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Lived Data: Tinkering With Bodies, Code, and Care Work

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Human-computer interaction research on personal informatics in health care has focused on systems that aim to support patient empowerment and enable better health outcomes with data monitoring and tracking. Through examining the lived experience of personal data used to manage chronic illness, we show how such technology design is also the site of radical dependencies, collaborative care arrangements, and wider sociopolitical concerns tied to new forms of technical labor and shifts in medical expertise. Drawing from ethnographic research with open source, do-it-yourself collectives engaged in opening up corporate-controlled type 1 diabetes devices and data, we propose the analytical lens of lived data. Lived data emphasize data as an integral way of living, enacted through a multiplicity of things, relations, and practices, from bodies and needles, social media support groups, and legal processes to writing code, making visualizations, and hacking devices. Building on critical and feminist scholarship of human-machine relations, we articulate the work that goes into

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producing and living personal data, the physical and emotional costs of data tracking, and the consequences of do-it-yourself as a form of individual empowerment in health and wellness.

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1. INTRODUCTION

Caring is a question of “doctoring”: of tinkering with bodies, technologies and knowledge—and with people, too. — Annemarie Mol, *The Logic of Care*

The cyborg is our ontology, it gives us our politics as we have become theorized and fabricated hybrids of machine and organism. — Donna Haraway, *A Cyborg Manifesto*

We need to ask how any object of analysis—human or nonhuman or combination of the two—is called out as separate from the more extended networks of which it is part. ... Our task as analysts is then to expand the frame, to metaphorically zoom out to a wider view that at once acknowledges the magic of the effects created while explicating the hidden labors and unruly contingencies that exceed its bounds. — Lucy A. Suchman, *Human-Machine Reconfigurations*

A 2014 *Wall Street Journal* article entitled “Citizen Hackers Tinker with Medical Devices” reported on people living with type 1 diabetes (T1D) who decided they were no longer waiting for medical device companies and the health care system to give them the personal data and the tools they needed to better manage chronic illness (Linebaugh, 2014). Starting as a small, informal group of like-minded technologists in the United States who began to hack a continuous glucose monitor, these ad hoc efforts rapidly expanded into an open source project called Nightscout, that is, a do-it-yourself (DIY) remote-monitoring system for diabetes data with global reach. Nightscout provided open source software code to access, view, and interpret data that commercial continuous glucose meters (CGMs) produced but had always been locked behind a black box, unattainable. Their hashtag #WeAreNotWaiting captured in a single phrase the hope that a DIY approach toward diabetes could be a force of positive change for people frustrated by the regulations and limitations of formal health care systems. A community of users comprising patients and parents of children with T1D grew quickly as Nightscout seemingly shifted control of health care management into the hands of individuals by giving them access to the data they felt was rightly their own. Media attention on Nightscout followed with enthusiastic headlines. More recently, elements of these stories—such as a patient’s right to access personal data—have received attention by scholars as an illustrative case of a much broader phenomenon often referred to as “end user innovation” (Torrance & von Hippel, 2015) and model of patient empowerment through data tracking (Neff & Nafus, 2016). At the same time, Nightscout has been discussed with both caution and optimism in the commentaries of medical journals, as clinicians worry about data privacy and risks associated with patients using their personal data in making dosing decisions (Klonoff, 2015; Walsh et al., 2015) and see potential for better engaging patients in the design of health technologies (Lee, Hirschfeld, & Wedding, 2016).

The narrative of personal data, this article sets out to show, is neither just an exciting story of individual empowerment amidst corporate control nor simply an issue of managing data privacy. For those engaged in the everyday practices of building and relying upon DIY devices to manage their health, it is both and much more: Nightscout and related DIY diabetes systems mean living with data, which is simultaneously hopeful and dreadful, empowering and isolating, highly individualizing and dependent on the help of others. Dana Lewis, cofounder of a project called OpenAPS (open source artificial pancreas system), has spoken publicly about these conflicting and multiple realities of living and managing her health as a DIY diabetes expert. In 2015, at a conference that we attended as part of a 1-year long ethnographic engagement with DIY diabetes technologies, Dana Lewis was one of the keynote speakers. Diagnosed with T1D at the age of 14, she told her story of personal health data to an audience of techies, Fortune 500 executives, and academics. “Close your eyes,” Dana Lewis directed us, “and imagine you are drifting off to sleep.” She waited patiently for the audience to grow silent. With our eyes shut and deprived of the usual PowerPoint visuals, Dana’s story began to morph into one that could potentially become our own. “Now imagine the feeling, the fear of not waking up. This is a true reality. It’s called ‘dead in bed.’ Imagine, how horrible that feeling is, that fear of not waking up, even though you do everything right.” Dana paused, the

room enveloped in silence. As we reopened our eyes, she spoke with added emphasis. “This is behind the ‘we are not waiting’ movement, so that this fear stops now and people stop dying overnight in their sleep.” As she described how the mundane act of going to sleep for someone living with diabetes could be an act of gripping fear, we learned that “dead in bed syndrome” is a phenomenon when someone with T1D goes to bed in good health and dies in their sleep. Although relatively rare, this condition is thought to account for about 6% of cases of all deaths in people with T1D who are younger than 40 (Koltin & Daneman, 2008). Lewis’s illustration reminded the audience that for her, and many others with chronic illness, diabetes is a matter of daily survival, one that is pressing and often grim.

“When patients say they are hacking the device,” Lewis continued her speech, “I want people to understand why they are doing it. Back in 2012, I did not have a way to get the data off my own medical device and do something with it. So I had this workaround”—she paused with a smile—“you might call it a hack.” She then gave us the story that we had been eagerly waiting for, how she created a functional artificial pancreas system when similar commercial prototypes were still in clinical trials and unavailable to consumers. Her inspiration came, she told us, when she lived alone and wanted to create an alarm that would be both loud enough to wake her up and automatically notify her family if her blood glucose levels dropped dangerously low during the night. The technical struggles and eventual success of getting data off of her medical devices opened up new possibilities for care, and her tinkering with technology slowly evolved into a larger project to build an open source, DIY artificial pancreas system, a technology that was entirely self-made, unregulated by the U.S. Food and Drug Administration (FDA), or “hacked” as Dana put it. The PowerPoint resumed, and with each of her slides showing graphs of her diabetes data, we were led through a powerful demonstration of how her DIY hack—the right to use her own data as she saw fit—led to radically improved glucose levels and peace to sleep through the night. We witnessed her system in action by watching her partner (and OpenAPS cocreator) in the audience periodically check Dana’s diabetes data in real time with a quick glance down at a smartwatch on his wrist. By the end of the talk we too believed in Dana Lewis and her story of ingenuity, creativity, and hands-on intervention. It felt celebratory worthy.

And yet, Dana Lewis did not end on this note of triumph, but circled back to the beginning of her talk, to the uncomfortable place of fear, anxiety, and strain. She still kept multiple juice boxes by her bedside in case of an emergency, she stressed, and access to data had not taken away the daily care work involved in living with diabetes. “Most people think diabetes is about eating healthy, exercise and insulin; this will give you good blood sugars. In fact, it’s not that easy. There are many variables: Am I sleep deprived? Am I excited? Am I stressed? There are a lot of variables that you can’t measure. How do you deal with all these variables? So, yes, I have insulin; I am fortunate to have access to a CGM, but even if you have the best technology, it’s still a hard chronic and incurable disease. The success of diabetes is not a perfect number,” she concluded, “but is the willpower to get to the next data point.”

Dana Lewis's story points to a narrative around the intersection of personal data and tinkering with one's health that is as exciting and empowering as it is complex, messy, and more than a self-made, individualized practice. In our ethnographic engagement with various DIY diabetes projects that formed around people like Dana Lewis, we found the lived experience of diabetes data to be multiple, presenting oftentimes contrasting and contradictory faces. On an intimate, physical level, people described being empowered, but also frightened by the devices in their bodies. Some people like Lewis performed high-risk experiments on themselves, because they believed data could provide a better quality of life; furthermore, as "patients" they often lived with their data in isolation from the professional medical community, marginalized by their own expertise and fluency with information technologies. In the popular media's numerous stories of Nightscout, "care" has been conceptualized as a heroic feat taken on by individuals who solder and code their way to health and wellness. For many relying on DIY technologies to manage diabetes, however, the expertise needed to address both daily challenges and critical care needs was more often found among software engineers and passionate computer geeks than trained clinicians. Should we, as human-computer interaction (HCI) researchers, view this as "empowerment" or rather point to the ways in which such stories of personal data and DIY/making mask important changes in how care is performed and who is responsible people's health and wellness? Should we hold up "DIY" as a celebratory model for health care or critique it?

This special issue encourages the HCI community to reconsider the relationship between data and design through examining the ways people appropriate personal data for varied uses. This article takes the conflicting and multiple aspects of living with/in/through data, or what we call "lived data," as the starting point of our investigation into DIY health. With "lived data," we propose a theoretical move from viewing data as a thing that exists in some ways external to people's lived reality and to data as modality, that is, seeing data as already an inherently central and relational part of being in the world. From traffic data to professional performance indices like the h-index to the numbers of one's Facebook likes, we increasingly live through data algorithms that make sense of us and in turn shape how we make sense of the world (Chun, 2011; Weiser, 1999). And yet we often talk about data metaphorically with distance—as a "flow" and a "commodity" that can be accessed, manipulated, and interpreted with the right kind of software skills, or in binary terms as "personal" data generated and used by individuals and the "big" data of the vast repositories that corporations or other collective entities create, aggregate, own, and use. The underlying goal of this article, then, is to open up and analytically unpack "data" itself.

"Lived data" as an analytical sensibility emphasizes data as integral way of living, collectively produced and engaged with. Our research shows that personal data are a multitude of things, sites, and practices at once: bodies, needles, emotions, legal concerns, writing code, hacking devices, making visualizations, and sharing memes. We tease apart these various modalities of data, not to artificially separate them but to illustrate how they play into contemporary sociotechnical shifts as software,

algorithms, and data increasingly shape how we care for our bodies, relate to one another, and evaluate what counts as productive work and labor—how we live.

The contribution of the article then is twofold. First, our work brings into conversation two previously largely separated areas of research: (a) personal data, quantified self, and lived informatics, and (b) DIY making and hacking ideas and practices. DIY making and hacking has rarely been studied in relation to phenomena such as the quantified self, data, and tracking. This is in many ways surprising, given that a foray of recent tracking devices, smart and health wearables were designed by startups, self-identified makers, members of hackerspaces, and incubator programs (Lindner, Hertz, & Dourish, 2014). Recently, scholars have begun to address the social and technical complexities of this emerging research space (Kaziunas, Ackerman, Lindner, & Lee, 2017; Nafus, 2016; O’Kane, Han, & Arriaga, 2016), and our work here adds to these efforts by highlighting the social context of DIY diabetes technologies. We examine not only how data and tracking devices are used but how they are made by people working outside the corporate context of R&D labs and how, in their making, what counts as expertise and care work is renegotiated.

Second, this article draws from a body of work that has evolved out of feminist technoscience studies, providing a rich empirical and analytical vocabulary for investigating DIY making and personal data practices. Such language is important in how we address the social dimensions and collective practices of data in human-centered design. We argue in this article that technology design as an enabler of individual empowerment cannot be divorced from dependencies and uncomfortable alliances of human bodies, machines, and organizations. Although celebrated as liberating individual patients from an often backward and beleaguered health care system, DIY health care creates new, arguably more precarious dependencies that rest on the free labor and goodwill of volunteer workers, patient advocacy groups, software coders, families, and friends. In the next section, we outline in more detail how we tie together these various strands of lived informatics, personal data, and DIY making to develop an analytical sensibility of lived data.

2. LIVED INFORMATICS, PERSONAL DATA, AND DIY MAKING

A central focus in research on personal informatics has been the ways in which data and technologies can “help” people achieve goals, independence, and even joy. Studies looking at personal data in the space of health and wellness, for instance, have examined the varied ways individuals in the Quantified Self movement interact with data using commercial tracking devices like Fitbit and Jawbone to promote behavior change, reflect, and form personal relationships (Choe, Lee, Lee, Pratt, & Kientz, 2014; Li, Dey, & Forlizzi, 2010; Lupton, 2014). There is also interest in examining the potential of “diagnostic self-tracking” to support people with managing chronic illness with studies of various clinical contexts, including irritable bowel syndrome

(Karkar et al., 2015), pain management (Felipe, Singh, Bradley, Williams, & Bianchi-Berthouze, 2015), and in patient–provider collaboration (Chung et al., 2016). Of note in the area of quantified health and DIY making is Ananthanarayan et al.’s (2014) work on “crafting health,” which seeks to help people create meaningful visualizations of personal health data through the use of digital fabrication technologies. For example, participants in their study collected personal data through a wearable UV tracker and represented that data in the form of an artistic visualization of a cherry blossom design. The authors frame an approach to personal data that is largely celebratory and positions DIY making as a design ethos for both empowering patients and democratizing health technologies.

Recent literature has begun to critically examine tensions in Quantified Self–styled data tracking (Bietz, Hayes, Morris, Paterson, & Stark, 2016). Alongside these explorations, a growing number of HCI scholars have explicitly begun to question overly rationalist, techno-centric, or biomedical framings of personal data in health and wellness (Churchill & Schraefel, 2015; Grinter, Siek, & Grimes, 2010; Kaziunas et al., 2015; Maitland & Chalmers, 2011; Ohlin & Olsson, 2015). In data tracking, this holistic view of health and wellness can be seen in the research and design around “lived informatics” (Elsden, Kirk, Selby, & Speed, 2015; Epstein et al., 2016; Epstein, Ping, Fogarty, & Munson, 2015). First articulated by Rooksby, Rost, Morrison, and Chalmers (2014) in a paper about fitness tracking as part of “a praxis of living,” lived informatics originally served as a sensitizing concept, an approach to data tracking that took seriously the social and material context of collecting and sharing data. They proposed several design recommendations from a lived informatics perspective, including (a) “attend to the physicality of tracking”; (b) “consider...the emotionality, the hope and fun people may have”; (c) “reconsider personal tracking as social tracking”; and (d) consider behavior change as something achieved by people across various technologies (Rookby et al., 2014, p. 1172).

Our article extends each of these design implications and puts them into conversation with their ethical, political, and social consequences. This includes (a) considering how the physicality of tracking extends beyond engagement with technological devices to include tinkering with the human body, (b) accounting for the (often invisible) emotional work and labor of self-tracking and self-care, (c) explicating how personal data are not just about supportive friendships but also—crucially—the site of often extreme dependencies and obligations, and (d) teasing apart the complex assemblages of bodies, machines, and institutions at work.

In our fieldsite, the stories of accessing and owning one’s data and the right to hack a commercial product were deeply intertwined. Together, they are indicative of a much larger endorsement of a DIY approach that intervenes in passive consumer culture by providing people with the tools to make their own, rather than purchase devices. A growing body of HCI research has stressed the importance of unpacking how the tools, values, and practices of making and hacking have moved beyond hobbyist pursuits, and how they are deployed across regions by governments, educators, and corporations to “upgrade” industries,

education, and work (Ames, Rosner, & Erickson, 2015; Avle & Lindtner 2016; Irani, 2015; Lindtner et al., 2014) and retrain students and workers to develop entrepreneurial thinking and hands-on approach to contemporary societal and economic problems (Chan, 2014; Lindtner, 2015; Neff, 2012). Making, here, is portrayed as site of individual empowerment; by training people in hacking and tinkering, they can, so the story often goes, intervene in passive consumption and corporate monopoly. In this article, we zoom in on how this much broader endorsement of a DIY approach toward work, education, and life plays out in the specifics of health care and tinkering with one's body through data.

We found that it took a great deal of work to both live with and legitimize the DIY maker approach to health care. Making was both the site to live out technological dreams of alternate futures and to deal—in a pragmatic fashion—with the day-to-day struggles of living with a chronic illness. We use the term “care work” in this article to refer to the varied sociomaterial practices (see Mol, 2008) that composed the everyday management of diabetes for people using Nightscout and OpenAPS. Living with T1D involved a wide range of activities that often included a mixture of medical, information, machine, and emotion labor, such as reviewing CGM data with family and friends, prepping insulin injection sites on the body, calibrating devices, tweaking an algorithm to dose insulin, fixing broken rigs, and collectively negotiating with the FDA. Moments of empowerment were interspersed with the reality of living with systems that themselves required constant upgrading and attention.

As DIY making and hacking continue to intervene in broader industrial, economic, and social processes, we are interested in how DIY health production draws attention to “making” as a form of labor that extends beyond current narratives of a hobbyist engagement with innovative materials or industrial entrepreneurship. In so doing, we take seriously the seductive draw that such stories of user empowerment have, all the while accounting for the work and relationships that go into producing, maintaining, and quite literally living those stories. We argue that an approach that neither simply celebrates nor denigrates it (Lindtner, Bardzell, & Bardzell, 2016) but rather engages in a careful and empathetic critique of DIY and data practices, offers insights for how HCI might formulate an ethical yet engaged research program for personal data. We aim for a narrative that accounts for the tensions people experience as both a “parent” and “DIY medical person,” as both a “citizen hacker” and “patient.”

Navigating between technophilia and dystopia (Dourish & Bell, 2011; Nardi & O'Day, 1999), then, we draw on work by feminist technoscience scholars such as Donna Haraway, Annemarie Mol, Lucy Suchman, and Adele Clarke to articulate an approach toward the study of personal data that draws attention to its multiplicity and livedness. Donna Haraway's (1985/1991) influential and enduring “Manifesto for Cyborgs,” for instance, pushes us to consider the multiple sides of data, including the uncomfortable aspects. Haraway's cyborg politics points to a future where people's relationship with technology is both alluring/fascinating and fearful/disturbing. Writing of the cyborg body, she maintained that

late 20th century machines have made thoroughly the difference between natural and artificial, mind and body, self-developing and externally designed and many other distinctions that used to apply to organisms and machines. Our machines are disturbingly lively, and we ourselves frighteningly inert. (p. 20)

And yet, Haraway argued, “in imagination and in other practice, machines can be prosthetic devices, intimate components, friendly selves” (p. 144). Haraway’s cyborg body articulates the tensions felt by many people in our study, especially those living with an artificial pancreas, whose dependency on the data, algorithms, and machines that dispensed potentially lethal amounts of insulin into their bodies is captured by this notion of “frightening intimacy.”

In the final chapter of *Human–Machine Reconfigurations*, Lucy Suchman (2007, p. 266) invoked Haraway’s figure of the cyborg, noting that it should not be viewed as a singular heroic, monstrous, or marginalized subject but a “multifaceted subject-object assemblage.” A cyborg sociomateriality views personal diabetes data as inextricably connected to a distributed and shifting network of bodies, processes, technologies, and people. Furthermore, Suchman argued that cyborg configurations and their consequences play out in the mundanity of everyday life, writing,

Along with the dramatic possibilities of the feminist cyborg, we need to recover the ways in which more familiar bodies and subjectivities are being formed through contemporary interweavings of nature and artifice, for better and worse. Put another way, now that the cyborg figure has done its work of alerting us to the political effects, shifting boundaries, and transformative possibilities in human–machine mixings, it is time to get on with investigation of particular configurations and their consequences. [emphasis added] (pp. 275–276)

Suchman referenced a selection of medical studies (e.g., patient anesthesia, fetal surgery) to illustrate some of these consequences, and her insights, although arguably bound to dated information technologies like novel uses of video communication, are more relevant than ever. Today, DIY hacking and personal data-tracking technologies extend as lived practice the kinds of configurations Suchman observed and theorized. They come with values such as individual empowerment and self-care built into the very purpose of their uses, and the consequences of such human–machine configurations have deep sociopolitical and ethical importance.

Engaging with such theoretical elaborations from feminist technoscience, this article offers a situated and multifaceted account of lived data by detailing the arrangements and configurations they entail. It further illustrates how familiar tropes of patient empowerment and user innovation mask social and economic consequences such as the shift in responsibility and expertise from the health care provider to the software coder and eventually to the user. We end the article by drawing out a lived data stance for HCI researchers and designers that includes a critical sensibility toward the politics and ethics of care within the shifting terrains of personal data and DIY technologies.

3. METHODS

3.1. Data Collection

Our data include 21 semistructured interviews with users of open source, DIY diabetes technology, focusing on members of the Nightscout community. Interviews were conducted with 20 participants in the Nightscout community (over the course of the study some participants were interviewed more than once, and some interviews included more than one person). Although participants had varying levels of technical expertise, experience with T1D, and participation in the community, all were currently and/or had used parts of the Nightscout system code either personally or with a family member in daily management of diabetes. Interviews were approximately 1 hr long and were recorded and transcribed; children were recorded with permission from their parents. These semistructured interviews took place both face-to-face at various diabetes conferences and electronically via Skype. Interviews focused on exploring (a) types of involvement in the Nightscout community and related DIY diabetes projects like OpenAPS, (b) everyday practices around diabetes management using Nightscout and related technologies, (c) impact of DIY diabetes technology on family life and clinical care, and (d) broader views on the ethos and motivation of those who participate in the DIY diabetes projects.

Interviewees were selected to represent a wide range of experiences with Nightscout and included 11 parents with children who have T1D (specifically three mothers and eight fathers) along with eight adults and one teenager all living with T1D. Participants involved in different types of work within the Nightscout community included core developers (nine), Nightscout Foundation board members (seven), Facebook group moderators (two), and active members of the technical support group (two); furthermore, all 20 interview participants were active members of the CGM-in-the-Cloud Facebook group. (These categories are not mutually exclusive, and several participants had multiple roles within the Nightscout community and other DIY diabetes projects.) Participants came from a wide range of ages as well as technical and educational backgrounds, although the majority of participants had advanced degrees. We also note that the core developers we spoke with all had previous training in computer science and/or work experience as software engineers or in the broader tech industry. We acknowledge that such demographic data shapes the experience of diabetes management and note that Nightscout users represent a small, self-selected population of patients and caregivers. Whereas only 11% of T1D patients currently use a CGM, the Nightscout community can be understood as a patient population of early adopters that embrace technology use in diabetes management (Rodbard, 2016).

These interview data were also informed by more than 12 months of ethnographic observations by the first and second authors of Nightscout presentations at diabetes conferences and a technology workshop, as well as informal planning conversations held by core developers and foundation board members. Observational data were recorded as field notes and later transcribed, adding to our understanding

of the Nightscout project. Additionally, over the course of the study, an ongoing analysis of DIY diabetes technology project-related websites, personal patient blogs, code repositories (e.g., GitHub), various technical documentation, news articles, and a wide range of social media, including Twitter feeds, Instagram accounts, YouTube videos, and Facebook posts, added to our understanding of people's experience using DIY diabetes technologies. In particular, we coded 664 distinct posts from the CGM-in-the-Cloud Facebook group to triangulate our interview and observational data.

The data reported in this article are a part of larger research project aimed at understanding the patient-centered technology design and the use of technology to manage T1D (Lee et al., 2016). Our understanding of Nightscout was also informed by a survey of the CGM-in-the Cloud Facebook group completed by 727 respondents (led by the fourth author). We report here only from the qualitative data collected in this survey that was coded and analyzed. Institutional Review Board approval for data collection was obtained along with participant consent. All interview and survey data reported here were anonymized and pseudonyms used.

3.2. Data Analysis

We followed a situational analysis approach as articulated by Adele Clarke (2005), which is a derivative of grounded theory. In situational analysis, iterative cycles of data collection and analysis inform one another. After a set of initial interviews were transcribed, the first, second, and third authors individually analyzed the data using an open-coding method to identify significant themes. Coded interviews were then discussed among the entire research team during data analysis sessions. New codes were generated collectively as important concepts were identified, compared, and revised. These subsequent codes were later used as probes in future interviews. The second stage of data analysis with new transcribed interview data resulted in consistent themes and confirmed our findings. Field notes and social media data were read, coded, and analyzed in a similar manner during data analysis sessions. Furthermore, utilizing Clarke's situational analysis mapping methods, we generated an array of situational, discourse, and social worlds/arena maps and analytical memos. These map artifacts and memos were discussed among the research group as theoretical insights emerged from the ongoing data collection and analysis.

4. THE BEGINNINGS OF #WEARENOWWAITING

T1D is a serious autoimmune disease in which a person's immune system attacks and destroys the insulin-producing cells in the pancreas. The pancreas stops producing insulin, a hormone essential for getting energy from food, and people with T1D are dependent on injected or pumped insulin to live. T1D can occur suddenly to both children and adults at any age, and although its causes are still being investigated, researchers believe that onset is linked to both genetic and environmental factors. As a chronic condition, T1D is currently unpreventable and has no cure.

The daily care management for T1D is challenging, both in regards to the medical care required, which involves the risk of serious health complications, and physically and emotionally in terms of fatigue, anxiety, and frustration. Blood glucose levels are routinely checked throughout the day and night, a process in which drops of blood are traditionally drawn through a special needle or lancet (e.g., “finger pricks”) and measured with a blood glucose meter. Doses of insulin must then be precisely balanced—by multiple daily injections or a continuous infusion through an insulin pump—with everyday activities like eating, exercise, and sleeping. Even with vigilant monitoring, people with T1D are constantly at risk for dangerous high or low blood glucose levels, both of which can be life threatening. Uncontrolled blood glucose levels for people with T1D can lead to serious health problems like kidney failure, blindness, and nerve damage and have been shown to reduce life expectancy up to 13 years (Walsh et al., 2015).

Given that less than one third of people with T1D in the United States achieve their target blood glucose control levels, technology has been viewed as an important way to better support T1D management (Rodbard, 2016). CGM systems, for example, are FDA-approved medical devices used to measure and display real-time blood glucose readings, allowing people to view and track fluctuations in their glucose levels. Advancements in the sensor technology in CGMs have given patients access to increasingly accurate blood glucose data; however, to date the FDA has determined that displayed data from CGMs are not safe (i.e., accurate enough) to be used in insulin-dosing decisions. Insulin treatments—such as bolus and basal—used to make corrections in person’s blood glucose levels require the continued use of blood glucose meter readings. Diabetes device manufacturers therefore carefully instruct users that CGM data are intended primarily to aid people in determining blood glucose patterns.

Although a helpful tool to many people managing T1D, as late as 2014 commercially available CGM systems from popular medical device companies like Dexcom had several limitations for patients and their families. Real-time blood glucose data could be displayed only on a designated receiver supplied by the device manufacturer; furthermore, the everyday usefulness of the display was hampered by the receiver having to remain within 20 ft of the CGM sensor (which was embedded in the arm of the person with T1D). A technical solution to these constraints—remote monitoring of CGM data on mobile devices—would allow people in the T1D community, particularly the parents of young school-age children with T1D, to track blood glucose levels from afar and potentially intervene if they observed these levels dangerously rise or fall. Although medical device companies developed such tools, the FDA approval process for classified medical devices often delays the release of new technology to consumers for years.

4.1. Nightscout

In 2013, a time when no commercial solutions for remote monitoring were available, a small group of concerned T1D parents and adults with T1D formed

online around the shared goal of intervening in the highly regulated and closed system of T1D data management to better manage patient care. Their efforts became an open source, DIY project to “put their Dexcom CGM in the cloud” and enable the remote monitoring of CGM data through mobile devices like smartphones or Pebble watches. Nightscout, as this project became known, was positioned as an “educational source code for monitoring estimated glucose values from a Dexcom G4 Receiver” (Nightscout, 2016).

Several versions of code exist, but most Nightscout members use the “community build” for monitoring blood sugars, which provides an interface for displaying different types of data. The configuration of devices also varies widely but typically consists of a “rig” (the combination of a smartphone + Dexcom CGM receiver), an Android application that transfers data from the CGM to the cloud, and a web application that displays the blood glucose values stored by the CGM, which can then be displayed as data on a mobile or wearable device such as a smartwatch. Nightscout is always in development, a shifting assemblage of digital tools, social support, and organizational resources that include websites, instructional YouTube videos, an associated 501(c)(3) foundation, memes, Github repository, community certificates and awards, diabetes conference presentations, “install parties,” and the thriving Facebook group called CGM-in-the-Cloud. The project began among a small group of like-minded “diabetes parents” with engineering and technology backgrounds who were interested in better, more livable diabetes management strategies for their children with T1D. A primary goal for these parents was to simply sleep through the night, as many were sleep deprived from years of routinely monitoring their children’s blood sugar 24/7. Since this time, Nightscout has grown into a community with a diverse group of users and perspectives on managing diabetes. Currently, the largest user group of Nightscout is children who have T1D and their parents, but there has always been a smaller and highly active group of adults with Type 1 who are interested in exploring new diabetes technology.

A number of subcommunities have also emerged around Nightscout to help support technological development and meet organizational needs. During the course of our study, a group of approximately 10–15 core developers (led by one long-standing and highly active member) worked on releasing new Nightscout software versions, fixing bugs, and designing new applications. The developers are all volunteers, contributing their labor for free and taking on projects as time and interest allow. Many of Nightscout’s current features were originally developed as personal tools by developers to meet their own idiosyncratic diabetes management and treatment strategies (e.g., louder alarms, push notifications, predictive algorithms). As the number of Nightscout users grew, there was an effort among developers to respond to design requests generated from the wider community (although our participants also expressed wariness that unmet requests could lead to tensions within the community and the burnout of developers).

As volunteers, the majority of developers juggled full-time employment and squeezed in a few hours of work on Nightscout late into the evening or on the weekends. To meet the needs of a growing number of nontechnical users, the CGM-

in-the-Cloud Facebook group was created in 2014 to facilitate the discussion and sharing of information around diabetes technology. Although this Facebook group includes conversations on a range of technologies and topics, CGM-in-the-Cloud quickly became the default forum for quickly disseminating Nightscout news and information. A volunteer technical support team for Nightscout was organized on CGM-in-the-Cloud to provide 24/7 assistance for installation and rig setup and field questions from a growing number of nontechnical users.

As of April 2016 the CGM-in-the-Cloud group had more than 17,000 members and activities had expanded past routine questions on setup and installation to include sharing expertise on self-management techniques, such as making insulin corrections during a child's growth spurt, conversations about pumps, showcasing DIY projects like designing rigs to fit small children or connecting Hue lights to Nightscout alarms as wake-up systems, and selling or giving away medical equipment like old pumps that are used for testing new software projects. CGM-in-the-Cloud also operates as place of camaraderie and emotional support for patients and caregivers of T1D.

Furthermore, a need to engage with larger governmental organizations like the FDA and medical device companies led to the creation of the Nightscout Foundation as an incorporated 501(c)(3) nonprofit organization. The foundation's mission is "to encourage and support the creation of open source technology projects that enhance the lives of people living with Type 1 Diabetes" (Nightscout Foundation, 2016). The foundation positioned the Nightscout community as both an innovator and advocate in patient-driven technology design and disease management. Nightscout was designed to provide remote glucose monitoring, basically displaying the CGM data in different formats, and the website takes pains to warn that the system is for educational purposes. People who embrace the use of open data in their care management, however, can find themselves in a gray area between "micro-dosing" and "remote bolusing," practices that the FDA has tried to discourage patients from engaging in due to safety concerns. Recently, there have been efforts among members of the Nightscout community to explore partnerships with other diabetes technology DIYers, particularly those involved in making their own artificial pancreas systems. Although there have been small, scattered collaborations of people building artificial pancreas systems, for the most part these have been technically savvy adults living with T1D.

4.2. Toward a DIY Artificial Pancreas

#OpenAPS is a growing open source, DIY diabetes project that aims to design a safe and effective basic artificial pancreas system that will automatically adjust an insulin pump's delivery to keep blood glucose within a safe range overnight and between meals. It does this by communicating with an insulin pump to obtain details of all recent insulin dosing (e.g., basal and bolus), instructing the CGM to obtain current and recent blood glucose estimates, and issuing commands to the insulin

pump to adjust temporary basal rates as needed. Even more than Nightscout, which is primarily concerned with data access and visualization, OpenAPS is highly experimental and requires constant monitoring by its users. Their website warns interested patients and caregivers that the system is not intended to be “set and forget” at this point for safety and technological reasons:

To maximize safety, #OpenAPS only doses basal insulin (not boluses), so patients still need to bolus for meals as they do today. This is a DIY implementation and it requires constant monitoring and testing to make sure the system is working as expected, (Lewis, 2016)

Although only a handful of people are actively involved in OpenAPS (approximately 34 “loopers” as of January 2016 have created their own closed looped artificial pancreas system), these projects, together with Nightscout, are part of a broader movement that seeks to “liberate” data from proprietary medical devices. Whether actively using the system or not, the DIY projects of Nightscout and OpenAPS are viewed by many supporters in the diabetes online community (or DOC, an amorphous collection of social media, blogs, and websites around living with diabetes; see Hillard et al., 2015) as a mechanism for pushing the FDA and the medical device industry to release commercially available systems to the T1D community faster. The stance of those in OpenAPS and Nightscout using the #WeAreNotWaiting hashtag is rooted in both a pragmatic DIY ethos of making life (even incrementally) better and a critical stance toward the formal health care system.

5. LIVED DATA: DEPENDENT BODIES AND COLLECTIVE CARE

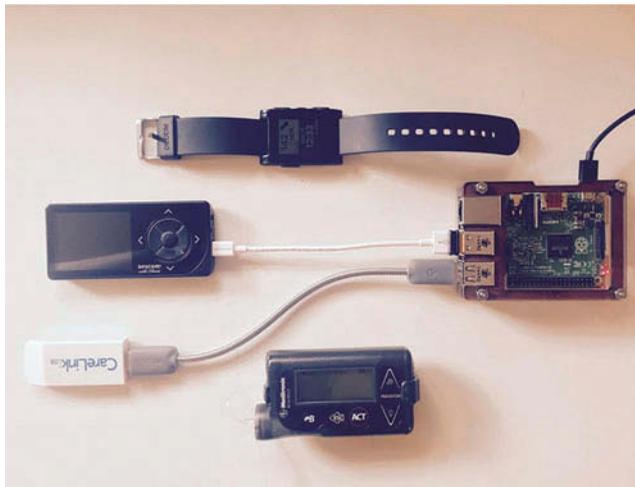
When parents monitor their children’s blood glucose levels through software apps at school and programmers write algorithms to trigger alarms when their glucose levels plummet during the night, DIY health care is neither something done “by yourself” nor easily reduced to an “act of innovation.” Rather, we found that people involved in Nightscout and OpenAPS performed continuous work of holding diverse subjects, objects, bodies, processes, and institutions together. The making of DIY diabetes technology, in other words, unfolded through a multitude of sites through which data were lived; from poking needles into the skin and managing the needs of family and friends, all the way to legitimating self-written code with regulatory bodies like the FDA and mobilizing a collective sense of “we” (as in “we are not waiting”) among patient groups. In the following sections, we unpack each of these sites and moments of data as lived through physical bodies, among social worlds, in new types of work arrangements, and across institutional boundaries.

5.1. Data That Hurt: Bodies and the Physicality of Tracking

A myriad of images that show how DIY diabetes systems work have flooded social media platforms like Facebook and Twitter, publicly displaying the various configurations of insulin pumps, open source hardware platforms like Raspberry Pi, batteries, and mobile phones. In these images, technology is arranged on a clean surface, parts and wires neatly and even beautifully arranged (see [Figure 1](#)). In many ways reminiscent of a whole genre of “open source hardware” hacks and “DIY maker” projects found online, this imagery demonstrates how the thing is made, giving off a vibe of “you can hack this too” and “this is how you can do it.” The images articulate a mode of production we have come to associate with DIY making: open, hackable, modifiable, doable.

Similarly, popular media articles have largely focused on the celebratory aspects of DIY diabetes technologies. Stories on Nightscout, for instance, often depict people happily holding up their Pebble watch to the camera, their blood glucose data on full display (Costik, 2015; Smith, 2016). In such images (see [Figure 2](#)), the Nightscout watch interface shows the person’s real-time blood glucose value and an upbeat saying, “Everything Is Awesome” or “Dont WRY be:” These watch shots are also hugely popular among Nightscout users who post them regularly on Facebook, Twitter, and Instagram, garnering numerous likes and comments of encouragement. People document their blood sugar data in relation to everyday experiences like eating pizza at a sleepovers and shopping at the mall, along with more extreme activities like bungee jumping and getting married. Diabetes data have also generated humorous memes on the CGM-in-the-Cloud Facebook group, exemplified by an air force pilot

FIGURE 1. OpenAPS system.



Note Image courtesy C. Hannemann (2015).

FIGURE 2. Nightscout pebble watch face.



Note. Image courtesy of Amy Stieglitz Kirk.

showing the Nightscout system working at 4,000 ft, who became known as “Commander of the CloudForce” (see [Figure 3](#)). Together these images present a powerful testimony—both intimate and public—documenting how data and DIY medical technologies have empowered people to reclaim parts of their lives often stolen by diabetes.

This public narrative of triumphant technology is only one aspect of lived data. Take, for instance, the photo (see [Figure 4](#)), which we took during a dinner with two developers centrally involved in Nightscout and OpenAPS. An everyday cyborg configuration sprawled across the table in a tangle of wires, pumps, gummy bears, smartwatches, beer glasses, and an old receiver held together with a rubber band. We watched as the developers checked their watches and phones, monitoring blood glucose numbers all the while dinner was unfolding. Haraway and Suchman’s socio-materiality calls for engaging this kind of “mess.” What became so visible at the dinner, amidst of wires, drinks, and Pebble watches, was how DIY innovation, no matter how creative or elegant, does not offer people a quick fix to chronic illness but instead requires constant work to manage the messiness of these configurations.

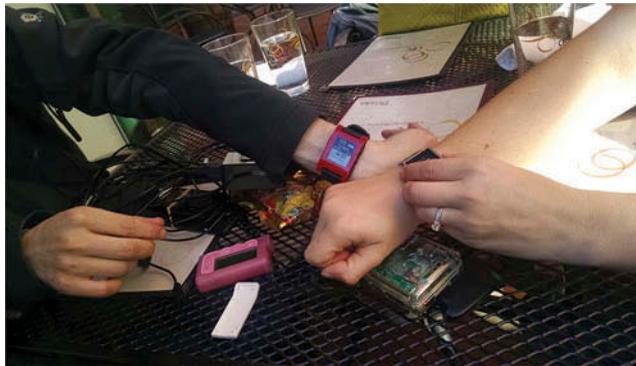
Side by side the imagery of empowering watches shots across social media is another type of photograph, one that documents a more visceral side of diabetes data where the physicality of tracking is represented by a sensor sticking out of a person’s arm (see [Figure 5](#)). This insertion site, the place where the tracking of blood glucose data begins, is rarely pretty. Skin around the sensor can break down, a condition known as dermatitis caused by the constant application of various adhesives like Tagaderm and SkinTac used to keep the sensor attached to the body (see [Figure 6](#)).

FIGURE 3. CGM in the cloud nightscout meme.



Note. Image courtesy of W. Ton 2015.

FIGURE 4. Living with diabetes data during mealtimes.



Note: Image courtesy of Elizabeth Kaziunas.

Some people in the Nightscout community try to make the sensor site itself more attractive, using tape and materials to decorate or camouflage the area; yet this aspect of data tracking, of technology being embedded in the body, is intimate and often distressing.

In DIY diabetes technologies, the physicality of tracking, both hopeful and hurtful, makes visible its sociomaterial complexity and its consequences through the

FIGURE 5. Experience of wearing a CGM sensor.



Note. Image courtesy of R. Rap 2015.

FIGURE 6. Dermatitis from CGM sensor adhesive.



Note. Image courtesy of J. M. Lagen 2015.

skin. Jose, a self-described “maker,” spoke about how the costs of data tracking are not well understood by those who see data as external to the body. Diagnosed with T1D as an adult, Jose explained how within weeks he was frustrated with the daily

grind of diabetes care and felt like he was doing a poor job of keeping his blood glucose levels stable with his CGM. After a few close calls in which he didn't catch his blood glucose levels dropping in time, he began typing search terms into Google, everything from "diabetes pump hacks" to "data tracking." His search eventually led him to a Quantified Self meetup where he hoped to pick up some ideas on how to better understand his blood glucose data. Jose described striking up a conversation with one of the regular QS attendees:

I met a woman ... and she was doing lots of experiments with her body regarding step counting and exercise counting and blood pressure. And I asked her, "Yeah, like this sounds incredible, you got all this information that tells you about what's happening in your body like around the day. But have you tried anything with measuring your blood glucose?" And she was like, "Oh no, that hurts a lot! I would never do that!" So I was like, "Yeah, of course, it hurts!" That is what is difficult about this!

The pain and discomfort of tracking that extracting data can actually hurt and are not typically discussed in studies of personal informatics or in the Quantified Self movement, where people use commercial wearables like Fitbits and Fuelbands. When needles poke bodies to get data, the story of empowerment comes at high cost. If one has diabetes, sensors need to be physically inserted into the body. Insertion sites—especially on the small and skinny bodies of young children—can easily become sore and need to be rotated from upper arm to lower back. People living with T1D know that data tracking hurts, and no matter how valuable, the high cost of getting data from the body needs to be carefully weighed. One mother of a small child with T1D described the physicality and pain of tracking:

A lot of this stuff is invasive stuff for your child. I mean, you're putting something under their arm and it stays there for two weeks. So there is a trade-off here and it's worth it for us, but it's not for everybody.

For another parent, tracking her son's glucose with a CGM was a decision that took careful consideration:

The reason it took us so long to get a CGM for [my son] is because he was already on the OmniPod [type of insulin pump], so its stuck on you. It's something that's on your body all the time. And I was unsure how he would feel about having something else stuck on him.

The invasive nature of data tracking—having something "stuck on you"—is important to understand, because the physicality of tracking not only is in the materiality of devices but also is as much about data's relationship to flesh and blood, skin and muscles. In our field sites, people maintained the body so that it could accommodate sensors without damaging the skin and considered the human form in strategically

placing the device so that a person could move about throughout the day without getting snagged on doorways or clothes. They gauged if/when it is possible to let the mind and body rest from the constant demands of data tracking. Indeed, some people took routine breaks from Nightscout altogether, despite the benefits of the system, because the physical, emotional, and social costs were too high. And yet others in the OpenAPS and Nightscout communities continuously used their diabetes data devices 24/7, 365 days a year—the merging of machine–body data becoming how they lived and who they were. One of our interlocutors who used a DIY artificial pancreas system described how using these systems shaped his ontology:

I'm a cyborg absolutely. ... It's a cybernetic technology; it's an appendage. ... I have needs in my body and they give me information. Some of them give information about my body, some of them change the chemical makeup of my body. So that makes us all cyborgs to some degree, me more so than most.

The Cyborg—to employ Haraway's figurative use of the term—is monstrous, is frightening, and gives pleasure at the same time. The cyborgian experience of diabetes data exemplified here entices as much as it repels:

I have a love/hate relationship with the pump. Because on the one hand, it's like when you go low, there are times I just want to rip it off and throw it against the wall or I'm afraid of it. Like, "Holy cow, I have a computer attached to me that is killing me" in a very palpable way. Like when you're 30 [blood glucose value], it is a very real feeling. Like, "This is killing me." So that can be difficult. But when you're 300 and you feel the insulin kicking in and it goes, "Woosh!" and you're back at 100. You're like, "Wow, that is amazing!" So it's very difficult to resolve that tension.

The tension between fear and amazement—of wanting to simultaneously rip the machine off and out of your body while your life depends on its silent stream of data—is a darker, visceral counterpart to the current narratives around personal data found in HCI literature. As wearables become smaller and increasingly embedded in the body itself, and as data are increasingly part and parcel to how many people learn, exercise, eat, are being evaluated, rate others, and so on, we need to consider such lived realities of cyborg politics. There is real work, both physical and emotional, in navigating the tensions of living so intimately, physically with data. Nightscout and OpenAPS highlight the physical cost of getting data and push personal informatics research to engage stories of despair, pain, and messiness, as well as stories about individual empowerment, as they are mutually constituting one another.

5.2. DIY and its Dependencies

The physicality of tracking diabetes data, although deeply personal, is also social. The work it takes to live well with one's machines is difficult to perform alone, and

managing diabetes through data often requires the support and guidance from others. Through the act of living data that is both celebratory and painful, people who use DIY diabetes technologies navigate the tensions of chronic illness together, leaving their relationships marked by dependencies and obligations that often sit in stark contrast to the more public stories of individual empowerment and self-care.

In successfully hacking a CGM to “liberate” their diabetes data, people were left with the difficult (and sometimes dangerous) challenge of interpreting those data to make appropriate therapeutic decisions. Access to personal data was perceived as a means to increase understanding of one’s body and open up new possibilities for diabetes management, but the benefits of data tracking also required people to engage in types of work that caused anxieties and concerns. Diabetes care, here, required expertise not only in the body’s biochemistry but also in writing and debugging software. Many people were excluded from the inner workings of their machines as they relied upon the help of others to make sense of their data as well as to help manage software labor. A version of the Nightscout interface for the Pebble watch face and website shows the wide range of data used to monitor, predict, and (with the addition of OpenAPS) control diabetes (see Figure 7).

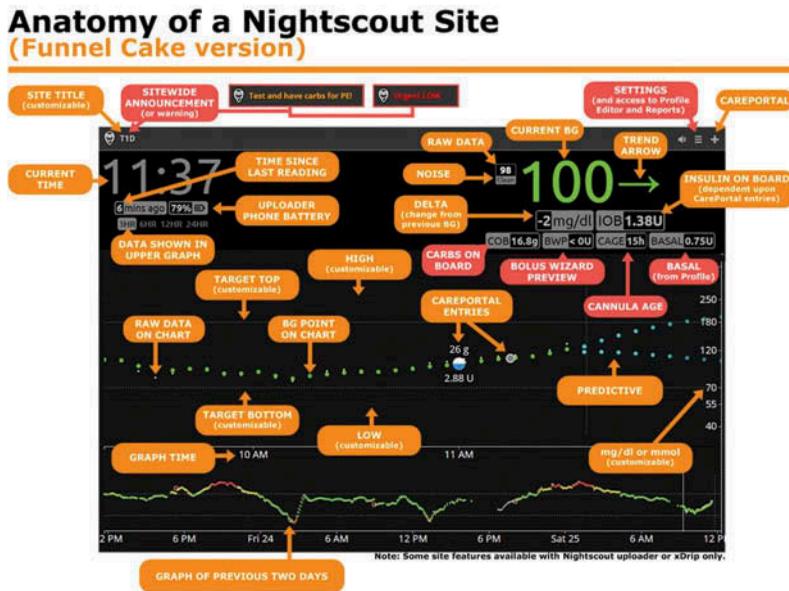
Small screens are jammed with information from real-time blood glucose readings to predictive graphs to noise levels. In Figure 8, the small slice of personal data on display is the outcome of the collaborative work of many people—multiple

FIGURE 7. Pebble 7. Nightscout pebble watch face CGM in the cloud version.



Note. Image courtesy of Nightscout 2015.

FIGURE 8. “What’s on a Nightscout Site?”.



Note. Image courtesy of Nightscout 2015.

developers, users, and their families—and doesn’t even account for the contextual data that don’t fit on the screen. As a result of such complexities, many people turn to the CGM-in-the-Cloud Facebook group for help to interpret personal data. An active and passionate group of Nightscout volunteers, for instance, offers technical support through the Facebook group 24/7. This team is staffed with people who have the technical skills needed to address questions involving installing and managing the DIY system, such as connecting the rig, updating software, troubleshooting coding errors, and creating a database. Many individuals also use CGM-in-the-Cloud to share insights on diabetes management and collectively arrive at best practices. Scrolling through the group’s Facebook feed shows how people help interpret one another’s data. For example, a confused parent posting a screenshot depicting the graph of their child’s blood glucose levels after dinner will elicit comments such as, “My kid’s graph looked like that when they were having a growth spurt” or “Did you happen to eat pizza?” (a notoriously tricky food for balancing blood sugars). It is in these moments of advice sharing and collective sense making of data that it becomes visible just how much DIY diabetes systems were enacted through mutual dependencies and collective support structures.

Shared and widely adopted by members of the DIY diabetes community, many of these informal data practices have influenced the design of software. Developers

connected to Nightscout and OpenAPS, for instance, have begun to create a wide range of open source data visualization and analysis tools such as Tidepool's Nutshell and Perceptus's GlucoDyn in order to assist people in this interpretive information work. Real-time and predictive data applications are considered crucial, as they made data actionable. As one of our participants explained, diabetes data interpretation is a dynamic process of understanding the balance between one's body, social and environmental contexts, and various insulin treatments:

Looking at historical data from my CGM isn't helpful. It's what can I do to change the situation? And it wasn't that my basals were messed up. I knew how to do things, but [a bad number] happened. I ran across the street; I got excited; I got adrenalin. All that stuff changes what your numbers are, what the outcomes are. So that's me figuring out how my body reacts to that. ... It's not data you can really track using any historical system.

A developer of GlucoDyn noted that this type of data work is extremely difficult and most people need help to understand "what's really going on with themselves or with their children."

Data brought increased insight for treating a critical health condition; yet, the more detailed and complex data visualizations and treatment strategies became, personal diabetes data also became a source of tension among family members and friends. With real-time data at their fingertips, parents described feeling negligent if they did not keep their child's blood sugars level and worried about becoming oppressive in their hypervigilance. For example, there were many passionate debates on CGM-in-the-Cloud about "helicopter parents" and making children with T1D feel judged for not maintaining perfect numbers. Adults also struggled through living with data together: A 40-year-old woman with T1D told us that she has a few close family members and friends with T1D who have access to her Nightscout data. Whereas her Nightscout friends check her data freely, her husband often feels uncomfortable looking at her real-time diabetes data for fear of invading her privacy. To mediate the role that data play in their personal life, they set up a variety of alarms to alert him only in case of an emergency. To navigate such tensions required routine emotional labor for both the person living with T1D and the family and friends. It was a complex system of dependencies that unfolded through these collective practices of sensemaking, frequent checking in, and legitimizing one's approach with others.

Such practices, people stressed, often reduced the psychosocial burden of tracking when a person's life was on the line. The sharing of source code, photographs of rigs and watches and insertion sites, and even the raw data from people's Nightscout applications happens openly on social media, GitHub, and blogs. The public nature of this data sharing was considered a radical step. Health data are typically viewed as something to be privately guarded, to be shared only with professional health care providers and perhaps close friends and family. Despite warnings from medical data security experts that open source health applications like Nightscout could lead to increased risks in privacy and medical device security

(Klonoff, 2015), the people we spoke with were often relieved to no longer be alone with their data.

Outcomes of freely sharing diabetes data were in crowdsourcing some of the information work but also in managing the emotional labor that comes with tracking chronic illness. One of our interlocutors explained,

Diabetes is such a lonely disease. You don't hang out with a bunch of other people with diabetes because there's just not enough of us. ... The data and the ability to share the data brings us together and gives us the opportunity to learn from one another.

This sentiment, echoed by many, points to how care work, when performed “by yourself,” was isolating. Sharing personal data and experiences online through social media provided people with a glimpse into how one could potentially better manage diabetes, all the while making visible the work that goes into living with a chronic illness. Furthermore, data itself were perceived as deeply relational. “Nightscout has more blood sugar data than the world has ever produced in one spot,” a Nightscout foundation board member told us. Generating such a significant “body” of data connected members of the community intimately to one another. One developer described creating a data visualization from all the Nightscout user data that allowed people to view their own personal data as part of a collective diabetes experience.

I set up an aggregator that shows everyone's blood sugar that enrolled at the same time. And one of the side effects of that is that the kids and parents are looking at this saying, “Oh, it's not just me. I am not at fault. I am not a terrible parent just because I'm having some readings, because look, everyone gets those readings.

Data, here, are both intensely personal and collective, as people donated bits of themselves, through pokes and pricks to the skin, into shared repositories. It also compellingly points toward a way of engaging the multiplicity of lived data in design: Through making the costs of tracking chronic illness visible, personal pain is not erased but becomes an experience of shared empathy rather than individual isolation.

Software and data analytics, although often assumed to increase objectivity and efficiency, required not only constant work to maintain and write code but also emotional labor to navigate mutual dependencies and obligations. Personal data offered people greater insight and types of control over their bodies than found in the traditionally passive role of the patient; yet, DIY health care creates new, and arguably more precarious, dependencies that rest not only on fragile bodies but also on the free labor and goodwill of volunteer workers, software coders, families, and friends.

5.3. Technical Labor and Care Work

Shared data gave those involved in Nightscout a newfound power as the owners/custodians of a valuable commodity. Everyone from medical device

companies, government agencies, and institutions of higher education (ourselves included) has expressed interest in “working with” groups like Nightscout. The sociopolitical stakes of personal data were especially visible in the technical work of developers who both collaborated to create open source tools and experimented together with data, often pushing at the boundaries of human–machine relations and legal, regulatory infrastructures. A number of activities in Nightscout involved advanced programming knowledge or technical skill sets, such as building and designing software and hardware, database management, coding, and calibration, and these activities were done by a small group of developers. Those with experience in software and hardware engineering, for instance, noted that they spent time investigating calibration issues with the Dexcom, assisting others in building and configuring xDrips, providing hardware support, contributing to the Nightscout repo (e.g., Github), and configuring Nightscout databases and web setups. Nightscout code is currently available for anyone to download, and although new builds are still being developed and released, the core developers tended to view remote monitoring of diabetes data as a problem solved and had moved on to explore a number of experimental projects, which included building their own artificial pancreas systems. In the creation of algorithms that dispensed insulin and experiments with bodies, coding itself became the expertise of care work. And yet, developers, in becoming experts in DIY health, also had to increasingly shoulder the burden of risk and responsibility. In what follows, we illustrate tensions in the work of writing software code for managing chronic illness.

Soldering Care and Negotiating Risks

Those who designed DIY diabetes systems formed a small-knit community of open source advocates and software developers who worked closely together in improving and maintaining the various software packages. Many of them were driven by the desire to design a system that managed to “close the loop”—and build the world’s first DIY artificial pancreas system. This technical work did not take place on the CGM-in-the-Cloud Facebook group; rather, the developers communicated privately through e-mail, IRC, Twitter, and Skype. Part of the reason for this was a concern over the liability in sharing code with people “who wouldn’t know what to do with it.” Data sharing, here, was a secretive, risky, and ethically fraught activity, especially when dealing with algorithms and technology that involved insulin dosing. Openness, in other words, was anything but a straightforward approach to simply adopt, but required careful negotiation of what was considered safe or risky to share. This is in stark contrast to avocations of open innovation and radical openness as solution to and intervention into corporate control and monopoly.

“What if something went wrong?” was a concern for developers while experimenting on themselves; however, it was something altogether different when sharing personal code on Github. As one developer put it,

I've been doing all these tests and all of the developments around how my body reacts to insulin and to carbohydrates and exercise and whatever. So like putting my code up there ... I feel that someone could get harmed with it, and I don't want that to happen. I don't want to have that on my head.

Although people used FDA-approved pumps and sensors in their DIY systems, tinkering with algorithms for dosing could easily have lethal consequences. "I don't want my algorithm to dose the crap out of some kid and kill him ... so we're in a grey areas here." Deciding when to share data in this technical and ethical gray area was precarious. Yet developers strongly argued for the importance of sharing despite the uncertainty, in part because they considered the improvements in people's daily life with T1D was worth the risk that came with open data sharing. The developer of a popular DIY diabetes device voiced his reasoning for putting his code on Github despite wariness about the FDA and possible legal repercussions: "I think I'm not doing anything that's terribly wrong. I think I have warned people: 'Hey, if you are soldering something together yourself, you may know that this is not the same as a store-bought medical device.'"

These may appear as harsh words at first, but developers, who themselves were living with T1D or were parents of diabetic children, understand the desperation that underlies open data sharing and participation in DIY projects all too well. We were told a story of one grandmother whom a developer had taught to use a soldering iron so she could assemble an xDrip for her grandchild with T1D. Although on one hand a celebratory ode to open source and open data, this story exemplifies a harsh reality: DIY health is precarious and risky, and means to literally solder care together. Care, here, is not only mediated by technology. The ability to code, solder, and debug software itself becomes the expertise of care.

Coding the Cyborg Body

Among the developers, there was a sense of excitement in being at the forefront of science and technology and revolutionizing a broken health care system. The processes of self-experimentation were central to this experience

We're just like doing and trying out different things. And we're experimenting with our bodies. ... I'm a little bit more open to risk, to try new stuff. I develop my own protocols for testing, but in the end, I go on and test it and see what happens.

To date, people have tinkered with just about every commercially available diabetes medical technology except for the actual sensor that measures interstitial fluid (used to determine blood glucose values) and, at least so far, the actual insulin pump. "The only thing that has not been touched is building an open source pump," a looper shared in an interview. "I've seen people modifying transmitters, I've seen people modifying receivers, I've seen people modifying everything around that, but not the

actual pump.” When asked to speculate on why the pump hasn’t been modified, he further reflected, “I think there is something in our heads that tells us that we shouldn’t mess with those little motors. ... Right now we can modify stuff that gives information, but not the thing that delivers the medicine.” Fear of messing around too much with the machine suggests that in DIY experimentation there is an ever-present careful calibration about just how far one should go in manipulating the boundaries of data, body and technologies.

Self-experimenting was also seen as a social good. When people were engaged in testing devices and trying out new algorithms, the #WeAreNotWaiting movement and the coding of one’s body became one and the same thing. Much of the earlier hacking and coding in Nightscout had evolved around the information visualization problems, but moved—especially as developers got to know each other better—into pushing at the boundaries of controlling the body through data. Others, who followed the innovative projects of such developers but were less familiar with software coding themselves, volunteered to “donate their bodies” to aid the cause. One such devoted DIY health advocate described how he hung out with people building DIY artificial pancreas systems:

I said, “Sign me up. When you build it, I’m your test subject.” ... I didn’t have the skill set to do that, but other people do and I think it’s fantastic. It’s really freaking dangerous, but when the people building it happen to be two of your closest friends, like fair enough. They are like, “We’re going to hook you up to it and then you go to sleep. And we’re going to stay up right next to you all night and make sure you’re okay.” And that was like the level of discussion we had, where it gets kind of scary.

Thad, diagnosed with T1D in his early 30s, got involved in designing his own artificial pancreas system to learn about how diabetes impacted his body. Recalling the early, stressful days of managing the disease, he noted,

During that point in time, I did not understand what was going on. As far as me taking care of myself as a diabetic, I really had no idea what I’m doing. I had very little idea of how what I was eating was impacting me and how I was taking way too much insulin.

After Thad connected with the DIY diabetes developer community, he started “playing with the data,” finding inspiration on Twitter and sites like Hackaday, a blog dedicated to open source hardware and tinkering. He eventually began developing his own artificial pancreas system, explaining,

I started working around doing code with the Raspberry Pi and the simulation stuff myself. And I started analyzing how my blood glucose curves would change with different types of carbohydrates. ... So I was doing all types of crazy experiments like eating stuff for the science.

On using his own DIY artificial pancreas system, he admitted to being both exhilarated and afraid:

Trying this thing on myself like for the first time was like a big thing. ... I spent like two whole days just watching the system give me recommendations and I just was manually bolusing [an insulin treatment]. ... And afterwards, I decided to put it into live mode. Wearing it for the first time, I was like super nervous for the first whole week. I was watching all the time what the system was doing.

Although he now “trusts it 150%,” Thad admits that at times it is still scary to know his artificial pancreas system is dosing him with enough insulin such that if the algorithm was off, it could be fatal. “This little machine is doing the work for me,” he told us, “It’s weird to see a machine doing that with entering amounts of insulin in your body that could actually kill you.”

Some adults involved in OpenAPS told us while they trusted their self-made machines, they would never use them on their child and viewed DIY data monitoring tools like Nightscout as a safer option to customize care. Even Nightscout itself has been the subject of a few critical commentaries from the academic medical community warning of potential risks from data privacy to dosing (Klonoff, 2015). All of the people we met with who used various arrangements of the DIY diabetes technologies, however, were well educated about these risks, taking them in stride. A Nightscout Foundation board member explained that those participating in this collective experiment, including those people with T1D, their families, and caregivers, grew adept at balancing the risk between data, diabetes, and bodies. “They’re the ones who are saying, I’m willing to accept the state of this code because the alternative of not having it is so much worse,” he maintained. “I’d rather have 6 hours of visibility overnight of my child’s blood glucose than zero hours of it.” In fact, managing the risks of DIY technology was minor compared to the acute and long-term risks of diabetes, itself:

The notion that a tool has to be perfect, or a tool has to be risk-free, I think is a misguided notion. Diabetes is a huge risk. We guess all the time with every single insulin dose. ... And the reality is we all suck at it, it’s just terrible. ... I would much rather have an imperfect system today, acknowledging that there is some risk that it could kill somebody. I totally get that, but people are dying today without it.

This all makes visible, in a very deeply felt way, what is at stake with the expansion of quantification and self-tracking more broadly. The act of volunteering to be a test subject while your friends watch over you at night to make sure you stay alive is a new data story, one that draws on the popular rhetoric of DIY making, personal informatics, and patient empowerment while undoing them. Our participants were forced to make nuanced distinctions between watching data (Nightscout) and acting on it (artificial pancreas dosing). Many walked a blurry line, experiencing

the dangerous/fantastic/mundane practices of data every day. The gap between what people were afraid to touch (e.g., those little motors that deliver medicine) and the types of technology, data, and bodily functions they felt free to tinker, modify, and experiment with argues for a complex understanding of personal data and what it means to interpret them, hack them, and live both the opportunities and risks.

Troubleshooting Diabetes: The Role of Clinical Care in DIY Health

Despite the complexity and risk involved in merging technical labor and care work, people indicated they rarely consulted physicians about using Nightscout, OpenAPS, and other DIY diabetes technologies. This response was partly pragmatic, as doctors were viewed as unable to provide the needed expertise in fixing either code or faulty hardware. “That’s not the doctor’s job,” explained one Nightscout user. “My doctor, he could spend an extra hour with me discussing technology or something; but that actually doesn’t help. Because he’s not a technologist, what is he going to do?” The absence of clinical care was also rooted in a misalignment between professional workflows and the dynamics of personal data. Physicians typically relied upon standardized clinical practices for engaging with patient data such as paper templates for charting blood sugars, food journals, and faxed printouts of CGM data. Such systems, however, were rarely helpful to people needing assistance interpreting blood glucose data in real time. Although clinicians continued to be regularly consulted for traditional diabetes management activities (e.g., ordering A1C labs, prescribing insulin), many of the people we met deliberately chose not to disclose their use of DIY diabetes technologies to their doctors. One man with T1D confessed he has no plans to tell his endocrinologist he uses a DIY artificial pancreas system:

I have this [OpenAPS] automatically adjusting my insulin levels and I just need somebody to write me lab orders. ... At this point, I think [my doctor] doesn’t need to know how I manage my diabetes on a day-to-day basis. He is there to troubleshoot any relations if I get seriously ill.

Others, however, felt strongly that clinicians needed to better understand technical types of care work. Those who brought their use of DIY diabetes technologies to the attention of clinicians received mixed responses. We heard positive stories of people being invited to share their experiences and demonstrate how Nightscout or OpenAPS worked at their local diabetes clinic. More often, however, clinicians didn’t feel responsible for understanding the details of people’s diabetes data practices. One woman described how a doctor dismissed the specificities of her DIY artificial pancreas system being irrelevant to clinical practice:

I took OpenAPS [to my endocrinologist] when I first started using it. In the second month I was already seeing a huge difference, like my blood sugar was

already dropping and my A1C dropped. And [my doctor] was kind of like, “Oh, how did you do this?” “Well, I built this tool, it pushes alerts ...” And he started talking over me, “Oh okay, but do you have less lows?” I’m like, “Yeah.” And he was like, “Okay, that’s all I need to know.” And he went back to his computer typed something and said, “Here’s your prescription.”

She confessed that this lack of interest in understanding the technology is frustrating, because the software she writes directly impacts her treatment strategies: “I’m annoyed when I try to talk to my doctor about OpenAPS, because it’s important for me to explain to him why I don’t see any improvements [in blood sugar levels], he kind of brushed it off.”

Negative or dismissive clinical attitudes were frustrating to those who relied on systems like Nightscout and OpenAPS to manage their diabetes but also expected. Living intimately with technology gave people insight into the nuances of diabetes data that fell outside the expertise of most clinicians. “I spend more time looking at my data than anybody else,” explained a Nightscout developer. “My doctor knows less about diabetes than I do, let alone my diabetes.” Such experiences suggest the emergence of new types of care work—those activities undertaken to manage a person’s health and wellness—centered around data practices and technical expertise. For others, however, the management of diabetes required facility in both technical work and clinical medicine, and we found that clinicians who engaged with Nightscout and OpenAPS were highly valued in these DIY communities. Another Nightscout developer explained how better care required creating collaborative data practices between the DIY diabetes community and healthcare professionals:

There’s an attitude today that each community solves needs for themselves. So the clinicians, doctors solve their own needs and the patients solve their own needs. ... As we start to get clinicians that are actually interested in solving the issues that patients have with providing better service, better treatment, better care, they could adopt some of these same sort of practices to take the data that the patients already have.

The tensions between clinical expertise and the role of technical labor is troublingly absent in popular narratives of personal data and the democratization of health technologies, as it is patients who must troubleshoot diabetes when bodies depend on the maintenance of data machineries. Care work, here, required expertise in computing, as well as access to equipment and a level of daring, something not everyone can easily afford to do. DIY technologies like Nightscout and OpenAPS, dependent on coding and data analytics skills, in turn shaped how care was practiced and who was able to perform it. Although considered experts, open source developers largely performed this work unpaid, at high personal risk, all the while carrying tremendous emotional weight and responsibility for wider patient communities.

5.4. Advocating for/with Personal Data

In the previous sections, we have explored #WeAreNotWaiting as a DIY/making culture centered around personal diabetes data in terms of its social arrangements and techno-material designs; however, it is also, important to note, a patient-led advocacy movement. As a slogan and rallying cry, “We are not waiting” calls attention to broader sociopolitical issues of data ownership and access: What is the role of regulation in personal diabetes data? When should data-tracking devices count as a medical technology? Whose responsibility it is to address the needs of people living with T1D and their families, and how should they be held accountable? Our study points to the ways in which people’s use of data in open source projects like Nightscout and OpenAPS should be read as a utilitarian work-around but also as a collective political and ethical stance. In this section, we “expand the frame,” as urged by Suchman (2007), to include in our analysis the relationship between diabetes data/bodies/technologies to political institutions and biomedical corporations.

A Nightscout father summed up the situation facing both his family and the broader U.S. health-care regulatory system: “Does the patient own their own data and can they do whatever they want with it?” People we spoke with described numerous challenges in using commercial products as medical device companies “black boxed” data through proprietary algorithms to gain market advantage. “In order for me to get my own data,” explained one programmer with T1D, “I had to hack my devices. And, you know, most people don’t really have the wherewithal to do that.” Along with the desired access to raw data, people were motivated by the fact that many commercial diabetes devices and data analytics tools were so complicated that they were unusable by most people. People felt ethically compelled to hack devices and create data tools for themselves and others, as one Nightscout father articulated:

The software that comes with those devices, what you’re supposed to use with those devices, it’s like crawling through broken glass in order to get it up and running. Like, I’m a smart guy. I run software teams for a living. I could not get CareLink [type of commercial diabetes data software] up and running even when I had all the requirements they said I needed. ... It was way too hard. And it became clear very quickly that we could do way better. It’s not rocket science to build well-designed software that just works. ... So I decided I wanted to do something in this crazy diabetes world.

For our participants, the data complexity that comes with living in “this crazy diabetes world” is not just a biological phenomenon or technical problem but, as Jain (2013, p. 14) argued, “a politics with which to engage and struggle.” We saw this struggle play out in the various kinds of advocacy work people performed, both in the effort involved for parents to enable their child use an unregulated medical device at a local school and in the collective labor needed to challenge the regulatory bodies that defined the categories of “medical device.” During our ethnographic engagement, we witnessed Nightscout foundation board members in the process of negotiating with the FDA about whether Nightscout should be classified as a Class II

medical device like a continuous glucose monitor. An FDA release of new guidelines on medical display systems, unleashed a flurry of political work as people wrote system documentation, puzzled over and analyzed past discussions with federal agents, and brainstormed their best legal options. A Nightscout parent mused, “The FDA, right now, I don’t think they’re really sure how to handle a bunch of do-it-yourself medical people. I really don’t. I think it is kind of uncharted territory for them.” The lines between data and device are often blurry for all parties involved. One developer reflected,

I wrote some code and put it online and it doesn’t necessarily do anything until you compile it and put it on something. At what point is it like, “Okay, you crossed this line, this is now too much, you made a medical device?”

At the time of our study, it was still unclear if the real-time display of data or only retrospective data would be acceptable to the FDA; furthermore, there was no agency guidance on using diabetes data for treatment decisions, and people generally interpreted those working on their own artificial pancreas systems as operating far outside the bounds of the FDA. “Basically, it’s just that the FDA will not allow remote bolusing,” explained one participant, referring to an automated injection of insulin to the body (controlled through custom algorithms based on real-time diabetes data) taken to cover an expected rise in blood glucose. Some who use DIY artificial pancreases seemed confident about finding ways around regulation, whereas others expressed wariness of their personal liberties. “I’m concerned that companies or the FDA might limit us. ... As long as I’m doing it for myself, to my body, I don’t think this should be a problem. I should have that freedom.”

The relationship between Nightscout and other open source DIY diabetes projects also caused concerns about the FDA confusing how data were being used by differently by each system leading to stricter regulation, even though in practice these devices often exist as shifting assemblages. One developer of DIY hardware for diabetes explained the situation:

At one point some people said that what I was doing was going to be hurting Nightscout and holding them back more. They were worried about me going too far outside the FDA and upsetting people. ... If someone confuses like what xDrip [a DIY device] is doing and what Nightscout is doing and lumps them both together, someone may think, “Oh Nightscout is dangerous, it does all these things with custom algorithms,” when it doesn’t. It just displays the same data with a little bit here and there for the raw data. Whereas xDrip has its own algorithm entirely.

Concerns about the FDA impacted data-sharing practices, especially around designs for DIY artificial pancreas systems. For example, some people exchange ideas but never code for fear that the FDA would “punish” people doing open source experiments with diabetes data. Some of our participants mentioned that the impetus

for creating the Nightscout Foundation, a 501(c)(3) nonprofit organization, was in part a response to protect the core developers from legal and regulatory threats. The data and devices they are willing to openly share and not share was subject to careful boundary work (Gieryn, 1983). Although some members of the community began partnering with the FDA, these relationships were continuously maneuvered and negotiated. Not all data were the same, and data artifacts differed based on how they might hold individuals accountable for actions potentially considered illegal. Typically, wearable devices such as Misfit and Fitbit not only track user behavior as data on the device but also send the same data to corporate servers. Presented to the customer as add-on value generated by the company's data analytics, this form of collecting and making sense of data is also Misfit's core business model (there are only small profit margins in the hardware itself). It is exactly such type of black-boxing of what data are and where they are stored and who owns them that the software developers of Nightscout and OpenAPS made visible.

Rooted in the pragmatism of chronic illness as well as a countercultural ethos that many inherently associate with DIY hacking and making (Coleman, 2012; Turner, 2006), the stakes of #WeAreNotWaiting are both intensely personal and political. In our conversations and interactions, people described their data activities as being grounded in pressing life-and-death concerns, as a legitimate work-around for people who did not have better options for the management of diabetes. A father who used a DIY artificial pancreas system with his teenager, for instance, discussed how he wanted the FDA to understand that even an imperfect data system improved daily life for his son in critical ways:

You've got the FDA saying, "Wait a minute, it's got to be super-easy to use, it's got to be perfect. You can have no risk and it's got to be used by the lowest common denominator." ... I can't give you a closed-loop algorithm that [can] go off and run and be perfect because my sensor data is not perfect. ... So we're in this what I call a horrible waiting game. It's right there. I can make it better. I can at least make it incrementally better. ... It's how do we get it through the FDA?

A number of people were also quite passionate about pointing out how open source projects like Nightscout and OpenAPS were challenging the status quo of health care, helping move product release dates forward as well as influencing the design of commercial medical devices. "I know that the Nightscout community has completely changed the future of type 1 diabetes community, of type 1 diabetes care," shared one of our participants, a programmer who also had T1D.

The FDA has changed largely as a result of Nightscout. Dexcom has accelerated its pathway largely because of Nightscout. Medtronic has completely changed directions largely because of Nightscout. ... These people are really, really, really influential. And I think that when we talk about hackers ... I get a bit defensive. ... When we look back on history, the people who influenced change, we don't refer to them as hackers, right? We think of them as game changers. ... The folks at Nightscout ... are more game changers than they are hackers.

Changing the game through creating a movement around DIY health technologies is not without significant costs. The collective contribution of countless hours of coding, inventing new algorithms and protocols, testing, calibrating, and documenting was brought about by a community's creativity and expertise but also daily desperation and, quite literally, people's flesh and blood. There are financial costs as well. One core developer of Nightscout lived off of his personal savings in order to work on Nightscout full-time, devoting himself to getting new, safe versions of Nightscout released to the community and helping people set up and use the system. The costs, from his perspective, were not simply monetary but also ethical:

To be honest, I get a little frustrated sometimes because the feedback that I get is often very encouraging and people often say, "Oh yeah, you're doing such valuable work." But at the same time, I've worked pro-bono for a year, so if it's so valuable to the industry then why am I paying the cost for it?

People weighed the costs of using personal data, not just to their bodies but also legally and ethically both as individuals and as collectives. Working with and living data meant negotiating directly with the FDA and working through the processes of classification, but it was also visible in the everyday ways people enacted care together, such as educating other T1D families about Nightscout, showing them their rigs and blood glucose results, and in people's fights with local school boards to allow their children to use unregulated medical technologies. Taken together, the impact of people's participation in Nightscout and OpenAPS was more than a work-around; it was also a form of collective activism that was possible only because individuals "donated" their code as free labor and their bodies as sites of experimentation.

6. DISCUSSION

The fields of HCI and CSCW have rich histories of unpacking the nuanced relationships people have with technology, of exposing the politics of artifacts, and of seeing design work as an ethical project. We need to remember these insights (exemplified in the work of Kling, Dourish, Star, Bodker, Sengers, Suchman, and others) in this time of excitement and enthusiasm around the possibilities of personal data and DIY/making in health and wellness. In a world where data tracking is adopted by a wide range of people and transformed in new contexts, the boundaries of personal informatics and our understanding of the nature of data itself need to deepen and become more complex.

This article shows the ways in which the uses and meanings of personal data around the management of T1D complicate conventional narratives of data tracking as necessarily "helpful" and DIY as "empowering." Our work is set in a realm of personal informatics that can look both similar and far removed from the activities of Fitbit enthusiasts and Quantified Selfers. Nightscout and OpenAPS—analyzed here

as extended networks of people, data, bodies, politics, technologies—demonstrate shifting relations around technology use and production. Exactly because of its many extremes, from personal self-experimentation to negotiations between DIY hackers and the FDA, our site makes visible how the analytical concept of user empowerment falls short in accounting for the sociopolitical processes and cyborg politics reported in this article. Our findings highlight how the concept of data itself abstracted out of these various sociomaterial relations can obscure the various meanings and ways of relating through data as lived.

The call for participation for this special issue asks, “How can we appropriate personal data to make it personally useful or helpful?” and “How do personal data archives and systems enhance human capabilities, without increasing our dependency on them?” These questions carry with them an underlying belief that data systems can be designed in ways that empower their users and enhance (rather than control) human capacities. We have shown in this article that technology design as enabler of individual empowerment cannot be divorced from dependencies and uncomfortable alliances of human bodies, technologies, institutions, and personal relationships. With empowerment comes dependency, with appropriation and ownership comes risk and vulnerability—from the software coders who risked working at the border of legality to people who risked their lives when living with data machineries.

When we speak of “lived data,” we seek to account for this instability and multiplicity of data and technologies as they are lived. Put differently, rather than designing systems that “reduce dependencies,” we suggest making dependencies, which we argue necessarily occur, visible and the site of legitimate care work. We have shown in this article how much of the human care work, as well as the machine work (writing and updating and maintaining code), remains largely invisible (Star & Strauss, 1999), with those who perform this work receiving little to no compensation. Rather than refusing human–machine dependencies, we follow Haraway in acknowledging that the human and machine in an age of networked capitalism cannot any longer be separated. Although we cannot un-design dependencies, we can remake them from within so that they are humane, start from a place of empathy, and value the work of care, a typically feminized and undervalued form of labor.

We began this article by taking Suchman’s (2007) directive, drawn from Haraway, as the starting point of our analysis: “Now that the cyborg figure has done its work of alerting us to the political effects, shifting boundaries, and transformative possibilities in human-machine mixings, it is time to get on with investigation of particular configurations and their consequences” (pp. 275–276). Our article offered one such investigation of particular configurations and their consequences in detailing the sociotechnical configurations of DIY/open source diabetes projects. Our task in this final section is to explicate the consequences of our findings about personal data for HCI. In the remainder of this article, we draw out some reflections for HCI to consider when researching and designing for personal data and/or data/technology DIY empowerment. In particular, we see our work here as adding to the efforts of those engaged in the research area of lived informatics through an explication of data as both a mode of being and an ethics of design.

6.1. Lived Data

By exploring the *livedness* of data in one of its most extreme contemporary forms, we found that data were a visceral and intellectual experience, a daily grind and a movement for social change, a matter of life and death, inspiring stories of both hope and despair. Data were very much a mode of being, both a dwelling-within and way of interacting in/with the world. We need ways of accounting for the multiplicity of modes (physically, mentally, emotionally, sociopolitically) in which data come to have meaning, not as the contextualization of a number or a feeling or the abstraction of a goal but as a way of experiencing life. Lived Informatics argues for seeing personal informatics as being done “over a range of lived activities” (Rooksby et al., 2014, p. 1171). We agree, but our findings also illustrate ways in which data become the medium and means of living within an unpredictable body. In lived data, we propose thinking of data as modality along with data as thing. In viewing data as a modality, the dynamics of this livedness become important to understand. Data in our study were simultaneously a way of controlling the body, negotiating with one’s government, and empathizing with a community. Designing for people’s experiences of/with/in personal data in health contexts and other areas of life calls for better understanding these new modes of being, but also for a moment of pause to consider the ethics of engineering and design.

In *The Logic of Care*, Annemarie Mol (2008) argued that the practices of managing diabetes—the tinkering with bodies, technologies, knowledge, and people—are both a site of innovation and a moral act. The history of diabetes shows how new drugs, technologies, and techniques have repeatedly changed the daily practices of those living with this illness.

Insulin, itself, has changed the moral landscape. As result of manufacturing insulin, “not injecting” has become a lethal act, and hence a moral activity. It is what technologies do. They shift both the practical and the moral framework. Do they do so in a good way? (p. 90)

Personal data technologies are again shifting the practices and ethics of care. Insulin can now be administered remotely through a DIY device or fabricated at home in one’s kitchen: To inject or not to inject? In Mol’s world clinicians are part of the care team helping people navigate such decisions, but the collaborative care work we discuss in our article happened outside of the clinic on social media. People tinkered with their bodies through code, algorithms, and making things together using exclusive skill sets. Data were lived as means of exploration and mode of tinkering together, creating new sets of relationships and obligations.

Adele Clarke et al. (2010) used “biomedicalization” to describe the ways information technologies have made “to know and take care thyself” the moral responsibility of individuals as well as clinicians. This shift in care work has blurred numerous boundaries (public/private, expert/lay, patient/consumer) and is “unleashing new and sometimes unpredictable forms of agency, empowerment, confusion,

resistance, responsibility, docility, subjugation, citizenship, subjectivity and morality” (pp. 184–185). In our findings, these new modes of being play out in and through data, including the collaborative, intensive care work. DIY health was rooted in both medical and information work that depended on emotional work, coordination work, technical work, and advocacy work. In everyday practice, data bound together these activities, generating new relationships and forms of labor to maintain this growing care network of data, bodies, technologies, and people.

We urge technology researchers and designers to attend to the hidden work involved in lived data. To live data is effortful, and despite the hype and stories of empowerment, it comes at a personal cost. People gave up life savings, weekends, and precious sleep to keep the Nightscout project going. They coped with daily stress both through memes and technical support teams. Some gave up their bodies for science, and others struggled with managing new legal anxieties related to personal data. This labor points to how, to a much larger degree, the promotion of self-empowerment and DIY making brings with it the demand to take on the work that used to be performed by the state and health care system. Framed only as a story of a resistance movement of individual empowerment against corporate control makes invisible this exact work and hides the spread of its neoliberal ethos that demands of all of us to become self-making individuals. Those deemed legitimate members of society, scholars who have studied neoliberal governance have shown (Chun, 2011; Foucault, 1978/2008; Ong & Collier, 2005), are those who fit and help expand a market-driven logic of value and worth. Those deemed unfit are increasingly excluded from health and other public benefits (Ong, 2006). We have shown in this article how as software development becomes an important part of care work, individual coders, parents, and children carry the risks and responsibilities of living with data. The story of individual empowerment masks all too quickly the challenging complexities of managing, working, and experimenting with bodies and the data they produce.

6.2. DIY as Individual Empowerment and Its Consequences

Lived data engage the sociopolitical context of the specific work and practices involved in Nightscout and DIY artificial pancreas projects, as they are all necessarily entangled together. Popular narratives of the intersection between DIY making and personal data dwell enthusiastically on “the magic of the effects.” Many of the systems, designs, and hacks that we examined in our study were inventive and inspiring; for our participants, these projects were often explicitly described as “life-changing.” This excitement, however, can obscure the consequences of health care as it is transformed through utopian ideals of self-management and self-care. The story of the empowered patient who takes matters into her own hand masks how the work of DIY health care—as we have shown in this article—is all but accomplished alone. Rather, DIY health care unfolds through a myriad of dependencies and relations, for example, children on their parents, people on their devices, devices on their

developers, developers on the FDA and regulatory system, the future of health care on the productive work of citizens turned makers, and so on.

Projects like Nightscout and OpenAPS provide a unique lens into a much broader sociopolitical phenomenon of shifting responsibilities in governance, employment, discipline, and health care from the state onto the individual. Nightscout, on first glance, appears like many other stories about DIY making, a success story of people who took matters into their own hands rather than wait for established institutions, professionals, and corporations to take action (we are not waiting!). And yet, what lurks underneath such stories of individual empowerment through technological making are institutional and regulatory shifts that increasingly require people to be self-actualizing and self-enterprising individuals in order to be deemed productive and healthy citizens (Gregg, 2011; Neff, 2012; Williams, 2015). In other words, the line between DIY as empowerment and DIY as extension of a neoliberal logic that tracks people's value based on their capacity to self-track, self-regulate, and self-enterprise is a slippery one. What appears as empowerment today might quickly turn into exclusion, job loss, and despair tomorrow (Neff, 2012). Nightscout is celebrated as a unique case for patient-centered/patient-based design and open innovation. We are wary of such quick, and arguably naive, utopian renderings of what is at stake when data tracking extends beyond fitness and sleep patterns and into the shaping of bodies, health care, and regulatory regimes. The individual and collective cost of DIY design work using personal health data needs to be wrestled with as a sociopolitical and ethical problem: How are cost and benefit weighted in determining the release dates and design of new medical devices? Who should pay for inevitable coding errors? Who suffers from the unintended consequences of institutional blind spots in healthcare? These are the questions that inspire innovation and keep our participants up at night with anxiety.

6.3. Considerations for HCI

Following Parker et al. (2012), we believe that the response of technology researchers and designers needs to go beyond design solutions that offer “help” and “support” to thoughtfully engage with larger systemic sociopolitical issues and historical contexts. This article urges HCI researchers and practitioners to consider what we lose if we merely stop at the moment of excitement that DIY health and data-tracking practices like the ones we have followed over the last year have generated. We overshadow the ambivalence that arises from lived cyborg realities with stories of success, we mistake dependencies for collaboration, and stories of individual empowerment mask the spread of neoliberal governance and its rhetoric. We have further shown that visions of technological futures have the capacity to shift legal and institutional arrangements, as in this case partnerships between DIY hackers and the FDA illustrate, as well as how people live and work and how care can be construed and valued. How can we move forward? We argue it requires acknowledging the consequences of narratives and questioning visions of a technological future, no matter be it a future of data or DIY making, as inherently improved and better.

The problem, we argue, lies in part in HCI's tendencies to approach DIY health as yet another site of human-centered design—a story of user participation that can be further extended by HCI design intervention. An immediate design implication that we could have drawn from this work is to argue for the need to design systems that support the users of Nightscout and OpenAPS in their efforts to get access to their data, share their data, and collectively interpret it. Is this good care? Or we could suggest an intervention is needed to bring clinicians and the DIY community together to interpret their data. Numerous studies on health in HCI have found that the interpretation of complex health data is a collaborative process that requires both the expertise of the patient and professional insights of the health care practitioner. The dynamics of lived data, however, no longer make it clear how and when clinical expertise is needed. The types of data we saw being produced were for personal use and not the health-care practitioner. Will collaboration necessarily shift care in a good way given the realities of the current U.S. health care, insurance, and regulatory systems? In many ways, the expertise of the physician has been replaced with the expertise of a system admin. And yet, our findings have made clear that the act of designing with data is a matter of life (and sometimes death). Whether or not this is “good” care is a question for HCI to consider and weigh. DIY devices are a part of the ecology of artifacts that people use to manage their chronic illness. In designing personal informatics tools for people living with diabetes, to promote health and wellness, or as part of a wider range of contexts altogether, we need to better understand the multiplicity of modes (physically, mentally, emotionally, sociopolitically) through which data are lived.

NOTES

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