

## ARTICLE

### Materializing Datafied Body Doubles: Insulin Pumps, Blood Glucose Testing, and the Production of Usable Bodies

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#### Abstract

The network of devices involved in insulin pump treatment reads and quantifies the physiological processes of Type 1 Diabetes as it performs life-sustaining functions inside and upon users' bodies. Together, these devices gather that information to produce what I call Datafied Body Doubles: numerical stand-ins for the body that recreate them as both usable and controllable for pump users and their physicians. By establishing and normalizing a system of quantification through blood glucose testing and temporally mapping body-readings into data collections, these Datafied Body Doubles fundamentally alter the conceptual and material experience of living with Diabetes. As medically-compelled users, people with Type 1 Diabetes participate in their own datafication through their continued use of those devices—a choice which is not much of a choice at all—but their bodies are re-created and used to drive their participation in those very techno-medicalized treatments nevertheless.

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## Introduction

People with Type 1 Diabetes (T1D) are in a precarious position.<sup>1</sup> Because their bodies no longer produce insulin, they live with a daily ultimatum: inject insulin or die. For the roughly 20 to 38 million people worldwide living with T1D, that choice isn't much of a choice at all. They are what I call compelled users; for a choice of non-use is a choice of non-life, and that reality has created a unique and bittersweet relationship between people and their treatment devices.

In this article, I attempt to flesh out how these medically compelled human–technological relationships influence users' understandings of Diabetes, treatment objects, and their own bodies. Now the standard of care and primary method of regulating blood glucose levels for the 3 million people in the United States with T1D, the network of devices involved in insulin pump treatment read and quantify users' physiological processes while they perform their primary life-sustaining functions inside, upon, and outside the body. These devices compile, analyze, and visualize that information to produce what I call Datafied Body Doubles: numerical stand-ins for the body that construct them as both usable and controllable for pump users and their physicians. These Datafied Body Doubles fundamentally alter the conceptual and material experience of living with T1D in the twenty-first century by, first, providing users a new technological/medical (and therefore expert) point of reference in their methods of reading and interpreting their own bodies; and, second, these Body Doubles are themselves materialized back in/on T1D bodies as people apply them to their ritualized daily Diabetes treatment acts. Through this process, insulin pumps and networks of Diabetes technologies come to function not only as medical periphery or attachments but as deeply intertwined and active constituents of the body.

**Crippling T1D and Insulin Pump Use:** Considering these human/technological treatment networks as active, reciprocal, and productive provides a compelling frame through which we can begin to crip conversations surrounding T1D and chronic illness more generally. It is perhaps unsurprising that Diabetes is not commonly framed within the discourse of disability,<sup>2</sup> but I draw them together to highlight some of the ways this connection would benefit scholarship surrounding both Diabetes and critical disability studies more broadly. First, at its base, the shift toward constant and concealed treatment practices is emblematic of a much broader system of biomedicalized control that devalues non-normative bodies, and thereby devalues a life lived with(in) one. Here I use the term biomedicalized to signal the late twentieth-century cultural shift in medical practice and culture Adele Clarke et al. (2009) have termed “biomedicalization,” wherein the goals of controlling disease and “individual perfection” prioritize the transformation of illnesses and bodies through technoscientific means (pp. 1, 11). These goals, rooted in a hope for healing/curing and improving patients’ quality of life, are nevertheless influenced by the power structures that are “automatically ‘built in’ and mobile, embodied through social practices and norms,” both within the field of medicine and in US culture more generally (pp. 4-5). Read with perhaps more nuance through the work of Sheila Jasanoff (2004), the structures of power, social practices and norms, and technoscientific medical interventions involved in late twentieth- and twenty-first-century Diabetes treatment are all co-produced together within and among various the institutions and discourses with which they engage.

And it is in the co-production of technoscientific medical practice, cultural norms, and definitions surrounding T1D, and patient identities where disability studies—and crip theory in particular—can help provide insights and tools for better understanding the implications of insulin pump treatments for the people with Diabetes who use them. First, and central to the very purpose of this essay, technological interventions in medical research and practice have transformed T1D from an acute condition to a chronic one.<sup>3</sup> Insulin injections keep people with T1D alive. Insulin pump systems, particularly those that incorporate blood glucose (BG) tracking

devices, have drastically improved patients' quality and duration of life. Because these life-sustaining treatments have been and continue to be co-produced alongside the social practices and norms of US and medical cultures, however, they also become sites upon which systems of power are and can be made manifest or "built [on]," to paraphrase Clarke et al. above.

The act of living with a chronic disease is compounded with various unseen yet nonetheless taxing forms of labor, work that has been made invisible by the long-term and large-scale normalization of able-bodiedness. As Robert McRuer (2006) details in *Crip Theory*, able-bodiedness is made socially compulsory in part by associating conceptions of embodied normalcy with the ability to produce labor value, but also by framing all disabilities as "essentially temporary, appearing only when, and as long as, they are necessary" (pp. 7-8, 29). Through this cultural logic, various disabilities and chronic illnesses such as Diabetes can be moved on and off stage as needed. They can be just palatable enough to systems of compulsory able-bodiedness when they need to be, yet out of view when they do not—a flexibility that can be enacted upon people and bodies, but that can also be deployed by people in productive ways.

For individuals who live with T1D, the permanent impermanence of the disease as framed by themselves, their doctors, and US culture more broadly produces some significant tensions. Geoffrey C. Bowker and Susan Leigh Star (2000) refer to similar tensions for tuberculosis patients as "torque." The interactions between people, institutions, and definition paradigms (in their case, categories about tuberculosis) make their uneasy conglomeration visible:

Each has a trajectory, and the trajectories may pull or torque each other over time if they move in different directions or at different rates. The threads that tie category to disease, to science, to bureaucracy, and thus to person, often become twisted and tangled in the long process of the disease. The texture of classification here is composed of thick filiations, encompassing much of a person's life, imposed from outside, and filled with uncertainty and contradiction. (p. 195)

As people live with the embodied experience of T1D and all of the vicissitudes associated with a fast-moving and dynamic chronic condition, the medical and cultural definitions and scripts for Diabetes are ever-present in co-constructing meanings associated with those experiences. As the “trajectories” or interpretations of those experiences by these three actors align, their interconnection is productive and often invisible. When those interpretations do not overlap, however, the mental/emotional/embodied torque produced can be excruciating. These tensions, I argue, are further complicated with the addition of technological quantification and injection systems detailed throughout the study below.

In this context, it makes sense all the more why many people with T1D constantly hope for a cure. That desire for a post-Diabetic life—so often actually conceptualized as a return to a *pre*-Diabetic life—is in many ways a desire to escape the labor and torque characteristic of life with a chronic illness. In practice, this desire is discursively linked to a desire for the experience of able-bodiedness in an able-bodied world, a desire to feel normal. The problem, however, is that regardless of a possible future cure, millions of people currently *do* live with T1D, and reiterating normalizing narratives within imagined futures for T1D further entrenches conceptions of T1D abnormalcy in the present.

I draw Diabetes into discourses of disability, and especially of crip technoscience, in order to politicize the technological relationships that have become so deeply intertwined with experiences of living with and treating T1D. As the need for repetitive treatment acts overlaps with ubiquitous calls for “the cure,” Diabetic bodies come to be framed in terms of what Alison Kafer (2013) calls “facile references of self-evident cyborgs simply by virtue of their use of ‘assistive’ or ‘adaptive’ technologies” (p. 120). In the context of Diabetes, this move flattens the varied human experiences with T1D treatment and packages them as uniform, depoliticizing those processes and the Datafied Body Doubles they produce, despite the cultural and economic structures required for them to function (and to exist at all). I aim to make visible those connections to the systems of medical practice, research, and device production, as well as how those power relationships structure or at least influence people’s daily lives and practices. In so doing,

I hope to open a space where we can begin to see the ways people are not only implicated in this technoscientific (re)defining themselves, but how people resist and, though still compelled, actively define the parameters of their own use in new and interesting ways.

### **Insulin, Blood Glucose Testing, and Twentieth-Century Transmuted**

**Disease:** In order to understand the techno-human relationships typical of twenty-first-century T1D, it is important to trace how the medicine and culture of Diabetes have changed. Not to be confused with its in-name-only counterpart Type 2, Type 1 Diabetes Mellitus—often referred to as Juvenile or Insulin-Dependent Diabetes Mellitus (IDDM)—is a chronic immune disorder in which the body cannot break down and use carbohydrates due to a total lack of insulin production. Though the particular combination of genetic and environmental factors at play in its cause is still largely unknown, something triggers an autoimmune rejection of beta cells in the pancreas that create insulin. As a result, patients with T1D eventually stop producing insulin altogether and require insulin injections to metabolize foods—any food, all food, any time (“Diabetes,” 2005; “Diabetes,” 2007; Marcovitch, 2006).

There were two major shifts in Diabetes treatment in the twentieth century that transformed not only how treatments functioned, or even how it affected everyday life for people with Diabetes, but that fundamentally altered the disease itself. First, in early 1921, Frederick Banting and his research team successfully isolated a hormone they named “insulin” from the pancreas,<sup>4</sup> and both the medical and popular response was so dramatic that commercial injectable insulin was produced and on the market within a year (Banting, Best, & Macleod, 1922; “Frederick Grant Banting,” 1966). Though references to Diabetes date back as far as 1500 BCE in India and Egypt, and though medical discourses have all changed significantly in the thousands of years since then, treatments (and, really, prognoses) for what we now call Type 1 Diabetes remained generally similar until the 1920s: diet and/or lifestyle changes centered on “abstaining” (Medvei, 1993, pp. 46, 49; Zajac, Shrestha, Patel, & Poretsky, 2010, pp. 1-5). Insulin injection treatment changed everything, essentially ridding patients of their

immediate side effects and eventually increasing life expectancy post-diagnosis twenty-fold (Brostoff, Keen, & Brostoff, 2007, p. 1352).

What was for centuries a terminal diagnosis accompanied by a doctor's suggestion to "make arrangements" became a chronic, life-long condition with fundamentally new challenges and side effects. In his book *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*, Chris Feudtner (2003) argues that the discovery and development of the "wondrous drug" itself accounted for the "bittersweet" transformation of Diabetes in the twentieth century. As insulin therapy was quickly institutionalized as the standard of care, it altered the "fundamental biology of the disease," stunting the so-called "natural" problems associated with Diabetes, while simultaneously giving rise to scores of new complications and lifestyle changes no one had lived long enough to develop. "The patient," Feudtner argues, "experiences an illness with a *transmuted course*" (emphasis added). Medical practice, as a series of interrelated human decisions, transformed Diabetes biologically, altered people's everyday labor and practices, and created a culture of medicalized control centered on rhetoric of individual responsibility and the "predicament of dangerous safety" (pp. 23, 29). This human-molded Diabetic world would serve as a primary site of further transmutations and the standardization of medical science more generally (Porter, 1996, pp. 31-32).

The second major shift in the twentieth-century Diabetic world began in the 1960s, as biomedical researchers began producing blood glucose test strips for use in emergency rooms and clinical diagnostics. These devices allowed physicians to take a small amount blood from their patients, run it across the strip to begin a chemical reaction, and compare the strip's hue to a chart to give them a range of where their blood glucose levels were at that moment. By 1970, these strips were altered to feed the chemical reaction data into devices that could produce a quantitative reading of the blood's glucose per deciliter, and glucose meters became available for patients' at-home use in the 1980s (Clarke & Foster, 2012, pp. 85-87).

As at-home BG measurement became institutionalized in the 1980s and 1990s, the general practice of testing biomedicalized crip users became institutionalized along with it. In their book *Biomedicalization:*

*Technoscience, Health, and Illness in the U.S.*, Adele Clarke et al. (2009) argue that the “technoscientization of biomedical practices” since the 1980s have coalesced into a medical paradigm they call “biomedicalization”—a late-century shift in American medicine focused more on *transforming* disease and the body through the use of technologies than on treating or controlling it (pp. 1-2, 197). This medical need to transform has disproportionately affected people with disabilities and chronic illnesses, who must also navigate the cultural and economic traps symptomatic of systemic “compulsory able-bodiedness,” discussed in more detail above (McRuer, 2006, pp. 1-2, 8). In essence, the intersections of these sociocultural forces at the end of the twentieth century have turned people with T1D into compelled users<sup>5</sup>—biomedicalized cripple users—who often blood-test their way into the Quantified Self (QS) movement whether they wanted to or not.<sup>6</sup>

Since the advent of BG testing, T1D-related research has primarily focused on making devices more manageable and user-friendly, on conducting more frequent BG readings (which led to the development of continuous glucose monitors), and networking BG testing devices with other treatment technologies such as insulin pumps. People with T1D now live a fundamentally device-connected life, one in which T1D bodies and epistemologies have been redefined in myriad ways heretofore underexplored. In what follows, I will engage with these devices to begin unpacking how the body is conceptually redefined through the compelled use of these networked treatment devices.

### **Datafied Body Doubles and the Network of T1D Treatment Devices**

Though the exact combination of technologies used for insulin pump treatment vary based on insurance coverage, physician recommendations, and individual tastes and aesthetics among other factors, the standard of care in T1D treatment today includes at least three components: an insulin pump, a continuous glucose monitor, and a blood glucose meter. Each of these devices works together to standardize T1D bodies and treatments, and to construct what I call Datafied Body Doubles. Below I will map out this

network of devices, their functions and connections to T1D bodies, and how they work (or sometimes do not work) together in both maintaining blood glucose levels and making T1D bodies medically usable.

**Blood Glucose Meters and Bodies as Numbers:** Tens of millions of people in the United States and around the world use blood glucose meters on a daily basis, paying into a nearly US\$9 billion market worldwide (Hughes, 2009, pp. 1219-1220). Though they make up one of the largest segments of global pharmaceuticals today, Diabetic glucose testing products were not developed and marketed for at-home consumers until the 1980s. By the turn of the new millennium, however, nearly every person in the United States diagnosed with Diabetes used a meter at home on a regular basis (Tenderich, 2013, p. 68). Glucose meters' rapid shift from medical obscurity to clinical ubiquity, I argue, has been accompanied by significant changes to definitions of Type 1 Diabetes (and Diabetes generally), altering the lived experience of embodiment for people who use these devices on a daily basis.

As I will show below, efforts to make the complex physiological processes associated with T1D more manageable have established and normalized a system of quantification that re-creates the body's processes as a number. In doing so, T1D bodies are overlaid with people's sensory experiences together with the numbers meant to represent them, conflating and redefining various ways of knowing into sets of integers that make treating such a highly complex condition possible—and in so doing, masking many of the complexities associated with their creation. These device-produced numerical stand-ins for the body set the stage for the creation of Datafied Body Doubles as T1D treatment becomes increasingly networked with more and more treatment and measuring devices.

How, then, does a BG meter actually work? By pricking their finger and placing a drop of blood on the end of a disposable test strip, an individual can receive an estimate of their blood glucose level in almost real time. Chemicals in and/or on the test strip react when users' blood is introduced, and the device measures that chemical change to produce a numerical measure of the amount of glucose present in that droplet of blood

(Clarke & Foster, 2012, pp. 86-88). In the United States, this is measured as milligrams of glucose per deciliter of blood (mg/dL)—calculated as millimoles per liter (mmol/L) in most of the world. According to the National Institutes of Health, fasting blood glucose levels for non-diabetic people average between 80 and 120 mg/dL (4.4 and 6.7 mmol/L), which acts as the approximate goal range for people using insulin injections (National Institute of Diabetes, n.d.).<sup>7</sup>

After nearly four decades of consistent and routine use by people with Type 1 and Type 2 Diabetes worldwide, these meter readings have come to be understood as snapshots, illustrative of users' BG levels—and of users' bodies more generally. As Barbara A. Koenig (1988) has argued, the technological imperative of care pervasive in the field of medicine makes the “routinization” and standardization of this type of techno-medical procedure difficult, if not impossible to resist. Medical professionals establish and maintain certain “treatment rituals” to help offset the uncertainties inherent in caring for complex health-related experiences such as these (pp. 466-467, 479).

In the case of T1D, the numbers produced by these devices have become so normalized as to be understood by doctors and patients alike as direct representations of a user's physiological state at the time of the test. This is not to suggest that either MDs' *or* patients' explicit and tacit knowledges can be so easily reduced or dismissed, but instead that the normalization process in medical science and practice is that influential. Often understood as the result of objective (and accurate) technoscientific observations, BG numbers take on the role of authoritative medical opinions in and of themselves. As Theodore M. Porter (1996) has argued, though scientific measurement systems are built within specific moments and contexts, decades of “regulation, education, manufacturing, and method” have redefined measurement as “precision and objectivity” (pp. 23, 32). Numbers produced with these supposedly objective measurements have the uncanny ability to reach across the sociocultural boundaries of medicine and American culture to deal with large and often difficult subject matter—in no small part due to their “ability to bypass deep issues” and distill them into small, digestible chunks (p. 86).

It is at the intersection of ritualized medical practice and the abiding “trust in numbers” Porter details within the United States where the cultural meanings of BG testing reside. After all, how do glucose meters depict or envision the body? As a number. This re-imaging, or translation of the body as a number has become normalized not only through the cultural authority of medicine (Pescosolido & Martin, 2004), but by the reiterated act of overlaying those numbers onto users’ sensory experiences with their own bodies. One of the most common linguistic idiosyncrasies shared among people with T1D is the tendency to use the numbers from their BG readings as direct references to themselves. Phrases such as, “I was 400,” “They told me I was 35,” and “Oh good, I’m 102,” denote a conscious acknowledgement of a state of being—one’s embodied knowledge of how that particular state *feels* merging with a system of quantification with which to categorize it.

More than just a common turn-of-phrase among participants, I would argue, this linguistic act of equating their bodies/selves with biomedicalized recreations thereof is not unlike the marking that comes with a diagnosis of Diabetes in the first place. I *am*, you *are* “Diabetic”—as a medical and social marker or identifier—becomes I *am*, you *are* my/your BG, and this marking process is carried over into the treatment acts patients conduct themselves. After a lifetime of mapping BG tests onto lived experiences, these numbers become so far divorced from the calculations and even bodies that produce them (and give them their medical authority) that they come to stand for themselves. The number *is* as much as one’s own body *is*—to use Judith Butler’s (1993) terms, years of reiteration have materialized the number as one’s body in and of itself (p. 2).

If the body is made to be understood as a number, it is made to be calculable. It becomes a data point, to be plugged into formulas in order to produce particular solutions. This is how medically “difficult” Diabetic bodies become scientifically usable—they are made into something else, something legible to those ways of seeing and knowing. In these attempts to simplify T1D bodies, however, several problems arise that complicate the process. What happens, for example, when someone *feels* as though they have low BG but their meter produces a number that says otherwise? Or

when the accuracy of test strip lots vary (often unbeknownst to the user), producing slightly inconstant results? The torque produced by these incongruent readings of the body, to again use Bowker and Star's (2000) term, can at times produce a "nightmare texture," difficult to understand and respond to (p. 27). As I explore below, the body's processes as they relate to BG are not static—but meter readings are. They are better understood as representations of something that *happened* than of something *happening*—and what emerges is somewhat of a temporal problem.

**Continuous Glucose Monitors and Bodies as Data Collections:** To begin dealing with some of the issues that arise from static BG meter readings, and keeping in line with the more-data-is-better streams of many contemporary medical and scientific cultures,<sup>8</sup> doctors and device designers alike have invested considerable resources into developing and advocating for the use of continuous glucose monitors (or CGMs). FDA-approved for clinical use in 1999 and for at-home use in 2003, CGMs are intended to perform the task their name implies: keep track of blood glucose levels over time (Sato, Hirose, & Watada, 2012, pp. 225-226). Rather than relying on a singular number gathered ten minutes or two hours ago to get an idea of where one's glucose levels are, CGM users attach a sensor onto their body (usually somewhere around the abdomen) with a small tube or wire inserted beneath the skin which takes a reading every two to five minutes. These readings are then wirelessly transmitted from the CGM sensor to either an accompanying monitor device or directly to a user's insulin pump, where they are stored, time-stamped, and visualized for the patient and their physician (Medtronic Diabetes, 2013a, pp. 2-3).

A process which previously would have required painstaking record keeping by patients—who must actually *live* their lives while they manage their blood sugar—large-scale BG data collection via CGMs affords users the ability to stay up-to-date with their BG levels in almost real time (even though CGM readings have been shown to be delayed and less accurate than BG meter readings) (Medtronic Diabetes, 2013a, p. 3). Co-produced alongside these new methods of mass-quantification, however, are new

*temporally* redefined T1D bodies. While BG meters construct a usable T1D body, the numerical stand-ins they create are always fixed past-tense representations—T1D bodies that *were*. CGMs, on the other hand, map a constant stream of automated glucose readings onto a timeline to produce usable T1D bodies in both the present and future tense—T1D bodies that *are* and *will be*.

Shifting and intersecting temporalities themselves are not necessarily new concepts for people with T1D. In her recent article, Laura Forlano (2017) details many of the temporal implications of living a device-connected T1D life. As a “disabled cyborg” herself, the biomedical objects connected to her body and necessary for her insulin treatment acts “introduce industrial clock time to [her] biological processes” (p. 4). Using Kafer’s (2013) concept of “crip time” as a point of departure, Forlano explores the tensions and possibilities associated with the artificial (yet medically compelled) convergence of two disparate temporal framings. Not only does her insulin pump build an injection schedule on an hourly system, but the CGM attached to her body allows her to see her BG levels without going through the process of pulling out her meter and pricking her finger—an act that frequently interrupts work and/or other social activities (pp. 15, 18-19). Beyond the surface difficulties of these experiences themselves, both examples here (and especially Forlano’s discussion of the CGM) gesture toward a fundamental shift in T1D crip time more broadly—and these shifts reveal new convergences and perhaps conflations between T1D crip time on the one hand, represented here by Forlano’s inherently political use of the CGM to restructure her work and social practices, and T1D “curative time” on the other, represented by the expansion of industrial time within these structured pharmaceutical treatments conducted on/with bodies’ physiologies.<sup>9</sup>

The biomedicalized repositioning of Type 1 bodies as current, present, and dynamic is a process of transforming their embodied temporality in order to *optimize* them (Clarke et al., 2009, pp. 2, 23). People with T1D turn to CGMs, whether at the suggestion of their physician or on their own, in search of better control of their BG levels—to optimize their Diabetes by tracking it. By plotting BG data points on a timeline, these body-

reading devices place current numbers in direct comparison to previous numbers, and in so doing reframe the fundamental meaning of both individual and cumulative readings simultaneously.

As I argued above, the numerical body-stand-ins constructed through these tests are made to represent physiological states of the body at particular moments. But streams of CGM readings re-visualize that same body every few minutes, usually in slightly different form. T1D bodies, like all bodies, are dynamic—attempting to control and optimize, or even understand such a slippery entity can be a frustrating and uncomfortable experience. What, then, *is* the body if it is re-written all day, every day? But, if each BG test and CGM reading primarily derive meaning based on how they compare to other numbers, then the data only create usable meaning as a set and begin to function as what I call Datafied Body Doubles. No longer reduced to 1-to-1 numerical representations of the body on their own, Datafied Body Doubles attempt to recreate the dynamic nature of T1D bodies' physiologies in data form.

If not simply present-tense but *active*, Datafied Body Doubles must also account for the movement of time in the way users' present relates to both pasts and futures. Thus, CGM manufacturers highlight the importance of BG *movement*—trends and trajectories, to echo the terms cited most often by manufacturers and users alike—in using Datafied Body Doubles for optimal control. Medtronic (2013a), the largest insulin pump and CGM manufacturer in the United States and the maker of the Minimed series of insulin pumps, suggests that users “focus on what matters, the **trends**—the **direction** and the **speed** of the sensor glucose readings and graphs. **Pay less attention to each individual glucose number**” (p. 4, emphasis original).

From a technical standpoint, this language by Medtronic makes sense. Unlike BG meters, which measure the glucose-to-blood ratio directly from users' bloodstream via a finger prick, continuous glucose monitors measure the glucose-to-blood ratio from *interstitial fluid* located in the layer of subcutaneous fat where CGM sensor tubes are inserted. As a result, sensor readings are always slightly behind what is happening in users' bloodstream at the time of the test, and people are advised to “Always

confirm your blood glucose with a BG meter” before making any treatment decisions at all (Medtronic Diabetes, 2013a, p. 3). What may be understood as a statement of medical “best practices” could also be read as a legal disclaimer to avoid (potentially fatal) blowback from inconsistent or inaccurate CGM readings. From a sales standpoint, this statement also lays the groundwork for the importance of networking the two measuring devices together, which has both clinical and economic implications for the company.

But as Medtronic says, the numbers *themselves* are not what really matters. Rather than giving patients and doctors a snapshot of BG levels at a particular moment, CGMs produce continual snapshots plotted over time to give patients and doctors *trends* and *trajectories*. Since their move into home use during the 1980s, BG meter readings have functioned within a medicalized value system with two primary outcomes at stake: outside the target range = bad (requiring action from the user, either in the form of insulin injection or glucose ingestion); within the target range = good (users can forget about it and go about their day). With a CGM, however, a target-range reading by itself is only part of the story, the less important part according to Medtronic. CGM visualizations of sensor readings are always accompanied by a trajectory marker of either “going up” or “coming down”—usually identified for users with hypervisible up- or down-arrows (and in the case of the Medtronic “Enlite” CGM system, double-up- or double-down-arrows if their BG levels are changing rapidly) (Medtronic Diabetes, 2013a, p. 4). Though positive and negative value is still built around individual numbers’ proximity to the target range, new CGM-specific value systems construct positive and negative connotations around an imagined *future* numbers’ proximity to the same.

These CGM-produced blood glucose trajectories, then, are embedded with a new sense of T1D futurity. No longer biomedically valuable to simply identify what/where a person or their body is in a particular moment, CGM systems attempt to predict what they will be. After all, “going down” from a BG of 80 is not about that reading or that moment, but it constructs its meaning from an expectation of a low in the future. This imagined future is intended to help users prevent potentially life-threatening

situations, as those low numbers ascribed with negative values can lead to significant (and immediate) consequences for people with T1D. At the same time, the expectation of constant future danger is also part of a remolded twenty-first-century version of T1D's "grim imagined futures"—to echo Kafer (2013)—that have dominated cultural conceptions of Diabetes for decades (p. 2). Long essentialized as little more than a bleak existence full of suffering, withering, and an ever-present threat of death (assumptions etched into the US cultural canon through films such as *Steel Magnolias* (1989) and *Panic Room* (2002)), T1D futures are so medically and culturally undesirable that diagnoses are often accompanied by the mourning of one's lost able-bodied past.

Though T1D futures reframed by CGMs as numbers, anticipated highs and lows, rising and falling may be stripped of their culturally charged language, numbers themselves "have often been an agency for acting on people, exercising power over them" (Porter, 1996, p. 77). CGM futurities are built on conceptions of what users should be—a specific target BG range—which keeps people with Diabetes in a constant state of dynamic precarity, heavily reliant on the Datafied Body Doubles these measuring devices provide. Because these datafied futures are so deeply bound up in the bioeconomics of the production, distribution, and consumption of pharmaceutical devices and medical science and practice, they are powerful, hegemonic, biomedicalized neoliberal futures—futures wherein, as Kelly Fritsch (2016) argues, the bleakness [of T1D] is necessarily "solved" via biomedical intervention and enhancement, and any possibility of alternative spaces or trajectories requires critical crip interventions (pp. 11-12).

First re-created by BG meters as individual data points, T1D bodies are conceptually redefined and temporally mapped into data collections: Datafied Body Doubles that make their subjects legible to medical science in new ways. To be made legible is to be made usable, and in a very real sense, coming to know blood glucose levels (and therefore T1D bodies) means little for actual people unless it is connected with the act of insulin injection.

**Insulin Pumps and Techno-Medicalized Control of Difficult Bodies:**

The network of Diabetic measuring devices and practices discussed up to this point have changed the way we think (and even can think) about T1D bodies. Though various treatment cultures may hint to the contrary, BG measurement is primarily a means to an end and not an end unto itself. Knowing the T1D body and quantifying its processes is only medically valuable to patients and physicians alike in its ability to be used in treatment and/or intervention.

Enter: the insulin pump. This device is the centerpiece of the current standard of care for people with Type 1, primarily because it is site where the life-sustaining act of insulin injection is performed. But assessed through the lens of the T1D treatment network more broadly, the pump also functions as a hub where users go to interact with all their treatment acts, devices, and even their own bodies together in one place. It is here, I argue, where Datafied Body Doubles are gathered and materialized back onto/into the bodies they were made to represent through networked insulin injection. In so doing, the insulin pump comes to function as a catalyst for biomedicalized control of T1D bodies on and through their own Doubles.

Insulin pumps consist of several parts that together perform the function of “delivering” insulin to the body. The device itself is usually about the size of a pager—somewhere in the range of two inches-by-three inches-by-one inch—and houses a motor and piston, a small on-board computer to program delivery schedules and dosage formulas, a display, and some means for user interfacing (in most cases physical buttons, though more recently Tandem Diabetes, makers of the T-Slim insulin pump, have included touchscreen capability) (Medtronic Diabetes, 2013b, pp. 4-5). In order for that little device to perform its prescribed function, however, it requires several peripheral components (mostly disposable) to connect it to the body and facilitate the movement of sterile pharmaceuticals.

First, and most importantly, an insulin pump is only useful for people with T1D when it is used in conjunction with a pharmaceutical-grade insulin product. Users fill a disposable reservoir or small tube with enough insulin to last about three days and insert it into the device where the plunger can drive injections. The insulin-loaded pump is then connected to a user’s body

by attaching a length of tubing between the reservoir and an infusion set—a port that includes a small tube inserted under the skin, serving as the conduit between the device and the internal workings of the body. With all these pieces in place, users can interface with the pump and give commands to inject insulin as needed—often referred to as a “bolus” dose—and set automated micro-injections to regulate BG levels throughout the course of an average day—known as a “basal” dose (Medtronic Diabetes, 2013b, pp. 4, 53-56).

But to know how much to inject, and when to inject it, users rely on their Datafied Body Doubles created by their blood glucose measuring devices to know “what they are,” and “where they are going.” Dosing a pharmaceutical such as insulin involves some rather complex calculations that bring together multiple sites and quantification systems. T1D bodies and their BG levels are measured in mg/dL or mmol/L through the processes outlined above, insulin dose recommendations are based on standardized “units” created by a panel of physicians in the early twentieth century,<sup>10</sup> and carbohydrates people ingest are usually measured in grams (though many foods—especially unprocessed foods without nutrition labels—are not easily quantifiable this way). All of these systems of measurement interact with and slightly alter each other, creating a muddy web of numbers that can be difficult to navigate.

To make that web more manageable, everyday users are no longer required to perform these complex calculations themselves. Insulin dose formulas are programmed into users’ insulin pumps and can be adjusted by their physicians to meet the changing needs of a dynamic T1D body. As people plug their Datafied Body Doubles into their insulin pumps, their devices perform the calculations for them and provide their dose amount. To make the process simpler still, most of the data produced by glucose meters and CGMs for networked users are automatically transmitted wirelessly to the insulin pump, requiring even less direct engagement with the “blackboxed” dose calculations (Medtronic Diabetes, 2013a, pp. 22-27). All they have to do is click “Yes,” or “Go,” and the insulin pump delivers that amount into the user’s body for them. So long as the Datafied Body Doubles and formulas are working and the outcome is what users expect (i.e., no

major unexpected fluctuations in BG levels), as Bruno Latour (1999) has argued in relation to scientific blackboxing more generally, users have no need to know the inner workings of the device (p. 304). As Datafied Body Doubles are used for insulin dose calculations, the already obscured T1D body is made even more opaque, and the invisibility of technoscientific medical processes work to make Diabetes invisible along with it.

As insulin pumps inject a dose into the body, people with T1D are inundated with sensory cues of the treatment act: the dose amount incrementally decreasing on screen, the cold sting of pharmaceuticals spreading from the infusion site, the action notification beeps and the sound of the pump's motor pushing the plunger ever so slightly, and sometimes even the clinical odor of the insulin itself. All of this combines with individuals' own sensory embodiment, which often fluctuates dramatically with changing blood glucose levels, as Datafied Body Doubles frame and categorize all of these experiences within the bounds of medical authority.

By reducing the body and its processes to data collections, it can be more easily used to *control* the effects of living with T1D—a central goal of BG testing since at least the 1970s (Walford, Gale, Allison, & Tattersall, 1978, p. 732)—but it is through networked insulin pump treatment that Datafied Body Doubles are used to materially alter T1D bodies themselves. As users directly and indirectly input Datafied Body Doubles into automated injections through their insulin pumps, what was created as a set of observations of the body becomes a part of the same. The conceptual redefinitions created through reiterated meter and CGM tests are made real by materially changing the body, and users' sensory experiences with them.

## Conclusion

I began this article by calling attention to the precarious position of people with Type 1 Diabetes. And though it may appear somewhat hyperbolic at first glance, the constant “predicament of dangerous safety” people with T1D live with on a daily basis, to again borrow Feudtner's (2003) term, is as real within the networked insulin pump era as it has ever been (p. 29). BG testing devices and insulin pumps have indeed made significant changes in

the ways that precarity is manifest, often in ways users define as life changing or miraculous. Their lives are still as dependent on insulin injections as they have ever been, and that is not likely to change any time soon, but the *feeling* of having just a little more control makes their continued use of these devices worth it.

It is *that* drive—*that* desire for some semblance of stability within their own bodies where there usually is very little—that compels many of these biomedicalized *crip* users to maintain their device-connectedness regardless of the possibility of complications, physical or otherwise. And though that drive is often bound up in the hope for (problematic conceptions of) more-able-bodied futures, it is also what drives the “crip aspirations” for a more nuanced and community-built future for T1D—to echo McRuer’s (2018) use of the term (pp. 176, 217). There are of course plenty of conscious non-users, and the economic barriers to entry in this type of hi-tech medical treatment abound (an issue in desperate need of further interrogation), but the cultural force driving any optimal medical treatment is difficult to avoid.

These compelled users are implicated in their own datafication through their continued use of those devices—a choice that, as I argued at the beginning of this essay, is not much of a choice at all—but their bodies are re-created and used to drive their participation in those very techno-medicalized treatments nevertheless. Though the construction of usable bodies via Datafied Body Doubles is made particularly *visible* in the case of the millions living with Type 1 Diabetes, similar methods of biomedicalized control are written into an array of other technologies used in other sites of body and health quantification. Giving due attention to these unique experiences of people with their treatment devices can help identify similar spaces of technoscientific meaning-creation, as well as help expand critical frameworks to better include the compelled use of medical devices by people with chronic illnesses.

## Notes

<sup>1</sup> In referencing the chronic condition noted here as Type 1 Diabetes Mellitus, I will use the terms *Type 1 Diabetes*, *Type 1*, *T1D*, and *Diabetes* interchangeably unless otherwise specified in-text. I capitalize these terms in order to call attention to the role diagnosis—the social, medicalized act of naming and classifying disease—plays in framing how any conversation of Diabetes is and can be conducted. See Rosenberg (1992).

<sup>2</sup> As a chronic illness that can supposedly be pharmaceutically controlled, claims to disability are more often tied to Diabetes-related effects rather than to Diabetes itself (and similarly, few people with Diabetes socially identify themselves as disabled). The US Social Security Administration's (n.d.) *Disability Evaluation Under Social Security* handbook (colloquially referred to as the Blue Book) notes that both Type 1 and Type 2 Diabetes are "chronic disorders that can have serious disabling complications that meet the duration requirement." The administration can therefore "evaluate the effects of endocrine disorders [such as Diabetes]" to decide whether a particular case is severe enough to qualify for benefits. Examples may include amputations, diabetic retinopathy, chronic skin disorders, or cognitive impairments due to diabetic peripheral neurovascular disease or chronic hyperglycemia (Sec. 9.00B5, 9.00C, 109.00B5, 109.00C, 109.08).

<sup>3</sup> See the history of "transmuted disease" briefly discussed in the following subsection.

<sup>4</sup> Though the term *insuline* had been used as a hypothetical placeholder term for a then unidentifiable product of the pancreas nearly a decade before Banting's research, it was Banting et al. who suggested the use of *insulin* as the scientific term for the pancreatic hormone known thereby today. See Banting, Best, Collip, Macleod, & Noble, 1922, p. 175; Schäfer, 1914, p. 84.

<sup>5</sup> Nelly Oudshoorn and Trevor Pinch (2003), along with the contributors to their edited collection *How Users Matter* and other science and technology studies scholars, have written extensively about the politics of use, and the coproduction of users and technologies. And though Sally Wyatt's (2008) call for a more nuanced, continuum-based understanding of relationships between people and devices included a nod toward what she called "forced use," the *compelled* user—for whom "choice" is but a mask for a system wherein there is none or very little—requires more attention in the user studies literature.

<sup>6</sup> For more on the Quantified Self movement, see Lupton (2016).

<sup>7</sup> The International Diabetes Federation's has identified a target fasting BG for non-Diabetic people of 4 to 5.9 mmol/L (72 to 105 mg/dL), incrementally lower than that outlined by the National Institutes of Health, whereas the World Health Organization has defined "normal" BG as never rising above 7.8 mmol/L (140 mg/L) (Ceriello & Colagiuri, 2008, pp. 1152, 1154).

<sup>8</sup> For more on the current drive for big data in medicine, see boyd & Crawford (2012); Murdoch & Detsky (2013).

<sup>9</sup> Kafer (2013) distinguishes between what she calls "curative time" and the more widely cited concept of "crip time." The latter is framed in direct opposition to the former, which is characterized by a sense of futurity that "cannot imagine or comprehend anything other than [biomedical] intervention" due to its deep and uncritical investment in compulsory able-bodiedness/able-mindedness (p. 27).

<sup>10</sup> Banting and the research team who discovered insulin named one "unit" after the dose amount needed to produce a certain level of hypoglycemia in rabbits weighing 2kg. Though divorced from the human subjects for whom insulin was intended, unit measurements were standardized at an international conference and have been used ever since. For more on the effect of this decision on cultures of medicine broadly, see Porter (1996, pp. 31-32).

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## Bio

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