

## **“Going Rogue”**

### **Re-coding Resistance with Type 1 Diabetes**

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#### **Abstract**

*This paper explores our collaborative STS and anthropological project with type 1 diabetes (T1D) hardware “hacking” communities, whose work focuses on reverse-engineering and extracting data from medical devices such as insulin pumps and continuous glucose monitoring systems (CGMS) to create do-it-yourself artificial pancreas systems (APS). Rather than using these devices within their prescriptive and prescribed purposes (surveillance and treatment monitoring), these “hackers” repurpose, reinterpret, and redirect of the possibilities of medical surveillance data in order to reshape their own treatment.*

*Through “deliberate non-compliance” (Scibilia 2017) with clinician-developed treatment guidelines, T1D device hackers deliberately engage with clinicians’ conceptions and formulations of what constitutes “good treatment” and empower themselves in discussions about the effectiveness of treatment guidelines. Their non-compliance is, however, neither negligence, as implied by the medical category of patients who fail to comply with clinical orders, nor ignorance, but a productive and creative response to their embodied expertise, living with a chronic and potentially deadly condition.*

*Our interlocutors’ explicit connections with the free and open source software principles suggests the formation of a “recursive public” (Kelty 2008) in diabetes research and care practices, from a patient-centered “medical model” to a diverse and divergent patient-led model. The philosophical and ethical underpinnings of the open source and collaborative strategies these patients draw upon radically reshape the principles that drive the commercial health industry and government regulatory structures.*

**Keywords:** STS; Hacking Communities; Biopolitics; Surveillance; Monitoring

In the last five years a radical shift in health care has occurred, initiated by a community of people living with Type 1 diabetes (PWT1D); this transformation comes from a collective endeavor that has wedged together reluctant industry (medical device manufacturers), the enthusiasm of patient expertise, and the

technological savvy of a variety of people who know how to use computer code to reverse engineer their medical devices. PWTiD live with a chronic, life-threatening illness. While the Quantified Self movement and consumer-facing digital tracking devices, exemplified by devices like Fitbit, have gained widespread use in the last decade, PWTiD exemplify a population with absolutely necessary self-tracking practices (Rock 2004, 2005). As one scholar has pointed out, nirvana for self-trackers is a daily hell for those managing type 1 diabetes (Mialet 2015).

Type 1 diabetes (TiD), previously called ‘juvenile onset diabetes’ because the majority of diagnoses occurred in children or young adults, is an autoimmune disease that prevents the pancreas from producing insulin (American Diabetes Association 2018a). Managing diabetes requires the patient or their caregiver (as TiD often develops during childhood), to count and to track the individual’s physiological and experiential states with a constant stream of information about the body’s interior (Feudtner 2003). PWTiD need to test their glucose levels throughout the day, which they do by pricking their fingers with a lancet, depositing blood on a test strip, and using a portable glucose meter to provide the glucose reading, a process known as the self-monitoring of blood glucose (SMBG) (American Diabetes Association 2018b). The finger prick provides information for a single moment in time, and individuals may alternately use a continuous glucose monitor (CGM) for glucose readings; the CGM is a device embedded in the skin and provides dynamic readings of glucose levels, usually at five-minute intervals (Ibid.). One CGM medical device manufacturer, Dexcom, on its website describes the finger prick reading as a static number that fails to allow users to “know the ‘speed and direction’ of [their] glucose” (Dexcom 2016). CGMs use relatively expensive and frequently replaced sensors, and newer versions now communicate with smartphone apps in addition to the manufacturer-supplied receiver, adding yet another medium to manage the data readings (Ibid.). One interlocutor, echoing Dexcom’s imagery, compared the practice of finger-prick SMBG to the CGM, “I feel like it was a snapshot instead of a video. You can miss a whole lot of information if you only get to see one tiny little picture of your blood sugar.” For many of our interlocutors, they could not imagine giving up their CGM. Its stream of information has shifted how they live with diabetes and how PWTiD make their daily decisions.

Another technological addition to TiD care is the insulin pump, a small device that most resembles a 1980s pager and delivers insulin to the person’s body through an infusion set; it allows PWTiD to receive insulin at continuous basal rate doses or to administer a bolus dose, which permits “on demand” delivery of insulin to anticipate eating a meal or to correct blood sugar levels (Medtronic 2018). Despite the advantages these new technologies offer, many PWTiD still use multiple daily injections (MDI) with syringes or insulin pens and use paper logs to keep track of their condition. Most PWTiD use SMBG rather than a CGM because CGMs tend to be expensive, may not be sufficiently reimbursed by Medicare, insurance companies, lack of endocrinologists’ support or encouragement to use

one, or for other reasons such as lack of information about the tools (Rodbard 2016). Medical oversight of diabetes and the demands it imposes on patients to manage diet, blood glucose surveillance, and self-care are highly disciplining practices (Foucault 1977). These practices and expectations impose normative assumptions about gender, good and bad behaviors, appropriate and inappropriate standards (Canguilhem 1978), racially-coded norms, and re-inscribe existing inequalities into biomedical practices (Hatch 2016).

In this paper, we focus on a community of patients, caregivers, and coders, to whom we refer as T1D “hackers.” As we will suggest, their engagement with health and identities as quotidian users of medical devices is multilayered and complex, in part because they do not use these devices or seek health care within the traditional clinically-defined model of patienthood (Mol 2008), nor do they use their devices according to commercially or regulatory defined practices. Although we will refer to them as a collective for the purposes of this paper, they employ diverse strategies and tools to reverse engineer their medical devices. We use the word “hacker” as an encompassing term, but the term reflects “great variance, ambiguity, and even serious points of contention” among those who use it to describe themselves (Coleman 2013: 18). Indeed, some point out that it “remains unclear what hacking is” even after more than twenty years of research on the topic (Jordan 2017: 1). While some hackers use the term for themselves, there are also popular representations of the nefarious hacker who is imagined as intent on wreaking havoc and damaging an existing system, a persona that some hackers refer to as “crackers,” to distinguish between their underlying motivations (Coleman 2013: 17).

Informed by how our interlocutors describe their practices, we deploy the term “hacking” as a productive and constructive tactic: a performative and embodied bricolage that PWT1D use to enhance and improve health and lives, and seek to further characterize what Laura Forlano describes as “a feminist hacker ethic” in which we “might embrace small everyday rituals and actions that seek to transgress and call attention to inequality and introduce alternative sets of value” (Forlano 2016). In this way, PWT1D hackers are not merely “submit[ting] their will and being to technology” (Coleman 2013: 13), but rather the inverse: they are reshaping their bodies and technologies to fit their will and ways of being. In their dual roles as patients and citizens, they re-imagine and reconstruct their relationships to care, health, clinicians, and disease.

## Methods

This paper draws on twenty-seven qualitative, in-depth interviews collected in 2018, with a cross-section of PWT1D, parents of PWT1D, patient advocates, and endocrinologists who treat PWT1D. All except three of the interviews were with U.S. residents, and twenty of these interviews were conducted remotely through video conferencing. Four interlocutors are parents of PWT1D, however one is also

a PWTiD. Six interlocutors were born outside of the U.S., including two of the parents of PWTiD, and although we did not explicitly collect data on ethnicity, four interlocutors self-identified as non-white. Interviewees were recruited through snowball sampling, Twitter, and recruitment in-person at T1D related events, and ranged in age from twenty-two years old to sixty-five years old. Other data used in this paper includes: ethnographic participant observation at three U.S.-based T1D hackathons, four diabetes-industry conferences, and two U.S. Food and Drug Administration (FDA) workshops; transcripts and documents from medical device companies, past FDA related-events; public Twitter conversations; Facebook open groups; popular media coverage; and other media sources, including online videos.

## Patient Advocacies and New Modes of Resistances

Historically, U.S. patient advocacies have called attention to their communities' social status as patients to navigate the "challenges of crafting complex political-economic relationships with the state and market" (Heath/Rapp/Taussig 2008: 160). These negotiations have generated new forms of "citizenship claims" (Ibid.), including those organized around genetic conditions, such as diabetes. The HIV/AIDS advocacy in the early days of the epidemic now exemplifies how patients can transition into "lay experts" to demand access to clinical treatments, enhance research agendas, and gain greater public recognition of a little understood condition (Epstein 1995). Similarly, in the 1980s, advocates for breast cancer awareness focused on research and cure agendas, but as breast cancer awareness advocacy gained broader public participation, many branches of the movement have tended toward a corporately-driven cast, with an emphasis on non-specific "awareness campaigns" (Ehrenreich 2009; Jain 2007; King 2004). The evolution of these patient movements over the years map onto the larger cultural shifts in health care and patient identities in the U.S. (Gottlieb 2013).

The often deliberative positioning by advocacy groups as possessing a "professionalized" lens serves to garner legitimacy and may also generate "unanticipated claims on democracy" (Heath et al. 2008: 161). As Epstein points out, "recent scholarly interest in patient groups and health movements reflects both the growing salience of the analytical object and the larger transformations of the biosciences and the political environment at the same time as it tracks broader substantive shifts in emphases and concerns within STS" (Epstein 2008: 504). Patient advocacies resist easy categorization, as the movements, even for the same health condition, may engage with diverse concerns, whether clinical, economic, political, or most often, a "hybrid and boundary-crossing" response (Ibid: 506). This hybridity can lead to osmosis and evolution across patient groups, where one group may engage with or take up another group's advocacies.

Patient advocacy strategies have responded to new technologies and conceptions of group identities; Rabeharisoa et al. explore how a shift to "evidence-based

activism” has produced “credentialed knowledge and ‘experiential knowledge’ that crafts their focus of activity” (Rabeharisoa 2013: 10). This fluidity shapes PWTiD hacking, where the boundary crossing is not just across chronic health concerns, although there are elements of this phenomenon, but also practices and discourses, absorbed from the data liberation movements. The multiplicity of the PWTiD hacking communities and advocacies demonstrates a “capacity to articulate various knowledges” that differs from the binary of expert/lay-expert categories delineated in past advocacies (Rabeharisoa 2013: 11). The PWTiD communities involved in open source data focus on user-controlled and customized technology as the next frontier for T1D management, rather than more traditional patient activism that seek transformations in biopharmaceutical interventions. Their impatience with commercial solutions and the dearth of choices brings their concerns into new domains of resistance.

The PWTiD hacking movements introduce novel questions about bodies, tracking transparency, and conceptions of care. Past and current diabetes advocacy efforts have depended on institutional advocacy mechanisms such as the Joslin Diabetes Center and JDRF; corporately-led advocacy communities, such as Dexcom’s Warriors, have provided a platform for patient advocacy, but these serve a dual purpose of patient support and also companies’ market interests (Gottlieb 2013; Zoller 2017). Corporate-sponsored patient advocacies reveal the merging of a larger cultural phenomenon, in which patients’ self-representations become co-opted by for-profit interests, and there is evidence of this beyond the health care setting. Computer companies’ marketing tactics, such as Apple Computer’s “Think Different” campaign that included icons like the Dalai Lama, and IBM’s “Peace, Love and Unix” (Coleman 2013: 192), have deployed similar tropes of consumer choice and empowerment that now also circulate in the pharmaceutical, clinical, and scientific research spheres (Mol 2008).

Data-oriented health movements, of which PWTiD hacking is just one, build on the ongoing process of the medicalization and biomedicalization of lives and bodies. Medicalization is hardly new (Lock 2001; Zola 1972) and has been well-entrenched in U.S. health culture (Clarke/Shim/Mamo/Fosket/Fishman 2003; Dumit 2012), but self-surveillance and the tacit or implicit sharing of one’s data that these devices permit necessitate new theoretical considerations of health-technology relationships. T1D data-oriented activism is part of a larger phenomenon in health, biomedicalization, which has transformed biomedicine from the “inside out” (Clarke et al. 2003: 162). Chronic health management demands patients’ active participation and engagement (to take their pills, observe restricted diets, or monitor their condition), and in the process disciplines patients but also cultivates expertise; in turn, health interventions and clinicians frame these as opportunities for “self-empowerment” (Scambler/Newton/Asimakopoulou 2014). Clinical management of T1D encourages patient expertise as essential to successful health outcomes, but PWTiDs’ interactions and relationships with clinicians are a very small part of living with T1D. Thus, the PWTiDs’ demands for improvements to

their T1D tools and devices may be understood as a transcendence of, or perhaps an ultimate form of, compliance, in which the process of domesticating clinical compliance transforms and translates medicalized *bodies* into biomedicalized *lives*.

## Hacking Devices

The kinds of hacks that our interlocutors perform range from (in their original form) re-assemblings of manufacturer-provided technologies with “off the shelf” parts, to custom-built and small-scale manufactured hardware platforms. In order to get what they want out of black-boxed medical devices, patient-hackers write their particular modes of resistance and what constitutes “taking care of their chronic illness” into their software code, utilizing frameworks and discourses from the open-source software movement. According to Gabriella Coleman, certain classically liberal ideals like freedom, community, and collaboration are norms of the open-source software movement (Coleman 2013). These ideals persist intentionally throughout the work that hackers are performing, and can produce what Chris Kelty calls a “recursive public,” where social and cultural norms reshape the sociotechnical arenas in which open-source software is used (Kelty 2008). In the T1D hacker community, these ideals mix with biomedicalized discourses about health, risk, surveillance, individualization, access, and bodily autonomy.

One early strategy and response to the limitations of diabetes devices, Nightscout, is a cloud-based real-time monitoring platform that PWT1D and their families created to remotely monitor CGM data (Nightscout 2018). Nightscout has expanded into a platform that not only provides remote monitoring but can also transform patients’ blood glucose and diabetes treatment data into legible and predictive representations of their historical, current, and projected blood glucose states. This project exemplifies the PWT1D hacking community’s impact on the commercial and medical communities because it provides the logical structure upon which most T1D hybrid closed-loop systems are built. The project contributors’ “breaching” and hacking of commercial software code provided PWT1D with the tools necessary to question openly the role of professionalized experts (both commercial and medical) as the sole determiners of diabetes treatment and care. Interestingly, some early participants in T1D medical devices hacking now work for the commercial device and software manufacturers, three of whom have contributed to this article’s data through their interviews. Their insider positions may potentially amplify the needs and concerns of the T1D hacking community, drawing attention and legitimation to concerns that patients have with closed-source medical devices.

In addition to online forums and platforms, such as “CGM in the Cloud” and Nightscout, two systems, the Open Artificial Pancreas System (OpenAPS) and Loop have facilitated PWT1Ds’ ability to automate the control of their insulin needs

and for the devices to use predictive and responsive algorithms to anticipate their blood sugar fluctuations. Although we do not have space here to elaborate on the many strategies that PWTiD use, the two systems, OpenAPS and Loop, have taken the extremely labor-intensive many-times-daily self-surveillance of living with T1D and transformed it into a nearly background chronic condition. These two systems are not just data platforms or media for device legibility, though those are important steps in the evolution of T1D care. OpenAPS and Loop allow the CGM and insulin pump to communicate and to interact. Importantly, the systems allow the devices’ previously discrete tasks to act together to inform insulin delivery as appropriate, or to shut off the pump’s delivery if a PWTiD’s glucose levels are dropping too precipitously. As Sandra, a PWTiD in her forties, explained,

On a just regular pump ... it’s been a pretty wonderful thing to be able to set for instance a temp basal, right, but then that’s a whole set of math and algorithms and stuff that we’re thinking about all the time. To set the temp basal more, less, shut the pump off, suspend ... I don’t have to do now ... to have the basal rates, you know, different basal rates is wonderful. To have the ability to change them temporarily is wonderful, but to have a machine do that is incredible. That’s a thing now, I have to think about it sometimes, you check the reports, you want to see what’s going on, but it’s like, ‘you, machine, you did that.’ ... And the brain labor, the brain thinking all the time about everything and changing the pump or changing that piece of it. Yeah. It’s a lot of work.

Not only do PWTiD need to perform quotidian tasks to keep their blood sugar levels “in range,” but they need to perform quarterly visits to an endocrinologist, who acts as gatekeeper for required prescriptions and assesses PWTiD’s “successful” control of their blood sugars. The endocrinologist translates these clinically-deemed “successes” or “failures” into a number denoting average control, called hemoglobin A1C or simply A1C, over time. Thus, automating diabetes care can relieve PWTiD of the constant emotional and physical labor they must do, as well as alters their experiences with clinical gatekeepers. Not only do the automated systems provide data streams that PWTiD use to translate their embodied expertise and experiences, but these automation strategies have shifted PWTiDs’ health and quality-of-life outcomes in persuasive and meaningful ways by keeping glucose levels within a specified target range, one of the key clinical markers when individuals work with clinical gatekeepers.

Unsurprisingly, not all those affected by hackers’ interventions perceive these strategies as positive and innovative. Patients’ endocrinologists, medical device makers and, to a lesser degree, the Food and Drug Administration (FDA) do not embrace fully this community’s disruption of institutionalized regulatory, research, and development processes. The medical device industry intends for their devices and software to be proprietary, and they resist patients’ rights to access and manipulate them, even though these devices are prosthetic parts of a patient’s body and do not generate data without the body to which they are attached.

## Code-breaking and Corporate Responses

“I think that the DIY community is dragging the much larger, deep-pocketed device community kicking and screaming, and you know they’re being pushed, to finally invest more than lip service in technology and advancing the tools that people with diabetes have.” (Kathryn, 29, PWTiD).

The PWTiD community initially focused their efforts to gain access to their data medical devices produce and to transform it to how patients wanted to live their lives, rather than simply imagining the data as record-keeping for clinicians. Ben West’s “Decoding Dexcom” project (West 2014) enabled patients to extract their CGM data from a “black-boxed” medical device, and in combination with Nightscout, allowed for caregivers of PWTiD to track remotely their kids’ health and well-being when they were asleep or not nearby (Nightscout 2018). In 2011, prior to the work decoding CGM communications, security researchers Jay Radcliffe and Barnaby Jack disclosed their breaching of the remote insulin delivery control algorithms of Johnson & Johnson and Medtronic insulin pumps. Medtronic immediately responded by patching what they viewed as a dangerous security vulnerability, but individuals in the T1D community later recognized this as an opportunity to gain more control over their lives, enabling them to build tools that could autonomously manage this disease that demands their never-ending care and attention.

A few years after the initial intercepting of the insulin pumps’ signals, and after Nightscout could provide a platform for CGM data, some PWTiD made use of their own reverse engineering tactics to produce *new* devices to assist in managing T1D. Through their public blog about their creation of a DIYPS (or DIY pancreas system), Dana Lewis, PWTiD, and her husband Scott Leibrand, who does not have diabetes, called for a solution to the limitations of diabetes medical devices in classic clinical language, to address “existing unmet needs in T1D management” (Leibrand 2014). Lewis, among many others, whose stories are not described here but merit acknowledgment and are essential to the success of the hacking projects, began by re-engineering her CGM and insulin pump to customize its assistance with her diabetes; these initial tweaks led her and Leibrand to harness others’ efforts and to design a semi-automated system (OpenAPS) that maximizes the potential of digital and sensor technologies to reduce the constant management of diabetes tools (Lewis 2014).

Lewis self-identifies as having a “hacker mentality” and does not see herself as a programmer, rather as a person with diabetes who has “a deep understanding of diabetes and how I want to treat it” (Lewis 2016); she and others “teach the computer how to give ... these alerts and responses ... teaching the computer what that [diabetes management] process is” (Ibid.). In this framing, the PWTiD is the expert who trains and disciplines her tools, to assist with a highly variable set of bodily states. These technologies still require “basic diabetes care” and manage-



ment, but they allow the users to outsource much of the labor to automation and to customize their device settings, and therefore to customize their care (Ibid.). This shift in what it means to care for oneself contributes to the shift in T1D management and individuals’ experiences of being a PWT1D. Ben West made a similar argument to the FDA’s Dr. Helene Clayton-Jeter in an open letter,

Many patients are actively harmed by lack of access to epistemic certainty of what to expect from their therapy. Eg, the fidelity of their care is poor because they are prevented from empirically understanding their own therapy or ensuring its safety ... I need the ability to inspect the device for bugs, to monitor it’s [sic] ongoing behavior, and to use the primitive capabilities of the device as recommended by my doctor. Without this, I’m constantly suffering from incorrect dosages of insulin ... I shouldn’t have to reverse engineer my own medical data. I don’t understand how they can get away with doing harm to people this way. I believe it is their intent to work with industry groups to allow read-only access to filtered feeds, and few people will even know that bugs in the device can be mediated using capabilities the manufacturer supports (West 2011)

As West articulates to Clayton-Jeter, dosages and devices are tied to the “care” involved in managing T1D. West challenges the notion that constrained choices are sufficient to adequately manage his diabetes or to care for himself; caring “is a matter of attending to the balances inside, and the flows between, a fragile body and its intricate surroundings” (Mol 2008: 34). By directly addressing the regulatory institution (the FDA) that controls medical device approval, West troubles the notion that the clinical gatekeepers or the medical device manufacturers ought to have final say over how the devices operate on the individuals’ bodies or that these device constraints suffice for what he identifies as “care.” West goes so far as to refer to the device’s “primitive capabilities,” which are sanctioned and condoned by his doctor. Yet, these parameters lead to suffering that he must overcome through “reverse engineering,” or, implicitly, hacking. Here, West re-codes, or re-interprets, for the institutional actors who are essential gatekeepers, how the devices work and how they get used. He simultaneously questions the FDA’s support of the parameters designed by medical device companies and asks why his deeply embodied knowledge of the devices’ functions cannot inform how he may use his tools.

Our interlocutors’ strategies of resistance to the opaque “black boxed” medical devices provide them with powerful insight into how corporate and regulatory structures have obscured their management of T1D. Their actions and queries disrupt the role of experts, clinicians, engineers, software coders, academics, and regulatory agencies as arbiters of appropriate T1D care. As West articulated to the FDA, many PWT1D perceive the devices were not designed to be user-friendly or mindful of patients’ experiences. Taylor, a U.S.-based thirty-year old professional software developer and PWT1D hacker, expressed her frustration when she first encountered the CGM. “As soon as I got the CGM, at that point, you couldn’t even pull the data out with it. I think you could get it as a CSV file and then was doing all

my own processing to it because, I mean, it was so bad.” The PWTiD community recognized these data-blockades exist not because the devices intrinsically *could not* provide the data they wanted, but because the manufacturers did not design the devices with the users’ experiences in mind. The constrained features map onto proprietary notions of device development and assume clinicians to be the primary users for data interpretation and analyses. This design assumption reifies and reinforces the medicalized doctor-patient relationship. Yet, for the community of PWTiD, the ultimate use case is their daily lives and the ability to manage their condition effectively.

PWTiD hackers’ modifications of the technical systems of T1D treatment are demands not just for improvements for their medical well-being, but they are also demands for changes to the clinical spaces in which they must enter periodically to gain access to the tools and devices they use. Technical and behavioral power over diabetes management systems has been tightly bound to professional expertise – expert clinicians and scientists write computer algorithms and behavioral codes, which patients are expected to use and to comply with as passive recipients. This double-coding of T1D treatment as a social and technical hybrid allows our interlocutors to leverage for changes in medical spaces and practices that they previously could not easily access.

## Code-breaking and Negotiating Clinical Care

The identity “patient” is a relational one, requiring a relationship with health care givers, especially doctors; but, while the relationship implies some prescribed hierarchies, the dynamics and implications of this relationship can vary greatly. For many PWTiD, the doctor-patient relationship creates a significant source of stress and tension. Access to medicines, medical devices, and peripheral accessories must pass through a prescribing entity, usually a clinician, whose opinion of a patient’s self-care can shape access to treatments that a patient is getting. Because patients are aware of this power imbalance, it influences how those using DIY artificial pancreas systems interact with their doctors. Many of our interlocutors hesitate to mention their DIY tools because clinicians may perceive it as non-compliant or breaking with what experts consider “good behavioral codes.” Certainly, the regulatory structures of U.S. health care do not make much room for independent actors. As a result, some interlocutors perceive their doctor as instrumental prescription-writers, not collaborators or participants in their care practices. Gatekeeping by clinicians has pragmatic implications for PWTiD seeking care, and they are attentive to it:

if I were to turn around and be like, I’m not going to do it, [follow physician recommendations] then you get that, like, oh, I hate this...but noncompliant, you get that stuff, and then she could potentially say I don’t think you’re being responsible enough. I’m not signing

your prescriptions for X, Y, or Z. You need to come in, and so that chain reaction of me saying that is possibly really bad. (Taylor, 30, PWTiD)

When PWTiD find that Loop or OpenAPS makes a meaningful difference in their lives, some of our interlocutors have avoided telling their endocrinologists what they’ve done to achieve such positive outcomes. This deliberate obfuscation is notable: it reveals distrust in the endocrinologist as a participant in the PWTiD’s care, and it reframes the management of T1D as the *patient’s* responsibility and domain of expertise. This has historically been the case (Bliss 2013; Feudtner 2003), as life with T1D can hardly be captured in a quarterly fifteen-minute appointment with a clinician, but these newer strategies make the responsibility, expertise, and tools for care explicit. Denis, a fifty-six-year-old European-born, U.S. based professor of electrical engineering, admitted it took him a while to reveal his hacking: “I actually didn’t know whether I should tell her ... what I’m doing ... And one meeting, the first meeting maybe two years ago, I didn’t tell her. She said, ‘Well, your results are really good. That’s great,’ and she was ... suggesting ... I should change this ratio or that ratio.” Denis’ omission of using Loop to achieve these “good results” exemplifies the coding and translational work PWTiD must do to preserve their autonomy and to navigate presumptive clinical expertise. In this case, expertise and authority come from the embodied experience of living with T1D and are “independently” confirmed by the (clinical) effectiveness of the DIY system; the visit with the clinician then serves as mere pass-through to access supplies. Holly, a forty-six-year old woman, also pointed to the perfunctory nature of the visits and the sense of isolation that her relationship with her clinician could elicit, “you’re kind of on your own guessing. And your doctor gets 10 to 15 minutes with you, and that’s it. I like my doctor, but he’s not here to help me get through every day of it.”

This clinician-patient relationship reveals points of contention. When clinicians “code” the patient and their interactions in a visit, they engage with a medicalized and institutionalized labeling discourse and its power structures. For clinicians, the coding process is partly documentation, focused on a single patient. The clinician assesses: how is a patient taking care of themselves? Are there “complications?” Where are these located in the body? Is the patient “compliant” with treatment? These diagnostic processes exist for the clinician’s analysis but also for insurance billing and processes outside of the direct care of the patient in the office. Patients may contest these codes and their relevance to their care, which reflects some of the tensions between patients and their doctors. While a clinician may see coding as a neutral descriptive process, part of her routine practice, patients see and bear its proscriptive effects: an “official” diagnostic code of non-compliant diabetes can have spillover effects in a patient’s life, such as loss of a driver’s license (American Diabetes Association 2014) or revocation of treatment by an insuring organization. As the clinician labels and translates the patient through these codes, patients are also doing their own coding and translational work.

Part of a diabetic's engagement with her clinician is to negotiate this medicalized discourse and to integrate her own (increasingly biomedicalized) subjectivity into the "objectivity" of the medical coding scheme. Tiffany, a thirty-five-year old woman, diagnosed in her teen years and now a mother of two, explained the limits of her care with her endocrinologists, "there's a lot of information that we're not given and that you have to really seek out. And until I knew where to seek it and where to find it, I kind of went by what my doctor said. And I didn't really question my doctor until I left my first endocrinologist and discovered that not all endocrinologists are equal; and not all doctors are equal, and that questioning your doctor isn't really a bad thing all the time." Tiffany's interest in the OpenAPS and Loop systems led her to explore tentatively what was possible, bringing her new endocrinologist into the discussion, only to find the doctor evaded giving an opinion. "I brought it up with my endocrinologist, and I kind of just mentioned it to her. And asked her ... what her thoughts were ... [She] gave me the generic, 'you know, I can't really say yes or no because it's not FDA approved. So I'm interested to see what you find but I can't really give you any support either way.'" As Tiffany demonstrates, even when PWTiD wish to collaborate with their clinicians, the doctors' fear of liability or distrust of these non-regulated systems can prevent a shared engagement.

This disjunction in communication and understanding between patient and clinician feeds into a notable ambivalence about medical experts' role in treatment, which plays upon many diabetics' always-already existing ambivalence to medicalized treatments. Diabetes is a labor-intensive disease that can challenge even the most assiduous. While clinicians can prescribe certain devices and behaviors, patients leave their brief clinical encounters expected to comply with clinical recommendations that often provide little real-world insight into the practicalities and fatigue that accompany idealized adherence. As Kathryn, a twenty-nine year old, noted, after her diagnosis at age thirteen,

so the ped[iatric] endo[crinologist] had said ..., 'we won't allow you to go on a pump until you have been successful in regulating your glucose with only injections and ... BG [blood glucose] meter tests.' And so after a year, I finally prevailed on her to allow me to have a pump, to give me more freedom ... because it was constricting to have to plan my day around my disease ... it seemed to make things unnecessarily difficult, when it's never going to be easy, but to make it harder simply because she wanted to ensure that I would be able to grapple with the disease if I had no tools at all, which I don't, yeah, I still don't quite understand that rationale.

Newer, patient-created interventions, like Nightscout, Loop, and OpenAPS, defy these "expert" dictated parameters for care, with patients actively remaking what constitutes health and care by involving both patients and clinicians. PWTiD repurpose "how-to" advice from others participating in the diabetes online and face-to-face communities, drawing on "community expertise" in translating patient

concerns into medicalized language. “Meeting other type ones and attending conferences and hearing from people who have type 1; and they’ve decided to go rogue, and this is what they’ve done. And this is the result that they’ve had, and realizing that you don’t always have to accept things for face value and that there’s sometimes more and better if you continue to look.” (Tiffany, 35, PWT1D)

One strategy patients use to convince their doctors of the DIY systems’ utility and effectiveness involves patients (re)coding their care practices into forms legible to medical professionals. Our interlocutors demonstrate how relevant Annemarie Mol’s concept of the logic of care is in these novel practices. “Articulating the logic of care is an attempt to contribute to improving health care on its own terms, in its own language” (Mol 2008: 97), but this language must be produced by patients to successfully bring doctors along. Patients must translate the subjective and qualitative logics of care *and* the quantified data produced by the patient’s body. What makes this effective is the translation process patients do for their clinicians and how their diabetic prostheses mediate the information. Open-source tools like Nightscout can generate reports explicitly designed for this translational purpose and provide a shared discursive space between patients and clinicians. Some of these reports reproduce the data that commercial diabetes management software produces, but, previously only clinicians could access these reports. Now, instead of doctors reading through reports and telling patients what the data (or quantified representations of patients’ experiences) say, patients can interpret and engage with the data as a primary source. Patients’ strategies for “self-empowerment” in this case involve the coding, translation, and domestication of clinical knowledge. Outside of a clinical encounter, patients spend time analyzing these reports and annotating them with their lived experiences of the quantified data, using them as a translation prosthetic to draw attention to their concerns, which are represented in the raw data (but are not “seen” by clinicians).

Prior to Nightscout, the only place that individuals could see high-level data analysis of their blood sugar management was in their doctor’s office. By having easy access to these data management and analysis tools, patients can analyze these reports at home and on their own, producing their own interpretations of their treatment data and how it relates to their daily care. This serves as an important moment of re-coding/translation between patients and clinicians. In annotating clinical reports with the quotidian experience of diabetes, patients can leverage medicalized language to produce outsized effects and to enroll recursively their clinicians into open-source logics (Kelty 2008) and what Mol terms “patientism” (Mol 2008). Kathryn described engaging her endocrinologist with the system she had built for herself:

[S]he didn’t really understand how the system worked, and so I had explained it in the simplest terms that I could muster and just said, you know, there are more safeguards, there is more predictability, and you know I am eating a medium-carb diet and so I think you’re going to view this as a net positive, and so I think my, well, admittedly aggressive framing

of the issue kind of compelled her to grudgingly accept it, and then now that I've had several other appointments with her since then, she's very much onboard.

Kathryn simplifies her explanation to persuade her doctor that her choices are appropriate. In addition, she stresses qualities that physicians find reasonable, such as “safeguards,” and “predictability.” Another example of this is patients’ use of “effectiveness,” which echoes the clinical trial criteria that the FDA and medical device manufacturers use to evaluate population-level outcomes. Dana Lewis and Scott Leibrand have cast the OpenAPS system, as described earlier, with its response to “existing unmet needs in T1D management” (Leibrand 2014). Unmet needs are one of the logics that merit FDA approval and can even justify expediting patients’ access to treatment. These opportunities allow patients to appropriate clinical language to legitimate patients’ strategies.

Within a clinical encounter, Nightscout data reports and patient performances of expertise (Hilgartner 2000) have a threefold effect on clinicians. First, clinicians may be persuaded of the effectiveness of patients’ care practices, as the reports act as a shared space of discourse around and upon which patients can talk about the triumphs and struggles of their life with diabetes. This performative process shows clinicians that patients are *attentive* (Mol 2008: 36) to their care practices, and demonstrate that they are *careful and* “good patients” because of the way they take “care of their data” (Fortun/Fortun 2008). The (serious) joke of the “deliberately non-compliant” patient (Scibilia 2017) points to the complex relationship between the logic of care, attentiveness, and carefulness – through this type of demonstration of expertise, patients show that their non-compliance with traditional medical guidance, regulatory structures, and treatment routines is both deliberate and *deliberative*. Denis described how “I prepared a little presentation for her, like, two pages of how the system is set up, and I brought in my results, and I showed her what I’m doing, and she was really enthusiastic. You know, she couldn’t believe it.” Denis came to his quarterly appointment prepared to defend the system he has lived with and knows to work better for him than any other strategies he has used in more than forty years since his initial diagnosis. His anticipation of the need for such documentation, translation, and defense of his re-imagined compliance reveal much about the patient-doctor encounters our interlocutors describe.

Clinicians are also demonstratively shown the ways in which technologies, such as a DIY APS, are assistive: they help to manage patients’ daily diabetes care routines and “empower” patients to refigure the demands that caring for diabetes makes on their lives. This approach is not *thematically* new, but the *means* with which patients are able to re-make, resist, and create transformative care practices *are* new. The reasons for their “non-compliance” have also introduced novel logics and have reshaped their identities and roles as patients. In the context of T1D hacking, “non-adherence” is not an expression of ambivalence or refusal, but a novel form of participation in re-constructing logics of care for diabetes. “Non-

compliance” represents the desire to decrease the burden of their constant participation in their disease and to claim a more reliable form of (embodied) expertise than existing clinical recommendations. Only a few months after starting to use Loop, Tiffany described this through an empowerment narrative and suggested that it reshaped the relationship between her and her clinician:

I mean I’ve always kind of felt like diabetes had the reins, and I kind of had to make accommodations in my life for it and make sacrifices because of it; and now I feel like I have the reins again, and I’m in control ... [I]t doesn’t really have a whole lot of say in what I do and when I do it ... one thing that it’s done is it’s given me kind of a boldness in that, I don’t know, I feel more equal with my endocrinologist ... I don’t see her as the all-knowing endo that gets to tell me what to do. I see her as a teammate in how to help me accomplish the goals that I have.

Tiffany sees the tools as a way to reshape care and to conscript her endocrinologist into the embodied knowledge that she lives with daily.

Lastly, these data-based persuasive works tend to enroll clinicians into the recursive public of PWTiD communities, extending and reproducing it inside of the professionalized medical community (Callon 1984; Kelty 2008). More importantly, this enrollment reshapes the role of clinicians in patient care from maintainers, controllers and gatekeepers, into accomplices in the effort to “cultivate an alternate identity that could be productively used for other types of social change on a larger scale” (Forlano 2016) such as increased access to assistive technology or life-saving medicines like insulin. As the awareness of PWTiD hacking projects spreads through the professional medical community (in no small part due to more traditional “patient activism” strategies by high-profile figures, such as Dana Lewis and others), it is easier for patients to take on these new patient-clinician relationships and identities. One PWTiD who seemed almost surprised that Loop was so easy to integrate into her diabetes management explained, “My doctor gave me some supplies and she has a number of patients who are looping, and it all just worked out” (Madeline, 62, PWTiD).

## Conclusion

There is much to laud and to appreciate in how this group of PWTiD hackers are radically altering life with diabetes. But these remain highly privileged spaces and tools, despite the community’s deliberate intentions to shift the models that govern TiD care practices. Open source and DIY strategies do not necessarily mean equality, equity, or universal accessibility (Dunbar-Hester 2010) and increasing reliance on computer software for managing medicine and allocating resources can greatly amplify inequalities (Eubanks 2018). Despite these significant limitations, the PWTiD community will need to grapple with structural issues such as

inequality of access in their commitments to effecting meaningful, widespread change.

PWTiD open-source hackers, through their multifaceted roles as patients, experts, and hackers *have* materialized biomedicalized solutions to some social problems that they see impacting diabetics. Their challenges to the medical and regulatory status quo raise questions about access and control over private personal data, the speed and focus of medical innovation, material access to biotechnological treatments, inequality in the US healthcare system, and a patient's bodily autonomy. Although diabetes has long been a disease of constant and active self-care, our interlocutors, with keen awareness of the kinds of communities and tools that they wish to build, have taken the "freedom of choice" embedded in SMBG to develop new sociotechnical systems, as well as new kinds of subjectivities. The shifts are not just in their own bodily experiences, but exist in relation to the communities in which they participate – perhaps most notably in relation to their clinicians, who have historically asserted their authority over patients in the clinic, but had limited strategies besides "encouraging" PWTiD to use monitoring and treatment tools that are often disempowering or alienating. Some clinicians now embrace the shifting dynamic of care, but these have been hard-won negotiations and exist as a result of patients' carefully reframed and translated discourses. In their actions as patients, our interlocutors have reshaped their relationships with their devices and their clinicians in constructive and critical ways. As Denis explained in his new era of using Loop and choosing to disclose it to his endocrinologist, "you get a note from a doctor right after an appointment, and she, normally in the past she would say, 'Hey, I was recommending this and that,' and last time she sent me a note and said, 'Hey, thank you for educating me.'"

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