman and Jackson (2013) suggest, every disciplinary institution and body of knowledge has “its own norms and standards for the imagination of data,” and “different data sets harbor the interpretive structures of their own imagining” (p.3). Thus in investigating the gaps between the anticipated

and actual appropriate use and users throughout the digital health ecology, we can ask, *How do data valences help explain the gaps in communication of and around health and wellness data across communities and institutional contexts of digital health?* Answering this question can help us understand at a deeper level the challenges for data use and reuse across digital health domains and point to the tensions that result in digital health efforts that fall short of expectations.

Organizational Restructuring and Intermediary Labors

New technologies often challenge existing organizational forms. To understand data-intensive transformations as they emerge and materialize across the field of health and wellness requires attending to the underlying processes of organizational and technological change. In particular, I seek to understand *how processes of organizing adapt with the introduction of digital health technology across different contexts?* In other words, *what is required organizationally for adapting to digital health technologies across different institutional contexts?*

My point of departure builds on work reviewed in the previous sections that views data-intensive transformation as processes of sociotechnical change, within which the relationship between technological and organizational change is mutually constituted (Bechky, 2003b; Houston & Jackson, 2003; Latour, 1991; Leonardi, 2009; Orlikowski, 2000). To study this mutually constituted relationship, scholars of technology and organizing have adopted multiple perspectives that engage this middle range between technological determinism and social constructionism.¹⁰ Answering these research question requires an approach to analysis that

¹⁰ For a detailed review of these perspectives see Leonardi & Barley (2010)

accounts for multiple perspectives in relation to this mutually constituted change. In my approach I leverage both the “organizational alignment” perspective and “technology-in-practice” perspective in articulating how processes of organizing and digital health innovation mutually adapt (Leonardi & Barley, 2010).

The organizational alignment perspective focuses on a process of mutual adjustment of technologies and organizational ordering. This perspective allows for the articulation of an ongoing mutual constitution: The ways the introduction of digital health technology occasions the reorganization of work practices and emergent organizational restructuring in relationship to the ways the existing organizational structures and institutional contexts participate in constituting the processes of digital health innovation. The technology-in-practice perspective, as described previously, affords an understanding of how the ontology of the digital health innovation emerges in organizational practice and how organizational practices are reconstituted through new sociomaterial assemblages that reconfigure agency across human and nonhuman actors. Leonardi and Barley (2010) note that technology and organizing scholarship has tended to focus on one or the other and has rarely brought these perspectives together. I bring these perspectives together in this analysis in order to understand how these processes are intertwined and to develop a more nuanced account of sociotechnical change and stability.

With the increasingly convergent and generative nature of digital innovation, processes of organizational alignment must mutually adjust across increasingly distributed and heterogeneous groups that are situated within different social domains. As noted in the previous section, supporting polyvalent data presents new organizational challenges. The types of labor involved in supporting sociotechnical interoperability across different contexts of use often remain unarticulated and underappreciated in processes of digital health innovation. Leveraging both

organizational alignment and technology in practice perspectives, we can ask, *What types of labor and processes of organizational alignment are important for supporting social interoperability and polyvalence for data across contexts?* Taken together, we can articulate their intertwined emergence across the different organizational contexts. This inspires the following question: *What are the implications of different technology-occasioned organizational adaptation processes across both cases for innovation in digital health?*

An Occasion for Organizational Restructuring

Prior research has demonstrated that digital innovations play an important role in reorganizing work among different occupational groups. In providing “an occasion for organizational structuring,” new technology creates new configurations of human and nonhuman actors that may transform the balance of power across organizational roles and renegotiate professional jurisdictions (Barley, 1986; Bechky, 2003a; Suchman, 2007). In particular, in cases of healthcare organizations, researchers have found that technologies can enable shifts in tasks, roles, and relations, producing new patterns of interaction among occupational groups (Barley, 1986; Davidson & Chismar, 2007; Edmondson, Bohmer, & Pisano, 2001). Further, shifts in agencies across new technology provide the opportunity for configurations that have political consequences for the redistribution of authority and knowledge within work practices, thus influencing boundary relations and how boundaries are (re)drawn (Barley, 1986; Bechky, 2003b; Benoit-Barné & Cooren, 2009; Suchman, 2007). By the same token, scholars have shown that technological innovations not only influence, but are often shaped by the existing configurations of power and boundary relations across the organizational contexts in which they are implemented (Boland et al., 2007; Holmstrom & Boudreau, 2006; Zuboff, 1988). Thus the processes of organizational alignment are complex, contextually specific negotiations that are

vitality important in shaping digital innovation processes. For instance, Edmondson et al. (2001) analyzed and compared the implementations of minimally invasive cardiac surgery at 16 hospitals and found that the most successful implementations occurred in those hospitals where traditional role relations among surgeons, nurses, technicians, and anesthesiologists became less hierarchical and more collaborative; in contrast, unsuccessful implementations occurred in those hospitals where work practices replicated and reinforced traditional roles in the surgical theater.

The question remains as to whether (and when, and in what contexts) digital health innovation will cause the redistribution and renegotiation of power and work across professional boundary relations and organizational roles, or whether such innovation will reinforce or reassert organizational divisions and boundary relations. Indeed, digital health efforts are often advanced with the expectation that the introduction of digital health technology will lead to organizational restructuring in its various forms, such as the re-engineering of organizational efficiency, the creation of new relationships of compliance, or the shifting of power across groups. With the increasingly convergent and generative nature of digital innovation, processes of organizational alignment must mutually adjust across increasingly distributed and heterogeneous groups situated within different social domains. As noted in the previous section, digital health innovation presents new organizational challenges, and the labor involved in translation across different contexts of use for digital health data often remains unarticulated and underappreciated in processes of digital health innovation. Thus I turn now to examining the mutual constitution of organizational and technological change as it relates to technology in practice and to the associated, often invisible, labors upon which organizational infrastructures rely.

Labors of technology-in-practice

Organizational infrastructures represent entangled organizational and material practices (Orilkowski 2007). Different forms of labor, emerging through the recurring interactions around the technology in practice, recursively reshape the processes of organizational alignment. Together these different forms of labor function to both translate across and gradually form the working infrastructures for digital health (Star, 1991, 1995). I draw on Star's (1999, p. 380) concept of infrastructure as fundamentally relational, a concept that brings out two important characteristics: Working infrastructure only becomes real "in relation to organized practices," and because those practices are normally invisible, the infrastructure may only become visible when broken or in conflict (p. 382). Thus different types of labor may emerge as visible and invisible depending on when, where, and for whom infrastructure operates (Star, 1999). In the remainder of the section I provide a brief overview of the different concepts for labor that are important for the analysis of digital health innovation across organizational contexts.

Informationalizing Labor

Healthcare work happens in a complex sociotechnical network, co-constituted through interdependent interactions and relationships among people, tools, information infrastructures, and organizational routines. Digital health innovation operates through processes of informationalization that work toward standardizing the labor around patient information and representing healthcare delivery and management processes as information-processing activities. These efforts aim to represent and make explicit clinical knowledge and decision-making as related to technical and algorithmic protocols. However, a perspective on healthcare work that conceptualizes networks of people, tools, organizational routines, and documents resists that idea (Berg, 1999). Whereas informationalized descriptions and models of healthcare work might be

useful, such depictions are incomplete and rigid because they misrepresent work practices that are contingent, dynamic, and situated, and which unfold in interaction (Barley, 1986; Berg & Goorman, 1999; Hogle, 1995; Latour, 2007; Orlikowski, 2007; Suchman, 2007). For example, Hogle (1995) illustrates, in her study of the standardization of organ procurement practices, how local re-interpretations, accommodations, and forms of resistance reflected the diversity of lived experiences and bodies across various situations. The interactions between local practices and standardized global imperatives initiated new perspectives on and processes around the human body and produced new medical information that then provided feedback into the macro-organizational level of policy (Hogle, 1995, p. 496).

The informationalization of labor entails making organizational activity explicit, and in that there is always the question of what counts and what doesn't, and what distribution of visible and invisible work will emerge (Star 1999). There are limits and tradeoffs to making work visible (Star & Strauss, 1999; Suchman, 1995). Visibility can evoke a legitimating effect, recognizing the full range of effort of many groups that may not have the power to advocate for themselves and recognizing particular forms of labor that had been accounted for in designing systems. On the other hand, visibility can also provide a site for reinforcing control and surveillance of work practices (Star, 1999; Timmermans, Bowker, & Star, 1998). For instance, Star and Strauss (1999) found, in the case of nurses, that making things visible and explicit came with the tendency to classify, categorize, track—in essence, to Taylorize—their work practice, further turning them into targets of surveillance. It is not always beneficial for designers to further identify and specify work beyond what may be formally represented and described; thus, as work practices are informationalized, the challenge lies in striking a balance across visible and invisible labor (Star, 1999).

Emergent forms of Labor

As new technologies become normalized in practice, they can co-produce new forms of knowledge and labor within the social and organizational arrangements in which they are embedded. For instance, Taylor (2008), in her research on the popularization of ultrasound technologies, describes how ultrasound images became central to producing medical knowledge and ultrasound examination normalized within prenatal care, creating new demand for sonographers and ultimately constructing new forms of labor. Jonathan Sterne (2003) offers the stethoscope as another example of changing knowledge demands and social interactions. Stethoscopes provided physicians with a powerful diagnostic tool for monitoring the body's internal functions, but to be used effectively, they demanded physicians develop and learn new sets of listening skills. This served to shift diagnosis from its previous practice as the collecting of patient illness information through doctor-patient interaction, to one where the doctor was responsible for collecting the information—a profound change in doctor-patient social interaction.

At the center of changing professional roles and boundaries within digital health, then, are new delegations of labor. Studies have demonstrated that the introduction of telemedicine devices redistributes the interactional work with patients from physicians to nurses, and generates new categories of health professionals that conduct telehealth work outside the clinic (Cartwright, 2000; Mort, May, & Williams, 2003; Oudshoorn, 2012). This body of literature has also taken up the new competencies and labor now delegated to patients across new configurations of telemedicine (Nicolini, 2006; Oudshoorn, 2008; Prout, 1996). As digital health innovation requires new organizational arrangements it will be critical to attend to the underlying forms of labor that emerge and how emergent forms and distributions of labor across people and things may co-construct new identities or serve to transform or reinforce existing identities

(Oudshoorn, 2008). This requires examining the scripts of delegation advanced through the design process and how these scripts are negotiated in practice across multiple contexts of use.

Invisible forms of Labor

Many scholars have pointed to the invisible forms of labor that support organizational infrastructures (Downey, 2001, 2014; Star, 1999). For the purposes of this project on digital health innovation processes, I identify articulation labor, repair labor, and information labor as types of labor that are essential but often invisible or overlooked. *Articulation labor* refers to a broad range of work that attends to iterative and dynamic challenges of accomplishing work through a process of adjusting in real-time (Star & Ruhleder, 1996). *Repair work* is a type of articulation labor in that it is concerned with “the subtle acts of care by which order and meaning in complex sociotechnical systems are maintained and transformed, human value is preserved and extended, and the complicated work of fitting to the varied circumstances of organizations, systems, and lives is accomplished” (Jackson, 2014, p. 222).

From a historical perspective, because information revolutions privilege the development of technological innovation rather than “the *role and position* of labor in the process” (Blok & Downey, 2003, p. 3), *information labor* has been rendered mostly invisible. Information labor involves both putting information into circulation and realizing its value by setting it in a particular context, moving across contexts, and resetting it in a new context. Downey (2014) calls this “jumping contexts,” a concept he further develops in terms of different types of context to be jumped.

Increasingly, information labor is being transcoded into algorithmic labor, invisible and woven inextricably into the social material fabric of everyday life (Latour, 1996). This presents challenges for locating agency across new configurations of human and nonhumans. Algorithmic

labor may both shift the nature of some information labor and further obfuscate the labors displaced and implied by algorithms.

To summarize, Table 1 outlines both the general and respective specific research questions that I have articulated in the previous section. For each set of research questions I note the level of analysis that I will adopt and the chapter(s) in which this analysis can be located.

Table 1: Summary of Research Questions

General Research Questions	Specific Research Questions	Level of Analysis
R1: How are the discourses of digital health framing the relationships between technology and social change across contexts?	<ul style="list-style-type: none"> a. How are different technological imaginations advanced across discourses of the field of digital health situated in relation to key themes characterizing the relationship of technology and social change? b. How do different technological imaginations around these key themes frame how digital health innovation is approached in design, implementation, and evaluation in the field? 	Discourses and Discursive Contexts (Chapter 2 & 3)
R2: What are the challenges for data use and reuse across different social domains of digital health? Why do so many digital health efforts fall short of expectations?	<ul style="list-style-type: none"> a. What are the primary valences evoked by digital health communities and stakeholders? b. How do data valences help explain the gaps in communication of and around health and wellness data across communities and institutional contexts of digital health? 	Communities and Practices (Chapter 4)
R3: How do processes of organizing adapt with the	a. What kinds of intermediary labor and	Organizational Structures and Labor (Chapter 5)

introduction of digital health technology across contexts?	<p>processes of organizational alignment are important for supporting social interoperability and polyvalence for data across contexts?</p> <p>b. What are the implications of different technology occasioned organizational adaptation across both cases for innovation in digital health?</p>	
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Research Design

To study data-intensive transformations across the emergent digital health ecology is an inherently multi-sited, multi-modal, and multi-scalar endeavor. Articulating the historically situated and contextually mediated nature of data-intensive transformation across the digital health ecology, then, requires a focus beyond the consequences of particular digital health tools or information to the interdependent interactions and relationships among people, tools, information, practices, and the social and institutional arrangements across different contexts. To conduct fieldwork in this setting, scholars have proposed ethnographic techniques that bound the field site with networks and interactions to further transition from a physical “bounded space that the researcher dwells within, to something that more closely tracks the social phenomenon under study” (Beaulieu, 2010; Burrell, 2009, p. 196; Fortun, 2009). The field site becomes a set of interactions and relationships through which one can trace how knowledge is transformed and produced across organizational and institutional arrangements. With this approach, project boundaries emerged collaboratively with research encounters over time, “as the outcome of the project, rather than its precursor” (Hine, 2009, p. 18). The stories of digital health innovation

remain unbounded by categories of designers and users or by places of development and implementation; rather they span all related actors and groups that mediate the multi-sited, iterative, and continuous process.

Marcus (1995) defines multi-sited ethnography and research as “designed around chains, paths, threads, conjunctions or juxtapositions of locations in which the ethnographer establishes some form of literal, physical presence, with an explicit, posited logic of association or connection among sites that in fact defines the argument of the ethnography” (p. 105). This is very much the case for this dissertation in that the interactions or “conjunctions” across the domains of digital health—clinic, lab, and home—emerged as evolving research sites and defined the central challenges and opportunities for data-intensive transformation.

I adopt a practice-based lens to examine a multi-sited and distributed field of digital health. The practice-based lens takes practice not to be simply a description of what people do, but rather to be the activities that make meaning, form identity, and produce order (Nicolini, Gherardi, & Yanow, 2003). A practice-based approach privileges a conception of knowing as a process, as relational, situated, distributed and contingent, rather than centered within any one entity (Gherardi, 2010; Nicolini et al., 2003; Orlikowski, 1992, 2000). From this view, practice becomes the empirical ground from which we can investigate relationships of the material and the symbolic, organizing and knowing-in practice, technology-in-practice and context of use (Gherardi, 2010; Nicolini et al., 2003). The field of digital health is inherently multi-sited, across which the “site of knowing” is distributed across a “nexus of interconnected” practices and relationships (Nicolini, 2011, p. 603). This moves the focus away from individuals and technologies, even particular cultural entities, to the interactions, practices, and relationships of digital health technology and health and wellness data.

To study the processes of digital health innovation across the U.S. and India is to study relationships of power that are shaped by race, class, and gender. These are essential and important considerations for understanding the social and historical positions that underlie the relationships among stakeholder groups and get reinscribed in how we design, implement, and evaluate technology. This research does not focus specifically on race, class, or gender, as each dimension could warrant its own separate study. However, my analysis considers these dimensions as they relate to power dynamics that are evoked through the discourses, practices, organizational structures, and labor of digital health innovation.

In this section I outline a mixed qualitative methodological approach to answer the set of research questions posed in the previous section. The research questions posed operate across a range of overlapping and distinct sites, scales, and models of data-intensive transformation, and consequently, require multiple methodological approaches that together can account for the entangled nature of the studied phenomena. Approaching this research situation demands mixed methods that are capable of (a) contextualizing different digital health innovation processes within the pre-existing institutions and broader discourses of technological and future technological imaginations and expectations; (b) mapping and comparing the discourses and practices around digital health data across different digital health communities situated within multiple social domains; and (c) articulating organizational adaptation of digital health innovation at a micro level to understand key implications for configurations of labor and organizational structures.

Levels of Analysis

My approach focuses on three levels of analysis: (a) discourses, (b) communities and practices, and (c) the organizational structures and labor. These three levels of observation and

analysis move beyond micro and macro level perspectives to trace data-intensive transformation across shifting sociotechnical interactions and relationships that are materialized in the shifting of interconnected practices around digital health technology across and within the field of health and wellness. This practice-based approach provides a way to see both local interactions around information and the ways the local interactions are situated within a broader texture of relationships and associations. Nicolini (2009) calls this process “zooming in and zooming out:” While a “zoomed in” lens affords a detailed understanding of the effects of particular practices, “all practices are involved in a variety of relationships and associations that extend in both space and time and form a texture of dependencies and references” (Nicolini, 2009, p. 1407) which require disentangling. Disentangling associations requires broadening the lens or “zooming out” to make visible and comprehensible the interconnections and translations across practices and the work of making associations and sociotechnical arrangements (Nicolini, 2009). In order to understand how practices are interdependently related through informational networks, I “zoom out” to analyze the translation of knowledge between different utilization contexts. Across the social domains of digital health, I focus on the network of associations and relationships around information that must be disentangled in order to translate knowledge meaningfully across different contexts of use.

Discourses of the Field/in the Field

To understand how the relationship of technology and social change is framed across the discursive contexts of my four research sites and the implications for shaping the process of digital health innovation, I conducted an empirical and comparative discourse analysis focused around the three themes characterizing the relationship of technology and social change: institutional change, democratization of power, and redistribution of labor. This analysis situates

and compares the dominant technological imaginations advanced within each discursive context around these themes. I draw on Anne Balsamo's definition of the term "technological imagination" as "a character of mind and creative practice of those who use, analyze, design and develop technologies" (Balsamo, 2005).¹¹ These imaginations develop particular relationships between subjects and objects, and offer frames to think with, according to certain logics, assumptions and values. I take the technological imaginations advanced across the field of digital health to be reflective and constitutive of the sociotechnical relationships and practices negotiated in the field. In other words, these discursive frames at a macro level are an important part of structuring the discursive, material, and relational emergence of digital health in practice.

To contextually situate these technological imaginations, in Chapter Two I outline the discursive contexts for digital health within U.S. government, ICTD, U.S. consumer health, India consumer health. The ways in which digital health is approached, talked about and discursively constructed in each discursive context represent important background for situating technological imaginations and their implications for processes of digital health innovation across contexts. To conduct the discourse analysis, I draw on key resources across the field of digital health, including academic literature, industry documents, gray literature, and stakeholder interview and observation data, and I situate the conversations and texts within their respective discursive context. As part of understanding data-intensive transformation in digital health, it is important to evaluate the technological imaginations advanced as part of the discursive context that shapes the processes and practices of digital health innovation. This represents an under-examined

¹¹ Balsamo notes that her use of technological imagination is intentionally building on C.W. Mills' notion of the "Sociological Imagination." She cites C. Wright Mills (1959), *The Sociological Imagination*.

dimension of informationalization processes, yet it is essential for understanding how sociotechnical components interact and shape each other in practice.

Practices and Communities of Digital Health

Empirical ethnographic research has proven to be an effective way of mapping out complex negotiations within and among organizations experiencing technological change (Barley, 1986; Bechky, 2003b; Neff & Stark, 2004; Orlikowski, 1992; Suchman, 2007). For the purposes of this study, I employ a combination of ethnographic observations, semi-structured interviews, and participation within communities across the field of digital health to trace the transforming practices and relationships around digital health innovation across different contexts. To do this I adopt two approaches: a broader ecological approach to attend to the dynamic multi-sited and heterogeneous nature of digital health innovation across multiple stakeholder groups and communities of practice; and an in-depth comparative case study approach to attend to and compare the micro-level processes of organizational adaptation occurring through processes of design, implementation, and evaluation.

An Ecological Approach

As described earlier in this chapter, digital health is emerging as a complex and evolving ecology of practices, actors, technology and discourses that constitute and reconstitute the healthcare system. To study the fluid, heterogeneous, interrelated, and multiple performances of digital health requires an ecological approach. Many scholars have adopted an ecological approach in recent decades (cf. Bowker & Star, 1999; Fuller, 2005; Gibson, 1982; O'Day & Nardi, 2003; Tacchi, 2006). This approach accounts for the entangled agencies and the inextricable relationship of communication, technology, and context of use (Hearn & Foth, 2007; Tacchi, 2006), and broadens the lens on information infrastructures and technology to the

interactions, networks, and relational infrastructures within which particular phenomena of study are situated and constituted (Bowker & Star, 1999; Star & Ruhleder, 1996). Using such an ecological approach, I take as a starting point that people, information, and technology inhabit multiple contexts and that what is at stake for digital health innovations is movement and translation of digital health data across contexts (Bowker & Star, 1999). This focus helps to guide ethnographic observations beyond the particular digital health tool or the particular goals of the digital health project to situate these efforts in a wider network of associations.

Ethnographic Methods for Digital Health Ecologies

I conducted two years of qualitative, ethnographic observations, participation, and interviews across communities and stakeholder groups within the clinic, lab, and home domains of digital health in India and the U.S. Altogether, this included 70 interviews with technology designers, clinicians, ehealth providers, and varied users of digital health technology and health and wellness data. These interviews focused on how respondents used particular digital health technology, how they engaged with health and wellness data, and the work that they did around this data, especially in relationship to other stakeholders. This method provided a way to map different values for data evoked in different discourses of and contexts for data. These three categories of respondents provided a conceptual frame for tracking how the contexts, discourses, and practices of data varied across them and bounded who and what I observed in this field; still, there were not always clean boundaries among them, and more often the memberships in groups and alliances within domains overlapped (Nafus & Sherman, Forthcoming).

In addition to the interviews across the various stakeholder groups, my fieldwork included participation and observation across many different sites within more formal healthcare settings and within consumer health and wellness communities in both the U.S. and India. (For a

more detailed description of fieldwork engagements, see Appendix A). Using a combination of the ethnographic data-gathering methods of participant observation, semi-structured interviewing, and analysis of documentary sources enables the ethnographer to “detect consistent patterns of thought and practice and to investigate the relationship between them—an important comparison, since what people do is not always the same as what they say they do” (Forsythe, 1999, p. 128). The challenge for ethnographers in attending to what people do in the material world, to a material culture, is to make sense of the “everyday discrepancies between what people say matters to them and what they actually give their attention to” (Miller, 1998, pp. 12–13).

Field Sites and Field Work

In addition to interviewing physicians and nurses about how they managed and negotiated patient generated data in the clinic within formal healthcare institutions, I observed digital health clinical providers (specifically, clinical providers in a telehealth call center and midwives using mHealth applications) and observed a range of users (telehealth patients, mHealth patients, and e-patients). I also drew on observations from the U.S. Telehealth and India mHealth projects; I describe these in-depth cases later in the chapter.

Consumer health and wellness communities of practice across the U.S. and India are a much more dispersed, nebulous, and heterogeneous compared to those engaging in digital health within formal healthcare institutions. In the U.S., I observed and participated in technology design (health technology startup meetups). I was privy to high-level conversations about digital health at conferences involving leaders, innovators, and advocates (such as TEDMED and QS, ICTD seminars) . I also engaged with digital health through the use of digital health technology (QS meetups, reflexive use of Fitbit and 23andme, personal genetics test). The QS movement,

started by former *Wired* magazine editors Kevin Kelly and Gary Wolf in 2007, began as a meetup for people interested in self-tracking in the Bay Area, a purpose illustrated in the tagline, “Self Knowledge through Numbers.” The movement has grown to include over a hundred different QS community meetups in 34 countries around the globe¹² and supports two different annual QS conferences. A primary focus for QS is on health and wellness. This has attracted the attention and participation of academic researchers, entrepreneurs, healthcare professionals, and technology industry stakeholders interested in how this movement can translate into preventative or personalized medicine (Lupton, 2013b) . For two years, I participated in QS through attending meetups and presenting at their national conference. In those two years (2011-2012), Lupton’s (2013b) content analysis of news media shows that QS had a momentous gain in coverage, moving from being framed by the media as innovative, geeky, and on the fringe to being represented as becoming part of everyday life, as growing in popularity, and as connecting to health promotion efforts. Further, Lupton’s (2013b) analysis affirms my own experience: The term “quantified self” has become part of the cultural lexicon, now often referring to the general practices of self-tracking rather than exclusively to the QS movement (p. 26).

The realm of consumer health and wellness in India was initially difficult to locate. I was initially searching for something that looked more like the Indian version of the QS movement (which did not exist at the time of my fieldwork, but now boasts a QS meetup in Mumbai), until I realized that consumer health and wellness in India was woven much deeper into the urban healthcare fabric than I could ever have expected. My ethnographic observation and participation in this field occurred across technology design (e.g. workplace observations with digital health

¹² Quantified Self <http://quantifiedself.com/> (Accessed April 30, 2014)

technology designers, conducted focus groups for digital health technology startup) and healthcare providers and users (e.g. private hospitals in urban centers, mobile health and telehealth call centers). Most of India's urban healthcare system is run through private industry, which means care is highly varied, mostly unregulated, and financially supported through out-of-pocket payments (High Level Expert Group, 2011). It appeared that on every other corner there was a kiosk selling glucometers, blood pressure monitors, and an assortment of other medical devices for in-home use. Indeed, this suggested that with the rising chronic disease rates in the urban middle classes, it was commonplace for urban consumers to self-monitor at home.

At all of the events I participated in across the U.S. and India, I observed the ways participants talked about data and what they did and demonstrated with data. At these meetings I participated in discussions, gave research talks, recruited interview and observation participants, and engaged in formal and informal discussions about the emergence of digital health. Together these methods provided insight into the multiple interactions, performances, and relationships related to digital health data within and across communities and domains of digital health. In my fieldwork I move across a range of utilization contexts to observe not just how people talk about digital health data, but what people do with data. I investigate the gaps across how different stakeholder groups talk about data and negotiate the challenges of digital health data within their respective practice and social context.

Organizational Structures and Labor in Context: A Comparative Case Study Analysis

To understand the relationship of organizational and technological change in processes of data-intensive transformation, I conduct an in-depth case study comparison of two digital health pilot projects focusing on the intertwined processes of design, implementation, and evaluation of digital health technology within rural low-resource contexts in India and the U.S. The data-

intensive transformations accompanying the introduction of digital health technology in the cases of U.S. Telehealth and India mHealth challenge previous organizational and institutional arrangements, providing two rich contexts for examining the entanglement of technology and organizing, and for disentangling the processes of sociotechnical change.¹³ The first, India mHealth, is an ICTD project developing mobile-phone-based data collection, clinical decision support, and video education for midwives to use in postnatal care in rural India. The second, U.S. Telehealth is a Medicare demonstration project implementing a telehealth device in the home with integrated care management for chronic disease patients in the rural U.S. Each project encompasses networks of participants spanning technology designer, clinicians and ehealth providers, and user categories amid the multiple social domains of digital health.

Ethnographic Ways of Seeing

Within these project contexts, I follow Horst and Miller (2006, p. 7; see also Miller & Slater, 2000) and agree that “(w)hat one has to study are not things or people but processes.” It is foregrounding the processes and practices around new forms of information and informationalizing efforts that help make visible the multiplicity of a technological artifact and its meanings (Mol, 2002b). Across both projects I examine how the scripts for appropriate use embedded in design processes are iteratively negotiated in practice, the challenges for information moving across contexts of use, and the work it takes to make information valuable for different stakeholders. In examining data-intensive transformation in relation to the processes of digital health innovation within different institutional contexts, I treat both the technology and

¹³ All names of organizations and individuals in my fieldwork have been omitted or given pseudonyms to keep confidentiality.

the healthcare context in which it develops as sociotechnical ensembles, that is, as objects of inquiry in their own right.

My methodological approach attends to the co-configuration of what Star and Strauss (1999) call the ecology of the visible and the invisible across sociotechnical systems. Investigating the dynamics of informationalization in each context requires a conceptual and practical set of methods that can reveal how it is that some activities count while other scopes of activity remain invisible. I perform what Bowker (1994) calls an “infrastructural inversion” which foregrounds the elements of work practice that “tend to fade into the woodwork, (sometimes literally!)” (Bowker & Star, 1999, p. 34). This approach recognizes “the depths of interdependence of technical networks and standards, on the one hand, and the real work of politics and knowledge production on the other” (Bowker & Star, 1999, p. 34). This allows us to trace analytically the work that goes into making associations within sociotechnical arrangements and that demonstrates the entanglement of labor and organizational infrastructures. In practice, this entails following the shifting sociotechnical interactions and practices with particular attention to moments of breakdown, communication gaps, and frictions as productive sites for making visible a broader association of networks, practices, and labors involved in the co-configuration of sociotechnical systems as well as the ongoing maintenance and repair of such systems (Jackson, 2014; Latour, 2007; Star, 1991).

Through this comparison I make visible the inextricable forms of intermediary labor and organizational structuring involved in data-intensive transformations and compare the implications of each across each multi-stakeholder projects. Both multi-stakeholder projects are situated at the interstices of institutional contexts and thus are characterized by multiple expectations and values around data. These digital health projects aim to use digital health

technologies as sufficient “solutions” to the lack of institutional structures and resources in rural healthcare contexts, such as the shortage of trained health workers and clinicians. They complicate boundaries between “developed” and “developing” world solutions because mHealth initiatives emerging in India have the potential to “leapfrog” devices used in the U.S. Mobile phones are capable of functioning as computers running complex software and serving as platforms for an array of biometric sensors, yet many of the biosensor devices in the U.S. are considered medical devices, subject to extensive regulation, and resulting in tighter coupling of hardware and software. I use the distinct institutional contexts of each setting to study the sociomaterial arrangements of sensemaking, the logics of knowledge production, and the co-construction of user, tool, and “appropriate” use that are inscribed through the processes of design and implementation and simultaneously negotiated and contested through local practices of communication and care. The following section provides a brief description of each multi-stakeholder project and the nature of my fieldwork for each.

Digital Health Pilot Projects

U.S. Telehealth

Project Overview

U.S. Telehealth was a Medicare demonstration project in the rural U.S. that used information gathered in the home via a telehealth device to manage chronically ill patients through an integrated care management program. The Medicare demonstration project was implemented by River Medical, a large rural healthcare delivery system with 240 physicians and mid-level practitioners providing primary and specialty care to residents in the region. The project tested a model of telehealth using a system called Health@Home, which facilitates digital health data exchange between patients in their homes and care providers in clinical settings. In order to lower Medicare costs, this system, combined with intensive care management, targeted

high-risk, high-cost patients by reducing the utilization of high-cost medical care, including ER visits and inpatient hospital stays. The Health@Home system's home-based handheld device collected patient data on a daily basis through educational dialogues that tailored questions about symptoms, vital signs, knowledge, and health behavior to the patient's diagnosis. The chronic diseases addressed are Diabetes Mellitus (DM), Chronic Obstructed Pulmonary Disease (COPD), and Congestive Heart Failure (CHF). The patient-generated data was sent to a server and coded algorithmically for low, medium, and high risk and then displayed on a dashboard as part of the Health@Home web-based application for River Medical care managers to review. This system provided the care managers with a tool for extending care into everyday interactions and spaces outside of the formal clinical setting and provided an opportunity to intervene or act on data accordingly.

Before the introduction of the Health@Home, River Medical's chronic disease management practice included care coordination and regular patient interaction with a nurse or case manager; however, these care management practices were embedded within a clinical setting, and interactions with patients were face to face. River Medical developed a new program of care management with the implementation of Health@Home, in which nurses are trained as care managers to occupy a central *intermediary* role in translating between home and the clinic. The majority of the care managers' work was located in front of a computer in an office space that had been converted from an old apartment building situated across the street from the clinic. Positioned at the interstices of the different social domains of clinic and home, for care managers the Health@Home program operated as a *distributed listening apparatus* across their large case load of Health@Home patients and prioritized the needs of these patients based on pre-defined measures of risk. This enabled the care manager to deliver more timely and informed

interventions and to manage more patients. Care managers were also responsible for translating patient-gathered data through Health@Home into valuable information for physicians in the clinic.

Multi-stakeholder Project

The U.S. Telehealth's project stakeholder groups include TechDev, a private technology development company, Medicare, one of the U.S. government's health insurance providers, and River Medical, a rural healthcare delivery system. As the funder and director of the research project, Medicare maintained ultimate project management decision-making power, while TechDev acted as a liaison between River Medical and Medicare. Chib, Ale, and Lim (2012) propose a Stakeholder Communication Model, for categorizing different stakeholder relationships across policy-research-practice realms on multi-stakeholder projects, a model that was first conceived of in the context of ICTD projects but is applicable in this pilot project as well. The three levels of stakeholders are (a) project management, referring to the decision makers in the stakeholder organizations, (b) operational, referring to those stakeholders involved in carrying out project tasks, and (c) beneficiary, referring to who are either directly benefitting or are interacting and communicating with the beneficiaries of the project (p. 101). This categorization is helpful across both pilot projects because it emphasizes the multiple, nested multi-stakeholder negotiations and interactions that occur within the project as a whole. At the same time that the levels are undoubtedly intertwined and, as Chib et al. (2012) note, not intended to be hierarchically structured, they reveal that project management-level negotiations may diverge from the operational- and beneficiary-level negotiations occurring in the field as they confront the challenges and opportunities of the project in their daily work lives. At the project management level, U.S. Telehealth was constructed across Medicare, TechDev, and

River Medical administrators as a clinical study testing the impact of telehealth within a fee-for-service payment model with research, policy, and practice implications. Within River Medical, another nested set of operational and beneficiary stakeholders, including the care managers, physicians, and administrators, had to coordinate in order to manage the implementation of the project. Aligned around the common overarching goal of the project, inter-organizational and intra-organizational stakeholders continuously negotiated and iterated the research study, technical, and programmatic protocols to manage different project stakeholder agendas and perspectives and the multiple data valences evoked as the project was implemented.

My fieldwork for this project entailed three different site visits to River Medical over two years, spending 2-3 days each time I went. My ethnographic observations followed the interactions around Health@Home data in the care managers' office, in conversations with patients, across documentation demands of River Medical administration and Medicare, and into the clinic, with particular attention to the work of translation and the changing relationships among stakeholder groups. I conducted workplace observations and ethnographic interviews with care managers at three time points throughout the project to be able to demonstrate the evolution of the work practices, organizational arrangements, and perspectives as the project continued. I also conducted ethnographic interviews with a TechDev representative, and with the physician and primary administrator associated with the project. I participated in multiple informal conversations about the project implementation as well as one formal workshop at River Medical around the evolution of the program after the Health@Home system had been removed.

India mHealth

Project Overview

India mHealth is a multi-stakeholder ICTD pilot project that designed and implemented a mobile health application tasked with shifting the process of paper-based data collection to a mobile-based platform, providing clinical decision support, and enabling a mobile video education tool for midwives to utilize in postnatal care visits. Mobile Postnatal Care (mPNC) is based on open source software running on smart phones and was developed for this project to be applied to an established healthcare delivery program providing postnatal care for mothers and newborns in rural India. This pilot project took shape through a transnational network of project stakeholder groups including global non-governmental organization (GNGO), a global NGO with a focus on global health and technology; University, a group of ICTD researchers at a large public U.S. university; and local non-governmental organization (LNGO), a local Indian NGO focused on healthcare delivery, research, and training. Within LNGO there was another set of stakeholders at the operational and beneficiary levels, including the midwives, field supervisors and the administrators, who were responsible for implementing the project in the field.

Ethnographic Methods for a Transnational Network

Especially in the ICTD context, in which the distance culturally and geographically can be so great among stakeholders, the impact of the role of different stakeholders and the configuration of different multi-stakeholder partnerships on the project is understudied and overlooked (Chib, Ale, et al., 2012). Similar to U.S. Telehealth at the project management level, this project had practice, research, and policy implications. GNGO provided the funding for the project, directly financing LNGO to support their implementation of the project. GNGO also provided University with local partnership access, while University developed mPNC and provided technical expertise and support and managed the research component of the project.

LNGO provided a healthcare context for implementing the project and local cultural and healthcare expertise to inform project articulation. Within LNGO there was another set of operational and beneficiary stakeholders, including the midwives and the administrators, who were responsible for implementing the project in the field.

Given the transnational, distributed nature of the India mHealth project, my fieldwork followed a similarly transnational and distributed form. Thus I was often occupying one of the multiple realities related to the project, exacerbating the already partial and partisan view that ethnographic methods inherently provide (Strathern, 2005). Jensen (2010) argues that, in particular, conducting ethnographic methods in the transnational and networked arrangement of ICTD work “appears to exemplify, indeed amplify, the barriers posed by distributed mediated phenomena to traditional ethnographic methods” (p. 73). He continues, “If ICT4Dev emerges as fluctuating and unstable phenomenon; one, which is exceedingly difficult to pin down, this is because it exemplifies a partially existing object emerging from multiple sites of activity that are partly visible, partly opaque to all involved actors, including the ethnographer” (p. 74). Rather than conceptualize these “asymmetries of knowledge” as barriers for ethnography, we can consider how the asymmetries we experience as ethnographers actually replicate important features of the phenomena we are studying and provide a point of entry into understanding the nature of distributed and mediated work. This was the perspective that guided my fieldwork, as I studied project implementation in multiple sites (in India, and with the design team in the U.S.). I took my multiple partial views and asymmetrical knowledge as reflective of how different stakeholders became positioned within the project.

The project-centered data collection included two years of multi-sited ethnographic fieldwork, including ethnographic observations, ethnographic interviews across all project

stakeholders in India and the U.S.¹⁴, and multiple levels of participation. I participated and observed multiple sites within the design process, occurring mostly on University and GNGO campuses, in the form of weekly meetings, conference calls with LNGO administrators, project communication across stakeholders via email, and project documents. Design team meetings included ICTD researchers in the computer science department from the University, including the doctoral student working on this as his dissertation project and two professors and three ICTD professionals from GNGO, with expertise in global health, computer science, and commercialization. I observed how different design teams interacted with each other and the values, expectations and assumptions evoked as they talked about and developed the mobile application. I also observed how they negotiated communication with LNGO and managed the geographic and cultural gaps that emerged throughout their interactions. I participated in design team meetings for almost a year before I conducted my fieldwork in India and continued to participate in meetings throughout the project implementation and post-implementation period. I also participated in the project at the level of conducting ethnographic observations and interviews with the midwives focused on the usability and feasibility questions the design team had about mPNC. More information regarding my field sites and field work within them can be found in the appendix.

Chapter Overview

The following provides an overview of my dissertation chapters. Chapter Two develops four discursive contexts for the relationship of technology and health across the U.S. and India. These contexts are important for situating digital health efforts and shaping informationalization

¹⁴ Interviews with midwives were audio recorded and then transcribed into Hindi and translated into English.

within the four field sites. Chapter Three builds on the discursive contexts established in Chapter Two to present a comparative discourse analysis of the relationship of technology and social change in health focused around the three key themes of institutional change, democratization of power, and redistribution of power. Chapter Four considers how different communities engage with digital health and how different practices with and ways of talking about data across these communities generate challenges for data moving across social domains. Chapter Five examines how organizational structures and labor matter through the comparison of processes of organizational and technological change in two digital health pilot projects. Chapter Six concludes by bringing together the key insights and findings from the previous chapters and reflecting on their implications for a range of scholars and practitioners.

Chapter 2

Discursive Contexts for Healthcare and Technology

This chapter introduces the four field sites as discursive contexts for the relationship of technology and health across the U.S. and India. These contexts are important for situating and contextualizing digital health efforts and shaping informationalization within the four field sites. In this chapter I present background information on the four field sites and outline the discursive contexts for healthcare and technology in order to demonstrate how digital health emerges in each research context. I argue that each of the discursive contexts for healthcare and technology is important for understanding processes of informationalization and the discourses, practices, and structures of digital health within each research context. In other words, the different ways that healthcare and technology are approached and talked about across these research contexts is as important as the particular healthcare and technology policy setting, for how digital health emerges in each context. For the purposes of this dissertation I present a brief overview of the state of the healthcare system within each context and then focus on how healthcare and technology innovation, health and healthcare information, and the organizational arrangements for health and technology are most predominantly represented and discussed within each research context. These discursive contexts provide an important analytical lens for situating future analyses and comparisons across the practices, discourses, and structures of digital health.

As described in Chapter One, in order to study the data-intensive transformations in healthcare across the U.S. and India I selected contexts in both rural and urban settings, as digital health technology is being leveraged in different capacities across them. As we know, informationalization is not an evenly distributed process in healthcare, in fact, many would claim that *healthcare* disparities could be characterized as *health technology* disparities (e.g.

Stroetmann, Pieper, & Stroetmann, 2003; Viswanath & Kreuter, 2007). Castells (2010) has emphasized that informationalization is not separate from, but rather “intertwined with rising inequality and social exclusion throughout the world” (p. 69), from which “a fourth world” emerges. The fourth world represents people in regions, developed and developing, rural and urban, that are bypassed by the globalized and technologically connected world. Efforts to bridge the “digital divide” and connect communities to the globalized and technologically connected world go hand in hand with efforts to informationalize healthcare, which often place information technologies at the center of the intervention to bridge the “medical divide” (Stroetmann et al., 2003). The medical divide between those who can access increasingly technologically mediated medicine and those who cannot is then ameliorated through the “the wiring of poor rural populations thus...bringing medically underserved rural communities into the health care loop, and bringing these communities up to speed with the newest in medical technology, in one fell swoop” (Cartwright, 2000, p. 352). Thus it is important to understand the discursive context for technology and health across the rural healthcare settings across both nations. In India, the discursive context is situated within Information Communication Technology Development (ICTD)¹⁵, which encompasses the range of stakeholders in healthcare and technology as the

¹⁵ Throughout this dissertation I use the acronym ICTD to encompass the multiple perspectives of research and practice, including ICT4D and ICT and Development. As a practice, ICTD is understood through the projects are implemented by governments or nongovernmental organizations to introduce ICT services within under-served communities, often focusing on a particular type of development outcome such as health or education. There is also a growing community of researchers engaged in ICT development for use in developing regions. These approaches tend to be labeled ICT4D and often follow a pilot project model, in which a particular ICT is introduced into a particular community towards a particular development oriented end and then evaluated regarding its success or failure. There is also another research oriented approach that focuses on understanding the role of ICTs in development unbound from

Indian Government is joined by a transnational network of other NGOs and academic and private sector stakeholders in the work digital health. In the U.S. the discursive context is situated within the U.S. Government which encompasses a range of healthcare regulatory, policymaking, and operational bodies.

While not completely separate from discursive contexts of the U.S. Government and ICTD, the two contexts of U.S. consumer health and wellness and India consumer health and wellness provide dimensions of contrast to the rural healthcare settings in each nation, in that they are focused on urban populations that are framed as individual consumers. The discursive context of these research contexts, while somewhat amorphous as it emerges across an array of stakeholders and sites, is situated within the growing and interpenetrated technology and market logics shaping each context within each nation. I emphasize health and wellness in these contexts to situate new models of care and emergent boundaries between regulated health care and medical technologies used by consumers and the unregulated wellness focused interventions and consumer devices. These discursive contexts emerge across networks of technology designers and innovators, entrepreneurs, ehealth provider and consumer groups. The dimensions of urban/rural, patient/consumer, and health/wellness do not fully bound or begin to complete the complexity and dynamism of each of these sites, yet they can help us parse and compare in meaningful ways the relationships between informationalization and particular healthcare contexts evolve. Together these discursive contexts offer a range of perspectives and orientations to healthcare and technology that are important for situating and comparing the role of context in shaping digital health.

a project framework and within the day to day lives of people within communities in the developing world (e.g. Horst & Miller, 2006; Slater & Kwami, 2005)

U.S. Rural Healthcare and Technology

The State of U.S. Healthcare

While the U.S. spends significantly more per capita on healthcare than the other OECD countries (17.9% of GDP¹⁶), driven in large part by high technology investment, pharmacological industry, and an aging population with chronic illnesses (G. Anderson & Markovich, 2009; G. Anderson & Squires, 2010; Squires, 2012), in terms of quality of healthcare parameters, such as number of physicians per capita, life expectancy, and infant mortality, the U.S. lags significantly behind other OECD countries. To rectify these challenges in quality and population health and reduce unsustainable healthcare costs the U.S. Government has turned to HIT to digitally transform the healthcare system as a solution (Agarwal, Gao, DesRoches, & Jha, 2010). An Institute Of Medicine (IOM) (2012a) report, "Best Care at Lower Cost: The Path to Continuously Learning Health Care in America" identifies three major imperatives for change: the rising complexity of modern health care, unsustainable cost increases, and outcomes below the system's potential. It simultaneously points out that emerging tools like computing power, connectivity, team-based care, and systems engineering techniques make possible the transformation envisioned toward a continuously learning health care system in America. Thus the two central goals that frame the government's healthcare HIT agenda: (a) increasing the efficiency of the administration and management of the system and (b) improving the quality of clinical care (Moses, Matheson, George, Sadoff, & Yoshimura, 2013). The unsustainably high medical costs have been shown to be driven overwhelmingly by chronic illness at every age. Over half of all U.S. adults have at least one chronic medical condition and account for 90% of

¹⁶ In 2011, or \$2.7 trillion, health has doubled in proportion since 1980 (Moses, Matheson, George, Sadoff, & Yoshimura, 2013)

health care spending (Machlin, Cohen, & Beauregard, 2008). With the burden of a growing population of patients with chronic disease that cannot be sustained by the current financial and professional resources, health information technology (HIT)¹⁷ is imagined as driving solutions for rescuing the healthcare system by making healthcare more efficient and less expensive and powering the healthcare of the future (Institute of Medicine [IOM], 2012a; Office of the National Coordinator for Health Information Technology [ONC], 2011). It is through the collection and movement of data that “health IT has the potential to empower individuals and increase transparency; enhance the ability to study care delivery and payment systems; and ultimately achieve improvements in care, efficiency, and population health” (ONC, 2011). As David Blumenthal, the National Coordinator for Health Information Technology (HIT), has written: “Information is the lifeblood of modern medicine, [and] health information technology is destined to be its circulatory system” (Blumenthal, 2010, p. 382).

The U.S. government has invested substantially in the informationalization of healthcare at a massive institutionalized scale. As part of the American Recovery and Reinvestment Act (ARRA), the HITECH Act authorized expenditures of \$20 billion to promote the adoption and “meaningful use” of EHR technologies that would be connected through the national health information network (President’s Council of Advisors on Science and Technology [PCAST], 2010). This vision for the future underpins the current high level discourses and policies, yet far from reflects current practice. As such, adopting and meaningfully utilizing an EMR system as stipulated under the HITECH Act is a primary focus and target of investment. EMRs are

¹⁷ HIT refers to an array of technologies including electronic health records (EHRs), personal health records (PHRs), telehealth devices, remote monitoring technologies, and mobile health applications

positioned rhetorically as enacting institutional improvements to standards of care and as a demonstration of the political will to bring U.S. healthcare into the “modernized” digital age. However the impact of health IT on quality and efficiency in healthcare has not been shown convincingly in one direction and the benefits continue to be weighed and questioned across different types and sizes of healthcare organizations (cf. Agarwal et al., 2010; Greenhalgh, Potts, Wong, Bark, & Swinglehurst, 2009; McCormick, Bor, Woolhandler, & Himmelstein, 2012)¹⁸.

In the 2010 report to the President “Realizing the full potential of health information technology to improve healthcare for Americans: the Path Forward”, the President’s Council of Advisors on Science and Technology refers to medicine as an “information-rich enterprise”, from which “a larger and more seamless flow of information will result in a transformation of care, organized around the patient, wherever he or she may be” (PCAST, 2010, p. 24). The volume of medical information is certainly growing, but in practice, the “seamless flow of information” is not a reality, which impedes potential for the predicted transformation of care. PCAST recommends a data-centric approach that entails being able to “disassemble” the information in electronic health records and then “reassemble” it in various ways. More recent policy documents build on this idea as the basis for a “learning health system, in which a vast array of health care data can be appropriately aggregated, analyzed, and leveraged using real-time algorithms and functions” (ONC, 2011, p. 5).

¹⁸ For instance, one of the issues that has been raised is that smaller organizations will struggle disproportionately to meet the requirements of meaningful use, because many of organizational challenges in accomplishing these tasks is not simply remedied by a financial incentive, but rather a question of expertise and resources to purchase, install, train staff, and use information technology to improve efficiency and effectiveness (Lohr, 2012).

Healthcare/Technology Disparities

This discrepancy exposes a broader healthcare and healthcare technology disparity that disproportionately affects rural and low-income communities and is a central feature of the U.S. healthcare system. Rural populations disproportionately suffer from chronic disease relative to the general public (K. J. Bennett, Olatosi, & Probst, 2008). Access to quality health care in rural areas is restricted by poor infrastructure and a smaller health care workforce, hindering the utilization of preventative health services and compromising the implementation of wellness and healthy lifestyle programs (National Advisory Committee on Rural Health and Human Services, 2011). It is also the case that even though rural communities make up almost a quarter of America's population, fewer than 10% of physicians practice in these communities (Gamm, Hutchison, Bellamy, & Dabney, 2002). Thus rural areas have become target sites for new informationalizing efforts within digital health, in particular ehealth and telehealthcare as a way to connect remote populations, extend services to these populations, and bridge gaps medical professionals (IOM, 2012b). The convergence of these trends of ICTs applied in healthcare and medical technologies in the home is in the nascent stages of scaling to general practice applications, however, the thrust of these trends has been accumulating over many decades. It began in the U.S. with hospitals extending care to patients in remote areas as part of national development initiatives to reach underserved communities, but "the use of telemedicine has spread rapidly and is now becoming integrated into the ongoing operations of hospitals, specialty departments, home health agencies, private physician offices as well as consumer's homes and workplaces" (American Telemedicine Association, 2011). Yet research demonstrates significant disparities still exist among those with higher incomes and education, younger and the employed in terms of access, communication, and usability of the health ICTs and these populations are that experience the greatest ICT disparity tend to be the most underserved by the healthcare

system, with the greatest health disparities (Calvert, Kaye, Leahy, Hexem, & Carlson, 2009; Viswanath & Kreuter, 2007).

Within the current state of telehealthcare there are multiple uses, from remote intensive care to specialty care at a distance to chronic disease management to mHealth applications that help patients with adherence to their medications to reducing referral times.¹⁹ Telehealth is a significant priority across government departments and investment will grow as the ACA is rolled out (IOM, 2012b). In relation to rural populations the ACA's focus on improving health care quality through team-based, patient-centered care relies heavily on ICTs and telehealth to link team members. In addition, the ACA focuses on addressing health disparities and improving public health, both of which are very important to rural areas and center around better HIT infrastructure for improved population monitoring and expanding access to health and wellness services (IOM, 2012b).

Healthcare System Optimization

With the Affordable Care Act (ACA), the government is promoting a new approach to healthcare that emphasizes patient-centeredness, prevention and wellness oriented care, interoperability, and open government. This approach is imagined as the solution to what is seen as an episodic, fragmented, siloed, opaque approach to healthcare (e.g. ONC, 2011; PCAST, 2010). The policies aim to change incentive structures to reward value more than volume and health outcomes rather than services delivered in concert with developing a HIT driven healthcare system powered through “data liquidity” (ONC, 2011). In popular discourse the U.S. healthcare system is often under fire from the private sector for being anti-innovation, resistant to

¹⁹ See Kvedar, Coye, and Everett (2014) for a review of connected health strategies.

change, and entrenched in the status quo. As a massive institution, their role in innovation is somewhat limited as it is not able to move as nimbly as entrepreneurs and must consider the benefits and costs, the opportunities and risks not only for particular groups, but for the whole system.

The Centers for Medicare and Medicaid Services (CMS) estimates that beneficiaries with five or more chronic illnesses account for just over three-fourths of Medicare spending (Swartz, 2011). These high risk and high cost patients often require hospitalizations to treat exacerbations or complications associated with their condition(s). For example, Congestive Heart Failure (CHF) is the leading cause of hospitalization for older individuals, with almost a third of hospitalized CHF patients requiring readmission within 30 days of discharge (Landro, 2007). High utilization and costs occur for a number of reasons, including inadequate patient self-care, follow-up after discharge, and continuity of care (Nielsen et al., 2008). As such, CMS aims to catalyze innovation within these areas in an effort to reduce the associated utilization and costs. For example, the Medicare Innovation Center established with the ACA to test new payment and delivery models seeks to fund projects that meet the triple aim to (a) improve the individual experience of care, (b) improve the health of populations, and (c) reduce per capita costs of care for populations. This includes innovation that aligns with the goal of reducing costs while maintaining or improving care outcomes, which are the criteria for evaluation of Medicare's telehealth demonstration projects, of which, one will be discussed in depth in Chapter Five as one of my case studies.

As the U.S. government confronts the high cost burden of chronic disease care they are also promoting a wellness and prevention oriented approach to healthcare in which the active role of patients is necessary to bring down costs and improve health status. U.S. healthcare

reform advocates envision a system characterized by patient-centeredness (IOM, 2011), in which the patient is framed as a valued resource and stakeholder in making healthcare more effective and efficient. In other words, the promotion of ideas around patient engagement and patient-centeredness are part of the solution of improving health outcomes and effectiveness of the healthcare system while reducing costs. The concept of patient-centered care was introduced into the mainstream discourse in the 2001 Institute of Medicine report *Crossing the Quality Chasm: A New Health System for the 21st Century* and defined as “care that is respectful of and responsive to individual patient preferences, needs and values” (IOM, 2001). Patient-centered care was one of the six aims of improvement that the report identified for the U.S. healthcare system and has since become a buzzword used throughout the government and healthcare industry discourse. The term rhetorically performs an apparent consensus around the idea of the patient becoming a central and active participant and resource in their own care. Behind this apparent consensus, however, are very different projections from a variety of stakeholders about what the terms of patient and professional control sharing within patient centered care should look like. There are some stakeholders that ascribe to a more “radical consumerism” perspective, which advocates for the patient being given all the control, while others ascribe to a more “classic professionalism” perspective, which submits that the medical professional needs to reserve control because patients won’t make decisions in their best interest or won’t want the control (Berwick, 2009).

Data Liberation, Data Regulation

There is a focus on the liberation of data, based on the argument that facilitating health data access for individuals and for stakeholders in the industry is the key mechanism through which the government can encourage innovation in the industry (ONC, 2011). In recent years the

government has tried to position itself as a catalyst for innovation by reaching out to entrepreneurs and entangling the narrative of the future of healthcare with the narrative of technological innovation and development. New healthcare policies and investments with ACA and the ARRA provide the backdrop for what U.S. Chief CTO Todd Park calls a “data-powered revolution in health care” (Park, 2013). With the Administration’s Health Data Initiative²⁰, a public-private partnership “committed to innovation through the use of public data” (ONC, 2011), health system data has been “opened” and “unlocked” to developers and entrepreneurs to innovate (Sebelius, 2011). Data are considered the “fuel of innovation, entrepreneurship, and discovery” and the government’s efforts to make those data available are expected to create transparency in the system and as Friedman noted, promote a “new marketplace and platform for innovation” (Friedman, 2013). By sponsoring innovation challenges, hackathons, and events such as Health Datapalooza, “a national celebration of data-powered innovation in healthcare”, the government is aiming to “unleash the power of American innovators and data to transform health care for the better from the ground up” (Park, 2013). The government is trying to rewrite a story of innovation in which the institution is a flexible partner of continuous learning and innovation rather than the entrenched institution that acts as a barrier to disruptive innovation. These efforts attempt to direct and exploit the energy of the private sector around digital health

²⁰ The Health Data Initiative is a public private effort that is one of the Health and Human Services flagship initiatives as part of the Open Government Plan. “The fundamental approach being taken by the initiative is to catalyze the advent of a network of community health data suppliers (starting with HHS) and “data appliers” who utilize that data to create applications that (a) raise awareness of community health performance, (b) increase pressure on decision makers to improve performance, and (c) help facilitate and inform action to improve performance” (U.S. Health and Human Services, 2010).

towards developing and deploying data-powered innovations for clinicians and the healthcare system to deliver better care at lower cost.

While the government stakeholders have engaged thoroughly with the discourses of consumer empowerment to encourage collaboration and innovation their responsibility for privacy, security, safety, and quality is often viewed by the private sector interests as impeding empowerment and innovation. The government recognizes the need for some of its regulatory framework to evolve to keep up with the pace of technological innovation and associated risk. As such, the FDA is working on a medical mobile application policy with the intention of adopting a “balanced” approach that “supports continued innovation”, while “assuring appropriate patient protections” (Foreman, 2013). As of April 2014, of the tens of thousands of health-related apps on the market, the FDA had registered or cleared just over 100 as medical devices.²¹

The potential of harnessing so-called “big data” to transform health and healthcare has also been a key tenet of the U.S. Administration’s healthcare reform narrative. A big data approach to health and healthcare for the federal government is primarily driven by its potential to reduce costs or create efficiencies in the system and secondarily to improve quality of care and deliver evidence-based medicine. Core to the government’s approach is the value of transparency through *open data*. The Obama Administration published the Open Data Directive in 2009²² and since then the Health and Human Services (HHS) has promoted open data initiatives, such as the Health Data Initiative (HDI). HDI involved the liberation of data, innovation challenges,

²¹ “103 FDA Regulated Mobile Medical Apps”, MobiHealthNews, <http://mobihealthnews.com/research/103-fda-regulated-mobile-medical-apps/> (Accessed May 4, 2014)

²² Open Data Directive, http://www.whitehouse.gov/sites/default/files/omb/assets/memoranda_2010/m10-06.pdf (Accessed May 4, 2014)

codeathons, and events such as Health Datapalooza. HDI grew into the Health Data Consortium, which is based on the premise that local and federal government, healthcare providers, business, research and educational institutions are all “generating an exponentially growing volume of health data that, if better integrated, could vastly improve health” (Health Data Consortium, n.d.). This collaboration among government, non-profit, and private sector organizations is aiming to “responsibly liberate and use this data” and “enable measurable and meaningful improvements in human health by exploiting the vast potential of health care data and all of its derivative uses.”²³ Thus through “liberating” data from HHS, CMS, the FDA, among others and making it accessible in downloadable, workable formats, driving the adoption of and meaningful use of EMRs, and inviting market based innovation and the development of advanced computing analytics the U.S. Government aims to create and sustain a health data ecosystem, supported by, and at times driven by HIT. Beyond the liberation of data, the government is also focused on stimulating and advancing research and development into technology to “access, store, visualize, and analyze” massive and complicated data sets.²⁴ Big data algorithms and advances in computing are promoted as the sensemaking tools that can generate insights and reveal patterns, relationships and evidence within and across the datasets that together will lend itself to predictive modeling of patients, populations, disease, wellness, and resources.

There are many in the community of practice who remain skeptical and cautious of the promise of big data to deliver benefits in reality. Some policymakers point out that the potential

²³ “Mission” Health Data Consortium, <http://www.healthdataconsortium.org/about/mission> (Accessed May 4, 2014)

²⁴ “Obama Administration Unveils “Big Data” Initiative: Announces \$200 million in new R&D investments”, Press release, Executive Office of the President, http://www.whitehouse.gov/sites/default/files/microsites/ostp/big_data_press_release_final_2.pdf (Accessed May 4, 2014)

to generate the promised value to the healthcare system through big data is predicated on the assumption that the organizations and providers are able to collect robust data, use the analytic tools, and are committed to acting on and making decisions driven by the data and the evidence provided. Many healthcare providers complain of information overload and not having the technical or organizational capacity to manage the work of collecting and making sense of greater volumes and varieties of data (see, for example iHealthBeat, 2012). Even with the high priority the U.S. government has placed on implementing EHRs, health care leaders report their organizations are struggling to leverage them: while 34% reported being able to capture data from EMRs to help patients, 43% said they were unable to collect sufficient data to improve care (Oracle Healthcare, 2012). The creation of a health data ecosystem, in which big data insights may be able to be leveraged to inform clinical practice and patient outcomes, relies in large part on the quality and coordination of the clinical front end production of data and a deeper understanding of how data can be made valuable for different stakeholders in different contexts.

Partnerships and Cross-Sector Collaboration

The Obama Administration's healthcare reform policies promote partnerships and cross-sector collaboration as essential for advancing healthcare system efficiency and effectiveness, biomedical and technological innovation, and scientific discovery. Transparency, collaboration, and participation are the three key stated principles of the Administration's Open Government initiative and of HHS's HDI (HHS, 2010, 2012). The Health Data Consortium (HDC) emerged through HDI as a way to promote "public and private sector innovation and action" through making data and information more useful and more available (HHS, 2010, p. 2). Through a series of innovation challenges and events, such as Health Datapalooza, HHS has sought to collaborate with entrepreneurs and technology developers around creating value around the liberated data

stores and creating applications that would improve health outcomes and reduce costs. The development of an ecosystem of data users and data providers is expected to break down barriers of collaboration and participation, enabling the creation of value and innovation directed towards improved decision making by policy makers, the public, health care professionals, and researchers (HHS, 2010, 2012). Further, this data ecosystem depends on the participation of the private sector and research groups as a way to accelerate and advance scientific discovery and its translation into practice. The rhetoric of collaboration through private public partnership performs as a way to signal a healthy balance of government regulation and market-driven power.

Partnerships are also leveraged as tools for developing or strengthening relationships of accountability and coordination. This partnership rhetoric is discussed in terms of strengthening the ties between federal, state, and community healthcare stakeholders (HHS, 2010, 2012). Health Information Exchanges are set up to help payers and providers work together to make care more efficient and effective (ONC, 2011). Patient-centered care initiatives promote a rhetoric of HIT enabled team-based care, where patient data is coordinated across a team of professionals and specialists. Better coordinated patient information is envisioned as better coordinated care (ONC, 2011). Partnership is leveraged rhetorically as the improved structure of care, marking a transformation from a fragmented, paternalistic healthcare system to one that is more integrated and coordinated through HIT around patients.

U.S. Consumer Health and Wellness and Technology

Consumerization of Health and Wellness

Digital health across consumer health and wellness in the U.S. emerges across many different intersecting communities of technology designers, entrepreneurs, health and wellness

consumers, e-health providers, e-patients, researcher and healthcare industry interests. The expanding domain of consumer health and wellness in the U.S. is situated within a number of different realities, agendas, expectations, and stakeholders. Yet the expanding domain relies on key shifts of the locus of care and the consumption, production, and sharing digital health information outside of formal health care institutions across different practices and arrangements.

Regulatory reform is shifting a balance between public and private sector participation in healthcare. While the public sector looks to optimize access and quality and reduce costs, they are looking to the private sector for innovation and efficiency (ONC, 2011). As the government confronts the high cost burden of chronic disease care they are promoting a wellness and prevention oriented approach to healthcare in which the active role of patients is necessary to bring down costs and improve health status. In part, the shift of responsibility and care into the realm of consumer health and wellness can be seen as a response to the unsustainable financial burden of the healthcare system and a system that is structured for managing acute care, rather than chronic care management and preventive, wellness oriented care that is overwhelmingly in demand. The consumerization of healthcare is not new and the reframing of patients as health consumers can be traced back to the 1980s (Eysenbach, Jimison, Kukafka, Lewis, & Stavri, 2005; Hardey, 2001). Researchers have also pointed to trends of changing patient expectations for healthcare, in which patients are increasingly demanding more convenient care, as evidenced in the rise of concierge medicine as well as alternative health and wellness practices outside of formal healthcare institutions (e.g. Conrad & Leiter, 2004; Moses et al., 2013). For consumers, digital health is expected to provide improved convenience, more active engagement in their care, and greater personalization (Steinhubl, Muse, & Topol, 2013).

The convergence of trends in the application of ICTs in healthcare and the trends in the uses of medical technologies outside the clinic is in the nascent stages of scaling to general practice applications. This is what Eric Topol, a cardiologist writing about these trends in his book *The Creative Destruction of Medicine*, calls the “super convergence”, in which the digital non-medical technologies and the digital medical technologies are both exploding and now converging. This series of convergences “finally coalesces the rapidly maturing digital, nonmedical world of mobile devices, cloud computing, and social networking with the emerging digital medical world of genomics, biosensors, and advancing imaging” (Topol, 2012, pp. 226–7). He echoes the narrative of disruptive innovation and places these technological capabilities and consumers at the center of this revolution. These data-intensive technologies developed outside of conventional healthcare institutions follow a market driven, consumer-oriented logic that some in the community expect will “disrupt” conventional organizational and institutional arrangements in healthcare by both undercutting the status quo with affordability and accessibility and creating new models for clinical care, personal health and wellness, and scientific discovery that democratizes consumers’ and patients’ access to data and diagnostic potential (Christensen et al., 2008; Topol, 2012).

The Entrepreneurial Engine of Digital Health

Wherever there is a consumer; there is an entrepreneur. The story of the entrepreneur that innovates around, in spite of, or within institutional constraints is very common across the discourse. Entrepreneurship itself can be said to be shaped and imagined in relation to the institution (Tolbert, David, & Sine, 2011). The entrepreneur in this case has to wrestle with how much it wants to try to integrate with the institution versus how much it wants to stay completely consumer-driven. For entrepreneurs and technology designers, the discourse around “disruptive

innovation” and “creative destruction” has generated a vision of consumer-oriented products, configuring the user as a consumer rather than a patient and healthcare professionals are often left completely out of the equation. This vision may fit squarely within calls for “disruptive innovation”, but it is also shaped in part by the perception that designing for consumers is a much easier, much less regulated process than designing for any aspect of the healthcare system, which requires much more investment upfront to comply with FDA and other institutional interoperability standards. The product does not need to go through the FDA if it does not make any explicit promises or claims about diagnosis or treatment. For example, a mobile application that tracks blood sugar levels for someone who is diabetic would not need to go through the FDA as long as it remained separate from clinical practice. As many have noted this regulatory environment creates a disincentive for technologists who might have otherwise built the application to inform both physicians and patients. What we see instead is explosive growth in consumer-oriented applications and providing consumer/patients with an abundance of personal data.

Thus there is a huge market of gadgets to collect personal data, but not as many effective ways to aggregate, integrate, and use that data, although innovations in big data and personal analytics are increasingly popular investments (Rock Health, 2014). We are experiencing a significant boom in the number of health technology companies and the number of health and fitness apps. According to research published in a report by Rock Health, a digital health accelerator digital health funding exceeded \$1.9B in 2013, with 195 venture deals. Total funding was up 39% from 2012 and 119% compared to 2011 (Rock Health, 2014). They predict that the digital health industry is expected to surpass total medical device venture funding in 2014 (Rock Health, 2014). The CEOs of digital health startups are overwhelmingly male (93%) and highly

educated (Rock Health, 2014), a trend that has long been problematized throughout feminist oriented scholarship revealing the strong alignments between technology and masculinity, particularly in the world technology design and engineering (e.g. Oudshoorn, Rommes, & Stienstra, 2004; Wajcman, 1991).

Big Data and the Macroscope

This discourse around the potential of data in this community often invokes metaphors of vision, in which data is a “window”, a “mirror”, a “microscope”, and a “macroscope.” Many self-tracking advocates, scientists, and technologists expect a range of personal health data to provide a transparent gaze into the body revealing the micro-level processes and patterns that would not otherwise be perceptible. While some may call the array of new personal health and wellness sensing and self-tracking tools a microscope, when combined with computing and analytics this “way of seeing” and knowing is much more akin to a macroscope. Gary Wolf, co-founder of the QS movement, describes this “new instrument of knowledge” as “data-gathering in nature, plus computing” and predicts the “macroscope will be to our era of science what the telescope and the microscope were to earlier ones. Its power will be felt even more from the new questions it provokes than from the answers it delivers” (G. Wolf, 2009) In aggregate these data provide a vista across macro-level processes and complex patterns that can be mined for insights. These data open or “unlock” 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” (Kelly, 2007)

From a scientific research perspective, Leroy Hood, the President of the Institute for Systems Biology, envisions a new paradigm for medicine, driven by the “convergence of Big Data, technology and patient-activated social networks” that is personalized, participatory,

predictive, and preventative, what he terms P4 Medicine (Hood, 2013). Hood heralds the power of data from inexpensive blood screening tests that “have made blood a window into health and disease.” With a “virtual data cloud of billions of health-relevant data points” surrounding each individual, P4 medicine is the way that this complex data will be reduced into simple hypotheses and insights about how to optimize wellness and minimize disease for each individual (Hood, 2013).²⁵ This data-driven mode of medicine relies on a constantly evolving predictive and personalized model of patient and population health and wellness that is sustained and advanced by the continuous generation of insights through seamlessly linking consumer, scientific, and clinical realms of data production. What is key to this paradigm shift for medicine, science, and society is that “analytic treatment of data is systematically placed at the forefront of intelligent decision-making” (Hilbert, 2013).

Data-based Partnerships

Underlying many of the visions for and new models for care and knowledge production is the concept of partnership, often constructed around or based on the terms of data use and ownership. Data is at the center of value co-produced across participating “partners” and thus becomes a basis for a wide range of collaborations, contracts, exchanges, and initiatives. The discourse of forming new partnerships and collaborations in digital health and wellness anticipate and map the new models of health and wellness that are rooted across multiple sectors, many outside of formal healthcare systems.

The reality is that in all the talk of the explosion of data, much of what scientists, pharmaceutical companies, technologists, and other stakeholders want to do with big health data

²⁵ P4 Medicine, <http://p4mi.org/p4medicine> (Accessed May 1, 2013).

to move towards more personalized, precision medicine, requires much more data than is currently accessible to them. Part of the discourse around partnerships reflects this need to find ways to generate, access, and utilize consumer data for research and development purposes. Partnerships come to represent the geography of new models of scientific discovery and healthcare. Many partnerships have emerged in the form of disintermediated data pathways and exchanges from consumer/patient to industry and scientific research and development stakeholders. In the case of Patients Like Me, an open platform for patients to share data with, learn from, and connect to other patients that have similar health issues, as a for-profit company, they broker access to their network of patient data through partnerships with “trusted nonprofit, research, and industry partners who use the health data to improve products, services, and care.” For example, a partnership between PatientsLikeMe, nonprofit Center for Information and Study on Clinical Research Participation (CISCRP), Sanofi (pharmaceutical company) was launched in 2013 to raise awareness about and connect patients to participating in clinical trials (PatientLikeMe, 2013). Leveraging their 200,000-member community and Clinical Trial Awareness tool, Patients Like Me aims to align patient and industry interests by matching patients with relevant Sanofi trials, working with CISCRP to provide educational materials about the clinical trial process, and providing a platform for industry’s clinical trial participants to “use tools to better manage their disease while participating in real-time research every day” (PatientLikeMe, 2013). Partnership is an influential value in the imagination of the expansion of consumer agency in managing their health and healthcare, reshaping models of care and knowledge production, and shaping and participating in scientific research and technology development. One vision of partnership is advanced by e-patient communities that imagine the “patient as partner” model of care, in which the patient provider relationship is collaborative and

both parties openly share and integrate patient-generated and clinic-generated data into a model of care in which care decisions are made jointly or driven by the patient (Ferguson & e-Patients Scholars Working Group, 2007). Another vision of partnership emerges through the idea of “peer-to-peer healthcare” or crowd-sourced, networked form of knowledge production, in which patients and caregivers share knowledge and data about themselves, their condition, or about others from which knowledge and research agendas emerge that are helpful to the patient networks. In 2012, 23andme and a peer-to-peer disease specific patient network “Cure Together” merged platforms as well as data. The power of the partnership is in bringing together Cure Together’s phenotypic data and 23andme’s genetic data to inform 23andme’s research program and develop further vulnerability and risk assessments to deliver more personalized health information to consumers. This partnership pushes the boundaries of unregulated consumer health and wellness as they walk a fine line between the desire to offer consumers more personalized and helpful genetic information and the ability to actually deliver personalized health and wellness information that could be perceived as diagnostic tools that would require regulatory oversight from the government (Empson, 2012).

India Rural Healthcare and Technology

State of Indian Rural Health and Healthcare

As a BRIC country, India, represents an emerging global economy, yet extreme disparities in healthcare and healthcare technology exist and disproportionately affect the rural population. India faces a widespread burden of infectious disease and has the highest incidence of maternal deaths and a 29% share of global newborn deaths. Moreover, nearly all these cases are preventable with proper information and care. For example, anemia, is the cause of nearly a fifth of all maternal deaths in India, but is highly treatable with iron and vitamin supplements

(Singh, 2013). Yet India's healthcare system is massively under-resourced, both in terms of physical infrastructure and human resources (For overview of the state of India's healthcare system, see, for example, Balarajan, Selvaraj, & Subramanian, 2011; Gill & Taylor, 2013). For instance, the National Health and Family Welfare Ministry reported that the country's government-run healthcare system is short of 76% doctors, 53% nurses, 88% specialists, 85% radiographers and 80% laboratory technicians. Indeed, although nearly 75% of Indians live in rural areas, more than 75% of Indian doctors are based in urban areas (Ministry of Health and Family Welfare, 2011). The poor infrastructure of rural health facilities makes it difficult to retain doctors in rural areas, resulting in a lack of care providers, making rural India a prime candidate for telehealth, mHealth and other informationalizing initiatives. At the same time, India has the second greatest number of mobile phones behind China, such that 59% of Indian households have a mobile phone (India Census, 2011). India is witnessing a huge growth in demand for ICTs, reflected in one study that anticipated "a 60-fold increase in the creation of digital information over the next decade on the back of the government's digitization efforts, technological advancements and the growing penetration of mobile phones" (Surabhi Agarwal, 2010).²⁶ However, in terms of the distribution of these ICTs, India is lagging behind the other BRIC countries and is the only one classified in the "extreme risk" bracket for digital exclusion (Maplecroft, 2011). This has prompted some to talk about two Indias, India's "'first world' with increasing demand for high tech medicine, while hundreds of millions of people in 'third world' India do not as yet enjoy assured access to essential medicine and basic health care" (Gill &

²⁶ "India's Digital Universe" is a joint study by information infrastructure solutions company EMC Corp. and market researcher IDC released in 2010.

Taylor, 2013, p. 26). This combination of pressing healthcare and development problems and high penetration of ICTs makes India a primary target for ICTD projects.

India's numerous ICTD projects are funded by a wide variety of actors, ranging from governments (national and state) to corporations to NGOs and foundations inside and outside the country. I will briefly outline the structures in place for rural healthcare, before I focus on the role of digital health within the broader discursive context of ICTD in India. While India's national government promotes the goal of "universal health coverage", the Government spent only 3.9% of GDP on healthcare in 2011. However, some have pointed to the international funds from organizations such as the World Bank and USAID that may have (paradoxically) diverted attention away from health priorities, which led to greater reliance on the private sector for health development resources in India (Ma & Sood, 2008). The Indian Government recognizes the importance of information technology for the healthcare system and has ambitious plans for extending mobile healthcare and telemedicine across tertiary healthcare centers and developing a Citizen Health Information System, a biometric based health information system with health records that update for every citizen (India Planning Commission, 2013).²⁷ Yet the government's large information infrastructure projects have run into significant challenges and their cited benefits have yet to materialize (see, for example Srinivasan & Johri, 2013). One of the first information technology intensive projects that the Indian government invested in is Rashtriya Swasthya Bima Yojan (RSBY), an insurance scheme for those below the poverty line, which

²⁷ <http://timesofindia.indiatimes.com/india/Telemedicine-set-to-boost-health-services/articleshow/12310829.cms?referral=PM>

In 2010, the planning commission of India convened a High-Level Expert Group (HLEG) on Universal Health Coverage to come up with a framework for providing easily accessible and affordable health care to all. In the twelfth five year plan they set out the guidelines for transforming India's healthcare system and the important role of information technology.

uses smart card technology to permit the immediate enrollment of new beneficiaries and facilitate cashless provider reimbursement payments, continues to expand (Lagomarsino, Garabrant, Adyas, Muga, & Otoo, 2012).

India has a multi-tiered healthcare system through which primary care is delivered through a network of sub-centers, primary healthcare centers, community health centers and district hospitals. In the rural areas most primary care is provided by sub-centers or primary healthcare centers, high rates of absenteeism plague the system (Gill & Taylor, 2013). There is also a thriving informal and uncertified set of rural medical practitioners (RMPs), according to one estimate 43% of doctors classified as allopathic in the rural areas have no medical training (K. Rao, Bhatnagar, & Berman, 2009). Alternatives to the allopathic medicine are also prevalent and have been characterized as the AYUSH system (including Ayurveda, Yoga and naturopathy, Unani, Siddha, and Homoeopathy)²⁸ (M. Rao, Rao, Kumar, Chatterjee, & Sundararaman, 2011). Public perception of government provided health services, based on people's experiences with the system, is that of being low quality, which leads to underutilization of services. The National Rural Health Mission (NRHM) formed in 2005 aims to address these gaps through a number of measures targeting disadvantaged populations, including poor women and members of scheduled caste/scheduled tribe communities²⁹. One core component is the capacity building, training, and programming for intermediary, community level health workers, including Auxiliary Nurse Midwives (midwives) and Accredited Social Health Activists (ASHAs), who are paid by the

²⁸ Under the National Rural Health Mission, a program was established to make these services available in the district and subdistrict health facilities, which helped to bring the AYUSH services into mainstream medicine (M. Rao, Rao, Kumar, Chatterjee, & Sundararaman, 2011).

²⁹ Scheduled castes and scheduled tribes are population groupings recognized by the Constitution of India and are communities that have traditionally been underserved.

Government for their outreach work at the village level around health promotion and increasing utilization of maternal and newborn services. It is at the intermediary, community levels that many of the ICTD projects, in particular mHealth projects, are gaining ground and intervening in care.

ICTD in India

The central policy discourses of international development, global health, the Indian government and ICT industries promote ICTs as a technological solution for bridging the poverty and healthcare development gaps for remote populations through a rhetoric of modernization and inclusion (Donner, 2008). MHealth is discursively constructed as *the future*, the inevitable, incontrovertible “path forward” (Brewer, 2011). ICTs are referred to as the “bridge” and the “portal”, to the information society, or as or as Former Secretary of State Hillary Clinton (2010) suggests, “an on-ramp to modernity.” Despite the degree of plurality and tolerance India boasts, Indian society is fractured by ethnic, religious, caste, class, and gender divides that contribute to the uneven distribution of health and healthcare across the country (Balarajan et al., 2011). Moreover, scholars have demonstrated that ICTs in rural India don’t necessarily function as a socioeconomic equalizer; rather they may reinforce existing divides and create new ones (Noir & Walsham, 2007; Sreekumar, 2007, 2011). Other scholars have expanded the view of mobile phones as instruments of development to illustrate the varied and dynamic motivations and reasons for appropriating the mobile phone in their daily lives that depend on a range of different factors (Donner, 2008; Horst & Miller, 2006; Sey, 2011).

The unbridled enthusiasm for the game changing effects of ICTs in development has been tempered somewhat as many within the field report a high degree of failure and a growing reflexivity across the field of ICTD has emerged (Avgerou & Walsham, 2001; Heeks, 2002b;

Toyama, 2011). This reflexivity across the field has emerged along with the wide swath of failed ICTD projects over the years, which brought the initiation of “FailFaire”³⁰, a conference where ICTD practitioners and researchers presented different failed projects, and multiple diagnoses of what was termed “pilotitis”³¹, or the proliferation of failed pilot projects. External and internal critiques of ICTD as techno-deterministic and techno-utopian have to some degree been subsumed into ICTD rhetoric. Some opted to rhetorically distance themselves from the techno-utopian aphorisms characterizing the field by pre-emptively acknowledging and repurposing the critique. It is common now for ICTD texts to begin with one of various admonitions that “of course” the mobile phone is not a “silver bullet”, a “panacea”, nor is it a “slam dunk.” The acknowledgment of this critique represents a shifted and adapted rhetoric that presents a more nuanced claim for the transformative power of the mobile phone. For instance, Kentaro Toyama, a prominent ICTD professional turned skeptic openly critiqued the work and rhetoric of ICTD by articulating his primary lesson learned: technology can only be an *amplifier* of human intent and capacity (Toyama, 2011). Still other scholars critique ICTD and global information society discourse and projects as veiled extensions and amplifications of the historic geopolitical modernization project of development communication (Chakravartty, 2009; Leye, 2009). Chakravartty (2009) argues that the discussions today about the global information society, while they carry a more politically neutral tone, emphasizing “the organic synergy between corporate benevolence and local community empowerment,” are, in fact, part of “a sophisticated revamping of technological determinism” that claims that access to “high tech innovations” will

³⁰ “About” Failfaire, <http://failfaire.org/about/> (Accessed May 5, 2014)

³¹ Cf. Chamberlain, Sarah (2012) “Pilotitis-What’s the Cure” *BBC Media Action*, <http://www.bbc.co.uk/blogs/bbcmmediaaction/posts/Pilot-it-is-Whats-the-cure-> (Accessed May 5, 2014).

“transform the lives of individuals and communities in villages, small towns, and urban slums across the ‘developing world’” and facilitate a seamless transition into modernity (p. 37). It is within a politically charged discourse of development and technology and an increasing convergence of commercial and global health interests that the informationalizing effort in rural India is situated.

Informationalization and Development

ICTD emerges from a long history of development communication, which is outside the scope of this project to review. Rogers (2000) argues that informatization is an “alternative strategy to previous strategies of development communication” (p. 71) in which new communication technologies are used as a means for furthering socioeconomic development as a nation becomes more and more an information society (Singhal & Rogers, 2001).

Conceptualizing development as a process of informationalization implies that the gaps in healthcare in the developing world are defined as information and communication gaps. In this view, the barriers to bridging healthcare development gaps as well are translated into problems of information and communication diffusion imagined through the lens of digital technology solutions. This is the foundation for a dominant discourse in ICTD research and praxis which relies a diffusion of innovations model (Rogers, 2003) in framing and understanding their work. In the diffusion of innovations model, while the process of diffusion has been revised to a multi-step process and open to “re-invention”, the innovation is conceptualized as being created and defined by ICTD professionals or experts, while users are configured and categorized based on how quickly they adopt a new technology (Burrell, 2012a; Sey, 2011). Thus many ICTD projects rely on “transfer and diffusion” approach which focuses on spatial diffusion adoption and connection, rather than “the social embeddedness approach” which focuses on the impacts on

socioeconomic structures (Avgerou, 2010). Countering this approach, are calls for more participatory approaches that position the users as producers and innovators rather than passive recipients and consumers (Heeks, 2008). While the dominant rhetoric on ICTD design has shifted from technology driven towards user-centered design, what Heeks (2008) terms “ICT4D 2.0”, the extent to which design practices across the field have shifted in meaningful ways is debatable. For instance, many have critiqued the institutionalization of “participation” in development, which they argue has rendered it an ambiguous, depoliticizing buzzword that places “emphasis on the techniques of participation, rather than on its meaning,” which is about power (Leal, 2007, p. 544)

India mHealth and Millennium Development Goals

The multiple perspectives on technology and development are often framed as synergistic, in that the objectives of ICTs and the Millennium Development Goals (MDGs) are both concerned with “the efficient, scalable, affordable and pervasive delivery of goods, services and information flows between people, governments and firms” (Gilhooly & Lal, 2003). Heeks (2008) describes the catalyst for this synergy beginning with when the Internet and ICTs were “a new tool in search of a purpose”, and the MDGs were “new targets in search of a delivery mechanism” (p. 27). First, the diffusion and deployment of ICTs is also a target unto itself in MDG 8 as making their benefits available to public and private sectors to develop global partnerships for development³². Since the MDGs were announced in 2000, the international development community, including organizations such as UNDP, USAID, WHO, and World

³² Goal 8 Target 18 proposes: “In cooperation with the private sector, make available the benefits of new technologies, especially information and communication”, UN Millennium Goals, <http://www.un.org/millenniumgoals/global.shtml> (Accessed May 5, 2014).

Bank, has called upon ICTs, and in particular mobile ICTs, to play a “catalytic role” in achieving the three health-related MDGs, around reducing maternal and child mortality and infectious disease.³³ Thus these areas of health are a primary focus for ICTD projects in India around improving the delivery of care and developing systems with more timely and reliable information flow. A UN Foundation/Vodafone Foundation white paper on mHealth claimed that “Technology can help open bottlenecks in data on maternal health and improve the delivery of service. Systemic eHealth and mHealth interventions are capable of closing existing gaps in care across the maternal health continuum” (Ranck, 2011). Here, digital technology enables data to be mobile, to flow freely without “bottlenecks”, which becomes discursively synonymous with delivering services and closing gaps in care. Care is framed as a problem of information and *data mobility* becomes the solution.

Big Data and Development

Many within the global health and ICTD community are discussing the potential of “big data” to address issues in global health and development (e.g. Hilbert, 2013; Kirkpatrick, 2013a). Big Data was a featured topic at the 2012 World Economic Forum in Davos, Switzerland, producing a report titled “Big Data, Big Impact.” People within the community are experimenting with applying big data collecting, mining, and analyzing techniques popularized within the private sector to understand markets and target consumers towards solving issues in global health and achieving development aims, such as identifying trends in population health,

³³ Health related UN Millenium Development Goals, “1. Reduce child mortality: Reduce by two-thirds, between 1990 and 2015, the under-five mortality rate. 2. Improve maternal health: Reduce by three-quarters, between 1990 and 2015, the maternal mortality ratio. 3. Combat HIV/AIDS, malaria, and other diseases: Have halted by 2015 and begun to reverse the spread of HIV/AIDS; have halted by 2015 and begun to reverse the incidence of malaria and other major diseases”, <http://www.un.org/millenniumgoals/> (Accessed May 5, 2014)

providing targeted and coordinated healthcare services, and predicting and preventing disease outbreaks (World Economic Forum, 2012a). The explosion of accessible and affordable mobile phones in development contexts and mobile health strategies has inspired new possibilities for data collection and data analysis in global health and development work. Yet much of the data being collected in healthcare is not being analyzed beyond the particular project setting, if at all (Hilbert, 2013).

MHealth projects often focus on the primary uses of data either in real time point of care or in health system strengthening through feedback loops, but there is a growing realization of the potential of the mobile phone to generate huge data sets that may have secondary and tertiary uses. At least three types of mobile-generated data potentially feed into this system: (a) Data collected by health workers, (b) Data submitted by individuals, and (c) “Digital exhaust” which refers to digital data traces or meta data that has been passively collected (UN Global Pulse, 2012). People are just beginning to have an imagination for this data and how it might be mined for discovering macro level patterns relevant to global health and development work. It was much more common to hear from ICTD, global health, and development professionals that: “We have all this data, but we don’t know what to do with it” (Field notes).

The promise of big data really emerges from the big data analytics or the development of macroscopic techniques. The promise of these techniques is that in a digital data-driven ecosystem through an ongoing cycle of end to end data flow description, advanced computation, and smart analytics, valuable insights will emerge that can act as “digital smoke signals” or an “early warning system” to inform more adaptive, informed, and precise decision-making (UN Global Pulse, 2012). To realize these benefits an environment of mobile-generated data sharing needs to be facilitated in which private and public sector actors commit to participating. Global

Pulse is a UN initiative aimed at creating this environment, engaging actors in what they call “data philanthropy”, in which “big data is a raw public good” that could make development and global health work more agile and effective (Kirkpatrick, 2013b; UN Global Pulse, 2012). For instance, a subset of researchers and data scientists are using the digital exhaust from mobile phones to trace the spread of disease to better target interventions and to create indicators of wellness. Examples include mining the mobile phone data reflecting people’s movements to trace the spread of malaria in Kenya (Wesolowski et al., 2012) and Google’s monitoring of people’s search data for dengue-related topics and symptoms can be used to predict dengue outbreaks in India, Indonesia, Brazil among others (Chan, Sahai, Conrad, & Brownstein, 2011).

Increasingly, there is emphasis on and pressure to demonstrate data-driven decision-making and transparency within global health and development communities as more and more data is accessible and computable due in part to increasing pervasiveness of digital infrastructures and the ubiquity of mobile technology. Bill Gates’ 2013 annual letter emphasized how tools and innovation in “measurement” are important drivers of achieving global health and development goals. The problem of “measurement” for the global health community operates in a multi-scalar way, such that it moves from a lack of quality and timely data about health status in communities to insufficient macro level data about what global health strategies are effective or not, and in what ways. “Poverty in material terms is inextricably linked with poverty of data” (Byass, 2009). Byass (2009) argues that too often policy is derived from incomplete data on the ground which makes it impossible to distinguish between the real gaps in the healthcare system and those that can be attributed to lack of data. Further, the quality of data collected in ICTD projects have been shown by many to often be complicated, unreliable, compromised, and messy (see, for example Burrell & Toyama, 2009; Patnaik, Brunskill, & Thies, 2009), for reasons that

are beyond the scope of what I will discuss here, that make it difficult to use in broader contexts. Many view mHealth as “closing the information gap” and leading to better health policies and health and development outcomes (Vital Wave Consulting, 2009).

Multi-stakeholder Partnerships

ICTD work is accomplished most often through transnational networks of some combination of NGOs, governments, communities, technology industry and researchers, which rely on partnerships and projects to stitch together different agendas and interests. There are at least three different constructions of multi-stakeholder partnership across the ICTD community in the health and technology development arena: (a) cross-disciplinary, (b) multi-sectoral, and (c) project funders and participants, typically referring to engagement between global and local stakeholders. The multi-stakeholder arrangements that span multiple contexts across which work is accomplished for ICTD projects in health create a unique and exceptional set of challenges for digital health projects which aim to support the flow of data across contexts.

The rhetoric of partnership is leveraged across multiple scales and for multiple purposes throughout the ICTD community. Over time, partnership has become a fixed and expected feature of any ICTD discourse because as Jensen and Winthereik (2012) observe, “No one can possibly be against partnership” (p. 91). In this way, the term is used as a rhetorical device to signal a positive, validating, and unassailable mode of engagement, while in practice referring to a wide and distinct array of relationships, arrangements, and agreements. Partnership has become the all-encompassing mode of development; it has been “*enterprised-up*” (Jensen & Winthereik, 2012, p. 88).

The multi-stakeholder approach is leveraged discursively to demonstrate scalability and sustainability. Many case studies and reviews show that ICTD projects lack sustainability and

scalability pushing many in the community to call for more rigorous monitoring and evaluation assessments (Heeks, 2008). Private public partnerships have become the hallmark of multi-stakeholder approaches and have proliferated across the field of ICTD, promising to support sustainability and scalability. Rhetorically multi-stakeholder partnerships are often leveraged to signal credibility and inclusiveness. The multi-stakeholder approach has been framed as a response to critiques of dominant paradigms of development as a strategy for fostering participation of civil society and private sector groups (Burrell, 2012a).

ICTD projects depend on local partners for piloting, implementation, and in some cases co-design of new ICTD solutions. Further, as many ICTD projects are forms of “applied research” (Chib, Ale, et al., 2012), local partners are often simultaneously constructed as the subject of particular ICTD research and a participant in implementing the ICTD project creating a complex web of incentives and relations of power. Having “local” partnerships rhetorically dodges the accusation of many ICTD projects that they “helicopter” or “parachute in” and don’t engage locally. Having a “local partnership” rhetorically validates the project motivation and the project itself, not as a self-interested effort in which “outsiders” claim to represent the interests of the community, but rather as a “joint” effort, that includes and incorporates participation from local stakeholders, thereby representing local interests. This rhetoric often collapsed “local partnership” with “local ownership”, which counters top-down, modernization critiques to perform the bottom-up nature of development projects (e.g. A. Cornwall & Brock, 2006; Crane, 2010). While the rhetoric of ICTD partnership has the potential to activate negotiations of power, they more often frame partnership as a technique of accomplishing development work (Crane, 2010; Leal, 2007; White, 1996). Thus in response to the call for more participation across development work, the locus of development appears to have shifted to within “partnerships.”

However, the funding and research interest for ICTD projects is mostly on a project to project basis which means that across many of these pilot projects, partnerships are forged for relatively short periods of time and function entirely around the structure of the project. This raises questions about what the partner relationship between funder and participant operates beyond the confines of the project and whether this project-based collaboration should actually be termed a “partnership” at all (Santana, 2010).

India Consumer Health and Wellness and Technology

India’s healthcare system faces unique challenges of a high rate infectious disease, especially in the rural areas, and a growing burden of chronic disease in the urban areas. Over 20% of Indians have at least one chronic disease, and 10% have more than one (Patel et al., 2011). India maintains great diversity between rural and urban areas as well as among different regions and states in terms of health and healthcare systems, which makes it very difficult, even potentially misleading, to ever talk about India as a single entity. I refer to the consumer health and wellness in India as a diverse array of independent physicians, nurses, clinics, hospitals as well as health insurers, pharmacies, labs, medical technology start-ups, mobile service providers, and technology industry.

Most healthcare in India is provided via the private sector, and due to a lack of affordable insurance protection it is principally funded through out-of-pocket payments. Thus India has one of the highest proportions of out-of-pocket spending on healthcare in the world, about 76%, compared to the U.S. at 13% (International Labor Office, 2010). This means that consumer markets for health and wellness is expansive and expanding across urban populations with increasing demands, awareness, and lifestyle diseases. Furthermore, there is evidence that the current system often fails to meet standards of care and is not well suited to meet the healthcare

needs of communities characterized by increasing chronic disease (cf. Gill & Taylor, 2013; India Planning Commission, 2013; M. Rao et al., 2011). Across industry, development, and government policy perspectives, there is a consensus that this increase in demand and low supply represents an important arena and market of focus.

Affordable Health Care and the Fortune at the Bottom of the Pyramid

Increasingly, India's emerging market and growing demand for ICTs has become a target for digital health initiatives that bridge commercial, global health, and ICTD research interests into Bottom of the Pyramid (BoP)³⁴ efforts. Many of these digital health efforts exist in spaces outside the government and encourage relatively low-technology solutions to address India's healthcare problems. The Prime Minister's Council on Trade and Industry's guiding vision for healthcare policy is in "creating an affordable and efficient health care system, balancing preventive and curative measures and establishing an enduring public-private partnership" (Prime Minister's Council on Trade and Industry, 2000). In this framework the growing gap between urban and rural healthcare needs is emphasized as well as the role of developing and utilizing ICTs to "finance and deliver efficient health care services, and to monitor their quality, effectiveness and equity" (Prime Minister's Council on Trade and Industry, 2000) and the need to increase the role of the private sector especially in secondary and tertiary care. The focus on affordability and accessibility in government policy and private public partnerships has led to an ecosystem of health and medical technology innovators and entrepreneurs specializing in "affordable and efficient health care" (Prime Minister's Council on Trade and Industry, 2000).

³⁴ BoP is a term that refers to the billions of people who live on a few dollars a day and who represent the potentially largest new market for IT companies (Prahalad, 2006)

MedTech Innovation the Indian Way

With advances in ICTs in India in recent years, the ICT industry has come to be seen as “not just a set of channels for development, but are one type of development itself” (Rogers, 2000, p. 73). Saxenian (2006) shows how the mobile, global network of cross-regional entrepreneurs called “the new Argonauts”, embody the “knowledge transfer” of institutions and relationships to technology entrepreneurship, facilitating “brain circulation” rather than “brain drain” (p. 18). These global networks have developed in India into its own “technopolis” in Bangalore and Hyderabad around its ICT industry signifying the expansion and shifting of flows of technological innovation, institutional knowledge and capital to urban centers in India (Rogers, 2000). Within this sector, health and technology industry, entrepreneurs, engineers, and medical experts are engaging in both high tech and affordable health care innovations.

Within these centers an ecosystem of medical technology innovators and entrepreneurs are thriving. This boom is in part a result of healthcare investments in India quadrupling from 2011 to 2012 (Chaudhary, 2013). There is increasing demand for high-quality, high-tech services within India’s upper and middle class, but also important is India’s role as a hub for high quality and cost effective health treatment and surgery with medical tourists. Since so much of the healthcare system in India is left to market forces (rather than planned growth based as part of an inclusive approach), there is a need for the private sector to cater to those for whom it is difficult to access or afford services. For example, New Delhi’s MedTech Row represents a whole ecosystem of health and medical technology innovators and entrepreneurs specializing in “affordable health care”, what some have called the “Sand Hill Road of cheap healthcare”, referring to its likeness to Silicon Valley type eco-system (Lavakare, 2012). This eco-system includes nonprofit global health organizations, for-profit companies, venture capital firms, and innovations labs set up as collaborations between U.S. and Indian universities (Lavakare, 2012).

The industry defines affordable health care as low-cost medical services designed for the 835 million people in India living at the bottom of the economic pyramid, earning less than 250 rupees (\$4.50) per day (Lavakare, 2012). The goal of this sector is to both to make medical services accessible to this population, while also making a profit.

This eco-system of affordable healthcare ventures is situated within a particular context for innovation in India best captured with the Hindi word “jugaad.” Jugaad refers to an improvised arrangement, innovative fix, or work-around, which has to be used because of lack of resources (Prahalad & Mashelkar, 2010). This term has been popularized and used to describe a particular type of innovation developed in India that is based on constraints. The concept has been iterated and other related terms have emerged in Indian national, and global discourses around innovation in healthcare. Such terms include “frugal innovation”, “reverse innovation”, “low-cost innovation”, and “Gandhian innovation” (Prahalad & Mashelkar, 2010). Frugal innovation has been taken up and transformed into a strategy for multinational companies aiming to innovate in medical technology for emerging markets. For instance, in India GE, Philips, and Johnson & Johnson have opened centers for medical technology innovation targeting India in particular, but emerging markets more generally. Further, GE established its global center of “low-cost innovation” in India, while promoting their “reverse innovation strategy” (Immelt, Govindarajan, & Trimble, 2009). Reverse innovation refers to the process of developing products to meet the constraints of developing countries and then repackaging the innovation as low-cost innovative products for markets in the developed world (Immelt et al., 2009)³⁵. This

³⁵ For example, GE developed a low cost, ultra-portable electrocardiograph machine for doctors in India and China that they are now selling in the U.S. at an 80% markdown compared with similar products.

strategy implies that the constraints experienced in India often placing design pressures on affordability, scalability, and simplicity can potentially drive innovation, not just for healthcare in India, but for healthcare around the globe. A slightly different variation of frugal innovation is envisioned by Mashelkar and Prahalad (2010). They capture the essence of the design logic in the guiding principle: “More features for Less money for More people” (MLM). The challenge of how to do more for more people with less is the core challenge India faces with 1.2 billion people, and a healthcare system that isn’t meeting the healthcare demands of a growing population (Kahol, 2012). It is MLM that underlies much of the discourse of innovation across India that pivots innovative thinking around inclusivity and how to reach the most people with the innovation, rather than how to design for the frontier of high technology. Mashelkar and Prahalad (2010) has suggested using “Gandhian innovation” rather than “jugaad”, which he thinks connotes a compromise in quality, to highlight to cornerstones of Gandhi’s philosophy, sustainability along with affordability.

Data Governance

Formally organized health and disease data collection and surveillance in India has mostly focused on infectious diseases and health status of the rural poor as that has directed by global health organizations and the Indian Government as provider of health services and national development initiatives in these areas. The discourse around big data in India consumer health has focused much more at the level of public health and biosurveillance in terms of tracking infectious and chronic disease and containing epidemics (India Planning Commission, 2013). In this discursive context there is more emphasis on how to respond, cure, treat, and manage these issues, than necessarily how to predict and prevent them. Data on the “health” or wellness of the urban populations is not as accessible and without interoperability among the

multitude of private healthcare services there are limited ways to integrate population health and wellness data. One aspect of the challenge in aggregating quality data even on infectious disease is that there the majority of Indians seek private healthcare which would require some formalized way of collecting and sharing data across private and public healthcare (India Planning Commission, 2013). For instance, in 2012 the government launched the Nikshay (in Hindi the two words “Ni” and “kshay” translate to “eradicate TB”) system, which is a web-enabled application for collecting and tracking TB patient data as well as monitoring TB patients through SMS capabilities. The application is used for monitoring and management at district, state, and national levels and importantly mandates that private healthcare establishments and Government health establishment not covered under Revised National TB Control Program (RNTCP) to inform about TB patients to report TB patient data bridging the gap in access to TB patient data across public and private healthcare (Manzar, 2013).

Public Private Partnerships

In the context of consumer health and wellness in India partnership discourses are around the commitment and investment of resources and the shaping of markets. There are at least two types of partnerships emphasized in the convergence of consumer health and technology. The first are public private partnerships (PPP), which have become an increasingly common model for bridging the gap in healthcare services in India. In confronting fiscal limitations on both state and federal levels for investing in healthcare systems, the Indian Government actively seeks engagement in PPPs to meet the nation’s healthcare demands (Price Waterhouse Cooper, 2011). It is private interests that are driving the expansion of healthcare in India. These PPP initiatives are often based on the BoP model in which private sector interests can profit from emerging market consumers while helping to bridge gaps in healthcare demand.

The second type of partnership is strategically forged across telecommunications and healthcare groups. In urban India, the healthcare market is dominated by private enterprise creating a confluence of interests between private sector, technologists, and healthcare stakeholders. This confluent interest has created a market in this convergent space that has spurred many partnerships around mobile health and telehealth initiative. Telecommunications companies and healthcare groups, for instance, envision their partnership embodying the market opportunity of high demand for healthcare services and high technology penetration. For example, the partnership between Apollo healthcare and Aircel Mobile launched Aircel Apollo Mobile Healthcare, which provides “Medical advice. Anywhere, anytime.”³⁶ These market-driven partnerships often promote the credibility of their medical resources to consumers, such that the rhetoric of partnership does the work of legitimizing the product to consumers.

This chapter introduced four field sites as discursive contexts for the relationship of technology and health across the U.S. and India and demonstrated the differences and similarities across the contexts. I argue that these discursive contexts are important for understanding processes of informationalization within each field site. Together they provide a context-rich lens for situating the subsequent comparative analyses discourses, practices, and structures of digital health innovation. The following chapter builds on these discursive contexts to examine different technological imaginations around three discursive themes characterizing the relationship of technology and social change.

³⁶ Aircel Apollo Mobile Healthcare, http://www.aircel.com/AircelWar/appmanager/aircel/delhi?_nfpb=true&_pageLabel=P18000595871294468421662 (Accessed May 5, 2014)

Chapter 3

Discourses of Technology and Social Change in the Field of Digital Health

Changing language is part of the process of changing the world
—Freire (1992)

Discourse is a critically important part of constituting and representing those relationships of technology and social change that I argue underpin the processes of design and use across the field of digital health. In this chapter I present empirical and comparative discourse analysis of how the relationship of technology and social change is framed across different research contexts, drawing on key industry documents, gray literature, and stakeholder interview and observation data. This analysis is focused around three discursive themes across four different contexts for digital health. I articulate and compare the technological imaginations framing the relationship of technology and social change in health and healthcare around the themes of institutional change, democratizing power, and redistributing labor. I take the technological imaginations (Balsamo, 2011) advanced across the field of digital health to be reflective and constitutive of the sociotechnical relationships negotiated in the field. Moreover, by situating these technological imaginations within a discursive context, a deeper, context-rich lens for analysis emerges for generating insights across different field sites.

Discourse analysis provides insights into how communities “accomplish personal, social, and political projects through language” (Starks & Trinidad, 2007, p. 1374). Given the historic and systemic failures of the healthcare systems in both nations, the international development community and state governments have the responsibility to “fix” the chronic social and economic problems facing healthcare. This means they are in the challenging position of having to do two things at one time: renewing and reinventing their discourse and practice enough to convince their constituents that they have made changes; and maintaining the basic structure of

the status quo on which the industry and institutions depend. My analysis builds from the work of many scholars who have revealed and critiqued underlying values, expectations, and assumptions latent or explicit across discourses of technology and healthcare across a range of contexts. However, discourses are always evolving and in need of new analytical tools to engage the new, evolving rhetoric of technology and societal change. My work contributes to this vein.

Evolving rhetoric operates through the laundering of terms, as is demonstrated in buzzwords that come and go in popular discourse. Though such buzzwords initially invoke power and politics, ultimately they become rhetorical devices through which to frame and justify solutions (Andrea Cornwall & Brock, 2005; Leal, 2007). This critical review and analysis aims to “keep pace with emerging, new ways of employing language and concepts in processes of negotiation, debate, and consensus building” (Burrell, 2012a, p. 135) across different digital health communities and contexts. This analysis of technological imaginations importantly demonstrates the discursive configuration of users, use, and contexts of use that shape processes of technology innovation and use. I articulate the dominant technological imaginations that emerge around the discursive themes and demonstrate how they are situated and leveraged across the different contexts. While there are not fixed boundaries between different imaginations, in fact many are overlapping. The ways in which they manifest to greater and lesser degrees across the contexts provides a way to understand the contextual shaping of relationships of technology and social change in health care in the field.

Institutional Change

Technology-driven institutional change is an important theme evident across all discursive contexts. This relationship between technology and institutions is evident when technology is talked about as doing something to, for, in spite of, and against institutions. I argue

that the relationship discursively constructed between technology and the institutional context is an important part of how digital health innovations are valued, imagined, designed, implemented, and evaluated. This theme helps us to recognize the institutional arrangements within which digital health innovations are imagined and to demonstrate the underlying expectations for how digital health will redraw or reinforce institutional boundaries, such as those between clinical and nonclinical and between health and wellness. With the convergence of ICTs and medical technologies producing new user publics and bringing clinical and nonclinical spaces together in new ways, it is clear that digital health is challenging the boundaries of previously established professional practices and conventional institutional arrangements. What counts as an innovation, who innovates, and for whom or to what end are the constructs that shape innovation discourses across different institutional contexts. As Akrich (1992) notes, “A large part of the work of innovators is that of “inscribing” this vision of (or prediction about) the world in the technical content of the new object” (p. 208). Thus discourses around innovation reveal particular images of the world and of the design process itself. These discourses of innovation perform a technological imagination, that is, people “think with technology to transform what is known into what is possible” (Balsamo, 2011, p. 6). The relationship of technology and institutions manifests differently within each context, reflecting different images of the world and different technological imaginations for innovating within it.

Filling Institutional Gaps

The discursive frame in which technology is called upon to fill institutional gaps is primarily observed in the ICTD context. This discourse positions ICTs, developed outside of formal healthcare institutions, as filling gaps and operating in the margins of healthcare institutions. Imagining ICTs as bridging the digital divide has long been a part of the discourse of

inclusion in the information society (Norris, 2001; Warschauer, 2002). In the context of health and development, access to mHealth is imagined to bridge the healthcare and health information divides. At the same time that the mobile is being framed as just a tool, the expectations for mHealth described by policy and industry leaders are on a scale and scope that frame the technology as having an institutional character far beyond its role as a tool (Avgerou, 2004). The mobile is charged with accomplishing a range of activities that are typically considered the work of formal institutions, from bridging gaps in maternal and child care, to training healthcare workers, to transforming disease prevention strategies (see, for example Dentzer, 2010; T. Lewis, Synowiec, Lagomarsino, & Schweitzer, 2012; Vital Wave Consulting, 2009). Technology is relied on for what Howard (2013) has called “institutional repairs” in contexts where states and institutions fail. What this means is that the expectations of technology reach beyond its role as a tool into a role of creating institutions, doing the work of the state, and compensating for the shortage of human and organizational capacity. In the healthcare context, agency is increasingly shifted into the technical realm, which relies on further informationalizing of healthcare work. The discourse shifts the focus from the mobile as an accessory or tool for improving development work to mainstreaming mobile technology as the underlying mechanism, infrastructure, and *platform* for all health development work.

Innovations in the margins are designed to optimize performance for and often work around the local conditions. This raises questions such as: Will innovations such as these align with needs and desires of particular communities, and if so, how? In the field, ICTD professionals wrestled with defining what counts as a gap or need and deciding what warranted the leveraging and appropriating of technology as an improvement. An ICTD professional tells a story about a recent trip to Nigeria, where he discovered that even though a rural clinic had a

blood bank cooler, they were unable to use it to do blood transfusions for people in need, as in this case of a woman with post-partum hemorrhage:

They actually have to stabilize the woman and go out to the community, get all her family and friends and come in and have them actually do a direct transfusion. They have blood banks, like they have fridges, we saw them, they are just not plugged in because they don't actually have power. They have a generator that runs four hours a day, and that's not good enough to keep blood cold consistently. So do you build them a solar power refrigerator or do you just help figure out the grid and why they're running out of power?...Which is the bigger need, and do you want to actually tax every single device with a solar panel, and have them invest in that, or have them figure out how to generate enough power? (ICTD professional)

For this ICTD professional, developing a solar-powered refrigerator appropriate for a context that doesn't have continuous power supply is a band-aid; it not only doesn't solve the core problem, it has taxing implications for the community and its infrastructure. However, the quick solution is something that is within their power to do, whereas influencing the access to electrical power in Nigeria is an institutional as well as a technical problem. Rather than take on institutional and infrastructural problems, many ICTD projects tend to focus on developing optimizations, workarounds, and hacks.

Strengthening Institutions

The U.S. is a context where there are great health and healthcare disparities between socioeconomic groups and between rural and urban communities. Health information technology is imagined as the infrastructure that augments and extends institutional capacity to manage individual and population health information, deliver appropriate and coordinated care, and reduce health disparities. For the Centers for Medicare and Medicaid Services (CMS), investing in ehealth systems as the backbone infrastructure for U.S. healthcare is “the vehicle by which healthcare can broaden the accessibility of applications, facilitate user exchange of information, and collapse time, distance, and the “information divide” to better deliver care to the patient

population.”³⁷ To address the healthcare burden in rural communities, the government sees ehealth as the solution for overcoming the specific challenges and barriers of rural healthcare, including distance, isolation, and constricted resources (Walsham, 2010; Zhang & Chib, 2013). This discourse is similar in nature to the discourse of technology filling gaps, but at the same time the ways in which technology is leveraged for bridging gaps is approached differently in terms of their relationship to institutions. In the U.S. context, healthcare institutions are often framed as part of the problem of ineffective, inefficient healthcare delivery; thus technology tends to focus institutional augmentation as a way to reduce costs and improve health outcomes for the overall system. Ehealth, and specifically telehealth, are imagined as ways to bridge the shortage of medical professionals in rural areas and to more effectively and less expensively manage high-risk, high-cost chronic disease patients (IOM, 2012b; ONC, 2011). Telehealth in this context is also imagined as a way to reduce costs, such as emergency care and hospitalizations, by shifting the location of care outside the clinic into the patient’s home and around transitions of care. Such a move extends institutional reach into the everyday lives of patients in an effort to coordinate care, manage patient compliance, and provide social support (Darkins et al., 2008; IOM, 2012b). This relates to goals of population health management along a three-pronged continuum of care: disease and care management for individuals who tend to be high risk and high cost; lifestyle and health behavior management for individuals who are at risk, but not currently sick; and health maintenance and promotion for those individuals with no known risk factors (IOM, 2012b).

³⁷ Ehealth General Info, CMS, <http://www.cms.gov/Medicare/E-Health/EHealthGenInfo/index.html> (Accessed April 30, 2014)

Leapfrogging Institutions

The discourse of technology leapfrogging institutions is observed primarily in India's emerging market and consumer health context. In this discourse, the mobile phone is heralded as the most important technology for propelling dual opportunities of creating new markets in and delivering healthcare to the bottom billion. Reports from the healthcare and technology industry present the mobile phone as one of the most visible examples of a leapfrogging technology, referring to how it bypasses the need for investments in intermediate technology such as telephone land lines and PCs (Price Waterhouse Cooper, 2012). An Economist Intelligence Unit report, commissioned by Price Waterhouse and Cooper (PWC), concludes that "the ability of [developing] countries to leap ahead lies in the paucity of existing healthcare: there is greater demand for change and, just as important, there are fewer entrenched interests to impede the adoption of new approaches" (Price Waterhouse Cooper, 2012). Without the legacy of entrenched healthcare institutions (framed as inhibiting forward progress), technological change is imagined to take hold more rapidly and dramatically in developing countries.

In this vein, ICTs may be expected to bypass, not simply older generations of technology, but also the institutions within which they are embedded. Leapfrogging is a term that has been used in many different ways, originating in economic development theory, where it has been defined as "bypassing stages in capacity building or investment through which countries were previously required to pass during the process of economic development" (Steinmueller, 2001, p. 194). Currently what are most prevalent in this context are discourses of "technology leapfrogging," referring to when a population adopts a new technological innovation without ever having adopted the preceding generation of technology (Fong, 2009). Mobile technology has enabled the potential for technical and computing capability in populations of India that had not previously been considered reachable, and it is this fact that provides opportunities for the

private sector to reach those populations, thus transforming them into consumer markets. Within India's already private-sector-dominated healthcare landscape, the discourse of technology leapfrogging within healthcare is often represented by images of a frontier, in which private interests are exploring the "the Wild West of entrepreneurial spirit" (Price Waterhouse Cooper, 2012; United Nations Development Programme, 2004). The image of the frontier refers to a market space without formal state regulation and without the entrenched interests of a deeply rooted healthcare system and its associated institutions.

Disrupting Institutions

"Will Disruptive Innovations Cure Health Care?" This provocatively titled article argues that "a whole host of disruptive innovations, small and large, could end the crisis—but only if the entrenched powers get out of the way and let market forces play out" (Christensen et al., 2000). This article demonstrates the discourse around the power of technology to disrupt institutions, something that is observed primarily in the U.S. consumer health context. Throughout industry texts and gray literature the term "disruption" is used as a way to describe the discontinuity projected to occur as the digital revolution meets the institutions of healthcare, more specifically, when the power of new more affordable and accessible technology and its associated data to transform influence healthcare's institutional arrangements.

Clayton Christensen's much-popularized theory of disruptive innovation as applied to healthcare systems positions the healthcare system as the industry incumbent that can be challenged and competed with in market-driven and technology-enabled ways. His theory imagines disruption as a "natural process" that, if allowed to flourish, can build a cheaper, higher-quality, and more convenient system than the status quo (Christensen et al., 2008). This view frames technological innovations as driving the disruption of the status quo from outside

the system, where the system is an inefficient and ineffective U.S. healthcare system, fundamentally broken, unsustainable, indeed, “the most entrenched, change-averse industry in the U.S.” (Christensen et al., 2000).

Communities of entrepreneurs, data designers, users, and technologists in the field of consumer health and wellness claim that a wide range of digital health technologies that enable pervasive, ubiquitous sensing of our bodies, our minds, and our behaviors will drive a revolution in the way we know and care for ourselves (Topol, 2012; G. Wolf, 2010). These data-intensive technologies developed outside of conventional healthcare institutions follow a market-driven, consumer-oriented logic. Many in the community expect that such technologies will disrupt conventional institutional arrangements in healthcare by undercutting the status quo with affordability and accessibility; by creating new models for clinical care, personal health, and wellness; and by making scientific discoveries that democratize consumers’ and patients’ access to data and diagnostic potential (Christensen et al., 2008; Topol, 2012). The imagination for data-intensive digital health technologies is about how to advance the precision, scope, and scale of personal health and wellness data collection and analysis, leading to the democratization of consumers’ and patients’ access to data and diagnostic potential.

Multiple narratives of disruptive innovation take aim at different dimensions of healthcare institutions. Technologists, investors, and users envision technological innovation emerging through the convergence of what might be termed classically medical instruments for diagnosis and therapy, on the one side, and consumer-oriented ICTs. Health professionals are being targeted with ICTs and devices that were formerly reserved for clinical use but are now available to consumers. For example, consumer-grade urinalysis is available as an app in iTunes. Part of the disruption narrative regarding this convergent space, then, is that innovative health

and wellness tools and data innovations are exploited through networks outside of healthcare institutions, thus enabling decentralization and disintermediation. As remote monitoring and diagnostics, self-care management, tracking, and diagnoses liberate healthcare from the confines of the clinic, the decentralizing of healthcare and data production is expected to disrupt the institutionalized places and spaces of healthcare management and liberate healthcare from the confines of clinic (see, for example Christensen et al., 2008; Khosla, 2012; Topol, 2012). Health and wellness management in this technological imagination becomes an always on activity that exists everywhere the consumer is (Price Waterhouse Cooper, 2012). What constitutes healthcare blurs with spaces of health and wellness in everyday life, disrupting institutional boundaries of the clinic, the home, and the lab.

Democratizing Power

The digital revolution and democratization of power theme is alive and well within digital health. In this trope, healthcare, one of the last institutional holdouts in the digital age, becomes something that can be transformed. As in digital revolution discourses in other sectors, digital health advocates imagine networked ICTs as tools for the democratization of healthcare, thus empowering users with an ICT-expanded capacity to act in the service of their own or others health and wellness (Christensen et al., 2008; Khosla, 2012; Topol, 2012; cf. 23andMe, 2008). However, scholars critiquing discourses of Web 2.0 and user-generated content discourses have marked the problematic slippage of democratization of information and use into the democratization of power (see, for example Beer, 2009; Gillespie, 2010; Kylie, 2008; Van Dijck & Nieborg, 2009), and that slippage is evident in this context as well. Empowerment is marshaled across technology and societal change discourses to highlight the role of technology in shifting relationships of power in health (Andreassen & Trondsen, 2010; Asiedu, 2012;

Hardey, 1999, 2001). For example, Hardey (1999) highlights the role of the internet in casting a “public gaze” (p. 832) on health professional expert knowledge in a process of “deprofessionalization” (p. 821). Across ICTD contexts, Asiedu (2012) charts how the laundering of the term “empowerment” for women is the dominant form of rationale for ICTD, yet the definition of empowerment used is often narrowly defined in terms of economic empowerment. Mobile phones, in particular, are heralded as “instruments of empowerment” in the hands of women and users everywhere.³⁸ The concept of empowerment is often left undefined throughout discourses in digital health, but it tends to imply forms of deprofessionalization, individual participation, and information access.

If informationalization is employed as a strategy for development (Rogers, 2000), then digital health is the current strategy for bringing healthcare into the information age. Burrell (2012a) describes how the concept of an information society was taken up by WSIS and realigned with the themes of development, equity, and poverty eradication, themes not originally central to the concept’s source texts. The WSIS outcome documents in combination with ethnographic observations demonstrate that “the central focus is on unencumbered information circulation as the key to realizing progress for all of humanity, including poor, marginalized, and vulnerable populations” and that “ICT is treated as the material embodiment of new opportunities and as a kind of tangible portal into information society” (Burrell, 2012a, p. 142). Similar to Burrell’s observations of discourses around “information society”, mHealth discourses

³⁸ See, for example “To reposition the mobile phone from a mere communication device to an instrument of empowerment that combines communication with proof of identity, fully secure financial and other transaction capability, multi-lingual services and a whole range of other capabilities that ride on them and transcend the literacy barrier” (National Telecom Policy 2011, India)

highlight access to timely and reliable data as the problem and the solution to problems facing global health.

The consumer health narrative of democratization in health, individuals' access to information and tools of digital production empowers them to act in the service of health and wellness and healthcare, and to challenge and evaluate expert knowledge, disrupting institutional configurations of power and the status quo (Eysenbach, 2008; Hardey, 2001; Topol, 2012). Henwood, Wyatt, Hart, & Smith (2003b) point to the dominant discourse of "rights" inherent in the emergence of consumer health informatics and to the emergence of Giddens' concept of the reflexive consumer. This latter concept bears the assumption that individuals want to take more responsibility for their own health beyond the visit to the doctor. As the authors point out, this is not the case with all individuals: "'Rights,'" they note, "carry 'responsibilities'" (p. 604), and from this perspective empowerment serves to shift the burden of responsibility away from institutions to the individual (see, for example Rose, 1999).

Countering discourses of ICTs and empowerment in health and wellness, scholars have pointed to the corollary neoliberal logic of responsabilization, in which the "power" to act is also construed as the responsibility to act (Henwood et al., 2003b; Lupton, 1997; Mol, 2008). In the realm of digital health, the democratization of information and the empowerment of the user are promoted as two sides of the same coin. Around this theme of democratizing power, very different configurations of the so-called "empowered" user and scripts for that use emerge, playing a critical role in shaping the evolution of digital health across different contexts. In a semiotic and relational sense, these scripts encompass and shape user identities and subject positions in relation to user agency, inscribing particular technical competencies and user-technology interactions (Oudshoorn & Pinch, 2003a). This leads to very different configurations

of the user in relationship to empowerment and to different configurations of how empowerment is defined in each context. In the following section I discuss the importance of different configurations of empowered user across intermediaries in care, and patients and consumers, and entrepreneurs.

Empowering Intermediaries

The idea of technology democratizing power through strengthening intermediation is prevalent across the U.S. government and ICTD contexts. In these settings, intermediaries, referring to individual or organizational level entities, can appear as the primary users of digital health technologies interfacing between patients and the clinic. Across the discourses of democratizing power in these two contexts, images of the user and context of use reflect the central role of the intermediary in relationship to digital health across these contexts. While in the consumer-oriented contexts, digital health tools are promoted for their *disintermediating* effects: Consumers directly access and make sense of clinical or biomedical knowledge and participate in its production. In the rural healthcare contexts, ICTs are promoted for their capacity to strengthen the *intermediation* between the patient and the clinic.

This technological imagination manifests in the ICTD context most primarily. In this context, mobile health technologies are “instruments of empowerment” for community health workers, who function as the intermediary user responsible for facilitating patient data collection, processing, and reporting data back to the clinic, while simultaneously delivering basic primary care to the patient (Earth Institute, 2011). Community health workers are often the solitary, tenuous links between communities and the healthcare system in many of the remote areas (Earth Institute, 2011; cf. K. Rao et al., 2009). In this discourse, mobile technology is an agent in the process of demedicalization (Williams & Calnan, 1996). Clinical-decision-support algorithms,

mobile-based point-of-care diagnostics and sensors, and connections to information sources enable community health workers to extend their function and amplify their productivity as intermediaries, as is evidenced in the mPowering Frontline Health Worker public-private partnership initiated by USAID and mHealth Alliance (M. Rao et al., 2011; cf. Mecheal, 2012). One can see, then, how in this imaginary mHealth enables the frontline health workers to reach more people and provide care within institutional gaps, including the ability to conduct clinical activities previously requiring a higher skill level.

Prior research has shown the importance of the role of intermediation in ICTD in enabling technology usage or information delivery to beneficiaries for whom it would previously have been impossible for a variety of reasons (Bailur & Masiero, 2012; Heeks, 2002a; Sein & Furuholt, 2012). In the rural areas of India, development projects often target patients that neither own phones nor have the technical competencies to use them (Chib, Cheong, et al., 2012). In many Indian states, large portions of the rural population need medical care but are also illiterate (Balarajan et al., 2011; Ministry of Health and Family Welfare, 2011). Sambasivan, Cutrell, Toyama, and Nardi (2010, p. 2587) conceptualize several intermediate interactions: proximate enabling; intermediation in inputting intent into the device; proximate translation; intermediation in interpretation of device output; surrogate use; and the kind of intermediation in both input of intent and interpretation of output where the beneficiary user relies on the intermediary user for technology access. Sambasivan et al.'s study as well as other typologies (Sein & Furuholt, 2012) suggests focusing on multiple relationships of intermediary and beneficiary use that designers should consider in these settings rather than on single users. In essence, information and services are most often accessed and delivered through a network of intermediaries.

Intermediation is a hallmark of ICTD projects, in which multiple organizations and individuals may perform intermediary roles between technology design and beneficiary use. Intermediary users often move between different social groups as well as between the technology and beneficiary users (Sein & Furuholt, 2012). The transnational development projects in India rely on a network of intermediary NGOs that maintain relatively local ties and expertise through which resources and a multitude of development projects flow (Chib, Ale, et al., 2012; D. Lewis & Madon, 2004). Especially in digital health efforts, data are often produced in anticipation of being circulated to other beneficiary users to be reused in different ways outside of the primary healthcare interaction. Thus the focus on a single user can be misleading for developers and designers because it tends to ignore the participation of multiple beneficiary and intermediary users embedded within a larger sociotechnical context that may give rise to other non-instrumental uses (Sambasivan et al., 2010). The beneficiary users are multiple, potentially including the patients, the administrators of a clinic or NGO, and the design and funding organizations. In effect, intermediary and beneficiary users are often the local organizational entities, such as the NGOs and clinics. However, digital health discourses of democratizing power in ICTD emphasize the ICT-enabled empowerment of individual community health workers for the benefit of patients.

Similarly, in a rural U.S. telehealth context, there is typically some intermediating entity, whether this a telehealth worker, case manager, or medical home team functioning between the patient and the clinic. The telehealth device may be placed in a patient's home, and the patient may or may not be responsible for actively gathering their own data; the intermediary is typically responsible for processing this data, making sense of it, and making it actionable in a clinical context. In essence, intermediaries are responsible for making the information "jump contexts"

(Downey, 2014) between the home and the clinic and providing value to the beneficiaries within each context. A more in-depth discussion about what information labor entails and what we can learn about sociotechnical change from examining digital health transformations from the perspective of the intermediary will be discussed in Chapter Five.

The empowered intermediary discourse is evident in the U.S. government's promotion of "Patient-Centered Medical Home."³⁹ This a team model of care, of which the patient is a participant, using HIT to empower a distributed intermediating team to coordinate patient care across episodes and specialties and to provide better access to health information and services in an effort "to meet patients where they are" (Berwick, 2009). While an initiative such as Patient-Centered Medical Home may integrate patient data streams, coordinate care, and promote a preventive, comprehensive approach, some in the healthcare community that question to what degree it will actually "shift power and control into the hands of patients, families, and communities," which many consider the criteria for empowerment (Berwick, 2009).

In both contexts the patient is configured as a beneficiary user and one that requires the help of an intermediary to benefit from their own data. In both contexts, the patient voice is largely absent from program design, implementation, and evaluation. In a sense, this discourse reflects what Mort et al.(2003) describe as the phenomenon of absent patients. Telehealth discussions in the U.S. government focus primarily on reducing costs to the system, and secondarily on improving patient health outcomes, patient access to care, and more recently, patient engagement (Ackerman et al., 2010; IOM, 2012b). In this context it may be more precise to say that patients are "absent intermediaries" (Mort et al., 2009, p. 21). This is because there is

³⁹ See for more information on "Patient-Centered Medical home", <http://pcmh.ahrq.gov/page/defining-pcmh> (Accessed April 30, 2014)

an expectation for expanded agency in the future on the part of patients. In contrast to a focus on engagement, the focus of mHealth in the ICTD context is often around enabling inclusion and access to information and services within institutional gaps. ICTD projects often frame rural patients as broader as communities, not individuals with voices and heterogeneous needs. ICTD project language often imagines rural communities as out of reach or excluded from healthcare institutions, and in need of an intermediary entity that can bridge distance, language barriers, cultural and educational gaps.

Empowering Patient and Health Consumer

Information Access and Consumption

Framing empowerment in terms of access to care and information consumption is apparent across all discursive contexts. Digital health advocates imagine the widespread accessibility and affordability of ICTs allow individuals to consume the right health information at the right time. This is evident in the health information dissemination programs across the ICTD and India consumer health and wellness contexts that often disseminate health information through extramedical channels outside traditional healthcare institutions, such as one-way SMS campaigns.⁴⁰ Oriented around closing the information gap, often these programs present a model of empowerment that hinges on access and consumption of information as inherently empowering (Warschauer, 2004). In the consumer-oriented context, there is a greater focus on disseminating health and wellness information. This is exemplified by Indian companies such as mDhil, which employ text messaging, mobile web browser, and interactive digital content, to

⁴⁰ For instance, Mobile Alliance for Maternal Action (MAMA), a USAID mHealth program that aims to empower expectant and new mothers in remote settings through delivering critical health information through mobile SMS, to put “the power of health in every mama’s hands”, <http://www.mobilemamaalliance.org/> (Accessed April 30, 2014)

“*empower* people to make positive outcomes in their lives” and close the health and wellness information access gap.⁴¹

The democratizing power theme relies on a model of empowerment based around access to technology and information. This democratized access shifts power to the individual or other marginalized groups through expanding their choices and capabilities (using Sen’s approach to development) (Kleine, 2010; Madon, 2005). This discourse is most prevalent in ICTD and U.S. government contexts. Women are typically the target users throughout much of the ICT and empowerment discourse across ICTD, and particularly within health (Asiedu, 2012). As noted by Mecheal, executive director of mHealth Alliance: “The digital divide continues to shrink throughout the world, but women in low-income countries do not have equal participation in this technological revolution... Technology can provide a valuable mechanism for advancing the cause of women’s empowerment, particularly as it relates to health” (Mecheal, 2013). Mecheal and many other ICTD advocates imagine ICTs as tools for addressing gender inequalities through expanding women’s capabilities and enabling participation in the “information society” and access to information in an effort to combat the structural inequalities that women face in health through access to information.

Similarly, underlying many of the U.S. government efforts to achieve and evaluate patient-centered care is the belief that having access to more information expands the capabilities of patients to engage in their healthcare and to be empowered to make decisions that align with and reflect their health goals and values. However, in this context, the emphasis is on accessing information within healthcare institutions. As such, the U.S. government’s 2011 strategic health

⁴¹ mDhil <http://www.mdhil.com/> (Accessed April 30, 2014)

IT plan states that “The single biggest lever to individual empowerment is access to data” (ONC, 2011). This discourse around individual access to health data is pervasive across new efforts to elicit engagement from patients in their own care. With the government’s focus on meaningful use of EMRs, the discourse frames the access and secure sharing of EMRs as helping “empower patients to take a more active role in their health and in the health of their families” (ONC, n.d.).

Information Prosumption

Framing the user as prosumer in digital health is an important discourse around the theme of technology democratizing power. “Patient-consumer 2.0” is another term used in the gray literature to refer to a user that is not solely an information consumer; instead, the user is a health information prosumer meaning they engage in a participatory culture around health. This is observed primarily in the U.S. consumer health context, though traces of it exist across the other contexts. Researchers and industry professionals frequently use the terms “patient engagement” or “patient empowerment” when discussing the apparent imminent revolution in healthcare driven by the new digital technologies (Barello, Graffigna, & Vegni, 2012; Eysenbach, 2008; Swan, 2012a). This discourse configures the patient or lay person as an engaged and empowered participant in self-care and as an individual who is situated “at the center of action-taking in relation to health and healthcare” (Swan, 2012a, p. 97). The empowered patient is a dimension of the discourse of a “new individualistic ideology” for the future of healthcare that shifts trust and power away from institutions and toward individuals; and relies on the full participation and activation of consumers to drive these changes (Topol, 2012). Empowerment, then, is emerges first from individuals having disintermediated access to personal and personalized data and second from individuals being able to translate and reveal oneself in data. These are deeply held

values across the QS movement (G. Wolf, 2010). This discourse refers to users as sources of data and innovators around their own care solutions.

Democratization of digital health tools and data empowers consumers through disintermediation, enabling the consumer to perform activities such as diagnosis, monitoring, experimentation and data sharing outside of clinical and scientific research settings without relying on an intermediary (Swan, 2012a). Within what is sometimes described as “DIY medicine,” consumers can autonomously conduct an array of at-home diagnostic testing and internet-based medical information searching (Khosla, 2012; Swan, 2012b). This disintermediated model of empowerment predicts direct access to personal health data will empower individuals to change their behavior; to actively participate in and make informed decisions about their healthcare; and to activate around particular research or drug development agendas (Topol, 2012; cf. PatientLikeMe, 2013).

Empowerment, for many in the community, is part of the narrative of disruption that aims to re-draw professional and occupational boundaries, relationships, and previously held notions of expertise, responsibility, and authority. The new geography of power and responsibility transforms the consumer and patient from passive recipient of expert medical advice to an empowered partner or equal stakeholder that can advocate for themselves in their own care and for broader changes to the clinical and scientific institutions of medicine. Many consider consumer-driven medicine to be an essential feature of disruption in healthcare through bringing (free) market logic to entrenched hierarchies and generating a participatory culture in health. For example, Sue Desmond-Hellmann, chancellor of University of California San Francisco (UCSF), describes how the democratization of information shifts power from the institutions of medicines toward patients and consumers. “If the hierarchy of doctors are the only ones that have that

power, that puts patients at a disadvantage. The power dynamic as a partner, as someone who has a stake in it, is different. Think of how much power you have every time you go to a consumer store” (Desmond-Hellmann, 2013). Hellman’s reframing of patient as a “consumer” with choice and buying power is an essential part of how this discourse manifests the democratization of power in healthcare. Yet this consumer logic of choice means the patient bears a greater responsibility for managing their data and then navigating the implications of that data.

A growing movement of e-patients are demanding direct, open access to their own data as they begin to assert their role as data producers. E-patients, frustrated by the paternalistic model of medicine that sequesters various forms of data (such as EMR data, physician notes, medical device data) within the walls of the clinic, are demanding a direct and open line to their own health data. A popular phrase within the community is “There should be no data about me, without me” (deBronkart, Kuraitis, & Kibbe, 2010). For example, one such e-patient, Hugo Campos, advocates for the rights of patients with pacemakers and implantable defibrillators, like himself, to gain electronic access to the data collected by their cardiac devices. In a TEDx Cambridge talk, Campos challenges medical device industry norms around data access by advocating for data liberation so that he can “paint a broader picture in high resolution of what [his] health looks like,” and utilize the potentially valuable data (such as information on heart rhythm, variations in chest impedance, and battery life) collected with these devices (Campos, 2011). For other patients data liberation is not about doing something specific with that data; instead it is about the potential for innovation and change. One such patient explains: “People often ask, ‘If we give you your data, what are you going to do with it?’ We don’t know—that’s the point: innovators haven’t gotten their hands on it yet!” (deBronkart et al., 2010). The

imagination for digital health technology, then, is that it will enable consumer- and patient-driven data production, sharing, and innovation.

Empowering Entrepreneurs

The theme of democratizing power also manifests as a discourse of empowering entrepreneurs to innovate from positions outside of institutions. This technological imagination is apparent across all contexts in different forms. Empowerment is typically reserved within Indian healthcare and technology discourses to describe the aim of affordability and accessibility efforts targeting the bottom billion or the rural poor in efforts of social inclusion (e.g. Prime Minister's Council on Trade and Industry, 2000). This more well-tread model of empowerment focuses innovations around on the one hand, delivering affordable healthcare and basic health information to marginalized communities and those with limited access to medical services, while on the other hand, innovating and generating profit (Prahalad, 2006). As the urban, tech-savvy communities produce low-cost diagnostic and therapeutic devices and software and accessories that transform the smartphone into a medical device, they are in search of models of consumer empowerment within which to pitch their innovation. Within India's already private-sector-dominated healthcare landscape, the imagination of technology leapfrogging in healthcare frames these innovations as emerging market opportunities that are unhindered by formalized state regulation and entrenched interests of a deeply rooted healthcare system (Price Waterhouse Cooper, 2012). For private industry, entrepreneurs and investors viewing the bottom billion as consumers makes the market scale potential tantalizing. Further, as the relatively small subset of urban consumers that can afford and access quality private healthcare expands and becomes more demanding (see, for example PWC and Federation of Indian Chambers of Commerce and Industry, 2011), the dual challenge will be in at once defining and articulating policy measures

that attend to upper middle class demand for more access to technologically-advanced, lower-cost, and higher-quality clinical services and chronic disease management and serve the needs of the rural poor in terms of affordable, basic access to primary care and disease control interventions.

Big data rhetoric tends to frame data scientists and hackers as the entrepreneurs of an emerging data-driven era. Much of the rhetoric around the U.S. government's open data policies refers to a user that will mine the data and find value in it for themselves and the public. These scripts for use configure the user as a hacker or entrepreneur acting autonomously to derive value from data. This is the logic that underlies the approach of codeathons, hackathons, and data liberation initiatives more recently promoted by the U.S. government in which hackers and data scientists can, as HHS Secretary Sebelius suggested, "have at it" (Sebelius, 2011). This approach begins with the data rather than a question and implies that the complex problems of healthcare can be solved through hacking data. However, many warn that the role of data scientists can be to explain the what, but they are not trained or prepared to answer questions of "why" in an area when they are not an expert (Davenport & Patil, 2012). Further, there is the idea that more. big data will lead to better health, better healthcare, and better development (Manyika et al., 2011; UN Global Pulse, 2012; World Economic Forum, 2012a). Big data discourses across consumer health and wellness communities center around a new approach of knowing through data, "one that requires us to lose the tether of data as something that can be visualized in its totality" and one that requires people to view "data mathematically first and establish a context for it later" (C. Anderson, 2008). This represents a view that data are waiting for meaning; in this case, a meaning that seems to be placed in the hands of hackers and data scientists.

There are convergent themes around the role of hacking in digital health innovation and the configuration of users and designers in the image of a hacker in the contexts of ICTD and U.S. consumer health and wellness. In ICTD, hacking practices reflect a need to stretch resources and to make tools work within under-functioning or broken healthcare infrastructures. The ICTD community often celebrates boot-strapped design around failing infrastructures and glorifies hacking and repair in these contexts. Such activities are often cited as signs of entrepreneurship and the innate capacity for humans to find value and make use of data and technology for their own needs (Ames & Rosner, 2013; Rosner & Ames, 2014). For example, Ames and Rosner (2013) describe the role of this hacker ethos in developing models of childhood education in One Laptop per Child and an East Bay Fixit Clinic. They demonstrate how these efforts configure the image of children as romanticized hackers and makers at heart. Across health and wellness contexts we observe this hacker ethos configuring users in similar ways; as one who manages their own information, creates value around it, and performs the necessary repairs. This was apparent in the reaction of India mHealth project team to an anecdote I relayed from my fieldwork, which, in their minds, illustrated an image of users as hackers. I described how one of the eight midwives I observed using the mPNC figured out how play mobile videos from the video gallery on her mobile rather than playing them within the mobile form sequence as they had been instructed when the form wasn't functioning properly. To my surprise, the project team attached to this anecdote, repeating it across multiple contexts and in conversations with others, and referring to it as a sign of the midwives' natural curiosity and determination to make the mobile work. In essence, the single anecdote became at once a testament to the inherent hacker capabilities and tendencies of midwives and an affirmation that technology was an appropriate solution in this context.

In an ICTD context, the hacking ethos also refers to how technology designers work around the perceived constraints of the system or the infrastructure become what is designed around, rather than within. This ethos drives a design that doesn't directly try to improve or alter the system, but instead works around it to accomplish the task in an indirect way. Streeter (2011) describes how, in the 1970s, the term hacker functioned to “distinguish obsessive and unplanned work styles from those that were rigorous and carefully planned” (p. 90). The ICTD discourse around technological innovation often validates this iteration of the term, referring to the development of code that functions for the aim of the project and for the user, and yet is not as robust as it could be and would need to be to scale and sustain. This leads to a hacking culture of innovation that configures users as individuals who hack solutions to problems daily. This culture is supported by a number of factors: short project cycles; a lack of resources for scaling pilot projects; research-based projects testing an idea rather than building a longer-term implementation; and an already boot-strapped design setting.

There is also strong rhetoric around the hacking culture in U.S. consumer health and wellness communities. The work of Turner (2006) and Streeter (2011) offers overlapping accounts of historical roots and resurgence of hacker culture. The authors trace its roots back to the 1960s counter-culture and its re-emergence through the associations that develop with the convergence of libertarian idealism and digital innovation, what Turner calls “digital utopianism,” in the 1980s. Turner (2006) charts how the “hacker ethic,” described by Levy’s (1984) *Hackers: Heroes of a computer revolution*, became one of many sites for generating a hacker identity and spawning cyberculture in Silicon Valley. He links the convergent logics of cyberculture to the logics that undergird the current approach to digital innovation. He reveals how this link was forged through a network of cultural entrepreneurs. One such entrepreneur was

Kevin Kelly, a founder of *Wired* magazine. *Wired*, along with many other cultural artifacts and icons of the time embodied, celebrated, and advanced this particular convergence and cybercultural meaning. Therefore, it is not surprising that Kelly along with *Wired* editor, Gary Wolf, became the founders of the QS movement—a movement with explicit associations between hacker culture and consumer-driven digital health and wellness innovation.

The QS movement discourse highlights many of the tropes of consumer-driven disruptive innovation and alternative models of knowledge production. The QS community maintains many diverse perspectives and motivations; including everyone from early technology adopters and technology entrepreneurs, to fitness enthusiasts, to advocates for establishing models of data-driven or personalized medicine, to people confronting medical issues that aren't managed well by the current healthcare ecosystem. Many in this community celebrate experimentation and design hacks around self-quantification and data sharing and even self-identify as “health hackers,” “life hackers,” and “citizen scientists.” The QS community glorifies the culture of hacking, encouraging individuals take it upon themselves to create their own technical solutions and shortcuts for optimizing health and wellness. This reflects a broader cultural trend, which positions hackers as popular heroes and cultural icons and as those who act on values of freedom and individuality (Coleman, 2013). Innovation is located within a cycle of self-tracking tool development, data design, data analytics and self-discovery that furthers the application of quantitative and scientific methods to personal health. Technology enables data gathering and data analysis in more sophisticated, pervasive, ubiquitous ways, such that participants “are turning their bodies —and their lives—into personal laboratories” (Tsuei, 2011) and privileging the “n of 1.” The idea that self-tracking and self-experimentation generates knowledge is apparent in the QS slogan, “self knowledge through numbers.” Although, as Nafus and Sherman

(Forthcoming) have observed “QS is less a “crowd” to be sourced, and more a multitude of analysts, each with an analytics of n=1.” Others in the community imagine the QS movement as “a revolution against expertise” (fieldnotes), in which the individual has the power to self-care, self-discover, and in some cases generate clinically and scientifically relevant insights outside of institutionalized pathways of knowledge production and clinical standards of care. The practice of health hacking reflects values of autonomy and individuality in the use of digital health tools to reprogram or optimize one’s health and wellness and in finding alternative routes that bypass standards of care and institutional norms. The discourses around using tools to hack an individual’s life, body, or health are linked to discourses around hacking the institutional norms and disrupting the status quo. Here, the expectation is that with digital health tools and data we can hack our way not only to better health, but better (and different) healthcare.

Redistributing Labor

As I have demonstrated in Chapter One, the redistribution of labor is central to discourses of technology and social change. Across the field of digital health this theme plays an essential role in framing and inscribing: the processes of design, use, and evaluation of technology; the delegation of work across human and nonhuman actors; and the emergence of new configurations of work (Akrich, 1992; Suchman, 2007). This section identifies distinct imaginations for technology use across different digital health contexts, which articulate, delegate, imply and displace labors and patterns of interactions across human and technical configurations.

Inherent in discourses of redistributing labor are issues of visibility and invisibility (Star & Strauss, 1999; Star, 1999). In healthcare, as in any sociotechnical system, the relationships of visible and invisible labor always depend on the situated perspective and on the process of

categorization that in and of itself reveals powerful assertions about how things are and how they should be (Bowker & Star, 1999; Star, 1999). The decisions about what work to encode and make explicit in the technology versus leave to tacit labor in practice represent particular relationships between labor and knowledge production. Examining the discursive representation of the relationship of technology and social change around different configurations of human and technical labor reveals expectations for the instrumental and social reorganization of labor around and through digital health technology. In this way, this theme calls attention to new ecologies of invisible and visible work

Rationalization of Labor

Rationalization discourses position digital health technologies as tools of optimization and management and are prevalent across ICTD and U.S. government contexts. This technological imagination aims to make healthcare more efficient through the rationalization of labor (Berg, 1997; Komaroff, 1982). In this imagination, digital health will make increasing amounts of human labor computable, further transform medicine into an information science through the informationalization of clinical decision making, communication, and care. As noted in Chapter One, discourses of techno-rationalization are not new and have a long history in medicine, as documented by scholars such as Berg (1997) and Komaroff (1982). These scholars reveal an underlying logic that presumes that what is termed the “art” of medicine is simply complex labor awaiting specification and scientific explanation. This technological imagination orients around a productivist view that privileges efficiency and control through the rationalization of labor (Beniger, 1986; Braverman, 1998). As Zuboff (1988) notes, information technologies present opportunities for *automating* and *informating*. Automation often positions technology as a substitute for human agency, a relationship linked with Industrial-era

management strategies. The potential for expanding beyond the logic of technological automation to the logic of informing presents new opportunities for reconfiguring labor. Zuboff (1988) suggests that this distinction between automating and informing, “provides one way to understand how this technology represents both continuities and discontinuities with the traditions of industrial history” (p. 10). In other words, the industrial-era logic is perpetuated through information technology as it is imagined, discussed, and implemented in the world.

The rationalization of medical labor is also intertwined with processes of *medicalization* and *demedicalization*. Following Halfmann (2012), I use these terms to represent the “continuous values” (p. 186) for understanding the more or less medically implicated discourse, practices, and identities, are in operation across the contexts. The terms are used most often to refer to: framing bodies, more or less as patients; defining physiological and psychological states, more or less medically; and requiring treatments and modes of care to be under the jurisdiction of more or less medically trained individuals. Across the field of digital health, the logics associated with these terms lead to imaginations for digital health technology at once amplifying intermediary productivity and supporting governance and compliance.

Amplifying Intermediary Productivity

Digital health stakeholders within ICTD and U.S. government contexts imagine digital health technology as bridging the gap of financial and human resources in rural healthcare delivery. The expectation for digital health technology is that it will decrease the reliance on higher skilled labor through shifting care work to smart technologies, lower skilled intermediaries, and the patients themselves, through standardizing and automating clinical decision algorithms and routines (see, for example Earth Institute, 2011; Green, Savin, & Lu, 2013; IOM, 2012a; Mecheal, 2012). For instance, the Indian Government and the international

development community imagines models of mHealth and telehealth that enable lower-skilled intermediaries, such as community health workers and midwives, to deliver more healthcare more efficiently (cf. India Planning Commission, 2013). This imagination reflects increased *demedicalization* of medical practice aimed at bridging gaps across a shortage of medical professionals. These demedicalization models imagine intermediaries as the users of mobile-based clinical-decision support and point-of-care diagnostics in order to serve an expanded set of extramedical roles traditionally thought to be reserved for medical professionals (Iyengar, 2005).

Conversations around telehealth and chronic disease management models in the U.S. also reflect a dimension of *demedicalization*. These models advance the idea that technology can partially replace the labor of medical professionals in order to reduce costs. They frame the labor of the intermediary, such as nurses, care managers, or telehealth workers, as operating within a middle ground between the clinic and the home, which implies a wider definition of care beyond what would be typically defined under strictly medical jurisdiction. In shifting the locus of care from the clinic to the home, the idea is also that telehealth programs help individuals remain independent and practice self-care (Ackerman et al., 2010; India Planning Commission, 2013; Jennett et al., 2005).

Both ICTD and U.S. government contexts increasingly define healthcare problems as information problems. This underlies imaginations for telehealth and mHealth that promise the amplification of productivity of less-professionally-trained individuals and the further extension of their work into the medical realm of care. The use of data-intensive technology does not only increase the rationalization of work through delegation of work to devices and algorithms, intermediaries, and patients/consumers. These uses also disrupt labor embedded in a matrix of

social and organizational relations (Barley, 1990) and displace labor around repair and maintenance of the technology-in-practice (Schubert, 2012).

Technologies of Governance and Management

The imagination for digital health technology as rationalizing tools of management and governance is prevalent across ICTD and U.S. government contexts. This includes the idea that information technology's algorithms labor can encode the labor of management and governance through increasingly sophisticated capacities for monitoring and tracking user behavior.

Discourses of rationalization are intimately tied with discourses of modernization in the ICTD context. As Noir and Walsham (2007) put it, there is an "institutional myth of technology," that understands technology as "synonymous with process rationalization and progressive modernity in every application and context" (p. 314). Techno-rational imaginations for mHealth in India entail the use of ICTs for surveilling intermediary healthcare work to ensure standardization and manage compliance and for public health governance (India Planning Commission, 2013). High rates of absenteeism across health workers and lower-skilled workers make governance and quality control core functionalities of digital health efforts in rural India. Situated within a post-colonial context of development, authorities leverage administrative practices of tracking, recording, and establishing governance structures in rural India to coordinate, control, and produce the modern nation-state (Das, 2004; Gupta, 2012; Hull, 2012; Sharma & Gupta, 2009).

In an Indian context, the implementation of digital health projects and its associated processes of informationalization become sites for population management and a part of a broader process of medicalization of rural populations. The extended reach of health workers and biomedical tools into areas with limited access to healthcare increases the *medicalization* of everyday life activities, such as childbirth. Similarly, in the rural U.S., chronic disease

management through telehealth can be characterized by the increasing *medicalization* of health and wellness and spaces of everyday life through the presence of telemonitoring of health and wellness indicators in the home (Mort et al., 2009; Oudshoorn, 2012). Telehealth workers or care managers engaging with patient data in a clinical context can now extend clinical surveillance to the patient's everyday life practices using telehealth devices in the home. Everyday life practices, then, become increasingly defined in medical terms in the context of lifestyle diseases.

Supplanting Clinical Expertise and Interpretation

The imagination for digital health technology supplanting clinical expertise and judgment is most evident in the U.S. consumer health and wellness context. This framing of the relationship between technology and clinical labor charges algorithms with performing the clinical interpretation labor in healthcare. In its extreme version, this imagination doesn't view medicine as anything more than a complex algorithm. More often, this imagination advances the view that a substantial part of what medical professions do, especially around diagnosis, can be represented with an algorithm. This view asserts that algorithmic labor represents a way to standardize care and shift the physician's labor around those aspects of medicine that can't be translated into an algorithm (Cohn, 2013). In this imagination of data-driven healthcare, the labor of medical professionals shifts to smart devices, thereby challenging forms of professional control and institutionalized understandings of medical expertise and judgment. For instance, many Silicon Valley investors and technologists talk about replacing doctors with algorithms. They often cite Vinod Khosla's⁴² prediction that data-driven and automated healthcare will

⁴² Venture capitalist and co-founder of Sun Microsystem,

displace up to 80% of physicians' diagnostic and prescription work in the future (Khosla, 2012, 2014).

Central to data-driven innovation is the codification of knowledge in medicine into algorithms. This codification process renders explicit what was previously held as the intuitive knowledge of experts and transforms it into algorithmic procedures that can be acted on by technicians. This process allows algorithms to be framed as the cheaper, more accessible, and potentially less good doctors of the future (Topol, 2012). For example, in 2011 the Qualcomm Foundation announced a \$10 million "Tricorder X" prize for mobile diagnostics in personal health. With its name derived from the Star Trek handheld device, the Tricorder X aimed to "reward the inventor of a single portable device that, without human input, can diagnose an array of diseases with the same level of accuracy as a panel of physicians" (Waters, 2011). The goal, then was not only to transform medicine into an information science; but also to transform medical labor into something computable. These types of efforts raise questions about: To what extent algorithms can supplant clinical expertise; and what other labor does the intended functioning of algorithms require? As Oudshoorn (2011) argues, new technologies are likely to become "a site of struggle about who controls the clinical gaze" and professional authority and autonomy will be challenged, disrupting the order of care (p. 11). As such, many within the medical profession and beyond have argued that this is a reductionist view of health care and medicine that doesn't value enough the messy, implicit, tacit, human connecting and intuitive aspects of what healthcare professionals do (Shaywitz, 2011) They advocate health technology innovations that work more directly with or complement healthcare systems and target healthcare professionals as users.

Individualization of Health and Wellness Labor

The consumer-oriented contexts in the U.S. and India share a technological imagination for disintermediation. This imagination expects digital health technologies to provide and enable self-care and self-augmentation outside of traditional health institutions. The technological imagination of digital health enabling individual self-care and self-augmentation is dominant within India and U.S. consumer health and wellness contexts, and to a lesser degree in the U.S. government context. The increased burden of chronic disease in the U.S. and India coupled with an increased focus on prevention has produced new markets around health and wellness tracking, management, and interventions that healthcare institutions aren't financially or professionally resourced to handle. With these new markets come new forms of labor distributed across individuals and the digital health technology, located mostly outside of formal healthcare institutions. These new configurations of labor across individuals and digital health technology prompt consumers to engage in the work of collecting, interpreting, and communicating their own health and wellness data. Designed for practices of individual self-care and self-management, digital health technologies within the consumer realm configure users as what Lupton (2013a) has called, the idealized "digitally engaged patient." Situated in the home, the use of digital health technology becomes part of very different social arrangements and practices than they would be in the clinic. Many scholars frame the individualization of labor as linked to discourses of neoliberalization in healthcare. This neoliberal discourse proposes shifting personal responsibility for health and wellness to the domain of the individual. This proposal overlooks many of the structural inequalities that this individualized model reproduces (Lupton, 2012; Nettleton & Burrows, 2003). For example, it overlooks such inequalities as differential access and competencies with technologies and those individuals who don't want to become "reflexive, agential, and empowered consumers" (Lupton, 1997, 2012).

Digital health advocates celebrate this ICT-enabled capacity as individual empowerment; yet this model of empowerment individualizes healthcare labor, placing the responsibility of achieving the appropriate health and wellness in the hands of the consumer (literally). For example, this model imagines individuals as “the CEOs of their health” through their expanded capacity to interface with devices and software algorithms (Khosla, 2014). Another example is 23andme’s direct-to-consumer genetics testing, which provides a model of consumer experience with health data that is generated outside of conversations with health care providers and outside of health care institutions. This model leaves the consumer to make sense of and manage the implications of potential health risk factors in their everyday lives. While individuals may opt to share their data with online social networks, 23andme represents a mostly disintermediated model. In India there is already a market-driven and consumer-oriented culture around disintermediated health and wellness, within which individuals engage in self-care and self-management using technology that performs as the intermediary. Due to several factors: the fragmented healthcare system often failing to meet the demands of consumers; growing health insurance penetration; and the increasing burden and awareness of chronic disease, individuals are responsible for doing more and paying more in managing their health and wellness. Technological imaginations for digital health center around creating more autonomy, control, and self-sufficiency for consumers within and outside a system that isn’t perceived as reliable.

To some degree this imagination overlaps with the imagination of rationalization in the context of telehealth in the U.S. The imagination for telehealth is around digital health technology at once engaging patients in managing their health at home and outside the visits to the clinic and shifting the work of monitoring and tracking to the individual-oriented home domain. Telehealth devices script acts of self-care in their use at home, through disciplining

patients to monitor and manage themselves on a daily basis (Oudshoorn, 2011, p. 201). Yet the individualization of care labor in the context of telehealth occurs within circumscribed and specific measurement practices scripted by the device or particular program while still delegating the labor of interpretation and intervention to a healthcare professional.

Particularly in the U.S., there are blurred distinctions between health and wellness; and between self-care and self-augmentation.. With the rising popularity of a range of self-tracking devices and wearable sensors are imagined as the path to optimizing the self, through outsourcing management and augmentation to technology (Barfield & Caudell, 2001; A. S. Pentland, 2001). The QS movement’s tagline “self knowledge through numbers” exemplifies this theme of self-augmentation and implies that through engaging with an array of tracking and quantifying tools the individual will interpret and find value in the data for themselves. In this imagination of self-optimization, technologies become extensions of the self, or “technologies of the self” (Foucault, 1988) that generate awareness, where awareness is “interpreted as a means to make the wearer visible and readable , whether to herself or others” (Viseu & Suchman, 2010, p. 164). This has also led to a vision of personal data—”digital data created by and about people”—as new “asset class” or the new “oil” across all aspects of society (World Economic Forum, 2011).⁴³ In this vision of a personal data ecosystem, the individual is at the center, producing and sharing data through their own activities in voluntary as well as unanticipated ways. For instance, the promotion of the use of “small data,” derived from an individual’s digital traces or “digital breadcrumbs”, to generate insights or draw inferences about their health (Estrin, 2014).

⁴³ As cited in http://www3.weforum.org/docs/WEF_ITTC_PersonalDataNewAsset_Report_2011.pdf, “Personal data is the new oil of the Internet and the new currency of the digital world” , Meglenna Kuneva, European Consumer Commissioner, March 2009.

Advocates of small data expect the “n=me” to generate personalized data-driven insights that operate as early warning signs or indicators of improvement, or “as a personalized ‘social pulse’” (Estrin, 2014). This movement advocates for people’s small data to flow back to them, so that “you’ll be the customer for the data about you,” and as individuals we have the opportunity and responsibility to do the data mining labor of making it valuable (Estrin, 2014). Taken together, this technological imagination delegates the labor of care and management across these contexts to individuals at home and extramedical market-driven intermediaries rather than to healthcare institutions.

The extreme disparities in healthcare across the Indian population prompt a strong rhetoric of inclusion through ICTs, in which ICTs resolve the barriers to accessing quality healthcare (e.g. India Planning Commission, 2013). ICTs represent healthcare market access points for consumers that did not have access previously and for others who can afford it. In this way, entrepreneurs market ICTs as more convenient forms of healthcare access that bypass some of the costs of time and money previously associated with trying to stitch together forms of care across India’s weakened healthcare infrastructures. To reduce inconvenience, private sector companies and startups have started mobile web services to perform tele-triage and help consumers find a doctor nearest their location or connect online or via phone to a medical professional of varying levels of expertise immediately.⁴⁴ Many Indians already use an array of information resources, home diagnostics and monitoring devices to “self-treat” and “self-monitor” to avoid the costs and inconvenience of accessing medical care (Price Waterhouse Cooper, 2012). Disintermediation through democratization of consumer health technology

⁴⁴ See Healthline 24x7, <http://www.healthline24x7.com/>

cannot happen to quite the same extent in the U.S. due to a stricter regulatory environment for medical interpretation and devices. Following the model of ICTs as self-care access points, technology and medical industry are working together to generate new telehealth and mHealth ventures. For example, there is an abundance of doctor call-centers and “ask a doctor” websites that connect consumers by phone or virtually with medical expertise so that they don’t have to see a doctor face-to-face.⁴⁵ Increasingly in both the U.S. and India there are partnerships between on one side, medical and healthcare stakeholders, and on the other side, telecommunications companies generating services that bypass formal medical intermediary institutions. For instance, Cellular One and iSelectMD are the first partnership to launch a mobile health service direct to consumers, providing them “real-time access to a physician”⁴⁶ and allowing them to add the payment for each mobile visit to their phone bill, excising health care insurers from the loop entirely.

Apomediation Model of Health and Wellness Labor

Following the trends of participatory culture in other industries, digital health advocates imagine the shift of labor from the formal medical experts and institutions to peer-to-peer models of care and networked forms of knowledge production (Eysenbach, 2008; Fox, 2011b).⁴⁷ This technological imagination reflects an apomediation model of health and wellness labor that is

⁴⁵ See Meradoctor, <http://www.meradoctor.com/>, Vodafone’s Ask a Doctor, https://www.vodafone.in/vas/health/pages/ask_a_doctor.aspx, Airtel’s Mediphone, <http://www.airtel.in/mediphone/>

⁴⁶ iSelectMD and Cellular One mHealth program, <http://www.iselectmdwireless.com/cellularone-mHealth-program.html>

⁴⁷ Susannah Fox describes peer-to-peer healthcare the following way: “Patients and caregivers know things — about themselves, about each other, about treatments — and they want to share what they know to help other people. Technology helps to surface and organize that knowledge to make it useful for as many people as possible.” (Fox, 2011c)

predominant across the U.S. consumer health and wellness context. In this model, rather than completely removing the intermediating role, networks of trusted users, peers, and collaborative rating, recommendation, and filtering processes partially fulfill an the intermediating role by providing credibility cues and meta-data that help guide and empower individuals to navigate the huge amount of health information available online (Eysenbach, 2008; Fox, 2011a). The apomediation model is exemplified by such platforms as Smart Patients⁴⁸ and PatientsLikeMe;⁴⁹ both of which follow a model where networks of patients (or networks of “micro-experts” about their condition) experience share and learn from each other. This results in the labor of knowledge production and gatekeeping shifting across the entangled practices of networked publics and algorithms. This technological imagination frames the individual as at once, a source of data, and also a source of individual and collective intelligence about that data. This implies an expanded potential for individuals to become involved in and contribute to the production and diffusion of biomedical knowledge and health and wellness information.

From a scientific discovery and clinical knowledge production perspective individual data are understood as part of the aggregated, networked data of many individuals . The concept of patient as data has led groups of researchers, clinicians, e-patients to advocate for “data donation” as a way to generate the big aggregated data necessary for discovery. The data donation model rests on the idea that individual patients represent huge stores of data that should be liberated so that data can have “a second life” (Abernethy, 2013). These multiplied lives for data are evident in the context of direct to consumer personal genetic testing company 23andme, for whom the strength (in terms of credibility) and volume of health risk insights they offer their

⁴⁸ Smart Patients, <http://www.smartpatients.com> (Accessed May 5, 2014).

⁴⁹ PatientsLikeMe, <http://www.patientslikeme.com> (Accessed May 5, 2014).

customers is dependent on the volume and distribution of collective genetic and phenotypic data and the subsequent co-production of algorithms. The 23andme arm of the company invites the consumer to “take a more active role in managing your health”⁵⁰ while the 23andwe research arm of the company invites the consumer to participate in research because “23andme isn’t just about you” and “your DNA can lead to a cure”⁵¹. This suggests that individual contributions of data and participation in health and wellness communities also need to be understood as part of networked production.

The shifts around interpretation labor to distributed networked communities are also part of configuring digital health and the labor of health and wellness outside the clinic. Hesse et al. (2011) describe these new models of care and knowledge production to improve health outcomes as relying on “community intelligence,” through which Web 2.0 technologies are leveraged in communities of care, communities of health, communities of science, and communities of practice. As we know from the Pew Internet and America Life Project, 80% of internet users gather health information online and in a growing trend of peer to peer health care, 18% of internet users report going online to find others who have similar health concerns (Fox, 2011b). Greater reliance on networked publics for health information requires consumers to have new forms of health information literacy and competence (Eysenbach, 2007; Gibbons et al., 2011), shifting labor of determining credibility to the individual and algorithmic labor. Across many of the peer-to-peer care platforms, such as Patientslikeme and SmartPatients, there is a shared view that expertise and knowledge emerge through crowdsourcing and networks of sharing and openness. As such, many individuals and patients who have firsthand knowledge of

⁵⁰ 23andMe, <http://www.23andme.com> (Accessed May 5, 2014).

⁵¹ 23andWe, <http://www.23andwe.com> (Accessed May 5, 2014).

their condition or a particular health situation share their experience online. In this context, the communities perceive these individuals as having a certain “experiential credibility” (Metzger, Flanagin, & Medders, 2010; Metzger & Flanagin, 2008). While lacking official medical authority, they perform “experiential expertise” through new models of open participation. Models of experiential credibility are often framed as challenging models of professional medical credibility (Metzger et al., 2010). For instance, the Crohnology platform, which states that it is a “patient-powered research network” for people with chronic medical conditions (currently Crohns and Colitis) that aims to “allow patients everywhere to be contributing their own treatment experimentation in a way that could be aggregated for us to learn what actually works for whom.”⁵² This platform locates knowledge production within the aggregate of “collective experience” rather than traditional forms of medical expertise.

The technological imagination of crowdsourced expertise relies on the ability “to aggregate individuals’ experiences or opinions, pool their information, and identify the expertise of ‘nonexperts’ based on specific or situated knowledge” (Metzger, Flanagin, and Medders 2010 p. 436). The crowdsourcing of expertise is exemplified through CrowdMed, a platform which positions the individual as part of the “wisdom of the crowd” in crowd-sourced diagnoses, where “you don’t need a medical degree to help save a life”⁵³ Individuals on the site are “MDs” (Medical Detectives) and participate by reading real medical cases posed by other users and offering their opinion about a diagnosis.

Epstein’s (1995) study of AIDS activists who became credible “lay-experts” and challenged established relationships of expertise in the construction of scientific knowledge is

⁵² Crohnology, <https://crohnology.com/> (Accessed May 5, 2014).

⁵³ CrowdMed, <https://www.crowdmed.com> (Accessed May 5, 2014).

instructive here because it alerts us to the potential reconfigurations of expertise across increasingly diffuse and distributed networks. Both disintermediated and apomediated models for patient and consumer empowerment frame the patient at once as a source of health and wellness data and also as a source of individual and collective intelligence in interpreting health and wellness data either for themselves or others. In other words, individuals provide dual sources of health and wellness problems to be solved and disease and wellness solutions. Importantly, most of these imaginations position the patient and consumer experience of empowerment with personal health and wellness data outside of healthcare institutions.

Together the comparisons across technological imaginations provide a discursive framing for different approaches to digital health across the research contexts. I summarize the comparisons of technological imaginations for the relationship of technology and social change in health across the four discursive contexts in Table 2 and use this as a basis for the discussion that follows.

Table 2. Technological Imaginations for the Relationship of Technology and Social Change in Health across Discursive Contexts

	ICTD	U.S. Government	India consumer health and wellness	U.S. consumer health and wellness
Institutional change	Filling institutional gaps	Strengthening institutions	Leapfrogging institutions	Disrupting institutions
Democratizing power	Empowering Intermediaries a. Community health workers b. NGOs, clinics Empowering marginalized groups (i.e.	Empowering Intermediaries a. Nurses, care managers b. Patients and care team Empowering patients through information access	Empowering Consumers Empowering entrepreneurs	Empowering Prosumers Empowering entrepreneurs

	women) through information access			
Redistributing labor	Rationalization of labor a. Amplifying intermediary productivity b. Technologies of governance and management	Rationalization of labor a. Amplifying intermediary productivity b. Technologies of governance and management Individualization of health and wellness labor (data production)	Individualization of health and wellness labor (data production and interpretation)	Algorithmic labor supplanting clinical expertise Individualization of health and wellness labor (data production and interpretation) Apomediation model of health and wellness labor

Discussion

This chapter has clearly demonstrated the primacy and relevance of the three themes of institutional change, democratizing power, and redistributing labor in framing the relationship of technology and social change in health care across the four research sites. In comparing the different technological imaginations in relation to each theme across the sites, a set of scripts and expectations emerge for digital innovation in the realm of healthcare. With these differently situated technological imaginations across the field of digital health come different configurations of users, appropriate use, and context of use that are important in shaping the processes of shaping digital health innovation in the field. These configurations and scripts advanced within the technological imaginations imply particular distinctions between categories of medical and non-medical, health and wellness, patient and consumer, and device and data. These distinctions have important implications for how digital health functions in practice across communities.

While digital health data instruments represent a form of technological convergence, their associated technological imaginations presume convergence on multiple levels through which institutional arrangements and configurations of power are transformed. The technological imaginations around institutional change are particularly important for reshaping boundaries between categories of medical and non-medical and between health and wellness. These divergent ways of situating digital health within, outside, in the margins or gaps, of formal healthcare institutions across the four sites imply different social arrangements and contexts of use within which the digital health tools are configured. Across the sites, the technological imaginations script new interactions and sites for health care within, outside, or at the interstices of institutions. These interstitial interactions and sites become the basis for renegotiating boundaries of medical and non-medical jurisdiction and for redefining health and wellness.

The technological imaginations around the theme of democratization of power locate shifts of power in relation to users and thus participate in configuring particular user identities. The relationship of empowerment is framed around digital health technology and health *consumers* in U.S. and India. This frame configures users as empowered within a market-driven logic of choice (Mol, 2008). Users, here, are autonomous and naturally inclined to be responsible for optimizing their own health, self-managing their care, and producing, sharing, and creating value with their personal health data. In contrast, the framing of empowerment around digital health technology and marginalized groups and patients, as is done in ICTD and U.S. government contexts, configured the user as someone in need of the information or a technology to achieve equality, inclusion, or a healthy lifestyle. In the realm of digital health, democratization of information and technology and empowerment of user are promoted as two sides of the same coin. The implications of linking empowerment with having access to

information or technology is that the individual is constructed as a user capable of making the tool work or acting on the information. The technological imaginations of democratization renegotiate the relationships of power between individuals and institutions within blurred social domains of clinic and home that function to redefine user identities through new interstitial sites and interactions. The technological convergence of digital health technology challenges the distinctions among user identities through making visible the “context collapse” (boyd, 2008) of an array of social domains and institutions within which different technical functionalities and multiple social expectations exist.

The technological imaginations around the redistribution of labor shape different scripts for appropriate use and the delegation of responsibility across human and nonhuman actors. Within models of rationalization across ICTD and U.S. government contexts, digital health technology is expected to enhance efficiency and capacity for management, reflecting its role in supporting managerial structures of labor. The shifting of human labor to algorithmic labor features across all contexts, but varies both in terms of the degree of clinical interpretation it is expected to perform and in terms of the relationship to human agency within particular practices. In other words, to what degree is an algorithm expected to supplant or augment human labor?

The technological imaginations for digital health challenge and generate new models of expertise. Expanding on this theme, Gillespie (2014) suggests that “algorithmic logic”, which depends on the “proceduralized choices of a machine,” is competing with and potentially supplanting “editorial logic”, which depends on the subjective choice of certified experts (p. 192). Algorithms, defined as the “encoded procedures for transforming input data into a desired output, based on specified calculations,” (Gillespie, 2014, p. 167) transform data instruments of representation into data instruments of representation, interpretation, and action. In the

technological imagination for data-intensive digital health technology, algorithmic labor blurs distinctions between data and device.

The blurring of category distinctions have important implications for the co-construction of digital health innovation in the field. For one, they provide a set of interstices between social domains for the renegotiation of design and use, which frames the approach to digital health innovation in the field. Second, they generate gaps between what technology is imagined to do and what it actually does in practice. The ways in which these discursive scripts, expectations, and configurations get negotiated in the field across multiple communities and stakeholder groups is what we turn to next in Chapter Four.

Chapter 4

Data Valences and the Social Performance of Digital Health Metrics

What you see and what you hear depends a great deal on where you are standing. It also depends on what sort of person you are.

—C.S. Lewis (1955)

Two examples from my ethnography presented contradictory perspectives on *data* as a discursive concept. The first emerged in an interview with a researcher who was studying sensing technologies used for elder care, who said that he was surprised at doctors' resistance to accepting the data from "smart homes" for their aging-in-place patients. He quoted one of the doctors in the study as expressing the problem, "I don't need more data; I need more resources." Data here are not the valuable resources (presumably more time and money per patient and less liability risk exposure), 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 labor. 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 (Data About Me)."⁵⁴ The video features cameos from Todd Park, the U.S. Chief Technology Officer and Jamie Heywood, the co-founder of the patient-data and informatics startup Patients Like Me, both espousing why data, in the hands of patients, is valuable.

⁵⁴ "Gimme my DAM data" <http://www.acmimimi.org/2012/02/elvis-our-newest-fellow.html> and <http://www.youtube.com/watch?v=0gpk-fbfg4Y> (Accessed June 5, 2013). The phrase is credited to "e-patient Dave" deBronkart and a series of keynote lectures he has given. <http://epatientdave.com/2012/09/14/crowdsourcing-a-keynote-gimme-my-damn-data-three-years-on/#.Ua-DLJwyRq4>

In these two examples, people are talking about data in distinctly different ways. The “e-patient” perspective holds that *data* is infused with individual meaning and is valuable because of that meaning. The doctor in the aging-in-place study viewed data as something she could or couldn’t act on, a failed resource for patient care, with little value compared to other resources. In both of these examples, the validity of data was not in question. Rather, both examples are evidence of people’s varying expectations for data in social and institutional settings. These two examples reflect a recurring tension that I found around how different people talk about what they want from data and how they expect that data to perform in interaction with others. Rather the tension revealed here and throughout my fieldwork across multiple sites was around how different people and communities talk about data, what they do with data, and how they expect data to perform socially, organizationally and institutionally. 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.” If communities and stakeholder groups across 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 mobile devices and ICTs more generally?

Unprecedented volumes of data are co-produced across an emerging digital health ecology that advocates claim have the power to improve health outcomes, transform clinical care, and advance scientific discovery. This is the promise of a big data approach to health: a seamless flow of endless feedback loops across individual, laboratory, and clinical contexts. Yet in my field research this promise was unrealized, emerging instead as the exact challenge and problem that digital health innovations faced. Indeed, as one ICTD researcher remarked about mHealth projects: “The hard part is getting the data to flow.” The powerful metaphor of data

flow and liquidity is used to conjure an image of frictionless data mobility which too easily overlooks the power dynamics and materiality of an interconnected web of data discourses, practices, and contexts. Across my field sites, data are exposed as insufficient to bridge social and institutional domains, and fall short of every one's expectations. This chapter addresses research question two: Why do so many digital health efforts fall short of expectations? Why is it so difficult to make the data flow?

To address this question I draw on ethnographic interview and observational data of how different communities and stakeholder groups across the digital health ecology talk about and evoke data in practice. I propose the term *data valence* to refer to wide range of people's expectations of and values for data that emerge from their discourses and practices across different contexts for data. Using an analytical process of retrodution (Ragin, 1994), I apply the theoretical concept of data valence to examining the gaps between the contexts for and practices with data to both generate a typology of different expectations and values for data among health and wellness communities and stakeholder groups and to further develop the theoretical concept of data valence. Through this retroductive analysis I aim to map the challenges and tensions around the use and reuse of health and wellness data across communities and contexts of digital health.

Metrics as Mediation

Communication theories of mediation provide a useful lens for examining the social processes of data. The notion of contested or socially constructed data has been thoroughly examined by STS 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 (see, for example Espeland & Stevens, 1998; Latour, 1993, p. 113; Mol & Law, 1994; Stark, 2009).

What is at stake within the different field sites of mHealth and health information technology is not the validity or social meanings around data. New kinds of data instruments now blur key categories between patient and consumer, device and data, healthcare and personal wellness. This blurring 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.

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 (Leonardi, Nardi, & Kallinikos, 2012; Neff, Fiore-Silfvast, & Dossick, 2014). As pointed out in the Introduction, Lievrouw (2014) defines mediation 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. Such a view allows scholars to see data as emerging from communication media, and therefore always contextually shaped and embedded into communication practices and materiality. However, the more widespread view, frames data as a stable material object; rather than as discursively and communicatively enacted by multiple stakeholders through various practices, and in ways that resist such stability. Gitelman and Jackson (2013), for example, challenge the common discourse of data as *a priori*, existing

outside of a social context and without material intervention. This *a priori* conception imagines data as “self-evident, the fundamental stuff of truth itself” (Gitelman & Jackson, 2013, p. 2).

A mediation approach understands the production of data as requiring the extraction, interpretation and interpolation. Increasingly, online communication technologies, mobile communication devices, and the metrics that parse the data collected act as tools of data mediation. Thus, methods of quantification are “strategies of communication” (Porter, 1995) and such technologies are “*communication* made durable.” (Lievrouw, 2014, p. 50). Data and information come to be seen as an objective product of its infrastructure and a fact about the world. Bowker (1994) calls this process an “infrastructure inversion” (p. 245), and scholars suggest that this conceptual slippage is widespread even when 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 support how people come to particular practices and meanings, but provide the mediation that makes such data even possible.

Problem of Data Multiplicity

The concept of boundary object is helpful in explaining the coordination of work and interests across multiple communities (Star & Griesemer, 1989). Boundary objects can coordinate work across multiple communities when they inhabit “several intersecting social worlds and satisfy the information requirements of each of them” (Star & Griesemer, 1989, p. 393). As a coordination device, a boundary object affords enough interpretive flexibility to mean different things to different communities and yet offers enough stability to serve to translate

across disciplinary or professional boundaries among different stakeholder communities. For example, a patient medical record serves different organizational, clinical, and institutional needs, so that “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). The boundaries between clinical and non-clinical settings are no different, as with ultrasound images that were reappropriated in different contexts to perform different cultural meanings, whether as a first “baby picture” to share with friends or as part of anti-abortion activist materials (J. S. Taylor, 2008).

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, Mengis, and Swan (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. However, 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 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. For example, Patterson and Nissenbaum (n.d.) describe how people have different privacy expectations across different contexts of use for health and wellness data, what they term “contextual privacy.” They

highlight the differences between the privacy expectations for lifestyle uses of wellness data and the expectations for healthcare uses of that data in a medical context. Boundary object theory, by definition, connotes a process of social construction or one of relativistic interpretation, leaving scholars with a gap in the existing theory for addressing people's expectations for how data will be used, as opposed to differing interpretations of the data.

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 behavioral goal (psychology). These definitions have very specific meanings within their respective disciplines, yet they all reference a particular expectation or relative value that mediates something's performance within 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. Instead, they can be polyvalent across multiple contexts, stakeholders and interactions. When multiple, potentially contentious data valences emerge in interaction, the differences among them help us understand the tensions among stakeholders and

institutions. Particular data valences are not necessarily consistently evoked by an individual; rather they are evoked 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. A data valence view places the communicative mediation work around data at the center of inquiry. I argue this view provides a multi-dimensional approach to the social and material lives of data.

Defining Data Valences in Sites of Digital Health and Wellness Innovation

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. Healthcare providers work within proscribed contexts for data and with a set of values around patient data shaped by legal, ethical, and medical concerns. However, innovation in data technologies in the U.S. is talked about in terms of “disruption” of healthcare—that is, of the power of data to transform existing institutional arrangements in healthcare. In the context of the U.S. 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. For designers and users, data are often defined outside of the healthcare setting but squarely in a (free) market for consumers.

The Quantified Self (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 a key lens onto different data valences.

Innovation in data technologies in India is talked about in terms of filling institutional gaps in healthcare and its role in working around failed infrastructures and informal networks of care. Across India, especially in the rural areas, different set of negotiations between what is considered medical or non-medical and formal or informal healthcare shape different contexts and expectations for data. In an national context of little enforced regulation, a shortage of medical professionals and resources, and a high demand for healthcare services, adaptive models of care have emerged to fill the care delivery gaps. Thus utilizing informal networks of care that do not fall within the official purview of “medical” standards of care is commonplace across many sectors of society and these informal networks represent the only effective care infrastructure in place in many areas. With the exception of several massive government public health programs, for designers and users, health data are often defined outside of formal institutions, within communities and networks of local and global NGOs. While BoP-oriented efforts aim to design affordable solutions for health consumers, ICTD efforts tend to orient design around patients and healthcare intermediaries. In practice, however, these efforts tend to overlap as they both function within a mostly unregulated set of interstices that blur user and usage categories of patient and consumer, and medical and nonmedical.

For ICTD communities, data is considered a scarce resource that is charged with functioning across multiple sectors and institutional domains. The field of ICTD maintains high expectations for data to “jump contexts” (Downey, 2014) and perform differently across a multitude of social and institutional arrangements. As highlighted previously in Chapter Two, the multistakeholder and transnational arrangements of ICTD projects are often implemented within institutional margins and gaps and are deeply concerned with scaling globally. These characteristics of ICTD work provides a unique set of contextual boundaries that data are expected to cross. Often the communities in which projects are being implemented, are framed as in need of information. Here, access to data is equated with access to healthcare and empowerment. Further, global health and development agencies are increasingly under pressure to conduct more rigorous monitoring and evaluation of their work and to create more transparency through data. For example, a UN/Vodafone Foundation report (2009) claims that mHealth is “closing the information gap that currently exists for patient data in the developing world, enabling public officials to gauge the effectiveness of healthcare programs, allocate resources more efficiently, and adjust programs and policies accordingly.” By filling this information gap, the claim is that better governance, more informed decision making, and ultimately better health outcomes will follow.

Data Valences in Institutional Interstices

Distinct data valences are more apparent in what we think of as interstitial interactions occurring in spaces between institutions 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 interstitial interactions between clinic and home, there is more flexibility and permeability among data valences. For instance, mHealth 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 health and wellness data, multiple, overlapping, and many times contested data valences emerge, as expectations for data's clinical performance must be negotiated with data's consumer-oriented performance outside the clinic. In the following section, I extend the definition of data valence to propose a typology of the valences we observed in health and wellness technology communities of practice.

Findings: Data Valences in Context, Discourse, and Practice

I present a typology of seven data valences and map their emergent symbolic and material performances across the discourses, practices, and contexts of the ecology of digital health. These valences are (a) self-evidence, (b) actionability, (c) connection, (d) transparency, (e) accountability (f) truthiness, and (g) discovery.

Self-evidence

The self-evidence valence holds that data are pre-made, requiring neither work nor interpretation. In its strongest 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, 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 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.

Discourses of big data center around a data-driven approach to knowing and evoke the valence of self-evidence. For example, in global health big data advocates argue that data sharing and interoperability across siloed funders, private enterprise, and governments will reveal trends and correlations across data sets. Big data sets and computational methods are valued with an authority over and autonomy from other forms of knowing in tracking and predicting such public health concerns as flu and malaria. In an influential big data article in *Wired* in 2008, Chris

Anderson argues for extending Google's algorithmic logic (a logic replacing other modes of knowing and investigation with massive datasets and applied mathematics) to scientific discovery. "We can stop looking for models. We can analyze the data without hypotheses about what it might show. We can throw the numbers into the biggest computing clusters the world has ever seen and let statistical algorithms find patterns where science cannot" (C. Anderson, 2008). Thus in public health efforts this translates into a perspective that big data and its statistical algorithms generate knowledge on their own and investigation ceases at the level of correlations. He continues: "Who knows why people do what they do? The point is they do it, and we can track and measure it with unprecedented fidelity. With enough data, the numbers speak for themselves" (C. Anderson, 2008). Data are expected to speak for themselves, yet data have no single voice and in the realm of health and wellness, it is not clear that bigger data means better quality data. The many steps of choosing what data to collect, making sense and interpreting the data, and drawing conclusions still require a model, theory, insight, or intuition. While big data approaches may be a helpful tool for identifying what people do, only combined with what Tricia Wang (2013) calls "thick data" could these approaches begin to speak to the why and how or find anything close to a cause.

Actionability

The valence of actionability emerges when data are called upon to drive or do something or 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 or patient, poses a distinct challenge to the actionability valence within the clinical setting.

Medical technology designers in India developing point of care diagnostics for the developing world prized actionability for data at the level of the community. One such medical technology design startup developed an affordable non-invasive anemia screening device to target the problem of anemia, especially in pregnant women, as its complications lead to major causes of death for this population. From a public health perspective the data generated through the use of the device drives patient compliance and behavior change and has potential to inform better allocation of resources when paired with an IT infrastructure with location-aware sensing. Some policymakers argue that since anemia is so prevalent across the population that the best strategy is to provide iron tablets to everyone regardless of whether they have tested positive for anemia. Others point to the issues of patient compliance with this strategy, in which many patients default due to side effects such as constipation and nausea. As described by one of the startup’s entrepreneurs, this anemia screening device was imagined as a solution for the problem of patient compliance.

If he or she can see a number increasing, that’s feedback for him or her to take these tablets or maintain a more healthy lifestyle. Essentially a feedback or a number which is...contributing to compliance... You cannot make people listen every time, or you cannot actually force anyone to do anything, you have to show them.

This data-driven patient compliance and other behavior changes are envisioned as happening on a community level initiated at sites such as community health screening camps. Data, here are expected to *show* them the reason for taking action or changing behavior.

Many marketing taglines for health and wellness self-tracking tools and websites promise to deliver actionability on a personal level, “you can’t manage what you don’t measure,”⁵⁵ “own your health...take control today,”⁵⁶ “know yourself, live better.”⁵⁷ As one technology designer explained, “we don’t just want to make it meaningful, we want to make it actionable.” While patients collecting their own data may be able to bring to bear other relevant personal context and experience to illuminate meaning through these data, engaging the discovery valence, these data have a different register and life, a different valence, once expressed in the clinical realm. For example, a clinician who works with diabetic patients explains that they often are more knowledgeable about their own bodies and can more accurately regulate their insulin around any given meal than the clinician. Thus while the fine-grained data on insulin levels may not necessarily be actionable in the clinical realm, they can have enormous potential for actionability outside the clinic, empowering individuals to manage insulin levels throughout their daily routines. However, for many users, just knowing that a behavior is healthy or unhealthy is not enough to change it. For instance, 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.”

⁵⁵ Inside Tracker, <http://www.insidetracker.com> (Accessed February 19, 2014).

⁵⁶ Wellness Fx, <http://www.wellnessfx.com/> (Accessed February 19, 2014).

⁵⁷ Jawbone, <https://jawbone.com/up> (Accessed February 19, 2014).

Connection

The data valence of connection is apparent in interactions around and through shared data, in which data become what Taylor and Van Every (2000) refer to as “sites for conversation.” For the patients in the U.S. Telehealth project, adjudicating or interpreting their data often meant using data to connect with their care 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 care managers insight into their patient’s home lives and the trends in their mood, behavior, and health. Conversations between patient and care manager were often full of patient stories, at first appeared to fall outside the medical realm, but then provided important information for the care 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, these are not the kind of data that are recorded in medical records. I observed the care 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 care management work and helped in interpreting the data. For example, data reflecting patient fatigue triggering an alert for the care manager was understood in context by the care manager, who knew that this patient attended an exercise class that day for the first time. This shared data also provided sites for conversations that motivated patients and inspired personalized recommendations for behavior change.

In the U.S. a patient and user experience designer struggling with multiple, not well understood, conditions wanted to find a way to summarize her symptoms and communicate what was going with her effectively to her doctor. She drew a picture of body and marked those places on her body where she was experiencing symptoms, illustrating and labeling each one (Figure

2.). She was able to translate the experience of these symptoms into an image, a type of data that she valued for its capacity to communicate and connect with her doctor. When the patient showed her doctor the drawing she found that her doctor “kept referring back to the drawing of the person, because it helped her remember everything, helped her keep in her mind everything that we were trying to address.” She described the way the image was helpful in structuring their conversation, in that “she’d quickly look at it and be like - um, OK, now what’s this and oh, yes, you said you had the burning - and it just helped her instead of me saying one thing and then the next thing, and then the next thing, it just helped her quickly understand.” For this patient the drawing ensured she would not forget anything and that she would communicate all that she wanted to the doctor in order to achieve understanding and the experience of being seen and heard. The drawing did not function as clinical data demanding clinical intervention; rather it functioned to more effectively structure the conversation and enrich the understanding between patient and provider.



Figure 2. This drawing represents what one patient created to communicate her experience of her body and symptoms to her doctor

For midwives in rural India, the data collection process during PNC visits provided an opportunity for counseling and education. For example, the anemia screening test is based on a value representing hemoglobin (Hb) density levels. The particular Hb value is not communicated to the patient, nor is the diagnosis of anemia. Rather the midwife communicates the diagnosis abstractly, as having “a lack of” or “less” blood, within a story around the potential consequences or within advice that is contextualized within the patient’s life experiences. The storytelling links the clinical diagnosis with real-life consequences, such as having to go to the hospital in the city or needing a blood transfusion. As one midwife explains, “We have to explain properly to them the consequences of anemia...we give examples that ‘that woman from your village who delivered was anemic...she had so many problems after delivery’ or ‘she had to be given a blood transfusion’ or ‘had to be taken to the city.’” Midwives used the negative consequences of anemia to persuade patients to get tested, change their diet, or take medications. While the Hb data evoke a valence of actionability in a clinical context, in terms of determining the appropriate dispensing of medicine, clinical follow up, and in extreme cases the potential need for injection or transfusion, more often the valence of communication was apparent in the PNC visits. As one midwife reports, “We explain to them that if you do not take these medicines, we will have to give you blood...who will give you blood? Your husband? Your father? Can anyone give you blood? Then they say, my husband is very thin, how can he give blood...he can’t...and then they have the medicine.” Another midwife explains, “We tell the anemic people that if you suffer from lack of blood, you have to go to district hospital...these people are scared of going to the big hospital...even if we refer them to the hospital for delivery, they say ‘Please do it here, we won’t go to the big hospital.’” In the interaction between patient and midwife,

clinical data generated from point of care diagnostics primarily provided a site for storytelling and advice-giving for the midwife.

Transparency

People evoke the data valence of transparency when they talk about the benefits of making data accessible, open, sharable or comparable across cases or contexts. This data valence often ignores the tensions and negotiations among the different relationships, expectations, and values that mediate data in different settings, and instead privileges the power of transparent data for individual and social change. The transparency valence is evident in rhetoric around data-intensive approaches to health in which seamless flows of endless feedback loops across the individual, laboratory, clinical, and administrative contexts link big data to personal medicine.

Open data for better health is a shared discourse across ICTD, U.S. government and consumer health and wellness community. For open data evangelists, there is an expectation that open data, data that is liberated and made transparent, will lead to better health, better governance, and better informed policy decisions. This presumes an inherent positive value in more open data. For example, as part of the U.S. government's Health Data Initiative, Medicare publicly released data on hospital pricing, shedding light on the wildly variant procedure costs across and even within the same region.⁵⁸ As some in the community have pointed out while this data reveals a description of variance in the system it does provide any insight into why there is this variance, whether the variance has to do with the length of stay in hospitals or the contextual pressures for different hospitals is not part of this transparent picture of hospital pricing

⁵⁸ For example, in Saint Augustine, Florida., one hospital typically billed nearly \$40,000 to remove a gallbladder using minimally invasive surgery, while one in Orange Park, Florida., charged \$91,000 (Meier, Mcginty, & Creswell, 2013)

(Ginsburg, 2013; Maughan, 2014). The expectation for the transparency of data in this context is that public visibility of variant pricing schemes makes known who is exploiting the system and those hospitals would then be forced to make price adjustments. However, the visibility of data doesn't necessarily reveal their meaning nor does it make them actionable. As one reporter points out, the variance is in part due to hospitals cost shifting rather than price discriminating (Munro, 2013).

The U.S. National Coordinator for Health IT, Farzad Mostashari, used the transparency data valence to say that for patients, "It is their civil right to their records" (Versel, 2013). Transparency can be evoked for the expectations of what individuals' access to own data can achieve, as with the U.S. Health and Human Services "Blue Button" initiative to make personal health information downloadable. Another way to evoke transparency is making self-tracking data transparent and available to a larger collective in order to improve knowledge and tools. The community practices of Patients Like Me, an online network of patients who share data about their healthcare experiences and outcomes, epitomizes this data valence. As their "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?" (PatientsLikeMe, n.d.). In this community data are expected to establish a transparency across patients and diseases that can transform healthcare through this openness.

Accountability

The data valence of accountability is apparent when data are expected to demand, enforce, or perform a relationship of "account-giving" or an assumption of responsibility for a particular set of actions or decisions. This valence is evoked in efforts to establish better governance, within which data operates as a site for the performance of accountability

relationships and embodies the practice of “account-giving.” For example, LNGO administrators on the India mHealth project, expected real-time mobile PNC data from the midwives’ visits to improve accountability by extending their oversight of their performance and their compliance. As explained by one of the LNGO administrators, “The moment you have an outreach worker meant to perform an action, and then report on that action, for the moment the information comes from the report but it’s speaking to an action or a set of actions. You need to be certain whether the action was actually performed or not, performed from time A to time B and performed in a certain kind of sequence.” Data here function to account for sets of actions and responsibilities beyond the primary report of patient data collected in the visit; providing a measure of health worker compliance. The metadata generated through the PNC visits are expected to perform “a kind of a policing function...we see this as a way of concurrent processing, make it as non-threatening as possible. But nevertheless, send a signal, make it look as if there is a way to assess where people are...” (LNGO administrator). Data are talked about as filling the gap of supervision that this organization faced by replacing the need to have supervisors travel into the field following up on and assessing the performance of each health worker.

For a few of the midwives, using the mobile to collect patient data during a PNC visit triggered an anxiety around the data’s accountability valence. I observed these midwives taking out scraps of paper during the PNC visit to quickly jot down the test result numbers for blood pressure, Hb, and the baby’s weight separate from entering them into the mobile form. The midwives wanted to have those data points in case the mobile did not work as intended and they were called upon by the office to account for the patient. They valued this data as evidence of their own labor and professional reputation with the administrators. They were responsible, less for the outcome of the patient visit and more for the patient data they collected during the visit.

While confident that they would remember the answers to the rest of the questions in the visit, they feared they would forget the numbers. Thus changing the nature of data collection and representation in the clinical context from a paper to mobile-based process challenged the data valence of accountability, which was imbricated in the material practices of paper-based accounting.

These account-giving data operate as the primary performance metrics for the intermediaries, who then, in part, shape their behaviors and practices around the expected performance of these data in the administrative context. Data practices are inextricable from the organizational and social relationships of power within which they are embedded. For the intermediary roles on the India mHealth project there was a responsibility to produce data to account for their labor, their decisions, and their use of resources. Weekly PNC forms were sent back to the office and once a month the rural clinics become what Latour (1987) has called “centers of calculation”, in which the midwives sat for hours in piles of registers and paperwork tallying and documenting monthly counts of visits, receipts, and procedures. Thus the clinical documentation and processing of these data to comply within the accountability relationship demands from the administrators was decoupled from the potential clinical actionability of or discovery from these data.

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” and “get the truth of it.” He considered the role of the doctor in assessment only important because the data was often self-reported, rather than the “factual”

truth generated through instrumented sensor data. 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 behavior to potentially alter whatever that outcome is...the tracking itself continues my behavior 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 marshaled 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!” For this woman 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 a different alternative practitioner, whom 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,

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* (my emphasis).

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; instead, it emerges through a validating interpretation of the data as truth.

In the India mHealth project the truthiness valence was evoked when mobile-based data collection forms and digital mobility between the field, clinic, and office were expected to produce more accurate data collection and processing and therefore more authority. One of the midwives explained that by using the mPNC she is “getting correct data in the mobile so there is no chance to do mistake...I am taking the pulse, respiration...it comes exact...we can write anything on the form, but in phone it comes on the screen while typing, so it is correct, more than correct.” Further, the NGO administrators expected that mobile-based point of care data collection would reduce transmission losses and “the number of layers of inaccuracy” that emerge with paper-based data transmission in which there are multiple points of data entry and processing. Tapping into the truthiness valence of data, the digital and mobile format was valued not only for generating more accurate data, more efficiently, but also for generating more valid and verifiable data. For instance, the timing data produced as a byproduct of how midwives are working their way through the mobile forms can be used to infer truths about the midwife patient interaction and whether the information was fabricated. For ICTD professionals this affordance of verifiability produced through a mobile-based interaction means that

You can almost kind of reconstruct the interview that happened maybe through a bit of a blurry image but at least you have some sense of what happened... Before with the paper you didn't even know if the interview even happened, it could just be all faked data. Now if I look at that information I can actually tell you with some probability that this is data that is realistic or is fabricated. (ICTD professional)

For the administrators, if they can collect the metadata of “where and when the data was generated, then we've authenticated it, irrespective of a self-report” (LNGO administrator). This valence of truthiness emerging from mobile-based interactions is contrasted with paper-based interactions where there is no user interaction data to verify certain aspects of the interaction.

Discovery

The valence of discovery is apparent when data become sites 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. As QS cofounder Gary Wolf explains, “Self-tracking is not really a tool of optimization but of discovery, and if tracking regimes that we would once have thought bizarre are becoming normal, one of the most interesting effects may be to make us re-evaluate what “normal” means” (G. Wolf, 2010). 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.

Across digital health discourses, innovations in pervasive and ubiquitous sensing technology, greater volumes and varieties of available data, paired with unprecedented interoperability and advanced computational tools promise to transform data into discovery. Health and wellness data is prized for its potential for discovery as it is mined for multiple uses in multiple different contexts, such as public health management and syndromic surveillance, scientific research, resource use and program evaluation. As Amy Abernethy⁵⁹ argued in her TEDMED presentation, data should be given a “second life”; “Data is a non-depletable resource, and the more we make use of it, the more valuable it becomes” (Abernethy, 2013). In the ICTD context, advocates of big data see the potential for mining data, once specific to a particular goal, for many other uses.

I think we’ve got to start thinking broader than that and saying we’re getting health data on people, we can use it in a lot of different ways, it’s not just for the one program that they’re enrolled in, it’s not just for the one hospital they’re working for, we’ve got to see

⁵⁹ Amy Abernethy, MD, is director of the Center for Learning Health Care, Duke Clinical Research Institute

trends across hospitals, across a nation, across nations - why is it different here than here, and as that data gets richer and richer, we'll start to see what correlates with what, and so I think it's a good general data mining statistical analysis problem that we're just barely starting to scratch the surface of... (ICTD researcher).

This is nowhere near an exhaustive list of possible data valences. Grounded in my research across multiple field sites, this typology helps expand the concept of data valence. I outline a summarized data valence typology in Table 3. The table details each data valence as it is evoked through discourses and practices across contexts as well as what challenges these expectations and values for data generate.

Table 3. 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”
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 sensemaking
Accountability	Data to improve governance, and act in place of human supervision	Intermediaries producing data as primary performance and compliance metric	Structures of accountability decoupled from structures of clinical actionability
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, ICTD research	Findings not connected to medical validation

Tensions and Challenges

Identifying data valences in the interstices reveals the challenges that emerge as a single data valence is evoked differently across discourses, practices, and contexts as well as when multiple, contentious valences that manifest in the interstitial interactions. Mapping the different data valences in these interactions helps to expose many of the tensions among stakeholders and institutions in sites of digital health

Data-driven institutional change

The rhetoric of data-driven institutional change in U.S. healthcare promotes 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 in the home. Yet many contexts present barriers to sharing health information, such as different communities not wanting data to be transparent for a variety of reasons. For example, while a recent Accenture survey showed that 82% of U.S. doctors want patients to actively participate in their own healthcare by updating their EMRs, only 31% believe patients should have access to their full EMR (Accenture, 2013). In a clinical context, physicians have concerns about how to negotiate “total transparency” with doctor notes in particular patient situations that demand sensitive, strategic management and communication of information. As demonstrated in the opening example to this chapter, for many doctors faced with accepting patient-generated data, data demand (instead of save) extra labor and resources and expose doctors to greater liability risk. Yet the value of data from a patients-rights activist perspective advocating for access to their EMR data (as in the “Gimme my DAM data” advocacy video), is that *data* about them are meaningful and potentially actionable.

As people continue to manage and share the data that they generate, their data may become occasions for connection, discovery and mobilization, in addition to any clinical or interpretative role. Patient/consumer advocacy for transparency and the myriad expectations for actionability, communication, and discovery inside and outside the clinic places pressure on doctors who do not share the same expectations for patient-generated data in the clinical setting. Discourses of “transparency” and “openness” make it possible to dodge the conversations about “open to whom” and “for what purpose”, which conveniently ignore other data valences that are evoked through these conversations.

Data-driven Logic

The new categories of data instruments in medicine aim to render computable the labor and knowledge of the field. In efforts to make healthcare computable, algorithms increasingly define the problem and the procedure for its solution driven by the available data, data rendered for algorithmic use (Gillespie, 2014). This logic supports discourses of data-driven behavior change, institutional change, and knowledge production in digital health. This discourse is operating at different scales and in different ways across the contexts. Data are expected to reformulate arrangements of institutional power, driving behavior change on individual and community levels, and generating insights that exceed the human scale of knowledge production. This data-driven logic generates microscopic and macroscopic renderings that are not perceptible by human experience (Kallinikos, 2009). Seeing the world at multiple scales rendered as data enables an enhanced vision, which many equate with enhanced knowledge. Yet in some cases we aren't able to actually know how some of the algorithms we are creating work. We don't know why something is, we simply trust that it is and then proceed to base decisions and judgments on this vastly complex computation. I have demonstrated the presence of this undergirding data-

driven logic in the discourses of digital health, in which only particular types of metrics and values get to count and data are continually reshaped to be algorithm ready (Gillespie, 2014). This logic represents particular assumptions about knowledge production as technical and cognitive, which stand in great contrast to what we know about knowledge production, especially in healthcare, as a messy, distributed, always partial process.

Across my field sites information determinism emerged as a common discourse. While there is also a technological determinism at play, the power of data and information as determinants of truth and action feature even more predominantly. The idea of information has different interpretations and instantiations across the literature. First, is the perspective that information and its infologic redefine the world and reshape an inevitable information-driven future (Brown & Duguid, 2000; Day, 2001). Second, information determinism is connected to the logic of neoinformationalism; “the belief that information should function like currency in free-market capitalism—borderless, free from regulation, and mobile” (Wang & Ames 2010). From this perspective “the more widespread information is, the more good it does, independent of its medium” (Wang & Ames 2010). Across these logics, information is perceived as singular, stable, and actionable and as determining action or behavior. Information determinism problematically conceptualizes information as abstracted from its context of production and as powerful on its own. Further, this view collapses the mediation work that links data to knowledge, sensemaking, and action. As such, the logics of information determinism are evident across the contexts and communities of digital health.

Information determines action

Behavior change is at the core of digital health efforts across the four contexts. In discourses of health care technology designers and advocates, data comes to represent a notion of

actionability, or the potential of data to drive action and decision-making. In these discourses, possessing data serves as a catalyst for behavioral change: In the words of one consumer health and wellness technology designer, “data leads to knowledge and knowledge leads to change.” This data-behavior model forms the logic of technology development in mobile health and wellness applications and digital health sites in ICTD and consumer health and wellness in U.S. and India. For technology designers in the U.S., this framework means they try to solve the seemingly inextricable problems of healthcare with what they see as well-designed, usable, personalized, and beautifully visualized interfaces for this data. This reflects a logic that: Data, if designed right, can lead to action. For ICTD and consumer-oriented digital health efforts in India, the dominant discourses frame the problems of healthcare as problems of access to health information. Patients and consumers are framed as information consumers that, once able to access information, are empowered to make different decisions, change behavior, and challenge social and cultural norms. Thus access to information is seen as synonymous with the capacity to act on the information. This is exemplified in the logic underlying many Short Message Service (SMS) projects in India that aim to disseminate information and change behavior around particular health issues. For technology designers in ICTD and in India, this framework means they design for the greatest level of inclusion and attempt to make information relevant on a community level.

The inevitable informational future

Digital health stakeholders across the contexts envision a future healthcare system based on digital health information networks. This informational future depends on the investment in particular information infrastructures and digital health technologies that can increase *data liquidity* and promote a digital health ecosystem. For the U.S. government and ICTD

stakeholders there is the prevailing notion that moving from paper systems to digital systems will make healthcare more efficient and effective, in large part due to the affordances of computability and data mobility. The U.S. government promotes the image of a “seamless flow of information” across personal, clinical, and institutional uses enabled through HIT. The expectation is that health information systems rendered in the digital realm will make the system more efficient and effective, but often the fundamental changes that occur in the nature of care, organizational labor and conditions of knowing as a result of changing the nature of information are overlooked.

Across U.S. government and ICTD contexts, information becomes both the problem and the solution. For example, paper-based health information systems are framed as the barrier to successful health information systems. Thus it is a *digital* health information system that is being designed as the solution, one that ostensibly bypasses the weakened infrastructures and organizational constraints that make paper-based systems inefficient and ineffective, and supports a *digital* information future. However, as one ICTD professional cautions, “there is a limitation; they [ICTD professionals] are basically creating all the existing infrastructure in a digital world, which does not solve problems. You have to have shorter solutions.” This future making is happening in mHealth discourses, as advocates imagine a future in which, mHealth solutions are “so seamlessly integrated into global maternal and child health programs that they cease to be thought of as ‘mHealth’, but simply as the ‘way programs are implemented’” (Labrique, 2013). Thus, the success for many advocates would be mHealth’s “disappearance—shifting the question from whether to go ‘mobile’ to which mobile approach to take” (Labrique,

2013).⁶⁰ In this imagination, the mobile is mainstreamed into health in such a way that the technological contribution ceases to be recognized. Because of its embeddedness and its inevitability no alternatives remain visible.

Neoinformationalism

The U.S. government, U.S. consumer health and wellness and ICTD communities all have a strong rhetoric advocating around the potential of free and open data. The Open Data policies of the Obama Administration undergird the Health Data Initiative that supports an open data ecosystem. There is an assumption that “liberating data” will create value on its own. As e-patients advocate for transparent doctors notes, access to their personal EMRs, and data collected in their personal medical devices, the free, untethered information flow becomes subject to regulatory and privacy concerns very much at the center of the government’s responsibility. The U.S. consumer health and wellness context features the discourse of democratization of health data, in which the free, transparent, and untethered flow of information is how innovation, discovery, and smarter, better models of health and healthcare can be achieved. The value of open and free data in these discourses is considered to be self-evident; it is *data waiting for meaning or action*. This discourse evokes multiple data valences as this notion of free and open data is divorced from the questions of open and free to whom and for what purpose. This tension will be discussed further in the following chapter.

The Mediation Work of Sensing

Digital health advocates envision new categories of data sensing instruments as essential innovations that afford more accurate and pervasive data production, reconfiguring more and

⁶⁰ Alain Labrique is Director of the Global mHealth Initiative at Johns Hopkins University.

more of our physiology, our world, and our experience in terms of data. As the development of tools for *sensing* outpaces the development of approaches for *sensemaking*, then more data is not always better, and has the potential to obscure, and even mislead. The more data collected may not make patterns and underlying mechanisms more transparent as promised by big data advocates. The promise of big data is that algorithms can make sense of huge volumes and varieties of data, configured digitally and organized relationally in databases. However, in this process of reconfiguring the world into data, “data need to be imagined as data to exist and function as such, and the imagination of data entails an interpretive base” (Gitelman & Jackson, 2013, p. 3). Thus it is important to examine the implications of algorithms not only in shaping what we know, but also in defining what is knowable or important to know. The 23andme television commercial equates your personal genetic data to “a self-portrait”, claiming that “the more you know about your DNA, the more you know about yourself” (23andme, 2013). But genetic data is co-constructed through its legibility to algorithms, while other data that is not legible is overlooked as noise. Gillespie (2014) describes a process of making data “algorithm ready”, in which “the information included in the database must be rendered into data, formalized so that algorithms can act on it automatically.” While this process may appear functionally *automatic*, there is mediation work involved in orienting and “cleaning up” the data. This mediation work, often invisible, can evoke tensions among data valences that are embedded in the “interpretive structures” imagined and harbored in different data sets (Gitelman & Jackson, 2013, p. 3). 23andme’s personal genetic data can then be understood as a self-portrait generated through datasets and algorithms that harbor their own interpretive structures, not transparent to user. Or as Gitelman and Jackson (2013) suggest, data should be understood as a photograph that is “framed and framing...according to the uses to which they are and can be put”(p. 5). An

Indian health technology startup designing a non-invasive Hb sensing device for point of care anemia screening faced challenges when negotiating the multiple data valences evoked in the process of reconfiguring the production of data. This digital point of care device would be replacing the Sahli test, which is a common method of Hb estimation, promoted by the Indian government and used by health workers across rural India in conjunction with a clinical assessment of physical symptoms for diagnosing anemia. Most doctors recognize the subjective nature of the Sahli test, citing the inconsistencies across different midwives color matching and the many variables at stake in the method, such as lighting and sanitation, which can compromise its accuracy. However, the clinical decision tree applied by midwives in the clinic doesn't account for the uncertainty and standard error in the test. The clinical algorithm operates under the assumption that the Hb value objectively represents the Hb density in the blood. Clinical *actionability* for the midwives is enabled based on the Hb density value generated from the test, even though many doctors accept that it represents a false *truthiness* when compared to the gold standard using an automated hematology analyzer⁶¹.

Clinical assessment of physical symptoms on its own often does not provide sufficient data upon which midwives can confidently act in part due to the required account giving of the Hb test result by the administrators. However, the clinical assessment does help confirm or prompt questioning of the truthiness of the Sahli test data. As one midwife commented “Some people have no signs of anemia. It happened with one patient. We checked her twice in a day because the color of her nails was good and on checking, the Hb was five gm/dl (gram/deciliter). Madame had doubts so we repeated the test, but even then it was five gm/dl.” If there is a

⁶¹ An automated Hb analyzer is a highly accurate, lab test that is not available in most rural areas in India due to expense.

mismatch between data generated through clinical assessment and through the Sahli test or between different Sahli tests, the test procedure is questioned and verified until confirming a number they can act on and for which they can account. Another midwife explained,

“It depends on the way of doing it. Suppose we are doing it and have taken blood and added distilled water to it. Suppose the Hb gram is less and we have added more distilled water, then obviously it will give a wrong reading. If we add more than required, it will not match, it will be wrong and will have to be re-checked or shake it after adding every drop, then it gives a correct result.”

The “correct result” or truthiness of the data is not simply defined through the test; it is co-produced through a larger web of practices, knowledge and expectations. The technology designers had to consider that more accurate or greater truthiness in this context of data production required complex mediation work in order to negotiate valences of actionability for the midwives and accountability for the administrators.

The technology designers, GNGO and I held a focus group with the midwives to try to understand the mediation work of midwives and the potential design implications. The designers showed a mock-up that presented the Hb value of seven gm/dl as a range of six to eight gm/dl to make transparent the plus or minus one gm/dl error of the sensing instrument (which is less error than is estimated for the Sahli test). When the midwives saw the range, they exclaimed “It’s dangerous!” They explained that having a range of six to eight gm/dl is a problem because they would not know what intervention to make; in other words, it would not be clinically actionable. The midwives were also concerned about how they would document this; in other words how would data presented as a range function for *accountability* when reviewed by the doctor or the administrators. One midwife expressed this concern as, “How will we even write it? The seniors will say we can’t write like this in our card, then how will they check the Hb? Between 6 and 8...the doctors will scold us! (*laughter*) What have you written? Do you not have an exact number?” This interaction revealed a tension between the designers’ expectations that greater

transparency around data uncertainty would lead to more informed decision making for the midwives, and the midwives' expectations that data are *actionable* and provide a means of *accountability* in the contexts of the clinic and the office.

Patient-Generated Data: Sensemaking in the clinical realm

Sensemaking conversations around patient-generated data between patient and clinician provided interstices 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 ongoing, every day, every hour, sort of issue and the doctor isn’t there all the time. You 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.” The doctor doesn’t “think in terms of data points”; instead “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 in the U.S., using patient-generated data in the clinical realm presents many challenges. One physician explains 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. 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;

instead of 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 physician 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 materialize. In the U.S. a huge concern is the 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 behavior interventions (such as pedometers) because there was very low risk involved in having a patient walk more or start taking the stairs. In contrast, he perceived a greater risk in accepting data on blood pressure or glucose readings, which could potentially demand more clinical action. In a rural Indian context, data can present a greater burden on an already overburdened and under-resourced healthcare system. As such, rural doctors expressed concerns that a class of affordable mobile point of care diagnostics may not have a high enough standard of accuracy, which could overburden doctors with unnecessary cases that would demand time and resources that are already in short supply. Thus the risk for patient-generated or intermediary-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. Data in the clinical realm, then, evoke a valence of actionability that tightly couples data to the interventions and actions demanded by the data.

Clinicians are also concerned about the resources of time and labor required to make sense of or make actionable patient-generated data that is not structured and parsed for clinical performance. For example, epileptic patients can use an online tool for tracking their seizures to learn about, better manage, and connect with online social networks about their condition. However many patients using the tool experience challenges with sharing their patient-generated data with their physician in a clinical context. Based on talking to a set of physicians the company hosting the online tool developed a physician oriented patient data profile to highlight patient-generated data in such a way that it was more likely to perform effectively in a clinical setting. A medical professional working for the company explained that the physician oriented profile sheet mostly changed how the information was organized and presented. The physicians “wanted to be able to see the data in a way that they could be drawn to it right away and see it and react with the patients, versus just being handed a doctor visit sheet which essentially is the whole profile.” For these physicians particular slices of patient-generated data, such as the number of seizures and the characteristics of the seizures, could potentially tap into valences of actionability, communication, and discovery in the clinical setting. These data could signal a need to change or adjust medication, for instance, which provides physicians with something actionable. In addition, the physicians felt these data could serve as sites for conversation around patient awareness of seizures and potential triggers. Further, clinicians imagine these data and related discussions could be part of a discovery process, providing opportunities to identify overlooked or undiscovered aspects related to understanding and treating seizures.

Encoding Data Valences

There is great pressure on designers to create devices and interfaces that encode meaning and actionability in the mediation of patient- and consumer-generated data. Designers of

consumer-facing mobile-based apps face a challenge in trying to develop an interface for interaction in the interstices. This is because they are at once, designing for consumers and everyday users, and also wanting these data to count elsewhere, either within healthcare institutions or scientific research. Technically optimizing for multiple things is incredibly difficult as points along the spectrum of patient or consumer engagement mean very different social systems around who monitors, maintains, and controls data. In consumer-oriented health technology design, the challenge is often articulated as actionability on the part of the user as consumer, not patient. One technology designer explains that the labor of making data meaningful and actionable is already encoded in his software. From the design perspective the tool should perform the interpretation, so that “the user shouldn’t have to work really hard to understand what’s going on, “ whether it is the healthy foods they eat, the therapy they should go to, or simply feedback based on their personal relative progress. However, this data needs to be structured narratively in terms of users’ lives. One organizer of QS meetups posed the problem by saying, “We haven’t gotten from data visualization to story yet.”

For designers in the U.S. consumer health and wellness context, technology reflecting this approach to behavior change then offers consumers “stuff they can do that’s kind of low-touch, frequent interactions rather than like a very high-touch, heavy clinical interaction” (technology designer). The actionability that is encoded into this product consists of lightweight actions and small behavior interventions that most people would not associate with any kind of clinical or medical interaction. The recommendations and action items are targeted outside of medical jurisdiction, not only in the legal sense, with disclaimers that specifically note that information for use is “not medical advice” and “not for medical use”, but also in the practical sense, as the company tries to engage people in behavior 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 and circumscribed in this extramedical, health and wellness-oriented space. Regulation has not yet caught up to the activity in this space. Yet this activity is expanding as efforts in preventative and participatory health efforts turn to wellness initiatives to assuage the costs of the U.S. healthcare system and support a population increasingly framed as struggling to fit normative standards of health.

One technology designer explains how they deal with the trend that so many users download a health app or obtain a tracking device, use it once or twice before their usage falls off completely: “So we often ask ourselves what can we do to get people to not just love it when they download it, but to continue to use it and integrate it in their lives. That’s a barrier, it’s very difficult, and design for us is a huge part of that, so we think that design is what’s going to pull through a lot of usage.” In the words of another designer, “We believe that things that are beautiful and fun and engaging are more likely to help people get healthy and stay healthy.” However, this does not attend to multiple expectations for the performance of data. Many designers found it easier to design for the already mainly healthy population, motivated to become healthier, a population of technologically savvy, wellness-oriented consumers. Such designers predict that self-tracking and consumer health monitoring will be as commonplace as email is today, assuming people find value in their data (Maqubela, 2012). Many advocates were simply not able to recognize the value of not knowing or of not wanting to quantify.

The Distribution of Sensemaking

With BoP and ICTD digital health efforts, designers must consider the constraints of affordability, weak infrastructures, and a shortage of clinically or technically skilled labor. They are challenged in trying to design for use by an intermediary (in the case of India mHealth a

minimally trained midwife) or a lay consumer population, while simultaneously making that data count and perform in different ways within field, clinic, office, and lab settings. Often this looks like designing for users with minimal to no clinical training and for usage in the medical and scientific realm. This configuration of use and usage in the health technology design communities is possible, in part, because of the lack of regulation and oversight in these domains. Thus both technically and clinically there is an expectation that much of the information labor and sensemaking work be scripted into the device or interface. As one ICTD researcher explained, the shortage of human resources in some of these areas “means technology has got to take on a role not just as an instrument but it has to start interpreting things, it has to start double checking and triple checking things and saying “I know you’re not as inexperienced medical person but here’s some help in getting this particular thing done, here’s how you do a proper EKG.” In essence, the distribution of agency and responsibility must shift towards the technology relying on further informationalizing of healthcare work into arenas of interpretation and calibration.

In the context of the U.S. Telehealth project, the Health@Home device had meaning and actionability encoded into the software interface. The program algorithmically coded patient-generated data for low, medium, and high risk, which displayed on the care manager’s dashboard with green, yellow, and red indicators. These data come to the care manager with an interpretation about patient’s risk level and response time urgency, yet I observed again and again that the care managers did not accept this data as self-evident; rather they worked with the data, communicated about the data, and applied individualized algorithms to the data before coming to any clinical understanding of the data. In many instances, the care manager receives a

red alert on her dashboard for one of her patients, acknowledges it, and quickly discounts it. She explains her response:

This little lady has got heart failure and her heart really can't manage a pressure of higher than what our parameters are for the Health@Home, so she always has a red alert because she's got low blood pressure. But I know, because I've dealt with her for months and months on end that that's her blood pressure and that's just what it is.

It was the care manager's longitudinal knowledge of this patient generated through communication and relationship development with her patient over time that is essential for making sense of the data. Her knowledge and insight into the patient informs how she expects the data to perform in a clinical context counter, which is different from the expectations scripted into the Health@Home algorithms. She knows that her patient's low blood pressure is always low, and that this data and its interpretation generated via the Health@Home algorithm is not meaningful or actionable for her or her patient. Instead there is another layer of knowledge and mediation work that the care manager applies to the patient-generated data. Thus if another care manager were to substitute for her, this individualized knowledge would need to be made explicit and actionable as instructions or an individualized algorithm, so that the new care manager would not expect the patient-generated data to be self-evident and would conduct the necessary calibration work to make sense of the data.

Anticipated Versus Actual Use and Usage

The India mHealth project process brought together multiple values and expectations for data, reflecting tensions and challenges among different configurations of anticipated versus actual use and user. An ICTD researcher, Jim, describes the different valences around health data which reflect the disciplinary and professional boundaries between public health and computer science, as well as alluding to different configurations of user and use.

We're not health people, we can't really do things that affect *actual* people's health, you have to have professionals there that understand that side of thing. So we want to work with them to see if we can make their job easier, better, more efficient, more complete, more consistent, and so we measure those indirect measures, right, we're not measuring the *actual* health outcomes: did less babies die, did more mothers have less complications. Well, yeah, I mean, those are important but we're leaving those to the health people to figure out. What we are trying to say is look, if you think this is a good program, and you've been convinced that what these people are doing leads to positive things, then we can let them do twice as much of it. Or we can help them scale it to a much larger size, and reproduce it at other places. (Jim, ICTD researcher, my emphasis)

This expectation for *actionability* can refer to different data performances. In computer science the valence of *actionability* for data can be a computational *algorithmic actionability*, in which data is configured as “algorithm ready”, in terms of what is knowable, what is relevant, and what is efficient for an *anticipated* user.

In India mHealth, Greg, the computer science doctoral student leading the project, aimed to transcode paper-based forms into mobile-based forms, with the primary goal of testing whether this technical intervention could make the PNC process more efficient, and consequently more effective. During the design process he visited the clinics in India and snapping photos of each page of the registers and forms with his smartphone in an effort to capture the categories and the organization of data being collected and processed. From these images he identified redundancies and gaps that he addressed when customizing the mobile based software in an effort to make the process more efficient for the anticipated user. Yet as Gillespie (2014) points out in the case of Google determining relevance, while algorithms tend to present an *algorithmic objectivity*, “‘relevant’ is a fluid and loaded judgment”; there is no single definition of relevance, nor is it a stable description. Similarly, efficiency refers to different things for different stakeholders in different contexts. Efficiency in information processing gets defined and measured through the logic of computational algorithms, abstracted from their implications and social interactions assuming an algorithmically anticipated user. Abstracted

from social interaction, efficiency in information processing is defined quantitatively and abstracted from implications, efficiency could be applied to some processes and not others as well as provoking unintended consequences of “making a bad process more efficient” (ICTD researcher), reifying and entrenching certain unsustainable logics within the development of the system.

The valence of *actionability* can also refer to the expectation for human actionability. This means data is expected to be actionable by an *actual* user. Examples could include midwives actually following clinical decision support or data-driven patient behavior change. This is the actionability that is valued in the context of the LNGO, the local community, and the ICTD professionals that are interested in directly improving health outcomes. These are different instantiations of the valence of actionability and for many digital health innovations, meeting the expectation for *algorithmic actionability* often does not coincide with meeting the expectation of human actionability. This challenge occurs for a host a different reasons that center around the differences in how the anticipated and actual user and usage is configured and the role of power relationships in shaping the ability of stakeholders to articulate and negotiate around different valences.

Conclusion

This chapter has outlined a typology for identifying data valences across the discourses and practices of different communities and contexts of digital health. This model helps us understand the challenges for data crossing social domains of digital health as beyond challenges of translating across multiple interpretations of data. I argue that the challenges for data moving across domains and multiple contexts of user and reuse are challenges in negotiating and translating among different expectations and values for data. A data valence analysis allows us to

see that multiple data valences exist at the intersection of social domains, and that they may conflict or that polyvalence may be supported. This then points to the tensions as well as alliances among institutions and stakeholder groups across the digital health ecology. The negotiation and management of multiple data valences mediates technology in practice and complicates our understanding of processes of design and use of data-intensive technology as they include practices, communities and networks of data. Understanding exactly how multiple data valences mediate processes of digital innovation and how organizations adapt to these challenges is the focus of the following chapter.

Chapter 5

Technology-Occasioned Organizational Structuring: A Comparative View of Organizational Alignment and Intermediary Labor in Managing Polyvalence in U.S. Telehealth and India mHealth

As digital health efforts continue to fall short of expectations, it is increasingly critical to investigate beyond the effects and outcomes of organizations adopting digital health technology in order to study the entanglement of technological and organizational change emerging throughout processes of design, use, and evaluation. Too often design and evaluation of digital health begin and end with measures of success and failure that isolate the technology. This approach omits much of what could be learned from multiple measures of success and failure that engage questions of how, why, and in which settings. The data-intensive transformations accompanying the introduction of digital health technology in the cases of U.S. Telehealth and India mHealth challenged antecedent organizational and institutional arrangements, providing two rich contexts for examining the entanglement of technology and organizing, and disentangling the processes of sociotechnical change. In this chapter I demonstrate the

emergence and implications of different processes of technology-occasioned organizational adaptation through an in-depth, comparative case study analysis of two multi-stakeholder digital health technology pilot projects, U.S. Telehealth and India mHealth. Drawing from ethnographic observational and interview data, I examine processes of organizational alignment and emergent forms of intermediary labor to understand how they contribute to the management of multiple data valences across stakeholders and contexts, with the goals of comparing their implications for the project beyond narrow measures of success and failure.

Theoretical Frames: Organizational Alignment and Intermediary Labor

To fully conceptualize the emergent process of technologically occasioned change in organizations requires multiple theoretical perspectives from multiple scales. In the context of these two cases, I study the process of organizational adaptation both at the level of organizational alignment and at the level of labor and technology in practice. By organizational alignment I mean “the process by which social orders and technologies configure or adjust to each other through emergent patterns of use” (Leonardi & Barley, 2010, p. 25). The alignment perspective, focusing on the mutual adjustment of technologies and organizational ordering, submits that the process of alignment relies on changing boundary and role relationships and patterned interactions, which may be altered when technology occasions changes in forms of labor and work practices (Leonardi & Barley, 2010).

A labor and practice perspective begins with how users are actually employing technology in their everyday work practice. From this view, organizing structures emerge over time and are enacted through recurrent interactions between users and technology in the process of accomplishing work (Orlikowski, 2000). In this analysis I consider the work practices and different forms of labor occasioned by the introduction of the digital health technology to both

reflect and constitute (on a micro-level) emergent structures on a macro-level organizational level. At the same time, I consider the power and influence of previous institutions on an organizational level in shaping the enactments of technology throughout design, implementation, and evaluation. Thus I understand technological change to present an occasion whereby the status quo power relationships and professional boundaries are either reified or challenged and renegotiated (Barley, 1986; Bechky, 2003a; Orlikowski, 2000).

India mHealth and U.S. Telehealth are projects that evolved within a larger digital health ecology in which health ICTs are promoted as enabling the digital production and exchange of data providing new links across contexts and stakeholders. Yet, as has been already established, in practice, data do not move, mean, or connect on their own. In contrast to other kinds of digital health efforts that focus on disintermediation or apomediation, both U.S. Telehealth and India mHealth are designed for intermediation. *Intermediary labor* provides a starting place for examining the layers of often invisible labor that accompany these data links in supporting a complex sociotechnical system, such as is the case in healthcare. Integrating new technology into work practices and making digital health data “travel” across multiple contexts requires new work practices and forms of labor (Mort & Smith, 2009). However, it is important to recognize that the work of intermediaries in digital health is not simply about translating the meaning of information across different contexts. It is also about managing and supporting multiple *data valences*, or multiple expectations and values for data across contexts. As discussed in Chapter Four, multiple data valences become more apparent at the intersection between social domains, and it is intermediary who embodies the work of managing the multiple valences in this intersection. As such, the midwives in the India mHealth project and the care managers in U.S. Telehealth project perform *intermediary labor*, that is, the labor that enables sociotechnical

interoperability and the circulation and structuring of sensemaking and value across different social domains.

Intermediary labor encompasses the entanglement of multiple forms of labor identified in the literature, including information labor (Downey, 2014), articulation labor (Gerson & Star, 1986; Star & Strauss, 1999), and repair labor (Jackson, 2014), that support the functioning and maintenance of sociotechnical systems. In this section I define each of these forms of labor and argue that they are essential for understanding how polyvalence is managed in each case.

Information labor is a concept developed by Downey that refers to the labor required “to set information in context, to move information across context, and to reset that information in a new context” (Downey, 2014, p. 149). Information labor is situated within the larger media infrastructures in which ICTs are embedded, developed, used, and understood; it functions to support information “jumping contexts” or to make information accessible through making it useful and putting it in circulation (Downey, 2014, p. 149). Downey (2014) proposes three types of information labor: (a) protocol labor, or the work of transcoding information across different sociotechnical environments and infrastructures; (b) metainformation labor, the work of producing or manipulating further descriptive metainformation to transpose information across institutional, temporal, and cultural milieu; and (c) accessibility labor, the work of translating the meaning of information across majority and minority communities. For the purpose of this analysis information labor provides a framework for making visible the space, time, and social relations of intermediaries that are bound up in organizational infrastructures spanning multiple sociotechnical environments, institutional arrangements, organizational cultures, and communities.

Algorithms configured to perform a growing portion of this information labor are at the center of the technology intervention in India mHealth and U.S. Telehealth. As such, both projects rely on informationalizing aspects of human labor, such as forms of clinical expertise and behavior patterns, and then encoding it in software in order to automate it as what Downey calls “algorithmic labor” (2014). For designers, algorithms represent decisions about how to delegate and divide labor among human and nonhuman actors (Akrich, 1992). In these projects, algorithms become another interface between domains, aiming to do the work of translating information in one context to information in another. Algorithmic labor within these projects is envisioned as replacing aspects of intermediary labor, extending and expanding the intermediary’s reach and supplementing their expertise, judgment, and intentions. Yet as prior scholarship has demonstrated, technology doesn’t often replace work; instead it redistributes, displaces, or transforms it (see, for example Barrett, Oborn, Orlikowski, & Yates, 2012; Oudshoorn, 2011; Schubert, 2012). Therefore, it is essential to understand the shifting patterns of intermediary labor and work practices that transform, redistribute and relate to new forms of algorithmic labor. Rather than focus on the “effects” of these algorithms (following Gillespie, 2014), I consider the “multidimensional ‘entanglement’ between algorithms put into practice and the social tactics of users who take them up” (p. 183). Thus, entangled algorithmic and intermediary labors represent an interface between domains, translating information from one context to another.

While information labor encompasses the work of making information accessible across contexts, articulation labor is focused on the work of managing the consequences of coordinating work across contexts and at the intersection of social domains. Prior scholarship has demonstrated the critical importance of articulation work in any cooperative activity, and

specifically for the role of nurses who mediate between groups (Gerson & Star, 1986; Schmidt & Bannon, 1992; Star & Strauss, 1999). From a Computer Supported Cooperative Work (CSCW) perspective, the practice of distinguishing between cooperative work and articulation work, where cooperative work is about managing the tasks of distributed work, and articulation work manages the consequences of the complex, distributed, and interdependent nature of the work, illustrates the recursive relationship between the two types of work (Schmidt & Simone, 1996). Articulation labor includes the “real-time adjustments” (Star, 1999) as part of a process of situated sensemaking that responds iteratively to the ever-present challenges of making information flow in the appropriate form to the appropriate places at the appropriate times.

Articulation consists of all tasks involved in assembling, scheduling, monitoring and coordinating all of the steps necessary to complete a production task. This means carrying through a course of action despite local contingencies, unanticipated glitches, incommensurable opinions and beliefs or inadequate knowledge of local circumstances (Gerson & Star, 1986, p. 266).

As described here, articulation work manages much more than information; it manages multiple, dynamic expectations across contexts and knowledge boundaries. Emergent in practice and not through representation, it is by definition “invisible to rationalized models of work” (Star, 1991, p. 275). In order to manage the consequences of distributed work in U.S. Telehealth and India mHealth, intermediaries performed articulation work. This work revealed the management of multiple valences through attending to the consequences of circulating information to multiple stakeholders within different social domains.

Articulation labor encompasses a wide range of work that is helpful to characterize around different foci. One important focus for the U.S. Telehealth and India mHealth is the work of repair and recycling throughout the project, occasioned by the multiple social and material breakdowns. Jackson (2014) has proposed the work of repair as a “facet or form of articulation work (and vice versa)” (p. 223) and as a fruitful device for supporting “broken world thinking,”

in which breakdown rather than novelty is the starting point of thinking about the relationship of technology and society. He defines repair work as “the subtle acts of care by which order and meaning in complex sociotechnical systems are maintained and transformed, human value is preserved and extended, and the complicated work of fitting to the varied circumstances of organizations, systems, and lives is accomplished” (Jackson, 2014, p. 222).

The importance of re-centering the analytical lens on repair and recycling is clearly evidenced through studies of e-waste recycling and cell phone repair ecologies in developing world settings (see, for example Burrell, 2012a; Jackson, Pompe, & Krieshok, 2011, 2012), where the expectation for breakdown is heightened, and breakdown becomes a site for cultural and economic activity (Larkin, 2008). These essential components of the technology landscape are often hidden from productivist perspectives focused on moments of technology design and production, eliding essential components as potential sites for innovation (Jackson, 2014, p. 227). For analyzing the evolution of U.S. Telehealth and India mHealth, this overlooked connection among innovation, instances of breakdown, and the continuous work of repair is essential for revealing moments when multiple data valences diverge or are in conflict, and the organizational gaps or innovations that emerge in the management of multiple data valences.

Two Case Studies: U.S. Telehealth and India mHealth

In this section I briefly introduce the contexts of U.S. Telehealth and India mHealth, highlighting the important ways they are complementary and distinct in order to foreground the comparative analysis of technologically occasioned organizational structuring. As discussed in Chapter Two, both project implementations are situated in rural, low-resource settings in two different national and institutional contexts. Both pilot projects center on the introduction of digital health technology into a healthcare system, but are distinct in how they advance

technological change in relation to the institutional context. In the case of U.S. Telehealth, it has to do with Medicare, the U.S. government-sponsored health insurance program. Medicare was piloting a telehealth system called the Health@Home as a means for augmenting and expanding care management of high-risk and high-cost chronic disease patients in order to improve health outcomes and reduce healthcare costs for the system. Embedded in the interstices between the clinic and home, U.S. Telehealth is imagined as strengthening the bridge between patients and formal healthcare institutions, expanding care management into patients' daily routines outside of a clinical setting, while maintaining close connection and integration with formal medical practice in the clinical setting.

India mHealth, an ICTD pilot project advanced by a transnational network of global health, academic, and local healthcare stakeholders, aimed to test a mobile health system called the mPNC as a means for institutionalizing postnatal care in an area where there was a significant gap in access to formal healthcare institutions. India mHealth was imagined as expanding governance and amplifying human resources through tightly coupling field, clinic, and office with ICT-mediated information collection, processing, and communication. U.S. Telehealth aimed to augment health outcomes and the financial performance of formal healthcare institutions, and India mHealth aimed to fill institutional gaps in healthcare through supplementing and extending organizational capacity to support postnatal care.

As pilot projects with multiple stakeholders, U.S. Telehealth and India mHealth were situated at the intersection of multiple social domains in which communication and sensemaking were challenged by the fact that information needed to jump multiple contexts. Although differently constituted and configured, both projects were characterized, first, by the intersection of multiple project management stakeholders groups, and second, by the intra-section of different

stakeholder communities within the organizational setting where the project is being implemented. When digital health technology mediates information production and exchange across stakeholders, it provides a new set of interstitial interactions between contexts and communities, whether it is between the field and office for the midwives or between home and the clinic for the care managers. These interactions evoke multiple data valences around which work practices and patterns of interaction emerge around the challenge of developing structures that support polyvalence. Data polyvalence refers to the capacity to evoke multiple expectations and values for data at the same time. Articulating emergent structures through intermediary labor and organizational alignment processes within each project is essential for understanding the different ways polyvalence is managed across both projects and the implications for the aftermath of each project.

Organizational Alignment of Professional Boundary Relations

This section highlights important differences in technologically occasioned processes of organizational alignment across both cases. This analysis focuses in particular on the restructuring and reinforcing of professional boundaries and role relations. These boundaries and role relations support sociotechnical interoperability and polyvalence around new informational capabilities linking different stakeholders across different contexts. Organization scholars have demonstrated how artifacts constitute and maintain a source of organizational order (Gagliardi, 1990; Kaghan & Lounsbury, 2006; McPhee, 1985; Pratt & Rafaeli, 1997), through defining and stabilizing organizational hierarchy, controlling information and communication flows, and producing distributed authority in organizational contexts (Bechky, 2003a; Benoit-Barné & Cooren, 2009; Marvin, 1987; Yates, 1989). Thus, as the material basis for organizing shifts with

the introduction of Health@Home and mPNC, sources of organizational order may be disrupted and adapted.

Prior literature on technological innovations demonstrates how they are often shaped by, and themselves reshape, boundary relations in organizational settings (Barley, 1986; Barrett et al., 2012; Boland et al., 2007; Zuboff, 1988). As Barley (1986) demonstrates in his study of the introduction of CT scanners into different radiology departments, the introduction of new technology provides an occasion for disrupting the professional boundary relations between radiologists and technicians. In that study, the CT scanner also provided new informational capabilities that led to shifting role relations and different network configurations that were based on new landscapes of information access, expertise, and information-sharing capabilities (Barley, 1990). In particular, Health@Home and mPNC afforded new informational capabilities and new mediating structures for linking together new contexts of information use and reuse. Comparing processes of organizational alignment, I demonstrate how the introduction of digital health technology occasioned the reinforcing (in the case of India mHealth) and the redrawing (in the case of U.S. Telehealth) of professional boundary relations and occupational divisions around accessing, interpreting, and activating information (Barley, 1986; Bechky, 2003a; Leonardi, 2007).

U.S. Telehealth: Redrawing Professional Boundaries

U.S. Telehealth and India mHealth approached technological change and organizational alignment very differently. The U.S. Telehealth project encompassed the introduction of the Health@Home technology as well as the development of a program of intensive care management. In other words, the introduction of the Health@Home occasioned the structuring of a care management program (Barley, 1986). Before the implementation of U.S. Telehealth, River

Medical's chronic disease management practice included care coordination and regular patient interaction with a nurse or case manager, but these care management practices were embedded within a clinical setting and interactions with patients were face to face. In advance of implementation project, stakeholders hired a lead care manager named Dee to figure out how to most effectively coordinate and implement the Health@Home system within the larger River healthcare system to improve health outcomes of patients without burdening the doctors with more work. U.S. Telehealth project stakeholders anticipated the need for organizational alignment around the intermediary role of care manager. Further, the communication-technology-mediated care management provided a new set of interstitial interactions between contexts and communities in which intermediaries were empowered to innovate. In this restructuring of a model for care management of high risk chronic disease patients, technological change became inextricable from organizational alignments that were essential for managing polyvalence across different social and institutional contexts. New informational capabilities and mediating structures occasioned by Health@Home led to redrawing the professional boundaries around care management and the shifting of role relations among patients, care managers, and doctors.

Expanding Boundaries of Care Management through Coauthored Algorithms

Care managers and physicians coauthored algorithms to bilaterally redraw the division of labor between them in order to support the activation of new informational capabilities of the Health@Home without overburdening physicians. The extant professional boundaries between the care managers and the physicians meant that there was relatively little that was clinically actionable for the care managers. This meant care managers would need to refer the majority of the situations they encountered through the Health@Home to the physician, increasing the

physician workload. To prevent the already overloaded physicians from becoming more overloaded, the lead care manager, Dee, and primary physician, Trevor, coauthored a set of algorithms that made explicit aspects of the physician's knowledge and captured the knowledge into sets of instructions or simple algorithms, which were to be readable and actionable for the care managers.

Redrawing professional boundaries empowered care managers to intervene with clinical authority and manage care in transitions of care and outside the formal clinical setting. As the power of algorithms often emerges from a claim to objectivity (Gillespie, 2014), these coauthored sets of assessment questions and associated clinical interventions afforded the collection of "objective" information across different care managers in a form that could be relied upon to consistently trigger the appropriate interventions. This extant structuring of data collection and sensemaking around Health@Home data expanded the boundary of care management, extending care manager authority and responsibility for clinical care. A care manager explains:

The 1-800 nurses, the nurses that are the insurance nurses, frequently are in another state, so they are calling [physicians] from Florida saying, "Oh, I just talked to Mrs. So-and-so and she's gained 3 lbs., or she's feeling short of breath." That's the only thing that they've got, they don't have the medical record that can look at the labs, look at the last visit, see what the physician's plan is for the patient, find out what the X-rays were—even know what current meds they're on. And so the physician's frustration with that, you know—"this is useless for me because then I've got to stop my day, call this patient because I've been alerted by somebody that she's not doing well"...Liability-wise he's got to call and find out what's really going on. And he's got to do that assessment...So, you know, why not let us start that process? And then when we call the physicians or send them a note on the electronic record—I talked to so-and-so, this is what's going on, this is the assessment, this is what I'm doing to help intervene—what's the next step? Where do you want to go? Do you want to see him?

The care manager suggests here that the occupational divisions of labor can be made more permeable by creating a more seamless process between them, in which the care manager does more assessment and interpretation of patient-generated data before the physician engages.

The care managers would often make a point of distinguishing themselves from the 1-800 nurses who had access to patient data but were not allowed to add interpretation or contextualization to make the data clinically actionable for physicians. Care managers, on the other hand, were integrated into the larger clinical and personal context of each patient, and thus could begin the process of clinical sensemaking and perhaps even avert the need for physician involvement. Together the physicians and care managers leveraged algorithms to extend the professional boundaries of the care manager in order to make Health@Home data more clinically actionable for care managers, while maintaining accountability within the formal medical context, and shifting the some of the workload involved in managing new informational capabilities from physicians to care managers.

Coauthored algorithms expanded the boundaries of care management in order to couple clinical actionability with chronic disease data management at the intersection of the clinic and home. As Mackenzie (2006) notes, “algorithms carry, fold, frame, and redistribute actions into different environments” (p. 43). In this case, the algorithm redistributed clinical interpretation and intervention around patient data into the intermediary domain, which then shifted the role relations between care managers and physicians. With expanded clinical decision making power and new opportunities for care interventions, care managers became both more autonomous and more collaborative in relation to physicians. They became more autonomous in the sense that they could intervene more using the algorithms without depending on the explicit approval of the physician. Their role also became more collaborative as they gained credibility with physicians and assumed the responsibility of translating patient knowledge and clinical interpretations of patient data into clinically actionable data for the physician.

Developing a Collaborative Approach to Care

Expanding the boundaries of care management was an important part of a broader shift towards a team-based approach to care that evolved over time with the Health@Home program. The collaborative relationship that developed among care managers and physicians was an essential element of the team-based approach and required getting physician buy-in to the program from the very beginning. Dee shared that it took a long time to build the necessary trust and confidence in the care managers and the Health@Home.

Over time we've finally got to the point now where we got the physician buy-in... We've built some cred with the physicians and they know that when I call them, and I've got a patient in trouble, that yes, it needs to get taken care of... They know that we're calling because we've already done the footwork and we've got the assessment... It's not the 800-nurses calling from California that haven't been talking to the patient every day for the past two weeks.

To build this credibility and trust, the physicians needed to witness the benefit of the Health@Home and see that the program wasn't adding to their workload. Then they were willing to reorient their practice around the Health@Home and shift their relationship with care managers.

The role and responsibilities of the patient also shifted in the context of the Health@Home-occasioned approach to care coordination. An essential part of starting a patient on the Health@Home program is the initial orientation, which involves the care managers meeting patients face to face to discuss what their medical and non-medical health challenges are and what aspects are important to them to work on. Together, they negotiate which Health@Home chronic disease program is most appropriate for them. The key shift was to engage patients as participants in their own care, ultimately moving them along the continuum of care to self-management, and coordinating care management around the values and expectations of the patients. The daily Health@Home data exchange between home and the intermediary

domain operated as a form of patient consent that allowed care managers to intervene in their day-to-day home lives outside of the formal clinical settings and as an opportunity for patients to actively do something in managing their own care each day. The paired care management and Health@Home program tightly couples communication and connection with the patient with the day-to-day data management of chronic disease, offering access to care outside of a clinical setting based on a trusted relationship that involves mutual participation from both patients and care managers.

India mHealth: Reinforcing Professional Boundaries

As opposed to the technologically occasioned organizational structuring evident in U.S. Telehealth, the introduction of technology in India mHealth occasioned very minimal organizational structuring. Project stakeholders framed the introduction of the mPNC as more of a technical intervention that would not require a high level of organizational restructuring. Unlike the stakeholders in U.S. Telehealth who had envisioned a new program of care management enabled through the introduction of the Health@Home, stakeholders in India mHealth envisioned “inserting” the mobile phone into an existing program to see if they could improve, extend, and amplify that program and test the impact of mobile phones on solving problems in the healthcare space. Initially, the mPNC intervention was talked about in both ways: as a “change in format” that “fits in” to current practice, minimizing risk around and disruption to program structures; and as way of building organizational capacity, amplifying the work of LNGO, and extending institutional presence into the margins. As one of the LNGO administrators explained, the real intervention has always been the PNC visits, not the technology. “The technology is simply a matter of format. Certain formats allow certain things.” she said, “This should allow us to monitor so we can have better governance and accountability.”

It was the PNC care program and associated organizational routines of documentation that had made this organizational setting appeal to the ICTD design team as an ideal way to test a mobile health intervention. In this setting, healthcare was already informationalized in many ways, as evidenced through the complex, predominantly paper-based information infrastructure that mediated every aspect of LNGO's care programs. The ICTD design team imagined the intervention to be testing the impact of technology on already established organizational routines. This would allow them to avoid testing a technology entangled within an associated set of new organizational routines, which would make the impact of the technology more difficult to isolate.

The project was envisioned around a perceived value match between the institutional character of ICTs and the institutional character of management in the context of healthcare work at LNGO (Avgerou, 2004). The project vision presumed organizational capacity of LNGO to support technological change. Prior research demonstrates that shifting from paper-based to digital information management often makes these work practices more visible and subject to management, surveillance, and reinforcing control (Berg, 1999; Star, 1999). This was a key strategy for India mHealth, which aimed to develop a technology that would institutionalize better management and delivery of PNC. In this process of informationalization in which organizational practices are made more explicit to be related to technical protocols, certain aspects of organizational labor are made visible, while others remain invisible. This process includes the negotiations of what counts and gets represented in formalized scripts of PNC and professional knowledge. MPNC codified professional knowledge and organizational practice in ways that reinforced professional boundaries and role relations within a hierarchical model of

care, and in practice magnified organizational and knowledge gaps and fragmented organizational routines.

Magnifying Organizational and Knowledge Gaps

I had spent a couple of weeks at the rural clinics and shadowing the midwives on their home visits before I sat down with the midwives, their registers, and their documentation routines. Here I describe the encounter: Large and cumbersome books collected dust on the shelf until the midwives took them out to complete their entries from the day or the week. Today, Jaya, sat cross-legged on the cot in the front room with small piles of registers and paper forms to one side. She opened the large PNC register across her lap and it extended beyond her knees. The corners of the book had been dulled and the reddish brown colored front and back cover had faded to a dusty pink. She flipped through the pages of the register to get to the right village to enter the PNC visit information from the form lying on the cot beside her. It was the afternoon before they were supposed to completely switch over to using the mobile phones as a replacement for their paper forms. As Jaya was entering the information into the register, she stopped abruptly and said plainly, “We can’t use just the mobile.” When I asked why, she explained, “There’s no place to put the ID number.” I was getting up to speed on all aspects of the project at that point, but I knew I hadn’t heard anything about an ID number. My heart sank a bit into my stomach, like it does when you forget something really important. “What ID number?” I asked. “This one, right here!” She pointed to the ID number column in the PNC register. Then she pointed to the number on the PNC forms and opened the delivery register to show me where it appeared there (field notes).

This breakdown around the ID number provided an opening for an “infrastructural inversion” to make visible “the depths of interdependence of technical networks and standards,

on the one hand, and the real work of politics and knowledge production on the other” (Bowker & Star, 1999, p. 34). In other words, the breakdown opened space for considering the work this number does and represents and how it was rendered in the process of design. This process revealed the multiple expectations and values for data evoked across stakeholders throughout the project and how they conflicted and diverged, magnifying organizational gaps and knowledge disparities across stakeholders.

An information-system process-efficiency perspective dominated the design team’s translation of the paper-based PNC form to the mPNC form. This perspective tends to abstract the information system from its social and organizational life (Heeks, 2002b), opting for a technical description that often mistakes procedures for generative organizational routines (B. T. Pentland & Feldman, 2008). In other words, the paper-based PNC information system is translated into a system of technical protocols that aim to support the same organizational functions, but to do so through more efficient pathways. In this system description, the ID number, having textual meaning and function within an information management process, is represented as information content. Greg, the ICTD researcher, in his assessment of the PNC information system, had judged that “from a process perspective, the ID is a useless bit of information,” an administrative device he deemed redundant and not generative. In discovering other redundant identifying information that seemed to serve the same textual purpose in managing information across the system, and in consultation with the LNGO administrators (who didn’t claim its importance), the ICTD researcher designed the mPNC without the ID number. Much as Heath and Luff (1996) demonstrate how small changes made in the computerization of a clinical record have social and organizational consequences, this small

decision favoring information system efficiency over redundancy turned out to have big disrupting effects on a wider network of information and organizational routines.

Invisible through the information systems lens of the ICTD researchers, an infrastructural inversion reveals the structuring work the ID number both embodies and performs in relation to other information and organizational routines. It reveals that beyond its textual meaning, the ID number functions as an organizational artifact that mediates relationships of accountability across stakeholders. As an “immutable mobile” (Latour, 1987), the ID number persists throughout all LINGO’s interactions with the patient during PNC, coordinating over time across organizational contexts of office, clinic, and field. As Porter (1995) has observed, numbers “conveniently summarize a multitude of complex events and transactions” (p. ix). As such, a number is copied and recopied across registers, forms, and databases to be used by village health workers, supervisors, data entry staff, administrators, and midwives. As a “strategy of communication,” the ID number, embedded in a broad network of organizational routines, performs as a standardized explanation and measure of accountability between the office, clinic, and field (Porter, 1995). Thus, the ID number is a standard metric and communicative device used to support translation when a problem is detected around a patient in the office, to rectify errors or incongruous information discovered in the database, and to uniquely account for individual patients in a context when many patients may share first and last names. Furthermore, in practice, the PNC ID, initially generated in and through the PNC register, makes it easy to locate patient information because the first two numbers of each ID number represent the patient’s village, which is also how the register is organized.

The breakdown experienced around the last-minute discovery of the ID number represents one of many examples revealing a gap between practice-based knowledge of

midwives and the knowledge and expertise of administrators and ICTD researchers. In addition, midwives were brought into the design process in more peripheral ways, reflecting the power differential between ICTD researchers, administrators, and the midwives (Forsythe, 1996). During my time at LNGO, midwives raised other concerns pertaining to some of the gaps between the mPNC and their practices in the field. Instead of being able to fix many of these issues in the field by directly communicating with the ICTD researchers, as the care managers had been able to do directly with TechDev, all of these issues required administrator-level intermediation and review. In the example of the PNC ID number, midwives required the administrators to approve the way in which they would handle that change in their work practice before they could start using the mPNC. My exchanges with the administrator overseeing the PNC program reinforced that although she had extensive knowledge of PNC from a medical perspective and of the health challenges of the rural areas, she did not have extensive knowledge about how the midwives actually worked or how the formalized PNC-related scripts actually functioned in practice.

The introduction of mPNC not only reinforced professional boundaries among midwives and administrators, it also rendered the patient non-existent throughout the design and implementation processes. The patient voice was absent from any of the design conversations, and there was very little interest in the patient's perspective from the ICTD design team or the administrators. Midwives often spoke for them and talked about them in the third person while we were in the room together. They explained to me that the patients are "backward"⁶², that they

⁶² Postcolonial theorists demonstrate how the image of social "backwardness" is historically rooted in relation to the West as the pinnacle of modernity. This relationship is connected to the modernizing role of the state (Chakravarty, 2004).

don't understand things and are not educated. Accordingly, the muting of midwife and patient voices during mPNC design reflected and reinforced the power differential among administrators, midwives, and patients; in this way, the privileging of expert over experiential and practice-based knowledge was inscribed into the design and implementation of mPNC (Forsythe, 1996, p. 558).

Reasserting Hierarchical Information Structures

The mPNC was designed predominantly as a tool of management, reinforcing the power differential between professional groups and reasserting the authority of administrator knowledge over the practice-based knowledge of the midwives. The mPNC represents technology that is both designed to measure the efficiency and effectiveness of organizational practice and to order the practices through which this work is accomplished. In Garfinkel's (1967) study of "good" organizational reasons for "bad" clinic records, he emphasizes the discrepancy between the record embedded in the practical local action of a clinic and the record as an objective account serving the interests of others. In the context of airline operations, Suchman (2007) looks at how an artifact, such as the airline schedule, is part of the same activity that it is designed to track. Specifically, "referencing and updating the schedule is a central activity of ground operations workers at the same time that the schedule is taken at the end of the day as a spatial and temporal representation of what they have done" (Suchman, 2007, p. 203). In essence, the organizational structures for *actionability* are aligned with the organizational structures of *accountability*. The India mHealth project failed to align these structures, orienting information structures more around producing records to benefit other "end users," including the administrators and the researchers, than to benefit the midwives and patients. Thus the organizational routines around mPNC functioned less to inform the midwife in the field than it

did to inform those in the office and the lab. This echoes prior literature that finds that the processes of data collection and information generation by community health workers in rural healthcare systems are more often about demonstrating accountability rather than about informing local decision making and action (see, for example Braa et al., 2001; Raghavendra, 2007).

Without restructuring organizational relationships of accountability, the mPNC reasserted hierarchical information structures. Most importantly, within these structures, the midwives were not empowered to openly resist these expectations. This led to more shrouded forms of resistance around adapting their practice around the mPNC. For instance, the midwives had to complete and transcode between the paper and mobile forms, and they had to perform that double information labor for two extra months beyond the original trial phase. In the face of this, they would often fill in the mPNC after the visit was done back at the clinic so they could enter the information all at once as quickly as possible or a little bit at a time. A couple of the midwives would have one of the more smart phone-savvy midwives enter their patient's PNC visit information into the mPNC form as if they were them. Thus organizational routines became fragmented, separating clinical care from mPNC information management structures, as they fell short of supporting polyvalence around new informational capabilities. In reasserting hierarchical information structures, in practice the mPNC supported the social valences of accountability and discovery in the contexts of office and lab over those of actionability and communication in the field.

Intermediary Labor in Translation

Both U.S. Telehealth's Health@Home and India mHealth's mPNC had technically linked social domains, but in neither case did data exchange on its own support translation across these

social domains. This section considers the intermediary labor involved in processes of translation around new informational capabilities and mediating structures across intermediary, clinical, administrative, and patient contexts. Intermediary labor is constitutively entangled with organizational-level processes of alignments and embodies the recurring interactions around the technology in practice at the intersection of social domains. The processes of translation refer to the processes by which information are changed, used differently or reappropriated; how their meaning may be recast; and, importantly for this analysis, how different valences may be evoked as information moves from one context to the next. Here, I focus on the ways in which forms of intermediary labor emerge through and around organizational structures and how these forms can recursively reshape the processes of organizational alignment.

The new informational capabilities introduced through the Health@Home and mPNC required new forms of intermediary labor to make information valuable and meaningful within and across different contexts. As Star (1999) notes, we can only understand why some systems work and others don't if we describe both the production/coordination task and the hidden tasks of articulation, together and recursively. This means we must understand the relationship of technological change to the work of coordination across social domains as well as to the articulation and repair work managing its consequences. I examine and compare the role of intermediary labor within three different translation processes: clinical and administrative sensemaking, patient engagement, and algorithmic calibration.

First, intermediary labor operates at the intersection of domains in both of these cases, functioning to translate patient data for clinical and administrative sensemaking. Following Weick (1995), I take sensemaking and organizing to be co-constitutive and communication to be an ongoing process of sensemaking. Thus sensemaking extends beyond interpretation to

encompass the processes of authoring, articulating, and creating (Weick, 1995, p. 8). It embodies the “the interplay of action and interpretation rather than the influence of evaluation on choice” (Weick, Sutcliffe, & Obstfeld, 2005, p. 409). The importance of the multiple roles of material artifacts in structuring sensemaking and organizing has been thoroughly demonstrated throughout the literature in organizational communication (Leonardi et al., 2012). Beyond communicating textually, documents⁶³ function in processes of organizing through structuring interactions, practices, and conversations (Neff, Fiore-Silfvast, & Dossick, 2013). The introduction of digital health technology into both contexts of healthcare work runs the risk of overlooking or obscuring the powerful social and material functions of documents and other material artifacts in the processes of sensemaking and organizing. As the materiality of communication across stakeholders shifts with the introduction of the mPNC and the Health@Home structures of sensemaking and communication, protocols are reworked through translation processes bound up in new material structures for mediation.

Second, intermediary labor is also essential in the translation of patient data for patient engagement. Patient engagement around their data can take many forms and evoke multiple valences. From the perspective of narrative medicine, health and health unfold as storied experiences, where stories are the “basic unit” of narrative (Fincham, 2002, p. 5) and embody local activities of sensemaking. Much as the QS community engages with and shares self-tracking data through storytelling, intermediaries try to engage their patients around their data through narrative. What is clear across cases is that data are not self-evident; they require the narrative translation back and forth between story and data. To engage patients around new

⁶³ Documents are defined broadly as a type of organizational artifact that incorporates paper documents, digital documents, and other material artifacts of organizing.

informational capabilities in the home and field contexts, the intermediaries use narrative as translation of medical and health information into the local contexts of patients' lives.

Third, intermediary labor plays a critical role in algorithmic calibration, the translation between intermediary processes for sensemaking and algorithms. As digital health technology is increasingly promoted as supplanting intermediary data collection and interpretation with algorithmic labor, it becomes critical to disentangle the relationship between intermediary labor and algorithmic labor in broader processes of sensemaking. Algorithmic calibration is not simply about the adjustments intermediaries make to the algorithm aligning the parameters with those at hand. It also encompasses other activities that may calibrate the inputs and outputs of algorithms within broader sensemaking processes in order to align them more closely. Algorithmic calibration involves information labor to translate across contexts and repair labor to continuously manage consequences of algorithm breakdowns and perform adjustments around misalignments.

Translating for Clinical and Administrative Sensemaking

Translation of patient data for clinical and administrative sensemaking was challenging for both projects. Within clinical and administrative settings there were different expectations for data and different organizational resources and capacities that shaped different sensemaking processes. These clinical and administrative settings had institutionalized understandings and communication protocols around data that made it difficult to introduce and adapt structures for sensemaking around new informational capabilities. In the U.S. Telehealth case, care managers were hired to figure out how to translate patient Health@Home data into clinically actionable data, whereas there was no such role designated in the India mHealth case. This turned out to be an important difference between the cases in terms of the role of intermediary labor in

translation. The introduction of the Health@Home occasioned breakdowns in translation through which the care manager led restructuring and generation of communication protocols to support clinical sensemaking and actionability for the care manager and the physician around patient Health@Home data. In the India mHealth case, when there were breakdowns in translation, midwives worked to preserve pre-existing communication protocols in order to maintain and safeguard their organizational functions and values.

Generating Communication Protocols for Clinical Actionability

U.S. Telehealth demonstrated how communication protocols were generated and restructured in order support multiple data valences across lab, clinic, intermediary, and home contexts. The Health@Home system supported the technical exchange of data among these contexts, but data on their own fell short of generating value across stakeholders within different contexts. The care managers struggled with the translation of home-collected Health@Home data into medically valuable data actionable within the institutions of the formal healthcare setting. For example, initially, care managers attempted to communicate Health@Home data to physicians with a patient trend report they sent once a month to physicians, in which the Health@Home software extracted trends across the patient's Health@Home data into a document. They discovered that the reports were discarded without the doctor ever seeing them.

The care managers experimented with different communication protocols aimed at supporting clinical actionability without overwhelming the physician. First, they restructured what information was included in the trend reports and when and how they were sent. After much iteration, they discovered that there were only certain times that receiving patient trend data was actionable for physicians. These times included when the patient had an upcoming appointment, when the trend data became part of a particular patient assessment, and when

feedback from a care manager related to a particular clinical intervention. Therefore, targeting communication of patient information around these key moments turned out to be essential for supporting clinical actionability in the translation across contexts. Second, care managers began to only include the actionable trend information for patients, shortening the otherwise lengthy report to one or two pages. Care managers figured out that physicians would glance at the paper and want to identify key information at a conceptual level key. For example, one care manager explained that she always used a graph to visualize blood sugar data so that the physician “can take a quick look at it and say, “oh, Gee, your blood sugars are falling within this parameter: We’re good.” Beyond generating graphs and tables to represent trends, care managers would often print the report so they could mark it up, highlighting key information and adding interpretation and contextualization of Health@Home metrics (metainformation) through annotations (See Figure 3). They found that their annotation helped the physician very quickly interpret and recognize the actionable aspects of the report. Most of the care managers would then fax the report to the physician’s medical assistant at times related to the patient’s appointment or assessment or to the fallout of an intervention. The care manager embedded within the clinical setting noted that her strategy was to print out, mark up, and physically hand it to the physician’s medical assistant minutes before the occasion it was needed.

Once the patient trend report became devoted to actionable trends and was routinely directed at physicians in these particular instances of practice, there was a distinct change in how the physician oriented around the report. Care managers noted that physicians began referring to the Health@Home’s trend report, then noting Health@Home patients and care managers (one even explicitly commented in the EMR, “Way to go, Health@Home!”). Health@Home became part of the physician’s clinical lexicon, reflecting its use to them as a resource for accomplishing

clinical work. This illustrates how generating communication protocols around the patient trend report was critical for translating Health@Home data into clinically actionable data. Integrating the patient data from the Health@Home device and extant knowledge from their own conversations with the patient (meta-information), care managers structured their communication with doctors so the data came to doctors already integrated with a health interpretation in a trusted information network, at a moment when it was clinically actionable, and without increasing their workload. In the words of one physician, “So that if one of these people showed up on your schedule, you had a note that said this is what’s already been done, this is why they’re here, and...there was a value to it in that regard.” Over time the newly generated communication protocols became standard aspects of the patient trend report, making the a routine part of clinical sensemaking.

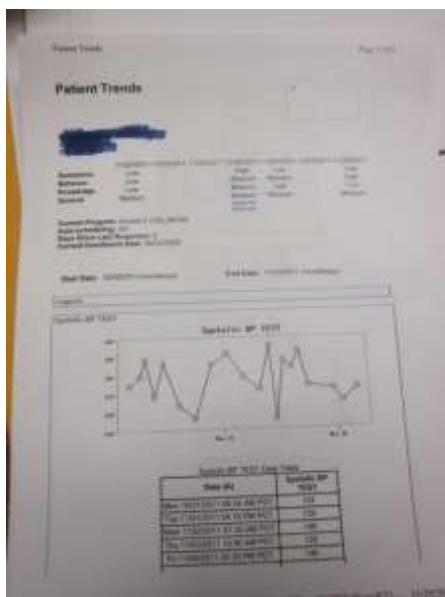


Figure 3. An example of a patient trend report.

Care managers performed metainformation labor to make Health@Home data jump institutional contexts through formatting clinically relevant information and adding interpretation in order to support actionability. In managing the series of breakdowns in translation across

contexts, care managers performed repair labor, iteratively attempting to (re)fit their patient trend report to the circumstances of the physician. Taken together, care managers made clinical sensemaking of Health@Home data possible through generating communication protocols.

Maintaining Communication Protocols for Accountability

Instead of generating new communication protocols in moments of breakdown as the U.S. Telehealth care managers were able to do, the midwives worked to preserve and maintain communication protocols to safeguard essential organizational functionalities. The introduction of the mPNC not only disrupted the mediating structures supporting institutionalized organizational relationships of accountability between administrators and midwives, but also multiplied accountabilities for midwives in the field. This disrupted multiple organizational functions and values of PNC data that were previously supported through the paper-based PNC data translation system among field, clinic, and office. Midwives worked to both preserve the organizational functions of pre-existing paper-based communication protocols and maintain accountability through new mPNC communication protocols. While the mPNC was advanced as a technology that would fill gaps of human resources and inefficient information systems, when implemented in the field, that promise was not fulfilled. Not only did India mHealth fall short in filling these gaps, but it put even more demand and strain on the organizational resources it aimed to support, and it failed to translate mPNC data for clinical and administrative sensemaking.

In the trial phase of the study, midwives completed both paper and mobile forms to acclimate to using the mPNC; in this period, they did not have to adapt their practice around new communication protocols. Because the mPNC had introduced a separate line of accountability to the mHealth project, the midwives did, however, have to perform double *protocol labor*,

transcoding between the paper at the same time as they mediated relationships of accountability with the office and the mPNC. While a key facet of the mPNC intervention was tightly linking the field, clinic, and office through faster, better mobile PNC data exchange, in practice the administrators were unable to access mPNC data, resulting in a breakdown in translation among the three settings. This resulted in a disruption to LNGO's capacity to process and manage data in the office context, where data are the basis for accountability (overseeing midwife activities), actionability (detecting patient problems and intervening), and discovery (researching population health trends two times a year). This prolonged the trial period of the project and ultimately led to the termination of the use of mPNC in the experimental phase. Although mPNC data were physically reaching the local server and therefore technically linking the field with the office, the administrators and office staff remained unable to access or use the data throughout the project. The administrators, in discussion with the ICTD researchers, had opted to upgrade their database system from the DOS version of Epi-info 6 to Microsoft SQL (software to which a few of their projects had already migrated). In practice, though, they realized that the PNC project members (none of whom had used SQL) would be unable to analyze data. There was no ecology of repair that could attend to these human and technological breakdowns to enable the sociotechnical system to continue to function and adapt.

Even as mPNC in practice led to breakdowns in translation across contexts, midwives were still responsible for maintaining the organizational functions and social valences of PNC data. Thus, midwives had to manage multiple accountabilities in the field and anticipate the consequences of translation breakdown. Their repair work preserved organizational functionalities of pre-existing communication protocols through a parallel set of PNC data practices. Even after the trial period had ended and the midwives no longer had to fill out the

paper forms in addition to the mPNC, a few of the midwives continued to generate a parallel set of records, jotting down vital signs on slips of paper during visits in anticipation of a breakdown or discontinuation of the mPNC. They selected the numbers to record in parallel, rather than the yes or no responses in the mPNC form, because the numbers would be harder to recall from memory should they need to do that in the future. They didn't trust the mPNC not to fail, nor were they fully confident in their own ability to correctly utilize the tool.⁶⁴ They still questioned its permanence in their work practice, and because they feared the new system would break down, they safeguarded the essential capabilities of the pre-existing system. In other words, they performed repair work in anticipation of breakdown rather than after breakdown.

Beyond preserving the functions of paper-based PNC, the midwives simultaneously worked to maintain the formal mPNC's protocols of the mPNC and failed to integrate them into their practice. Relatedly, Chib (2010) found in evaluating an mHealth project with midwives in rural Indonesia that while the mobile technology afforded many other opportunities for midwives, it was not used by midwives to generate new knowledge within their day to day practice. As previously discussed, India mHealth failed to align structures of accountability and structures of actionability, leading to a fragmentation of organizational routines. The midwives performed articulation labor in which unanticipated contingencies are dealt with "by packaging a compromise that 'gets the job done', that is, that closes the system locally and temporarily so that work can go on" (Gerson & Star, 1986; as cited in Berg, 1999, p. 91). Amidst the contingent, pragmatic demands of their everyday healthcare work, midwives compromised their use of the

⁶⁴ Prior research has demonstrated that lack of confidence in ability to use technology has been a factor in the reluctance of community health workers to accept any technological intervention (see, for example Chib, Law, Ahmad, & Ismail, 2012; Chib, 2010; Ramachandran, Canny, Das, & Cutrell, 2010)

mPNC. Sometimes they didn't use it at all within the clinical encounter, instead simulating the visit later when recording PNC data, or they used it within the clinical as tool for documentation rather than local action. Paradoxically, formal tools like mPNC “seem to be kept ‘alive’ by the very same ad hoc and pragmatic activities that they are often set out to erase” (Berg, 1999, p. 97). In order to continue get their work done and maintain the multiple accountabilities, the midwives maintained parallel communication protocols, using mPNC as a site for accountability while resisting it as a tool for local actionability in the field.

Translating for Patient Engagement

Both U.S. Telehealth and India mHealth aimed to engage patients around new forms of health and medical information. The intermediary labor involved in the translation of such data into the patient context for engagement went beyond explaining the meaning of data. Translating for patient engagement around maternal and child health or chronic disease was about using narrative as a translation device through which multiple valences could be evoked. Expectations around health information technology often fall prey to the logic that technology reduces the demands of talk and story in patient care. Talk is often characterized as “messy”, while technology offers a supposedly “clean” and frictionless path (Dossick & Neff, 2011) for communication as data exchange. Furthermore, stories are often discounted for being subjective, and therefore unscientific and unreliable as medical evidence in comparison to the supposedly objective technology-mediated data collection.

However, in the U.S. Telehealth case, the Health@Home data collection in the home provided an occasion for structuring new forms of personalized talk and narrative rather than reducing or eliminating them. Care managers worked to coauthor patient narratives, translating back and forth between story and data and evoking multiple valences of connection on the one

hand and actionability on the other. In the India mHealth, midwives constructed sole-authored community-level narratives rather than personalized narratives around mPNC data. The midwives did not translate the informational capabilities of the mPNC mobile video into new forms of talk and narrative; instead they presumed the information to be *self-evident*.

Coauthoring Patient Narratives for Connection and Actionability

Care managers generated communication protocols around daily Health@Home data exchanges in order to support multiple valences of actionability and communication/connection across patients and care managers. To support the valence of communication, care managers leveraged the daily exchange of Health@Home data as a routine, sanctioned path to intervention in the patient's home life, giving them a "reason to call" and talk about a common problem they both wanted to solve. As one care manager explained, "It is hard to develop that let's-work-together-on-this-problem kind of thing, without having the data that, 'Gee, I know that your blood sugars are off, I know your blood pressure is high.'" The highly intertextual conversations between the care managers and patients referred to some aspect of the patient-generated Health@Home data while simultaneously referencing extant stories, events, and trends outside of the specific Health@Home alert. The Health@Home data exchange became the basis of a "high touch" approach embodying multiple access points and communicative interactions around clinical and nonclinical aspects of care.

Health@Home data, on their own, are decontextualized and disembodied, but connected to patient stories or combined with extant knowledge or *metainformation* they became a tool for local sensemaking and a resource for action (Orr, 1996). Through conversations with patients, care managers extract "narrative knowledge" from patient stories that is valued as a resource for informing clinical interpretation and different courses of intervention (Charon, 2001). For

example, after reviewing a high alert for weight gain on one of her congestive heart failure patients, Linda is concerned and doesn't know what the weight gain indicates. She phones the patient and learns that the patient's family had visited from out of town and they had been celebrating over the last week with lots of rich foods, including a cherry pie that the patient proceeded to describe in detail over the phone. Relieved this didn't appear to be the sudden weight gain that can be indicative of imminent heart failure, Linda mentions to her patient, "It's OK to splurge every once in a while, as long as you get back to a healthy routine." As Linda hung up the phone with this particular patient, she chuckled to herself, "You never know until you start talking to them." The intermediary's narrative knowledge of the patient in this instance was essential for contextualizing and appropriately interpreting the patient's Health@Home data.

In addition to contextualizing health factors, the daily interactions with the Health@Home and care manager were sites for communication and connection for patients in the home. Narrative is a central feature of communication between providers and patients (Harter et al., 2005, p. 10). Patient narratives are "implicitly relational" (Beck, 2005, p. 71) because the patient's experience of chronic disease is inextricable from the relationships within their daily personal life. The Health@Home data allowed opportunities for care managers to connect to patients outside of clinical settings through patient narratives that encompass the clinical and the nonclinical and the personal and the professional. For instance, Linda, a care manager, wrote a note in the Health@Home program to call a particular patient on this particular day because his dog was being put down. These kinds of non-medical interventions provided emotional support and demonstrated the application of narrative knowledge to structuring communication as part of

the patient's longer life story, of which chronic illness is only a part, and did so as part of a meaningful social relationship (Charon, 2001, 2006).⁶⁵

Daily interactions around the Health@Home not only occasioned daily moments of listening and storytelling, but also daily moments of action. Just the daily practice of answering the Health@Home provided many patients a way of participating in their health and practicing self-management. In addition, the care managers coach patients on how to talk about their health and their disease management to their doctors; in other words, how to be good clinical storytellers. The Health@Home educational dialogues and data exchange become the basis for conversations and provide opportunities for patients to practice talking about their disease with others, as part of learning how to do their own translation of their data into the clinical realm. The care managers envisioned themselves as supporting patients towards their own health goals and within their own health narrative through a form of *accessibility labor*. As one care manager said, "It is about patient empowerment and not about the expert... Instead of us telling them, it is us teaching them to take care of their own health." Or as Beverly explained to her patient, "You are the captain; we are the hired hands."

Making Information Accessible through Community Narratives for Actionability

In contrast to the transformative coauthored narrative strategy in U.S. Telehealth, narratives were single-authored and served to challenge cultural norms, at the same time that they reinforced a hierarchical model of care. During the PNC visits the midwives would ask

⁶⁵ Narrative medicine proposes health and healing unfolding as a storied experience, and is "practiced with the competence to recognize, interpret, and be moved to action by the predicaments of others" (Charon, 2001, p. 83) Thus, patients and care managers draw on "narrative competence" in order to coauthor narratives of the experience of illness and care in the context of a patient's longer life story.

routine questions and perform tests to measure vital signs, but they almost never shared the results of the tests with the patient themselves, nor did they typically engage in talk beyond the PNC examination questions. However, as discussed in Chapter Four, midwives would tell the patient when there was something of concern and use the moment as an opportunity to give health advice. This *accessibility labor* involved the midwife translating from clinical data into a community narrative that drew on simple, culturally sensitive terms and logic in order to make the information *accessible* to a patient population that was less educated and considered to be of lower socioeconomic status in society. However, the narratives that the midwives constructed to translate to patients were not typically co-constructed with the patient, nor did they often become a site for dialogue. The community level narratives didn't pull on factors involving individual behavior; instead, they foregrounded the cultural norms and beliefs across the rural communities that are perceived as barriers to improving maternal and child health. In contrast to the care management model of behavior change in the U.S. Telehealth, this behavior change model operated at the level of community rather than the individual and did not engage the patient as agents or intermediaries in their own care, reinforcing the hierarchical model of care and privileging expert knowledge.

Within the context of the home, the midwives also confronted another mediating layer of hierarchy within the family structure, that of the place of mothers. Mothers were most often young women who had given birth at their in-laws' household and were subject to the decisions of the mother-in-law regarding the pregnancy, delivery arrangements, and post-partum practices. They were mostly not empowered to make decisions about their reproductive lives, including their diet, where they delivered, or how to care for the infant. Most of the young mothers became incredibly shy and mostly silent in the presence of their mothers-in-law and midwives. When the

midwife would ask the patient the PNC examination questions, the mother-in-law would often interject her own answers, silencing the voice of the patient. Thus the term “absent patient” (Mort et al., 2003) that has been used to describe the absence of patient voices in design might be better described in implementation of this project as the *muted patient*.

Translating as Algorithmic Calibration

In both case studies, algorithms were designed to perform a greater share of data interpretation labor so they could supplement the clinical sensemaking and decision making of the intermediary. This algorithmic labor did not mean that intermediaries did less work. In other words the algorithm did not simply replace the intermediary’s interpretation work; rather it displaced onto the technology or other workers that are part of the broader organizational sensemaking process. Thus, the intermediaries’ sensemaking work was displaced around the mediating algorithm. In both cases, the care managers and the midwives were doing new forms of calibration work in relation to algorithmic labor. For care managers, this took the form of protocol calibration, in which algorithmic interpretations needed to be calibrated within broader sensemaking processes around the individual. Care managers developed individualized protocols over time that consistently calibrated algorithmic interpretations and ultimately they were able to revise the parameters encoded into the algorithm itself for particular patients. For the midwives, this meant they performed reflexive calibration in which they revised their behaviors based on feedback from the algorithm and manipulated their documentation practices in order to shoehorn their responses into generating particular algorithmic outcomes. The care managers’ calibration work was considered routine and was made visible in the sense that for each deviation from the Health@Home algorithm, care managers could “talk back” and document their adjustment in their notes. The calibration work of the midwives, though, remained invisible, out of range of

any space for documentation or any arena for exercising their voice of disagreement or deviance in relation to the mPNC algorithm.

Protocol Calibration for Actionability

The Health@Home algorithm applies pre-defined high, medium, and low-risk parameters that trigger particular educational scripts on the Health@Home for the patients and the red, yellow, and green alerts on the Health@Home dashboard for the care manager that indicate different protocols for clinical intervention. The algorithmic labor encompassed the management and interpretation of patient Health@Home data through automatically coding data based on formalized clinical parameters to generate clinical risk indicators. The algorithmic labor afforded care manager's expanded productivity through outsourcing much of the data management and prioritization work involved in managing a large case load of patients. Algorithmic labor translates patient-gathered data in the home to health data for care managers through interpretation that assumes Health@Home data are self-evident (as discussed in Chapter Four) and that they can speak for themselves. However, the algorithmic interpretation aimed at supplementing care managers' clinical decision-making often required intermediary labor to calibrate algorithmic protocols within a broader sensemaking process.

Care managers performed routine algorithmic calibration around what Gillespie (2014) would call "bluntly approximated" algorithms. To compensate for the bluntness that leads to unnecessarily triggered alerts care managers translated the interpretation presented through the algorithm into the local context for sensemaking around a particular patient through a process of calibration. This involved *metainformation labor*, which integrated extant, contextual, narrative knowledge around how and why a particular alert was triggered into the sensemaking process. Care managers consistently discounted alerts triggered by the algorithm for certain patients. This

was not because the care managers weren't taking the time to respond to the alert. Instead it was that they took the time to deconstruct the interpretation through the Health@Home algorithm and to develop parallel individualized sensemaking structures around the data, re-constructing and re-interpreting the Health@Home data in light of the larger context of the patient's health and state of being. Through protocol calibration, care managers translated algorithmic protocols into individualized protocols for care.

Most of the Health@Home's chronic disease programs at the time of my fieldwork didn't allow the care managers to adjust the parameters so that the algorithm could be personalized for what was defined as normal or abnormal for a particular patient. Dee reflects on the instability and uncertainty of defining "normal" for many of these patients.

Most patients need an individual parameter, like there's no normal blood pressure. If you're on a blood pressure medication, the physician is going to know what parameters are going to be acceptable, it's a matter of, it's kind a gestalt of, you know, what is their kidney function, what is their heart function, how much medication are they on, have I tried other medications and maybe this is the best effect I can get with only this medication kind of thing? So it's a whole picture of, you know, their blood pressure is this because—and so many people need to have that individualized number, there's no real normal.

As Dee suggests here, translating algorithmic protocols requires a complex dance of contextualization and synthesis. It is not an exception, but rather a norm in care management. During the time when care managers couldn't change the clinical parameters within the algorithms themselves, they documented any adjustments or the individualized protocols that had developed over time in relation as part of calibrating algorithmic protocols. Empowered to override, work around, and adjust the Health@Home clinical interpretation based on their own more complexly situated clinical judgment, care managers could talk back to the algorithmic interpretation. This documentation became a routine part of the sensemaking structure referred to by care managers who might fill in for each other.

In identifying the gaps in translation between the clinical interpretation executed through algorithmic labor and the sensemaking process based on creating and interpreting together other clinical, narrative, and extant knowledge of the patient, the care manager was able to consistently and continuously repair, or manage the consequences of, misaligned algorithmic interpretation. One consequence of the “bluntly approximated” Health@Home algorithm is that it informs the educational script presented to patients, offering advice based on its interpretation. Through algorithmic calibration, the care managers reinterpret the algorithmically generated advice to apply to the individual context of the patient. For instance, Christine, a congestive heart failure patient, has persistent low blood pressure, and even though Dee discounts the alert on the clinical interpretation side of the Health@Home algorithm, it triggers the low blood pressure education script and advice on the patient’s Health@Home device. To manage these consequences, Dee explains to Christine that she can routinely discount the low blood pressure related messages from the Health@Home, which are being triggered by parameters that aren’t calibrated for her situation. Dee emphasizes to Christine that the important thing is that “*I know what your blood pressure should be*” (my emphasis). Through continuous repair labor, care managers developed and structured parallel sensemaking processes around algorithmically generated patient advice and clinical interpretation to correct the translational gaps both in the context of patient engagement and in their own clinical decision making.

This leads us to question the purpose of these “bluntly approximated” (or at other times overly specific) Health@Home algorithms to better articulate the evolving interaction between care managers and algorithms. Gillespie’s (2014) perspective that “algorithms are not always about exhaustive prediction; sometimes they are about sufficient approximation” is instructive here as we observe how the algorithmic labor performed through the Health@Home algorithm is

only one of many layers of translation (p. 174). We understand metainformation labor and the continuous repair labor as the “social tactics” that are entangled within algorithmic calibration in this case. These social tactics to support translation between technical and cognitive representations of knowledge encoded in algorithmic interpretation and the tacit, practice-based, communicative knowledge processes

Reflexive Calibration for Accountability

The mPNC algorithms in India mHealth also performed algorithmic labor of interpretation in the form of clinical decision support for midwives. Similarly to the care managers, midwives performed a kind of algorithmic calibration, but this involved calibrating their own behaviors and documentation practices to align with algorithmic interpretations and outcomes, rather than calibrating the algorithmic protocols themselves. Reflexive calibration translates between midwives’ local, situated behaviors and knowledge and the algorithmic interpretations they produce. Reflexivity is “the movement whereby that which has been used to generate a system is made, through a changed perspective, to become part of the system it generates” (Hayles, 1999, p. 8). Hayles (1999) notes that it “confuses and entangles the boundaries we impose on the world in order to make sense of that world” (p. 9).

The technologically mediated reflexivity experienced by the midwives interacting with the mPNC, which automatically provides them with adaptive feedback in the moment of their use, affords the opportunity for reflexive calibration. In other words, using the mPNC meant that midwives’ documentation practices were immediately linked to particular clinical interpretations and protocols that had previously remained separated by months of processing in the office with paper and even then there was not the adaptive feedback at this level of detail.

As midwives interact with the algorithm's feedback mechanism, they recognize the ways in which data must be "cleaned up" (Gillespie, 2014), manipulated, and massaged to be readied for the clinical decision support algorithm. This had less to do with any algorithmically generated interpretation or recommendation informing the midwife of something she didn't already know or some information essential for making a decision. It was much more that the interpretation or recommendation either validated decisions or alerted midwives to a mistaken entry at some earlier point in the mPNC form that could have triggered the wrong diagnosis. On a number of occasions I observed how midwives, upon arriving at a "diagnosis" screen, stopped, and then anxiously navigated back through the form to the point at which an incorrect response was given in order to correct it, thereby changing the diagnosis. In this process of reflexive calibration, a layer of automatically generated metainformation became part of how midwives ensured they were representing their clinical practice and information correctly for the office to evaluate.

There were also instances in which the algorithmic interpretation did not reflect the clinical situation observed by the midwives. In these instances the midwife would enter data based on clinical observation, but then disagree with the diagnosis reached by the algorithm. Within the hierarchical model of care and its matrix of power relationships midwives could not openly resist, modify, or *calibrate* the algorithmic protocols. Instead of overriding the diagnosis based on their own clinical judgment as the care managers had done, they calibrated their own documentation practices to align with the correct diagnosis. Put another way, they performed repair labor to bridge the translation gaps between observed and clinical diagnosis by shoehorning data into appropriate algorithmic outcomes. Specifically, during one PNC visit, Aditi, prompted by the mPNC form, asks if the mother is experiencing pain in urination. The

mother replies that “Yes, there is pain...because of the stitches.” She explains that at the hospital there was cutting during delivery, which is why she needed stitches. Later on in the examination Aditi is prompted with a diagnosis screen telling her the patient has an infection in her urine. Immediately Aditi looks confused and then says she knows what she did wrong. Aditi knew the pain in this mother’s urination was caused by the stitches and not an infection, yet her answer “yes” to the pain in urination question in the form had triggered the incorrect infection diagnosis. She navigated back to the question of whether the patient had pain in her urine and changed her response from “yes” to “no,” revising the data to reflect the appropriate diagnosis based on algorithmic logic. It was more important for Aditi to have a correct diagnosis, even with incorrect data, because she would be held accountable by the administrators for the clinical actions that diagnosis demanded.

This example reflects how with the mPNC Aditi’s actions and her data are now subject to an *algorithmic accountability* that requires new information labor to ensure the “relevant”⁶⁶ information and interpretation jump from the field to the office. Aditi’s act of changing the answer to a question to match the diagnosis generated by the algorithm reveals the shoehorning of her actions and her data into responses that were “algorithmically recognizable” (Gillespie, 2014). In a sense this was a learning process; the algorithm was training her how to account for her clinical interpretation in terms of the algorithm. It is only through manipulating data that her interpretation can be registered and heard in this datafied clinical support mechanism. For Aditi, the demands of the algorithmic accountability were brought into conflict with her own clinical actions and her relationship of accountability with the administrators, in which she is responsible

⁶⁶ See Gillespie (2014) for a discussion of the relative construction of “relevance” in algorithm production

for filling the correct patient information in the mPNC form. While Aditi prevented an incorrect diagnosis of an infection, her actions are part of a potentially dangerous cycle of having the PNC data not reflect the actual symptoms of the patient, something that could become critical at a later point. The relationship of accountability with the administrators was now mediated through algorithms that co-produced different structures and logics of accountability than had existed previously through paper.

These algorithmic calibration practices reveal much about what different valences were at stake in these different contexts and the role of the algorithm in mediating practice. For the U.S. Telehealth care managers, the Health@Home algorithms were “sufficient approximations” in processing patient risk alerts that provided occasions for communication and actionability. The U.S. Telehealth care managers continued to do the work of calibrating these sufficient approximations and were empowered to draw on them as resources for action or communication rather than to view them as actionable and self-evident on their own right. They could override the alerts and calibrate the protocols for each individual patient based on the care manager’s own developed forms of expertise and experience; in other words, they maintained the power to determine interpretation and action and voice disagreement. In this context, the intermediary labor in protocol calibration was made visible as dialogue with the algorithm, supporting multivocality in algorithmic calibration.

For the midwives in the India mHealth project, the mPNC algorithm was designed to function much more as a script for action, in which the documentation of patient data and midwives’ clinical actions would be tightly coupled with the algorithmically generated interpretations and actions. However, in practice, the midwives’ local sensemaking processes were mostly decoupled from mPNC clinical decision support. Thus mPNC became a site for

accountability that imposed its own algorithmic protocols of translation. This algorithmic accountability required midwives to justify their clinical actions through the logic of the algorithm. Since midwives were not empowered to openly resist or modify the algorithmic protocols; instead, they had to do the work of reflexive calibration, shoehorning data practices into algorithmic outcomes that registered their accountability in the office. Whereas the care managers’ calibration work was made visible in the sense that for each deviation from the Health@Home algorithm care managers could “talk back” and document their adjustment in their notes, the calibration work of the midwives remained invisible, lacking a space for documentation or an arena for exercising their voice of disagreement or deviance in relation to the mPNC algorithm.

In summary, this section outlines and compares the different kinds of intermediary labor that are relevant for translating across multiple data valences within both U.S. Telehealth and India mHealth. Table 4 demonstrates the differences in the role of intermediary labor in translation of digital health data for clinical and administrative sensemaking, patient engagement, and algorithmic calibration across both cases.

Table 4: Intermediary Labor in Translating Across Multiple Data Valences

	U.S. Telehealth	India mHealth
Translating for Clinical and Administrative Sensemaking	Generating communication protocols for clinical actionability	Maintaining communication protocols for preserving accountability
Translating for Patient Engagement	Coauthoring patient narratives for communication/connection and actionability	Making information accessible through community narratives for actionability
Translating as Algorithmic Calibration	Protocol calibration for actionability	Reflexive calibration for accountability

Aftermath

The funding for both projects was ultimately removed, indicating the pilot projects had failed to live up to expectations set up during the outset of the project. Even though the U.S. Telehealth project had been able to structure institutional sensemaking and translation around data such that those data were enormously beneficial to patients and physicians, such organizational innovations were not valued within the financial compensation routines of formalized medicine. The explicit aim of the U.S. Telehealth project was to reduce costs for Medicare while improving health outcomes for high-risk and high-cost patients. Medicare's evaluation found that the program, despite its successes with patient outcomes and its reduction in costs, did not reduce costs enough to warrant continuation of funding. Even though the data were enormously beneficial to patients and to physicians, Medicare terminated the program, deeming the team of trained care managers needed for the program too expensive.

Project funding also came to an end with India mHealth. While each of the project stakeholders framed their perspectives on the failure and success of the project differently, they all agreed it was not sustainable in its current form. Certain project expectations had not been met. In particular, the administrators had been unable to easily and reliably access the PNC data from the mPNC in the office, which meant that the midwives, overburdened with protocol labor as they transcoded between paper- and mobile-based PNC forms, resisted adapting their practices. Conversations at the end of the project with LNGO were focused around how to shoehorn the mPNC data back into their old system, rather than around how to move the project forward. As is common in ICTD projects that straddle multiple contexts and stakeholders, divergent expectations produced what Winthereik (2010) has referred to as a "project multiple," where fragmentation and differences across stakeholders are continuously produced within and

through the project. What began as a coherent collective agenda ended up with stakeholders determining versions of success and failure in siloes.

This final section considers the aftermath of both projects in order to understand and learn from the ongoing processes of repair beyond the failure to secure continued funding to transition from a pilot project to full adoption. As Jackson (2014) puts it, “Repair occupies and constitutes an *aftermath*, growing at the margins, breakpoints, and interstices of complex sociotechnical systems as they creak, flex, and bend their way through time” (p. 23). Jackson (2014) calls for scholarly attention to this aftermath in an effort to remedy a productivist bias across groups, appealing especially to technology designers as well as to scholars of media and technology studies, who tend to focus on moments of production (p. 234). Approached by those with more a productivist perspective, the aftermath in both of these cases would frame the question in terms of success or failure, where success is defined in terms of whether the technology was adopted and whether it was still in use. These questions and logic of evaluation closely align with a diffusion of innovations approach (Rogers, 2003), in which what is at stake in the process of diffusion is whether the innovation is or is not adopted. If instead we take the breakdowns, discontinuations, and failures as starting points for thinking about the design, use, and implications of digital health technology, as Jackson suggests, then we can more effectively occupy the aftermath. Through a lens of ongoing repair and restoration of both technological and human orders, a very different picture emerges, beginning with the fuzzy boundaries of what technology is and what it becomes.

Breakdown and Repair

Occupying the aftermath of continuous breakdowns and repair throughout both U.S. Telehealth and India mHealth highlights key differences in the processes and outcomes of

organizational adaptation. As Jackson (2014) argues, breakdown and repair function as the engine of innovation (p. 228). While a virtuous cycle of breakdown and repair fueled organizational innovation in U.S. Telehealth, breakdowns in India mHealth generated open loops without resources for repair. Instead this meant that repair work focused on the maintenance of pre-existing organizational functionalities. The differences across the projects reflected the power differentials that shape who has ability to do the necessary repair work and therefore, whos is able to innovate.

The U.S. Telehealth project demonstrates how technological innovation relies on the ongoing repair work entangled in organizational and technological structuring beyond moments of production, into moments of sustainability. Scholars have pointed out extensively that in the design and implementation of health ICTs, users adapt and may re-invent technologies as they explore their practical uses and potential for their own work practices (see, for example Berg, Langenberg, Berg, & Kwakkernaat, 1998; Berg, 1999). This process of adaptation refers to a variation of user-centered design rhetoric having an emphasis on the need for “user-led processes of adaptation” (Hartwood, Procter, Rouncefield, & Slack, 2003, p. 263); this concept extends development into the actual contexts of use rather than only designing for what users may say they want before they have been able to adapt and innovate within their own work contexts. In a complex, messy practice such as healthcare, those individuals and organizations, or user-innovators, which are embedded in the day-to-day labor of making it work, are often the source of great innovation because they understand their needs and use context better than anyone (Von Hippel, 2006, p. 67). We can understand this user-led adaptation process and the work of user-innovators as a form of repair that co-evolves with technological development and practice. In U.S. Telehealth, user-led processes of adaptation highlight the essential role of care managers as

user-innovators (Von Hippel, 2006). When organizational alignment processes expanded the boundaries of care management and developed a collaborative approach to care, it meant that when breakdowns occurred, care managers had the resources and power to do something about it or to try something new. For instance, the translation of patient Health@Home data into the clinic broke down, at which point care managers generated new communication protocols to translate patient Health@Home data into clinically actionable data. They did this iteratively, innovating through their repair work in the junctures of breakdown.

In India mHealth, when things broke down there were very few, if any, local resources for repair of technological and human ordering. This was exemplified when the data exchange breakdown between office and field occurred and the office staff and administrators were unable to access data from mPNC in the field. The administrators, then, decided they wanted to revert back into their old database system, but this required shoehorning the mPNC program back into a system for which it was not designed and could not translate to easily. The translation was complicated by a network infrastructure in the office that manifested as a complex maze of different software capabilities on different aging computers, each with their own set of constraints. The administrators and the midwives were increasingly concerned about being able to access their data and keep it together and consistent so they would be able to detect problems and draw comparisons by running the same analyses and queries they always had.

The administrators felt strongly that accessing and analyzing their data should not require a person with “high technical skills” and that should it become necessary this person should be able to change particular fields in the database without relying on the professionals from University or GNGO.

I'm not sure whether you need easier technology or whether these people need to be better trained or like if every new person has to be trained in not only in how to provide

high quality services and how to do the counseling or how to do a certain test or an examination or you know take a decision on something if you also have to train them on how to use the technology it becomes that much more difficult for an organization like us. (LNGO administrator)

The burden of retraining the limited human resources available elevates the risk experienced around technology upgrades or changes. The organizational risks were too great as they anticipated the costs of failure and capabilities required for yet another layer of digital complexity in what Yoo et al. (2012) have referred to as an implication of *combinatorial innovation*. As systems and components can be mobilized across different contexts, this mobilization “creates greater risks of failures because of the heightened complexity of digital capabilities” (Yoo et al., 2012, p. 1403). Thus, their perceived risk of mPNC skyrocketed and diverted the project course. The administrators wanted a technology that was so simple “it doesn’t fail.” One morning in the office on my way out to the field for the day, one of the administrators stopped me to ask, “How when you and Greg are gone, what will we do if something goes wrong? That is why we have been hesitant to go just to the phones and no paper. Who will be able to fix the problem? We don’t have confidence that we can manage and fix the problem.” I didn’t have a good answer for her, and in that moment I experienced personally this organizational gap in repair. There was no one, no mechanism, no repair ecology in place that would be able to fix the technological and human breakdowns that would inevitably continue to occur.

The difference in the repair ecologies between the two cases meant that breakdowns in U.S. Telehealth occasioned intermediary-led adaptation and innovation while breakdowns in India mHealth magnified organizational gaps, within which LNGO preserved and maintained pre-existing structures and resisted adaptation. Here I consider how the differences in the processes of organizational adaptation, as described in this chapter, manifest in the aftermath of

both projects after the Health@Home and mPNC were removed from their respective organizational settings. U.S. Telehealth's intermediary-led adaptation process supported virtuous cycles of breakdown and repair, in which organizational and technological structures co-evolved to support data polyvalence, therefore leaving a technological residue even after the technology was removed from River Medical's care management program. This challenges us to see how technological innovation extends into a wider network of organizational practice. This fruitful process of co-evolution did not occur in the context of India mHealth. Instead, breakdowns were mostly left without proper repair, so that pre-existing organizational structures were maintained in parallel to mPNC to manage multiple data valences separately. Falling below all stakeholders' expectations, the aftermath is characterized by multiple "local minima" (ICTD researcher), or a multiplicity of local compromises, in which the boundaries between technological and organizational structures were made more explicit.

Technological Residue

Even though the U.S. Telehealth program significantly improved health outcomes, the financial compensation routines of formalized medicine did not find the project cost-effective. When Medicare deemed the care management team too expensive and stopped funding the U.S. Telehealth program, the care managers had to slowly wean all their patients off the program, and River Medical had to re-articulate what care management was without the Health@Home. I attended the day-long workshop at River Medical aimed at exploring exactly this issue with care managers. This workshop, in addition to a set of interviews and observations with the care managers within their non-Health@Home organizational setting revealed that a *technological residue* still remained. Technological residue refers to what remains after a part of the

technology is removed, separated, or after a technological process has been completed.⁶⁷ The technological residue continued to influence organizational structures and practice even without the presence of the once-inextricable material structures afforded by the technology. Embedded in this concept is an understanding that the agency of technology can persist in material ways after the physical technology has been removed, challenging the ontological boundaries of the technology. As Akrich (1992) notes, “The boundary between the inside and the outside of an object comes to be seen as a consequence of such interaction rather than something that determines it. The boundary is turned into a line of demarcation traced within a geography of delegation, between what is assumed by the technical object and the competences of other actants.” (p. 206). This concept deepens our understanding of how technological change can occasion organizational structuring and extends our framework for evaluating technological innovation.

In the wake of failing to meet Medicare’s standards of success, a group of care managers, doctors, and administrators at River Medical reflected on their own standards of success. In Kirsch and Neff’s (n.d.) conceptualization of the materiality of failure, they examine abandoned organizational artifacts from a failed law firm in order to reveal the “residue of the social organization that once animated them.” Organizational artifacts, they argue, can be interpreted as part of the process of organization and de-organization and can embody a “residual agency” even when the organizational structures have dissolved. In the case of River Medical, the notion of residue was reflected in the conversely constructed situation, in which the Telehealth technology

⁶⁷ Based on Residue. (n.d.). *Merriam-Webster.com*. <http://www.merriam-webster.com/dictionary/residue> (Accessed January 14, 2014)

left a “residual agency” distributed across organizational practices after the telehealth technology was discontinued and removed from organizational routines.

Knowledge and new forms of intermediary labor accumulated through practices with and around the Health@Home, slowly calcifying into new organizational routines that recursively shaped structures on an organizational level. In other words, the technological and organizational structures co-evolved. When the Health@Home system was removed, many of the social and organizational routines reliant on the material affordances of the technology were rendered non-functional, while a few routines and structures appeared to remain, like a residue. In spite of operating without the affordances of the technology, certain care management routines and structures still embodied the technological structures. This suggests that organizational routines can be imbued with a technological residue that continues to shape how new organizational routines and structures are developed, applied, and understood. The technological residue emerged within this organizational setting as definitional work of organizational roles and user categories and information management and communication structuring in absence.

Definition of Organizational Roles and User Categories

Since the program of care management at River Medical emerged with the introduction of the Health@Home, many of the organizational roles and identities defined in care management were inextricable from the material and symbolic structures of the Health@Home. Thus, care managers found it very challenging to articulate their role as care manager or the practice of care management without the Health@Home. In one care manager’s words, “Health@Home made us the case managers we are today.” The routines and capabilities that developed around and through the device structured what they knew to be care management at River Medical.

At the workshop on care management, the group discussed how to define different care management populations. Jake, a representative from the administrative side of the clinic suggested they divide the care management sub-populations into chronic disease management and acute conditions categories. The care managers were then asked to list the diseases and conditions that would be subsumed under each category in an effort to differentiate between and bound the acute and chronic populations. This process quickly led to confusion as care managers kept thinking of particular Health@Home patients that didn't fit neatly into categories of acute and chronic. After much discussion of what counted and what didn't, as a group they finally decided that it was easier to define the chronic disease management population in Health@Home terms, namely as "Health@Home people." For the care managers, the chronic disease management category could be most effectively understood and operationalized if the defining question for each patient was, "If you had a device to put in her home, would you?" Dee then wrote on the white board, next to "chronic disease management," "(anybody that would need a Health@Home)." With this definition, the category of chronic disease management was clear to the care managers. The meanings of the organizational roles and patient categories had co-evolved through the use of the Health@Home in practice. Thus, Health@Home patients had become a recognizable group identity to the clinical team, and this group identity was now being used to define the boundaries of the chronic disease segment of care management. This demonstrated that the Health@Home patient group identity embodied a residual technological agency as River Medical continued to structure and define categories of care management without the Health@Home.

Structuring in Absence

A third form of residual technological agency operates through alternative structures and practices developed as a consequence of the *absence* of Health@Home. In the absence of some technological affordances of Health@Home, there are organizational routines and innovations that become unworkable. Yet people still organized around the absence of some of the organizational structures that had co-evolved with Health@Home. In other words, technology's absence remained a force in organizational life. I conceptualize the agency of absence drawing on theories around the materiality of something without "matter," in which both invisible and intangible phenomena can have great material consequences (Burrell, 2012b; Shah, 2012). For instance, Burrell (2012b) demonstrates how rumor, "through its continual re-performance endures well beyond more ordinary and everyday acts of speech" (p. 316). On the material consequences of absence, Shah (2012) notes that "absence is not a deficiency but can be productive of political life." In the absence of the Health@Home, a residue, without matter, continued to materialize through communicative scripts and alternative organizational structures and practices.

Communicative Scripts

In the aftermath, care managers translated affordances of the technological device, such as its communicative scripts, into human labor in order to sustain their function without the actual device in operation. Care managers found conversations with patients much more difficult without the daily Health@Home data exchange as a spark, or basis, for inquiry. Beverly commented that it felt much more like cold calling because you had to ask how they are doing with no data, whereas "with the Health@Home you had concrete data so you could start the conversation with 'I see you have gained 6 pounds in since last time we spoke...'" In the

Health@Home's absence, care managers not only encouraged patients to continue self-monitoring at home, but also began asking patients many of the same Health@Home questions that had been part of the Health@Home program script in their conversations with patients because, as Kim explains, "I want them to still continue with that thought process that Health@Home gave them." Recognizing that patients had enjoyed the Health@Home's trivia questions, Kim had even copied them down to ask at the end of conversations with patients. Kim, along with other care managers, performed parts of the communicative script of the Health@Home in their own conversations with patients in order to simulate some of the device's affordances even in its absence.

While there were some aspects of the communicative script that could be taken up to shape new case management practice, much of the communicative function of the Health@Home had disappeared with the removal of the device. Care managers acknowledged that without the Health@Home offering a direct line to their care manager and the daily interactions building the same rapport, patients weren't likely to call in to the clinic. Thus care management without the Health@Home resulted in a much more unidirectional mode of communication, one in which it is much easier for patients to fall through the cracks.

Alternative Structures of Information Management

The Health@Home program's structures for prioritizing, documenting, and interpreting patient information became inextricable from the practices of care management. All the care managers agreed that their work wouldn't have been possible without the Health@Home:

If I had to manage 100 patients and do it all by calling them on the phone and saying how are you today, what's your weight—I wouldn't get to them all in one day, and I'd never be able to prioritize which ones needed help today versus, you know, just calling them and saying, you know, how are you doing today.

Care managers reflected on how the Health@Home trained them to be effective care managers by demonstrating through its program architecture and algorithms how to prioritize patients, organize patient information, and intervene effectively with patients. In the absence of the Health@Home, care managers reproduced some of prioritizing and documenting practices core to care management work even without the supporting technical structures for doing so. The care managers opted to create alternative systems for prioritizing patients and documenting patient information through patchy, less efficient and effective combination of paper-based notes and inbox reminders. Generating alternative structures in the Health@Home's absence, care managers used paper to jot down observations from conversations with patients and set inbox reminders to alert them with whom to follow up and when. However, many of the affordances of the Health@Home system could not be recreated within this patchy system. For instance, they did not have a place to store the extensive patient notes, including clinical and nonclinical information, that they used to keep separate from the EMR. This meant they simply didn't record this information, making it difficult to monitor important changes that didn't make it into their medical chart and to develop personal relationships with patients.

The absence of Health@Home also reshaped, on the one hand, the relationships between care managers and physicians and, on the other hand, the autonomy care managers who were experienced in their ability to interpret patient information and make clinical decisions. The absence of Health@Home data for a patient meant the care managers could not get an accurate trend to make a report, map, or graph for communicating something valuable to the physician. With the Health@Home data they could often make a judgment call right on the phone, but without Health@Home data they typically had to call the patient in for an appointment, reverting back to status quo hierarchical relationship between physicians and nurses. In the absence of

Health@Home data as evidence for making clinical decisions, care managers were forced to depend on other ways of gathering data through face to face appointments and to rely more on physicians in process of making clinical decisions

Multiple Local Minima

As this chapter has demonstrated, in contrast to the U.S. Telehealth case, the introduction of mPNC occasioned minimal organizational structuring, and as a result fell short of supporting the management of polyvalent data. Project stakeholders expected mPNC to provide more, better data faster across field, office, clinic, and lab, and that this data would form the basis for strengthening accountability, extending clinical actionability, and promoting discovery for LNGO and ICTD researchers. Yet in practice, this system failed to generate these values and meet these expectations on all fronts. The project magnified and reinforced organizational and knowledge gaps, leaving project stakeholders with divergent expectations for the project. These gaps emerged through a series of breakdowns, mostly without repair, and consequently produced further difference among stakeholders. Thus we can examine multiple aftermaths to this “project multiple” (Winthereik, 2010). Across the aftermaths project, stakeholders were left occupying the gap between the anticipated and actual course of the project. Within these gaps and in siloes stakeholders forged a compromise between the two. These multiple local compromises, or “local minima,” characterized the aftermaths of mPNC.

Whereas a *technological residue* persisted after the Health@Home had been removed from River Medical, for LNGO, not much was left behind besides a handful of smart phones in a drawer in the office. Because the mPNC system was implemented mostly in parallel with the pre-existing paper system, the mPNC never co-evolved with the organizational structures enough to leave traces in organizational relationships and routines. Yet beyond the termination of the

project, there are multiple variable materialities of India mHealth that continue to perform in practice and in relation to the multiple different stakeholder groups that engage with them in different contexts. Project stakeholders maintained very different understandings about why and how this happened, which, in turn, shaped each of the local minima. Akrich (1992) uses the term “reversible reaction” to describe how the industrialists and the users had reverse explanations for why photoelectric kits did not work. When there was something wrong technically, the industrialists reasoned it was misuse in the social realm, and when something didn’t work socially, the users argued that it had been misconceived in the technical realm. A reversible reaction of sorts played out in the India mHealth case, with project stakeholders adopting different, opposing frames for making sense of what didn’t work. The breakdowns throughout the mPNC implementation were framed by LNGO as problems resulting from the technology not having been designed and configured for the organizational capacity and routines of LNGO. The same breakdowns were framed by the ICTD design team as problems of organizational capacity for and investment in adapting organizationally to make the technology work. Accordingly, these explanatory frames relied on defining explicit boundaries between technology and organizing.

Technology Can’t Fail

LNGO’s greatest challenge was having human resources to build organizational capacity and develop strong institutions in an area bereft of them. LNGO administrators engaged in India mHealth at the same time it engaged in a host of other multi stakeholder development projects. As one administrator put it, they did this to enable “fast tracking change and as a way of compensating for some of the capacities which we are not able to build.” In the case of India mHealth, a technical solution was developed to compensate for the lack of human resources and organizational capacity. Yet for LNGO, as mentioned previously, they wanted a technology that

wouldn't "fail," that was so simple that it required negligible organizational cost. Already adapted around technical and organizational infrastructures that continuously broke down, the appearance of organizational stability was an incredibly effortful and fragile accomplishment.

ICTD projects tend to embody this inescapable paradox: ICTs are considered solutions to problems of human and organizational capacity, but in practice they require that human and organizational capacity be implemented effectively and sustained. The administrator explained how the lack of skilled human resources should not be a surprise or an afterthought because that lack itself is the fundamental problem.

You know what that high mortality and under-development is all about? It's all about that lack of such people here. So don't be surprised that, you know, you're not finding people who are up to speed on any of these things, that's why, there's a lot of these situations out there. If they were all here, then you wouldn't get in such a situation. (LNGO Administrator)

He noted that this lack of organizational capacity and skilled human resources needs to be factored into any technology design project or experiment in this setting. As the administrator pointed out, even when capacity is built, "there's a lack of capacity everywhere, and so they might just move on." As it turned out, this very common experience—investing in developing human resources, only to have those essential human resources leave for other opportunities—occurred in the middle of the India mHealth project. Kalpana, a doctor who was serving as project supervisor, left LNGO for another job opportunity, leaving a gap of expertise and experience around the use of the MPNC in the field and a gap in communication between the researchers and GNGO professionals, the midwives in the field, and the administrators in the office. The mPNC had required more capacity than was available and threatened to disrupt the organizational and technical capacities they did have without delivering any marked benefits.

The aftermath of these breakdowns reveals that, not only can we see that no capacity existed for technological repair, but in the fact that Kalpana's role was not refilled, we also see

that no capacity for restoring human order existed either. The effort of developing new technological and organizational capacities and managing the collaboration of the multi-stakeholder project itself hangs in a fine balance with the already constrained resources and capacities of LNCO. As stated by the administrator, “Given that lack of capacity is an issue, you find that the best possible way of experimenting and trying things out, documenting them and learning the lessons, having the insight, you know, might take a whole lot of effort.” For administrators, India mHealth and other development projects were always honing around a local minima, as they represented a compromise of trying to do their best to faithfully carry out a project within a reality of significant constraints.

Madeline Akrich (1992) tells us, “We have to go back and forth continually between the designer and the user, between the designer’s projected user and the real user, between *the world inscribed in the object* and *the world described by its displacement*” (p. 208, author’s emphasis). Both worlds taken together, this case warns about the “self-referential nature of digital technology,” in which “digital innovation relies fundamentally on various forms of digital technology as an enabling technology for its creation, diffusion, appropriation, and expansion” (Yoo, 2012, citing Kallinikos, 2006). For user innovation around digital technology to thrive, an ecology supporting other digitally connected technologies, activities, and repair needs to also be in place. Otherwise, as in India mHealth, it is likely that intended benefits won’t materialize and the breakdowns of technology in practice will accentuate organizational gaps rather than inspire innovation.

Underestimating Organizational Change

The challenge of implementing mPNC from the perspective of the ICTD design team was framed as one of low organizational capacity and low investment in and understanding of the

organizational restructuring required to achieve benefit from the project. As one of the ICTD researchers noted, “I think they (LNGO) were just looking at it as a process efficiency thing. It’s like, ‘Oh, what we were doing before, now we can just do it faster!’ But in fact you’re getting so much different kinds of data that you can do so many more things, but they are not equipped to deal with those things.” From one ICTD researcher’s perspective, “they weren’t ready as an organization to really change their processes. It didn’t have anything to do with technology.” The limits of the technology had been reached, and the ICTD researchers agreed that LNGO needed to take steps to upgrade and develop capacity around a new system before their project could provide them with any benefit. As with many mHealth projects, there is a tension between two poles: on one side, investing in mobile technology for data collection on the periphery of organizations and to informationalize aspects of daily life that weren’t possible previously, and, on the other side, the investment required to develop an informational and organizational infrastructure that can interpret and make valuable the data being collected. This organization restructuring, essential for creating any kind of sustainable solution, was perceived by ICTD researchers as separate from testing the technology.

So if you really inject this as opposed to just testing it out and, you know, doing it in parallel to what you already do, but if you really start injecting it then you’ve got to think about, well, all right so now I’m turning off this spigot of data, and turning on this other spigot of data—is that really going to flow where I want it to flow. And that’s not always true, in fact it’s rarely true, and in this case it wasn’t any different. And I think [LNGO] underestimated the amount of effort they would have to put in, in thinking about that. I think they were thinking more a compatible thing or something that you wouldn’t be able to tell the difference. (Jim, ICTD researcher)

Thus the project reflects an over-emphasis on the technical aspects of implementing mPNC, and a relative neglect in addressing problems of information flows and local and organizational use, capacity, and repair.

The explicit bounding between the challenges of LNGO's organizational infrastructure and capacity and the mobile health project then afforded bounded, siloed evaluations of technological innovation and success. As one GNGO professional explained, "I think (mPNC) worked, it's just we didn't accomplish...everything we wanted to accomplish. And I think we have to look at it like that's different from their overall system having problems. We can't fix that, like we're not going to come in and fix LNGO. We can try to test our project." The perspective reflected here raises a question about what exactly is being tested in this project and what ontological boundaries emerge between the technological intervention and the organization. Here, the success of mPNC is being determined separately from the organizational challenges that the mobile health intervention aimed to improve. This reinforces ontological boundaries between technology as an intervention coming from outside and organization as an entity that can either make the technology work or not. Thus what is being tested is not simply the technology, but also the organizational capacity to make the project work. Organizational challenges that ICTD pilot projects face are easily dismissed as unique to that particular context and reflect on the organization rather than the merit of the ICTD project (Toyama, 2011). Granted, ICTD projects manage a tenuous balance between not wanting to disrupt an organizational system too much with a pilot project that has no guarantee of sustaining after the project funding ends and needing to reconfigure organizational arrangements enough to implement a technological intervention. Feasibility is often what gets measured across ICTD projects, referring to whether the success of the technology implementation is "possible," not whether it was necessarily accomplished, and certainly not whether it was sustained.⁶⁸ Often how

⁶⁸ In a review of reports and literature reviews for mHealth and Maternal Newborn Child Health

projects stop short of building organizational capacity and investing in organizational structuring while they are in the process of scaling up this metric.

Optimizing for Short-Term Solutions

ICTD pilot projects are mostly short term and often proposal-driven, with funding for doing a particular implementation with no assurance of what funding or resources might be available in the future. Noting the implications of this project structure, a senior ICTD researcher explained,

That means you've got to aim for some pretty short term things...I think that leads to the projects being structured in a way that...maximizes the use of those limited initial funds, but doesn't do the best optimization overall if the project were to really go forward. And so you end up in these bad local minima...It's like, yeah, that was the right way to do that if that's all there was, but if we knew that this other thing was coming down...

The investment in organizational change and capacity building is often beyond the scope of ICTD projects aiming to design and test technologies in the field. Thus the structure of ICTD pilot projects tends to lead to “bad local minima,” in which technology is optimized for short term solutions that rarely extend technological innovation into solutions for the sustainability that would require a wider scope of organizational structuring.

On a global scale, pilot projects in the ICTD arena are notorious for their high failure rate. Many call the phenomena “pilotitis,” referring to the “NGO graveyard of pilot projects” in developing countries that never make it to scale or that burn out at the end of the project funding cycle. There were concerns voiced early on in the India mHealth project about not wanting to be the project that “shows up, tries something, runs away...or puts something in place and then just

(MNCH), a gap was found in evidence that mHealth improves health outcomes, either primarily or secondarily. The authors found that the reports and reviews used indicators such as feasibility, usability, acceptability, return visits, and appointments, but did not offer further evidence for how any of these measurements were linked to improved health (Tamrat & Kachnowski, 2012)

leaves.” One GNGO professional referred to the phenomenon as the *orphan model*, where “you hand it off to whoever is there, in our case LNGO, and you walk away and who knows what happens to that. Yes, you orphan it, and that’s the model that most of our systems operate under.”

Although there was an impressive amount of reflexivity and capacity for self-critique among design team members, practical realities often shaped how projects were accomplished. As the India mHealth project continued through a series of breakdowns in the field and office, the ICTD researchers and GNGO professionals began to recognize the scope of organizational restructuring and repair that was necessary to sustain mPNC. The exit strategy for the India mHealth project became complicated, as it often does for ICTD projects, when the ICTD design team meets their local minima in terms of testing feasibility and learning what does and doesn’t work. Once GNGO and the University pull out as project stakeholders, there is no one to sustain the project. As one GNGO professional questioned, “Who is available to pick up the phone and do technical support, and be there for the implementation? And who can stay with the project beyond the year that LNGO takes a project for funding?” Consequently, there is no one to do the repair and restoration work that is essential for sustaining any innovation through ongoing breakdowns and adjustments. As one GNGO professional noted, the absence of organizational capacity on the ground to sustain mobile health has left “a complete vacuum...so that even if we create the perfect product, there is nobody to take it and run with it.” In other words, even with the right technology, these mHealth projects tend to hone around a local minima. This suggests that the high failure rate of mHealth pilot projects may have more to do with the repair ecology around such technologies than the design of the technologies themselves.

A Compromise between Research and Impact

Within the ICTD design team, there were also multiple local minima as the team advanced dual goals of developing a technology that positively impacts the organization and studying the impact of technology based on a research agenda. Throughout the project there were multiple times when intervening organizationally conflicted with the experimental conditions set up to test the impact of the technology. This reflects a tension between technology development and research. Technology development would aim to tightly couple knowledge production with an iterative process of development, working to fix and mitigate problems as soon as possible. The structure of research studies often distance these processes, creating cycles of knowledge production that may not feed back into the product development on that project. For example, as one ICTD researcher noted, without the structure of a research study on this project, they could observe and measure things without worrying about it being statistically significant. He gave the example of being able to simply observe and work with the midwives using mPNC and see, as he said, “Oh, nobody is using the respiratory rate counter, let’s go out and find why out—is it a training issue, is it whatever. And use the data that way, to look at trends.” Similarly, a GNGO professional noted that if this were product development outside of the University, there would be more iteration because “in the real world you can’t cause that kind of pain to a user.” The expectation that the project data would be used in a lab context or research setting for discovery influenced how the project was designed and implemented, requiring more controlled and rigorous protocols. Within the ICTD design team, the expectations to produce knowledge and discovery through statistically powered data were in tension with the expectations to produce knowledge and action based on evidence around the impact of a technical intervention. Thus the project represented a compromise between these expectations.

Thus, mPNC was entangled within multiple contexts of stakeholder groups, each in practice engaging with different materialities and negotiating different expectations. This meant that whether the project was deemed successful by funders, groups continued to engage with materialities that produced intended and unintended consequences. In this case, for the ICTD design team, the knowledge and experience accumulated through this project spawned several follow-on projects, including an educational video project, an mHealth project incorporating the respiratory rate counters, and a project looking at the problem of falsified data. The open source code of the software allows for others to develop further on a capability or feature, customizing it for a particular problem. In the context of GNGO, the project also becomes part of building evidence for mobile health and for attracting future funding. Another GNGO professional explained how mPNC has “become a marketing piece” throughout the organization, showcasing their work on mobile health. Similar to Pinch’s (1993) analysis of testing a clinical budgeting system for the NHS that appeared a failure but then was touted as success, what many would have deemed a failed pilot project, when refracted through political interests and social negotiation emerges a success. Thus, “what is at issue in such tests is not so much the projection from ‘test’ to ‘actual use’ of the machine, but the projection from test to actual use of the user!” (Pinch, 1993, p. 33). Spun as a success across GNGO, the mobile health platform presented as “a broad and vague concept” became “all things to all people.” In this silo, India mHealth mattered less for particular project outcomes and much more for the project simply taking place and for being able to claim experience in mHealth. MHealth, in this case and across many others, embodies the promise of generativity for users, a platform for endless innovation, rather than a particular innovation in use.

Conclusion

I have demonstrated the differences in the processes of technologically occasioned organizational structuring by comparing processes of organizational alignment and intermediary labor across both cases. Now I can argue that differences in processes of organizational alignment between reinforcing and redrawing professional boundaries, and differences in the role of intermediary labor in translation of digital health data for clinical and administrative sensemaking, patient engagement, and algorithmic calibration, are essential in making the support of polyvalent data possible in the U.S. Telehealth case and, conversely, not possible in India mHealth. Further, although both projects were discontinued, in the U.S. Telehealth case, the co-evolution of technological and organizational structures, fueled by a virtuous cycle of breakdown and repair, generated a technological residue within organizational practices and structures in the aftermath of the project. In India mHealth, minimal organizational structuring and therefore negligible co-evolution occurred, such that mPNC breakdowns were mostly left without repair as project expectations fragmented, leaving an aftermath characterized by multiple local minima within siloes of sensemaking. This matters because it suggests that the emphasis on technological innovation in digital health in design, use, and evaluation overlooks essential organizational and communicative dimensions of informationalizing healthcare. It suggests expanding beyond measures of success and failure to see how technological innovation extends into and constitutes a wider network of organizational practice.

Chapter 6

Conclusion

The ends of information, after all, are human ends. The logic of information must ultimately be the logic of humanity. For all information's independence and extent, it is people, in their communities, organizations, and institutions, who ultimately decide what it all means and why it matters.

—Brown and Duguid (2000)

The informational mode of development, as these chapters have demonstrated, takes many forms, yet they are all “oriented towards technological development, that is, toward the accumulation of knowledge and higher levels of complexity in information processing” (Castells, 2000, p. 17). The rise of digital health and its processes of informationalization raise questions about whether medicine will be reduced to an information science and healthcare to information delivery, with technology as the delivery system. This line of questioning tends to pit against one another the art and science of medicine, on one hand, and human and algorithmic knowledge on the other.⁶⁹ These discourses capture both our hopes and fears about the informationalization of healthcare, but they do not provide terribly helpful discursive frames for moving forward and solving the complex, entrenched problems in healthcare that we face today. Brown and Duguid (2000) note, “The way forward is paradoxically to look not ahead, but to look around” (p. 8). My research aims forward by looking around the present at the often overlooked ways in which art and science, humans and algorithms, technology and organization are already intertwined and entangled in practice. In their extreme, these questions are easy to dismiss, as there are always aspects of healthcare and medicine that would seem to escape these boundaries. Yet when framed in terms of how much, when, to what extent, in what context, and for what purposes, they

⁶⁹See “The Robot Will See You Now” (Cohn, 2013), among many others.

become the central and consequential questions for shaping the future of digital health. Further, by examining these negotiations across diverse digital health contexts—consumer health and rural health in U.S. and India, from primary care to chronic disease management to wellness—I have shown what is at stake with these questions across different communities and generated conceptual frameworks and communicative bridges that can lead us forward.

In just the three years that I have been closely studying these trends in the health arena, major policy, technological, social, and institutional changes have begun to take shape around emergent interstitial interactions. Indeed, the cases of U.S. Telehealth and India mHealth represent two pilot projects within data-intensive transformations that are in their infancy in many ways. Thus it becomes critical to attend to the dynamic discursive contexts for healthcare and technology across the four field sites in order to understand data-intensive transformations in health. Chapter Two begins with an introduction to the four field sites as discursive contexts for the relationship of technology and health across the U.S. and India. I articulate these discursive contexts around health care and technology innovation, health care information, and the organizational arrangements for health and technology in order to map the distinctions and overlaps between them. Understanding the processes of informationalization across the field sites requires engaging with the discursive contexts that are shaping at a macro-level the ways in which digital health materializes across the sites. Establishing this context-rich lens enables the subsequent comparative analyses of the discourses, practices, and structures of digital health innovation that I summarize next.

Chapter Three presents empirical and comparative discourse analysis of how the relationship of technology and social change is framed across different research contexts, drawing on key industry documents, gray literature, and stakeholder interview and observation

data. I take the technological imaginations advanced across the field of digital health to be reflective and constitutive of the sociotechnical relationships negotiated in the field. In other words, these discursive frames at a macro level are an important part of structuring the discursive, material, and relational emergence of digital health in practice. I argue that technological imaginations advanced across the field of digital health emerge around three primary themes characterizing technology-driven social change: institutional change, democratizing power, and redistributing labor. Having demonstrated the primacy and relevance of these themes across a wide range of digital health contexts, I then argue that the scripts and expectations advanced around these themes frame how digital health innovation in the field is approached in design, implementation, and evaluation, showing the gaps between what technology is imagined to do and what it actually does in practice.

What is at stake in the recursive loop of discourse, action, and structure is a negotiation process that represents and reproduces relational subject and object positions and the scripts of appropriate use and context of use. This matters for two reasons: First, these configurations and scripts continually reshape boundaries between categories of medical and non-medical, health and wellness, patient and consumer, and device and data; and second, these distinctions have important implications for how digital health functions in practice across communities. Chapter Three's analysis provides a partial look into the macro level discourses shaping the co-construction of digital health innovation design and use, but it also shows where we need to go. We need to examine how these discursive configurations and scripts are adapted, resisted, negotiated, and ultimately, materialized at a meso-level within and across different communities and stakeholders groups and, further, how practices and contexts of production and use around data challenge how technology functions across the digital health ecology.

In Chapter Four I examine these meso-level negotiations of digital health technology in practice through exploring a contradiction that emerged through my fieldwork: When different communities and stakeholder groups across the digital health ecology talk about and evoke data in practice, they are often talking about different things and expect data to perform differently socially, organizationally, and institutionally. Using the theoretical concept of data valence and a lens of mediation, I draw on ethnographic interview and observational data to present a comparative analysis of the discourses, practices, and challenges for data as it is mediated across social domains for digital health. Chapter Four's analysis demonstrates that data valence is an important theoretical concept. First, it helps us understand differences and gaps in communication about health and wellness data across communities within different social domains of digital health. Second, it advances a framework for identifying multiple, and conflicting, expectations and values for data across the digital health ecology. Across communities of digital health and wellness I identified the following social valences for data: actionability, self-evidence, accountability, truthiness, discovery, connection, and transparency. I argue that the multiple valences of health and wellness data become apparent at the intersection of the social domains of digital health, and that these distinct valences mediate technology in practice, point to tensions between institutions and stakeholders, and highlight the challenges for data to perform differently across multiple contexts of use and across social domains that maintain different expectations for data. As stakeholders try to link big data and small data across individual, clinical, and lab contexts, social interoperability becomes the greatest challenge. What they end up having to support is not just the interoperability of multiple ways of interpreting the meaning and validity of data, but they must negotiate the different expectations and sets of values around data as a discursive concept. Data valence presents a model for

identifying and understanding many of the challenges and tensions around the use and reuse of health and wellness data across communities and contexts, but questions remain about how processes of digital health technology design, use, and evaluation in particular networks and organizations adapt to these challenges and tensions, what processes of organizational structuring and types of labor support the management of multiple valences, and how digital health innovations materialize through across different processes on a micro level.

Chapter Five demonstrates the emergence and implications of different processes of technology-occasioned organizational adaptation through an in-depth, comparative case study analysis of two multi-stakeholder digital health technology pilot projects, U.S. Telehealth and India mHealth. Drawing from ethnographic observational and interview data, this chapter analyzes the co-constitutive relationship between technological and organizational change through integrating lenses of organizational alignment and intermediary labor and technology in practice. The goal is to understand what is organizationally required to facilitate sociotechnical interoperability and the management of multiple valences for digital health data across stakeholders and contexts, and to compare their implications for the project beyond narrow measures of success and failure. Demonstrating the differences in the processes of technologically occasioned organizational structuring by comparing processes of organizational alignment and intermediary labor across both cases allows me to argue that differences in processes of organizational alignment affect polyvalence.

These differences between reinforcing and redrawing professional boundary relations, and in the role of intermediary labor in translation of digital health data for clinical and administrative sensemaking, patient engagement, and algorithmic calibration, at one time support polyvalent data in the U.S. Telehealth case and hinder it in India mHealth. Furthermore, although

both projects were discontinued, for U.S. Telehealth, the co-evolution of technological and organizational structures, fueled by a virtuous cycle of breakdown and repair, generated a technological residue within organizational practices and structures. On the other hand, for India mHealth, minimal organizational structuring and therefore negligible co-evolution occurred, such that mPNC breakdowns were mostly left without repair as project expectations fragmented, leaving an aftermath characterized by multiple local minima within siloes of sensemaking. This matters because it suggests that the emphasis on technological innovation in digital health overlooks essential organizational and communicative dimensions of informationalizing healthcare and needs to be expanded beyond measures of success and failure to account for how technological innovation extends into and co-evolves with a wider network of organizational practice.

Taken together, the analyses in Chapters Two through Five reveal important insights into the social and organizational implications of digital health and into the ways communities, stakeholder groups, and organizations are participating in and adapting to data-intensive transformations in health and wellness across different contexts. This dissertation adopts a requisite interdisciplinary approach in order to engage the multi-dimensional, multi-sector systemic problems around ICTs and healthcare. As a result, this research speaks to conversations across multiple disciplines and communities of practice. The theoretical contributions will be of interest to a range of investigators: scholars of discourse, technology and organizing; researchers in the fields of ICTD, health communication, social informatics, human-computer interaction scholars; and ethnographers studying data-intensive fields and communities of big data. This project contributes to central questions in STS and communication technology research around the construction of “user” and “use,” both in the articulation of technology and context of use

across design, implementation, and evaluation and in the mutual constitution of technological and organizational change. Furthermore, this work is of great import for technology designers, policymakers, and planners in the field of digital health. Many of these insights and frameworks, while grounded in the field of health and wellness, are portable to other fields and communities undergoing data-intensive transformations. This work also has implications for technology designers across health and wellness and global development, and for any other arenas engaging in data-intensive technology design or the management of resulting data streams.

What We Gain from Bringing Communication Technology Theory to Data-Intensive Transformations

Across the technology-driven field of digital health, the appropriate uses for digital health technology are configured as technological fixes for solving problems of data access or increasing processing efficiency without attending fully to the problems of data as mediated communication. Thus the complexities of care, organizing, and communicative practice tend to get separated from information processing and exchange (Kallinikos, 2009). The entangled social and material lives of data get collapsed into a singular technological definition of data, obfuscating data multiplicity and the communicative structures and labor required to support polyvalence across social domains. This perspective at its worst forgets that information systems are social systems (Heeks, 2002b) and often frames ICTs as neutral and passive means delivering and transmitting information, tending to overlook qualities of data as mediated and embedded in a communication process and materiality. As such, a technology-driven approach to informationalizing healthcare can mistake informational efficiency for organizational efficiency or information access for care or communication. I have demonstrated that a communication technology theory lens on data-intensive transformations fills this gap and helps move beyond

productivist, information-driven approaches by attending to data as mediated communication and data-intensive technology as media technology.

This mediation and media technology lens allows us to attend to data-intensive technology as a sociomaterial assemblage of artifacts, practices, and social and institutional arrangements. This is hugely beneficial for studying data-intensive transformations in health because it allows us to situate information processing and data within materiality and within a range of complex care and communication practices, rather than keeping them separate. We can locate the sociomaterial agencies of computation through examining the affordances and constraints within the interpenetrated artifact and content as well as within a communication process. As we have seen with digital health innovation, the greatest challenges are associated with the frictions generated in moving data across multiple contexts of use and reuse and the negotiation of multiple data valences across social domains. A mediation lens allowed for taking into account a multi-valenced, multi-dimensional view of data as the site for multiple material and interpretive practices. Without expanding our view of co-configuration of technology and use to include the sociomaterial agencies of computation as they are entangled in communication processes, the multiple social and material lives of data and their associated practices, communities, and networks would be overlooked.

Through this mediation lens, I was able to theorize the data valence concept, which provides an important step in expanding our view of data as mediated communication to include multiple material and social enactments. Through this we can understand the different expectations and values for data across multiple communities and contexts, just as we understand data's communicative frictions as part of the co-configuration processes of digital health technology. In keeping a view of data emerging from communication media and embedded in a

communication process, this lens reveals generative sites and occasions for communication. For communication technology scholars, data-intensive practices can sharpen our view of the materiality of communication as it is entangled in logics of computation. This raises questions for communication technology theory about how computational logics in our increasingly technologically mediated society are shaping not just what and how we communicate, but the basis for our communicative practice (Gillespie, 2014; Kallinikos, 2009).

In particular, data valence helps us articulate frictions without losing sight of the power differentials among communities. This work demonstrated that the ability to shape technological innovation is, in part, about the capacity to negotiate among valences within and across communities. We observed across communities that certain valences are privileged over others due to the matrix of power relations. The capacity to articulate valences within communities and negotiate among valences across communities was key for explaining why some communities were able to innovate and others are not. Data valence, then, opens up a way to articulate and make visible the important role of power relationships within data-intensive transformations. It in productive ways. This suggests that technology design approaches, such as user-centered design, that focus on the individual and how they engage material affordances in their use of a technology may fall short of accounting for these power relationships. This is especially true in considering the design of data-intensive technology, in which the technology is co-configured across multiple contexts of use. Creating technology around an individual or persona, as user-centered design approaches often do, mutes the possible valences that would emerge as data moves across contexts.

Expanding Co-Configuration

My research shows that expanded models for conceptualizing use and user to end users and proximate users are helpful in accounting for the power relations and distributed nature of work in healthcare. For instance, the notion of the “implicated actor” is important in explaining how the midwives and patients were configured in the development of mPNC in the India mHealth case. The gendered spaces of male-dominated technology development and female-dominated care that I occupied mattered in this process across my research contexts, yet gender was one of many distinctions that distanced development and users. In a very concrete way, I experienced this on the India mHealth project, when my gender became an asset to a male-dominated project. As a female in that cultural context I could connect, communicate, and access midwives and mothers in ways that the male project stakeholders could not. When shadowing the midwives on their postnatal care visits, as a woman I was able to enter the intimate domestic home spaces of women who had just delivered, something that would have been culturally inappropriate for men.

The conceptions of end users and proximate users begin to help us expand our view of co-configuration to different groups downstream or peripheral from the human computer interaction. At the same time, they don't fully capture the multiplicities of data performances that escape an “end user” definition, some of which take the user completely out of the loop. Nor do they help us conceptualize the role of inadvertent co-production and generativity through various activities that are outside the frame of use but connected through a pervasively mediated environment. The lives of data multiply across convergent user experiences, technologies, and industries and through anticipated and unanticipated generative data production (Yoo et al. 2012). What happens to the processes of configuring appropriate use and the context of use when data production and processing occur across multiple contexts of use that hold different

expectations for the role of data, what data will do, and how it will be used? Bringing communication technology theory to data-intensive technology expands the view of co-configuration to include the increasingly networked, diverse, and multiple enactments of digital health technology. This includes the ways in which the entangled social and material lives of data extend across multiplying contexts of use, user identities, and appropriate use. Even so, how can we conceptualize the unanticipated data multiplicity as it binds with other data in a process of aggregation to be either repackaged back to the user or to shape other unknown contexts of use? As Gitelman and Jackson (2013) point out, the word *data* itself is an “odd suspension” between the singular, mass noun and the plural that reminds us that “data are aggregative,” that they are always “relational, based on potential connections” (p. 8).

Data valences provide a first step in expanding our view of co-configuration to include the multiple material and social lives of data and explain how digital health innovation materializes differently across multiple contexts and communities possessing different values and expectations for data. While the data valence framework presented here is grounded in communities of health and wellness, I suggest that this framework is portable to other data-intensive fields in which multiple communities or organizations share and produce data across social, organizational, and institutional contexts. This work suggests expanding our explanatory framework for co-configuration of technology and use to consider a range networks, communities, cultures, and practices of data in process over a longer period of time.

As a bundle of material and symbolic agencies, media technology in practice includes the ongoing reconfigurations of agencies and that different agencies may be activated or materialize across different interactions and contexts. This multiplicity of data performances is not just an outcome of the transforming digital health ecology; it is an integral component of design, use,

and evaluation. My research affirms the necessity of an expanded view of co-configuration of technology and use; it also suggests that we apply a communication technology theory lens to studying the nature of data-intensive transformations. These lenses help us answer the important questions of data—for whom, when, and for what purpose—and help us show how these answers matter in shaping processes of design, use, and evaluation.

Convergence and Generativity

My research has important implications for scholars of technology and organizing, and in organizational communication more generally. Healthcare is one of many sectors undergoing huge technological and data-intensive transformations. Organization and communication technology scholars are increasingly interested in the emergence of new organizational arrangements and the mutually constituted processes of technological and organizational change in relation to data-intensive transformations across industries, along with the implications for how we collaborate and communicate. Characterized by convergence and generativity, organizational innovation with digital technologies point to new orientations and relationships of organizational and technological time and space (Yoo et al., 2012). My research contributes to deepening our understanding of the nature of organizational and technological change in relation to convergence and generativity.

Thickening Data Flows

In media studies, convergence is a term used to describe “the flow of content across multiple media platforms, the cooperation between multiple media industries, and the migratory behavior of media audiences” (Jenkins, 2006, p. 2). Thus, convergence here is more than technological; it is industrial, organizational, cultural, and social. In the context of digital health, convergence emerged most predominantly as technology-driven phenomena, with the

anticipation that the other interconnected layers of convergence would follow suit. The technological links affording flows of data across stakeholders and contexts did not automatically lead to organizational convergence; rather, in many cases those links generated friction for data flows or simply didn't flow at all. My analysis in the digital health sphere contributes not only a portable data valence framework for conceptualizing many of these different expectations for data, along with a way to map the tensions among stakeholders. Also, and importantly, it reveals how different forms of intermediary labor and organizational alignment processes co-configure digital health innovation.

That these co-configuring processes matter for digital health innovation appears to be a simple assertion. Yet across the current climate of digital health, it is evident that often, to varying degrees, digital health technology is expected to stand in for, generate, or supplant the need for communication, intermediary labor, and organizational structuring. As technology converges between consumer ICTs and medical technologies, user-centered (consumer) research and design tends to get privileged over a system-oriented design (Oudshoorn et al., 2004; Von Hippel, 2006). This can lead to overlooking relationships of power within organizational settings and thereby missing the organizational structuring and innovation that are necessary to explain the co-configuration of technology and use and that are important considerations for guiding processes of design and innovation.

Technological convergence in digital health challenges organizational structures to support polyvalent data across different domains and contexts. This requires more than a simple translation around data; instead it requires a translation that extends beyond interpreting and conveying the meaning of the particular data values across different expectations for the data's role and performance in particular social, institutional, and organizational contexts. I identify the

essential role of information, articulation, and repair labor in making data flow across multiple contexts of use. This intermediary labor, otherwise invisible from dominant discourses of convergence, thickens our view of data flows and situates the labor and flows in particular places and political economies.

Organizational Changes as the Residue of Technological Projects

In relation to generativity, my more nuanced examination of digital innovation in organization emphasizes multiple materialities and an extended view of the innovation lifecycle. In the U.S. Telehealth project, a technological residue materialized in the aftermath, continuing to influence organizational structures and practice even in the absence of the once-inextricable material structures afforded by the technology. To understand this technological residue, it is helpful to think about materiality as “performed relations” (Latour, 2007; Orlikowski, 2007; Pickering, 1995). Looked at this way, we can see that the ontological boundary between the inside and outside of this technological innovation emerges iteratively through interaction. The boundary-making between technology and organization is not self-evident; rather it is a dynamic, relational ongoing configuration (Akrich, 1992; Suchman, 2007). Following the technological innovation and its ongoing reconfigurations over time and across space, across multiple occasions and sites, beyond its physical materiality, and outside its imposed configurations, the accomplishment of momentary boundary making continues to reveal itself. As Suchman (2007) notes, “It is about cutting the network in such a way that the line is enacted not given, where the cut is not a matter of aligning with some independently existing ontologies, but instead depends on our ability to articulate its basis and its implications” (p. 284). This digital innovation research shows that in both cases the discursively constructed ontologies, bounding technical

from organizational entities, conditioned what counted as technological innovation and what would be evaluated as its impact.

My analysis suggests that in the case of U.S. Telehealth, the formalized structures of medicine that evaluated the success of the Health@Home program pre-defined the boundaries of the technological innovation and its lifecycle too narrowly. Doing this caused them to overlook the co-evolution of the Health@Home with organizational structures and practice and its ongoing boundary making, as evidenced by a technological residue that continued to materialize even in the absence of the physical device. In the case of India mHealth, the discursive bounding of technology and organization from the beginning of the project shaped how the technology was designed and implemented in practice. Since the organizational structure and technological innovation did not co-evolve, the evaluation further deepened the separation and distinction between the entities. However, the aftermath of this project provided a way to understand how these distinctions materialized within different groups as local minima. My research highlights the omissions endemic to what Latour (1987) labels a “diffusionist’s perspective,” the common tendency to consider “that one particular segment of a program of action is the essence of an innovation, and that the others are merely context, packaging, history, or development” (Latour, 1991, p. 115).

The results of my study suggests that examining which distributions of work and responsibility across human and nonhuman actors function to *sustain* organization is a productive line of inquiry (Jackson, 2014). Occupying the aftermath of technological innovation allows for making visible the “dynamic and multiple forms of constitution” and the ongoing process of boundary making (Suchman, 2007, p. 268). My research suggests that to conceptualize digital health innovation (along with other digital innovations) within and across

organizations benefits from a view of materiality as performed relations and as the extension of the lifecycle of innovation. When conceptualizing technological innovation and organization, this view of materiality as performed relations helps deal with a particular challenge in studying digital innovations because it renders visible material relations beyond physical materialities, revealing how they are always sociomaterial, emergent, multiple, and dynamic. Performed relations materialize digital health technology as artifact and as media and thus help to more flexibly define the boundaries of technology-in-practice.

The boundaries of products and services may be unknowable and may remain incomplete throughout their lifetime, in intended and unintended ways (Garud, Jain, & Tuertscher, 2008; Neff & Stark, 2004). This may be particularly true with digital innovation through what Yoo et al. (2012) have described as *combinatorial innovation*, a kind of innovation that adds, morphs, and adapts new digital features and capabilities through the generativity afforded by digital technology. Combinatorial innovation was evident in two areas around the India mHealth project: Some mPNC features and the open source platform itself lived on to be recombined into different innovations for different purposes, and communities in the QS movement shared and recombined data capture, analysis, and visualization tools. Along with other scholars who have challenged the boundaries of design and use and called for an extended lifecycle of innovation (Von Hippel, 2006), Yoo et al.'s idea of combinatorial innovation calls for eschewing traditional bounded models of innovation that assume stable and fixed boundaries around a product or service, replacing them with the conceptualization of more dynamic and permeable product and service boundaries.

My research suggests the dynamic and permeable boundaries between digital innovation and organizational structures also deserve consideration, beyond digital recombining. This

expands the concept of the innovation lifecycle to include the multiple lives or lifecycles of data, and extends the innovation lifecycle into the aftermath. This helps us conceptualize technological residue in terms of the emergent, ongoing boundary making between digital innovation and organizational structures. This suggests that *organizational changes become the residue of technology projects* and provides an opportunity for scholars to further investigate and reframe the impacts of technology and the boundaries of innovation processes.

Sensemaking and Data-driven logic

Digital health innovation generates new categories of data instruments in medicine that aim to render computable bodies, patients, and populations and to codify labor and knowledge of the field. This technological imagination advances a virtuous cycle of data, computation, and technology function as the engine of knowledge production and institutional and behavioral change, thus redefining the healthcare system in technological terms. This data-driven mode of medicine relies on a constantly evolving predictive and personalized model of patient and population health and wellness, one that is sustained and advanced by the continuous generation of insights through seamlessly linking individual, lab, and clinical realms of data production. Bringing together data-intensive biomedicine and movements of participatory health and wellness, big and small data approaches are expected by many to generate a virtual *macroscope*, in which distributed data collection feeds into computing algorithms that discover and predict patterns and processes at a scale of complexity too great to perceive otherwise. This is at the heart of personalized medicine, where the expectation is that the more data that can be captured and processed on a macro level, the sharper the definition of a particular individual. Yet who owns this data, who will make sense of it, and who benefits from it remain open questions.

As our capacity for datafication through ubiquitous sensing and pervasive mobile tracking outpaces the generation of sensemaking structures, assumptions about more data being better, or more data providing a clearer picture, don't hold up. Without structures of sensemaking, simply providing more data can potentially obscure or mislead, and generating that data is not without cost. Scholars tend to treat algorithms as inclusive of their associated technology and databases, creating a discursively conjoined package (Gillespie, 2014), with no distinction made between data and the mechanism through which data are transformed. Without the databases, the algorithm is meaningless—yet data represent the stuff of reality, rendered for computation. As Manovich (1999) claims, “together, data structures and algorithms are two halves of the ontology of the world according to the computer” (p. 84). As humans render the world as computable data, the algorithms modeling and shaping this computable world are increasingly imagined as tools for sensemaking and as the data instruments with the power to reprogram our behavior, institutions, and knowledge. Such data instruments discursively collapse data and device, obfuscating the “double articulation” of media technology as object and media. As a result, this positions technology less as a mediator and medium between humans in a communication process and more as a tool for supplanting many of the interactions and mediations around data as it automatically gathers, processes and computes. This conflating of data and its technology collapses the steps of representation, interpretation, and communication around data.

There are many creative reconfigurations of human and nonhuman agencies as well as new types of labor generated to maintain functionality or sustain new relationships with algorithmic labor. Because of this, the roles of algorithms in digital health can shift between functioning to supplant data processes and to augment them. However, as algorithms are

designed to perform more and more of the interpretive work, we have to pay attention to what labor this displaces and what processes around data are obscured or made invisible. As we know, the introduction of new technologies in healthcare settings often heads toward redistribution rather than reduction of work, leading to new delegations of responsibility among professional groups (Cartwright, 2000; Mort et al., 2003).

Importantly, algorithmic labor, while performing interpretation, does not preclude the need for sensemaking work. As Mort and Smith (2009) suggest, knowledge and action in healthcare are often achieved in spite of, rather than as a result of an information system, as healthcare workers triangulate and rework information to make diagnoses and clinical decisions. Algorithms rest on categorization, and we know that any pre-existing categories drive political negotiations and interventions around what the categories mean, what is supposed to belong in them, and who, in practice, decides how to implement them; these adjustments constitute the proposed contours of an ecology of visible and invisible work (Bowker & Star, 1999). When labor is delegated to devices, it is problematic because it makes invisible all the work of operating the technologies (Oudshoorn, 2008). In the case studies presented in Chapter Five, I focus on the work of intermediaries. One of the things this focus accomplishes is to demonstrate and make visible the complexity of work around data-intensive communication and the messy interactions which many digital health technologies aim to supplant or collapse into a disintermediated human-to-machine or machine-to-machine interaction.

Observing intermediary use of algorithms in practice as they engage in a range of calibration practices makes the distinction between algorithmic interpretation and sensemaking a stark one.. We can see that multiple layers of intermediary labor are mostly invisible as intermediaries sensemake around algorithmic outputs and the process of algorithmic production

and interpretation itself. The study of intermediary labor across both case studies reveals that processes of sociotechnical calibration encompass layers of labor essential for the accomplishment of the work that goes into disintermediating digital health technologies in the consumer health realm. We need to rethink algorithms representing the codified knowledge and procedures, seeing them, instead, as supporting multi-vocal, contingent, and dynamic knowledge production in the context of healthcare clinical decision support.

Processes of sociotechnical calibration depend on the context of use and the expectations and values around data. The QS movement provides a fascinating site to extend thinking about forms of sociotechnical calibration. The QS movement uses the process of quantification to develop a language for the self; in other words, they informationalize the self. As with the intermediaries, it is typical for QS-ers to calibrate the outcomes and the methods of quantification themselves. As Nafus and Sherman (Forthcoming) point out, the practice of self-tracking can be understood as “soft resistance” to dominant structures of expertise and data, focusing on the n of 1 to confront the categories generated through large datasets. We can also see the processes through which they both internalize and resist these categories as a forms of sociotechnical calibration, in which “they traverse between what is inside and outside the body” (Nafus & Sherman, Forthcoming). A glance at some of the forum topics and show-and-tell talks reveals a continuous thread of critique of metrics or device that didn’t quite capture the rich life experience of the individual. Many of these user-innovators resorted to some kind of hack or workaround (perhaps a story) that allowed them to calibrate self-tracking and self-knowledge.

With its “big tent policy” (Nafus & Sherman, Forthcoming), QS includes a diversity of interests and individuals engaging in different types of tracking and calibration. A debate within the QS movement (as well as in the broader realm of consumer health and wellness) centers

around the advantages of active versus passive tracking. This raises interesting tensions around the work of sociotechnical calibration and how and for whom questions become relevant, and for what purpose. On the side of passive tracking, stakeholders see the primary barrier to widespread self-quantification being that people don't want to have to do the work or couldn't be trusted to do the work of gathering, scrubbing, and interpreting their data. This view celebrates the advancements in passive tracking as sensors become increasingly connected, miniaturized, and ubiquitous as part of what has been termed "the Internet of things," collecting and interpreting data on people without requiring their active participation (or calibration). This passive approach is promoted as generating more "objective" and accurate data, data that can serve as a site for building evidence or "truthiness,"—accountability, in terms of patient compliance, for instance, or discovery—as many across the QS hoped more scientifically rigorous self-experimentation could bring.

On the other side of the tracking debate are those who advocate active tracking as the path to real behavior change and self-knowledge. These people believe that the act of tracking itself is what is transformative. The close attention to and traversing between metrics and the self provides feedback in the moment and generates in situ self-awareness and, ultimately, self-knowledge.⁷⁰ From this view, the accuracy of the data points is not as important as their calibrated relationship to the self and the practice of self-tracking. Consequently, it is essential from this view that people actively participate in making and tracking their own data through a process of sociotechnical calibration in which metrics and the device were tailored to the individual situation. This active approach is often talked about more in terms of data practices

⁷⁰ See Nafus and Sherman (Forthcoming) for an extensive discussion of a similar observation of the role of manual tracking in QS.

that evoke the valence of connection, discovery, and actionability in a meaningful way for the individual. Of course, the lines of this debate aren't as neatly drawn as I have presented them here. What I am illustrating is that embedded in these debates within the QS, and in the realm of self-tracking more broadly, is an overlooked process of sociotechnical calibration on multiple levels of data mediation and interpretation that is expected to accomplish different things in different contexts.

As Gillespie (2014) notes of algorithms' entanglement in social practice, it is a "recursive loop between the calculations of the algorithm and the 'calculations' of people" (p. 183). Thus fundamental questions remain about how much context can be represented as information, and thus be computable, and to what extent contextual calibration work can be encoded into algorithms. One must examine these algorithms closely to understand how they were made, how they work, and whom they benefit. Are the algorithms imagined as scripts, as "sufficient approximations," or as resources for action? Does the algorithm in practice support multi-vocality, flexible work, or soft resistance? These questions are at the heart of negotiating the relationship of sensemaking and data-driven logic and the ways responsibility is delegated across human and technical actors.

Design and Policy Implications

This work has important implications for digital health technology designers and policy makers. In particular, the concept of data valence can be applied in the context of design and policy to both identify the design opportunities and challenges for data-intensive technology and the management of resulting data streams. This includes using the framework to identify at once what expectations and values for data exist within particular communities and also the power relationships that shape the negotiation of those valences. The framework may also be applied in

inscribing particular values and expectations across communities into the design of the technology and in considering the power differentials and labor of translation in the design of the organizational structures for managing resulting data streams.

The data valence framework allows us to map tensions between the terms and consequences of *actionability* between clinical and non-clinical contexts. As demonstrated in Chapter Four, the predominant usage script applied in a technology design community reflects a data valence of actionability; in other words, data leads to knowledge, which leads to change. Yet I found that much of what people and communities do with data and how people talk about data doesn't fit the narrow scope of actionability; rather their practices suggest that there are many other competing expectations for data, especially as it travels across domains. The findings from studying multiple communities suggest that digital health design and planning processes could benefit from considering data valences evoked through multiple practices with, through, and around data as a way to open up a wider range expectations and values shaping its use. Working against the prevalent information determinism in the current climate, designers and planners should work to bring back into the picture the communicative aspects of information. Thinking beyond the human-technology interaction to what people do with data and to how people negotiate, share, and dismiss meanings is important. Further, to make data actionable is to account for the organizational and institutional contexts in which the data will perform. This includes the power relationships that frame the capacity for different communities to articulate and negotiate among multiple valences. Often people refer to "actionable data" as if actionability were a property of the data themselves, rather than a valence that is variable, emergent, and relational across different contexts.

An example of the challenges for actionability in the context of mHealth programs around maternal and child health in India is the way behavior change messaging confronts powerful cultural norms based in rich history, experience, and social meaning. My experiences during the postnatal care visits brought the tenuous connection between information and actionability into sharp relief, highlighting the clash of technology and culture. I realized quickly that much of the diagnostic and health promotion information that midwives could provide for mothers and infants did not lead to the intended actions. For instance, with the anemia screening test midwives can diagnose severe anemia and then refer mothers to the hospital in the city for a blood transfusion. In practice, however, that diagnosis is mostly not something that can be acted upon. People in the villages believe hospital care is not worth the expense and that they won't receive good treatment based on their socioeconomic position. Further, there is not usually a family member who can donate blood. These circumstances all contribute to make potential actionability after diagnosis a moot point.

In other cases, diagnostic information is actionable in the most horrific and unintended ways. For example, the spread of access to prenatal ultrasounds in this area in the mid-1980s resulted in an increase in sex-selective abortions (Arnold, Kishor, & Roy, 2002). The partiality for males over females in this culture shapes actionability in various ways, from having sex-selective abortions to decisions about how to care for and feed living female children (Arnold et al., 2002; Hesketh & Xing, 2006). In one instance, as we walked out of a postnatal care home visit with a family who against the midwife's counsel refused to take their deathly ill infant girl to the hospital, the midwife said to me, "If the baby had been a boy, they would have gone to the hospital." The relationship of information and cultural norms is not self-evident, yet I'd argue that technology that rubs right up against these norms has less the power to inspire action and

more to occasion the kind of talk that may negotiate frictions among experiences and forms of expertise. As Atul Gawande (2013) writes in his article on slow ideas, “We yearn for frictionless, technological solutions. But people talking to people is still the way that norms and standards change.” I couldn’t agree more.

In the U.S., the digital health apparatus is being leveraged around different ideas of health and wellness through promoting lifestyle and cultural norms around what constitutes health and wellness (Lupton, 2012). Out of the metricization of health and wellness emerges shifts of personal responsibility for achieving healthy lifestyles. Metrics define that responsibility as belonging to individual consumers, configuring the ideal “digitally engaged patient” (Lupton, 2013a), and in the process overlooking many of the structural inequalities that this model reproduces (Lupton, 2012; Nettleton & Burrows, 2003). Within the market logics underpinning formalized healthcare in the U.S. and India, there is a tendency to overlook the power of data as sites of conversation and *connection* among peer networks, intermediaries, clinicians, and the self. This which appears to yield little cost savings and further strain human resources when compared to a valence of actionability. Yet an abundance of research has demonstrated that conversations and trusted relationships with providers or intermediaries are one of the most influential factors in making healthcare decisions and motivating behavior change (Charon, 2001). I argue that much more opportunity lies in embracing how data-intensive technologies can support the important conversations and connections that can lead to transformative change on individual, community, and institutional levels.

Much of the pertinent academic literature and popular discourse discusses U.S. physicians as part of the institutional resistance to digital health and frames them as barriers to the adoption of digital health technology (Cerrato, 2012). Rarely does this frame do justice to the

contexts in which physicians would choose to adopt digital health tools; nor does it take into account the consequences they might encounter for adopting those tools given current health financing and incentive models. Physicians are key stakeholders in the future shaping of digital health, and while they themselves may not need to be primary users of digital health technology and associated data, they need to be bought in to new programs from the beginning so that they can inform expectations for and practices around data. In order to make patient-generated data count in clinical settings, we need to be thinking beyond physician's resistance to the broader institutional and organizational barriers. The ACA is shifting financial compensation schemes from fee-for-service models to annual fee models in order to incentivize wellness-oriented care. However, this still doesn't address many of the other issues around physicians engaging with patient-generated data. For instance, it takes resources to engage with such data, and physicians are not compensated for that time. The increased risk and liability around patient-generated data for physicians is also an issue that hasn't yet been addressed. In the current environment, intermediary roles are likely to emerge in the extramedical sphere to manage and mine this data, along with new models of physician engagement that cater to actionability at the point of care.

Negotiating Innovation and Regulation

Consumer health technology design is often approached based on a narrowly scoped form of context, focusing on technical innovations whose use is circumscribed within a nonclinical individual health and wellness context. As part of a trend toward user-centered design (Oudshoorn et al., 2004), this level of scope often doesn't account or design for interactions with healthcare providers, institutions, or the broader network of sensemaking around health and wellness data. This neglect is in part driven by market and regulatory forces that make it more technically complex, and therefore more time-consuming and expensive, to design at the

interstices of consumers and healthcare institutions. We also see how, in practice, the discursive blurring of distinctions between medical and non-medical and between patient and consumer, is, in some cases, generating new subject positions and interstitial interactions and sites for innovation. Discourses in the India consumer health and ICTD contexts emphasize more consumption-oriented transformations, in which medical data and clinical expertise are consumed outside of clinical settings or traditionally medical sources. This discourse has expanded spaces of demedicalization, generating more sites for intermediary-based care and self-care through digital health technology, in many ways reflecting and reshaping an already vast and vibrant informal healthcare ecology. If no concern is shown for regulating medical devices or for this already vibrant consumer-oriented and informal healthcare ecology, the blurred distinctions promoted through digital health discourse blend well with previously established subject positions, interactions, and sites. However, the emphasis on production-oriented transformations that require consumer data to travel into clinical settings is less common, though it may be gaining ground with new mobile apps that track chronic disease related metrics (see, for example, Uchek app). The ICTD context has mostly produced information for administrative and research ends and has not been very successful at packaging valuable information back to patients and local organizations.

Discourses prevalent in the U.S. consumer health context emphasize prosumption-oriented transformations, in which medical and consumer data would travel to non-medical and clinical settings, respectively. In practice, however, this data mobility and its associated values were not supported by communication infrastructures mobilizing consumer data in the clinical realm. The explosion of consumer-oriented sensing technology outpaced any institutional sensemaking of patient- or consumer-generated data in the consumer realm. Further, different

data valences made it very difficult for data to perform differently and generate value across contexts. However, the Medicare Telehealth study presented a successful example of how River Medical first supported patient engagement and then made institutional sensemaking of the home-collected patient data possible as health and medical data. This did not happen on its own; rather, it required organizational structuring and intermediary labor to support polyvalent data across stakeholder communities. Medical data produced in the consumer realm faced regulatory challenges as U.S. government bodies aimed to regulate medical devices, including medical interpretation or diagnosis, through FDA approval and regulate medical information through HIPAA. Without FDA approval and HIPAA compliance, what could occur in these new non-clinical sites and interactions was restricted, and the types of self-care available, and the production of medical data via digital health technologies, were narrowed. Various forms of intermediation, such as care managers, nurses, and genetics counselors, expanded to provide the communicative link between home and clinic and to translate between medical and individual contexts.

Thus innovations in these non-clinical spaces tend toward two paths: In order to count in both settings, they can go the route of seeking approval from regulatory bodies in order to afford interoperability between clinical and non-clinical settings. Alternately, they can take the path of focusing on wellness and prevention-oriented measures and interventions that skirt medical jurisdiction by a hair. In the latter case, the metrics around fitness, diet, wellbeing, and interventions may provide data without complete medical interpretation or present disclaimers that the information is “not for medical advice.” This shaky bridging of the divide between official medical information and self-help begins to challenge the boundaries of health and wellness. We have seen wellness metrics and interventions explode in this interstitial

medical/non-medical space, along with healthcare policies that promote health through prevention and through the medicalization of lifestyle and wellbeing outside of the clinic rather than through episodic clinical encounters and disease treatment.

With my seemingly disparate research contexts that cross the developed and developing world and traverse from high tech to low tech, what resonates across them all is a negotiation of emergent extramedical interactions around technological convergence, where clinic meets home, medical technology meets consumer ICTs, and health meets wellness. One sees this most emblematically captured in the idea of the “smartphone physical,” encompassing as it does a range of technologies, from mobile pulse-oximeters to mobile heart rate monitors to mobile urinalysis, that traverse between developing and developed world settings. Consider the journey of a mobile urinalysis app developed by a startup in India that transforms the mobile phone into a lab. The mobile app with accessories uses urine test strips and a camera phone that can analyze test strip colors compared to a color-coded mat on which the strip is placed. The app claims to analyze over 10 different parameters including glucose, Bilirubin, Ketone, Specific Gravity, pH, and Protein, to name a few. The use scenarios for this app are multiple. The first category of use is for at-home urinalysis for an urban Indian population increasingly burdened with self-managing chronic disease. The second category of use is in clinics and labs, too small to afford the gold standard auto analyzers, which serve Indian populations who lack access to healthcare. The startup that developed the urinalysis app also attempted to enter a U.S. context of consumer health and wellness by releasing a downloadable iPhone app for the U.S. population. They were initially stymied by a warning letter from the FDA explaining that they would need to seek class II medical device approval. At the same time, a group of futurists in Silicon Valley designed a similar urinalysis device called Scanaflo for consumers to self-manage and self-diagnose at

home. For this device they are undergoing a required approval process in which the FDA seeks to regulate, not the data itself, but the medical interpretation of the data. I bring up this app not to discuss its actual use, but because it points out the multiple imaginations for these convergent technologies across very different institutional contexts with different regulatory frameworks and motivated by different healthcare problems

The Roles for Ethnographic Practice in Data-Intensive Communities

As industries and disciplines become increasingly data-intensive, multi-stakeholder partnerships and collaborations around data will be dominant as an organizational form. Thus my discussion of the role for ethnography in these specific multi-stakeholder partnerships and projects as well as multiple communities of practice engaged in a digital health data ecology in fact addresses more than the situations in this dissertation. The dynamics at stake for the role of ethnographic practice applies more broadly across many sectors undergoing data-intensive transformations and engaging across stakeholders and contexts around data.

What is the role for qualitative methods and ethnographic practice in this increasingly computationally driven society? Somewhere in the middle of the hype and hope for so-called big data are the communities and organizations and practices that mediate the production, sharing, aggregation, processing, and consumption of these data. In these processes and relationships of mediation lie necessary and important opportunities for ethnographers to engage with data-intensive endeavors. Big data and small data operate on macro and micro scales that are imperceptible at a human scale and often disembodied from an understanding of context and experience. Nonetheless they are powerful tools that generate that which is otherwise unseen, an emergent pattern, extending our senses in a particular way. This is the grand promise of discovery associated with both personalized and big data analytics. Ironically, given the

computationally driven approach to knowledge, it also sounds a lot like the role of ethnographic practice in its charge to attend to rhythms, sounds, and relationships that are otherwise unarticulated. This follows Gray's (2011) suggestion that ethnographic practice *is* a kind of big data analysis. This view allows us to think about ethnographic practice as time-lapse and quantitative methods as a snapshot. Time-lapse stitches together snapshots, changing the time scale to elicit patterns and rhythms we would otherwise not detect. As ethnographers we do time-lapse in two senses: We stitch together frames into a crafted story in time, and we play with and manipulate time-space or context in order to reveal the most essential and relevant patterns, aberrations, and insights. We live and breathe in the context, and context is infinite, which is why defining and bounding a field site is such a powerful analytical assertion. It orients the frame of our time-lapse.

It is important to understand relationships at multiple scales in order to make the abstracted correlations so easily generated through big data analytics more meaningful and more connected to the realities on the ground. Conversely, through a practice of "ethnographic looping" (Fortun, 2012), substantive logics derived from fieldwork supplement design logics. In other words, insights from the field can condition and shape the computational modes of inquiry and the design of systems and technology used in the field to elicit emergent new forms through reactions, practices, and consequences, and then cycle that learning back to inform deeper ethnographic understanding:

Ethnography...can be designed to bring forth a future anterior that is not calculable from what we now know, a future that surprises. Ethnography thus becomes creative, producing something that didn't exist before. Something beyond codified expert formulas... The future is anteriorized when the past is folded into the way reality presents itself, setting up both the structures and the obligations of the future (Fortun, 2012, p. 450).

Ethnographic practice can provide the qualitative, experiential, contextual dimensions of microscopic and macroscopic views of data as well as create the links from the present to the possible futures associated with these views.

My ethnographic work within multiple stakeholder communities around data-intensive health and wellness revealed these important differences in how data itself was imagined, discussed, and valued, providing a necessary “thick data“ (Wang, 2013) layer to big data inquiry. As ways of generating “truth” or ways of knowing become increasingly computationally driven, ethnographers are well-positioned to develop means of translation across different cultural groups and stakeholder communities. Through observation and engagement in questions around what data are valuable, when, to whom, and for what purpose, ethnographers can work with communities to generate alternative and complementary metrics, numeracies and hypotheses that support multiple data valences.

An ethnographic approach can also help us understand the sociotechnical mediation of data-intensive knowledge production, and what is required in terms of organizational and information labor and infrastructure to facilitate meaningful and productive collaborations and enable a contextual approach to data-driven discovery. As increasingly data-intensive industries and stakeholder communities confront the challenges of big data (cf. boyd & Crawford, 2012; Neff, 2013), ethnography and qualitative methods should be essential parts of not only shaping the sensemaking processes of big data, but also defining the questions and problems themselves. But to do this ethnographic and statistical significance have to be valued (Gray, 2011).

There is also a great opportunity for ethnographers to support design and communication of data back to the communities in which they work. Across many organizational stakeholders in digital health across all research contexts people didn't know what to do with the data they had.

A subset of those stakeholders were interested in doing something with the data, reusing it and repackaging it back to the communities of patients or consumers but didn't know what would be valuable or how to do it. These problems are not the ones you hear about in dominant discourses of data-intensive transformations. Ethnography has an opportunity to generate meaningful translations back to communities and support multiple data valences, especially those underappreciated in this work.

The Multiple Doings of Multiple Sitings

My ethnographic practice had particular challenges in reconciling the multiplicity of perspectives, until this multiplicity became generative in the sensemaking process. Margery Wolf (1992) describes how when taken together, her ethnographic data represented quite different versions of what had happened.

Where once I was satisfied to describe what I thought I saw and heard as accurately as possible, to the point of trying to resolve differences of opinion among my informants, I have come to realize the importance of retaining these “contested meanings.” But only to a point...I still see my ethnographic responsibility as including an effort to make sense out of what I saw, was told or read—first for myself and then for my readers (M. Wolf, 1992, pp. 4–5).

This balance between making sense and providing coherence, on the one hand, and preserving the messy, contested, multiple nature of experience on the other, is indeed, a great challenge. Even more challenging is when your role as an ethnographer is to weave together disparate and seemingly unrelated experiences and contexts, as when field sites are multiple; when the object of study is a network or an ecology; or when your case studies are multi-stakeholder projects, which are inherently multi-disciplinary and multi-sectored. Further, because my ethnographic work was engaged in public practice and forms of action research, the diversity of audiences, accountabilities, and attachments multiplied. Thus my own role was not about creating some sort

of resolution; instead, I was called upon to be what Hine called an “embodiment of tensions” (Hine, 2007, p. 657).

Many ethnographers have pointed to ethnography’s dual role, in the gathering of data and producing texts and knowledge, and in the enacting the performativity inherent in fieldwork, what Pigg calls the doing of the sitting: “Ethnography produces knowledge (both for the researcher and the research subjects) on the spot, in the *doing of the sitting*, through a doubling of folding back on the everyday that occurs as a result of everyone’s efforts to make sense of what is going on” (Pigg, 2013, p. 132 my emphasis). As many organizational ethnographers before me have noted, the conversations and meditations on the process that happen in the course of ethnographic interviewing and participation in the project are beneficial in conceptualizing the different perspectives on the multi-stakeholder project.

Winthereik and Verran (2012) remind us that ethnographic stories are generative for the people and practices the stories are about. In attempting this dual role of ethnographic practice within the multi-sited digital health projects, I found myself investigating the project wake more than riding the project wave. In focusing on studying the project and participating in the project, I was always slightly out of step, attending to “what falls out of view or falls between the cracks” (Pigg, 2013, p. 132) or what Fortun (2012) calls “discursive gaps and discursive risks” (p. 452). In my role as an ethnographer, a data valence of discovery was evoked in the moments in which the project faced breakdowns; these moments became spaces of multiplicity for me. These were the spaces in which my active role in consulting and participating in the project aligned with my roles as a researcher. It meant that these moments of breakdown were opportunities for me to ask more questions, to move deeper into what was at stake. Mostly this served both roles well.

However, the challenge became the working both within and beyond the particular knowledge representations and frames already in place across different groups (Marcus, 2008).

Reflecting on Multiple Attachments

Before I traveled to the India field site of the India mHealth project, much of my fieldwork occurred between the university and the GNGO headquarters at ICTD design team meetings or on team conference calls with LNGO. I was acutely aware in these meetings that I was dispensable from their point of view. In negotiating my participant observer role and exploring options for action research, I had proposed conducting the qualitative interviews they had planned with the midwives along with observations of mPNC in practice, which had not been part of their initial research agenda. I was hopeful, but not certain, that my ethnographic observations and interviews would yield insights and develop practical knowledge that would be useful to the team and iteratively inform the process. I embodied what Fortun (2012) describes as a unique quality of ethnographers that positions us as being able to “tolerate the unknown; we have an affordance for unimaginable futures” (p. 458). I now understand this as a form of ethnographic faith, a conviction outside of knowing. During meetings I brought up concerns about certain design decisions, such as the absence of a place where midwives could take freehand notes in the mPNC, but without practical knowledge from the field I experienced myself as more of a nagging critic. Sitting in meetings, the conversations often moved into areas where I had little expertise to contribute, such as the affordances of the latest version of particular software as compared to previous versions or which airports in Africa are the best and worst to be stuck when traveling for work. Initially, the ICTD design team saw my contribution as an added bonus to their already established research plan, but certainly as not an essential component of the project.

This all changed as soon as I was in India and the team remained in the U.S. Once I occupied their field site my attachments and roles on the India mHealth project multiplied and I experienced my participation in the team becoming increasingly indispensable. Engaging at a deeper level with the network of stakeholders on the project, I became a researcher, a troubleshooter, an informant for the ICTD design team, as well as a liaison. My intention upon arrival had been to spend time developing relationships with the LNGO project stakeholders as the project was being implemented. I wanted to distance myself as much as possible from the ICTD design team's investment, in particular, from the outcomes of the India mHealth project, so that local stakeholders would be open with me when I was conducting the qualitative evaluation and I would be able to examine their relationships with the design team stakeholders throughout the process. While I was able to develop relationships with local stakeholders, this distanced position turned out to be unsustainable for a number of reasons. First, not being invested in the successful outcomes of mPNC was difficult to maintain when I arrived and found the project in great need of repair. Things were preventing the project from moving ahead, and it was obvious that I could help fill the gaps and facilitate its forward progress; and in any case, I had never intended to turn down unanticipated invitations to participate and help. These multiple attachments occasioned reflecting on what and whom I served in my role of researcher.

Second, I was already perceived by local stakeholders in different ways as part of a broader development agenda that had come from "outside," fitting a common conception in this region that "change comes from somewhere beyond the local" (Pinto, 2004, p. 340). While I established my relationships in spite of this conception, I was not able to completely shed it in this context. As Pinto (2004) illustrates in her ethnography, "One who comes from 'outside' to reform or to educate bears a familiar sign of enfranchisement and respectability but is also a

locus of suspicion and threat” (p. 342). I operated within these already established frames, constantly reflecting on how people interacted with me as a symbol and locus for much that lay beyond my role as an individual researcher. Conversely, I negotiated a fragile positioning, around which the subjects of my research were also the audiences of my research, and my collaborators. Ultimately it was the multiple roles I embraced in the field, however uncomfortable they made me, that enabled me to experience the complexities and contradictions of the multi-stakeholder project at multiple levels.

As I mentioned previously, I discovered a project in the field that only loosely resembled the project that the ICTD design team had been talking about for months in the lab. The project was at a standstill even as the ICTD design team thought it had moved further along. Positioned in the gaps between the anticipated and the actual, I became an informant for the ICTD design team working to investigate and communicate the actual realities on the ground. As issues came up in the field I became the person people talked to; I was the person from “outside” that was there. The midwives began coming to me to ask me questions about using mPNC, explaining that there would be “nobody who knows this when you are gone,” nobody who could answer their questions. As a troubleshooter, I worked to update the software on the phones, to gather data from any paper records the design team was missing, and to further train midwives in using the phones. The first few days in the field with the midwives revealed a significant training gap on the basic operation of the smartphones and the mPNC software. I began to process my own role in training the midwives in this ad hoc way and the ways my own presence in the field may have been creating a site of authority that was making midwives comply with using the mPNC when they had not had done so previously.

Uniquely positioned within these gaps, I experienced multiple partial realities that did not make up a whole. Beyond troubleshooting and informing, I took on a role of liaison, in the sense that I acted as a link between different stakeholder groups supporting their communication. From the perspective of the ICTD design team I was now indispensable. I was their lifeline to advancing this project. Managing across these multiple attachments I found myself doing the translation work across stakeholders, between the office, the field, the clinic, and the lab. This meant I was often put in a position of representing one group to another. This includes voicing the midwives' concerns to the ICTD design team and the administrators. I was able to voice many of the concerns that emerged in the field as midwives began using the mPNC. As issues were raised in the field, I often emailed the lab team immediately from my smartphone each evening, as if I had a direct line to the answers and solutions. For many of the issues I was able to make a practical difference. For instance, when midwives noted incorrect field entries on the form, I was able to facilitate some of the revised translations. A host of times, though, I ran into barriers when the problem represented deeper structural issues with both organizational and technical implications that would require a greater level of investment in the future sustainability of the project. It became clear that a subset of issues I unearthed through my fieldwork would be attended to in mPNC version 2.0, a version that was never realized.

During a debrief meeting with the ICTD design team after I returned from India, I noted that the balance had shifted. I now had knowledge and experience that was valuable. As the team discussed next steps with the project, they would look to me and ask, "Do you think LNGO would go for that?" While I felt flattered that they were looking to me for guidance, I also felt uncomfortable in this position of speaking for LNGO. At the same time, I realized that I was the only one who could possibly speak for them or represent some of their concerns in this meeting.

Once back in the U.S., the day-to-day life of the midwives once again felt far away and inaccessible, with little communication except the data coming to Greg from the mPNCs. Because the user interaction data showed that the visit times had become significantly shorter, Greg began to doubt that the midwives were still using the smartphones in visits. When I asked one senior ICTD researcher why many of these problems kept recurring while the knowledge about these technology-driven pitfalls kept growing, he suggested that “at some level...we’ve all got to learn from our own mistakes.” Though this response was unsatisfying, and even disturbing, there was some truth in the idea that individuals with the best of intentions cycled through the same systemic challenges.

Individual Intentions versus Systemic Challenges

The relationship of individual intentions and systemic challenges provides another way of conceptualizing the recurring gaps. In Chapter Five I identified three key systemic reasons ICTD projects fail: the tensions between research and impact-driven projects; the short term optimization of ICTD projects; and the lack of appropriate repair ecologies. From one perspective, these factors can be construed and critiqued as part of a postcolonial approach to development. Yet this interpretation doesn’t reflect the conversations throughout the project; nor does it capture the complex and dynamic realities and decisions individuals faced. In fact, the design team did everything in their power as individuals to prevent these postcolonial pitfalls and reflected on these systemic-oriented mistakes, even as they were repeated.

The systemic reasons for failure bring out the ICTD paradox that ICTs are considered solutions to problems of human and organizational capacity, but that in practice they require human and organizational capacity to be implemented effectively and sustained. A shift in the focus of organizational relationships toward longer term partnerships (rather than projects) is

needed (Santana, 2010, p. 22), a focus that addresses the aftermath from the outset so that organization capacity can develop to sustain and maintain progress if technological innovation does not. Although grounded in the context of ICTD, the organizational challenges of digital health can apply more broadly to technology projects in healthcare settings, especially those with low resources.

Emergent Organizational Role: The Gap Minder

In part, it was the gaps that I observed, experienced, worked within, and partially filled that made visible the information, articulation, and repair labor as well as communicative infrastructures unaccounted for in this project. This has direct implications for ICTD policymakers, researchers, and practitioners and is relevant for health technology implementations more broadly. In processes of technological innovation in organizations, then, a key organizational role develops around the articulation work to sustain, and the repair work to maintain, work that remains mostly invisible to the dominant construction of health and technology projects more generally. More than maintaining and sustaining, this work can be a site for innovation, as we witnessed the care managers perform in the case of U.S. Telehealth. This is not just repair and maintenance in the technical sense; this is repair and maintenance in the organizational sense. The overlooked role of repair also sits within a larger ecology of support that conditions the agency of the role, enabling the role to have the authority to engage organizational stakeholders. This organizational role emerged in minding various organizational gaps; and in doing so on a practical level, revealed what was missing in the ways that current communicative and organizational infrastructure functioned. As a participant in a multi-stakeholder project, my relationships and attachments to all the stakeholders helped make visible the gaps in labor and communication from all sides. It was also the affirmation of my

contributions from all the different stakeholders that allowed me to see the ways my ethnographic practice functioned on multiple levels. I'm calling this emergent organizational role: the gap minder.

The Future Doesn't Speak For Itself

Making visible the multiple social and material lives of data reveals not simply how data are mediated in ways that are neither singular nor neutral. Primarily, my concern has been to develop a lens on digital health that considers the mutually implicated discursive, material, and relational dynamics involved in integrating the technological links of data processing and exchange with the complexities of care, organizing, and communication. As ICTs increasingly mediate greater portions of human activity, we need to both understand how that activity may be transformed through informationalization and how new mediations recursively shape and materialize complex processes of communication in the anticipated and unanticipated generation of data, big and small. I argue this also requires an approach that thickens our concept of and language around data and engages new models of computational and qualitative inquiry. Without expanding our lens in this way, healthcare problems and solutions will continue to be defined in the computational realm of data structures and algorithms (Manovich, 1999), and they will, as a result, continue to fall short of expectations to solve the social and economic problems of healthcare. As has been suggested, technological innovation is not simply about the particular gadget or tool; it is also about “designing the technocultures of the future” (Balsamo, 2011, p. 6) and then reproducing them. In the context of digital health, then, technological innovation is not simply about the convergence of medical technology and ICTs. It is also about designing the future institutional and cultural forms around health and wellness and the organizational cultures around care.

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Appendix: Methods

India mHealth Implementation Field Sites

LNGO has three clinics that do in-patient care and deliveries as well as outreach care in a population of 64,000. There are eight midwives distributed across the clinics, and each clinic is staffed by a doctor two days a week. In addition to providing a range of reproductive and child health services in the clinics, the midwives also conduct household PNC visits within the first week of birth. LNGO's PNC program has the goal of visiting all women who gave birth in their area, independent of whether they delivered in the clinics. The household visits are done by a midwife and a motorcycle driver. In most cases, the houses are accessible by motorcycle, although in some of the cases, the midwives have to hike up to a mile to get to a patient's home. The PNC examinations cover both the mother and the baby and use a nine-page form filled out by the nurse during the examination, a form which the mPNC aimed to replace with mobile-based data collection. The standard of care is that each mother receives two PNC visits, the first (PNC1) within 72 hours of giving birth, and the second (PNC2) within seven days of giving birth. In the case of a clinic delivery, the PNC1 is conducted in the clinic.

LNGO already had extensive healthcare information system in place, as evidenced by the fact that almost all facets of clinical work were transcoded into information mediated through a complex network of paperwork and information labor. Midwives performed a tremendous amount of information labor to ensure data jumped contexts, laboriously recording, transferring, and accounting for data across a network of registers and forms and computers. Beyond the daily rhythm of documentation, there were also monthly and weekly days of accounting. These days of accounting transformed the clinic into a "center of calculation" (Latour 1987), in which several midwives sat with a calculator and multiple large register books piled on top of the other in her lap for hours as they document a wide array of patient and administrative information, from staff

attendance, to monthly counts (number of PNC examinations), to balancing or taking stock of clinic resources (cash, injections, iron supplements). All these paper-based calculations were taken to the office where they were re-entered into the computer by the data entry clerks. The two offices also serve as the base for managing a range of projects in which LNGO is involved.

India mHealth Project Goals

The research agenda and implementation goals for mPNC established across the LNGO and the design team included three categories of system improvement: governance, standardization, and efficiency and accuracy in data processing. Improving governance involved reducing the time it took for the data to pass from the field collection into availability in the office database in order for doctors to detect and manage problems in the field more rapidly and to provide feedback to midwives more continuously. The previous system of supervision had an average of one month delay for data to be processed in the office database, and supervisors needed to accompany midwives into the field. MPNC was envisioned as providing immediate transfer of field data to the office, reducing the time and the labor involved in transcoding information across paper forms in the field, the clinic, and ultimately, the office database. MPNC also provided new kinds of metadata or user interaction data about the midwives' PNC visits. This data would then be used for better governance of midwives, detecting problems and holding them accountable.

Secondly, mPNC was envisioned as an effort to standardize the visit's counseling across midwives. Mobile video was seen as a way to reduce the variance in messaging across midwives and to standardize information that mothers received, with the hope of improving the knowledge of mothers and enhance their likelihood of following advice. Third, mPNC shifted data collection and processing from a paper-based system to a mobile-based one. The digitization of

data collection and processing was expected to improve accuracy and efficiency through disintermediation, that is, bypassing multiple stages of transcoding that had been identified as “error-prone” and time consuming. Further, the mPNC form could enforce self-correction and provide complete information on the role of the midwife at the time of the visit through requiring responses to advance, scripting a sequence of clinical actions, and providing clinical decision support. This was hypothesized to improve data collection accuracy, support midwives’ clinical actionability in the field, and reduce reliance of midwives on supervisors.

Fieldwork

My fieldwork in India related to this project entailed a month at LNGO’s multiple sites, including three clinics in the rural areas and two offices located in the closest small city. I conducted workplace observations in each location, with administrators and data entry staff in the office and with midwives and supervisors in the field, focusing in particular on how data are managed, talked about, and used in each context; how stakeholders engaged with the project; and how their practices and communication relate to other stakeholders. With a local translator, I observed 22 PNC visits (at least one PNC visit with each midwife) and a mix of PNC visits using paper, paper and mobile, and solely mobile in order recognize what patterns of interaction and routines may have shifted. There was also an extensive set of baseline data from previous interviews and observation that the design team made available to me for reference. Observations of PNC visits consist of shadowing the midwife throughout the day as she carries out her work, focusing on how the midwife used the mPNC, how mPNC mediated interactions with patients and other stakeholders, and how midwives negotiated relationships with doctors and administrators. Almost one quarter of my visits were conducted in the clinics, while the rest were in remote village homes.

I also conducted workplace observations with professionals at GNGO in their location in New Delhi as they engaged in a broader set of global health and technology projects and partnerships. This allowed me to contextualize the work and perspective of GNGO professionals on the India mHealth project within the conversations and activities in the broader transnational network of global health and technology stakeholders across the ICTD community. Field notes were recorded during all observations and interviews and typed up at my earliest convenience to maintain the richness of data.