

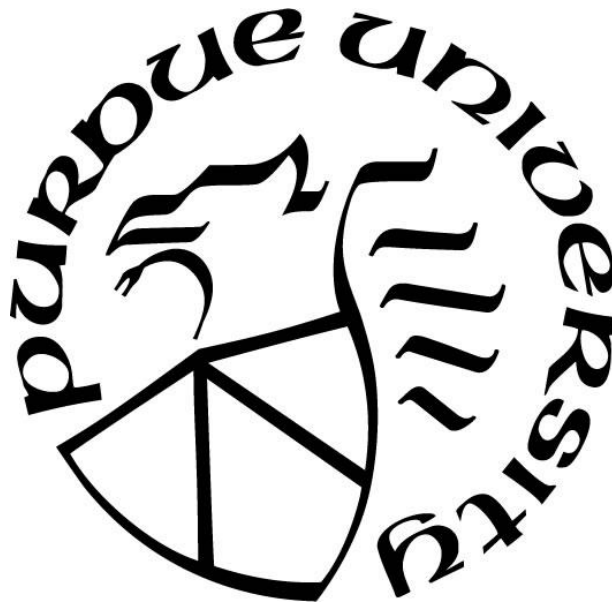
**INSULIN PUMP USE AND TYPE 1 DIABETES:
CONNECTING BODIES, IDENTITIES, AND TECHNOLOGIES**

by
Stephen Horrocks

A Dissertation

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THE PURDUE UNIVERSITY GRADUATE SCHOOL
STATEMENT OF COMMITTEE APPROVAL

Dr. Sharra Vostral, Chair

Department of History

Dr. Rayvon Fouché

School of Interdisciplinary Studies

Dr. Shannon McMullen

School of Interdisciplinary Studies;

Patti and Rusty Rueff School of Design, Art, and Performance

Dr. Mary X. Mitchell

Department of History

Approved by:

Dr. Rayvon Fouché

Dedicated, unequivocally, to Melissa

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LIST OF ABBREVIATIONS

A1c – Glycated Hemoglobin (HbA1c)

ADA – American Diabetes Association

AHRQ – Agency for Healthcare Research and Quality

ANT – Actor-Network Theory

ARM – Ames Reflectance Meter

BD – Beckton, Dickinson, and Company

BG – Blood Glucose

CGM – Continuous Glucose Monitor

CSII – Continuous Subcutaneous Insulin Infusion

DBD – Datafied Body Double

DKA – Diabetic Ketoacidosis

FDA – Food and Drug Administration

HIPAA – Health Insurance Portability and Accountability Act

JDRF – Juvenile Diabetes Research Foundation

MDI – Multiple Daily Injections

PHI – Personal Health Information

SSED – Summary of Safety and Effectiveness Data

STS – Science and Technology Studies

T1D – Type 1 Diabetes

ABSTRACT

Since the late 1970s, biomedical researchers have heavily invested in the development of portable insulin pumps that allow people with Type 1 Diabetes (T1D) to carry several days-worth of insulin to be injected on an as-needed basis. That means fewer needles and syringes, making regular insulin injections less time consuming and troublesome. As insulin pump use has become more widespread over the past twenty years among people with T1D, the social and cultural effects of using these medical devices on their everyday experiences have become both increasingly apparent for individuals yet consistently absent from social and cultural studies of the disease.

In this dissertation, I explore the technological, medical, and cultural networks of insulin pump treatment to identify the role(s) these biomedicalized treatment acts play in the structuring of people, their bodies, and the cultural values constructed around various medical technologies. As I will show, insulin pump treatment alters people's bodies and identities as devices become integrated as co-productive actors within patient-users' biological and social systems. By analyzing personal interviews and digital media produced by people with T1D alongside archival materials, this study identifies compulsory patterns in the practices, structures, and narratives related to insulin pump use to center chapters around the productive (and sometimes stifling) relationship between people, bodies, technologies, and American culture.

By analyzing the layered and intersecting sites of insulin pump treatment together, this project reveals how medical technologies, health identities, bodies, and cultures are co-constructed and co-defined in ways that bind them together—mutually constitutive, medically compelled, cultural and social. New bodies and new systems, I argue, come with new (in)visibilities, and while this new technologically-produced legibility of the body provides unprecedented management of the symptoms and side-effects of the disease, it also brings with it unforeseen social consequences that require changes to people's everyday lives and practices.

CHAPTER 1: INTRODUCTION

In November 2014, my wife and partner Melissa purchased a new insulin pump. It had been five-and-a-half years since, in preparation for a study abroad program, she finally gave in to her endocrinologist's nudgings and switched from multiple daily injections to insulin pump treatment. The transition was, as she tells it, both anxiety-inducing and freeing. Rather than giving herself five or six shots a day, she attached this device to her stomach once every three days—no more running to the bathroom for shots, just pressing a few buttons and going about her business. To put it broadly, the insulin pump was life-changing.

But over time that first pump, as happens with many of our devices, began showing signs of daily wear-and-tear and was eventually branded with the dreaded tech title: “outdated.” Working with her endocrinologist, Melissa waded through the insurance process to purchase a new insulin pump. Top-of-the-line and auto-synced with her blood tester and a new continuous glucose monitor, her new feature-rich pump required instructional sessions at the clinic before she could take it home and—perhaps, surprisingly, the most conflicted part of the process—return her old pump to the manufacturer for data scraping.

And it is at this point that we must take a step back. Diagnosed with Type 1 Diabetes at age nine, shots and finger-pricks have inundated Melissa's everyday life for nearly two decades. Everywhere she went, a bag full of supplies went with her: a blood glucose meter, needles and a vial of insulin (later switched out for insulin pens), and a sugary pick-me-up in case of low blood sugars (usually a juice box). Those contents changed dramatically when she went on the pump; her insulin was now loaded into the device in her pocket, and the tubing running from there to the infusion site on her abdomen took the place of her needles. The insulin-giving devices she used were no longer carry-along objects, but connected ones, integrated with her body in ways they never had or could before.

Thus, as she packed her old insulin pump into the small shipping box for return—the device which had been attached to her day and night, continuously injecting the life-sustaining pharmaceuticals she needed for over five years—she found it difficult to let it go. She was excited for her new pump and couldn't wait to try out some of the new peripherals that had been so adamantly talked up by her doctors, but the emotional weight of separation from this thing that had so long been a part of her was real, and heavy. Tears flowed as she dropped her pump into

the UPS mailbox; “This is so stupid...,” I remember her saying, “I don’t know why I’m crying.” But we both understood what we couldn’t put into words. She and I sat in car, hugging and processing that moment together before pulling out of the lot and driving home.

Co-Constructing Type 1 Diabetes and Insulin Pump Treatment

Melissa’s story, though unique and deeply personal, is not altogether unusual—approximately 1.25 million people in the United States have been diagnosed with Type 1 Diabetes, and about 40% of them use an insulin pump.¹ Not to be confused with the more common “Type 2,” characterized by cells’ resistance to insulin and/or a reduction of its production, Type 1 Diabetes Mellitus (or T1D) is an autoimmune disorder which eliminates the body’s ability to produce insulin altogether. Because the body uses this hormone to break down and use carbohydrates for energy, people with T1D must take multiple daily injections of artificial insulin to process the food they eat and prevent other related health problems from developing.² But as I hinted toward in Melissa’s story above, the constant, repeated, ever-present shot-giving that typifies life with T1D can be exhausting and burdensome.

Therefore, since the 1970s biomedical researchers have funneled massive resources into developing and marketing portable insulin pumps: devices that would allow people to carry several days’ worth of insulin and inject it via the pump’s tubing on an as-needed basis. This means fewer needles and syringes, making the average 4-7 insulin injections per day much simpler and easier on the body.³ But as insulin pump use has become more widespread over the

¹ Statistics derived from: Centers for Disease Control and Prevention, “National Diabetes Statistics Report, 2017” (Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services, 2017); Lutz Heinemann et al., “Insulin Pump Risks and Benefits: A Clinical Appraisal of Pump Safety Standards, Adverse Event Reporting, and Research Needs: A Joint Statement of the European Association for the Study of Diabetes and the American Diabetes Association Diabetes Technology Working Group,” *Diabetes Care* 38, no. 4 (April 1, 2015): 717, <https://doi.org/10.2337/dc15-0168>. This data includes incidence of Type 1, Type 2, gestational, and other temporary forms of diabetes together.

² George S. Eisenbarth, “Type I Diabetes Mellitus,” ed. Jeffrey S. Flier and Lisa H. Underhill, *The New England Journal of Medicine*; *Boston* 314, no. 21 (May 22, 1986): 1360; Michael P. Morran et al., “Immunogenetics of Type 1 Diabetes Mellitus,” *Molecular Aspects of Medicine*, Pancreatic beta cell failure and Diabetes, 42 (April 1, 2015): 42–60, <https://doi.org/10.1016/j.mam.2014.12.004>.

³ Winston Crasto, Janet Jarvis, and Melanie J. Davies, “Insulin Management in Type 1 Diabetes,” in *Handbook of Insulin Therapies* (Springer, 2016), 146–47, https://doi.org/10.1007/978-3-319-10939-8_5. See also; John Pickup et al., “Long-Term Continuous Subcutaneous Insulin Infusion in Diabetics at Home,” *The Lancet* 314, no. 8148 (1979): 870–873.

past twenty years among people with T1D, the social and cultural effects of using these medical devices on their everyday experiences have become both increasingly apparent for individuals yet consistently absent from social and cultural studies of the disease.⁴

In this dissertation, I explore the technological, medical, and cultural networks of insulin pump treatment to identify the role(s) these biomedicalized treatment acts play in the structuring of people, their bodies, and the cultural values constructed around various medical technologies. As I will show, insulin pump treatment alters people's bodies and identities as devices become integrated as co-productive actors within patient-users' biological and social systems. By analyzing personal interviews and digital media produced by people with T1D alongside archival materials, this study identifies compulsory patterns in the practices, structures, and narratives related to insulin pump use to center chapters around the productive (and sometimes stifling) relationship between people, bodies, technologies, and American culture.

By analyzing the layered and intersecting sites of insulin pump treatment together, this project reveals how medical technologies, health identities, bodies, and cultures are co-constructed and co-defined in ways that bind them together—mutually constitutive, medically compulsory, cultural and social. New bodies and new systems come with new (in)visibilities, I argue, and while this new technologically-produced legibility of the body provides unprecedented managements of the symptoms and side-effects of the disease, it also brings with it unforeseen social consequences that require changes to people's everyday lives and practices.

Uncovering these sites of techno-medicalized meaning creation destabilizes the assumptions at the center of dominant cultural definitions of Diabetes, placing technology at the heart of Diabetic identity construction. Furthermore, understanding how technoscience, identity, and bodies intertwine in the context of the contemporary United States highlights how that process structures understandings of ourselves and others within modern biomedicalized cultural paradigms. As health practitioners and manufacturers produce and market new devices, treatments, procedures, and pharmaceuticals to “revolutionize” T1D treatment, it will be increasingly important to maintain critical perspectives of the context of use afforded by this

⁴ Heinemann et al., “Insulin Pump Risks and Benefits,” 717.

⁵ “Management” and “control” of non-normative bodies through biomedical means is a problematic social framing—one which has been the focus of much disability and crip STS scholarship. I engage some of those conversations below, but aim to broaden that engagement throughout each chapter that follows.

study. Though med-tech advances often do make significant improvements to life with Diabetes, as insulin pumps and CGMs most certainly have, they also create wholly new unintended effects on the material, social, and cultural experience of living with Type 1 Diabetes.

Diabetes in/and American Culture

As a large-scale public health concern that affects millions of people, broad interest in more efficient and less invasive treatments for Type 1 Diabetes is unsurprising. What *is* surprising, however, is the frequency with which these studies all but leave out discussion of the real people who must manage their chronic illness on a daily, even hourly basis—especially in relation to their daily social and personal experiences. As these devices become integrated with individuals’ physiological and social selves, people’s identities and bodies are fundamentally changed in ways that deeply influence their everyday lives—as well as the ways their bodies and devices are understood by others.

And it is that last point, how people with diabetes and their bodies are understood by themselves and others, that gestures toward a larger and equally important cultural phenomenon: “Diabetes” is largely misunderstood. Though the several “types” of Diabetes are denoted by the same name, they each represent very different processes within the body and radically different experiences with daily living and treatment.⁶ These illnesses are therefore frequently conflated as one and the same, despite their fundamental differences. From film and television to social media and standup comedy, U.S. popular culture constructs Diabetes as a one-dimensional, choice-driven illness inscribed upon obese bodies as a result of their dietary and exercise habits—Diabetes is the butt of the joke. This narrative is deeply troublesome and full of misconstrued (and often wholly untrue) information, but as it is repeated, reiterated, and normalized, “Diabetics” become discursively synonymous with and stigmatized by these cultural stereotypes. Diabetes, sugar, and obesity are understood as one and the same; a package deal. The circulation of these stereotypes defines this Diabetic social and medical status in relation to particular visual

⁶ There are approximately two-dozen separate medical entries under the term “diabetes” among Black’s, Stedman’s, and Dorland’s Medical Dictionaries. Though these various conditions are related by changes in blood glucose levels, their causes, physiological processes, and effects (both long-term and short-term) differ widely. See: Dr Harvey Marcovitch, “Diabetes Mellitus,” in *Black’s Medical Dictionary* (Lanham, MD: Scarecrow Press, March 7, 2006); “Diabetes,” in *Stedman’s Medical Dictionary* (Philadelphia: Stedman’s, December 14, 2005); “Diabetes,” in *Dorland’s Illustrated Medical Dictionary* (Edinburgh: Saunders, June 1, 2007).

and cultural constructions of embodied normalcy, cultural standards that place constraints on the ways people with Diabetes are and even can be understood by others—as well as how they understand and experience their own bodies.

It is these bodies and individuals, after all, that matter in the context of understanding Diabetes, both in a medical and a cultural sense. Because of the widespread misunderstanding of Diabetes, the person and the body are lost and/or dissolved within the discussion of the disease. I contend that the “healthscape”⁷ of Diabetes within American culture generally conflates three major discursive components: the body (as the site of medicalized difference and embodied otherness), individual *choice* (as the assumed instigating factor, usually associated with diet and exercise, and framed by liberal conceptions of individualism), and technologies (including vials of insulin, syringes, insulin pumps, and blood glucose meters as the sites of biomedicalized treatment *and* of social marking as capital-D “Diabetic”)—which together function as sustaining metrics for the collection of systemic normalizing practices Robert McRuer calls “compulsory able-bodiedness.”⁸

But where does Type 1 Diabetes fit within this Diabetes healthscape? It is clear that these cultural structures are not equipped to take into account *their* bodies or experiences. Nevertheless, those same frameworks still inform a wide range of social readings and practices performed on and in relation to their bodies, including those performed by themselves and their devices. It is in these spaces, where the limits of healthscapes built on compulsory able-bodiedness are made visible, that I consider the ways Diabetes, Diabetics, and treatment technologies such as insulin pumps are culturally co-constructed, both inside and outside of this simplistic body-choice matrix. This study, by conducting interdisciplinary cultural analyses of the technological and cultural networks of insulin pump use, fills an important (and glaring) gap in scholarship dealing with both medical devices and the contemporary experience of living with Type 1 Diabetes, shedding light on the sociocultural roles chronic illnesses play within the United States more generally.

⁷ “Healthscapes,” as defined by Adele Clark, et al., refer to the visual cultures of (bio)medicine, health and healing as circulated within a particular cultural paradigm. See Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2009), 3.

⁸ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: NYU Press, 2006), 2.

Diabetes, Technoscience, and Culture: A Review of the Literature

As I gestured toward above, the human experiences of living a device-connected T1D life have been largely under-studied from social science and humanities perspectives. One likely reason for this dearth of scholarship is the linguistic association between Type 1 and Type 2 Diabetes, as an abundance of work has been done in relation to the latter over the past few decades under the auspice of the “Diabetes epidemic.” Despite its dominance of medical, public health, social scientific, and cultural dialogues around Diabetes—and understandably so, as it is diagnosed at ten times the rate of Type 1—some important interventions have been made in the study of Type 2 that inform understandings of socio-technical T1D experiences. Significant social and cultural research has been conducted in recent years which details, among other things: the role of stigmatization in the construction of Diabetes illness narratives and how contextualization can aid in the process of de-stigmatization;⁹ the inherently global nature of medical and cultural definitions of Diabetes as a product/producer of colonialism, especially as it has been constructed around the production and movement of sugar;¹⁰ the co-construction of Diabetes, race, gender, and class;¹¹ and the ways in which Diabetes genomic research, especially at the site of “risk,” has served to produce and reinforce scientific notions of race and white superiority.¹²

Though these studies draw directly from and speak directly to the particularities of Type 2 Diabetes, the confluence of a multiplicity of illnesses under the “Diabetes” umbrella locates Type 1 within the production, movement, and application of Diabetes illness narratives and

⁹ Sheila Bock, “‘Grappling to Think Clearly’: Vernacular Theorizing in Robbie McCauley’s Sugar,” *Journal of Medical Humanities* 36, no. 2 (June 1, 2015): 127–39, <https://doi.org/10.1007/s10912-015-9326-8>; Sheila Bock, “Contextualization, Reflexivity, and the Study of Diabetes-Related Stigma,” *Journal of Folklore Research* 49, no. 2 (2012): 153–78, <https://doi.org/10.2979/jfolkrese.49.2.153>; Sheila Marie Bock, “‘A Little Sugar’: Interactions between Professional and Lay Understandings in Diabetes Education” (The Ohio State University, 2010).

¹⁰ Amy Moran-Thomas, *Traveling with Sugar: Chronicles of a Global Epidemic* (Oakland: University of California Press, 2019); Lesley Jo Weaver, *Sugar and Tension: Diabetes and Gender in Modern India* (New Brunswick, New Jersey: Rutgers University Press, 2018).

¹¹ Harshad Keval, *Health, Ethnicity and Diabetes: Racialised Constructions of ‘Risky’ South Asian Bodies* (New York: Springer, 2016); Harshad Keval, “Risky Cultures to Risky Genes: The Racialised Discursive Construction of South Asian Genetic Diabetes Risk,” *New Genetics and Society* 34, no. 3 (2015): 274–293.

¹² Michael Montoya, *Making the Mexican Diabetic: Race, Science, and the Genetics of Inequality* (Oakland: University of California Press, 2011).

definitions nevertheless. Operating under this framework, some scholars have written about Diabetes as a fundamentally social and cultural experience of chronic illness that has implications for every individual diagnosed with a condition by that name. Shared among these socio-medical discourses, for example, are contested issues of patient agency and expertise at the site of medicalized treatment which simultaneously requires them in practice and denies them rhetorically.¹³ Likewise, cultural representations of Diabetes carry substantial influence on the lives of people who live in diagnosis, as stigma can have direct effects on individuals' realities and experiences.¹⁴

Yet among these studies, it is still difficult to differentiate experiences of people with Type 1 from those of people living with another diagnosis. And although there is much that translates among their collective experiences, the physiological and social realities of life with T1D necessitate research focused directly thereon. Historical research has primarily focused on the development of insulin and its social/biological effects.¹⁵ Some social scientific research has also focused on the experience of life with T1D, focusing primarily on rhetorical problems with Diabetes framings such as "management" and its assumed proximity to able-bodiedness, though some work has been published regarding online Diabetes communities and underground supply exchanges.¹⁶ These works make considerable and important additions to academic literatures, highlighting the essential humanness of clinical research practices that led to the development of arguably the most significant biomedical intervention of the twentieth century. Others open a

¹³ Lora Arduser, *Living Chronic: Agency and Expertise in the Rhetoric of Diabetes* (Columbus: The Ohio State University Press, 2017).

¹⁴ Bianca Claire Frazer, "Diabetic Aesthetic: From Stigmatizing Diabetes to Acknowledging the Lived Experience on Stage" (University of Colorado, 2019).

¹⁵ Chris Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness* (Chapel Hill: The University of North Carolina Press, 2003); Thea Cooper and Arthur Ainsberg, *Breakthrough: Elizabeth Hughes, the Discovery of Insulin, and the Making of a Medical Miracle* (New York: St. Martin's Press, 2010). For a more in-depth discussion of Feudtner's interventions and its implications for this project, see Chapter 2 of this dissertation.

¹⁶ Jeffrey A. Bennett, *Managing Diabetes: The Cultural Politics of Disease* (New York: NYU Press, 2019); Jeffrey A. Bennett, "Containing Sotomayor: Rhetorics of Personal Restraint, Judicial Prudence, and Diabetes Management," *Quarterly Journal of Speech* 104, no. 3 (July 3, 2018): 257–78, <https://doi.org/10.1080/00335630.2018.1486033>; Michelle L. Litchman et al., "State of the Science: A Scoping Review and Gap Analysis of Diabetes Online Communities," *Journal of Diabetes Science and Technology* 13, no. 3 (2019): 466–492; Michelle L. Litchman et al., "The Underground Exchange of Diabetes Medications and Supplies: Donating, Trading, and Borrowing, Oh My!," *Journal of Diabetes Science and Technology*, December 4, 2019, 1932296819888215, <https://doi.org/10.1177/1932296819888215>.

wholly new academic space for discussions of American cultural constructions of T1D, as well as the role of digital life and culture in what it means to live with this condition in the twenty-first century.

At the time of this writing, however, there are only two authors who consider the interactive and agential role of treatment technologies within the context of T1D life to any considerable degree. Annemarie Mol took Diabetes life and treatment as her primary example of what she calls “the logic of care,” a focus on what it means to live with disease as opposed to the “logic of choice” which dominates health care and markets. Living with disease, and Diabetes in particular, can only be understood along with the treatment regimes and technologies that sustain life with disease.¹⁷ Embodying that sentiment, and bringing it within the auspice of a crip feminist technoscience analytical framework, Laura Forlano narrates her own experience as a “disabled cyborg” to highlight the ways her insulin pump and CGM mediate her experience with the world. The “data rituals” at the core of those experiences open an important space for feminist critiques of medicalized control and techno-determinism.¹⁸

Even in the context of these two pieces of scholarship, which both frame Diabetes and treatment in new and important ways, the depth and breadth of a device-connected T1D life has remained under-studied. The medical, technological, and cultural networks of T1D life and treatment is vast yet personal, and the mechanisms and textures of those networks in people’s lives vary. This dissertation brings together people’s material and social experiences with T1D, their own bodies, and their treatment devices in order to flesh out the ways they interact and constitute each other within current biomedicalized practices in the US. By focusing on personal interviews, informants’ voices and stories inflect my analysis of factors compelling the use of insulin pumps and other Diabetes treatment devices. This also serves to maintain focus on the tensions between these devices’ significant effects on patient-users’ quality-of-life on the one hand, and their unintended (and often uncomfortable or painful) social and material consequences on the other. This research posits that the circulation of socio-technical Diabetes

¹⁷ Annemarie Mol, *The Logic of Care* (New York: Routledge, 2008), 10, 73; Annemarie Mol and John Law, “Embodied Action, Enacted Bodies: The Example of Hypoglycaemia,” *Body & Society* 10, no. 2–3 (June 1, 2004): 43–62, <https://doi.org/10.1177/1357034X04042932>.

¹⁸ Laura Forlano, “Data Rituals in Intimate Infrastructures: Crip Time and the Disabled Cyborg Body as an Epistemic Site of Feminist Science,” *Catalyst: Feminism, Theory, Technoscience* 3, no. 2 (October 18, 2017): 3–5, <https://doi.org/10.28968/cftt.v3i2.130.g267>.

treatment among those various networks produces new social and material T1D bodies. People who experience those circulations (and shifting bodies) make clear that technology is at the center of Diabetic identity formation, and provides an important lens into life in a biomedicalized United States more generally.

Use as a Transformative Act

Medical devices pose an increasingly important problem for scholars devoted to understanding the social, cultural, and political nuances of science and technology. These technologies' various relationships to the institutions of Medicine and Big Pharma create links to power structures with histories of both large-scale social healing and systemic oppression.¹⁹ But what is more, the positionality of some medical devices (and insulin pumps in particular) as *both* inside and outside the body forces us to rethink the ways bodies, identities, and technologies are created in biological, social, cultural, and especially political ways. Insulin pump treatment—made up of various devices, pharmaceuticals, and prescribed routines and practices for patients with T1D—revolves around a system of what I call *compelled use*. Therefore, I will engage with two major veins of STS research throughout this project that can, I think, help illuminate the intricacies of medical device use, creation, and their sociocultural function and meaning. In what follows, I will bring together User Theory with Feminist and Crip STS conceptions of situated bodies and knowledges to show that in the context of insulin pump treatment, bodies, identities, and devices are all constantly redefined as new forms of biocapital with unique relations to each other and larger sociopolitical structures.

¹⁹ As Adele Clarke, et al. argue, the institution(s) of Medicine is deeply connected to systems of social and economic power in ways that structures the lives and relationships of doctors and patients alike. Thus, as Rosenberg has identified, defining processes such as diagnosis necessarily place socioeconomic values on people and bodies within those structures, framing not only their existence in the present but both their nostalgic pasts and imagined futures—a framing which, as Kafer has shown, particularly devalues and dismisses those outside the bounds of able-bodiedness/able-mindedness. See: Clarke et al., *Biomedicalization*; Charles E. Rosenberg, “Framing Disease: Illness, Society, and History,” in *Framing Disease: Studies in Cultural History*, ed. Charles E. Rosenberg and Janet Golden (New Brunswick, N.J: Rutgers University Press, 1992); Alison Kafer, *Feminist, Queer, Crip* (Indiana University Press, 2013), <http://www.jstor.org/stable/j.ctt16gz79x>.

Users and Compelled Use

Theories regarding *users* of technologies—or the people who engage with technologies—can help uncover the cultural and economic power structures that influence the relationships between people and things. Compiling the research of fourteen scholars from around the world, Nelly Oudshoorn and Trevor Pinch’s *How Users Matter: The Co-construction of Users and Technologies* works through some of the problems and issues that arise from: 1) the act of using (or not using) technology, and 2) how “users” are defined as such, and what that means for themselves and their position in relation to social structures. Assessing the several works together, Oudshoorn and Pinch argue that users and technologies are co-constructed (taking a conscious step away from both social and technological determinism). While it is true that technologies often do act upon the user, users also change the meaning and even materiality of devices and objects through the act of use as well.²⁰ Bringing together aspects of feminist inquiry, semiotic methodologies, and cultural studies theories, User Theory (as I will refer to it here for shorthand) identifies the active role users and non-users play in reconceptualizing socio-technological change through consumption, modification, reconfiguration, and resistance.²¹

Discourses concerning the social interactions of technological artifacts with people, as agents with social meanings in and of themselves, highlight the cultural values placed in the productions of technoscience and how those values and meanings are inscribed thereon. In an attempt to hone and reframe his career-long project to theorize these kinds of human and technological relationships, Bruno Latour outlines Actor-Network Theory (ANT) in *Reassembling the Social: An Introduction to Actor-Network Theory*. In general, he argues, sociologists are too hasty in their use of labels on large-scale social systems (including “society,” “power,” and “structure” among others—all of which, it should be noted, I have used in this introduction). These shorthand notations too frequently encourage the drawing of uncritical associations between the specifics of a study and some amorphous entity that can supposedly

²⁰ Nelly Oudshoorn and Trevor J. Pinch, eds., *How Users Matter: The Co-Construction of Users and Technologies* (MIT Press, 2003), 2.

²¹ Oudshoorn and Pinch, 1, 4, 7, 11, 16.

explain everything within simplified terms and connections.²² His solution: slow down and trace the connections and relationships between the actual people and things within the parameters of the study and their effects. In short, ANT should function as a “negative, empty, relativist grid that allows us *not* to synthesize the ingredients of the social in the actor’s place.”²³

Though Latour’s decades-long work on ANT has been intensely debated across several academic disciplines,²⁴ his major point about giving due attention and credit (socially speaking) to each individual component of social assemblages is a useful framework for seeing and understanding relationships between people, bodies, and technologies. But as I will show within this project, Latour’s conception of ANT can be expanded to consider the network of constituent parts and processes *within* the body as well, a network that is complicated by the use of devices such as insulin pumps which function both inside and outside the body.

Applying this constituent-focused methodology along with User Theory to a study of the use of insulin pumps, I contend, reveals new iterations of user identities and practices on the one hand, and new constructions of devices as actors themselves on the other. Though the user studies within Oudshoorn and Pinch’s text identify several forms or types of users and non-users, they do not address what I call *compelled use*, a practice and designation made visible by giving credence to the specific material and sensory experiences of people with Type 1 Diabetes themselves. In most of the studies informing the scholarship identified above, there was some form of choice on the part of the user as to whether they would engage with the technologies (even in cases where users were *constrained* by social or infrastructural systems, which is essentially ubiquitous), but as is often the case for medical technologies that treat chronic illness, a decision of non-use is a decision for non-life. These devices perform regular life-sustaining

²² Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory*, 1st edition (Oxford; New York: Oxford University Press, 2007), 22, 137.

²³ Latour, 221.

²⁴ Latour’s Actor Network Theory has been influential in various social scientific discourses, and has garnered many points of critical debate. See, for example: Langdon Winner on the role of *intentionality* in theories of agency; Andrea Whittle and André Spicer on ANT’s ontological realism and the perceived denial of existing power structures; H. M. Collins and Steven Yearly on the limits of ANT’s inclination toward endless relativist regress. Langdon Winner, “Upon Opening the Black Box and Finding It Empty: Social Constructivism and the Philosophy of Technology,” *Science, Technology, & Human Values* 18, no. 3 (1993): 362–78; Andrea Whittle and André Spicer, “Is Actor Network Theory Critique?,” *Organization Studies* 29, no. 4 (April 1, 2008): 611–29, <https://doi.org/10.1177/0170840607082223>; H. M. Collins and Steven Yearly, “Epistemological Chicken,” in *Science as Practice and Culture*, ed. Andrew Pickering (University of Chicago Press, 1992), 301–26.

acts that change the physiology of users' bodies. In so doing, they become integrated into the bio-social network of the individual user and become a form of biocapital in and of themselves.²⁵

Situated Bodies, Devices, and Knowledges

Unpacking the networks involved in the compelled use of insulin pump treatment requires an expanded focus on the situatedness of bodies, knowledges, and technologies—both in relation to scientific practice itself and in relation to frameworks for understanding subjects of study such as bodies and devices. A clearer focus on situatedness (in a foundationally ANT sense) can help to identify how those human-technological relationships function, as well as how individual or cultural ideologies and epistemologies frame those experiences. Using various feminist theories, Donna Haraway has argued that holding onto and even privileging the positionality of the scholar in relation to the world and their subjects of study can help shake loose some of the gendered problems embedded in the practice of what Thomas Kuhn called “Normal Science”²⁶ (or the socially constructed norms of scientific practice). Rather than striving for what Lorraine Daston calls an unobtainable “aperspectival objectivity,” Haraway calls for a framework of “embodied objectivity” that can accommodate paradoxical feminist-influenced scientific projects; which “means quite simply *situated knowledges*.”²⁷ Whereas

²⁵ For more on the co-production of devices and bodies, see Chapter 3 of this dissertation. See also my discussion of the datafication of bodies in: Stephen Horrocks, “Materializing Datafied Body Doubles: Insulin Pumps, Blood Glucose Testing, and the Production of Useable Bodies,” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (2019): 1–26.

Biocapital is a term that extends Foucauldian theories of biopolitics and biopower, which bring “life and its mechanisms” under the umbrella of governance and social power systems, claiming that current biotechnological regimes 1) cannot be understood apart from the economies of which they are part, and 2) adjust those bioeconomic frames to the microscopic, redefining capital in terms of the cellular, molecular, and genomic. See: Michel Foucault, *The History of Sexuality Volume 1* (New York: Vintage, 1978), 148; Kaushik Sunder Rajan, *Biocapital: The Constitution of Postgenomic Life* (Duke University Press, 2006), <https://doi.org/10.1215/9780822388005>; Stefan Helmreich, “Species of Biocapital,” *Science as Culture* 17, no. 4 (2008): 463–478; Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2009), 8.

²⁶ See Thomas S. Kuhn, *The Structure of Scientific Revolutions*, 2nd edition (Chicago, Ill: University of Chicago Press, 1970), 5–6.

²⁷ Lorraine J. Daston, “Objectivity and the Escape from Perspective,” in *The Science Studies Reader*, ed. Mario Biagioli (New York: Routledge, 1999), 111–12; Donna J. Haraway, “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective,” in *The Science Studies Reader*, ed. Mario Biagioli (New York: Routledge, 1999), 176.

aperspectival objectivity strives for consensus and universalities, embodied objectivity values dissent, contestation, and “hope for transformations of systems of knowledge and ways of seeing.”²⁸ By directly addressing and calling attention to the observer’s own position and embodied seeing within scientific practices, those hidden systems of power are brought front-and-center to be negotiated by both the scholar and those around them. By extending those concepts, position and perspective can not only play a significant role in improving scientific practices, but can also call attention to how the people and objects they study are positioned in relation to each other in new and important ways.

In theorizing the particular interconnected situatedness of people and technological objects in the frame of insulin pump treatment, however, it is important to identify (and destabilize) some of the assumptions operating in and around those relationships. And here, another one of Haraway’s seminal works may help de-center certain privileged normativities and open a space for a more robust understanding of a device-connected life with T1D. In “A Cyborg Manifesto,” Haraway constructs a “blasphemous,” “ironic” critique of identity politics within feminist scholarship and activism in the form of the cyborg:

By the late twentieth century, our time, a mythic time, we are all chimeras, theorized and fabricated hybrids of machine and organism; in short, we are cyborgs. The cyborg is our ontology; it gives us our politics. The cyborg is a condensed image of both imagination and material reality, the two joined centres structuring any possibility of historical transformation.²⁹

This hybridity, she argues, is constituted by both social realities and political fictions, and makes visible (and vulnerable) the boundaries between the technological and the biological, nature/women and culture, human and animal, reality and fiction, physical and non-physical. Cyborgs are at once the “illegitimate offspring” of militarized patriarchal capitalism and state socialism, as well as the means for its potential demise—“illegitimate offspring are often exceedingly unfaithful to their origins. Their fathers, after all, are inessential.”³⁰ And it is this last

²⁸ Haraway, “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective,” 178.

²⁹ Donna Haraway, “A Cyborg Manifesto: Science, Technology, and Socialist Feminism in the Late Twentieth Century,” in *Simians, Cyborgs, and Women: The Reinvention of Nature*, 1 edition (New York: Routledge, 1990), 150.

³⁰ Haraway, 151.

point, cyborgs' connectedness to global structures of power and domination, which highlight the transformative possibilities of the cyborg as a framework for feminist liberation and coalition-building. Women are cyborgs not simply due to their positionality in relation to technology, but due to their political (inter)actions. Haraway employs Chela Sandoval's work on "Women of Colour" as an inherently political postmodern identity born of oppression to shift the focus away from coalitions built on identity, and instead toward coalitions of "affinity"—socio-political connections based on a shared "oppositional consciousness" without reproducing the imperializing processes of the West (including Western socialisms and feminisms).³¹

Though Haraway's construction of the cyborg provides a meaningful point of theoretical entry for radically re-centering a study of insulin pump use by people with T1D, its deployment of disabled bodies requires some important revision. In her book *Feminist, Queer, Crip*, Alison Kafer identifies a problematic use of disabled bodies in Haraway's formation of the cyborg:

"[...] far too often, disability functions in cyborg theory—including Haraway's manifesto—solely as an illustration of the cyborg condition. Markedly absent is any kind of critical engagement with disability, any analysis of the material realities of disabled people's interactions with technology. Disabled bodies are simply presented as exemplary, and self-evident, cyborgs, requiring neither analysis nor critique. If, as Haraway insists, cyborg bodies are not innocent, but are 'maps of power and identity,' then a close crip reading of the cyborg is long overdue."³²

According to Kafer, if the cyborg is to be a useful metaphorical or material framework for understanding disabled—and I would add chronically ill—bodies, or for imagining a more nuanced grasp of the dual "pleasure and responsibility" of new disabled futurities, we must crip the cyborg. Disabled bodies are not cyborgs due simply to their proximity to and/or reliance on devices, nor are they simply a model for not-yet-cyborged nondisabled bodies. Instead, "pushing" and "filling" the cyborg to allow agency within crip experiences can help break down

³¹ Haraway, 155–56; Though many of Sandoval's concepts cited in Haraway were unpublished at the time, they were later published as an article in *Genders* and a full book-length monograph from the University of Minnesota Press. For more, see: Chela Sandoval, "U.S. Third World Feminism: The Theory and Method of Oppositional Consciousness in the Postmodern World," *Genders*, March 1, 1991, 1–24, <https://doi.org/10.5555/gen.1991.10.1>; Chela Sandoval, *Methodology of the Oppressed* (U of Minnesota Press, 2000).

³² Kafer, *Feminist, Queer, Crip*, 105.

the able/disabled binary, and highlight the centrality of political decision-making and consciousness-building in experiences of crip cyborgs.³³

In the case of insulin pump treatment, people with T1D are situated within several intersecting networks that play a significant role in framing how they experience their treatment, and in a larger sense, their world. Material networks of technologies are perhaps the most easily identifiable—they make up the entry point for this research, after all, in no small part due to their visual/tangible nature—but equally influential are the materialities of individuals’ physiological networks continuously interacting with (and necessitating) those treatment devices. As I discuss in further detail in Chapter 3, these two networks weave together through the act of insulin pump use, transforming both bodies and technologies alike.

Taking a step toward the conceptual, various social networks establish and define the ways material networks of insulin pump treatment are (and even can be) experienced. Norms established for/within the institution of Medicine put names and identifiers on the materialities of living with T1D, and centuries of research conducted under the umbrella of Medical Science led to the creation of the technologies at the center of these treatments themselves.³⁴ Add to that the US insurance-based health care system, which acts as a gatekeeper providing and denying access to these objects and knowledges,³⁵ alongside people’s personal social relationships and broader cultural norms regarding (dis)ability, race, gender, class, sexuality, age, and size in the United States, and the networks of intangible (yet powerful) influences congealing in and around the material networks insulin pump treatment make up the tensions central to the research conducted throughout this dissertation.

Methods

Due to the intimate and embodied nature of the material under consideration, this study requires research and analysis through several methods and approaches. By analyzing personal

³³ Kafer, 118, 120.

³⁴ For a detailed history of Type 1 Diabetes as a diagnosis and its various treatments, see Chapter 2 of this dissertation.

³⁵ Chapter 6 unpacks in more depth some of the large-scale and individual issues related to Type 1 Diabetes and access to necessary treatments and medical devices within the US health care system.

interviews and digital media produced by people with Type 1 Diabetes alongside archival materials, this study identifies patterns in the sociocultural practices, structures, and narratives of insulin pump treatment to foreground the productive (and, often, simultaneously stifling) relationship between people, bodies, technologies, and American culture.

Interview participants were selected via a snowball sampling of people with Type 1 Diabetes, with leads generated through personal and professional acquaintances in the Greater Lafayette, IN area as well as open solicitations for participation in local endocrinology offices and online diabetes community forums. Though this participant selection method was initially selected for practical purposes—it is particularly suited for research dealing with potentially personal content,³⁶ and since people with T1D only make up about 0.5-1% of the US population, finding individuals through already-established social networks lightens that process—it has also served an important conceptual role in how individuals' own stories are framed throughout this dissertation. As Chaim Noy has argued, “snowball sampling relies on and partakes in the *dynamics of natural and organic social networks*” [emphasis original]. A move informed by feminist and constructivist hermeneutics, conceptualizing informant-generated participant pools as organic social networks highlights, 1) the dynamic and constant production of social knowledges, and 2) power relations between researchers and participants, as well as among the participants themselves.³⁷

In total, fifteen individuals volunteered to participate in interviews which took place between May 2016 and August 2017, and lasted an average of approximately an hour each. Though ages ranged from twenty-six to eighty-one years, the majority of participants were in their early- to mid-thirties. Seven informants were diagnosed with T1D as children (prior to age eighteen), six were diagnosed in adulthood (including one who was diagnosed in his late forties), and two were parents of children with Type 1. Seven identified as male and eight identified as female, while fourteen identified as white and one identified as Latinx/Hispanic. All participants were involved in monogamous relationships at the time of the interviews, and fourteen individuals described their current relationships as heterosexual while one described theirs as

³⁶ Patrick Biernacki and Dan Waldorf, “Snowball Sampling: Problems and Techniques of Chain Referral Sampling,” *Sociological Methods & Research* 10, no. 2 (1981): 141.

³⁷ Chaim Noy, “Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research,” *International Journal of Social Research Methodology* 11, no. 4 (2008): 329.

homosexual. All but two were geographically located throughout the continental United States (from New England to the Gulf of Mexico, from the Midwest to the Rocky Mountain region), with one residing in Canada and another in New Zealand.

Interviews focused on participants' experiences living with the chronic condition and their relationship with their treatment technologies (which may include insulin pumps, continuous glucose monitoring systems (CGMS), blood glucose meters, syringes, pharmaceuticals, and/or other devices used primarily for treatment purposes), though the semi-structured format of the interviews allowed for unique and illuminating divergences from those core questions. Individuals narrated their personal stories in what was essentially a collection of oral histories, but the intimate and embodied nature of this content produces certain vulnerabilities. Thus, names and identifiers of all participants have been changed in this text using the US Census Bureau's list of the most common names for babies during their birth year—with the exception of Richard K. Bernstein, a public figure whose information and health status is already widely accessible in his own and other publications.

As I will show throughout this project, the individual health practices of people with T1D are, at their core, social intimate knowledges, and as such they differ with time and location (geographically and socially speaking). Mapping those differences highlights the extent to which social and economic power relationships affect the production and movement of those knowledges, and also points toward the limitations of a sampling of this nature—limitations I call attention to at various points in the chapters to follow. What is more, it became increasingly clear that due in part to the relatively low incidence of T1D in the US generally, geographically-bound networks of people with T1D were difficult to locate (in places where they exist at all). Instead, people turn to online communities and forums by the thousands, both for the practical sharing/seeking of advice and for social interaction with others who share some of their experiences. Thus, these digital media productions have become an important site for what I would call the cultures of T1D, and have been engaged with throughout this dissertation.

Use of Terms and Abbreviations

Throughout this dissertation, I reference "Type 1 Diabetes" many times by name. The use of this term is necessary, as it is one of the most widely circulated and understood identifiers for this particular autoimmune disorder, but it is itself situated in a particular time and place. A

slightly shorter version of the medical term “Type 1 Diabetes Mellitus,” “Type 1 Diabetes” is a relatively recent naming convention. It has likewise been known as “Juvenile Diabetes” and “Insulin-Dependent Diabetes Mellitus,” but both have largely faded away from clinical use due to problems with the assumptions written into their names (this condition is not only diagnosed in children and adolescents, nor is it the only form of Diabetes requiring insulin injection). In order to acknowledge both the process of naming and the role of diagnosis in producing diseases and disorders, I will capitalize “Diabetes” and its various naming conventions throughout the text. For the sake of brevity, and to mirror common parlance used by informants and members of online communities considered in this study, I will also use shortened versions of the name somewhat interchangeably (“Type 1,” “T1D,” and even the general term “Diabetes” except in cases when I draw distinctions between Type 1 and other forms).

I have struggled throughout this process of this research with the most representative and concise way to refer to people diagnosed with T1D. “Diabetic” functions as a social and medical label placed on individuals to some stigmatizing effect in US culture broadly, and I have therefore opted to omit its use except in quoting informants and other primary source materials. “People with Type 1 Diabetes” highlights the focus on humans themselves rather than the diagnosis, and I therefore use this term at times throughout the following chapters—particularly when referring to people who are not necessarily in the context of physicians or Medicine. Even when it is paired with shortened versions of the medical term, however, that identifier can be a bit verbose. I also wanted to emphasize individuals’ interactions with their devices, and “pumpers” felt somewhat out of place (and even a bit awkward). “Users” is a nice short-hand term that signifies a relationship between people and things, but it also carries with it a variety of cultural definitions that can be somewhat problematic, especially in the context of pharmaceuticals and injections. “Patients” is useful when referring to people in relation to their physicians and the institution of Medicine more generally, but it loses its specificity when used in other contexts. For much of the dissertation that follows, I have opted for the use of “patient-user.” The hyphenated term highlights the particular situatedness of people with T1D in relation to both Medicine and their treatment devices, and the inherent social and political implications of that position. Though this term carries some of the implications of both terms separately, in using them together I hope to maintain an awareness of T1D as a physiological experience that is socially and materially built.

Though the clinical term for insulin pump treatment is “Continuous Subcutaneous Insulin Infusion” (CSII), it has almost no circulation outside research and medical circles. Therefore, in keeping with commonly used terms and identifiers by informants interviewed for this study, I usually employ the terms “insulin pump use” or “insulin pump treatment.” Though the former highlights the active role of individuals within the context of this practice, the latter combines the medical and technological signifier implied in “patient-user,” and more thoroughly keeps with the tone of my analysis. In some other places, I gesture toward the centrality of various devices and bodies working in conjunction through the term “networked insulin pump treatment,” or a variation thereof. While this does some important work in defining relationships, it begins to slip into verbosity in a way that detracts from the purpose of the text.

The last set of terms requiring clarification refer to the disposable materials that attach insulin pumps and CGMs to patient-users’ bodies. The device made up of an insertable tube and adhesive pad which is attached to the body and acts as a channel between human bodies and insulin pumps is usually referred to as an “infusion set,” or a set of devices through which pharmaceuticals are infused into the body. Many people, however, use the term “infusion site,” or even just “site,” to refer to the same device interchangeably. Though I attempt to privilege the first, technical term, I use the others somewhat interchangeably at times as well.

Chapter Outline

Before unpacking the intricacies everyday living with insulin pump treatment in later chapters, Chapter 2 provides an overview of the history of what we now call Type 1 Diabetes and its treatments. Building on Chris Feudtner’s claim that the development of insulin injection treatment in the 1920s fundamentally transformed both Diabetes itself and people’s experiences under that diagnosis, I argue that two other significant transformations took place in the late twentieth century as blood glucose testing and insulin pump treatment became standard practice.

Switching from vials and syringes to insulin pump treatment affects nearly every aspect of patient-users’ lives, from their material interactions with the world to the ways they understand their own embodiment and sociality. Informants also commonly narrate this change through the lens of new or increased “freedom,” both material and social. Drawing from personal interviews, the technical/instructional literature accompanying treatment devices, and archival materials such as FDA Summary of Safety and Effectiveness Data (SSED) reports, Chapter 3

investigates how insulin pump networks become integrated within users' physiological, social, and cultural worlds through their continuous attachment at once inside, upon, and outside the body. This process of reiterative connecting and connectedness, I argue, produces altered people, altered bodies, and altered devices—both materially and conceptually—that does not and cannot always live-up to the freedom narrative on which it relies.

The social implications of insulin pump connectedness become particularly relevant (and newly visible) within the practices associated with the intimate closeness of bodies. Through a set of online forum discussions alongside personal interviews, Chapter 4 interrogates how what I call new techno-intimate relationships are understood and produced at the intersection of device use, new media participation, and sexual practice. All three of these intersecting social/medical practices are altered through their convergence at this site of techno-intimacy, and people's foundational relationships with others are necessarily altered along with them.

As the preceding chapters detail, human-object relationships are central to the use of medical devices such as insulin pumps. In Chapter 5, I draw on Madeleine Akrich's conception of technological scripting and "de-scripting" to analyze the "casuality" of informants' possession and ownership of Diabetes treatment devices. Insulin pumps, CGMs, and blood glucose meters are scripted as both biomedicalized saviors/miracles, materializing the authority of medical science and practice through use, and as techno-emotional extensions of patient-users themselves. In this way, I argue, they function as contested objects at once possessed and dispossessed, their use both "freeing" and compelled. As I will show, informants utilize unique material and affective systems of cultural meaning-making and valuation to build networked relationships with their devices that at times reinforce dominant cultural scripts, while at others further complicate the already contested claims surrounding insulin pumps and their related network of treatment technologies. These narratives, I argue, come to reveal human-object relationships in insulin pump treatment as something that is primarily *felt*, even when it is not (or cannot be) fully understood.

This dissertation focuses primarily on the relationships between people with Type 1 Diabetes and their treatment technologies, but central to how those relationships are and can be *established* is the question of access: Who gets to pump? Access to hi-tech medical devices such as insulin pumps and CGMs requires a variety of privileging factors that necessarily exclude people based on social and economic variables, particularly race and class. By analyzing

informant narratives related to device and supply costs and insurance coverage, Chapter 6 details the significant barriers-to-entry typical of insulin pump treatment, CGM use, and other hi-tech medical interventions. Though a body-connected medical device functions as a technological marker of disability and/or chronic illness—a sign of an *abnormal* body, with the weight of cultural systems of compulsory able-bodiedness in tow—it also signals one’s ability to buy-in to a class-exclusive site of care and support.

I conclude this dissertation with an eye toward future directions in Diabetes treatment and care. Medical and science journalists report on new devices, procedures, and pharmaceuticals currently under research and development that will revolutionize T1D treatment and T1D life itself—even carve a path toward the Holy Grail of Diabetes research: the cure. This conclusion aims to complicate the ableist, often uncritical narrative that typically surrounds these biomedical innovations by situating them within the context of use afforded by this study. Though these med-tech advances often do make significant improvements to life with Diabetes (as have insulin, insulin pumps, and CGMs), they also create wholly new physiological and social situations with unintended effects on the material and sociocultural experience of living with Type 1 Diabetes.

CHAPTER 2: TYPE 1 DIABETES TREATMENTS AND DEVICES: A PRIMER

Not to be confused with its more common counterpart Type 2, Type 1 Diabetes Mellitus—historically known by various names now deemed obsolete by the American Diabetes Association including Juvenile Diabetes, Insulin-Dependent Diabetes Mellitus (IDDM), and Child-Onset or Juvenile-Onset Diabetes—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—an important hormone that makes glucose delivery into the body’s cells for energy possible. As a result, patients with Type 1 Diabetes (T1D) eventually stop producing insulin altogether and require insulin injections to metabolize foods.¹ Type 2 Diabetes Mellitus, on the other hand, is a metabolic disorder most often characterized by insulin resistance in the body’s cells, often alongside reduced (but not usually absent) insulin production. Type 2 is far more common than Type 1, affecting approximately 30 million people in the U.S., and therefore functions as the cultural default under the term “Diabetes.”² These chronic conditions may share a clinical name and perhaps some symptoms, but they are characterized by very different physiological processes and—most importantly here—very different histories and *experiences* by people with this diagnosis.

¹ “Diabetes,” in *Stedman’s Medical Dictionary* (Philadelphia: Stedman’s, December 14, 2005), 528–30; Dr Harvey Marcovitch, “Diabetes Mellitus,” in *Black’s Medical Dictionary* (Lanham, MD: Scarecrow Press, March 7, 2006), 194–95; “Diabetes,” in *Dorland’s Illustrated Medical Dictionary* (Edinburgh: Saunders, June 1, 2007), 513; American Diabetes Association, ed., *Diabetes Ready Reference for Nurse Practitioners: Clear, Concise Guidelines for Effective Patient Care* (Alexandria: American Diabetes Association, 2012), 2–5.

² National Center for Chronic Disease Prevention and Health Promotion, “2014 National Diabetes Statistics Report” (Atlanta, GA: Centers for Disease Control and Prevention, 2014).

Type 1 Diabetes, Insulin, and Transmuted Diseases³

The earliest references to Diabetes⁴ date back to approximately 1500 B.C.E. when Egyptian physicians identified a condition of “too great emptying of the urine,” likely a description of the excessive thirst and urination common among people with the condition. Recommended treatment included a diet of wheat grains, fruits, and sweet beer. Physicians in India around the same time observed that the urine of some patients attracted gnats and flies, and created the first recorded clinical definition and test for what they called “madhumeha,” or “honey urine.”⁵ It was not until about 230 B.C.E. that Greek physician Apollonius of Memphis first used the term “Diabetes” (a Greek word meaning “siphon” or “to pass through”) as a clinical description for what was then considered a disease of the kidneys, often treated with bloodletting and dehydration. “Mellitus,” from the Latin word meaning “sweetened with honey” and the other half of what is now the widely accepted clinical term, was not used in Western medical practice until British Army surgeon John Rollo first used it in the late eighteenth century.⁶

Though important and of interest in its own right, the history of terminology, diagnostic practices, and symptomology above fails to capture the experience of living with Diabetes throughout these many centuries. As Greek physician Aretaeus of Cappadocia put it in his second century work *The Causes and Symptoms of Chronic Diseases, Book II*,

Diabetes is a dreadful affliction, not very frequent among men, being a melting down of the flesh and limbs into urine. [. . .] The patients never stop making water

³ This is not intended as an exhaustive medical history of Diabetes Mellitus, a project endeavored by many scholars cited herein, but is rather intended as a snapshot of some major shifts in scientific and/or medical theories and practices related to the condition(s) over time.

⁴ In discussing the history of Diabetes, it is important to note that the condition and its various symptoms have been named and renamed, characterized and recharacterized by many people in many places for nearly 3500 years. I will refer to historically situated observations and terms themselves when possible, though for the sake of comprehension and continuity the term Diabetes (or Diabetes Mellitus) may be used as a placeholder for the condition and symptoms currently defined through that term.

⁵ Jacek Zajac et al., “The Main Events in the History of Diabetes Mellitus,” in *Principles of Diabetes Mellitus* (Springer, Boston, MA, 2010), 1, https://doi.org/10.1007/978-0-387-09841-8_1, See also; N. S. Papaspyros, “The History of Diabetes,” in *The History of Diabetes Mellitus*, ed. G. T. Verlag (Stuttgart: G. Thieme, 1964), 4–5.

⁶ Zajac et al., “The Main Events in the History of Diabetes Mellitus,” ⁵; Alvin Silverstein and Virginia B. Silverstein, *The Sugar Disease: Diabetes* (New York: Lippincott Williams & Wilkins, 1980), 17; See also; “Diabetes Mellitus, n.,” in *OED Online* (Oxford University Press, n.d.), <http://www.oed.com.ezproxy.lib.purdue.edu/view/Entry/39917509>.

and the flow is incessant. [. . .] The nature of the disease, then, is chronic, and it takes a long period to form; but the patient is short-lived, if the constitution of the disease be completely established; for the melting is rapid, the death speedy. Moreover, life is disgusting and painful; [. . .] Or if for a time they abstain from drinking, their mouth becomes parched and their bodies dry; the viscera seem as if scorched up, they are affected with nausea, restlessness, and a burning thirst; and at no distant term they expire.⁷

Areataeus's illustration of the disease is vivid, bleak, and yet was mostly representative of people's experience with Diabetes until the early twentieth century. Though there were shifts in research and understandings about the condition—including Thomas Cawley's theory that Diabetes was in fact *not* a kidney/urinary-tract disease but a pancreatic one⁸—severe fasting and restrictive diets were the only treatment methods available until the 1920s. These diets were miserable, and life expectancy remained very short.⁹

In May of 1921, Toronto-based medical researchers led by Frederick G. Banting began experimental trials on the pancreatic cells of dogs and rabbits, and by December they published a report identifying “an internal secretion acting on carbohydrate metabolism.”¹⁰ By January they had extracted and purified enough of this “secretion”¹¹ to begin trials of a needle-injected hormone treatment with their first human subject. The results were so overwhelmingly positive and immediate that a pharmaceutical-grade insulin was produced for broader testing by summer

⁷ Areataeus, “On Diabetes,” in *On the Causes and Symptoms of Chronic Diseases, Book II, in The Extant Works of Areataeus, the Cappodocian*, trans. Francis Adams (London: Sydenham Society, 1856), 338–40.

⁸ V. C. Medvei, *The History of Clinical Endocrinology: A Comprehensive Account of Endocrinology from Earliest Times to the Present Day* (Pearl River, N.Y.: Parthenon Publishing, 1993), 55–56; Zajac et al., “The Main Events in the History of Diabetes Mellitus,” 4.

⁹ Medvei, *The History of Clinical Endocrinology*, 46, 49; Zajac et al., “The Main Events in the History of Diabetes Mellitus,” 3–4; Chris Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*, 1 edition (The University of North Carolina Press, 2003), 6–7.

¹⁰ Frederick G. Banting, Charles H. Best, and John J. R. Macleod, “The Internal Secretion of the Pancreas,” *American Journal of Physiology* 59 (1922): 479. Banting's research team included Charles H. Best, James B. Collip, and John J. R. Macleod.

¹¹ 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: Edward Albert Schäfer, *An Introduction to the Study of the Endocrine Glands and Internal Secretions: Lane Medical Lectures, 1913*, (Stanford University, California: Stanford University Press, 1914), 84; Frederick G. Banting et al., “The Effect of Pancreatic Extract (Insulin) on Normal Rabbits,” *American Journal of Physiology* 62, no. 1 (1922): 175.

of that year, and the first commercial insulin went on sale by October.¹² Banting and Macleod were awarded the Nobel Prize for Physiology or Medicine in 1923 “*for the discovery of insulin.*”¹³

The impact of insulin therapy on the lives of people with Diabetes cannot be overstated. Post-diagnosis life expectancy ranged from a few weeks to three years after diagnosis up until 1922. In the three years following the introduction of insulin therapy that rate jumped to 14.3 years post-diagnosis, and more than doubled *again* by 1928 (31.7 years). By 1945, life expectancy for children with Diabetes increased to 45 years post-diagnosis.¹⁴

What was once a terminal acute diagnosis accompanied by a doctor’s suggestion to “make arrangements” became a chronic, life-long condition accompanied by new challenges and side-effects. In his book, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*, Chris Feudtner documents how the discovery and development of the “wondrous drug” itself accounted for the “bittersweet” transformation of twentieth-century Diabetes. Insulin therapy, he argues, is a prime example of the role medical practice plays in altering the “fundamental biology of the disease.” As insulin therapy became standard practice, so-called “natural” problems associated with Diabetes were stunted or halted altogether, giving rise to wholly new complications and lifestyle shifts 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.”¹⁵ This human-created Diabetic world served as the site of both further transmutations and the emergence of a Diabetes healthscape.¹⁶

¹² “Frederick Grant Banting (1891-1941) Codiscoverer of Insulin,” *JAMA* 198, no. 6 (November 7, 1966): 660–61, <https://doi.org/10.1001/jama.1966.03110190142041>.

¹³ “The Nobel Prize in Physiology or Medicine 1923,” Nobelprize.org, accessed August 31, 2017, https://www.nobelprize.org/nobel_prizes/medicine/laureates/1923/.

¹⁴ J. M. Brostoff, H. Keen, and J. Brostoff, “A Diabetic Life before and after the Insulin Era,” *Diabetologia* 50, no. 6 (June 1, 2007): 1352, <https://doi.org/10.1007/s00125-007-0641-0>.

¹⁵ Feudtner, *Bittersweet*, 23, 29.

¹⁶ In their edited collection *Biomedicalization*, Adele Clarke et al. describe the visual and popular cultures of biomedicine as healthscapes, claiming that “things medical” are not only represented in popular culture, but are

Blood Glucose Meters and At-Home Blood Testing

Here I pivot briefly in order to provide some contextual grounding for the twentieth century medical interventions that serve as the focus of this chapter. In 1990, David Michael Levin and George F. Solomon published an article in *The Journal of Medicine and Philosophy* where they narrated what they called paradigm-shifts in discursive understandings of the body in medical science and practice. In classical medicine, they argue, the body was generally discussed as *rational*—a universal type which was a reflection of cosmic order. Early modern medicine, influenced by/influencing enlightenment philosophies, began framing bodies as primarily *anatomical* theorized in terms of its internal structure. During the nineteenth century, however, medical researchers and practitioners increasingly centered their work on what Levin and Solomon call *the physiological body*, a body-machine with components and mechanisms to be controlled, fixed, and/or described in terms of their functions. This paradigm functions as a driving force behind both the compulsive need for controlling Diabetes and for more focused and specific understandings of the body’s “mechanisms.” Those conceptions were magnified throughout the twentieth century, as the narrowing of medical definitions created a discursive system of cells and molecules coalescing in the *biochemical body*.¹⁷ The convergence of the last two so-called paradigms were driving forces behind the shift toward the understanding of the body as data, which I discuss in more depth in Chapter 3, and opened-up a new way of understanding T1D bodies.

Since the advent of insulin therapy, and influenced by these medical definitions of the body, at least two significant shifts in Diabetes treatment likewise made fundamental changes to the course of Type 1 Diabetes, physiologically, socially, and culturally. First, dissatisfied with the accuracy and efficiency of then-standard urinary glucose tests, biomedical research teams in the mid-twentieth century worked to develop ways of testing glucose levels in individuals’ blood directly. Beginning in the nineteenth century, physicians added reactive agents such as copper to patients’ urine samples to detect the presence of glucose, measured either by a change in the

constructed there. This also includes all sites of care, inside and outside the clinic. See: Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2009), 3, 33.

¹⁷ David Michael Levin and George F. Solomon, “The Discursive Formation of the Body in the History of Medicine,” *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 15, no. 5 (October 1, 1990): 526–27, <https://doi.org/10.1093/jmp/15.5.515>.

urine's color or by using some form of mass-measurement methods. Widespread, reproduceable urine glucose testing emerged from Stanley Benedict's copper reduction method in 1908, which remained the standard for nearly fifty years.¹⁸

In 1965, the Ames Group of Miles Laboratories created a visually-monitored blood glucose (BG) test called Dextrostix. The first commercially available dry-reagent test strips on the market, the Dextrostix were flat non-reactive strips about three-and-a-half inches long with an absorbent tip containing a chemical that changed colors when exposed to glucose. The bottle came with a pamphlet containing a color-coded reference guide, against which the tip of a blood-soaked strip could be compared to determine an approximate BG level measured in mg per dL of blood—a gray-scale gradient with references for 0, 25, 45, 90, 130, 175, or 250 or more. Physicians and lab technicians quickly noted the unreliability of the color readings, which did not very well account for variations in use or visual assessments. An engineer with the Ames Group by the name of Anton Clemens developed a device in 1970 that analyzed the Dextrostix by reflecting light off the strip and measuring that signal with an analog dial (represented as mmol of glucose per L of blood on a sliding needle scale). The Ames Reflectance Meter (ARM) was a heavy black faux-leather-wrapped box about seven inches tall by four inches wide, and was the first meter built to produce quantitative blood glucose readings for use in emergency rooms and the clinical diagnosis of Diabetes.¹⁹

In October 1969, an engineer by the name of Richard K. Bernstein came across an advertisement for the Ames meter in a trade journal. Thirty-five years old at the time, Bernstein had lived with T1D for approximately twenty-three years and was rapidly developing severe side effects including gastroparesis, neuropathy in his arms and legs, a foot deformity, and kidney damage. Even more significant than these health issues, however, was the psycho-emotional toll his hypoglycemic (or low-blood glucose) episodes had on his family. “My kids still envision their early lives as traumatic because of my hypoglycemia,” he recalls. “Every day, in and out.” The single, large daily shot of insulin his doctor prescribed meant his blood glucose levels would drop dangerously low at each injection, followed by equally dangerous high levels as he ate

¹⁸ S. F. Clarke and J. R. Foster, “A History of Blood Glucose Meters and Their Role in Self-Monitoring of Diabetes Mellitus,” *British Journal of Biomedical Science* 69, no. 2 (2012): 83.

¹⁹ Clarke and Foster, 85–86.

throughout the day. “It was very distressing to my family, and the only reason for getting the meter was for the hypoglycemia.”²⁰

In an effort to curb those “hypos,” Bernstein asked his wife, a medical doctor practicing near their home in New York, to purchase the E.R.-only Ames meter for him. After modifying its AC power input with a series of nine-volt RadioShack batteries, strapped onto the bottom of the ARM in a stereotypically home-engineered fashion, Bernstein became the first person to test his blood glucose at home. Running his blood through the ARM multiple times a day—morning, night, and before each meal—Bernstein noted how drastically his levels fluctuated throughout the day. “*Then* I started reading,” he remembers, visiting the Academy of Medicine in Manhattan to begin scouring studies related to exercise and the complications of Diabetes (most of which were conducted on mice and other animals). “Instead I found that, one: exercise lowered triglycerides in non-diabetics, and two: normal blood sugars reverse the complications. Reversed kidney disease, amongst other things.” Excited about the possibilities for his own treatment, Bernstein took this information to his doctor. “When I discussed this with my doctor he said, ‘Well, you’re not a mouse. It doesn’t apply to you.’”²¹

His doctor’s dismissal was a turning point for Bernstein’s personal at-home blood testing, and by connection the Diabetes world more generally in at least two major ways. First, Bernstein’s interpretation of his own experiment signals toward a shift in the fundamental idea undergirding Diabetes treatment that took place more than a decade later. “At that point, in addition to trying to catch hypoglycemia,” he notes, “I started trying to *normalize* my blood sugars.”²² Though a seemingly minute pivot from reducing or avoiding drops in blood glucose, this conceptual shift toward “normalization” has changed how Diabetes and Diabetics are understood both in medical discourses and in U.S. culture more generally. A concept used extensively in a variety of humanities and social science discourses, “normalcy” acts as a shorthand for the complex webs of social values, the processes and systems of power involved in their creation and maintenance, and their various sociocultural implications. The use of this shorthand term in the context of Medicine and medical science, however, serves the purpose of

²⁰ Richard K. Bernstein, interview by Stephen Horrocks, May 26, 2016.

²¹ Bernstein.

²² Bernstein, Emphasis added.

identifying the standards of an assumed universal “human body,” that can be deployed as a benchmark for comparison. In other words, “normalcy” in Medicine is often understood as-is, per the authority of scientific practices and discourses that have established it as such. As we saw with the advent of insulin treatment, Diabetes became something that not only could, but *should* be controlled. When layered with the language of normalization, which relies heavily on cultures of Medicalized normalcy built on centuries of exclusionary and often oppressive practices and discourses, measures bringing individuals with Diabetes closer to the established norm become nothing short of compulsory—a force made even more pronounced in the context of medical need, as I will argue and covered in more depth throughout the following chapters.²³

Second, with the proliferation of Bernstein-esque home glucose monitoring toward the end of the twentieth century, T1D bodies and their processes became quantifiable at an unprecedented scale. As American and Japanese engineers began building lighter-weight, simpler, battery-powered glucose meters throughout the 1980s, endocrinologists prescribed home blood glucose testing for all patients with T1D.²⁴ Beginning with the earliest related medical publications in the late 1970s, the purpose of home testing was clear: *better control*.²⁵ This purpose is no surprise, as control had been the focus of Diabetes treatment since the 1920s, but it is the *means* of that control that is most important here. Now formulated in terms of normalization, control could be conceptualized and conducted through numbers and was thereby quantifiable. Regularized blood tests provided a method of physiological quantification which, on the one hand, gave people with T1D a sense of “where they are,” so to speak. These methods also, on the other hand, allowed doctors and patients to reduce their bodies and experiences to normal or abnormal, further entrenching the Medically constructed notions of normalcy within individuals’ treatment acts—a phenomenological shift highlighted in Chapter 3 which has

²³ For more on normalcy as a social construct, see: Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body*, First Edition (London ; New York: Verso, 1995); Laura Mauldin, *Made to Hear: Cochlear Implants and Raising Deaf Children* (Minneapolis: University of Minnesota Press, 2016); David Serlin, *Replaceable You: Engineering the Body in Postwar America* (University of Chicago Press, 2004).

²⁴ Clarke and Foster, “A History of Blood Glucose Meters and Their Role in Self-Monitoring of Diabetes Mellitus,” 86–87.

²⁵ See, for example: S. Walford et al., “Self-Monitoring of Blood-Glucose: Improvement of Diabetic Control,” *The Lancet*, Originally published as Volume 1, Issue 8067, 311, no. 8067 (April 8, 1978): 732–35, [https://doi.org/10.1016/S0140-6736\(78\)90855-3](https://doi.org/10.1016/S0140-6736(78)90855-3).

become all the more pronounced as development and use of continuous glucose monitors (CGMs) has boomed over the past two decades. Thus, as at-home blood glucose testing was instigated by T1D's effects on Bernstein's relationships with other people, "normalization" and "control" remain as much socially-compelled practices as medically-compelled ones.

Insulin Pumps and the Visualities and Materialities of 21st Century Diabetes

The second major shift in the post-insulin Diabetes world also began in the 1960s with technological interventions that provided the scaffolding for insulin pump treatment. Referred to as Continuous Subcutaneous Insulin Infusion (CSII) in clinical settings, insulin pump treatment uses an automated device to inject pharmaceuticals into the body. Following its initial (unfeasible) conception during the 1960s and nearly four decades of technical unattainability, the so-called artificial pancreas has been framed as the holy grail of T1D treatment. Despite some significant setbacks during the 1980s and early 1990s, automated insulin pump treatment has become the standard of care for people with T1D in the United States, making both insulin pumps and Diabetes present and visual in new and significant ways.

Dr. Arnold Kadish conducted the first documented trial of an artificial pancreas in 1964, and his "closed-loop" concept has remained a central research problem in the decades since.²⁶ Kadish's device was approximately the size of a World War II-era military backpack, and was described as a "closed-loop" due to the three simultaneous functions it was programmed to perform: 1) continuous blood-glucose monitoring via a cycling blood draw system, 2) insulin infusion with an on/off switch automatically triggered if BG readings were too high, and 3) glucagon (pharmaceutical glucose) infusion with a similar on-off switch triggered if BG levels were too low. Thus, the term "closed-loop" came to stand in for these three processes together, none of which had been attempted before. Importantly, it required no direct input from the user. Though the concept of a device programmed to automatically perform the function of a human

²⁶ Though Kadish's experiment was the first trial featuring the closed-loop system, the first recorded experiments with Continuous Subcutaneous Insulin Injection (CSII) were conducted by a London-based medical student in 1934.

pancreas was revolutionary in and of itself, Kadish's device was too impractical and inaccurate for wider use.²⁷

Over the next decade, several clinical researchers took Kadish's initial concept of insulin infusion in two directions which established much of the field's focus through the end of the century and beyond.²⁸ In 1974, E. F. Pfeiffer, et al. began insulin infusion tests which led to the development of the Biostator, a cabinet-sized console featuring a closed-loop system similar to Kadish's design with computer-controlled blood-draw and insulin/dextrose infusion. Blood glucose levels were sent to a printer every sixty seconds for tracking purposes.²⁹ That same year, Paris-based researchers Gérard Slama, et al. conducted tests on the first successful clinical "open-loop" insulin infusion system. Rather than automatically adjusting insulin delivery as the closed-loop did, this significantly smaller device was programmed to inject small doses of insulin consistently throughout the day and larger doses at meal times.³⁰ Though both devices had issues preventing their wider use—the Biostator was a large stationary computer, and Slama's device used metal intravenous needles prone to infection—their incorporation of

²⁷ A. H. Kadish, "A Servomechanism for Blood Sugar Control.," *Biomedical Sciences Instrumentation* 1 (1962): 171–176; Arnold Henry Kadish, "Automation Control of Blood Sugar a Servomechanism for Glucose Monitoring and Control.," *ASAIO Journal* 9, no. 1 (1963): 363–367; A. H. Kadish, "Automation Control of Blood Sugar SUGAR. I. A Servomechanism for Glucose Monitoring and Control.," *The American Journal of Medical Electronics* 3 (June 1964): 82–86; F. M. Alsaleh et al., "Insulin Pumps: From Inception to the Present and toward the Future," *Journal of Clinical Pharmacy and Therapeutics* 35, no. 2 (April 1, 2010): 128, <https://doi.org/10.1111/j.1365-2710.2009.01048.x>.

²⁸ Between 1974 and 1978, five research groups conducted major studies of automated closed-loop treatment systems based on Kadish's concept. One of those, conducted by Pfeiffer, et al., was used as the basis for the development of the Biostator, the first commercial device on the market. See: A. M. Albisser et al., "An Artificial Endocrine Pancreas," *Diabetes* 23, no. 5 (May 1, 1974): 389–96, <https://doi.org/10.2337/diab.23.5.389>; E. F. Pfeiffer, Ch Thum, and A. H. Clemens, "The Artificial Beta Cell - A Continuous Control of Blood Sugar by External Regulation of Insulin Infusion (Glucose Controlled Insulin Infusion System)," *Hormone and Metabolic Research* 6, no. 5 (1974): 339–42, <https://doi.org/10.1055/s-0028-1093841>; J. Mirouze et al., "Evaluation of Exogenous Insulin Homeostasis by the Artificial Pancreas in Insulin-Dependent Diabetes," *Diabetologia* 13, no. 3 (May 1, 1977): 273–78, <https://doi.org/10.1007/BF01219712>; E. W. Kraegen et al., "Control of Blood Glucose in Diabetics Using an Artificial Pancreas*," *Australian and New Zealand Journal of Medicine* 7, no. 3 (June 1, 1977): 280–86, <https://doi.org/10.1111/j.1445-5994.1977.tb03687.x>; M. Shichiri et al., "Computer Algorithm of Artificial Pancreatic Beta-Cell," in *Artificial Organs*, vol. 1 (Malden, MA: Blackwell Science, Inc., 1977), 141–141.

²⁹ Alma Young and Steven Herf, "Biostator Glucose Controller: A Building Block of the Future," *The Diabetes Educator* 10, no. 2 (June 1, 1984): 11–13, <https://doi.org/10.1177/014572178401000203>; Alsaleh et al., "Insulin Pumps," 128–29.

³⁰ G. Slama et al., "One to Five Days of Continuous Intravenous Insulin Infusion on Seven Diabetic Patients," *Diabetes* 23, no. 9 (September 1974): 732–38; Alsaleh et al., "Insulin Pumps," 129.

continuous glucose monitoring and open-loop infusion programs, respectively, caught the attention of clinical researchers throughout Europe, Japan, and the U.S. Soon thereafter, Harry Keen and John Pickup from Guy's Hospital in the United Kingdom began testing the first portable dual-rate pump known as the Mill Hill Infuser, a battery-powered open-loop device with no display or interface originally designed to deliver hormones for livestock.³¹ The Mill Hill Infuser's clinical success in controlling patients' BG levels, alongside the commercial success of their more adjustable competitor Autosyringe in the UK four years later, piqued the interest of the pharmaceutical industry and served as the bridge between insulin pumps as clinic-only tools to pumps as patient-carried routine treatment devices over the following long-decade.³²

From the late 1970s through the 1980s, over thirty pharmaceutical and medical research companies built proprietary insulin pump systems to be used with their own brands of insulin. Eli Lilly, Beckton Dickinson (BD), Siemens & Halske, Hoffman-La Roche, Smiths Medical, and Nordisk Insulinlaboratorium and Novo Terapeutisk Laboratorium (Danish firms that merged as Novo Nordisk in 1989) are just a few of the massive multinational corporations who jumped at the possibility of consolidated market shares alongside newcomers such as MiniMed Technologies and Disetronic Medical Systems, the former launching its first device in 1983 and receiving FDA approval shortly thereafter. Though this flood of production included a few important changes that later became standard features—the Nordisk Infuser's industry-first portable microprocessor and the MiniMed “Sof-set” flexible replacement for stainless steel needle inserts, for example—pumps produced throughout most of the 1980s were still quite large, housed faulty auto-injection systems and unreliable tubing, and lacked safety measures to alert users when they failed resulting in widespread cases of Diabetic Ketoacidosis (or DKA, a result of dangerously high blood glucose). What is more, though many of these companies commercially operated in the UK and Europe, Disetronic dominated the European market and MiniMed produced the only pump approved by the FDA for at-home use in the US until

³¹ J. A. Parsons, D. Rothwell, and J. E. Sharpe, “A Miniature Syringe Pump for Continuous Administration of Drugs and Hormones: The Mill Hill Infuser,” *Lancet (London, England)* 1, no. 8002 (January 8, 1977): 77–78; Alsaleh et al., “Insulin Pumps,” 129; John Pickup and John Davis, “A History of Insulin Pumps by Important People Who Matter,” *INPUT Newsletter*, no. 6 (Winter /2006 2005): 6–7; G. R. Chambers et al., “A New Generation of Pulsatile Infusion Devices,” *Uppsala Journal of Medical Sciences* 89, no. 1 (1984): 91, 93.

³² Alsaleh et al., “Insulin Pumps,” 129.

Disetronic gained its approval in 1991, leaving all other competitors to fight over a small segment of the market.³³

As functionality and usability problems made consistent at-home use unfeasible for everyday patients, and as two companies monopolized sales in the US and Europe, the CSII market shrank despite various consumer and clinical successes. Insulin pump profits waned in the late 1980s and could not support the kinds of profit margins producers expected earlier in the decade, driving nearly all of them to pull out of the market altogether. The largest of these—Novo Nordisk, Eli Lilly, and BD—each established contracts with MiniMed to facilitate all of their former patients’ use-related needs going forward (including the sale of required consumables such as cartridges and tubing, support for malfunctioning insulin pumps, and general customer service—all of which were based in Europe and the UK). Smaller companies, however, did not have the same access to capital and influence as their larger counterparts, leaving them unable to establish similar extended support contracts. Thus, patients who used devices from any of these smaller company were “left to make their own arrangements, and were, consequently, unable to obtain consumables or have their pumps repaired.”³⁴ In short, by the early 1990s, insulin pump-using patients in the US and Europe only had two options: MiniMed, which had already cornered the US insulin pump market with the only FDA approved pump and had recently overtaken nearly all competitors in the UK and Europe, or Disetronic, the Europe-dominating Switzerland-based manufacturer which MiniMed was challenging. These two devices remained the only two consumer options in both markets until new devices were introduced around the turn of the twenty-first century.

Due to their large (monopolistic) share of the US insulin pump market, MiniMed had a sizeable customer base from which to conduct user surveys regarding design and usability. Following the reveal of its 502 model insulin pump at the American Diabetes Association convention in 1983, MiniMed conducted consumer surveys “to identify the most desirable features” users requested. Soon thereafter, the MiniMed 502A hit the market with many changes

³³ Pickup and Davis, “History of Insulin Pumps,” 7; Alsaleh et al., “Insulin Pumps,” 130; Chambers et al., “A New Generation of Pulsatile Infusion Devices”; Irwin Feller and Maryann Feldman, “The Commercialization of Academic Patents: Black Boxes, Pipelines, and Rubik’s Cubes,” *The Journal of Technology Transfer* 35, no. 6 (December 1, 2010): 613–14, <https://doi.org/10.1007/s10961-009-9123-5>.

³⁴ Pickup and Davis, “History of Insulin Pumps,” 7.

directly addressing user concerns. The 502A was smaller than its predecessor (about the size of a one-inch-thick credit card), had a more programmable microprocessor on-board, and a longer battery life—three issues that have remained at the center of their insulin pump development projects until the time of this writing. Throughout the 1990s, both MiniMed and Disetronic began including new safety features alongside the convenience-focused changes such as size, shape, and battery life. Pump designers used the increased computing power and digital storage to facilitate more comprehensive injection schedules and insulin logs—data sets that could be used to assess various aspects of patients’ use and the devices functionality. What is more, MiniMed developed new alarm and alert systems to notify users of pump or tubing malfunctions, as well as low insulin reservoirs or batteries (each a too-common and rather severe problem for many insulin pump users throughout the previous decade).³⁵

These and other changes to insulin pump design throughout the 1990s, alongside the consolidation of the world’s largest insulin pump markets within the hands of two corporations, emblemize pump producers’ three primary conceptual and material areas of focus during that time: first, securing economic control of insulin pump production and distribution, and thereby the ability to define insulin pumps and the bounds of what they could be; second, designing new safety features to both persuade “safe” use and dissuade “unsafe” use; and third, creating user-friendly interfaces and attractive material design to simplify the act of use and build-out a wider customer-base. With these core ideals at the fore, both companies rode the success of slight revamps of these devices for over a decade, focusing on incremental design changes rather than major overhauls as they were purchased by larger international medical device companies. Pacemaker and defibrillator maker Medtronic, Inc. purchased MiniMed in 2001 (rebranding their insulin pump line under the Paradigm mark soon thereafter) and Swiss pharmaceutical giant Hoffman-La Roche bought their way back into the insulin pump market when they acquired Disetronic in 2003 (likewise rebranding under the AccuChek mark).³⁶

³⁵ Feller and Feldman, “The Commercialization of Academic Patents,” 613–14; Alsaleh et al., “Insulin Pumps,” 130; Medtronic Diabetes, “Innovation Milestones,” accessed June 1, 2018, <https://www.medtronicdiabetes.com/about-medtronic-innovation/milestone-timeline>.

³⁶ Thomas M. Burton, “Medtronic to Buy Medical Research, MiniMed in Deal Valued at \$3.7 Billion,” *The Wall Street Journal*, May 31, 2001, sec. Health, <http://www.wsj.com/articles/SB991225266787150611>; Alison Langley, “Roche to Buy No. 2 Maker Of Pumps For Insulin,” *The New York Times*, February 11, 2003, sec. Business Day, <https://www.nytimes.com/2003/02/11/business/roche-to-buy-no-2-maker-of-pumps-for-insulin.html>.

These purchases, alongside the FDA approval of the first insulin pump from newcomer Animas Corporation in February 2000,³⁷ changed the US insulin pump market in ways that re-centered the industry's holy grail: the artificial pancreas. Automation between glucose testing and insulin injection processes was and continues to be central to the ideal promoted by Arnold Kadish in the 1960s—reducing or removing the need for direct engagement by the user to more closely resemble the actions of a functioning pancreas. Thus, Medtronic, Animas, and other device producers increased the rate of development and testing for continuous glucose monitoring systems (CGMS) which would transmit a constant stream of BG data directly to the insulin pump. Though Medtronic had been involved in this research since the mid-1990s, at-home use of their coin-sized, clam shell-shaped Guardian CGM was not approved by the FDA until 2004. This increased investment in glucose monitoring reinvigorated the race for the artificial pancreas, reaching a crescendo in 2016 when the FDA approved Medtronic's MiniMed 570G closed-loop system—a networked version of their redesigned insulin pump, the Enlite CGM system, and a BG meter designed for use with Bayer-made test strips which was the first to receive federal approval for automated responses to both high and low blood glucose levels—heralded as a “critical step in the development of an artificial pancreas” by the American Diabetes Association.³⁸ Throughout the 2010s, device manufacturers doubled-down on these networked BG reading-insulin delivery systems as both physicians and patients jumped at the prospect of less time and energy required to manage what is often an all-consuming treatment and maintenance regime.

The Socio-Technological Feedback Loop

The institutionalization of both blood glucose monitoring and insulin pump therapy have fundamentally altered the experience of living with T1D in the twenty-first century. The network of devices and treatment practices typical of continuous subcutaneous insulin infusion in the late

³⁷ Though the first Animas insulin pump was fast-tracked for approval by the FDA, with less than five months between application to approval, it was recalled two years later for faulty vents. See: “Defective Vents Prompt Recall of Insulin Pumps,” *Biomedical Safety & Standards* 32, no. 1 (January 15, 2002): 7.

³⁸ American Diabetes Association, “American Diabetes Association Applauds FDA’s Approval of the First Hybrid Insulin Delivery System,” September 28, 2016, <http://www.diabetes.org/newsroom/press-releases/2016/american-diabetes-association-fda-approval-first-hybrid.html>.

2010s is hyper-present in ways that deeply influence users' daily lives and practices—even, or perhaps especially practices that are not directly involved in those treatments themselves. Continuously connected to bodies and to each other, physically and wirelessly, these devices maintain a material presence on/for people with T1D that makes both Diabetes and its treatments visible in ways they have never been before.

I have narrated this history in this chapter and in this particular way to show that T1D treatments and devices, and thus their broader biological and social influences, are and always have been rooted in the actions and decisions of researchers, physicians, manufacturers, and patient-users. The context of those actions and decisions matters and frames the ways treatments and devices are developed, prescribed, and used on an all-day-every-day basis. Pharmaceutical insulin, BG measurement devices, and insulin pumps—like all other technological innovations—are socially and historically produced alongside their scientific and material production. The networked closed-loop insulin pump system does not exist in its current form because it is necessarily the best or only way to treat T1D (in an absolute sense), nor is it the materialization of Medical/Western/human “progress.” It exists because people have created it, and continue to do so—through biomedical research, manufacture, and use—and because people place value in its material and immaterial implications for both global economies and individual health practices/outcomes.

Regardless of how we narrate its inception and creation, however, the networked closed-loop insulin pump system is reality for millions of people with T1D. It exists, inasmuch as Diabetes itself exists, and becomes a central component of users' embodied daily life. In the following chapters, I explore the textures of that reality in various ways, settings, and contexts—material embodiment and experience, social interactions and closeness of bodies, possession and valuation of devices, and access to treatment/pharmaceuticals—to begin unpacking what Diabetic life means in the twenty-first-century US.

CHAPTER 3: DIABETIC BODIES AND DEVICES: MATERIAL EXPERIENCES OF INSULIN PUMP TREATMENT, T1D BODY IMAGES, AND USE AS A TRANSFORMATIVE ACT

“Diabetes—you don’t control Diabetes, you manage it. There is no controlling it.”¹

As I detailed in the previous chapter, people with Type 1 Diabetes (T1D) cannot live without insulin injections, and as insulin pump treatment has emerged as the medical standard of care for that process people are increasingly driven to the use of these networks of devices. For some, these automated injection and blood glucose monitoring systems have proved life-changing—nothing short of a “miracle,” as one individual put it—and understandably so.² A chronic illness requiring constant attention and awareness of what is happening with(in) the body, T1D can be overwhelming and overbearing. Given the conglomeration of medical, social, financial, temporal, and emotional complications of living with and treating Diabetes, the prevalence of Diabetes burnout is alarming if still unsurprising.³ Any respite from T1D’s constant presence can be, in a word, liberating.

But that “miracle” means constant connectedness with—and repetitively connecting to—multiple medical devices in ways that fundamentally transform T1D bodies, materially and phenomenologically. As people use and engage with these devices, they become embedded within (and extensions of) people, their bodies, and their social selves. That process produces altered people, altered bodies, and altered technologies through a situation of compelled use. In this chapter, I analyze informant discussions of their treatment practices at the nexus of their bodies and their Diabetes treatment devices, first as a material experience and then as a phenomenological or conceptual one, in an attempt to answer two primary questions. First, what does the act of use do to/for informants’ material experiences with their treatment devices and

¹ Michael, interview by Stephen Horrocks, male age 41, diagnosed with T1D in 2010, May 19, 2017.

² Ashley, interview by Stephen Horrocks, female age 26, diagnosed with T1D in 2000, June 1, 2017.

³ See: William Polonsky, *Diabetes Burnout: What to Do When You Can’t Take It Anymore* (American Diabetes Association, 1999).

their world? And second, how does that material experience influence the ways they *understand* their bodies and use experiences?

The material culture of insulin pump treatment, I argue, constructs and is in turn built by data-centric images of the Diabetic body. The act of using insulin pumps, continuous glucose monitors, and blood glucose meters relies on conceptualizing the body as data—what I call Datafied Body Doubles—and through constant connectedness, incorporates these images into people’s lives and bodies. Though these medical devices are frequently framed as technological gateways to users’ freedom and independence, those discourses rely on a definition of Diabetes as medically un-free, inflecting people’s embodied experiences with ableist assumptions of dependence.

In what follows, I will begin by describing and analyzing some of the most influential locations of device-connected T1D materialities, as identified by informants—namely their infusion sets (where the pump attaches to/under the skin) and their pump devices themselves. I will then turn to the material traces left by these devices in/on the bodies of patient-users, examining the experience and implications of rashing, scarring, and so-called infusion site rotation. Last, I will follow those networked devices in their production and deployment of Datafied Body Doubles: from new measurements systems and blood glucose meters, to technologically produced “freedom” in continuous glucose monitors, to the contradictory framework of freedom through control and insulin pumps. As I will show, material and conceptual bodies are also fundamentally social, and the examples that follow require an agency-centered reframing of bodies/the body, as well as the technologies and use acts entangled in these practices to account for the complexities of *choice* and materiality in T1D treatment and life more generally.

Material Experiences of Networked Insulin Pump Use

Two weeks before the beginning of his fifth-grade school year, a boy whom we will call Jason went to see his doctor for a yearly physical examination. For reasons he can no longer recall, Jason was sent from there to have some blood tests done at the hospital where he was later diagnosed with Type 1 Diabetes. Because they had caught it so early, he recalls, “I didn’t go through the whole, you know, almost-death experience a lot of people do when they’re diagnosed because their blood sugars are skyrocketing, you know. [. . .] My blood sugar was

only 200 when I got diagnosed because we caught it at a physical.” He was, however, still admitted for a three-day hospital stay while they stabilized his glucose levels and began the process of educating Jason and his parents regarding daily T1D treatment.

Reflecting on his diagnosis experience in the hospital, Jason emphasized the significant role his first finger-prick blood glucose (BG) tests played in redefining the new material reality of his life with a chronic condition. “The lancets they had at the hospital at that point [in 1993], I kid you not, were like 1/16-inch razor blades that, like, shot out at you.” He was horrified by the long gash the lancet left in his ten-year-old fingertip, and the way the throbbing lingered, often for hours. Upon his discharge, Jason’s parents purchased a small portable home glucose meter he would use multiple times a day for the coming months and years:

It was so nice to get my own meter, my own blood sugar meter. [. . .] When it comes to devices and things like that, that was, I guess, when I first started realizing that I was going to be carrying something around with me at all points in time for the rest of my life.⁴

For the past twenty-five years Jason has pricked his fingers multiple times a day—every day, with no exceptions—to test his BG levels as part of his daily treatment routine. Before each meal, in order to calculate how much insulin he will need to inject to counter-balance the carbohydrates he’s about to eat, Jason tests his blood; the finger prick is usually the first thing he does in the morning, and the last thing he does at night; as he starts to feel the effects of what could be high or low blood glucose levels, Jason tests again to decide whether he needs to eat something or give himself a so-called “correction dose” of insulin. If he does not keep track of those glucose levels, or perhaps more to the point for my purposes here, if he does not have access to his BG meter at all times, he runs the risk of severe high or low BG, statuses with serious immediate and long-term health implications.

Jason’s interconnectedness with medical devices for daily treatment typifies that of most people living with Type 1 Diabetes in the United States today, particularly since switching to insulin pump treatment a year after his diagnosis. The ever-presence of various technologies in, on, and around the body come to resituate both the materiality of the body itself and the ways people understand and interact with it. Deeply influenced by the affordances and constraints of the devices’ designs, framed by diagnosis and doctors’ interpretations of physiologies, the

⁴ Jason, interview by Stephen Horrocks, male age 35, diagnosed with T1D in 1993, June 23, 2017.

material world people with T1D inhabit is thick with Diabetes—a presence that every person with T1D has to adjust to in one way or another.

At their most base material level, insulin pumps and continuous glucose monitors (CGMs)⁵ can only serve the function of treating and tracking T1D bodies if they are physically attached to them. A reality for users created by these products' utility and design, device connecting and device connectedness set the parameters for the ways people do (and even can) engage with these life-sustaining objects. How these devices are structured, the components included and the ways they are intended to/can be used by people is primarily an issue of design affordances. First coined by James Gibson in an attempt to theorize animals' perception of their environment and later used to prescribe how objects should (not) or can(not) be used, the term “affordance” in the context of design most often refers to actions *afforded* to a user as they interact with an object.⁶ Insulin pumps, CGMs, and BG meters each have a set of particular uses for which they are designed; calculating doses and injecting pharmaceuticals, calculating chemical ratios in various bodily fluids and estimating glucose levels, the devices involved in networked insulin pump treatment are and were created to fulfill particular medical purposes—at times because they proved most effective, at times because they proved least ineffective (or to have the fewest negative side effects), and at times because that is simply the way things had always been done.

These design decisions produce the very situation wherein people with T1D can receive automated injection treatments as they exist today. At the same time, however, those decisions also produce a number of wholly new concerns users must deal with as a result of their use. First and foremost: where to put the devices during use? Both an insulin pump and the infusion site

⁵ Continuous glucose monitors (CGMs) are worn devices usually made up of two primary components, a sensor to measure glucose levels and a transmitter to send data to insulin pumps or other devices for storage. In the US, only three manufacturers sell CGMs currently approved for use by the FDA: Medtronic, makers of the Enlite and Guardian systems (and the highest-grossing medical device company in the world); Dexcom, makers of the G-series systems; and Abbott Laboratories, makers of the FreeStyle Libre system. Medtronic controls the insulin pump market and is likewise the largest CGM producer, followed (somewhat distantly) by Dexcom who garners the most brand loyalty among its users, while Abbott has made only a marginal entry in the US market despite their dominance in the EU.

⁶ James Jerome Gibson, “The Theory of Affordances,” in *The Ecological Approach to Visual Perception* (NJ: Houghton Mifflin, 1979); Donald A. Norman, *The Psychology Of Everyday Things* (New York: Basic Books, 1988); Jonathan RA Maier and Georges M. Fadel, “Identifying Affordances,” in *Proceedings of ICED 2007* (International Conference on Engineering Design, Paris, France, 2007), 1–11.

(with its accompanying tubing) are material objects which, while performing their utility, take up physical space on and around users' bodies. They must be connected to the outside of the body somewhere and, since tubing can only be so long, that placement must take into account how the pump itself will be stored as it continuously injects their medication—a treatment schedule which runs twenty-four hours a day, seven days a week.

Infusion Sets and CGM Sites on/and Bodies

Nearly all of the people consulted throughout this research attach their infusion sets somewhere around their torso, and the majority of those placed them within a few inches of their belly buttons. Unsurprisingly, this near-consensus on placement is in part due to the training they received from their physicians and/or insulin pump educators when they first went on the pump. As one informant notes, she puts her pump on her hip or back just above the waistline of her pants (the “muffin-top area” as she called it) and her CGM on her stomach because “they’re where I started.” With each of the five or six insulin pumps she has had over the past fifteen-or-so years, Ashley was required to go through a training session with a representative of the pump manufacturer. In each of those trainings, representatives told her that the best place for an infusion site is on the stomach. “They’re the [spots] that they teach you, that are FDA approved. . . . That it has the best absorption, or whatever.”⁷

Though Ashley is correct in citing the FDA’s recommendation as a primary reason why most pump users place their sites on their abdomen, she was the only informant who mentioned it as contributing to their personal treatment decisions. Though the FDA has published two Summary of Safety and Effectiveness Data (SSED) reports for the Medtronic 670G since its FDA approval in 2016 (documents outlining instructions for the safest and most effective use of a device as per the cited clinical trials),⁸ most people placed their sites on their abdomen for

⁷ Ashley, interview.

⁸ The FDA published an SSED for the 670G when it was initially approved for use in 2016. Medtronic’s Closed-Loop system released in the US with this model was marketed as the next big step toward a functioning artificial pancreas. At that time, Medtronic had not conducted trials on the effectiveness or safety of the use of this network of devices by children ages 7-13, and the FDA required them to do so before it would approve these devices for use by children. The 2018 SSED includes data and analysis of studies fitting that description from 2016-2017. “Summary of Safety and Effectiveness Data (SSED), MiniMed 670G System” (Silver Spring, MD: U.S. Food and Drug Administration, U.S. Department of Health and Human Services, September 28, 2016); “Summary of Safety

utility purposes and/or at the advice of their personal doctors or educators, as Ashley noted above. Though the FDA data likely inform those experts' advice, the pump users in this study tended to rely more on their doctors' words than the numbers behind them.⁹ Over time, however, even that advice acts as a reference point for a routinized practice that patients *just do*. When asked why she places her infusion site on her abdomen, long-time insulin pump user Sarah recalls:

I have always put it there. I think when I first got the pump, I think that's what the Medtronic nurse. . . she suggested I do it there. And so I have ever since then. [. . .] I've tried moving it to the back of my arm. I've done that for, like, a couple of weeks at a time, but I just don't like it. It's always in the way, it's not comfortable.¹⁰

The first reason Sarah gives for her site placement is her own routine. Throughout the seventeen or eighteen years she has used an insulin pump, Sarah has inserted, removed, and reinserted hundreds of infusion sets into/onto her body. She, like everyone else who uses these devices, discards the pump site, tubing, and reservoir attached to her body and replaces them with fresh ones approximately every three days. As those actions become part of semi-weekly routines, and as the busy-ness of life settles in post-diagnosis, the initial reasoning behind those placement decisions can take a backseat to the need to just-get-this-thing-done. When she pauses to think about the roots of her own placement decisions, she reaches for a vague memory of a nurse's instructions, only to default back to "And so I have ever since then."—a phrase that not only signals the routinization of her practices, but that also implies a level of reliance on her own experience above past expert advice.

And here Sarah also provides a break from what can at times be mis-read as a lack of agency on the part of patient-users: between the authoritative direction from physicians (signaled by the title of "patient") and the rhetorical objectivity associated with automated devices (signaled by the title of "user"), insulin pump treatment sets considerable bounds on acceptable

and Effectiveness Data (SSED), MiniMed 670G System" (Silver Spring, MD: U.S. Food and Drug Administration, U.S. Department of Health and Human Services, February 13, 2018).

⁹ It should be noted here that though all of the recommendations for the Medtronic 670G cite the abdomen and upper thigh as most effective and safe, the clinical and non-clinical studies they cite in their report only report data on people who used these devices in those two body locations. In other words, there is no recommendation for other locations because there have been no studies conducted that include devices placed elsewhere.

¹⁰ Sarah, interview by Stephen Horrocks, female age 30, diagnosed with T1D in 1993, August 14, 2017.

and/or possible actions by the people engaging with it. Stated another way, patient-users are to be acted upon by professionals and medical devices. As Mary Specker Stone has argued, agency within the modern biomedical model lies with practitioners who treat disease as a discreet entity to be managed or cured by them. The sick body, in this framing, is but a “scene, the site of disease to be treated,” rhetorically separated from the person themselves. Though this framing has shifted since the late-twentieth century, efforts to re-conceptualize patients as whole psychosocial embodied persons has been built around “compliance” to self-management regimes which retain the physician-as-agent-of-healing dynamic.¹¹

In practice, however, patient-users such as Sarah are deeply active participants in their own treatment practices in ways that alter both the constraints and the affordances of the device-expertise metric of insulin pump use itself. Sarah’s statements refer to her own testing, placing her sites in different places on her body to see how they worked (and did not work, as she noted with the back of her arm). She then assessed the results of that test, compared them with her experience wearing it elsewhere, and concluded that it was less effective and less comfortable than on her abdomen. Sarah acts here as an agent of care and device testing in real-time, echoing the long-established (and controversial) practices of self-experimentation in science and medicine.¹² Though she reverted her daily placement to the advised location on her body, she did so not only on the advice of her care team but based on her own experience pushing the boundaries of the devices’ design constraints.

¹¹ Mary Specker Stone, “In Search of Patient Agency in the Rhetoric of Diabetes Care,” *Technical Communication Quarterly* 6, no. 2 (April 1, 1997): 203, 205, https://doi.org/10.1207/s15427625tcq0602_5.

¹² The history of medical research is complicated by the need for testing practices, treatments, and methods on humans. Experimentation on/with human subjects is rife with historical examples of ethical gray areas and, in some cases, blatant disregard for the wellbeing or life of test subjects (the Tuskegee syphilis experiment and Nazi eugenics-based experimentation are perhaps the most commonly cited examples). One way researchers have attempted to side-step those ethical concerns is to conduct experiments on themselves, a practice which has itself been a subject of considerable ethical debate. For a monograph-length discussion of self-experimentation in Medicine, see: Lawrence K. Altman, *Who Goes First?: The Story of Self-Experimentation in Medicine*, Paperback Edition (Berkeley, CA: University of California Press, 1998); For a shorter history, see: I. Kerridge, “Altruism or Reckless Curiosity? A Brief History of Self Experimentation in Medicine,” *Internal Medicine Journal* 33, no. 4 (April 1, 2003): 203–7, <https://doi.org/10.1046/j.1445-5994.2003.00337.x>; For a discussion of the ethical concerns related to self-experimentation, see: S. C. Gandevia, “Self-Experimentation, Ethics and Efficacy,” *Monash Bioethics Review* 24, no. 2 (April 1, 2005): S43–48, <https://doi.org/10.1007/BF03351434>.

Managing Insulin Pumps and Tubing Near Bodies

Despite the language used by informants regarding where they put their pumps, most of those statements actually refer to the placement of the infusion sites in/on the body and not the pump object itself. It must also, by virtue of the devices' design and function, be near/on the body in order to inject the insulin patient-users need. In order to pump pharmaceuticals into people's bodies, the pump device must be connected to an infusion site with a length of tubing, and as I alluded to above, that tubing can only be so long before tangles and wasted insulin become a serious issue. That requires the pump to have a storage location on the body relatively near the infusion site, in most cases near an article of clothing where the pump can be clipped or inserted. Given the usual torso-centered placement of the infusion set, pants pockets are the most common location informants identified for storing the pump on an average day. "I don't ever hide anything," thirty-five-year-old Jason says, "but my insulin pump is normally in my pocket."¹³ Their proximity to the belly and their long-established cultural practice as a worn space for storing things make pockets an obvious location for the pump. That assumption, however, is laden with problems given the material difference between sets of pants and cultural norms of fashion.

On a practical note, not all pants have pockets. Oftentimes jeans, dress pants (or slacks), and sweatpants are made with front pockets and one or two back pockets of some form as well. When they do, however, not all pockets are made with the same storage/utility purposes in mind. Men's jeans and dress pants are frequently made with deep front pockets, perfect for storing an insulin pump when the infusion site is placed on the abdomen as Jason discussed above. Pants made from lighter and/or more draping fabrics such as sweatpants and nursing scrubs, however, have a difficult time holding an insulin pump even when they have pockets. Amanda, a registered nurse who works in a labor and delivery unit, points out the difficulties of putting a pump on your body at work. "Scrub pants already don't want to stay up, so when you put something on it—it just makes it more annoying, you know?"¹⁴ Technically speaking, those scrubs have a pocket—on the back—but using the back pocket for insulin pump storage is impractical as she engages with her physically demanding work throughout a shift. Instead, she

¹³ Jason, interview.

¹⁴ Amanda, interview by Stephen Horrocks, female age 30, diagnosed with T1D in 1993, August 4, 2017.

clips her pump on the waistband, which makes it accessible and near her infusion set, but that extra weight also pulls her pants down. Sweatpants or gym shorts with pockets share this complication; aided by the tightening of drawstrings, but always a concern.

People who participate in athletics frequently run into this problem, forcing them to make some pump-related decisions. “I do gymnastics still,” says Jennifer, “and at least once a month a site will fall off during gymnastics.” She opts to take her pump off from the infusion site while engaging in sport altogether, but the site itself is still there and must be accounted for. In her case, the nature of the activity itself frequently scrapes her infusion site off, requiring her to insert a new one before she can reattach her pump. “I tend to wear compression shorts or something to keep them. . . especially my Dexcom, I wear compression shorts so it doesn’t get moved around.”¹⁵ The very design of the devices, such as the Dexcom CGM she references here, require her to make particular fashion and treatment decisions in order to accommodate their use during these activities. Other informants discuss similar decision-making processes as they participate in competitive swimming and water sports, even when their devices are purported to be waterproof.¹⁶ These examples demonstrate the ways in which clothing design and activities can both afford insulin pump users certain spaces to store the pump and limit their ability to do so.

This problem of pump placement and clothing is also deeply gendered in ways that place a heavier burden on women. As Joanne Entwistle argues in *The Fashioned Body*, the act of dressing is a “situated bodily practice” framed by cultural definitions of gender, played out upon fabrics and clothing. In the process, clothing “turns nature into culture, layering cultural meaning on the body” and does the work of naturalizing those cultural conceptions in the process.¹⁷ Women’s jeans and dress pants, unlike those designed for use by men, often have very limited space in the front pockets and even less in rear pockets, if they are designed with them at all. Women’s pants are, in a general sense, produced with pockets that serve more of an aesthetic role than a utilitarian one. In 2018, Journalist-Engineers Jan Dieme and Amber Thomas

¹⁵ Jennifer, interview by Stephen Horrocks, female age 35, diagnosed with T1D in 1985, May 22, 2017.

¹⁶ Amanda, interview; Sarah, interview.

¹⁷ Joanne Entwistle, *The Fashioned Body: Fashion, Dress and Social Theory*, 2nd Edition (Malden, MA: Polity, 2015), xi, 143.

measured the pocket sizes of twenty of the most popular brands of jeans in the US and found that, on average, women's front pockets are 48% shorter and 6.5% narrower than men's pockets. In practice, that means that only 40% of the jeans tested could completely fit one of the three leading smartphone brands.¹⁸ Though insulin pumps are considerably smaller in size than the current trends in smartphone design, the smaller aesthetic-focused pockets are still difficult to use, and non-pant clothing options culturally produced for women such as dresses and skirts are even less likely to have pockets.

Gender-specific clothing storage limitations require women to find other means for storing their devices near/on their bodies. Sometimes that means repurposing components of the clothing they already wear; other times that means including new articles altogether. One of the most difficult things about using a pump, recounts twenty-six-year-old Ashley, is "finding clothes that fit with the system." She cannot wear a variety of pants, because the rise on the waistband rubs on her infusion site or CGM and "irritates everything," but her pump requires her to find things with pockets—a dilemma that often leads to her making different clothing choices altogether.¹⁹ One option, as other informants have detailed, is clipping the pump to the user's bra. Thirty-one-year-old Jessica says she wears it in her bra, largely for the reasons Ashley laid out above, but that decision comes with its own complications. As Ashley noted later-on, "I've had a couple of times where it lights up with an alert [for low BG] and people are like, 'um. . . your shirt is lighting up?'" Through her laughs she joked, "It looks like Iron Man."²⁰ Awkward social situations can be humorous, but they can also be very distressing for the person who is newly on display, particularly as they relate to one's health and a work environment.

There are other, everyday-use issues that arise from putting one's pump in their bra as well. As Jessica reflects, "Sometimes in the summer, like when I'm doing yard work, I'd get very, like, hot and sweaty." On its face, this seems like a minor issue, but because her pump is not waterproof that moisture can seriously affect the device's ability to perform its function—and a faulty pump means inaccurate injections. "That's where my mom kind of helped again.

¹⁸ Jan Diehm and Amber Thomas, "Pockets," *The Pudding*, August 2018, <https://pudding.cool/2018/08/pockets/>.

¹⁹ Ashley, interview.

²⁰ Ashley.

[. . .] So my mom made this insulin pump cover for me, and it's plastic on the inside but cloth on the outside, so I can actually clip it on my bra and the water won't get to my insulin pump."²¹ Together with her mother, Jessica found a way to not only deal with the pockets issue but the new concerns that arose with her experimental storage practices. Ashley's primary work-around, she says, is to wear dresses—usually the most difficult articles to wear with a pump:

It took me years to figure out how to wear dresses. I wear—they have these bands that are for exercise, and they have all these little pockets in them—so I wear those now under dresses. But I only discovered that in the past three or four years. And that was something I always used to Google and could never find, like, 'What to do with a pump while wearing a dress?' That was my biggest problem while in high school.²²

Rather than deal with the inadequate pockets on her pants, Ashley opts for an extra article of clothing that can provide the on-body device storage she needs. Repurposed from an elastane athletic band with slip pockets worn on the thigh (Lycra or Spandex, for example), Ashley's pump-holder functions as an innovative response to what is in practice a serious design limitation for women with Type 1. She circumvents those constraints by using both her clothing and her insulin pump in ways neither was necessarily intended—a practice that highlights both the technologies' use limitations and the creative possibilities of reorientation when one is compelled to use them anyway.²³ In adopting this object and practice, she not only reclaims her ability to fit the pump to her needs as a patient-user, but she consciously maintains a less-device-friendly feminine aesthetic in the process.

²¹ Jessica, interview by Stephen Horrocks, female age 31, diagnosed with T1D in 2000, August 18, 2017.

²² Ashley, interview.

²³ In her analysis of the TRS-80 computer user-base, Christina Lindsey discusses the ways unintended forms of use creates new and often unexpected relationships between people and devices. Though users in that case are not compelled as are individuals here, their creative interactions with technologies redefine the devices themselves in the process. See: Christina Lindsay, "From the Shadows: Users as Designers, Producers, Marketers, Distributors, and Technical Support," in *How Users Matter: The Co-Construction of Users and Technologies*, ed. Nelly Oudshoorn and Trevor J. Pinch (Cambridge, MA: MIT Press, 2003), 29–50.

Tracing the Traces of Medical Device Use

Insulin pumps, CGMs, and BG meters have a significant material presence in the lives of people with Type 1 Diabetes. As they are used and re-used daily over the span of years, these devices leave material traces of themselves in/on the bodies of the people who use them. From adhesives and injected objects to scarring and bruising, the traces of insulin pump treatment can be seen and felt for days, weeks, and even years.

Adhesive Problems, Skin Reactions, and Pain at the Site of Infusion

In order for insulin to flow properly from the pump device into patient-users' bodies, the connection between the two must remain air-tight. This requires both a sturdy gasket on the pump and a well-adhered infusion set inserted into/stuck onto the body. The same holds true for the CGM: in order for the sensor to take consistent readings, it must be inserted and adhered well to the skin. A majority of people interviewed here reported complications with the adhesives and infusion sets that at times made use an uncomfortable and even painful act. The most basic of these issues is a lack of stickiness, leaving CGMs and infusion sets detached from people's bodies. Ashley, who discussed her creative methods for wearing her pump above, related her frustration with the way the adhesives interacted with her body. "I have really sensitive skin, and really oily," she says, "so I have trouble getting a CGM to stay on. Then it gets really uncomfortable, even though they're supposed to last for like a week. [. . .] The first time I tried it I could only keep it on for like two days. It was really disappointing."²⁴ If these devices are not adhered to the skin, they cannot inject any insulin or take any glucose readings, leaving them unusable (and therefore unused).

Patient-users, then, are left to find a way to make their "life-changing" and extremely expensive medical device work for them. Ashley describes various tapes she has used, especially after she first got her insulin pump, that can be placed over the top of the site's adhesive to help it stick longer and/or more effectively. To deal with her child's ineffective CGM adhesive sites, Brittany also uses single-use tapes that manufacturers include with devices' disposable

²⁴ Ashley, interview.

supplies.²⁵ Even then, those tapes are often not enough, and both of these informants discuss cleaning wipes and creams they have experimented with to prepare the skin for a more effective adherence. In her statement above, however, Ashley alludes to the issues involved in these types of chemical/technological fixes, which cannot always supersede individual physiology.

When site adhesives do stick well, their effective use carries its own set of unintended consequences for the bodies to which they adhere. The chemicals on those sticky-pads can cause skin reactions that range from mildly irritating to seriously painful. Though Brittany mentioned her daughter's CGM adhesive falling off above, the adhesive for her Omnipod insulin pump remains attached very well. When applied to her abdomen or arm, the adhesive attaches and disconnects without much issue. In other body locations, however, that process is less simple. "When it's on, like, her upper-butt area," Brittany explains, "she breaks out in a rash. So, something with that area is really sensitive to the adhesive of the [Omni]pod."²⁶ In the case of Brittany's daughter, two variables related to device adhesives make the importance of individual physiology to use experiences quite clear. First, the materials used in devices and adhesive agents vary from manufacturer to manufacturer, and even at times among production lots of the same device, meaning bodies interact with each device in unique ways. Whereas the CGM adhesive is gentle on the skin yet disconnects easily from Brittany's daughter's body, the insulin pump sticks very well yet frequently causes dermal reactions. Though objects may perform similar functions, and they may be understood as the same in the act of use, their compositions may vary considerably. Second, despite being linguistically denoted in the singular, the body is itself a variable and multi-sited assemblage of physiologies and microbiomes.²⁷ The skin, what is happening on and beneath it, and how clothing and patient-users' other practices affect bodies'

²⁵ Brittany, interview by Stephen Horrocks, female age 35, child diagnosed with T1D in 2016, August 11, 2017.

²⁶ Brittany.

²⁷ In her study of toxic shock syndrome, Sharra Vostral discusses the importance of framing research questions and practices at the intersection of bodies and devices in ways that provide space for the multiplicity of technological and biological actors that exist in and on bodies. Tampon-related toxic shock, she argues, results from "biocatalytic activity between technology and bacterium" within the microbiome of the vagina leading to illness and even death, not simply activity between the object and body tissue themselves. While body locations typical of insulin pump use such as dermal and subcutaneous areas of the abdomen have microbiomes that differ greatly from those of vaginas, this perspective complicates the body-reaction-to-devices frame in important ways. See: Sharra L. Vostral, *Toxic Shock: A Social History*, Biopolitics (New York: NYU Press, 2018), 2, 19.

reactions to devices are different on the lower back than they are on the tummy or the back of the arm. The Omnipod adhesive only causes a reaction on her “upper-butt area,” after all, and not in any other location they have tried.

Often these types of reactions are so severe that treating their effects becomes a regular part of the Diabetes treatment regimen. Another parent-caregiver of a child with Type 1, Heather, describes similar reactions with her son’s skin related to his past skin-related condition. “He, um, when he was little, he had eczema,” she recalls, and when he attaches a CGM site now “he does tend to get rashes.” Whether Heather drew that connection based on her own care relationship with her child or whether a physician noted it is unclear, but she noticed a pattern in her son’s CGM skin reaction that constrains how they can and cannot use the device. As noted briefly above, and as I cover in detail in Chapter 6, the disposable components of CGMs and insulin pumps are quite costly, ranging from approximately \$15 per insulin pump site to \$120-\$150 per CGM site. Though out-of-pocket costs vary widely based on insurance coverage, many CGM users in particular attempt to ease that financial burden by leaving their sensors connected for days longer than advised—a practice with which Heather is familiar, but cannot participate in due to his reactions. “We make sure we change his. . . some people will leave the site on longer than they tell you you’re supposed to,” she notes, gesturing toward some of the Diabetes online communities that facilitate those discussions, “but we do not because of. . . he does have that rash issue.” The family instead follows FDA-approved use guidelines, but when they change out his sites they still require adjusted treatment practices. “And so when we change the site we just have to put on, like, hydrocortisone cream so it can heal.”²⁸ Each time he peels off his device, which for the Dexcom CGM is no more than every ten days, Heather applies an anti-inflammatory cream to stave-off his persistent reaction. This requires yet another step in the already time-consuming practice of glucose monitoring—which is itself a part of insulin pump treatment with even more frequent interaction and site-changes.

For others, adhesive rash can be a deterrent from engaging in what would otherwise be a beneficial practice in treating their T1D. “My skin’s quite reactive to having to, you know, being taped and those sorts of things,” says thirty-six-year-old Christopher. He has used an insulin

²⁸ Heather, interview by Stephen Horrocks, female age 34, child diagnosed with T1D in 2015, August 10, 2017.

pump for a couple of years, and though the device itself has proved quite helpful in facilitating his insulin treatment, he has dealt with adhesive reactions the entire time. He inserts an infusion set, which initially functions without irritation, until a few days go by and the itch sets in. “I get itchy after three days with that on, also it depends on where it is on my stomach. [. . .] I’ve got a couple of sites, because I rotate throughout different sites, a couple of sites get itchy quicker.” He muses that perhaps the reaction is due to a lack of subcutaneous fat, but in the end the cause is less significant to him than the effect. Those reactions have kept him from seeking out a CGM device, despite being convinced it would greatly benefit his day-to-day BG levels. “I’m not confident that I can last two weeks with the CGM,” and though he could adjust his use patterns to cycle them out more frequently, that would result in even more costs atop the already large investment required for this treatment regime. “But you’re investing thousands,” he exasperates, “and then if it turns out that my skin can’t handle the adhesives, that’s thousands of dollars that I’ve just spent and I can’t use it.”²⁹ And, at least until the time this interview was conducted, that was enough to keep him from using a CGM altogether.

In this, Christopher is somewhat of an outlier among informants for this study. The parents cited above are visibly frustrated by the adhesive-related issues their children experience whenever they connect these devices, but the promise of more or better treatment is compelling enough to continue using them. Other informants experience pain and use-related issues that are, in some ways, even more amplified or long-term. Sarah, who has been using an insulin pump for nearly eighteen years, discusses issues she has with her CGM. “I . . . to me, I think it’s painful after a couple. . . so you can leave it in for five days, I usually only leave mine in for three days because they get, the actual site gets sore.”³⁰ Unlike the Dexcom CGM Heather and Brittany describe above, the Medtronic-made Enlite and Guardian CGM systems are only recommended for five to six days of continuous use before changing the sensor site. Despite the much shorter timeframe, Sarah’s site becomes painful mere days after inserting it, causing her to cut the interval short. Though this carries considerable financial concerns for Sarah in the long-term, as switching out sites early means purchasing more of those expensive sites overall, it means regularly scheduled device-related pain every few days in the short-term.

²⁹ Christopher, interview by Stephen Horrocks, male age 36, diagnosed with T1D in 2013, June 20, 2017.

³⁰ Sarah, interview.

Pain at the site of infusion can be related to scores of issues, as some informant experiences have highlighted in this chapter already, but the cannula—a tiny catheter-like tube inserted beneath the skin for insulin pump infusion—often plays an important role in patient-user (dis)comfort. As infusion sets are inserted into/onto the body, a needle pierces the skin and the cannula is left just beneath the skin to act as a channel through which insulin can be injected, metered in intervals via the programs written into the pump. Before the flexible materials currently used for this purpose were developed and approved, manufacturers used metal ones. As Christopher recalls, “They started me off on a steel cannula, which was eight mil [mm] long, or six mil [mm] long, and I just was, I ended up. . . I don’t have enough subcutaneous fat, and so it actually scratched against the muscle.” This description, without hyperbole or visual language, is vivid enough to make his next sentence almost humorously under-stated. “So it was actually, it was quite uncomfortable.” Though some manufacturers still produce steel cannulas, very few are prescribed due to these and similar issues; Christopher, after all, was only diagnosed with T1D in 2017. He was able to use his scratched abdominal muscle as cause for his doctor to prescribe infusions sets made with different materials. “So I have a Teflon cannula,” he explains, making it clear that it has never scratched him in the same way since. The new material comes with its own issues, however, complicating the effectiveness of this non-metal alternative. “The Teflon is more prone to having blockages,” he bemoans, “because it can kink it when you insert it.”³¹ In dealing with the complications of pain-inducing infusion sets, the new device that fixes that problem carries its own—which can actually stop injection, the primary purpose of the entire system, altogether.

Scarring and Bruising, Physical and Social

These devices, even when attached and inserted without kinks or major injury, can leave visible and tactile traces on the bodies of those who use them. Scarring and bruising, in the context of Diabetes treatment, is not an insulin pump- or CGM-specific concern. In fact, people with T1D have managed these types of reactions for decades as needle injections and finger-prick BG testing were institutionalized during the twentieth century. Though needles carry more of a cultural association with fear and phobia, finger-prick lancets actually tend to cause more

³¹ Christopher, interview.

pain and scarring. Matthew, an information technology specialist living with Type 1 for a little over a decade, describes the fallout from his BG meter use. “It’s typically the pinky and then the ring finger of my left hand,” he says. “I’m right-handed, so I picked the left hand because I’m using it less, but I definitely favor those two fingers, and I’ve got. . . I don’t know if you can see it. . .” Matthew holds his left hand up to the camera he is using for our video call, “Probably not very well because it’s a crappy camera, but there’s little tiny black dots all over the end of my finger, repeatedly checked.” Those black dots, he explains, are dozens of points-of-entry for the lancet’s hyper-sharpened tip, puncturing his skin with a spring-loaded “tunk” before squeezing a droplet of blood onto the meter’s test strip. “The finger, like, I can feel some callouses under there,” he describes as he runs his thumb over each fingertip. “Those are the two that I’ve favored for the last, probably, ten years.” Matthew audibly laughed as he said this, realizing just how long he had been stabbing those two fingers almost exclusively. Over time, the build-up of that scarring and callousing actually makes a considerable difference in individuals’ ability to extract blood for their tests. “I have to turn the distance up, I guess. Like, the injection distance up, on the lancet,” increasing the tension on the spring in order to force the lancet harder and deeper into the toughened skin. Those pokes, five to ten per day, can be incredibly painful both on the initial impact and in the minutes (sometimes hours) following. Exacerbated by his infrequent replacement of the lancet blade (a common issue among testers—“I don’t think I’ve ever talked to a Diabetic who is good about lancets,” he laughs), those device-initiated body-healing processes produce new tissue that makes future treatment acts increasingly difficult and painful.³²

Whereas lancets can cause visible and tangible issues with fingertips, needle injections can have similar effects on arms, legs, and torsos. When thirty-one-year-old Jessica was in middle school and high school, prior to her switch to insulin pump treatment, she was active in various athletic extracurricular activities. “When I was, I mentioned earlier that I played volleyball, but I did sports year-round.” Her regular insulin injections—two shots of long-acting insulin and fast-acting insulin whenever she ate—had some unexpected effects on her body. “The shot size was pretty significant, to the point that it was giving me large bruises on my legs.” These bruises were not only painful, but hyper-visible to the people around her in a way that

³² Matthew, interview by Stephen Horrocks, male age 32, diagnosed with T1D in 2006, May 25, 2017.

carried serious social consequences. “I was a swimmer during summer and wintertime, and those bruises caused a lot of. . . a lot of attention. I mean, they were huge bruises. I used to give myself one shot and the bruise would swell up the size of, like. . . I’m trying to think, you know, like an eight-inch bruise, or something.”³³ No matter what changes or adjustments she and her parents made to her injection materials or process, they resulted in massive bruises that led to uncomfortable interactions with other students, coaches, and other adults, often with assumptions of harm from others or herself. In a sense, there *was* harm being done to her body, though it was inextricably linked to the life-sustaining medical treatment she had no choice but continue.

If possible, informants seem to describe the material traces of their insulin pump and CGM use on their bodies in even more extreme terms than finger pricks or needles. Nearly every individual interviewed here describes infusion set-related scarring as one side effect of use that is both frustrating and potentially dangerous. Ashley, cited above for her adhesive-related reactions, describes the changes scar tissue has made to her body, particularly from CGM use. “Definitely, like, with the CGM, and to a lesser extent with the insulin pump, my stomach and my back where you do insertions are just covered in scars and scar tissue,” she explains, noting that these problems do not subside very quickly. “It’ll get really red and inflamed, and it’ll stay like that for like a week. So really uncomfortable, really ugly to look at.” Per her description, she hates what her treatment devices have done to her torso. As a resident of a Gulf state, boating and water sports are significant cultural activities for her and the communities of which she is part—activities she now participates in less frequently, and in different ways, due directly to her device-related scarring. “I don’t wear two-piece bathing suits anymore,” she says with finality. “That’s a huge deal, though. It looks really gross.”³⁴ Regardless of, or perhaps due to the socially-constructedness of hatred/revulsion for scarred, maimed, debilitated, and other visibly disabled bodies,³⁵ Ashley is hyper-aware of the visible markers of non-normativity dotted around

³³ Jessica, interview.

³⁴ Ashley, interview.

³⁵ For a history of the stigmatization and criminalization of visible disability, see: Susan M. Schweik, *The Ugly Laws: Disability in Public*, New York Press edition (New York; Chesham: New York University Press, 2010); For a discussion of state violence, race/ism, and debility, see: Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham: Duke University Press Books, 2017); For a critique of popular representations of disability as unworthy of display, or any existence at all, see: Alison Kafer, *Feminist, Queer, Crip* (Indiana University Press, 2013), <http://www.jstor.org/stable/j.ctt16gz79x>.

her mid-section—and she is so ashamed of them that she chooses to alter the ways she participates with her own community.

And these scars, dots, bumps, and red marks can persist for days, weeks, even months or more in some cases. Musing on the markings she bemoaned above, Ashley touches her abdomen, “I can feel where my last three sites were. There’s still a little red bump there, so it’s easy to keep track of.” When I asked how long those bumps usually remain on her skin, she responded, “It’s hard to say how long, like, right now on my stomach I can see eight sites. And those weren’t all back-to-back, so some of those had to be, like, more than eight weeks ago. [. . .] Some of them are really red, but some of them have faded to brown.”³⁶ Those “pump bumps,” as they are often called in clinical literature,³⁷ are now essentially permanent parts of Ashley’s body. Even if each individual pump bump eventually goes away (after months of slowly changing in color, size, and shape), Ashley sports a shiny new red bump every time she removes her CGM—a weekly routine. Paired with the various rashes, bruises, and skin reactions she and others have discussed, these outward traces of device use make Diabetes treatment acts visible to both the patient-user themselves and those around them even when the devices are not attached to the body. They remain visible and tangible reminders of the constant poking and injecting typical of daily life with T1D, and as Ashley’s example demonstrates, that kind of medicalized change to bodies’ tissues can have significant psychological, emotional, and social implications.

But the material traces of insulin pump treatment often take felt-yet-unseen form. During a visit to his doctor’s office, Jason recalls informing them about his infusion site placement. He usually inserts the device in the same area of his stomach, he said, and his doctor responded by affirming his trust of Jason’s decades of experience: “looks like you know what you’re doin’,” was the response, as he retells it. Despite this verbal support from his physician, however, Jason expresses a rising unease with his consistent site placement. “Now, you know, I’m noticing that there is some build-up of scar tissue there because of that,” small hard bumps of tissue he can feel just under the skin where the cannula was inserted. This scarring can be disconcerting, in part due to its form as an unidentified hard mass inside the body, “and that’s why I’m trying to

³⁶ Ashley, interview.

³⁷ Dorothee Deiss et al., “Insulin Infusion Set Use: European Perspectives and Recommendations,” *Diabetes Technology & Therapeutics* 18, no. 9 (August 15, 2016): 520, <https://doi.org/10.1089/dia.2016.07281.sf>.

move it around a little bit more.” Though he has experienced this body response consistently throughout the decades he has been using an insulin pump, Jason (and much of the medical literature) did not understand some of its implications for treatment. In recent years, however, research has shown that scar tissue at the site of insulin injection can inhibit the insulin’s ability to regulate blood glucose.³⁸ “And now that they know that that impedes insulin absorption, you know, like, okay, well, I guess we gotta change.³⁹ That hardened tissue inside his abdomen is more than an annoyance, but can actually make his insulin injection regimen dangerously out-of-sync with his own expectations. And scar-inhibited insulin injection, as another informant noted succinctly, can have serious repercussions: “Well. It, uh. . . it doesn’t work.”⁴⁰

Site Rotation and Its Limits

The practice most of these patient-users turn to for their pain-, scarring-, and irritation-related issues is site rotation. In order to limit body tissues’ exposure (and subsequent reaction) to infusion sets and adhesives, pump users are advised to attach them in different locations on the body every time they change them out. Inserting new sites at least two inches away from previous ones has been shown to greatly reduce the risk of scarring, as well as so-called “pump bumps” and Lipohypertrophy (small red bumps of tender skin and “a thickened rubbery swelling of adipose tissue that may be soft or firm,” respectively).⁴¹ While site rotation is described by most participants in this study as generally helpful in reducing these side effects, there are limits to the practice’s feasibility and, in some cases, even new/magnified social issues. Echoing Ashley, whose pump bumps and adhesive reactions were discussed above, thirty-nine-year-old Joshua notes the difficulties of balancing the need to maintain effective injection with the all-over scarring that creates.

³⁸ M. E. Wallymahmed et al., “Nodules of Fibrocollagenous Scar Tissue Induced by Subcutaneous Insulin Injections: A Cause of Poor Diabetic Control,” *Postgraduate Medical Journal* 80, no. 950 (December 1, 2004): 732–33, <https://doi.org/10.1136/pgmj.2004.019547>.

³⁹ Jason, interview.

⁴⁰ James and Mary, interview by Stephen Horrocks, male age 75, diagnosed with T1D in 1987, female age 73, August 14, 2017.

⁴¹ Deiss et al., 519–20.

“I try to rotate those as much as possible, but I like the front of my stomach better than anywhere else, so you can see that I do have some scar tissue, and then every once in a while you’ll get like a bad one where, like, you know, it kind of bleeds or, you know, you take the site off and it’s just kind of noticeably red for a few days. Even if I took everything off and went to the beach, you would still look weird because either, one, I’m gonna have somewhat of a tan wherever my last site was, or you can still see where my older sites are. So it’s, you know, no matter what, my stomach is, it looks different than anybody else’s because, you know, I’ve been pricked so many times.”⁴²

For Joshua, site rotation is limited in part by his own experiential knowledge of most injection-effective (or even just most enjoyable/least unenjoyable) placement on his body. Unfortunately, at times that tacit knowledge is at odds with medical best-practice, building site-of-action tensions between known comfort/scarring or bleeding on the one hand, and rotation/potentially uncomfortable or painful sites on the other. Part of what makes that artificial binary so difficult, however, is that patient-users can expect some form of pain and/or bodily discomfort regardless of how they structure their site placement regimen. The very act of using these devices requires unpleasant material interaction between/within bodies and insulin pumps or CGMs. Likewise, some of the social fallout of living a device-connected T1D life within cultural settings devoted to compulsory able-bodiedness are unavoidable, whether rotating infusion sites as directed or not. Joshua’s own assessment of what makes his presence at the beach “weird” is built on an assumption that visible signs of individuals’ non-able-bodiedness make them and their bodies undesirable, uncomfortable (for the able-bodied), and unwelcome in public.

In the end, however, bodies have a finite amount of skin surface area conducive to insulin pump and CGM attachment. In most cases, people who rotate their placement with each new infusion set will eventually cycle back to a location they have already used, regardless of how regimented a system they employ. Repeated insertion in or near the same spot increases the risk of scar tissue and other related issues detailed above, and as Ashley demonstrates, the limits of site rotation can be rather anxiety-inducing for the person embodying that experience. “I’m always worried I’m going to run out of space,” she admits. “Especially, like, I haven’t gotten any new scar tissue in a while, but if I got too much scar tissue, I really wouldn’t be able to use one of those spots and then I’d have to find another spot.” Her already limited options for site

⁴² Joshua, interview by Stephen Horrocks, male age 39, diagnosed with T1D in 2008, May 23, 2017.

placement are encroached upon by her own body's reactions to those very devices. "I rotate really well, as much as I can, but I do feel like eventually I'll run out of spots."⁴³ If or when she does run out of spots, Ashley's options for using currently-standard insulin pumps will be limited, in theory to the point of compelling her to take-up her former practice of needle-and-syringe multiple daily injections.

This, along with the myriad traces of insulin pump treatment on the bodies of people with T1D, can make using those devices too difficult, too painful, or just not worth the added physical and psychological stress. A small number of informants interviewed here have actually stopped using these devices in part due to these very concerns, and each of the others describes the weight that everyday use places on their metaphorical shoulders (and their material abdomens). And yet, despite the often frustrating and occasionally overwhelming side effects of insulin pump and CGM use, these devices perform important life-sustaining functions these individuals would rather (or medically cannot) live without.

Device-Connected Type 1 Body Images

As the material traces of insulin pumps and CGMs are imprinted and impacted into/onto Type 1 bodies through constant use, the *conceptual* traces of those devices redefine T1D bodies as quantifiable, usable, and controllable—T1D bodies as data. But as people engage with this process directly, they construct and re-construct those datafied T1D bodies themselves, actively negotiating their social values, cultural meanings, and materializations. At times these T1D body images,⁴⁴ which I call Datafied Body Doubles, afford people new and meaningful ways of thinking about life with a technologically mediated chronic illness. At the same time, however, Datafied Body Doubles place significant constraints on what constitutes a "good" embodied experience with Diabetes, producing a value system which places actions, physiologies, and

⁴³ Ashley, interview.

⁴⁴ Here I use the term "body image" in the phenomenological sense, referring to what Shaun Gallagher defined as "a perceptual, cognitive, or emotional awareness of the body." They are inflected with individuals' conscious interactions and take-on components of identities. Though these definitions have been philosophically debated extensively, the term as defined here does the work of representing the body processes I aim to highlight in this study. See: Shaun Gallagher, "Body Image and Body Schema: A Conceptual Clarification," *The Journal of Mind and Behavior* 7, no. 4 (1986): 541–54; Frederique de Vignemont, "Body Schema and Body Image—Pros and Cons," *Neuropsychologia*, The Sense of Body, 48, no. 3 (February 1, 2010): 669–80, <https://doi.org/10.1016/j.neuropsychologia.2009.09.022>.

bodies themselves on a good-bad binary with significant social and medical consequences for every person diagnosed with T1D.

Datafied Body Doubles

As I have argued elsewhere,⁴⁵ the network of devices at the center of T1D treatment today perform life-sustaining functions in/on Diabetic bodies, while simultaneously reading, quantifying, and re-visualizing them in number-form. In so doing, these devices produce what I call Datafied Body Doubles (DBDs), or “numerical stand-ins for the body that construct them as both usable and controllable for pump users and their physicians.” These DBDs become vessels through which Diabetic bodies are redefined and experienced by people with T1D. This data-render of the body comes to be understood as “a new technological/medical (and therefore expert) point of reference in [people’s] methods of reading and interpreting their own bodies.” As these body doubles are applied to daily treatment acts, individually at a global scale, they are “materialized back in/on T1D bodies” interweaving a fundamentally new twenty-first century Diabetic body.⁴⁶

The datafication of Diabetes and its treatment is part of a larger logic and program permeating American culture since the mid-2000s. Datafication, according to Minna Ruckenstein and Natasha Dow Schüll, is the “conversion of qualitative aspects of life into quantified data,” and has powerful proponents in various industries.⁴⁷ A fundamentalist movement toward big-data logics operates under the conclusion that gathering data at a massive scale about, well, everything can eventually produce data sets large enough to replace the need for theory and science. As *Wired* magazine editor in chief Chris Anderson argued in 2008, for example, “faced with massive data, this approach to science — hypothesize, model, test — is becoming obsolete.”⁴⁸ In the site of health and Medicine, this shift toward a big-data model comes in many

⁴⁵ Stephen Horrocks, “Materializing Datafied Body Doubles: Insulin Pumps, Blood Glucose Testing, and the Production of Useable Bodies,” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (2019): 1–26.

⁴⁶ Horrocks, 2.

⁴⁷ Minna Ruckenstein and Natasha Dow Schüll, “The Datafication of Health,” *Annual Review of Anthropology* 46, no. 1 (2017): 262, <https://doi.org/10.1146/annurev-anthro-102116-041244>.

⁴⁸ Chris Anderson, “The End of Theory: The Data Deluge Makes the Scientific Method Obsolete,” *Wired*, June 23, 2008, <https://www.wired.com/2008/06/pb-theory/>.

forms and permeates medical research, public health, and (most directly applicable to this study) clinical care between doctors and patients. Some critical data studies scholars have argued that data itself produces and exerts power onto societies and individuals in ways that create, reproduce, and reinforce structural inequalities—processes that are magnified by large-scale data projects.⁴⁹ Nevertheless, people do and must live in a datafied world and find ways to navigate it, use it to connect to others, or even embrace it as a method of self-actualization.⁵⁰ What is more, data and data-related technologies themselves function as actors in this process, and as Annemarie Mol and John Law argue, devices such as BG meters actively train people how to understand their own sensory experience with low blood sugar, a process they call “intro-sensing.”⁵¹ As people are compelled to use insulin pumps and CGMs—by a medical need for insulin injection and the social pressures of using the standard-of-care to do so—these life-sustaining devices produce, gather, and transmit data about their bodies and practices both to be used for their own treatment and to be used for device-makers’ financial benefit, reframing embodied experiences of T1D in the process.

Blood Glucose Meters and T1D Measurement Systems

Each component of the insulin pump treatment network performs a different role in the creation and materialization of DBDs as people engage with them for their daily treatment. In an effort to make the complexities of Diabetes more understandable and manageable, physicians and public health advocates have promoted the use of at-home blood glucose testing (via BG

⁴⁹ Andrew Iliadis and Federica Russo, “Critical Data Studies: An Introduction,” *Big Data & Society* 3, no. 2 (December 1, 2016): 2053951716674238, <https://doi.org/10.1177/2053951716674238>; danah boyd and Kate Crawford, “Critical Questions for Big Data: Provocations for a Cultural, Technological and Scholarly Phenomenon,” *Information, Communication & Society* 15, no. 5 (June 1, 2012): 662–79, <https://doi.org/10.1080/1369118X.2012.678878>; Mark Andrejevic, “Big Data, Big Questions| the Big Data Divide,” *International Journal of Communication* 8 (2014): 1673–1689.

⁵⁰ For more on one cultural practice of datafied self-actualization, see Lupton’s study of the Quantified Self movement, Deborah Lupton, *The Quantified Self: A Sociology of Self-Tracking*, 1 edition (Cambridge, UK: Polity, 2016); For a discussion of social networking through data-gathering smartphone applications, see: Antonio Maturro and Francesca Setiffi, “The Gamification of Risk: How Health Apps Foster Self-Confidence and Why This Is Not Enough,” *Health, Risk & Society* 17, no. 7–8 (February 1, 2016): 477–94, <https://doi.org/10.1080/13698575.2015.1136599>.

⁵¹ Annemarie Mol and John Law, “Embodied Action, Enacted Bodies: The Example of Hypoglycaemia,” *Body & Society* 10, no. 2–3 (June 1, 2004): 48, <https://doi.org/10.1177/1357034X04042932>.

meters using a finger-prick blood sample read by a meter device) to such a degree that in the twenty years following the practice's inception in 1980s nearly every person with Diabetes in the US used a BG meter on a daily basis.⁵² As a result, insulin treatment regimens can account for patients' dynamic glucose levels throughout a given day, and both morbidity and mortality rates for people with Diabetes have dropped considerably since the mid-1900s as a result.⁵³ At the same time, this rapid large-scale shift in daily treatment practices for millions of people created and normalized a system of quantification that conceptualizes Diabetic bodies as numbers.⁵⁴

As Jason recalled earlier in this chapter, the moment when his parents first purchased an at-home BG meter had a significant effect on the materiality of his experience living with Type 1 thereafter. Also implied in his statement, however, is a shift in the way he *understood* that material experience with his own body, and thereby the way he understood his body itself. He talks about the importance of having his "own" meter, a new human-technological relationship that rhetorically redefines both the device and the body as inherently his; specifically, they are his as they exist together. Not only did this event mark the beginning of his constant physical nearness to medical devices, but also his own realization of this new (and future) Diabetic materiality. For Jason, this new technological/embodied futurity was comforting and even empowering, and it remains so as demonstrated through his demeanor and word choice as he discussed it decades later. Though there was (and is) much he did not know or understand about his own physiological changes, having a device at arms-length that could produce something knowable at any time was (and is) reassuring.

Jason is not alone in his psycho-emotional reliance on his devices and the body readings they produce. Christopher, a thirty-six-year-old assistant professor and recent insulin pump user, was so ensconced in his numbers that he only tangentially discussed any other aspect of living with T1D or his devices for the first hour of our conversation. The numbers seemed to tell him what he needed to know, about his body and therefore about his life on a given day, so using them to translate his experience to me in conversation fit with the data-based sense-making

⁵² Amy Tenderich, "Use of Blood Glucose Meters Among People With Type 2 Diabetes: Patient Perspectives," *Diabetes Spectrum* 26, no. 2 (May 1, 2013): 68, <https://doi.org/10.2337/diaspect.26.2.67>.

⁵³ David E. Goldstein et al., "Tests of Glycemia in Diabetes," *Diabetes Care* 27, no. 7 (July 1, 2004): 1763, <https://doi.org/10.2337/diacare.27.7.1761>.

⁵⁴ Horrocks, "Materializing Datafied Body Doubles," 9–12.

paradigm he lives day-to-day. “I was just talking about my management strategies,” he assessed afterward, “which is very pragmatic. It does take a lot of time and attention and so on.” That preoccupation went so far as to push his own theoretical and scholarly training into the background, which surprised even himself. “But then, I’m a Foucauldian scholar, and so I’m trained in subjectivities, and I’m all, ‘Of course! I’ve got all this stuff about subjectivities I should tell you!’”⁵⁵ Without calling direct attention to it, and without citing some scholarly authority, he *did* in fact speak extensively regarding his subjectivity. He, as a T1D subject, lives in a world of numbers and calculations—data produced by/from/about his body that requires his constant attention. Those number systems “get easier” with time and experience, as other informants have noted, but they remain a central factor in Diabetic life day-to-day.

Distilling the complexities of a dynamic chronic condition into number form can have considerable and complicated effects on the general well-being of patient-users. Accessing information about their BG on-demand allows people with Diabetes to treat hypo- and hyper-glycemic episodes quickly, greatly reducing debilitating short-term and long-term effects. As I noted earlier in this section, T1D morbidity rates have fallen and life-expectancy has increased drastically since these practices began. But for Diabetic patients, getting acclimated to new measurement systems can be a daunting task; when numbers represent one’s proximity to imminent health dangers, or when one’s knowledge of those systems directly influences treatment decisions—and therefore immediate health and well-being—the numbers themselves come to carry a physiological weight that can be mentally and emotionally heavy for meter users to carry. As one informant remembered, her fear of unexpected low blood sugars led her to sleep in her mother’s bed for the first several nights after switching to an insulin pump as a teenager.⁵⁶

Similarly, two informants discussed the emotional weight of parenting children with T1D. Immediately following diagnosis, patients (and in this case their parents) are “hit” with a rush of new world-shifting information that is both “overwhelming and scary.”⁵⁷ From education on T1D itself to physiologies and hormones, carbohydrate amounts and ratios to the insulin treatment process, the flood of information post-diagnosis can take a lot out of people who are

⁵⁵ Christopher, interview.

⁵⁶ Amanda, interview.

⁵⁷ Brittany, interview.

already overwhelmed by the physical experience. Patient-users must not only learn BG measurement systems, as well as the medicalized meanings of those metrics (“high” vs. “low” BG, numbers’ associated risks of Diabetic Ketoacidosis or coma, etc.), but they must also learn new methods for quantifying the world around them. “Carb counting” as a cultural practice appears simple on its face, particularly due to its heavy circulation in large-scale dieting programs such as the Atkins Diet and, more recently, the Ketogenic Diet,⁵⁸ but the limits of that simplicity are made uncomfortably clear for new T1D diagnosees. Somehow, among their psycho-emotional exhaustion, patients and the people around them must somehow lay these new ways of knowing onto their already-existing lives and make them work. Sleepless nights pricking fingers and drinking juice, days full of devices and calculations, and constant adjustments to how all of these numbers *feel* remain part of people’s experience long after the novelty of diagnosis fades into everyday life.⁵⁹

These meter-produced numerical representations of the body were and are limited in their scope, however, as each test represents a snapshot of one’s BG levels at a particular moment—a body that *was*. While that information has proved useful and life-extending in its effects, for millions of people and over decades, bodies are dynamic and can only be represented by a static depiction to a limited degree. To begin addressing that limitation, researchers and device manufacturers invested considerable resources to develop and market continuous glucose monitors (CGMs) which take glucose readings every few minutes and re-construct this medicalized, numerical body as a constant stream of snapshots—a body that *is* and *will be*—and in effect frame T1D bodies as datasets to be plugged into treatment algorithms and practices.⁶⁰

⁵⁸ In his first book, published in 1972, Dr. Robert Atkins outlines his diet regimen based on high-protein/low-carbohydrate meals. He released a new edition of the book in the early 1990s, and was a *New York Times* bestseller for approximately five years. Ketogenic dieting, unlike Atkins, was originally developed as a treatment for epilepsy in the 1920s and was all but written out of the field by the 1990s. Revived in the field due in part to a *Dateline* segment detailing its efficacy, Ketogenic dieting has been taken up as a biomedicalized twenty-first century low-carb alternative to corporatized diets such as Atkins. See: Robert C. M. D. Atkins, *Dr. Atkins’ Diet Revolution: The High Calorie Way to Stay Thin Forever* (New York: D. McKay, 1972); James W. Wheless, “History of the Ketogenic Diet,” *Epilepsia* 49 (2008): 3–5.

⁵⁹ Heather, interview.

⁶⁰ Horrocks, “Materializing Datafied Body Doubles,” 12–16.

CGMs: Technological Freedoms with Technological Tethers

BG meter limitations were and are more than technical or conceptual for people who use them every day. A BG meter snapshot only tells users about their bodies at one hyper-specific moment, so even if someone tests their blood five times per day (as the standard recommendation suggests),⁶¹ that is a miniscule view into what happens with T1D people's BG throughout the day. It comes as little surprise, then, that constantly-reading CGMs have been received by many with passionate and unequivocal praise. Upon hearing about a device that could not only track her BG in real time, but predict how it would change in the future, informant Ashley said it "seemed like a miracle"—and one she would seek out no matter the cost. "I would have done anything . . . anything . . . I was so excited to try it." And though she discusses some issues with her devices in a practical sense, they have lived up to the hype.⁶² One informant said these devices were "life-changing,"⁶³ while another claimed they were "the most amazing thing ever."⁶⁴ And though this type of hyperbolic language was common among informants, most gestured toward an intangible and indescribable effect/affect from their CGMs. In the words of Jennifer, a health policy worker living with T1D:

As someone who has dealt with this for a number of decades, these devices . . . they have made . . . I can't even describe the difference that they have made in my life. The ability to manage Type 1, particularly [with] the Dexcom [CGM], but the pump as well . . . Everything I hoped for but I never thought I'd be able to do was because I had access to these things. [. . .] If there is any soapbox that I'm gonna die on, besides everybody having health insurance, every Type 1 should have access to this stuff.⁶⁵

Accessing knowledge about their own physiologies makes the unpredictability of Type 1 easier to live with. The personal toll associated with living in a constant state of both immediate yet uncertain health concern can be exhausting, and likely contributes to the higher-than-average rate

⁶¹ Mayo Clinic Staff, "Blood Sugar Testing: Why, When and How," Mayo Clinic, accessed January 26, 2020, <https://www.mayoclinic.org/diseases-conditions/diabetes/in-depth/blood-sugar/art-20046628>.

⁶² Ashley, interview. Her "miracle" language is cited in the introduction to this chapter.

⁶³ Christopher, interview.

⁶⁴ Amanda, interview.

⁶⁵ Jennifer, interview.

of clinical depression among people with T1D.⁶⁶ It is no surprise, then, that informants refer to a newfound feeling of “freedom” through CGM use—freedom of movement, freedom of psycho-emotional weight, freedom from (most) finger pricks.⁶⁷

As many scholars have argued, freedom rhetoric such as this is rooted not only in nationalist projects, but binary-based social systems more generally. At its base, conceptions of freedom are defined in their opposition to those of unfreedom, often in contradictory and oppressive ways. As David Roediger has argued, freedom discourse is invested in possession—of things, people, and/or of freedom itself—and expanding social structures that support individualist possession is always built on inequality.⁶⁸ Gender, race, class, sexuality, ability, and other social identities function as not only culturally privileging factors, but are institutionalized in ways that construct them as conditions of freedom themselves.⁶⁹ In practice, these narratives are part of a liberal teleological project assuming the inevitability of contemporary rights-based freedom structures, which covers over human decision-making in regard to both freedom and unfreedom in the past and present.⁷⁰ Freedom, like technological and/or medical change, is not inevitable. It is a product of agents’ actions, and as such also carries cultural baggage that plays on people and social interactions in often significant (if unseen) ways.

With patient-users’ newfound technological freedom comes wholly new technological tethers. Not only must the CGM be connected to the body at all times (lest it lose the “C” and with it the novelty of its function), but in order for that stream of BG readings to aid in patient-

⁶⁶ Nicole Gendelman et al., “Prevalence and Correlates of Depression in Individuals With and Without Type 1 Diabetes,” *Diabetes Care* 32, no. 4 (April 1, 2009): 575–79, <https://doi.org/10.2337/dc08-1835>.

⁶⁷ Heather, interview.

⁶⁸ David R. Roediger, *The Wages of Whiteness: Race and the Making of the American Working Class*, Revised Edition (Verso, 1999).

⁶⁹ On freedom, race, and gender see: Jennifer L. Morgan, *Laboring Women: Reproduction and Gender in New World Slavery* (Philadelphia: University of Pennsylvania Press, 2004); On freedom, citizenship, and sexuality see: Margot Canaday, *The Straight State: Sexuality and Citizenship in Twentieth-Century America* (Princeton, N.J.: Princeton University Press, 2011); On disability, freedom, and publics see: Schweik, *The Ugly Laws*.

⁷⁰ Histories of freedom and enslavement, and historical projects in a more general sense, have long been associated with and/or directed by nation states. As such, that framing as the standard has long gone unquestioned, and has been used to directly and indirectly misrepresent violences enacted in the name of the state and even freedom. See: Peter Linebaugh and Marcus Rediker, *The Many-Headed Hydra: Sailors, Slaves, Commoners, and the Hidden History of the Revolutionary Atlantic*, Reprint edition (Boston: Beacon Press, 2013).

users' well-being it requires their attention and a connection to their other devices. CGMs take glucose readings and transmit them so that users can see the numbers and get a sense of where they are, so to speak. Thus, the act of checking the CGM has become a major part of T1D life. Jennifer, for example, cannot overstate the usefulness of her CGM, and has become so enamored with/reliant on it that checking her numbers has become habitual. The first thing she does every morning is check her Dexcom, one of the three FDA approved CGM devices at the time of this writing. Because it takes readings from interstitial fluid rather than from blood, the CGM requires calibration via a finger prick BG test about twice a day,⁷¹ and Jennifer is on it before she rolls out of bed. Laughing, she admits to being "a slightly compulsive Dexcom checker," peeking at her numbers about every half-hour throughout the day. Because the Dexcom can send data to her iPhone, and formerly her smart watch, she checks her BG nearly every time she looks at her phone.⁷² On the one hand, that constant awareness has made it easier to "correct" for slight highs and lows, leading to more consistent BGs overall. On the other hand, that ease and convenience can lead to an obsession with "normal" glucose levels and its associated potential anxieties.

Most novel, perhaps, is the CGM's ability to produce trends and trajectories based on past BG readings, providing patient-users predictions about where their numbers are going. Complete with handy up- and down-arrows for clarity (or even double-up- and double-down arrows for rapid changes), these predictions help reduce the anxieties associated with the ambiguities of BG numbers' *meanings*. Brittany, a parent/caregiver of a T1D child, put it this way:

Thinking about it, before we had the CGM we'd check her blood and she was at 100. Which is a great number, but is she going up? Is she going down? When does the food kick in? When does the insulin kick in? With the CGM we get to see all of that. It really helps us manage, and it gives her independence. It helps her manage on her own, because she can look at that and get an idea of what she needs to do, or how her body is responding to exercise, or certain foods.⁷³

⁷¹ Medtronic Diabetes, "Getting Started with Continuous Glucose Monitoring for the MiniMed 530G with Enlite" (Medtronic Minimed, Inc., 2013).

⁷² Jennifer, interview.

⁷³ Brittany, interview.

What, then, does a static BG reading mean for such a dynamic physiological process? Or perhaps more to the point, what does that static reading mean for people as they treat or manage life with that dynamic chronic condition through their new technologically-provided “independence”? The independence Brittany gestures toward here builds on the freedom narratives constructed by others above, highlighting the centrality of individualism to the larger freedom project. As detailed by legal historian Amy Dru Stanley, liberal conceptions of individualism move the onus of freedom-making away from societies and institutions and toward individual people, rhetorically linking one’s freedom to their own actions. By connection, however, individualism narratively links unfreedom to individuals’ decision-making and practices as well, and in so doing the responsibility for/to that unfreedom lies with them and not institutions or larger social factors.⁷⁴ When that individualism uncritically frames technologies as the providers of that freedom, as in the case of CGMs here, the narrative is teleologically constructed around devices as the primary determining factors in the inevitable expansion of freedom—an able-bodied freedom, in the case of Diabetes treatment.⁷⁵

Within this context, the CGM has completely reframed what individual BG readings can and do represent in relation to Brittany’s child’s body. Though it may be a “great number” by itself, it is not great *enough* unless it is understood in relation to other numbers over time. The numbers themselves, though still charged with “good” and “bad” cultural values individually, have become newly temporal and re-visualized as points on a timeline. Perhaps most importantly here, that timeline always includes predictions based on the up and down movements of past readings—predictions that produce a new sense of Diabetic futurity. This T1D future-building

⁷⁴ Stanley identifies contract as a central site where individualist conceptions of freedom were constructed in debates surrounding freedom and enslavement, wage labor (and non-wage sex work), and marriage. See: Amy Dru Stanley, *From Bondage to Contract: Wage Labor, Marriage, and the Market in the Age of Slave Emancipation* (Cambridge ; New York, NY, USA: Cambridge University Press, 1998).

⁷⁵ In the widely cited introduction to his co-edited collection on technological determinism, Merritt Roe Smith identifies the long-established cultural assumption that technology plays a larger role in societal change than any other factor. Langdon Winner and others have interrogated the merits of technological determinist models of analysis, likewise calling into question sole-reliance on social determinist models. As Alison Kafer has argued, however, both technological and social determinist models have historically been used to justify the supremacy of dominant groups and identities, operating from an assumption that able-bodiedness is normal and universally sought-after, and has been deployed to control divergences. See: Merritt Roe Smith, “Technological Determinism in American Culture,” in *Does Technology Drive History?: The Dilemma of Technological Determinism*, ed. Leo Marx and Merritt Roe Smith (MIT Press, 1994); Langdon Winner, “Do Artifacts Have Politics?,” *Daedalus* 109, no. 1 (January 1, 1980): 121–36; Kafer, *Feminist, Queer, Crip*.

can be deeply comforting, as CGM data can be used to alert users of possible high or low BG before they go too far. That same T1D futurity, on the other hand, is rooted in problematic conceptions of medicalized bodily control, and the independence it is meant to provide requires a new (and/or expanded) dependence on numbers.

That dependence carries serious weight, since though CGMs produce numbers that look like those from BG meters, they actually measure very different things. Rather than constantly pulling directly from a blood source (a process which has been shown to be difficult and full of adverse effects over decades of research),⁷⁶ CGMs take readings of glucose levels in interstitial fluid. This fluid surrounds cells in the body, and contains nutrients diffused from capillaries as well as waste discharged from cells. A small sensor wire is inserted beneath the skin of the abdomen (usually) to track glucose levels in the interstitial fluid there and run them through algorithms to estimate what the user's BG would likely be at that moment. Because they measure glucose diffused from the blood stream, CGM readings of interstitial fluid lag about a half-hour behind BG levels in the blood.⁷⁷ That means the numbers displayed on users' CGM devices are always, in every case, algorithmic *estimates* and not actual real-time readings.

For everyday users, however, glucose numbers are understood as BG numbers regardless of which device they come from. And in most cases, the formulas programed into the devices are so effective in their estimates that there is very little discrepancy between CGM and meter readings. As thirty-two-year-old Matthew recalled, he had serious reservations about the CGM's glucose delay of which he had only vaguely been informed. "The CGM—it's like what you *were* at. I don't even know how delayed it is, I just know that it's not perfectly up-to-date." Following his six-day trial with the device, however, he was surprised by the estimates' accuracy. "When it was uploading all of the information [from the CGM], the nurse and I went through all of my logs for all of that time, [. . .] and then sort of plotted those along the graph. They were pretty bang on."⁷⁸ Despite the congruence of his meter and CGM readings during the trial, the CGM's process of estimation was too worrisome for Matthew and he opted to stop using the device altogether. Inaccuracies do in fact happen for users on a fairly regular basis, but whether the

⁷⁶ See my discussion of closed-loop artificial pancreas trials in Chapter 2.

⁷⁷ Medtronic Diabetes, "Getting Started," 3.

⁷⁸ Matthew, interview.

numbers showing on the CGM screen match a finger prick test or not, the information users are most often seeing about their bodies are not actually measurements of blood glucose at all. Manufacturers know this (and are quick to advise users, in bold all-caps, not to base treatment decisions on CGM readings), doctors and patient-users know this (to some degree), but the medical and personal value inscribed upon the trends and trajectories make any of those possible concerns worth the risk.

Of perhaps greater concern in the big-picture, though lesser concern for most individuals interviewed here, are the data produced by, for, and through the use of these devices. Only a small number of informants expressed any concern regarding how the data was produced by their meters and CGMs, where and how they are collected and stored, and for what purpose/by whom they are used. For most informants, the data exist so the doctor can see their BG trends over the long-term and adjust their various treatment plans. For insulin pump users, all the data collected by their meter or CGM are stored on the pump's hard drive; for CGM users without an insulin pump, the data are stored on the CGM's control device. They either upload all that data through an online portal or take it to the clinic and have the staff do it for them.

For most, informing their doctor is the extent of their interaction with their data once it is collected—sets that actually hold a lot of important personal health information. “What I really want is to see what I download every two weeks is available to me,” says partner of a T1D spouse (and in-practice caregiver) Mary, “but mostly I don’t pull it up and look at it. I just send it on and let them analyze it.”⁷⁹ This sentiment is understandable; part of the novelty of these devices is that use allows people the technologically-mediated privilege of giving their chronic illness less attention, lightening the burden of constant awareness and interaction required of T1D. Less focus on Diabetes means more opportunity for focus elsewhere, hence the freedom rhetoric used by some earlier in this chapter. Unfortunately, uploading glucose and insulin pump data is not without its barriers. Most upload systems have hyper-specific operating system, browser, and plug-in requirements that bar many from uploading at home. As Christopher laments, “It’s a pain to upload them, because you’ve gotta—I’ve gotta take my pump off and suspend it, and then it’s a little funny Bluetooth connection that takes forever. I can only do it on my wife’s PC laptop . . . it’s a horrible laptop. . .” Once he is finally logged in and uploading, it

⁷⁹ James and Mary, interview.

can be quite useful. The site sends his data directly to his clinic, where doctors and nurses can access it at any time to adjust treatment plans. Even then, Christopher notes, the system leaves something to be desired. “But the quality of the data—the visualization of the data—is just really poor.”⁸⁰

More to the point, and more related to the importance of the data to *him*, “I can’t really access this, and it is a real frustration to me; how much data I produce, but how hard it is to actually access that data in a meaningful way. I have to shut my pump down in order to actually access data from the pump, and that seems ridiculous.”⁸¹ Not only is the upload process cumbersome, requiring people to disconnect their devices and halt injection to do so, it is the only means of accessing the data beyond the small graph displayed on the insulin pump. What Christopher did not note, however, is that this process effectively locks patient-users’ data—their own personal health information—behind a proprietary software wall. Device makers’ software, and theirs alone, can pull the data, store it, and visualize it. And if that was not enough, the software use agreements require individuals to allow device companies access to the data in order to see it at all. The “asymmetric relations” between manufacturers collecting the data and individuals whose data they target is clear—patient-users’ agency in relation to their own data is restricted by corporations.⁸² If T1D informants’ primary (or even only) data-related concern is access, or at least the feeling of having access, then this big-data-hording project on the part of device manufacturers becomes particularly egregious.

Insulin Pumps and Freedom through Control

Despite the significant cultural and medical weight both BG meters and CGMs carry in framing the experience of living a device-connected T1D life, those devices and their technological/medical purposes are means to an end and not an end unto themselves. Making Diabetic bodies readable and measurable makes the pharmaceutical intervention at the center of T1D treatment possible and/or more effective. Without insulin injection, even the most

⁸⁰ Christopher, interview.

⁸¹ Christopher.

⁸² Andrejevic, “Big Data, Big Questions| the Big Data Divide,” 1673.

thoroughly datafied T1D body could not survive. Thus, as the site where life-sustaining injections are facilitated, the insulin pump remains the centerpiece of Diabetes treatment writ-large. Because this happens as part of the networked production of Datafied Body Doubles, however, the insulin pump necessarily becomes the hub where patient-users interface with data collection and visualization, dosage calculation formulas, insulin injection, and—as DBDs are integrated into intervention practices—even their own bodies. These DBDs are gathered at the “hub” and materialized back onto/into T1D bodies, the very bodies they are created to represent, networked insulin injection. Through this process, the insulin pump functions as a “catalyst for biomedicalized control of T1D bodies on and through their own Doubles.”⁸³

Though it happens to a notably lesser extent, informants still often talk about their insulin pumps in the same overwhelmingly positive terms they use for their CGMs. Switching from a regime of multiple daily injections, measured into a syringe straight from the vial and needle-injected every time one eats or needs a so-called correction dose, to an insulin pump re-inserted just once every three days frees up time and attention in ways that can feel quite liberating. Though tubes and devices are always connected to the body—an issue with serious consequences at times, as I detailed above—the ability to quickly press a few buttons, put the device back in a pocket, and let it inject needed insulin by itself disentangles patient-users from the constant presence of their chronic illness.

Combined, these brief moments of respite afforded by networked medical devices give people with T1D not only a sense of biomedicalized freedom, but a sense of *control*; control of their chronic illness, control of their own bodies, and even control of the world around them. That is what drives many to seek out insulin pump treatment in the first place. “I just learned that it would keep you in better control,” remembered James. “We investigated right away about it and got me on the insulin pump.”⁸⁴ For James and his partner Mary, it was as simple as that. “Better control” here, of course, refers to BG levels as the part of “you” in need of control. It also gestures toward individuals’ actions involved in BG fluctuations in T1D bodies. As one informant remembers, it was the moment when her doctor told her “You could eat a chocolate chip and take insulin for just that chocolate chip without a shot,” that she knew she wanted to

⁸³ Horrocks, “Materializing Datafied Body Doubles,” 17.

⁸⁴ James and Mary, interview.

switch to insulin pump treatment. “I was like, ‘SOLD!’”⁸⁵ Eating practices and their associated injection acts, then, also fall within the category of things requiring “better” control. This new advent of micro-dosing through insulin pump injection, or making “micro-corrections” as some informants refer to them, allows for even smaller margins for maintenance of BG than before. By micro-managing food and insulin intake throughout each day, while comparing BG readings and trends from the CGM, patient-users such as Jennifer can keep “tight control” of their numbers within the “normal” range for people without T1D.⁸⁶

This need for control rhetorically implies that the BG (and bodies) of people with T1D are themselves *out* of control. Cultural norms structured around compulsory able-bodiedness require people and bodies that exist outside those bounds to be corrected—a process that defines non-normative embodied experiences as undesirable (or even, as Alison Kafer argues, not worth living at all) and enacts violence on Othered bodies in the interest of maintaining the bounds of normalcy themselves.⁸⁷ And while certainly medically useful, control rhetoric can be culturally problematic when applied to people and their bodies. What happens when someone does everything they are advised to do yet still does not attain the control they’ve sought out/been promised through their new device? As Ashley noted regarding her switch to the pump, “My control didn’t get drastically better like I think happens with a lot of people when they go on the pump. It *slowly* got better, and it’s still just *slowly* getting better.”⁸⁸ Ashley had a sense of what she thought should happen to/with her body when she started the new treatment regime, but that newfound control did not come, at least in the form or timetable she had wanted. Taking that notion a step further, Amanda says about her decision to go on the pump, “I don’t know, just, I felt like my life was gonna be more controlled.”⁸⁹ Not just her BG, not just her body or health practices; Amanda switched to an insulin pump because she thought it would give her *life* a

⁸⁵ Jessica, interview.

⁸⁶ Jennifer, interview.

⁸⁷ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: NYU Press, 2006), 2; Kafer, *Feminist, Queer, Crip*, 2.

⁸⁸ Ashley, interview.

⁸⁹ Amanda, interview.

greater sense of control. T1D can often be an all-consuming chronic illness to live with, and controlling it would mean—at least for Amanda—controlling her life itself.

If this last example seems to give a sense of urgency and gravity to the complications associated with redefining and treating Diabetes, it is because the culture and practice of networked insulin pump treatment often means everything to the people who use it to live. Living with a chronic illness such as Diabetes is defined, medically and culturally, by factors primarily and/or entirely outside the control of patients or doctors. The “freedom” informants discuss above is, at its base, a reference to patient-users feeling any increased distance between their day-to-day lives and Diabetes. T1D is framed as something to be wrangled—a wild part of one’s self needing to be controlled—in order to get back to the way things were before their chronic illness.

Why, then, must Diabetes be controlled? Why is control the operative conceptual framing around which all Diabetes treatment is built? What cultural forces are at play as individuals participate in the creation and maintenance of a regime of control? A glimpse into what being controlled feels like, as someone navigating these biomedicalized narratives and practices while trying to live with T1D, may provide some useful insights:

Sometimes I honestly feel like I’m a bad Diabetic. I guess I just feel like that because sometimes I think, ‘If I want to eat this, then I’m gonna eat it, and I’m gonna give myself the insulin for it. [. . .] And I’m sure a lot of Diabetics have times when they feel like that, where they’re like, ‘I’m gonna eat this if I wanna eat this.’⁹⁰

Amanda, a registered nurse and long-time insulin pump user, highlights here a common thread woven throughout most of the interviews conducted for this study. The value-laden “good Diabetic” vs “bad Diabetic” dichotomy Amanda references permeates cultures of Diabetes in the US and produces a highly problematic vertical social structure among T1D patients. Fully participating in Diabetic control regimes and displaying the desirable bodily outcomes rhetorically associated with them produces a “good Diabetic.” Displaying any breakdown in either one’s participation in those regimes or the bodily outcomes tied to them produces a “bad Diabetic.” Good Diabetics are in control, bad Diabetics are out of control. Even as they participate in the maintenance of that binary, informants discuss the structural limitations that

⁹⁰ Amanda.

complicate the binary in their own experience. As Michael notes about his post-diagnosis, twenty-one-year-old self, “I can tell you I was really not a very good diabetic at that point in my life. [. . .] I was the type of guy who would go for 2 extra-large Slurpees a day.” Once again, as with Amanda’s invocation of the binary, the “good” and “bad” here is defined by an individual’s eating practices. As Alice Julier has argued, however, eating practices are themselves socially and culturally stratified based on other markers of inequality such as class, race, gender, geography, and ability, and cannot be so simply boiled down to liberal conceptions of choice.⁹¹ Michael acknowledges this in his statements immediately following his indictment of his younger self: “But it was actually really hard,” spending several weeks trying to get in to see an endocrinologist and receive general treatment guidance, “and the [E.R.] doctors weren’t super helpful when they first diagnosed me. They would just say, like, ‘Well you know what to eat.’ And I was just like, ‘I actually don’t. I have no idea about this,’ and I didn’t have any friends who were Diabetic. So it was definitely a big learning curve.”⁹² In the act of labeling his past self “bad” for not following the control regime, present-day Michael recalled the breakdown between the medical expectation of his knowledge and his actual knowledge. He was not a “bad” Diabetic, he was just newly diagnosed. The flood of new knowledge paradigms that comes with a T1D diagnosis takes years of experience and practice to get a firm understanding of, yet new diagnosees are still pejoratively labeled when they do not comply with them.

The freedom these informants have been promised through their devices, and have in some cases sought out with vigor, is actually a freedom from their own bodies and lives deemed unlivable. To call back to Michael’s statement in the epigraph to this chapter, despite the treatment regime requiring control over one’s body and one’s self, “you don’t control Diabetes, you manage it. There is no controlling it.” Yet people with T1D are stuck in a medicalized system both compulsory and unrealistic, both life-sustaining and body-controlling. The tension built into that type of liminal experience can be a lot to handle, especially when added to the experience of living with chronic illness in general. In response, some people use that tense in-between space to push back against the defining and confining that networked insulin pump treatment can produce.

⁹¹ Alice P. Julier, *Eating Together: Food, Friendship and Inequality* (University of Illinois Press, 2013), 4.

⁹² Michael, interview.

Patient-Users Materializing New Type 1 Bodies

As many of the examples above demonstrate, people with Type 1 Diabetes who use insulin pumps and CGMs are not passive in their interaction with their devices nor with the culturally defining processes surrounding T1D. Indeed, at times patient-users engage with their devices and their chronic illness in creative ways that challenge the biomedicalized body images at the center of this chapter. By embracing T1D and a new, often jarring device-connected life, patient-users materialize their own conceptualizations of what a Type 1 body is and can be. Use can be a transformative act—not only within the established cultural and technological parameters of T1D, but by pushing at those boundaries and setting new ones themselves.

By making an otherwise invisible chronic illness visible on the body, connected devices signify the users' biomedicalized status to those around them (even when others are not familiar with their particular purpose). This technologically-produced visibility can be socially uncomfortable and even dangerous, but some patient-users have opted to magnify that visibility in order to reclaim at least some of the power they otherwise feel being pulled from them. One informant added some color to that visibility and paid for a scrawling forearm-sized "Type-1 Diabetic" tattoo. "I should have a medic alert bracelet," Matthew says, "but I hate them, so I got this big tattoo that I can't hide or forget." In some ways, then, the tattoo is practical and fills the role otherwise filled by a medical alert bracelet. "If I get in a car crash or something, they're gonna pull up my sleeve to check my pulse and say, 'Hey, he's probably Diabetic!'" (a hypothetical example that actually occurred for another informant⁹³). In a deeper sense, however, this permanent and hyper-visible graphic on his arm is a practice in self-acceptance and public-making. As he offhandedly relates in his statement, he cannot hide or forget the ink so frequently in his line-of-sight. Even if or when he wants to forget it, T1D is a significant part of his body, his life, and his self. "It's part of who I am," he reflects, so if others see the tattoo they'll know as well. And even when others miss the mark with their genuine (yet misplaced) regard for him, he wants T1D to be visible. "The day after I got this, one of my coworkers was like, 'But they're gonna cure Diabetes next month! They're curing it with, like, wheatgrass!'" He joked with them,

⁹³ Joshua, interview.

but in retrospect decided, “if they manage to cure it, I’ll get a big rubber ‘VOID’ stamp tattoo over top of it.”⁹⁴

Where Matthew opted for an increased visibility of Diabetes on his terms, others push the boundaries of what Diabetic bodies look like and/or can do via athletics. Michael, a forty-one-year-old tradesman, was so affected by some of his co-workers’ taunts and dismissals of him due to his Diabetes that he decided to begin weightlifting in order to better posture himself toward them—an endeavor he claims is aided by his insulin:

I also understand that insulin is one of the most anabolic hormones in the body. Knowing what I know about insulin, I am a weightlifter. I lift my weights, within two hours I eat, and then I take insulin. So I put on a serious amount of muscle, and people were asking me if I was on steroids, and I’m not. It’s the insulin. So if you know how to use the insulin to your advantage, use it. So I do. And within probably a year, I put on maybe thirty pounds of muscle, and it changed my look dramatically.⁹⁵

Michael’s assessment of insulin’s anabolic role in the body is not off-base, as insulin has been used as a performance-enhancing stimulant by bodybuilders.⁹⁶ What is interesting about this case, aside from the problematic hyper-masculine posturing surrounding Michael’s choice to lift, is the way in which he deploys an agent of medicalized survival for his own benefit (in this case, in building his body and his conception of his masculine self). Whereas Michael’s mix of diabetes and athletic participation centers on maneuvering male dominance in a workplace, Christopher’s centers on maneuvering his glucose levels. A recent PhD himself, Christopher was diagnosed with Type 1 Diabetes at roughly the same time his child was born and he began working in his first Assistant Professor position. While at an academic conference, his BG spiked for the first time and he turned to physical activity to deal with it. “I ended up doing things like going and finding stairwells and climbing up and down stairwells. I’d go for walks through the park next door to the conference venue. I’d go and try to exercise my way back to good blood glucose, because I’d never really needed to correct outside of meal times.”⁹⁷ Though much of

⁹⁴ Matthew, interview.

⁹⁵ Michael, interview.

⁹⁶ Josiah D. Rich et al., “Insulin Use by Bodybuilders,” *JAMA* 279, no. 20 (May 27, 1998): 1613–1613, <https://doi.org/10-1001/pubs.JAMA-ISSN-0098-7484-279-20-jbk0527>.

⁹⁷ Christopher, interview.

this experience was born out of his inexperience with Diabetes treatment, Christopher essentially turned to physical activity to perform the function otherwise designated for insulin injection. He later learned, of course, that exercise cannot always bring BG back down and that correcting with insulin is important and often necessary, but the lesson he learned at his conference remains present every day. He found an alternate treatment route, unsustainable as it may be, that at the very least opened to him the feeling of agency within the sphere of his own physiology and medical treatment beyond what he had felt until that point.

These examples begin to expand and complicate the conversation about what liberation for people with T1D looks like, feels like, and can be. This chapter began by highlighting informants' "freedom" rhetoric in relation to their insulin pumps and CGMs, and while I explore/challenge those ideas at points throughout the pages above, it is worth posing a concluding question: From what do people with T1D desire freedom? Throughout most of this chapter, and directly by informants' own language and focus, there is a sense that what is desired is freedom from their medical/physiological condition. And while this is undoubtedly true—Diabetes is just plain hard—the primary concerns informants respond to in this conclusion are social ones. From compulsory able-bodiedness and normalcy, to toxic cultures of masculinity, to the more general idea of control, many of the day to day concerns people with T1D face as they use their devices are not specifically about their physical bodies. Material and conceptual bodies always also exist as social ones, and these examples require us to rethink definitions of bodies/the body as well as the technologies and use acts entangled in these practices if we are to account for the complexities of *choice* and materiality in T1D studies in the future.

CHAPTER 4: “PUMPS AND SEXY TIME”: ONLINE DIABETES COMMUNITIES AND TECHNO-INTIMATE RELATIONSHIPS

*It's definitely weird, I mean [. . .] Here I am with a hard on and nothing to clip my pump to because I'm buck naked. You know? I mean, what do you do?*¹

*I got my pump and CGM when I was with my current spouse, but I definitely think it does make me more self-conscious [during sex]. [. . .] I mean, my partner will say she doesn't care, I have mentioned it to her before, and she's like "I don't care, it doesn't bother me." But for me, I think it does bother me a little bit. Not a whole lot, but it's kind of always there in the back of my mind.*²

Locating Techno-Intimacies Online

The statements in the epigraph above frame sexual practice and the intimate closeness of bodies as particularly significant social issues related to the use of treatment devices such as insulin pumps and continuous glucose monitors (CGMs). On the one hand, in the first quote above, the materiality of Joshua's insulin pump as an ever-present and constantly connected treatment object is made especially obvious to him in the moments during and surrounding sex with a partner. On the other hand, in the second quote, though both Jennifer and her partner tend to downplay its significance, Jennifer's treatment devices are always lingering “in the back of [their] mind[s]” in the context of sex and intimate interactions, commanding attention in ways that make Jennifer feel somewhat insecure and/or uncomfortable, both because of and in spite of the devices' physical presence. The situatedness of devices and bodies unique to insulin pump treatment produces a rich site of complex meaning-making, especially when other(s') bodies enter the equation.

What makes these statements all the more intriguing, however, is their novelty in the context of in-person and telephone interviews. Of the fifteen participants in this study, Jennifer and Joshua were the only two informants willing to discuss insulin pumps' effects on their intimate and/or sexual relationships in any real depth. All other informants vaguely acknowledged whether their devices influenced these interactions and, most often, then pivoted

¹ Joshua, interview by Stephen Horrocks, male age 39, diagnosed with T1D in 2008, May 23, 2017.

² Jennifer, interview by Stephen Horrocks, female age 35, diagnosed with T1D in 1985, May 22, 2017.

toward subject matter with which they were more comfortable. It was clear that for most of them, an interview with me (which, regardless of my attempts to create and maintain a comfortable tone during our conversations, is still framed in part by the power dynamics of a researcher-informant interaction) was not a safe enough space to discuss their personal sexual practices. Their reservations are understandable, as I would likely have some of my own in a similar position. Though these conversations did not usually open up during interviews, however, they were opening up in some surprisingly productive ways online.

In what follows, I analyze a collection of online forum discussions among insulin pump users with Type 1 Diabetes to explore the impact (figuratively, and perhaps literally) of insulin pump use on users' social practices of sex and intimacy. Using a queer studies framework informed by Robert McRuer's work on disability, sexuality, and systems of "compulsory able-bodiedness,"³ paired with Adele Clarke, et al.'s theory of the Biomedicalization of American culture and medical practice,⁴ I will attempt to answer: How do insulin pump users produce/consume new media content to manage their health and sexual practices and identities? How do the practices of insulin pump use change in the context of sex and the intimate closeness of bodies? And how does sexual practice itself change as a result of pump use?

In lieu of other comfortable offline spaces, I argue, insulin pump users turn to online Diabetes communities to work through the fears and anxieties associated with what I call techno-intimate relationships. As medical devices become integrated with users' bodies, they alter the ways those bodies contact and interact with other bodies, forcing both users and their partners to adjust their sexual and intimate practices to accommodate a new technological interloper. In these moments of shifting relationships, users turn to the Diabetes community to mine those networks for new techno-intimate practices. As these forum discussions open up, however, the spaces that facilitate exploration of new technology-altered sexualities also serve a deeply normalizing function, policing cultural standards of able-bodied and heterosexual normalcy.

This intersection of disease, medical devices, sex, and new media demonstrated within sex-and-insulin-pump forums is one space where compulsory able-bodiedness is expressed,

³ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: NYU Press, 2006), 2.

⁴ Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2009), 2.

produced, and at times challenged by people with Type 1 Diabetes. As a culturally defined set of social practices between people and bodies, sex and its many forms, practices, and ways of knowing can offer a unique yet wide lens to view how the acts and processes associated with the use of medical devices—as well as those associated with sex itself—both construct and rely on sociocultural grammars of normalcy.

Biomedicalization and Compulsory Able-Bodiedness

Building off of previous research conducted by historians Roy Porter and Paul Starr, Adele Clarke, et al. attempt to identify what has happened to healing practices and the field of Medicine since the 1980s in their book *Biomedicalization: Technoscience, Health, and Illness in the U.S.* From the mid-eighteenth to the mid-twentieth century, identified by Starr as the period of “Medicalization,” health practices were centralized and corporatized in ways that placed a primary focus on *controlling* disease.⁵ Since the mid-1980s, Clarke et al. argue, “technoscientific” changes to medical practice and organization have coalesced into “*biomedicalization*”—the second major shift in American medicine focused more on *transforming* disease and the body than just controlling it.⁶ This shift has brought with it several changes that pose potential problems along with so-called “advancements.” One major focus has been an increased focus on the use of technologies for treatments for disease and health generally, stemming in part from what the authors call the “technoscientization of biomedical practices”—i.e. practice framed in terms of science and technology, not necessarily treatment. Under this new paradigm, patients are required to be more knowledgeable about their own health and illness, fundamentally altering the cultural relationship between patients and doctors, and by connection, responsibility for treatment and health has shifted in new and complicated ways.

But if diseases are able to be “controlled,” what purpose is served by transforming diseases and the body beyond that point? Robert McRuer, a disability and Queer studies scholar, identifies the cultural systems of power that may influence some of those decisions. In his

⁵ Paul Starr, *The Social Transformation Of American Medicine: The Rise Of A Sovereign Profession And The Making Of A Vast Industry* (Basic Books, 2008); Roy Porter, *The Greatest Benefit to Mankind: A Medical History of Humanity (The Norton History of Science)* (W. W. Norton & Company, 1999).

⁶ Clarke et al., *Biomedicalization*, 1–2; David Serlin, *Replaceable You: Engineering the Body in Postwar America* (University of Chicago Press, 2004). Emphasis original.

influential book titled *Crip Theory*, McRuer develops the concept of “compulsory able-bodiedness,” as a framework for understanding how disability and non-normative health and body identities are constructed through the cultural normalization of an unmarked, invisible, able-bodied non-identity. McRuer builds off of the foundational work of two scholars, Adrienne Rich’s “Compulsory Heteronormativity and Lesbian Existence,” which traces the ways sexual identities are defined around “normal” relationships that create compulsory conditions through a constructed “abnormal” status, and Lennard Davis’s *Enforcing Normalcy: Disability, Deafness, and the Body*, which identifies the historically constructed concept of “normalcy” and the “normal body” rooted in cultural systems of power.⁷ McRuer points out that cultural normalcy has the same compulsory effect in relation to able-bodiedness as it does to heterosexuality.⁸ These norms are created as such through “repetitive performances,” a concept McRuer molds from Judith Butler’s concept of performativity through cultural reiteration and citation.⁹

As health norms have been constructed and reiterated over time in the U.S., diabetes—and especially Type 1—has been situated outside the bounds of able-bodied definitions of “normal.” As medical treatments were developed to control the disease during the early twentieth century, the invisibility of the disease allowed those who suffered from it to pass as able-bodied.¹⁰ But as the technoscientization of American medical culture rapidly expanded from the 1980s onward, new research focused on treatment methods that could more fully normalize people with Diabetes—or at least make them tolerable enough to be palatable to systemic conceptions of embodied normalcy.

Enter: the insulin pump. As a technology of medicalized control, the device allows people with Diabetes to carry several days-worth of life-sustaining insulin on their person (and on their body), to be injected at will any time they eat. The use of this device makes immediate responses to dangerously high blood glucose levels much quicker and easier, which in turn could

⁷ Adrienne Rich, “Compulsory Heterosexuality and Lesbian Existence,” *Signs* 5, no. 4 (1980): 631–60; Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body*, First Edition (London ; New York: Verso, 1995), xii, 2.

⁸ McRuer, *Crip Theory*, 1, 2, 7.

⁹ Judith Butler, *Bodies That Matter: On the Discursive Limits of Sex* (New York, NY: Routledge, 1993), 2.

¹⁰ For an example of how medical devices and treatments can be used as vessels for passing, see Sharra Louise Vostral, *Under Wraps: A History of Menstrual Hygiene Technology* (Lexington Books, 2008).

mean stabilization for blood glucose levels overall. Most importantly in relation to compulsory able-bodiedness, however, is that fact that insulin pumps remove the need for multiple daily injections via vials and syringes. Rather than repeatedly sticking these medicalized devices such as needles into arms and tummies, pump users engage with a “cool gadget” and a uniquely techy interface. Through the use of these new technologies, the old markers of medicalized difference are no longer visible, and bodies and identities are transformed to fit able-bodied norms in an inherently biomedicalized fashion.

But as the examples below will show, that transformation is not so simple. Producing embodied normalcy through technological means is messier than it may seem. While insulin pumps transform bodies to hide the visibility of certain “abnormalities,” others remain visible—and in some cases, the very use of that technology itself signals non-normativity in new and unexpected ways.

A Brief Note on Methods and Digital Ethics

In this chapter I explicate and analyze a collection of forum discussion threads from two major Diabetes community websites to trace how these complicated relationships play out for people in practice. I have selected the American Diabetes Association and Diabetes Daily primarily because they are relatively high-profile organizations compared to some other Diabetes community sites on the web, which would likely facilitate more overall traffic from people recently diagnosed with T1D who may not have not explored the breadth of community forums available.¹¹ Discussion threads were chosen based on the content of their titles and/or initial posts, which all in some way deal with the implications of insulin pump use for sexual interactions and practices. In all, a total of eleven discussion threads dealt specifically with insulin pump use and sex within these two online communities, all of which are analyzed to some degree below.

¹¹ Diabetes-related Reddit communities such as r/diabetes, r/diabetes_t1, and r/T1D often serve similar discussion- and inquiry-centered purposes as the ADA and DD, but do not have the same relationships to Diabetes-specific institutions as the two communities under consideration here. They remain potentially rich sites for uncovering related conversations among pump users, though they happen to fall outside the scope of this particular chapter.

For the purposes of this chapter, the usernames and thread titles are included directly as they appeared in the forums. While the terms and conditions of both websites make clear statements defining users' submitted posts and usernames as publicly available information, the health and sexual nature of the content divulged in these settings requires extra care to protect the identities and well-being of these users. One of the difficulties here, however, is that much of the power and meaning-making associated with these discussions comes from users' words themselves, and any use or reference to content from the web such as this is potentially searchable. Changing or omitting users' words in an attempt to protect that information would remove both the original posters' intended meanings/purposes for their comments, and would require my summary and/or paraphrasing to such an extent that shifts the linguistic agency from users themselves to me as researcher-interpreter in ways with which I am not ethically comfortable. Thus, usernames and submitted content appears unchanged throughout this chapter.

Killing the Mood? Sex and Insulin Pump Connectedness

In July 2015, a user known by the pseudonym chrissy17 initiated a forum discussion on the Diabetes Daily community website titled "Pumps and Sexy Time." As someone who was only recently diagnosed with Type 1 Diabetes, chrissy17 is beginning to work through how the disease, as well as the technological network involved in its treatment and management, may affect her interactions with other people—specifically sexual interactions:

I'm 25, single, and recently DX [diagnosed] t1d. I was thinking about getting a pump, but a thought has occurred to me. Is a pump going to kill the mood? Is having this device attached to me going to be a turn off, even if I explain it before hand?¹²

With these initial questions, chrissy17 raises two major points that users regularly attempt to work through in nearly all of the sex-and-insulin-pump forums across both the Diabetes Daily (DD) and the American Diabetes Association (ADA) websites, and function as two primary instigating factors for the decision to begin a thread on this topic. First, users have major concerns about whether or not their connectedness to a medical device will "be a turn off" for their sexual partners (or even themselves), acting as an inhibitor to their otherwise un- or less-

¹² "Pumps and Sexy Time," Diabetes Daily, July 29, 2015, <https://www.diabetesdaily.com/forum/womens-corner/85037-pumps-sexy-time/>.

inhibited sexual practices. Second, users express worry, fear, embarrassment, and/or undesirability associated with *showing* their constant connectedness with an insulin pump to their sexual partners—and even with the phenomenon of that connectedness itself. As pump users breach these topics within the DD and ADA community forums, they are able to receive affirmations from others who have had similar feelings and experiences, and mine these broad networks of other pump users for new practices that may help them maneuver their technological and social relationships.

A 2011 American Diabetes Association forum discussion, started by the user identifying as haleh, highlights some of the fears and stresses people with T1D experience when considering the switch to insulin pump treatment:

I have been a type 1 for 8 years now (after having gestational Diabetes) and now my doctor is telling me I am a great candidate for a pump. I am totalling freaking out [sic], the last thing I want is having something attached to my body all the time, I am worried about how it will effect my relationship with my husband, how would I sleep with it, would the injection site get infected, will i be full of holes using this? what if while I am asleep I roll over it and hurt myself (I am a restless sleeper).....so many questions and really scared about it. can anyone offer me some help on this. I would really appreciate it.¹³

Both the language and the tone of this post are thick with fear and anxiety, emotions haleh ties back to the prospect of always having this thing attached to her body. The range of issues identified here—potential relationship problems, impacts on sleep, health issues and bodily markings, even the emotional state represented by the post as a whole—all stem from the *thought* of a connection between the body and a medical device.

The device, it seems to this user, would fundamentally change the state of the body itself, simultaneously leading to potential illness and marking it as something other than what it had been. The language of being “full of holes” constructs a vivid, even horrific image that in part signals the user’s fears. More importantly, however, what could be interpreted as hyperbolic language does in fact represent the reality of an infusion site’s effects on soft tissue. The infusion site punctures the skin and inserts a small subcutaneous tube through which insulin is injected into the body. To avoid infection, this site must be removed and replaced once every three days, which means that within a month’s time, users will have created approximately ten new holes

¹³ “Insulin Pump,” American Diabetes Association, April 23, 2011, <http://community.diabetes.org/t5/Adults-Living-with-Type-1/Insulin-Pump/td-p/32542>.

around their abdomen and/or other places on the body—“full of holes” indeed. These concerns about pumps’ effects on the body and everyday health practices are in fact rather common. “I’m worried about the ‘attachment’ with a pump,” user Webel stated in another discussion thread, specifically identifying concerns regarding “swimming, sleeping, showering, sex.”¹⁴

Beyond the physical issues that insulin pumps may create for users, the fears associated with the attachment of medical devices to bodies has interpersonal and social ramifications as well. Sex, as a practice where the sociality of bodies is made particularly visible, changes when medical devices are introduced into those interactions. Such a technological interloper can have major implications for “the mood,” as chrissy17 pointed out above. As the user withloveandagun points out in a thread titled “Kinda a Taboo Subject”:

My Endo wants me on the pump. I’m scared about having that attached to me and trying to have sex. Plus it seems like it would just be a burden. I would like tighter control but part of me would rather stick with MDI [multiple daily injections]. [My husband] got used to the CGM [continuous glucose monitor] but I feel like the tubing from the pump would freak him out a little bit.¹⁵

So while the infusion site (as the mechanism of attachment to the user) inspires concern for the users themselves, withloveandagun’s comment makes it clear that the tubing—a significant part of the insulin pump’s overall network of technologies—can also impact the users’ *partner* in ways that may affect their sexual interactions. Pump tubing ranges in length between 23 and 43 inches and extends out from the body in a way that resembles being “plugged in” to a device, in a way a continuous glucose monitor (CGM) does not. While CGMs require a small object to be attached to the outside of the body, that integrated “plugged-in” nature of an insulin pump includes a shift in perception from human to cyborg or post-human in a more visible way that inspires this “freak out” response (in experience or imagined—either the user or their partner *do* experience that fear to some degree).

In this case, the device functions as an interloper that exists in a sexual space where it often acts as an interrupter. withloveandagun points out one of the ways in which an insulin pump can dampen the mood for a user’s partner, but as iowagal points out in another thread,

¹⁴ “Insulin Pump,” American Diabetes Association, August 11, 2014.

¹⁵ “Kinda a Taboo Subject,” American Diabetes Association, June 23, 2012, <http://community.diabetes.org/t5/Adults-Living-with-Type-1/kinda-a-taboo-subject/td-p/241840>.

users themselves experience similar impacts to their sexual experiences. “I was a bit nervous,” she begins, “and felt less desirable with even the [infusion] set only.”¹⁶ Some of the problems these users identify, this example makes clear, affect users’ very self-perception in relation to managing sexual practices with their partners. Users such as iowagal see themselves differently as sexual actors, in this case as less desirable, and in effect the *possibility* that their partner will see them differently as well is made real to them at the same time—whether or not it materializes in practice.

These perceptions are necessarily bound up in the cultural constructions of gender, ability, and desire that frame users’ very understandings of themselves and their partners. These themes will be explored more fully later in this chapter, but at this point it is important to reiterate the relationship between pump attachment and users’ understandings and fears regarding sexual attraction and desirability. In early 2010, a Diabetes Daily user known by the pseudonym Meoney1508 was considering moving onto an insulin pump as her primary form of treatment. She began a thread titled “Insulin Pump andsome Awkward Questions.....” to seek feedback from other pump users, despite being “a bit embarrassed”:

1. What do you do with this pump attached to you when having sex? How does one manage this gadget?
2. Then, being a girl, we all want to look and feel good, you still want [to] feel attractive. Is this possible with a pump attached to you and the tubing? [...]

Desirability, as Kelly Fritsch has argued, is culturally reserved for able-bodied peoples.¹⁸ As a disease which is not inherently visible, Type 1 Diabetes is made visible through the use of an insulin pump (i.e. its attachment to the body), and in so doing, this medical device-body hybrid signifies a non-normative ability or health status to both the user and their partners. As an individual whose able-bodiedness is now made suspect, their desirability defined thereby is made suspect as well. Thus Meloney1508’s concern about the very possibility of feeling attractive

¹⁶ The infusion set iowagal refers to is the always-connected port adhered to the body, onto which the pump tubing is attached for continuous injection (or infusion). “Insulin Pump andSome Awkward Questions.....,” Diabetes Daily, February 13, 2010.

¹⁷ “Insulin Pump andSome Awkward Questions.....”

¹⁸ Kelly Fritsch, “Desiring Disability Differently: Neoliberalism, Heterotopic Imagination and Intra-Corporeal Reconfigurations,” *Foucault Studies* 0, no. 19 (June 17, 2015): 44, <https://doi.org/10.22439/fs.v0i19.4824>.

while connected to this device is not only understandable, it is entirely in line with the boundaries set by reiterated normalizing practices of sexuality and compulsory able-bodiedness.

In moments such as those above, sexual interactions between insulin pump users and their partners become visible as what I call techno-intimate relationships, mediated through online discussion forums. As bodies and sexual practice become integrated with medical devices, the meanings associated with all three are bound up together and redefined. And although these discussion threads are most often instigated to work through issues of pump connectedness and its implications for “the mood,” through the discussion process they become spaces to discuss and advise other members of the T1D community on techno-intimate practices specific to sex and insulin pump use.

In the remainder of this chapter, I will explore how these online forums facilitate and/or reveal techno-intimate relationships in practice. First, I will look at discussion threads concerning the disclosure of insulin pump use to sexual and intimate partners, as well as the productive possibilities and dangers involved in that process. Second, I will analyze these same texts to explore the ways in which both insulin pump use, and online community forums, change sexual practices for people with Type 1 Diabetes and their partners.

Disclosing Diabetes and Pump Use

Disclosure is a complicated issue in relation to health identities and Queer politics. Defined in part as the act of sharing an aspect of one’s health or embodied identity with others who may or may not be aware, disclosure includes acts ranging from “coming out” narratives (the revealing of any number of LGBTQ+ identities) to communicating a health status with a potential partner (HIV+, for example). The various purposes, stakes, and subjects involved in these cases highlight the complex mixture of ethics, safety, and health (physical, emotional, social, and mental). These moments can be positive and productive, but they also expose particular vulnerabilities which—depending on how those disclosures are received and handled by others—can have damaging and painful long-term effects on their well-being.

Type 1 Diabetes, as I have mentioned above, is not an inherently visible or visual illness. A person with T1D is only identified as such through similar moments of disclosure. As one Diabetes Daily user makes clear, it is sometimes possible for people with T1D to avoid revealing their health status as long as they desire. “I dated a guy for two years back in the late 1980's who

never knew about my type 1.” Two years seems like a long time, especially in light of the regular treatments and monitoring that T1D requires. But missitaly makes it clear that she felt she had something to hide. “Oh yeah, I was ashamed to have diabetes.”¹⁹

In stark contrast to missitaly’s experience in the 1980s, however, engaging in insulin pump therapy changes the visibility of the disease in culturally and socially significant ways due to the constant connectedness of these devices to bodies. Whereas people with T1D would usually be able to uncover their bodies without any visual identifiers of their health status (as, it is assumed, missitaly was able to do for two entire years), the infusion site and tubing connected to a pump user’s abdomen create a situation where an encounter with the device is immanent when the clothes come off. The use of these medical devices necessitates pre-sex disclosures for people with T1D that would not otherwise be required, and those now-compulsory disclosures carry with them significant concerns and vulnerabilities. As some users make clear in sex-and-insulin-pump discussion threads, however, those concerns and vulnerabilities can also lead to productive moments for relationship-building or -strengthening, and even self-realization and affirmation.

One user expressed some of difficulties associated with disclosure when that communication breaks down and the connections she tries to make clear are not fully understood or comprehended by the other party:

[miss b:] I hate how I get embarrassed/ ashamed [sic] about my diabetes but it honestly feels like this.... you can explain type 1 to someone for hours and after that conversation [sic], you are low, you drink coke in front of them and they look at you and still don't understand!!! [...]²⁰

As miss b points out here, there are certain limits to how effective disclosures can be in some cases. The meanings associated with coming back from a moment of low blood sugar, for instance—which happens so regularly it becomes second-nature to people with T1D, but could nevertheless have major repercussions for their long-term and short-term health—may not fully translate to others despite those disclosures. And if those meanings are not decoded by users’ partners in a way that carries those meanings, the very purpose of those disclosures is left unfulfilled, leaving nothing but the embodied and technological signifiers of the users’

¹⁹ “Intimacy and the Pump Wearer,” Diabetes Daily, May 22, 2008, <https://www.diabetesdaily.com/forum/type-1-diabetes/16080-intimacy-pump-wearer/>.

²⁰ “Intimacy and the Pump Wearer.”

medicalized status open for interpretation. One user compared an experience with her now husband, in which he simply showed an interest in the device, to that of someone she disclosed to online: “[...] This, in comparison to the guy (I never dated, but talked to online) who was worried that diabetes might be catching [sic].²¹ The fear of “catching” Diabetes is not an uncommon response, though it demonstrates a clear break between the discloser’s encoding of the message and the discloser’s decoding thereof.

While they can at times break down completely, moments of disclosure that are able to “get through” to a potential partner carry with them other compulsory structures that require even more social labor from the discloser. Once people with T1D state their health and/or treatment status, the conversation does not simply end in resolution. The process of question-and-answer following this type of health disclosure can be emotionally exhausting, often requiring people with T1D to debunk false and problematic cultural understandings of Diabetes that carry worrisome stigmas.

Diabetes Daily user bettadiabetta usually discloses their health identity and/or device use by publicly pulling out the pump and delivering insulin for a meal or drink. “Then I brace myself for the usual questions: ‘How often do you have to do that?’ ‘How long have you had it?’” And, worst of all, “‘So do you, like, have the same life span as a normal person?’” This barrage of questions is so uncomfortable, bettadiabetta notes, that despite all of the other health, social, emotional, and psychological effects the disease may have, “My biggest problem with the disease is explaining it to people-- no doubt about it. I hate, hate, HATE when people ask me about my mortality-- I mean, does *anybody* know how long they have to live?”²² These frustrations are understandable—and, to a certain extent, many of the questions an unfamiliar potential partner may pose are understandable as well. Both parties, in the case of disclosure more generally and in the case of T1D/pump use, are caught between the necessity of the act and the (often unintended and invisible) social repercussions of engaging therein.

In some cases, even the actions of a partner with the best of intentions can take a toll on people with T1D post-disclosure. As DD user coravh points out, the overly-interested and -concerned partner can be a nuisance as well:

²¹ coravh in “Pumps and Sexy Time.”

²² “Intimacy and the Pump Wearer.”

[...] I absolutely despised the people I knew who always brought up my diabetes regarding every decision - do you need to test first? go to the bathroom? take some insulin? eat?.....etc. And the constant obsession with was I getting enough exercise, and how were my blood sugars..... I agree that the person you are dating should know about it and get some info, but to my mind, going at it too much would make me feel like a child again and that I was living with my mother during my teenaged years.²³

In light of miss b's and bettadiabetta's experiences, coravh's post highlights the paradox at the center of T1D disclosure events. In one sense, it is entirely possible that your disclosure will have no resolution due to a break-down of communication between the involved actors. Even if that communication gets through, the receiver's response may be distasteful and damaging to the emotional and psychological well-being of the discloser. And yet, in the event that the disclosure is decoded in a productive way by the pump user's (potential) partner, who does not react in a way that reaffirms able-bodied normalcy, the ways in which that disclosure alters the relationship between individuals may create awkward, painful, even unbearable situation for the discloser or their partner.

The root of the anxieties associated with disclosing one's health status, or the use of a device that signals that status, is difficult to locate and as varied as individual experiences. Though for one user, after being prompted by others on the discussion thread to try and express where those reservations are coming from, the tensions within that moment of disclosure are linked to the vicissitudes of another:

[missitaly:] I think it really stems from being dx'd [diagnosed] @ 12 yrs old. It was right before the start of 7th grade; on the cusp of adolescence. I was dealing with those changes and now this? It really messed with my head. And the insulin we all had to take back in those days was not on the cutting edge. What a recipe for disaster!²⁴

It makes sense, in a way, that the fear of telling someone else about your diagnosed medical condition would in some way connect to the moment when their own status was first disclosed to them. The diagnosis event is a crucial point in the lives of people with chronic illnesses, which alters the ways people understand themselves.

²³ "Pumps and Sexy Time."

²⁴ "Intimacy and the Pump Wearer."

In his chapter “Framing Disease: Illness, Society, and History,” Charles Rosenberg identifies the ways in which framing a physiological phenomenon as a disease—labeled as such during the moment of diagnosis—influences people’s entire interactions with the world around them. “Once crystallized in the form of specific entities and seen as existing in particular individuals,” Rosenberg argues, “disease serves as a structuring factor in social situations, as a social actor and mediator.” As a social actor in and of itself, a disease takes on specific social characteristics, “and thus triggers disease-specific responses.”²⁵ Framing things as diseases can thus alter the options people have to frame themselves and their own behavior—and I would add bodies, as is made explicit in many of the case studies herein. From epilepsy in the early twentieth century to cancer or Diabetes today, “an individual became, in part, that diagnosis.”²⁶ It does not come as a surprise, then, when missitaly closes by acknowledging, “I will always feel ashamed [of having Diabetes]. However, it doesn't bang the drum (of shame) as loudly as it once used to.”²⁷

At times, the act of disclosure can be consciously employed/deployed as a means of discovering or determining the efficacy of potential relationships with new partners. As one user point out, disclosures can be quite useful:

Well, actually [...] the way someone reacts to learning that you have Type 1 diabetes could be a very good indication of their character.

Personally, I would not want someone who just said, "Oh, you have diabetes? OK" and that's it. I would want someone who wanted to know a little more about it. Who showed sensitivity about suggesting what restaurants to go to. Someone who wanted to know what they could do to help you stay healthy-- shop and cook together? work out together? [...] ²⁸

In this way, the moment that contains so many fears and tensions for people with T1D can actually be used as a tool, a test even. The way a person reacts to the newly revealed health identity of a potential partner, in the way this user narrates it, can be used to not only feel out

²⁵ Charles E. Rosenberg, “Framing Disease: Illness, Society, and History,” in *Framing Disease: Studies in Cultural History*, ed. Charles E. Rosenberg and Janet Golden (New Brunswick, N.J: Rutgers University Press, 1992), xviii.

²⁶ Rosenberg, xix.

²⁷ “Intimacy and the Pump Wearer.”

²⁸ Chrysalis in “Pumps and Sexy Time.”

their response to the status itself, but to feel out their overall “character.” It is interesting to note that what this user sees as acceptable markers of a person’s character in this context: someone who cares enough about the person behind the disclosure that they show a certain curiosity about their experience. This in stark contrast to the way coravh responds to a partner’s constant interest above. On the one hand, a partner’s interest and (regular, constant) consciousness about the other person’s health status can be endearing, while on the other hand, it can be frustrating and infantilizing.

If the user above finds disclosure to be a useful tool, consciously employed to feel-out a potential partner, the following example shows how consciously *withholding* that disclosure can serve important purposes for people with T1D as well. Under the thread “Intimacy and the Pump Wearer,” user missitaly (who began this section) opens up a conversation that gives insight into some of the ways compulsory able-bodiedness structures the ways people with T1D interact with the people around them:

I fit my sickness to suit my life; how you hide [it] from those around you, how the lies you tell are the lies you want to believe and so they become the truth. You couldn't see it anyway. That's what made it so easy. Although that's not to say I threw caution to the wind and lived dangerously. I did the best I could. However, I've never given myself credit for the hard work I've put into staying alive.

Ashamed might not be the right word (though it certainly plays a part). It's more like embarrassed. Those who know me would be shocked by that.²⁹

In a conscious deployment of disclosure *decision making* similar to that of the user above, missitaly purposefully withholds that information about herself in an attempt to construct a reality where her health status did not mark her as abnormal. Diabetes’ lack of visibility made it easier for her to do this than some other diseases or identities would have allowed, and it is clear that she was not using an insulin pump as her primary method of treatment (lest it would give away the information she worked so hard to hide). There is real potential danger in this disclosure decision, as missitaly acknowledges, as partners and other people she comes into contact would not be able to provide the immediate assistance a dangerous hypoglycemia could require—though it is clear that the dangers she perceived that could result from her disclosure of

²⁹ “Intimacy and the Pump Wearer.”

a non-normative health identity were no less real, as the shame and embarrassment she opens up with can attest.

The pressures as well as the potential social and cultural backlash associated with the disclosure of an abnormal health identity structure all of these responses to the disclosure moment. In fact, the need for disclosure is itself is a symptom of cultural values being ascribed to and associated with particular subjectivities. Those values are reinforced and reiterated as the norm as it goes unspoken and unidentified by those who can at one time or another be labeled as such. But it is also important to note that in all of the cases of disclosure worked through above, no matter the mode of expression (or lack thereof) or even the ways potential partners react—all of these actions participate in the reiteration of a culturally defined “normal.” People with T1D are constrained, and in order to interact with other people (and even survive, in some cases) they must act and react in some way. There is no way around it, and thus the system of compulsory able-bodiedness implicates the “abnormal” in their own continued stigmatization.

Pumps and Sexy Time

At some point in all of these conversations and theorizations about how insulin pumps affect sex, desirability, and relationships, pumps actually *do* move into the bedroom. Within the confines of these community discussion threads, pump users share ideas, tips, and experiences about insulin pumps and sex in practice. It is clear from all of the threads on both the American Diabetes Association and Diabetes Daily websites relating to insulin pump use and sex that the users dominating discussion in these spaces are deeply invested in maintaining hegemonic heteronormative sexualities. Every account details sexual engagement between a cis-gender man and a cis-gender woman, more often than not functioning within the confines of a state-sanctioned, monogamous marriage. As such, the sexual practices they outline, and which I analyze here, are structured in ways that exclude (and indeed do not even acknowledge) non-normative sexualities and work off of assumptions that reaffirm culturally dominant forms of sexuality—an issue with which I will engage more fully toward the end of this chapter.

As pump users, and especially prospective pump users venture into the sex-and-insulin-pumps forums on the ADA and DD websites, they will encounter several discussion threads devoted to where users put their pumps during sex. A fairly straightforward and practical topic, with some fairly straightforward and practical responses. When read in conjunction with users’

concerns about insulin pump connectedness and disclosure, however, and framed by the cultural processes of biomedicalized normalization, these seemingly unremarkable details about sexual practices take on deeply significant meanings for users and their partners—and for their understandings of sexual practices themselves.

So where do users put their pumps during sex? Usually users have pockets, belts, waistbands, bras... any number of clothing items to which they can clip their pump as they go about day-to-day activities. But when the clothes come off, as Joshua pointed out in the epigraph for this chapter, they have nowhere to clip the device. In response to this problem, there appears to be a rift within these communities between those who detach the pump from the infusion site before sex, and those who leave it on. “During the FUN times -” points out one user, “you can either take your pump off, then start it again after or you could leave it on and just leave it beside you on the bed. It depends how active you are if you get my meaning!”³⁰ On a basic level, the decision boils down to either removing the pump or keeping it on. “You don't have to disconnect your pump,” says liz71, “I put mine under my pillow.”³¹ One solution, then, is placing the device on another surface away from the body, in this case on the bed (though the tubing would have to be quite long to reach all the way from the infusion site on the user's abdomen to the device tucked under a pillow). While this seems like a generally acceptable option, this approach does limit the types of practices sexual partners can engage in. The pump user would almost always have to be lying flat in order for the tubing to reach a surface on which the pump could rest.

But for pump users who want (or need) to keep their pump attached during sex, other forum members offer alternatives to the pump-on-the-bed model. Pump manufacturers (and, increasingly, some small business owners) produce cloth straps and belts with sewn-in pump pockets that can be wrapped around legs, arms, and abdomens. JennHu, for instance, shared some insight after thirteen years of pump use:

When my husband and I "make love" I wear a thigh belt with a pocket for my pump. [...] I don't like to remove my pump for more than an hour because I develop ketones. My husband doesn't mind my wearing a pump one bit because

³⁰ april in “Insulin Pump andSome Awkward Questions.....”

³¹ “Insulin Pump,” April 23, 2011.

he knows that it is a part of me and helping me control my diabetes. It doesn't get in our way 😊³²

Though the pump *may* get in the way, because this user does not want to risk negative health effects of taking the pump off, she dons a clothing item designed specifically for this purpose and attaches the pump to that. So while taking the pump off would no doubt get it more out-of-the-way, doing so would compromise the effectiveness of device's very purpose.

But JennHu makes another statement in the comment above that has major implications for the role of this device in its users' sexual practices. "[H]e knows that it is a part of me," she says. It does not get in their way, it seems, because the device has become an extension of the user's body—and more than that, the language "part of me" signifies a much larger and deeper connection between user and device than simply physical attachment. Becoming "part of me" includes an integration, at some level, between the device and the user's sense of self in a way that resembles the mashing-together of the body and the self. Being "part of [a] me" means being part of all the experiences and interactions that "me" engages in.³³

In the context of sex and insulin pump use for JennHu (and in some ways, people with T1D in general), the pump becomes part of the user's (and their partner's) sexual practices themselves. Though internally conflicting in interesting ways, one pump user's comment illustrates how despite being largely tangential to the overall practices, insulin pumps are involved in the acts themselves:

My husband wants whatever is best for me and I don't think I have ever noticed him noticing [the pump]. With the tubed pump, however, you have to stop and "unplug" the infusion set from the site.³⁴

In one line, this pump user attempts to reassure another community member that her husband does not seem to react to her pump use at all during sex. The next line, however, points out that this is not, and even cannot be the case. Either the user, their partner, or both must at some point in the process of engaging in sexual practices divert attention directly and specifically to the

³² "Sex & Insulin Pump & Body Issues," American Diabetes Association, May 8, 2012, <http://community.diabetes.org/t5/Adults-Living-with-Type-1/Sex-and-Insulin-Pump-and-Body-Issues/td-p/222247>.

³³ For more on human-body-device interconnections, see my discussion of the transformative act of device use in Chapter 3, and my discussion of human-object relationships in Chapter 5.

³⁴ jgrohmann in "Insulin Pump," April 23, 2011.

device to disconnect it (or in JennHu's case above, tuck it in her thigh belt). Though it serves an obligatory purpose, the act of direct engagement with the device in the processes and practices of sex implicates the device as a part of those very practices (if, in this case, a rather passive part).

But pumps do not always fill such a passive role. In fact, in some cases insulin pumps become an integral part of sexual practices. Frequent DD commenter coravh remarked, "Let me just add that taking off/disconnecting my pump became part of our ritual of 'oh, let's have some fun'."³⁵ Working with and removing coravh's insulin pump became a sort of foreplay, getting both her and her partner in the mood. As the act of removing the device from the body becomes integrated into these instigating practices through repetition and reiteration, it would be difficult to differentiate where the pump as an *object* could be absolutely differentiated from the pump removal as an *action* within the context of sex. The fact that its *removal* is the instigating factor for sexual advances seems to imply that its continued presence would not be welcome, and taking the interloper out of the equation serves as a freeing act, in a sense—removing the marker of not only medicalized difference, but also the social and psycho-emotional stressors it represents.

Even when the pump and tubing are detached and removed, however, the technological network of the insulin pump still remains a part of the user's body, and therefore the user's sexual interactions with their partner. Infusion sites do not lay flush against the skin, but extend outward between an eighth and a quarter of an inch, depending on the particular brand and model. As one user known by the pseudonym chigginson points out, "The port will have to stay on even if you disconnect your pump," and its continued attachment to the body during sex can have unfortunate and even painful effects. "We have ripped it out before when active[,] it is a bummer because then you losses [sic] what was left in the pump and have to start a new sight [sic]."³⁶ Having that little tube torn out from under the skin unexpectedly can be uncomfortable, to say the least, which can potentially weigh on continued sexual desire (especially for the user). But when an infusion site is unexpectedly ripped out and the user must attach a new one in its stead, sexual practices begin to have economic consequences as well.

³⁵ "Pumps and Sexy Time."

³⁶ "Insulin Pump andSome Awkward Questions....."

Pump manufacturers have created clip-on covers for when the pump is detached, ideally smoothing out some of the sharp edges that can catch on other bodies, articles of clothing, or objects. As PeterPumper shares:

For my Medtronic pump, I use their quick-set infusion sets, which come with a cute little cover that snaps onto the "nipple" of the infusion set when you remove the tubing. It is labeled for uses such as swimming, bathing, etc... I don't swim often. I take showers, and seem fine without the cap. But it is great for "sexy moments", because instead of a "nub" with abrupt edges, the cover creates a smooth little bump that won't scratch either of us.³⁷

That scratching can be of real concern. One ADA user shared this experience: “[I] had a site on my side and a sharp edge of [it] cut a nice gash on the inside of the wifes [sic] thigh.³⁸ By the time they got the wound cleaned up and tended-to, sex was the last thing on either of their minds. So while this level of injury may not be common, the scratching and scraping that takes place when the infusion site comes between the intimate closeness of bodies would be. That motion-related, painful interaction with the device is part of what caused one user to note, “I felt like a science experiment with this plastic thing sticking out of my stomach.”³⁹

Even when the site is not scratching, it remains present between intimate bodies and can inhibit their practices. One user stated that “This past week, I had a sure t [brand infusion site] in the abdomen, and I could not hold my hubby, and ya know cause it hurt.”⁴⁰ The very pressure of another body against hers pressed the infusion site into her abdomen in such a way that the pain associated with it stopped her from holding her partner. As this example shows, pump use not only affects sexual activity (used here as an action verb), but also the non-sexual intimacies associated with the closeness of bodies.

Most often, however, insulin pumps play a middle-ground, moderately active role in the sexual practices of their users—usually as a presence that must be acknowledged and worked with/around during users’ sexual interactions. Whether the pump or the infusion site causes

³⁷ “Pumps and Sexy Time.”

³⁸ damytewok in “Sex & Insulin Pump & Body Issues.”

³⁹ miss b in “Intimacy and the Pump Wearer.”

⁴⁰ cheryl in “Intimacy and the Pump Wearer.”

problems or not, both users and their partners have a constant awareness of the device. As Schmancy, a DD community forum contributor shared:

My D is a part of who I am and I leave it [the pump] on during times of intimacy [sic]. Like [the previous user] said I just leave it to my side and have gotten good at grabbing it for position changes. My fiancé is also always aware of where my site is so he doesn't yank on it or pinch it, I use my butt. It is something you will adjust to.⁴¹

For users who keep their pump attached during sex (especially those who do not use some sort of sleeve or strap, as mentioned above), position changes become moments of device interaction as they must use a free hand to grab the device and resituate it after the change is made. A seemingly minor interaction, though the comment that follows is particularly instructive. Schmancy's fiancé is always aware of where the site is placed on her body. Were he not aware, the chances of scratches, gashes, or yank-outs as detailed by previous commenters would create interactions with the device that are much more problematic and time consuming than a mere grab-and-switch. And as a result, some users use these threads as opportunities to instruct others on specific positions that avoid infusion sites (and the various related potential issues). "Find a position where the pump does not interfere!!!" implores dturney. "Try the spoon works great...."⁴²

Pumpers Policing Gender Norms and Compulsory Hetero-Monogamy

It is clear from these and other interactions that online Diabetes forums often provide a space where pump users can share knowledges and experiences in productive, if often practical ways. Deeper in these sex-specific comment threads, however, the forum is maintained as a space to reiterate normalizing narratives surrounding health, sexuality, and gender which leave little room for non-normative subjectivities. In this section I will discuss how these community forums themselves become ambiguous, normalizing spaces wherein users claim validity and respectability of their own techno-intimacies, while at the same time deploying problematic gendered sexual norms as tools to do so. Through sexual stereotypes and standards of intimate interactions constructed around male pleasure, some users insert themselves at the expense of

⁴¹ "Insulin Pump andSome Awkward Questions....."

⁴² "Sex & Insulin Pump & Body Issues."

other community members. In the process, non-heteronormative and non-monogamous sexualities are policed—particularly for women—in ways that compel community members to conform to those norms (at least in-text) or leave the forums altogether.

As discussed in various examples above, the presence of body-connected devices within intimate relationships can weigh on partners both mentally and emotionally—at times interrupting or dissuading interactions altogether. In seeking support from other forum users who may have had similar experiences, T1D women are frequently met with advice that reiterates gendered sexual scripts as the heal-all for any intimate difficulties. Responding to a question regarding insulin pumps and new sexual partners, user Coastall outlines what she sees as a root problem:

I don't have a pump, but I have been married to the same guy for 28+ years. The one thing I've learned about sex is that very often we women think too much about how to create and exact some kind of perfection. That, and we often expect men to initiate everything in the bedroom. I like [the other user's] advice: take the pump off, put something sexy on (and everything that entails) and then relax, yet be committed to it. You know it's worth "the trouble".⁴³

Coastall's comment initially reads as a critique of the social obligations requiring nothing short of "perfection" from women when it comes to establishing the setting and tone for sex with men, implying that women can (and/or should) act as sexual agents themselves in initiating at least *something* "in the bedroom." But in context, that agency remains framed here by the sexual desires and will of the man and universalizes a hyper-emotional and over-thinking woman trope as the *real* cause of the problem. The standard of perfection itself is not questioned here; indeed, it is taken as a given, a constant to which women must adapt and navigate. Going through "the trouble" is worth it, she says, but that trouble is still clearly framed as extra labor disproportionately required of women that is not required of men.

Her advice for women with insulin pumps, then: get sexy. Buck-up, as it were, and take one for the team. Coastall is not alone in comfortably offering this uncomfortably charged platitude. Take off the insulin pump and "put on something sexy," suggests one user, "and I bet you can change his interest."⁴⁴ If you aren't comfortable taking off the pump, says another, then

⁴³ "Sex & Insulin Pump & Body Issues."

⁴⁴ sunritef in "Sex & Insulin Pump & Body Issues."

clip it onto a “sexy looking garter, like one wears when they get married,”⁴⁵ or as jt_type1 does, put it in some “thigh highs from victoria secrets [sic]”.⁴⁶ Among these suggestions runs a particular set of ideas dictating what “sexy” is, what it is not, and for whom sexiness is performed and embodied. Perhaps the most commonly shared assumption in these and the other comments throughout this chapter is that being connected to a medical device falls outside the bounds of the sexy, marking users’ bodies (to themselves and/or their partners) as sexually undesirable by association. It must therefore either be removed or hidden, taken out of the equation in order to reopen the channel for desire, and more specifically, men’s heteronormative desire. The narration of practices associated with “getting sexy” is not only about quelling women’s insecurities arising from insulin pumps’ presence on their own bodies, but defining and creating *which* women’s bodies are themselves worthy of men’s sexual desires or energies.

In stark contrast, men who use insulin pumps are not-so-subtly narrated as the primary sexual agents in their relationships. Whereas women who use pumps are told (and tell each other) they must engage in practices and performances to make their bodies more desirable/less undesirable for their partners, men who use pumps claim the right (even necessity) to “train” their women partners how they should accommodate the technological interloper. As Dennis1947 relates, figuring out how to deal with the insulin pump took some learning for both him and his wife. She passed away from cancer-related complications, he notes, “and [I] had to start all over with a new Woman and ReTrain her..” Initially that training focused on getting her to “open up” and disclose her various sexual preferences, he says, followed by an effort to “go thru alot [sic] of things to see if she would like them.”⁴⁷ Neither the act of discussing preferences nor experimentation with various practices are inherently coded with disproportionate agential power. Indeed, both of these play important roles in constructing healthy sexual relationships of all sorts. But as they are narrated here, the ability to actively engage preferences and experimentation lie in the hands of Dennis1947 as the trainer; his “new Woman,” on the other hand, is narrated simply as able-to-be-trained.

⁴⁵ trisha01 in “Sex & Insulin Pump & Body Issues.”

⁴⁶ jt_type1 in “Sex & Insulin Pump & Body Issues.”

⁴⁷ “Kinda a Taboo Subject.”

Not satisfied with projecting these types of problematic gender constructions onto others' sexual practices alone, users often use the discussions regarding sex and insulin pumps to build the forum space itself in that same image. I want to close by explicating one comment thread from *Diabetes Daily* that emblemizes how this often plays out in similar online discussions. In 2008, a user by the screen name *laura w* opened a discussion thread titled, "Intimacy and the Pump Wearer," asking for some practical insights from others who may have some experience:

I am wondering what you pump wearers do with your pump before being intimate with someone, especially if they are not aware you are diabetic, or if they do not know you wear a pump. Do you remove the infusion set, and the pump, or just the pump. Or neither. Does sexual intimacy effect bs? Oh boy, I can't wait to see the answers to these questions.⁴⁸

The same problem at the center of many discussions cited above, namely: where to put the pump during sex, is *laura w*'s primary reason for starting this comment thread. More specifically, she asks the question in regard to new and potential sexual partners, as that context creates its own particular needs and constraints for people in light of whether or not they have previously disclosed their health status. Though she likely "can't wait to see" how other users respond due to the implied sexual content of any answers to her questions, the discussion that followed focused more on the basis of her questions than the questions themselves. "Seems to me if you are 'intimate' with someone," responds a user by the pseudonym *Spike*, "chances are you would have disclosed that you are a diabetic. Sounds more like you are confusing 'sex' with intimacy." And, to set the tone for the conversation that follows, *Spike* inserts a pointed non-answer to *laura w*'s original question, "Both my wife and I have pumps and they do not interfere one whit with sex."

Rather than sharing insights into the overlaps between disclosure and devices' presence during sex, *Spike* passively undercuts the validity of *laura w*'s original inquiry by policing her use of the term "intimacy." Clearly used in the original post as a stand-in for sexual practices generally, *Spike* reclaims the word intimacy—as well as the entire comment thread which follows, and thereby *laura w*'s sexuality itself—as a marker for monogamous respectability. Intimacy, he implies, is reserved for long-term relationships such as his own marriage.

⁴⁸ "Intimacy and the Pump Wearer."

“Personally,” chimes in another user, “I think it's an oxymoron to ‘be intimate’ without ‘being intimate.’”⁴⁹

At this, another half-dozen-or-so other forum members enter the conversation to reiterate their disapproval for what many of them term “casual” sex. “WITH MY HUSBAND” yells one user, “(I do not condone casual sex partners.. guess I'm old fashioned.. [sic] and just plain old) I either leave it on or off.”⁵⁰ “Being Married,” chimes in another, with a seemingly strategic capitalization, “I don't really go for the ‘Sex with strangers thing’.” Sex between married men and women is passive-aggressively reiterated numerous times throughout the comment thread, such that laura w is compelled to distance herself from the kind of “sport intimacy” these others condemned.⁵¹ Users including Spike trolled her to such an extent that she apologized to everyone in the thread for even implying such sexual practices exist:

I M NOT IMPLYING i HAVE EVER HAD CASUAL INTIMACY, BUT i THINK THE YOUNGER GENERATION TREATS IT AS SOME SORT OF SPORT. NOR DO I ENCOURAGE CASUAL SEX FOR ANYONE. [. . .]

I'm not yelling. I am a really bad typist who accidentally hit the cap lock button. Secondly, I apologize to anyone I have offended. I did not mean to imply that there are diabetic pump wearers in the world having casual intimacy with those who don't know their diabetic. I am watching too much television which portrays intimacy between people who don't know each others names I will limit future questions to carb counting and spaghetti strands.⁵² [sic]

Clearly frustrated by the barrage of attacking and trolling responses to her post, laura w is compelled to tie herself back to the systems of sexual normalcy being so intently policed throughout her thread. While the end of the last-quoted comment above has some sarcastic bite aimed at the community as a whole, it is clear that the disapproval for anything outside the heteromonogamous norm is so intense that she walks-back her own statements (benign as they may be) in order to side-step the shame associated with related sexual practices.

⁴⁹ Mary J in “Intimacy and the Pump Wearer.”

⁵⁰ smip in “Intimacy and the Pump Wearer.”

⁵¹ “Intimacy and the Pump Wearer.”

⁵² “Intimacy and the Pump Wearer.”

The driving force for the intensity of that shaming: a fear of sexually transmitted infections, specifically HIV/AIDS. As user linda comments, “Since I am not in the habit and would not deem of catching AIDS!!!!, if I were single I wouldn't be having casual sex and being with someone who didn't know most everything about me.”⁵³ [sic] Those five exclamation marks frame Spike's other references to “STD infection rates,” and “catching a miserable disease or even death,” narrativizing an association between non-heteromonogamous sex and medical risk in a way that stigmatizes participants as irresponsible. Even when the user missitaly attempts to defend laura w's ability to make her own sexual decisions by noting her four decades of experience with Diabetes and posing the question, “Does she really need to be read the riot act re sex? I think she's old enough to make her own decisions in that regard,” respondents defend their ability to let the discussion “roam” wherever it will, directing infantilizing and sexist tropes toward women such as missitaly who were calling them out. “No need to get your panties in a wad ladies. You don't own the board or the topic, just let it flow where it goes???....lol.”⁵⁴

And here the final comment on the thread, posted by a man identified as SugarfreeB, is telling:

As a T1 diabetic who does occasionally engage [sic] in casual sex (and still disease free, tested regularly), I've never had a problem with my partners knowing I have diabetes. And I've never missed the opportunity for sex because a potential partner had qualms about my condition.⁵⁵

Despite clearly identifying many of his own sexual encounters as “casual,” as laura w never actually did despite the backlash, SugarfreeB's comment does not garner the same kinds of fear-mongering and shaming for its apparent improprieties as do the comments by laura w and other women on the thread. The blatant disproportionate responses to women's sexualities in this thread further normalize heteromonogamy in a space where, in essence, technologically-altered non-normative sexualities are being openly discussed and managed. Those norms are deployed in order to connect users like Spike and HaulZitAll to normative discourses in the interest of

⁵³ “Intimacy and the Pump Wearer.”

⁵⁴ HaulZitAll in “Intimacy and the Pump Wearer.”

⁵⁵ “Intimacy and the Pump Wearer.”

marking others' experiences outside them. The social forces associated with that process weigh heavier on women than they do men, as is made clear through SugarfreeB's acceptability.

No matter the intensity, nature, or purpose of the interaction, every one of the insulin pump users discussing their sexual and intimate practices in these discussion forums necessarily must engage their medical devices during sex. The device, as both an object and an immaterial social actor, becomes a part of bodies, identities, and relationships in ways that move the bounds of their sexual and intimate practice. Effects and implications of this body-device integration are as wide-ranging as the experiences of the individual users, but in each case above they approach the online Diabetes community to manage these biomedicalized techno-intimate relationships. In so doing, and largely unconsciously, the sets of norms built around the system of compulsory able-bodiedness is constantly reinforced through users' actions and the ways they narrate them online. Gender and sexual norms are likewise re-inscribed through these same practices, so while the engagements with other pumpers can prove productive in some ways, they also serve a normalizing function that leaves little room for non-normative subjectivities of any sort (oddly enough, at times, even that of people with Type 1 Diabetes themselves).

CHAPTER 5: DE-SCRIPTING HUMAN-OBJECT RELATIONSHIPS IN INSULIN PUMP TREATMENT

In June 2015, Dexcom, Inc. announced a marketing collaboration with Nick Jonas, recording artist and actor with Type 1 Diabetes. One of only two continuous glucose monitors (CGMs) approved by the FDA at that time, the Dexcom had secured a reputation as the more reliable option—a point they lean into hard in their press release.¹ Throughout the text of their announcement and the accompanying three-minute video clip,² Jonas details the difficulties and uncertainties associated with his diagnosis and the notable change his Dexcom has made in day-to-day life. After detailing the device's various conveniences and before asking viewers to visit the Dexcom website, Jonas makes a pathos-heavy anthropomorphizing statement about his device. "Having a CGM is like having a best friend that always looks out for you."

Jonas's words here, whether written by him or Dexcom, Inc.'s marketing department, do the cultural work of scripting certain conceptions of human-device relationships—a central theme throughout this dissertation. In previous chapters I have discussed, for example, how these devices become embedded within the biological and material processes of the body, thereby redefining how T1D bodies are and even can be understood by patient-users and others. That redefining process orients the context for patient-users' interactions with other people in order to account for these technological interlopers within their relationships, variously defined.³

In listening to informants discuss their experiences with insulin pump treatment, one common linguistic idiosyncrasy opens up a particularly intriguing cultural problem that echoes Jonas's sentiment and serves as the basis of this chapter. In each of the twelve interviews with current and former insulin pump users conducted for this study,⁴ informants referred to the

¹ Dexcom, Inc., "Dexcom and Nick Jonas Raise Their Voices for Diabetes Awareness," June 10, 2015, <https://www.dexcom.com/news/nick-jonas-dexcom-cgm>.

² Though the press release is still archived on the Dexcom website's news section, all other materials related to Nick Jonas's collaboration have been removed. The short video clip has also been removed from the Dexcom YouTube channel. To this date, neither party has addressed this change.

³ See Chapters 3 and 4 herein, respectively.

⁴ Though this study included fifteen total informants, one informant had never used an insulin pump (though they had consistently used other glucose testing devices for many years), and two informants discussed their experiences as caregivers for children with Type 1 Diabetes (one of whom used an insulin pump, while the other

devices as “my pump” and “my CGM.” In the months (and in some cases years) following these interviews, I took this linguistic move at face value; referring to the pump as *theirs* builds a common-sense descriptive relationship between the person and the device, a relationship which served as the primary focus of our conversations before, during, and after the interviews themselves. Within that context, participants referring to these devices in relation to themselves fits within the very framing I helped create, and I therefore did not read into it beyond that.

Upon further reflection, however, this casual deployment of linguistic possession gestures toward another, more significant question: what *makes* the insulin pump theirs? Is it theirs simply as a result of a purchase agreement? Perhaps it is the amount of time a person spends with an insulin pump which produces this type of connection. Do users’ proximities to these devices, constantly attached to one another in a material sense, produce that connection? Are these conceived as property relationships, leaning on institutional definitions of ownership? Imbuing these human-technological relationships with cultural value, the use of the possessive “my” implies a vague and ambiguous sense of ownership which functions as a common-sense stand-in for what is, in practice, a deeply complex process of both human- and object-produced meaning creation.

In this chapter, I unpack the casuality of patient-users’ possession and ownership of Diabetes treatment devices. Drawing Madeleine Akrich’s conception of technological scripting and “de-scripting” together with Peter-Paul Verbeek’s theory of how these scripts are imbued with ethical definitions for human actions, I analyze informant descriptions of their connections with their Diabetes and their devices. Insulin pumps, CGMs, and blood glucose (BG) meters are scripted as both biomedicalized saviors/miracles, materializing the authority of medical science and practice through use, and as techno-emotional extensions of patient-users themselves. In this way, I argue, they function as contested objects at once possessed and dispossessed, their use both “freeing” and compelled. Though, as I will argue, property claims to these devices, technologies, and the data they produce are fractured and distributed in interesting and important ways, neither the informants interviewed for this study nor a majority of the forum interactions under consideration elsewhere in this dissertation engage these conversations to any notable

was still awaiting insurance approval). Both caregivers, however, used the possessive language “their pump,” mirroring the linguistic framing of the devices among the twelve other pump-using informants.

degree. Instead, as I will show, informants utilize other systems of cultural meaning-making and valuation that at times reinforce their devices' cultural scripts, while at others further complicate the already contested claims surrounding insulin pumps and their related network of treatment technologies.

In what follows, I briefly work through concepts of social scripting of non-human objects and technological mediation in order to analyze informants' discussions of device-connectedness and emotional and/or affective experience as central locations where human-object relationships are built and maintained. In so doing, these narratives come to reveal human-object relationships in insulin pump treatment as something that is primarily *felt*—physically and/or psycho-emotionally—even when it is not (or cannot be) fully understood. These felt connections reveal larger cultural narratives and stigmas related to T1D and medical device use, and at times highlight productive breakdowns within insulin pump social scripts that redefine what these human-object networks are and can be.

De-Scripting Technological Mediation in Diabetes Devices

In her widely cited chapter titled “The De-Description of Technical Objects,” Madeleine Akrich describes the cultural work produced through interactions between humans and technologies. Using a semiotics-based actor-network approach, Akrich argues that technologies “participate in building heterogeneous networks that bring together actants of all types and sizes, whether human or nonhuman.” As participative social actors themselves, technical objects can define the roles people take-on in various situations (i.e. they create actants, or actantial roles to be filled by people within particular social narratives or scenarios), and in so doing, they influence “new arrangements of people and things.”⁵ Within this framework, deeply influenced by the work of Bruno Latour,⁶ objects can be understood as agents themselves which contribute directly to the fabric of social dynamics in a given collective.

⁵ Madeleine Akrich, “The De-Description of Technical Objects,” in *Shaping Technology / Building Society: Studies in Sociotechnical Change*, ed. Wiebe E. Bijker and John Law, Second Printing (Cambridge, Mass.: MIT Press, 1997), 206–7.

⁶ Akrich acknowledges Latour in the notes of this chapter, citing her discussions with him as central to her process of working through her theoretical conclusions. She likewise turns to his work on delegation throughout the chapter, which was published as a chapter in the same collection. For a revised version of his ground-up approach to

But importantly for Akrich (and for the discussion in this chapter), those social objects can never be understood independent of people due to the constant human interaction that defines them. People involved in creating technological objects inscribe them with their own intentions and visions of the world, a process that results in what Akrich describes as “scripts” or “scenarios.” These objects (as social scripts) set the framework for the actors and space involved in their use.⁷ In the case of insulin pumps, for example, the device is designed around the specific purpose of intended users attaching it to their abdomen and injecting insulin. Designers, programmers, and manufacturers imbue the device with this intention, and both the pump itself and the narratives surrounding it take-on this purpose, such that users interact with the device through that specific use program even before their first interaction. There is no insulin pump without its designers, nor without intended users—following this point a few steps further, there is also no insulin pump without Diabetes, or insulin, or biomedicalized intervention more generally. These scripts weave yet another thread into the web of social factors that compel people with Type 1 to use insulin pumps as their primary means of insulin treatment.

As with any framework, however, the ways people and things function within it can be quite fluid, and they often locate sites where those structuring narratives breakdown. In Akrich’s read, the innovator and the user locations are two sites where the limits of these scripts are identified, tested, and at times challenged and/or revised, especially when the imagined user and the actual user are understood as separate actants within that program. These fissures in the script are where the scripting itself becomes visible, and they provide a window for analysis Akrich refers to as “de-description:”

It is the inventory and analysis of the mechanisms that allow the relation between a form and a meaning constituted by and constitutive of the technical object to come into being. These mechanisms of adjustment (or failure to adjust) between the user, as imagined by the designer, and the real user become particularly clear when they work by exclusion, whether or not this exclusion is deliberate.⁸

actor networks, see: Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory*, 1st edition (Oxford; New York: Oxford University Press, 2007).

⁷ Akrich, “The De-Description of Technical Objects,” 208.

⁸ Akrich, 209.

By identifying and interpreting the “mechanisms” by which technologies construct the material world and its meanings, as well as those that conversely construct objects and their meanings, social studies of technologies can de-script objects and their social contexts and take more effective account of non-humans as social actors themselves.

In challenging those technological scripts, users identify practical issues that arise from a breakdown between an imagined user and an actual one. Those challenges can also be emblematic of a breakdown in values between designer and user, or perhaps between user and the script. Taking the concept of the scripted object into the site of human action, Peter-Paul Verbeek argues that these interactions are fundamentally ethical in nature. As Akrich, Latour, and others have claimed, the common-sense assumption that technologies simply exist to perform a function does not account for the ways they influence the actions of people. In a more nuanced sense, Verbeek argues, technologies actually mediate both human perceptions of the world around them and their actions in relation to it. Social meanings embedded within these devices, i.e. scripts, therefore perform significant roles in mediating human action and understanding as well.⁹ This perspective is particularly alarming in the context of normative or normalizing world views, as social hierarchies are reproduced and enacted through that scripting-use program.¹⁰ Throughout that process, technological scripts construct what Akrich calls “casuality” that normalizes the world views of the script into the unacknowledged *everyday* which can be damaging, even violent for non-normative peoples.¹¹

⁹ Peter-Paul Verbeek, “Materializing Morality: Design Ethics and Technological Mediation,” *Science, Technology, & Human Values* 31, no. 3 (May 1, 2006): 362–63, <https://doi.org/10.1177/0162243905285847>; Verbeek expands on the theories outlined in this article in his book published five years later. There he delves more fully into his non- or post-humanist ethic and how that standpoint can aid scholars working on/with technologies in de-centering the human in their analysis. As I am not employing a non-humanist ethic in this dissertation, I opted for a more thorough discussion of his article here. See: Peter-Paul Verbeek, *Moralizing Technology: Understanding and Designing the Morality of Things* (Chicago: University of Chicago Press, 2011), <https://ebookcentral.proquest.com/lib/purdue/detail.action?docID=836899>.

¹⁰ See, for example, Safiya Noble’s discussion of inequality in the expansion of Geographic Information Systems (GIS) and inequalities in data production/ownership: Safiya Umoja Noble, “Geographic Information Systems: A Critical Look at the Commercialization of Public Information,” *Human Geography*, November 1, 2011, <https://doi.org/10.1177/194277861100400306>; see also Mark Andrejevic’s work on digital surveillance and control on networked communication: Mark Andrejevic, “Surveillance in the Digital Enclosure,” *The Communication Review* 10, no. 4 (December 5, 2007): 295–317, <https://doi.org/10.1080/10714420701715365>.

¹¹ Akrich, “The De-Scripting of Technical Objects,” 207.

In the case of insulin pumps, the object is culturally scripted as both a part of medical practice/treatment and as commodity/property. The function of the former is an inherently casual relationship between the device and both its creators and users. Filling a medical need for BG regulation is the common-sense function for the device, and hyper-visibly so, though concluding an analysis here does not account for the nuances of its social “life,” to borrow a term from Arjun Appadurai.¹² Even in the context of its primary medical function, the ways it has been and continues to be scripted carries myriad social effects outside its intended use.¹³ But the casuality of Diabetes devices as property, on the other hand, is co-produced with a particular invisibility that makes this script both analytically slippery and intriguing.

De-scripting Diabetes Devices as Property

Property theory, as a legal framework, offers both an interesting (and in practice, limited) lens into people’s relationships with their Diabetes devices. In relation to both legal practice and social theory, property plays a significant role in structuring US society and culture. Legal historian Stuart Banner traces a snapshot-style long-narrative history of the shifts that have characterized conceptions of property in America, and argues that despite theorists’ and legal scholars’ attempts to locate property’s “‘true’ nature,” it is impossible to define in such definite terms. “It is a human institution that exists to serve a broad set of purposes. Those purposes have changed over time, and as they have, so too has the conventional wisdom about what property is ‘really’ like.”¹⁴ Property, then, is historically and socially contingent—an argument which has been made in relation to numerous institutions, social, legal, governmental, and otherwise. Some of these definitions/understandings have remained particularly potent in US legal education and practice, however, and therefore frame issues of property related to insulin pumps in ways that can affect both claims to those devices and individuals’ experiences with them.

¹² Arjun Appadurai, ed., *The Social Life of Things: Commodities in Cultural Perspective* (Cambridge University Press, 1988).

¹³ See Chapter 3 for an in-depth exploration of the material experience of Diabetes device use and its effects on Diabetic body images; see Chapter 4 for a discussion of the devices’ active role in social and intimate relationships between people; see Chapter 6 for a system-level analysis of individual financial burdens associated with the use of these devices.

¹⁴ Stuart Banner, *American Property* (Harvard University Press, 2011), 289.

Property as a legal doctrine is commonly understood as a *relationship* between people and things (and/or between people), as opposed to property as *things* themselves. Property-as-relationship has deep roots in Anglo-American legal doctrine, established by theorists such as eighteenth-century British judge/politician William Blackstone. Blackstone proposed a relationship that is two-fold: first, property is primarily defined by man's ability to claim complete control over material things in the world around them—a problematic and colonialist rhetoric, his language of “absolute dominion” over “external things of the world” gestures toward property as fundamentally relational, “man” to “things,” in which decision-making power lies solely with the former.¹⁵ Second, property defines certain relationships between or among people rather than simply relationships between people and things. Though this shifted relational theory had circulated in a limited capacity throughout the nineteenth century, American jurist Wesley Newcome Hohfeld brought this reading into mainstream legal thought in the US around the turn of the twentieth century. Suggesting that property is not actually about person-thing relationships at all, Hohfeld argued that property is about interpersonal rights and obligations like all other legal formulations (contracts, for example), and only differs in scope (or, whereas contracts define rights and obligations for the specific parties involved, property defines the same in a general sense).¹⁶ Thus, as a legal and social institution property defines the parameters of certain interactions between people, and possession only becomes property when it is socially recognized as such.¹⁷

And it is here, with the necessity of social recognition in property relationships, where insulin pumps scripted as property becomes particularly slippery, especially in the cases of the informants interviewed for this study. Property relationships between people in relation to things within the US are primarily defined within a rights-based framework. Because multiple rights and obligations have been doctrinally associated with property in the US, in the twentieth and twenty-first centuries property is most commonly defined as a “bundle of rights.” This bundle

¹⁵ William Blackstone, *Commentaries on the Laws of England, Volume II, of the Rights of Things* (Oxford: Clarendon Press, 1766), 2–3.

¹⁶ Wesley Newcomb Hohfeld, “Fundamental Legal Conceptions as Applied in Judicial Reasoning,” *The Yale Law Journal* 26, no. 8 (1917): 718–22, <https://doi.org/10.2307/786270>.

¹⁷ Banner, *American Property*, 103; See also: Thomas Davidson, “Property,” *Journal of Social Science: Containing the Transactions of the American Association*, no. 22 (1887): 107–12.

usually includes rights to possession, use, transfer, profits stemming therefrom, and to enforce one's sole claim to one or more of those rights (commonly referred to the exclusive right to exclude).¹⁸

As a foundational concept—or as some have argued, the primary concept—in Anglo-American property rules as a whole, the *exclusive right to exclude* is one of the most interesting and contested ideas in all of property doctrine. The US Supreme Court has reiterated that private property simply cannot exist without this right.¹⁹ As the argument goes, if someone cannot maintain their ownership/use/possession of things by excluding those rights from other people in relation to those things, there is no private property because anyone could come and do what they will with whatever they will. But therein lies the heart of Marx's critique of private property, and capitalist economic exchange as a whole. If the exclusive right to exclude is the central tenet of property doctrine, then property itself is primarily about power relationships and not things or rights to things at all.²⁰ As Cheryl Harris points out, the legal right to exclude on the basis of property has historically gone hand-in-hand with legal and cultural rights to exclude on other bases such as race and gender, or as Margot Canaday has pointed out, on the basis of sexual “perversion” or “deviancy”—language depending on the historical moment—not to mention the actual conflation of property and human beings characteristic of the history of global capitalism.²¹ So while the economic determinism central to early Marxist thought created limits to its ability to understand certain aspects of capitalist exploitation (due in part to the limitations of determinist ideologies in general), the Marxist critique of systems of private property help us understand the ways in which exclusion has played out on a larger and broader scale.

These limits of the theoretical, and fundamentally human roots of US legal doctrine complicate the analysis of the property scripts of insulin pumps and CGMs. Considered in light

¹⁸ Lawrence C. Becker, “The Moral Basis of Property Rights,” ed. James Roland Pennock and John W. Chapman, *NOMOS, Property Special Issue* 22 (1980): 189–90.

¹⁹ As quoted in Thomas W. Merrill, “Property and the Right to Exclude,” *Nebraska Law Review* 77, no. 4 (1998): 730.

²⁰ Karl Marx and Friedrich Engels, *The Communist Manifesto* (New York: International Publishers Co, 2014), 10.

²¹ Cheryl I. Harris, “Whiteness as Property,” *Harvard Law Review* 106, no. 8 (June 1, 1993): 1707–91, <https://doi.org/10.2307/1341787>; Margot Canaday, *The Straight State: Sexuality and Citizenship in Twentieth-Century America* (Princeton, N.J.: Princeton University Press, 2011), 11–12.

of these doctrines writ large (and especially the exclusive right to exclude), insulin pump users cannot usually make a simple claim to ownership of their devices. Instead, those rights are fractured and distributed among several stakeholders with often considerable material implications for device users. Patient-users themselves hold certain claims to their devices through the acts of possession and continuous use, rights that play important roles in the aforementioned “bundle.” They also, to a certain extent, can make similar claims based on their purchase agreement. That last claim is complicated, however, as few if any patient-users can purchase their devices outright. As I will detail in Chapter 6, insulin pumps and CGMs cost thousands of dollars and are unobtainable for most without an insurance company fronting most of that financial burden (at a significantly discounted rate). This adds another party into the site of purchase, muddying the waters of that particular right. What is more, device manufacturers hold a variety of intellectual property claims to dozens of those devices’ components (patents, trademarks, copyrights) giving them the exclusive right to *pumps* plural even where patient-users may have claims to their *pump* singular. That distributed or fractured ownership has serious implications for people when that object has become a part of both their body and their everyday social practices as a site of medical treatment.

Despite the myriad and rather important ways in which property influences people's relationships with insulin pumps, those issues were imbued with a scripted causality such that they never came up with informants in any of the discussions throughout the duration of this study. Thus, while a study of their connections to their devices through the lens of property or ownership is timely and worthy of future intellectual labor, the discussion that follows attempts to de-script the medical and legal frameworks written into informants’ human-device relationships in order to highlight that which was of utmost importance to the informants themselves: how it feels to use an insulin pump. It was not ownership, in a legal sense, that produced a human-object relationship for these informants. It was their constant connectedness and affective experiences with their bodies and devices together—in essence, how device use felt—that subtly and consistently resurfaced as primary sites of meaning creation between informants and their material world.

Material Culture, Possession, and Affective Value in Things

Though insulin pump users may not necessarily hold the exclusive right to exclude in relation to their devices, they do produce an insulin pump that is intrinsically *theirs* through their various cultural practices. Wading through the vast bodies of scholarship regarding discursive and visual theories/methods for understanding things and their relationship to people garners hotly debated disagreement. Central to these endeavors, whether theorists agree with its implications or not, is the assumption that there is *something* to which the linguistic and visual signifiers point—a material object that exists. Due to the socially and culturally constructed quality of textual and visual representations of objects, however, the possibility of ever actually attaining an understanding of things as they ontologically exist is questionable (and according to some, an outright impossibility).²² Nevertheless, all of our sensory engagements with the world connect us to and between material objects, and their proximity and situatedness in relation to people and bodies (which are likewise material in their own right) demonstrates significant influence on lived experience.

For people with T1D, the materiality of their bodyminds and physiologies are affected by their unique proximity to treatment devices in their possession. Citing Ferdinand de Saussure's semiotic work on sign systems, Ian Woodward argues that rather than serving a straightforward, utilitarian purpose, material objects actually fill a symbolic role in allowing people to "construct and assign meanings within their cultural universe." Through the possession of objects, people inscribe them with social meaning and make the categories of culture visible.²³ According to Woodward, then, material objects visualize culture—or rather people visualize culture through those objects.

But where Woodward is careful to keep agency within the realm of human action, Carl Knappett argues for a more distributed co-construction model. In his book *Thinking Through Material Culture: An Interdisciplinary Perspective*, Knappett claims that humans and artifacts in

²² As one example among scores of theorists, Levinas subscribed to the idea that The Other, understood as anything outside the self, is unknowable in an absolute sense. It is always understood through the self, taking the foundational concepts behind Plato's and Aristotle's constructions of mimesis to its limit. See: Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, 4th edition (Norwell, MA: Kluwer, 1991); Plato, *Plato's The Republic* (New York: Books, Inc., 1943); Aristotle, *Aristotle's Poetics* (New York: Hill and Wang, 1961).

²³ Ian Woodward, *Understanding Material Culture* (Los Angeles: SAGE Publications Ltd, 2007), 67, 95.

their possession constitute each other simultaneously. “[T]he human and the non-human bring each other into being,” they “intermingle” in an actor-network sense, and thereby the social is crystalized into this human-object assemblage.²⁴ This notion calls-back to the distributed, or “delegated” systems of social agency theorized by Akrich and Latour that operate as the networks wherein social scripting (and de-description) takes place. Under the pseudonym Jim Johnson, Bruno Latour argued in 1988 that all “purely” technical objects are themselves active agents within social systems and deserve critical sociological study.²⁵

Extending Latour’s work on agency into cultural production and language, Lorraine Daston edited a collection of essays that interrogates how and why things “speak” to us, emotionally or emblematically. In her introduction to *Things That Talk: Object Lessons from Art and Science* titled “Speechless,” Daston argues that “talkative objects” speak to their observers as “chimeras,” embedded and embodied with a plurality of social and cultural signifiers from the time of their creation to the time of the observation and everything they came into contact with in-between.²⁶ That agency is still limited, however, as it is still rooted in the agency of the human—things speak because we give them voice. As Nicholas Saunders has argued elsewhere, objects derive meaning far beyond their intention in production. In becoming cultural assemblages themselves, objects “occupy a dynamic point of interplay between animate and inanimate worlds, inviting us to look beyond the physical world and consider the hybrid (and constantly renegotiated) relationships between objects and people.”²⁷

Considered in the context of material possession and human-object relationship-building, that interplay can have significant effects on how people understand objects. Joann Peck and Suzanne Shu have argued that merely touching objects increases people’s perceived sense of ownership—in a psychological sense rather than a legal one. Building that sense of ownership

²⁴ Carl Knappett, *Thinking Through Material Culture: An Interdisciplinary Perspective* (Philadelphia: University of Pennsylvania Press, 2005), 170, 83.

²⁵ Jim Johnson, “Mixing Humans and Nonhumans Together: The Sociology of a Door-Closer,” *Social Problems* 35, no. 3 (June 1, 1988): 298–310, <https://doi.org/10.2307/800624>.

²⁶ Lorraine J. Daston, *Things That Talk: Object Lessons from Art and Science* (New York; Cambridge, Mass.: Zone Books, 2007), 24.

²⁷ Nicholas J. Saunders, “Memory and Conflict,” in *The Material Culture Reader*, ed. Victor Buchli, First Edition (Oxford ; New York: Bloomsbury Academic, 2002), 176.

requires “the ability to control the object, coming to know the object intimately, and investing the self in the object,” experiences facilitated through tactile interaction with things.²⁸ If mere touch produces responses to this degree, then the constant touch and attachment associated with insulin pump treatment and CGM use would serve to amplify the types of psychological and material connections Peck and Shu identify here. As people build understandings of their bodies and devices together, constantly materially and psychologically present, new notions of possession and technological agency are produced, and complicated affective experiences emerge as a result.

Constant Connectedness

Living with diabetes in the twenty-first century is by necessity a device-connected experience. Since the development of insulin in the 1920s, multiple daily injections (MDIs) have been the standard of care in managing T1D. MDIs require regular, repeated interaction with syringes and pharmaceuticals such that patients must remain in close proximity to these devices for their scheduled (and possibly emergency) injections of insulin. Likewise, since doctors began prescribing daily blood glucose (BG) monitoring and maintenance en masse during the 1980s and 1990s, patients engage with their BG meters (as well as their paraphernalia) so frequently that they must keep their meter with their person at all times. This need—medically compelled and life-sustaining—requires not only a shift in daily health practices and interactions with objects, but a shift in the ways individuals understand the very structure of their own inhabited world.²⁹ As one informant noted, his parents bought his first BG meter immediately after leaving the hospital where he was diagnosed. Jason was ten or eleven years old at the time, but as he recalls, “It was so nice to get my own meter, my own blood sugar meter.” It was nice to have his own device, in part, because the finger-prick lancet devices used at hospitals are much larger and

²⁸ Joann Peck and Suzanne B. Shu, “The Effect of Mere Touch on Perceived Ownership,” *Journal of Consumer Research* 36, no. 3 (October 1, 2009): 434–47, <https://doi.org/10.1086/598614>.

²⁹ Refer to my discussion of the material experience of insulin pump treatment in Chapter 3 of this dissertation.

sharper than those sold with at-home meters—blades that scarred him physically and mentally such that he still spoke of them with exasperation thirteen years after-the-fact.³⁰

Beyond the hospital lancets, however, Jason was excited to have his own meter because it became *his*. It was always with him, and he put himself into the device in a very real sense. Multiple times per day and thousands of times throughout the life of his BG meter, Jason inserted biomaterial from his own body into the meter as part of his regular treatment rituals. That requires tactile interaction with the zip case, test strips (and the “snap” of their container), meter controls, meter displays, and lancets during every test. That level of material “intermingling,” to again echo Knappett,³¹ produces non-material connections between users and devices binding them together in the act of maintaining a burdensome chronic condition. Every zip, every snap of a lid, every spring-loaded jab of a fingertip, and every beep from a meter becomes part of Jason’s personal and embodied experience living with T1D. The objects became ritual in themselves, imbued with not only the script of its own function individually but that of their functions and practices collectively, and thereby reflects that back onto the cultural meanings associated with that entire network of devices.

Jason’s memory of the significance of his first BG meter, as quoted above, is made all the more illuminating as his treatments changed in the years following diagnosis. In 1994, a year-or-so after his parents bought his first meter, Jason’s doctor prescribed the use of an insulin pump as his primary method of treatment—a treatment system he has continued to use throughout the following two decades. This decision was an important one, as clinical consensus surrounding insulin pump treatment as the standard of care in managing T1D did not emerge until well into the twenty-first century. Jason would be considered an early adopter, one of the earliest in fact, as he was informed by his doctor that “for about nine months [he] was the youngest person in the country to be on an insulin pump.”³²

But Jason’s early adoption of insulin pump treatment has had a much more deep and abiding impact on his lived experience than it has on clinical treatment of T1D children and youth. About nine months after Jason switched to a pump, he was told by his doctor that another

³⁰ Jason, interview by Stephen Horrocks, male age 35, diagnosed with T1D in 1993, June 23, 2017.

³¹ Knappett, *Thinking Through Material Culture*, 83.

³² Jason, interview.

child (much younger than him, only about six months of age compared to his thirteen years) had been put on the pump and his tenure as “youngest” had ended. He narrates this unique patient-user status with such pride that his disappointment is palpable as he describes its abrupt removal. A piece of himself, a portion of his notion of Jason-ness was suddenly absent despite the continued presence of the objects with which it was constructed. Put another way, this exclusive patient-user status had become part of his identity, and he still engages deeply with that during his interview over twenty years later.

What likewise did not end is Jason’s reliance on an insulin pump as his primary mode of managing his blood glucose levels. He has had an insulin pump connected to his body—adhered to his skin, inserted into his tissue, constantly injecting pharmaceuticals—for two-and-a-half decades straight.³³ His pump is on his body, in his body, carried in his pocket. He looks at its screen numerous times per day, he pushes its buttons and navigates its user interface, and he feels the cold insulin disperse throughout his abdomen. In short: his insulin pump is always there, and he feels that presence in myriad ways every day.

Considered in a broader sense, T1D itself requires constant connectedness with a variety of objects that make life manageable, even possible. Insulin injections necessitate the use of a number of objects, and when someone takes multiple shots per day—wherever they may be—those objects must always be near them. Prior to switching to an insulin pump as a teenager in the early 2000s, Stephanie recalls, “at that point my doctor had changed me to the fast-acting insulin, the Humalog, so I took a shot every time I ate.” That meant syringes, vial(s) of pharmaceuticals, and alcohol swabs (though often left unused) had to be stored in a carrying case and placed in her bag at all times, not only for meals but in case of unexpected high BG levels as well. Add to that the BG meter device, bottles of test strips, and lancet device she had to carry to test her blood throughout the day—along with the juice boxes, candies/snacks, and/or Glucagon-injection pen in case of low BG—and the T1D go-bag begins to take up considerable space. In some ways, insulin pump treatment simplifies that process for patient-users, requiring far fewer

³³ Because they are programmed to inject small amounts of insulin at regular intervals throughout the day (“basal” injections), insulin pump users are advised to keep the device attached at all times. This means when, for example, the reservoir runs out of insulin, or the tubing catches on a door handle and pulls the infusion site out of the user’s body, they are advised to re-attach it with a new site and/or reservoir as soon as possible to resume its regularized injection processes. Though there are of course circumstances when users cannot insert a new site immediately, the high BG levels that result from being disconnected for an extended period of time is a significant driving factor for users’ usual swift reconnection.

things to be carried with them at all times. What would otherwise require either vials and syringes or pens and needle tips is facilitated by a single mechanical device and tubing. And though about two-thirds of that go-bag are still important to carry at all times, having an insulin pump connected to the body allows Stephanie and other patient-users to leave the insulin materials at home; “I could take a shot without having to carry all this extra stuff around.”³⁴ This slightly lighter load to carry has made a significant impact on several other informants as well. “It’s easier just to like get up and go somewhere,” notes Ashley, “I didn’t have to carry so many things with me. You know, just like a meter.”³⁵

This ambiguous, life-saving burden associated with the physical presence of medicalized things is not only created as people “intermingle” with these several devices,³⁶ but as objects intermingle with each other through the act of use. In the above examples, informants were genuinely relieved that they no longer had to carry around vials and syringes once they began insulin pump treatment. Yet, even as they cast off their syringes, people with T1D must carry on/in their body a new and physically heavier object. At the same time, they must still keep their BG meter within arm’s-length, and hypoglycemic episodes can still only be treated by ingesting or injecting some form of carbohydrate. Similarly, but to a lesser degree, if syringes and vials existed individually within T1D material experiences their physical and conceptual weight would be lighter than when they exist alongside all of the other go-bag devices and objects. After switching to an insulin pump, the majority of the go-bag is still, generally speaking, compulsory.

What, then, accounts for the lighter burden they experience despite no measurable change in physical weight they carry? I would suggest that the tactile, hands-on means of injection when using syringes signifies patient-users’ medicalized condition such that it takes on some of the meaning associated with Diabetes itself. So heavy is that weight, as it is built through/alongside people’s social and physiological experiences within their own bodies, that removing the syringe and vial objects takes with it some of those material reminders of T1D more broadly. When syringes are replaced by tubing and vials are replaced by an on-board reservoir in the context of insulin pump treatment, the medicalized objects are replaced by hi-tech “cool” devices, and that

³⁴ Stephanie, interview by Stephen Horrocks, female age 31, diagnosed with T1D in 1993, May 23, 2017.

³⁵ Ashley, interview by Stephen Horrocks, female age 26, diagnosed with T1D in 2000, June 1, 2017.

³⁶ Knappett, *Thinking Through Material Culture*, 83.

non-physical (and even physical) weight feels substantially lighter despite the new device penetrating their space and skin. In some ways, these frustrations with T1D go-bags may provide as significant a lens into the psycho-emotional experience of Diabetes as do the objects themselves.

As people's constant physical touch and attachment to these devices becomes routinized and regularized over the span of decades, so too does their non-physical attachment. For people such as Jason, Stephanie, and Ashley engaged in insulin pump treatment, the act of use requires round-the-clock attention and cognitive interaction with their physiologies and devices. Not only do Diabetes and devices influence their physical interactions with (and presence in) the world but is ever-present in the ways they sense and understand it as well. In her 2017 essay, "Data Rituals in Intimate Infrastructures: Crip Time and the Disabled Cyborg Body as an Epistemic Site of Feminist Science," Laura Forlano details many of the perceptual and temporal implications of living a device-connected life with Diabetes. A self-identified "disabled cyborg," Forlano viscerally expresses the tensions and possibilities of, for example, when her devices "introduce industrial clock time to [her] biological processes" by mapping injection cycles onto an hourly system:

On March 16 at 7:49 PM, my pump displayed a "Low Reservoir" alert. At 11 PM, when I returned home from dinner at an Italian restaurant with a new writing group, I checked to find that only 2.9 units of insulin remained, which would last just over five hours, according to the pump's settings. I decided to refill and reset the pump before I went to sleep rather than getting up in the middle of the night or very, very early.

My glucose monitor, on the other hand, announces with a high-pitched alert that it will need to be reset in two hours. Never mind that I am teaching on Wednesdays and am in the middle of a lecture in my Designing Futures class. I dismiss it but again, about ten minutes later, a shrill beeping sound and no way to silence it. It seems to sound louder and louder every time, unaware of its surroundings.³⁷

Clock time is scripted as a framework onto which insulin pump treatment is built, but as Forlano demonstrates in these two paragraphs, that temporal system does not fit well with what her body is doing. Instead, in performing the function they were built and coded to perform, her insulin

³⁷ Laura Forlano, "Data Rituals in Intimate Infrastructures: Crip Time and the Disabled Cyborg Body as an Epistemic Site of Feminist Science," *Catalyst: Feminism, Theory, Technoscience* 3, no. 2 (October 18, 2017): 4, 15, <https://doi.org/10.28968/cftt.v3i2.130.g267>, Emphasis original.

pump and CGM become hyper-present throughout a range of everyday rituals and actions. In so doing, both the devices and rituals are transformed—in some cases pushed into compliance with the capitalist time system as scripted, and in others used as channels for de-scripting and redefining the structures around an expanded T1D “crip time”³⁸ that accounts for the particularities of Diabetic experiences.

Reframing patient-users’ perception of the world can have lasting effects on the ways they understand their bodies and themselves—positively, negatively, and (most often) both positively and negatively at once. The transformation of perception through diagnosis and device use produces complex consequences for people’s conscious and unconscious experience. Though I do not intend to unravel the web of psychological and philosophical implications of this shift in serious depth here, it is worth considering to a limited degree through the lens of one informant’s example. Just before completing his doctoral defense, Christopher was seriously injured while playing competitive ultimate frisbee which required surgery, and he had come to the conclusion that he would no longer be able to compete at that level. Soon thereafter, he accepted his first academic position just as he and his wife found out they were expecting their first child. If this was not enough change all-at-once, he was hospitalized about six months later and diagnosed with Type 1 Diabetes. Reflecting on the difficulty of that period three years later, he realizes that Diabetes has had a particularly interesting effect on his subconscious. “What I’ve discovered in the last, probably in the last year,” he says, “even when I dream, I’ve got Diabetes.” A notable change for him, Christopher unpacks these dreams further:

Well I used to have dreams where I’d be playing ultimate and I realized that I couldn’t play because of my leg, [. . .] or I can’t play because of my back, but I was never Diabetic in my dreams. In the last year, my dreams are that I’ll be playing ultimate, I’ll somehow end up playing a game that I hadn’t planned on playing, and I’ll realize I’ve just had lunch and I’ve got eight units of insulin on board. And so, in the dream my panic is around. . . as a Diabetic, I can’t, you know?³⁹

³⁸ Here Forlano uses the “curative time” vs. “crip time” dichotomy as defined by Alison Kafer, differentiating between the normalizing and oppressive temporalities of compulsory able-bodiedness typical of the former, and the revolutionary and liberating re-framing of temporality to the experience of disabled experiences typical of the latter. For more, see: Alison Kafer, *Feminist, Queer, Crip* (Indiana University Press, 2013), <http://www.jstor.org/stable/j.ctt16gz79x>.

³⁹ Christopher, interview by Stephen Horrocks, male age 36, diagnosed with T1D in 2013, June 20, 2017.

The traumas of his injury, the surgery, and perhaps most importantly in this context, being compelled to stop playing the sport that has played a significant role in his life for many years, linger in Christopher's mind and body. He was already experiencing anxiety dreams related to his inability to physically endure a game for some time, which made it possible for him to notice a change in the driving force of his fear during the dream. Now, a few years since both his injury and his diagnosis, it is not his leg or back that cause him anxiety during his dream-game—it is his Diabetes. Because he has just eaten, Christopher input the carbohydrates he ate during lunch to his insulin pump, which calculated his dose amount and metered-out the insulin to his body. When he says he still has eight units “on board,” he means that the insulin he injected has not yet fully worked its way through his body, and intense physical exertion could cause dangerously low BG levels. His T1D and his medical technologies force his dream-actions: “as a Diabetic, I can't, you know?”

And just a few minutes before he relayed this memory and reflection to me, Christopher was interrupted by a slight dizziness and inability to connect his thoughts. He paused, pulled out his BG meter, pricked his finger and tested for what he already knew, i.e. he had low blood sugar. He apologized, I assured him it was unnecessary, and he proceeded to eat a small carbohydrate-based snack while we made small talk and his BG came back up. Both his reflection on his dreams and his mid-interview hypoglycemic episode make it clear that Diabetes and its devices are always present, and always connected to Christopher and his life—physically and socially.

The example above, though based on an informant's memory of a dream(s), does the work of highlighting the role that affect or feeling (generally defined) play in living a device-connected T1D life. From the panic surrounding a hypoglycemic episode to the fear of T1D-caused social isolation, the shock and stress of new Diabetes-specific information and treatment systems to guilt and trauma of the familial cost of chronic illness, affect, emotion, and feeling dominate certain aspects of T1D experiences. In what follows, I will analyze several informants' statements for the ways their affective content and/or implications reinforce and/or challenge the social scripts of their devices; first, in relation to living with Diabetes generally, which is baked into the human-technology relationship due to the devices' primary scripted function, and second, in relation to using those Diabetes treatment devices specifically. In doing so, these informants paint an important mosaic of what it *feels like* to live with the materialities of Type 1

Diabetes in the twenty-first century, re-inscribing their devices with human feeling in the process.

Affective Meaning in Diabetes and Devices

The study of affect long predates the institutionalization of Affect Theory and takes place under the auspice of many other areas and fields. Whether conceptualized as a bridge between the humanities and biological and/or psychological sciences, a consideration of subjectivities, a project of self-understanding or one of social critique, the study of affect most often seeks to identify “movements, flashes, or outbursts of feeling” in order to better understand human experiences. Affect itself can be conceptualized in at least three interrelated ways: as unconscious experience of affect, an “immediate awareness of reality” often defined by philosophers as emotion, and the conscious experience of affect.⁴⁰ In the cases that follow, informants describe and narrate their experiences utilizing a combination of all three of these conceptions, and the textures of those descriptions highlight the role affect plays in scripting—and at times de-scripting—their relationships with their devices.

During the majority of the interviews conducted for this study, informants indirectly described or directly identified fear as a significant factor in at least part of their experience with T1D. That fear begins at the moment of diagnosis, as the weight and gravity of a life-long chronic condition is felt for the first time. When her child was diagnosed at the age of six, Brittany took on the majority of the responsibility for his care and treatment. “Then we were just hit with all the information,” she remembers. “That’s when things just got really overwhelming and scary.”⁴¹ The need to know about the illness, its treatments, its effects, and the myriad other new knowledge systems that go along with a T1D diagnosis is understandable, as that knowledge can be the difference between life and death. All of the *unknowns*, however, are made apparent to patients and their caregivers post-diagnosis as well and become all the more distressing. And as scary as those unknowns are at the time of diagnosis, they are magnified as newly diagnosed

⁴⁰ Marta Figlerowicz, “Affect Theory Dossier: An Introduction,” *Qui Parle* 20, no. 2 (2012): 4, <https://doi.org/10.5250/quiparle.20.2.0003>.

⁴¹ Brittany, interview by Stephen Horrocks, female age 35, child diagnosed with T1D in 2016, August 11, 2017.

patients leave the constant observation of doctors for the first time. As one informant points out, “It’s pretty terrifying when you get sent out of the hospital for the first time, and you go home and you’re on your own, so to speak.”⁴² With no more nurse/MD safety net, people leave the hospital with a little more knowledge and an acute awareness of what they do not yet know but should.

Coming to terms with T1D’s and its treatments’ permanence can be a fear-inducing process as well. “I was really confused, and scared,” Ashley recalls of her post-diagnosis experience as a nine-year-old. “I remember it was really hard for me understand that it was always going to be like this. You know, asking if I could get better.”⁴³ She just could not get her head around the fact that things would not go back to the way they were, that she would have this for the rest of her life. That irreversibility is difficult to grasp, for adults and children alike, and the need to inject pharmaceuticals multiple times per day adds yet another layer of complication. “I was scared to give myself shots for the longest time,” another informant, Amanda remembers of her diagnosis at the age of six. “Either the nurse would do it, or, you know, just someone that I knew.” A fear of needles is rather common,⁴⁴ but that fear is especially difficult when someone requires a shot multiple times per day. And though insulin pump use does not require the same number of shots, it carries its own fear-inducing factors for Amanda as well. “When I first got the pump, I went and slept with my mom because I was so scared I was gonna be, like... super low. Worried it was going to give me too much.”⁴⁵ In this case, Amanda feared her own body’s response to too much medicine injected by a malfunctioning device—a fear only exacerbated by the unseeable black-boxing of the algorithms responsible for calculating and running dosing programs. And in each of these examples, dissociating from the fear-inducers remains difficult if not impossible: there is always more information than people have time and resources to process;

⁴² Christopher, interview.

⁴³ Ashley, interview.

⁴⁴ Approximately 10% of adults in the US show symptoms of needle phobia, though this number is likely lower than actual. Cases of people with Type 1 Diabetes suffering from needle phobia have been identified, but no comprehensive study has been conducted to suggest significant implications. See: J. G. Hamilton, “Needle Phobia: A Neglected Diagnosis,” *The Journal of Family Practice* 41, no. 2 (August 1995): 169–75; A. Zambanini and M. D. Feher, “Needle Phobia in Type 1 Diabetes Mellitus,” *Diabetic Medicine* 14, no. 4 (1997): 321–23, [https://doi.org/10.1002/\(SICI\)1096-9136\(199704\)14:4<321::AID-DIA356>3.0.CO;2-H](https://doi.org/10.1002/(SICI)1096-9136(199704)14:4<321::AID-DIA356>3.0.CO;2-H).

⁴⁵ Amanda, interview by Stephen Horrocks, female age 30, diagnosed with T1D in 1993, August 4, 2017.

physiologies of T1D are constantly changing; Diabetes remains a permanent chronic diagnosis; without insulin injection, people with Type 1 will die. Also, however, in each of these cases people adjusted themselves to the fear and the factors that terrified them.

As I have noted throughout this dissertation, Diabetes is not only a personal physiological condition. It is also fundamentally social, and cultural norms and practices influence the ways it is defined and experienced. Informants' fears, when considered in relation to other people, reveal moments of embarrassment and social isolation in their memories and experiences. Particularly those who were diagnosed as children or teenagers discussed the social fallout they experienced as a result of both T1D and its treatment devices. "I honestly remember feeling left out sometimes, and embarrassed," recalls Amanda. "Left out in the sense of. . . it's somebody's birthday, all the parents knew I was diabetic. While everybody's eating, you know, cupcakes they would bring me, like, peanut butter crackers." A gesture of goodwill and support, undoubtedly, parents' decision to separate out Amanda's treat from the rest of the group signaled their effort to accommodate her needs (though crackers are themselves quite carb-heavy, still requiring insulin injection) while also participating in the reiteration of her already-established feelings of social isolation due to her chronic illness. As these small instances pile up over the span of weeks and years, they can produce health-related social anxieties with serious consequences. Amanda describes one experience that exemplifies how that reiterated distancing and discomfiture can lead to more serious issues:

When I was really young, I remember feeling super embarrassed to tell the teacher I felt low, or, you know, going behind—back by the cubbies and drinking a juice box really quick—it was just embarrassing at times. I remember one time particularly, in second grade, I was too scared to tell the teacher I was feeling low, and one of my best friends told the teacher, 'Amanda doesn't look like she feels good,' and got me help.⁴⁶

Not only did she feel disconnected from her peers, she was too afraid to treat her symptoms during class, leveraging her own physiological well-being against the possible social fallout of her stigmatized treatment acts. Whether her teacher would have actually made things more awkward for her, or whether classmates would have in some way held her medicalized difference against her, past experiences dictated that she avoid the possibility altogether. And the

⁴⁶ Amanda.

two things that would have signaled her chronic illness and potentially triggered the situation she feared were her treatment objects, the BG meter and the juice box.

Amanda's fears in this case were not unfounded, as the (largely inaccurate, wholly problematic) stigmas surrounding Diabetes/Diabetics circulate widely and loudly, permeating American culture. As other informants detailed, these all-too-common assumptions require almost daily navigation. "There's almost a stigma about it," reflects Matthew. "People don't like, necessarily, telling people that they're Diabetic, because people who don't know always just assume it's because you were really fat and ate a lot of candy."⁴⁷ This kind of misinformation—both ableist and sizeist, and leveraging the materiality of people's bodies and their treatment objects in the maintenance of able-bodied social comfortability—is circulated in essentially every public space people with T1D enter. Teachers, classmates, and classmates' parents share these assumptions in schools with some regularity, and as T1D parent Brittany bemoans, requires her to "do a quick little rundown," on repeat: "That's not what it means, that's not what it is."⁴⁸ Another informant said in some cases, she has waited years to tell coworkers or employers that she has Type 1, because they make such a big deal about it. "When people would find out you were Diabetic," Jennifer remembered, "it was like, 'oh my. . . ' they treat you like you were so fragile, or you were just going to pass out at any minute."⁴⁹ Much of the misunderstanding that these informants and numerous others come up against is rooted in the oft-repeated, and vastly oversimplified Sugar-Obesity-Type 2 Diabetes matrix circulated as the cause of the global Diabetes epidemic. These are, despite having no connection to Type 1 Diabetes whatsoever, the assumptions that frame people's interactions when they disclose their chronic illness to others and/or use their treatment devices in public. Uncomfortable at best, deeply damaging at worst, these cultural understandings of Diabetes constantly surrounding informants are deeply rooted and will operate for the foreseeable future. In the meantime, people live, and the permanence of T1D's physiology makes it theirs, whether they want it or not.

Beyond embarrassment and cultural stigmas, the affective experience of a device-connected T1D life can have significant social and familial implications. Echoing some of the

⁴⁷ Matthew, interview by Stephen Horrocks, male age 32, diagnosed with T1D in 2006, May 25, 2017.

⁴⁸ Brittany, interview.

⁴⁹ Jennifer, interview by Stephen Horrocks, female age 35, diagnosed with T1D in 1985, May 22, 2017.

sentiments shared by Amanda above, Ashley remembers missing out on things like sleepovers as a kid with T1D, feeling left out and isolated from what she saw as valuable socializing time. At one point, things even moved into the realm of bullying as a new classmate moved into town. “I do remember one time in fourth or fifth grade, there was a new girl and she didn’t like me, and she used it to make fun of me. Like, she’d call me a Diabetic freak, and make fun of me when I’d test my blood sugar.”⁵⁰ It was just that one person, she recalls, who ever used her health status as a weapon against her in that way, but it was significant enough to have stayed with her for decades afterward. The emotive experience of health-related bullying ties those hurtful words and ideas to people’s illnesses, to their bodies, making the stigma feel as much a part of them as their Diabetes—and perhaps that is why those things are hard to forget, even two decades later. And the material contexts of the bullying Ashley recalled during the interview were centered around moments when her BG meter abruptly made visible her chronic illness which otherwise operated invisibly. Here Ashley’s meter spoke, to again invoke Daston on “talkative objects,” and in doing so acted as a catalyst for a stigmatized/ing and deeply troubling social interaction.

At times, these ideas can make their way into romantic relationships as well. One informant reflects on the role her health status played in her dating practices, particularly during her twenties. “And I think, I definitely think. . . I’ve never had anybody tell me directly, this is the reason they ended a relationship with me. It could just be because I’m, like, messy at home. [laughs] I don’t know, but I definitely think it was a factor in some relationships.”⁵¹ Undoubtedly, this informant had experienced various small signifiers of that influence—too small, perhaps, to recall in detail years later, but which combine to provide her a sense of T1D’s uneasy effects on her romantic endeavors.

When those long-term relationships are established, or even pre-date a diagnosis, T1D can play a major affective role for both patient-users and their partners. In some cases, that may relate to the ever-present possibility of crisis. Matthew discusses the emotional weight his chronic illness piles onto his wife. “She gets really freaked out if I have a low in the nighttime,” a common fear based on very real possibilities. “That’s just what she’s always freaked out is going to happen, is that’s going to happen in the middle of the night and then she’s not going to

⁵⁰ Ashley, interview.

⁵¹ Jennifer, interview.

wake up, and she's going to come downstairs in the morning and find me dead on the floor.”⁵² A horrifying image, to be sure, and though it signals a worst-case scenario, it is also a scenario that every person with T1D has had experience with to some extent. The feeling of having low BG is bad enough on its own, but the anticipation of that experience by both oneself and a romantic partner adds another layer of emotive complexity. To an even greater degree, actual experiences of dangerously low BG can leave deep emotional scars for everyone involved. As an informant by the name of Sarah relays, the fear and tension of a BG crisis remains long after the moment itself:

I had, I'll never forget it, four years ago I had a really low blood sugar, and it was during Mardi Gras here in New Orleans, so it was probably a whole mix of just not taking care of myself, and eating. . . or drinking and not eating and then went low. I woke up and I couldn't move my body. And my boyfriend at the time was with me, and I ended up peeing the bed, because I had no control over my body at all. So it's just things like that that definitely puts a different strain on our relationship.⁵³

At its core, Sarah's relationship never recovered from her overnight low. She expresses later a range of affective responses to this event, including the terror related to her loss of muscular control and the paralyzing embarrassment afterward related to her bladder evacuation, and what she understood as the inevitable loss of her romantic relationship. She will never forget it, as she says, in part because the feelings associated with that whole experience exist outside the temporal framing of the moment, reemerging as she remembers and relays the experience years later.

Combined, the medical, technological, and social factors of T1D can be a lot to bear, and imagining anything outside that lens can be difficult as they travel with a person over time and place. In light of examples such as Sarah's above, what does (or can) a T1D future look like? Christopher wrestled with this notion soon after his diagnosis. “I think there was a period of time where I was trying to think of a future that would be better,” notes Christopher somberly. Having just had a child, “and just being [diagnosed] Diabetic then, made me worried that I wouldn't

⁵² Matthew, interview.

⁵³ Sarah, interview by Stephen Horrocks, female age 30, diagnosed with T1D in 1993, August 14, 2017.

have that future.”⁵⁴ That fear of something lost—of a future without his past able-bodiedness and the privilege it afforded him in a world built by and for that experience—was devastating. This is an enactment of the problematic temporal framing of embodied otherness that Alison Kafer argues so vehemently against: a life without able-bodiedness is not a life worth living, or in some cases, considered a life at all. There is no future for the Diabetic outside the biomedicalized hope for a future un-othering.⁵⁵ Thus, alongside their physiological function of maintaining BG levels, insulin pumps offer a partial technological fix for that othering that allows incremental distance from the social realities of their illness—because in permanent, daily experience, living with T1D can be downright exhausting, and any respite from its daily, even hourly requirements is often desperately welcomed and sought-after.

And here I want to make clear: I do not intend to misrepresent T1D experience as ubiquitously fear- and embarrassment-centered. In fact, that kind of dire narrativizing of T1D is part of the stigmatization that the people in this study have pushed back against throughout their lives. Though life with Diabetes does require navigation through dynamic physiologies and a deeply stigmatized cultural narrative, it is also nuanced in ways that can produce powerful senses of hope, excitement, and even joy. This is particularly evident in the ways people talk about their insulin pumps and CGMs, highlighting the ways they feel and have felt the devices’ effects on their overall well-being. Though in practice their narrations reinforce the “miracle fix” notion with which these treatment devices are scripted, people layer those scripts with genuine human experiences that serve to stabilize the social definition systems at play, simplifying the “casual pathways” Akrich identifies as essential to their persistence.⁵⁶

Thinking back to the moment when she switched from multiple daily injections to insulin pump therapy, Amanda describes her reaction to the life-altering conveniences that device affords. “I didn’t switch to the pump until I was twenty. After I got the pump, I was like, ‘This is the most amazing thing ever! I don’t know why I never did this sooner.’” She almost immediately walked that statement back, remembering that the financial burden a pump purchase

⁵⁴ Christopher, interview.

⁵⁵ Kafer, *Feminist, Queer, Crip*, 2.

⁵⁶ Akrich, “The De-Description of Technical Objects,” 221.

placed on her family deterred her from making that change for many years.⁵⁷ But she was so elated with the new device and her simplified injection system that she could not remember much else about how her day-to-day experiences changed; “I was just more excited to get something new.”⁵⁸ In this Amanda is not alone. Ashley spoke with similar excitement about her CGM. “It just seemed like a miracle to me. [. . .] It was really exciting.” After hearing all of the marketing for the new device, she thought adding a CGM to her treatment program would change everything for her. “Which it did. I mean, I would have done anything—switched to a new pump. . . anything—I was so excited to try it.”⁵⁹ The notion of a simpler, less attention- and action-invasive treatment system was so enticing, so exciting to her that she was willing to change an array of other aspects of her life and treatment system just to give it a shot. That Diabetes-distancing narrative is incredibly powerful, especially as it reaches those who live with T1D’s complications every day. As another informant gestured toward, again and again, “I feel very passionate about insulin pumps. [. . .] There’s just so much good in insulin pumps, and there’s so much coming around the corner. [. . .] It’s just extremely exciting. [. . .] It’s just really amazing.”⁶⁰

But a technologically-mediated Diabetic future cannot free people from the feeling of living with T1D, as it is still beholden to the same “curative time” framings that produce and reinforce many of the stigmas and issues outlined above.⁶¹ There is often a tension in this device reliance, identified separately by several informants, between the way they feel and what their devices tell them they are. This dissonance can be jarring and confusing, as Stephanie points out, leaving patient-users to make some tricky decisions. As she pricks her finger and places her blood on her meter’s test strip, she notes, “there have been times that it has been 49 and I’ll feel like it’s about 90, and there have been times that I’ll test it because I feel like it’s like 300 and it’ll be like 125. So it’s weird.” Weird indeed. This is, in all of its complexity, an important

⁵⁷ For an in-depth analysis of informants’ access to care and treatment, see Chapter 6 of this dissertation.

⁵⁸ Amanda, interview.

⁵⁹ Ashley, interview.

⁶⁰ Jessica, interview by Stephen Horrocks, female age 31, diagnosed with T1D in 2000, August 18, 2017.

⁶¹ Kafer, *Feminist, Queer, Crip*, 27.

breakdown between the device's medically-scripted function and the patient-user's experience-based perception of their own physiology. The disconnect between what she feels her body doing and what her BG meter says it is doing requires her to make a judgment about which information she trusts: "Maybe after twenty-five years I'm losing my feeling."⁶² In this moment, Stephanie uses her device—which she trusts to know her body better than she does herself—to calibrate her sensory experience of her body's physiology. In Akrich's words, here Stephanie adjusts the script in order to maintain its integrity and, at a practical level, ensure her own bodily safety.

Numbers aside, these devices do cultural defining work that functions outside the scope of quantification. Diabetes is a chronic illness that does not, in most cases, display outward signifiers on or in relation to people's bodies—as noted in Ashley's bullying story above. It is, in a sense, invisible to others and at times even people with T1D themselves. The recent advent of always-connected devices involved in treatment, however, produces new technological signifiers of disease that make Diabetes visible in new ways. As one informant describes:

I feel like when you're wearing devices like this there's a perception that you're sick, and that there's something wrong with you. And I think it's such a weird contrast in my mind because I'm actually a really healthy person, I'm really athletic, I've run marathons, I do gymnastics—I'm a very healthy person. And so it's this weird, sort of, like, conflict in my mind, like when I see it it's like, "Oh, I'm a sick person," but I don't feel that way. I feel very healthy. If you were to ask me on any given day, I'd say probably healthier than 90% of people who *don't* have Type 1 Diabetes.⁶³

So while these devices can, on the one hand, give people a bit of relief from the constant-ness of their Diabetes, they can also act as an always-on reminder of that same health status back to the patient-user. Even when that techno-medical signification is in direct opposition to what someone may understand about themselves or their own bodies, it can disrupt that vision in ways that destabilize their sense of wellness. These objects *only* exist on/in bodies to treat Diabetes, and thus compel patient-users to take some sort of ownership of both their disease and their devices.

As all of these intertwined, mashed-up affective experiences with insulin pumps and glucose monitors come together, they produce a deep feeling of connection between people and

⁶² Stephanie, interview.

⁶³ Jennifer, interview.

things that goes beyond the material. One way this is made most clear, for the patient-users interviewed for this study, is what they feel when the devices are gone. A long-time user of the Dexcom CGM, Jennifer had set up her iPhone and Pebble brand smart watch to sync her glucose data for easy access on her phone and wrist. A few years later, corporate decisions made by some of those manufacturers made her BG tracking system impossible. “The Pebble was sold to FitBit and I guess they’re no longer supporting the operating system, so the people who were using the Pebble with their iPhone there’s like a bug and it stopped the Dexcom data from being sent over.” For Jennifer, that meant no more BG readings on her wrist. “Which is a bummer, because I really miss that thing. Like *really* miss it.”⁶⁴ She returned to this point several times throughout the course of our hour-long conversation, making it clear that the convenience and immediacy of syncing her Pebble watch with her CGM made a significant difference in her treatment and overall well-being. It was not, for her, simply an extra feature; It was essential, a fundamental part of her treatment practices. It changed her relationship to her other devices, and it changed her relationship to Diabetes itself.

If the abrupt removal of a smart watch is disorienting, the sudden absence of one’s insulin pump is nothing short of a shock. While on vacation in a remote area several hours’-drive from home, then-twenty-something Amanda’s insulin pump flashed an error message on-screen and stopped all functions. In a panic, she drove into a cellular service area and called her pump manufacturer’s customer service line for help. After some time, they could not reset the device to resume its regular functions. Unfortunately, her device had just lapsed out of its warranty period and she was required to purchase a new insulin pump altogether (which meant nearly \$1000 out-of-pocket after insurance). Customer service was able to ship a new device to her in two days—a quick turnaround, to be sure, but she could not go that long without insulin. So she spent the next few hours communicating between her doctor and a local pharmacy to fill prescriptions for syringes and both fast-acting and slow-acting insulins, which she would have to inject directly until she could set up her new pump. “It made me realize how glad I am to have a pump, because doing that for like two days, and having to give insulin all the time, it’s like, I’d rather just not eat so I won’t have to check my blood sugar and give insulin.”⁶⁵ Amanda lived many years post-

⁶⁴ Jennifer.

⁶⁵ Amanda, interview.

diagnosis giving herself multiple daily injections, but since she transitioned to insulin pump treatment the material and temporal burden of those constant needle pokes became even more apparent to her.

Like Jennifer and her Pebble above, Amanda missed her insulin pump. Not only was it hers, it was her means of a less-intensive and less-invasive treatment regime. It simplified her everyday practices, and thereby simplified her life. At the same time, its absence complicated both her treatment and her general experience. In this case, distance may not have made the pancreas grow fonder—its beta cells were still dead, after all—but it certainly made her emotional and physiological fondness for her device stronger and more apparent.

Complicated Human-Technological Friendships

Since the Dexcom-Jonas collaboration in 2015, the company has released multiple new monitoring devices and received FDA approval to sync their devices with any FDA approved closed-loop insulin pump system.⁶⁶ As these examples demonstrate, insulin pumps and CGMs do in fact come to stand-in as many patient-users' "best friends," to return to Nick Jonas's statement that introduced this chapter. But as is the case with many long-term relationships, that "friendship" is defined by its many highs and lows—both in terms of affective experience and BG levels. These human-object connections complicate conceptions of T1D and the role of medical technologies in patient-users' lives, and in some cases go as far as to de-script their cultural framings in the interest of their own medical and/or affective needs. In the context of insulin pump treatment, possession and use are framed in terms of both psychological ownership and medical need, each greatly amplifying the affective connections people make through daily, hourly, minute-to-minute device-connectedness.

What the Jonas video does not say, however, is that these med-tech friends are locked behind a paywall. At a base level, people can only experience these relationships if they use these devices, and insulin pumps and CGMs can only be used if they are prescribed and

⁶⁶ Dexcom released the G5 model two months after they launched this marketing campaign, received FDA approval for the G6 in June 2018, and likewise for the G6 Pro one year later in 2019 (for a brief discussion of the G6 Pro, see Chapter 7). The G6 is approved to be used in conjunction with insulin pumps that can be programmed to automatically adjust insulin doses based on real-time CGM readings—an approval that had, until this time, only been granted to Medtronic's system of devices.

purchased. In the chapter that follows, I will explore the systemic problems that limit access to these types of hi-tech medical treatments and analyze informants' run-ins with Diabetes treatment devices as sites of privileged otherness.

CHAPTER 6: INSULIN PUMPS, CONTINUOUS GLUCOSE MONITORS, AND THE BOUNDS OF HI-TECH MEDICAL TREATMENT

“The Prince & The Pauper”

On October 1, 2018, FOX Broadcasting Company aired an episode of their primetime medical drama *The Resident* titled “The Prince & The Pauper.” In keeping with the case-of-the-week narrative models made popular (and profitable) by television shows such as *ER*, *House*, and *Grey’s Anatomy*, *The Resident* centers each episode on a unique medical quandary that provides a scaffolding for both the dramatic tension of the episode and the season-long character developments for the main cast. In episode two of the show’s second season, the stories of two young child patients are narrated simultaneously, continually jump-cutting between scenes depicting Jack, a boy who was life-flighted to the hospital after a severe abdominal injury he sustained while roller skating, and an unnamed girl who showed up at the emergency room with Diabetes-related symptoms but without a parent or guardian. Jack is rushed into the operating room, as his father makes an overt statement about paying for “anything” he may need. Meanwhile, the unnamed girl is all but forgotten by emergency room staff and she is depicted stealing medical supplies from a pharmacy cart.

Upon closer examination, Jack is diagnosed with early stage pancreatic cancer, and his accident caused internal bleeding requiring immediate surgery. The unnamed girl passes out as she injects her stolen insulin, nearing Diabetic Ketoacidosis and a possible coma as medical staff work on her in the intensive care unit. Her name is revealed in the last moments of her segment of the episode, as Abbie nearly dies on the table and she is connected to various life-sustaining machines. Due to the proliferation of his cancer, surgeons had to remove Jack’s pancreas entirely. He and his family are informed that without a pancreas to produce insulin, he will be Diabetic for the rest of his life—and at that moment a medical device rep enters the room and pitches Jack and his parents on their brand new top-of-the-line insulin pump, which carries a \$10,000 price tag.¹

¹ Nicole Rubio, “The Prince & the Pauper,” *The Resident* (FOX, October 1, 2018).

First, it is important to note the ways this episode's writers deployed stereotypes of Diabetes in structuring the narrative tension of the episode—drugs and syringes, mistaken as an opioid addict, always on the verge of death, Diabetic coma. These tropes are common among popular representations of Type 1 Diabetes, what I often refer to as the *Steel Magnolias* effect, as images of fragility and the ever-present threat of death dominate these depictions. Also of note, Abbie had no voice and no almost no dialogue throughout the forty-four minute episode. Jack, the wealthy roller-dancing boy, had lines consistently spaced until the end of the episode. This may in *effect* highlight the often unspoken issues surrounding Diabetes, as is evidenced by the staff's discussion about starting a new free/low-cost Diabetes clinic, but in its framing, pairing Abbie's silence with these depictions—and going so far as to leave her unnamed until she is on life support at the end of the episode—only serves to further those problematic stereotypes.

Most importantly, however, is the overt contrast created between health care access for the wealthy and a general lack thereof for the poor.² “Money is no object,” Jack's father says as they discuss a life flight helicopter ride from Atlanta to Houston. Meanwhile, Abbie ends the episode strapped to a table with a breathing tube because she could not afford to purchase her insulin. Though the title references a Mark Twain novel by the same name, a story of two young boys identical in every way besides their social position who accidentally switch places, Abbie and Jack can never fulfill that same narrative arc. Though Jack ends the episode with Diabetes as a side effect of his surgery, his economic position and that of his family make certain he will have access to the medications and devices he needs. Abbie, on the other hand, enters the episode already unable to gain access to treatment and ends it on the brink of an almost certain death. She was not seen as one who could add value to the hospital, and she was thus not valued herself—and in fact, without a name herself while a conscious person, Abbie was not seen by the healthcare system at all.

In previous chapters, I have argued that Diabetic treatment devices build such deep relationships with people, their bodies, and their sociality as to redefine them altogether. Central to how those relationships are and can be established, however, is the question of access. Treatment via hi-tech medical devices such as insulin pumps—though almost universally

² Though often used interchangeably, the terms “healthcare” and “health care” refer to systems of care and individual sites of care respectively. As such, both terms appear throughout this chapter.

considered the standard for managing the effects of Type 1 Diabetes—requires a variety of privileging factors that exclude people based on social and economic variables. Race, gender, age, geographic location, and social class determine much about the treatments people receive and their overall health outcomes more generally.

These devices do, as I have argued elsewhere, visually and materially signify their users' position outside the able-bodied cultural norm in the United States. But as I will show here, insulin pumps and continuous glucose monitors (CGMs) act as markers of both otherness and privilege simultaneously. By reading informant narratives of supply costs and insurance coverage through an intersectional technoscience lens, I argue that these devices are bound-up with social ambiguities in and of themselves, materializing both the medicalized need for technoscientific treatment and the significant barriers-to-entry typical of these types of hi-tech medical interventions at the same time. Though a body-connected medical device functions as a technological marker of disability and/or chronic illness—a sign of an *abnormal* body, with the weight of cultural systems of compulsory able-bodiedness in tow—it also signals one's ability to buy-in to a class-exclusive site of care and support. As demonstrated on-screen in “The Prince and the Pauper,” this technological fix cannot account for the social issues surrounding T1D and healthcare in the United States because those very devices represent the ways privilege requires the creation and maintenance of oppression.

T1D and Inequality in Health Care

Inequality in health care, though a booming discourse in 21st century America, has deep roots in the social divisions built into the foundation of the United States. Identity and socioeconomic position have always played a central role in people's access to social institutions, and healthcare and medicine are no exception. In order to begin making sense of the current shape of healthcare in the US framing the problem of access to insulin pumps, I turn to the work of Kant Patel and Mark E. Rushefsky from 2008. Though much has changed since the publication of their book *Health Care in America: Separate and Unequal*—The Patient Protection and Affordable Care Act of 2010 is perhaps the most significant structural shift in this vein—their metrics for assessing health care inequality remain central to understanding how individual people experience healthcare systems in the US. And though marginal improvements in some disparities based on race, ethnicity, gender, age, and geographic location have been

made in the past decade, these social markers remain primary factors in determining the health and wellbeing of individuals and groups. To flesh out what these inequalities mean for people with Type 1 Diabetes, I will discuss these disparities based on Patel and Rushefsky's three primary metrics: access to care, quality of care and treatment, and health outcomes.³

In order for people to receive medical care and, ideally, thereby improve their health outcomes, they must be able to access that care in the first place. Addressing Congress in September 2009, President Barak Obama made the case for the large-scale health reform bill that was soon headed for a vote on the House floor. Central to his justification for provisions such as the individual mandate, subsidized healthcare Marketplaces, and state Medicaid expansions was the inability of millions of people to access care due to a lack of insurance coverage.⁴ But access goes beyond whether or not individuals are enrolled in an insurance plan. The Agency for Healthcare Research and Quality (AHRQ) is a federal agency that conducts and compiles research in order to "make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used."⁵ AHRQ reports identify broader measurements of access to care that give a fuller picture of people's ability to receive treatment. These measures include (but are not limited to): having an established or familiar source of care, whether people experience barriers when they seek out care, and whether they are able to receive care when they want it.⁶ This also requires the ability to get to a site of care, which itself depends on one's proximity to clinics and transportation systems to support them. Access also requires the ability to connect with care professionals who can help with individuals' specific needs.⁷

³ Kant Patel and Mark E. Rushefsky, *Health Care in America: Separate and Unequal* (Armonk, NY: Routledge, 2008), 14, 23–24.

⁴ "Obama's Health Care Speech to Congress," *The New York Times*, September 9, 2009, sec. U.S., <https://www.nytimes.com/2009/09/10/us/politics/10obama.text.html>.

⁵ "About AHRQ," Agency for Healthcare Research and Quality, accessed March 9, 2020, <http://www.ahrq.gov/cpi/about/index.html>.

⁶ "2018 National Healthcare Quality and Disparities Report" (Rockville, MD: Agency for Healthcare Research and Quality, September 2019), 17.

⁷ Patel and Rushefsky, *Health Care in America*, 37.

When assessed on each of these markers—individually, on their own—there exist considerable discrepancies in access based on social identity. To use the AHRQ’s words, people in the US have historically and currently “experienced variable access to care based on race, ethnicity, socioeconomic status, age, sex, disability status, sexual orientation, gender identity, and residential location.” Though, based on certain markers, some discrepancies have improved since the turn of the century, others have remained constant and some have even worsened. Income remains a major factor, as the access gap between those living below the Federal Poverty Level (FPL) and those with high income (compared to FPL) continues to widen. Poor individuals are less likely to have health insurance (especially private coverage offered through employers) and are therefore less likely to have a usual site of care and regular contact with care professionals.⁸ Low socioeconomic status is also related to a lack of access to qualified providers, fewer monetary resources, and lower rates of continuity of care.⁹ In short, though the proportion of poor people with health insurance has increased in recent years, their overall access to care has either remained the same or gotten worse during that same period.

But socioeconomic status is one of many markers of inequality in access to care. Where healthcare has been historically linked to capital (i.e. one’s ability to pay for it), so too have social constructions of race. Whiteness has been inscribed with social and economic value through governmental, legal, and social institutions in direct opposition to non-whiteness.¹⁰ As a result, the cultures and systems that privilege whiteness simultaneously disadvantage racialized Others. As an institution itself, American Medicine and the US healthcare system more broadly have not only been inflected with racial bias from surrounding dominant cultures, it has been a central site of its creation and maintenance.¹¹ As Nadine Ehlers and Leslie R. Hinkson have

⁸ “2018 National Healthcare Quality and Disparities Report,” 25–26.

⁹ Patel and Rushefsky, *Health Care in America*, 37.

¹⁰ Cheryl I. Harris, “Whiteness as Property,” *Harvard Law Review* 106, no. 8 (June 1, 1993): 1707–91, <https://doi.org/10.2307/1341787>; Michael Omi and Howard Winant, *Racial Formation in the United States: From the 1960s to the 1990s*, 2nd ed. (New York: Routledge, 1994); Erika Lee, *At America’s Gates: Chinese Immigration during the Exclusion Era, 1882-1943*, First Paperback Edition edition (Chapel Hill: The University of North Carolina Press, 2003); Paul Ortiz, *An African American and Latinx History of the United States* (Beacon Press, 2018).

¹¹ Joe Feagin and Zinobia Bennefield, “Systemic Racism and U.S. Health Care,” *Social Science & Medicine*, Structural Stigma and Population Health, 103 (February 1, 2014): 7–14, <https://doi.org/10.1016/j.socscimed.2013.09.006>.

argued, the American healthcare system has “racialized both access to and quality of health care,” and the systems of race-based health care that emerged to deal with that problem have only propagated them further.¹²

For people, in practice, this system has created not only a racial differential in access, but in the care and treatment people receive from health clinics and professionals. Though state-run programs such as Medicare and Medicaid have made in-roads in improving both access and quality of care for disadvantaged people, both problems largely persist.¹³ In real terms, that means non-white people tend to have fewer doctor visits and less preventative care overall. When they do, practitioners tend to give different care for non-white patients than they do their white ones. Mortality rates are more than fifty percent higher for Black and Hispanic patients than white patients, and both have significantly higher rates of almost every major disease or condition (including heart disease, stroke, cancer, Type 2 Diabetes, and HIV)—and this as a direct result of the consolidation of capital resulting in uneven development of (and therefore access to) resources.¹⁴ Meanwhile, due to bias among some health workers, disproportionately low poverty levels, clinics requiring hours-long drives, and a lack of resources for many preventative and non-urgent needs with wait times between two and six months, Native Americans and Alaska Natives receive some of the overall worst care and treatment within the federal, treaty-required Indian Health Service.¹⁵

Though the preceding discussion focuses primarily on race and class, other social identities play significant roles in care and treatment as well, necessitating a fundamentally intersectional approach to analyzing this large-scale problem. Inasmuch as race makes a difference, so too do gender, age, and (dis)ability. Inequalities in the US workforce mean women have less access to

¹² Nadine Ehlers and Leslie R. Hinkson, eds., *Subprime Health: Debt and Race in U.S. Medicine*, 1 edition (Minneapolis: Univ Of Minnesota Press, 2017), viii; For more on the critique of race-based medical science and practice, see: Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-Create Race in the Twenty-First Century* (New York: The New Press, 2012).

¹³ Patel and Rushefsky, *Health Care in America*, 14; See also: Sidney D. Watson, “Race, Ethnicity and Quality of Care: Inequalities and Incentives,” *American Journal of Law & Medicine* 27 (2001): 203.

¹⁴ David Whiteis, “Poverty, Policy, and Pathogenesis: Economic Justice and Public Health in the US,” *Critical Public Health* 10, no. 2 (June 1, 2000): 264–66, <https://doi.org/10.1080/09581590050075989>; Eric C. Schneider, Alan M. Zaslavsky, and Arnold M. Epstein, “Racial Disparities in the Quality of Care for Enrollees in Medicare Managed Care,” *JAMA* 287, no. 10 (March 13, 2002): 1288–94, <https://doi.org/10.1001/jama.287.10.1288>.

¹⁵ Patel and Rushefsky, *Health Care in America*, 14, 123–37.

work through employers that offer subsidized health coverage, making significantly lower income on average while their bodies have remained primary cultural battlegrounds for health-related issues such as abortion and domestic violence.¹⁶ Children and elderly people likewise operate within a particularly vulnerable position, made all the more insecure based on other social factors such as race, gender, socioeconomic status, and geographic location. Though many markers of children's health have improved considerably over the past several decades, mortality rates in particular, inequality in access remains consistent due in large part to a lack of insurance.¹⁷ Despite their eligibility for one of the only federally available public healthcare options in Medicare, elderly people still experience inequality in access to care, especially so for aging people of color and women.¹⁸ For people with disabilities, the above issues are layered with often-inaccessible able-bodied labor markets and embodied experiences that necessitate extra labor day-to-day, making access to private health coverage less likely and increases the need for consistent clinical and at-home sites of care.¹⁹

And here an intersectional approach helps begin to make sense of the interwoven privileging and disadvantaging factors bound up in individual persons' social position.²⁰ Individuals do not exist in society as singular identities, but rather as embodied assemblages who constantly engage with social systems (and their own selves) through many identities at once—race, gender, class, sexuality, ability, religion, age, and ethnicity being some of the most cited

¹⁶ Sam D. Sieber, *Second-Rate Nation: From the American Dream to the American Myth* (New York: Routledge, 2005), 82, 99, 234–35.

¹⁷ In 2018 the number of uninsured children in the US rose to 5.5%, largely due to a decline in public coverage in states where Medicaid and CHIP programs received significant funding cuts. See: Edward R. Berchick, Jessica C. Barnett, and Rachel D. Upton, "Health Insurance Coverage in the United States: 2018" (United States Census Bureau, November 8, 2019), 9, <https://www.census.gov/library/publications/2019/demo/p60-267.html>.

¹⁸ See: "2018 National Healthcare Quality and Disparities Report."

¹⁹ David Mitchell and Sharon Snyder, "Disability as Multitude: Re-Working Non-Productive Labor Power," *Journal of Literary & Cultural Disability Studies* 4, no. 2 (January 1, 2010): 179–94, <https://doi.org/10.3828/jlcds.2010.14>.

²⁰ The concept of the intersectionality of oppressions has long been a focus of Black feminist scholars and activists, and was academically institutionalized in the large-scale in an article by Kimberle Crenshaw. An intellectual leader within the development of Critical Race Theory at Harvard Law School during the 1980s as well, Crenshaw's work focuses primarily on the experience of Black women within social, cultural, and legal systems that have been built and maintained to disadvantage them. See: Kimberle Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43 (1991 1990): 1241.

examples. These intersecting social positions are tied to long histories of systemic advantage and oppression, and since people embody them all together, they likewise embody their markers of privilege and oppression simultaneously as well.²¹

In the context of living with a chronic illness such as Type 1 Diabetes, inequalities in access, care, and overall health outcomes makes treatment unequal as well. As a hormone-balancing treatment, insulin injection requires considerable consultation with primary care physicians and specialists such as endocrinologists, and access to these clinics varies widely based on the markers identified above. If someone does, in fact, have insurance and access to a specialist with whom they can consult regularly, the cost of insulin has increased so dramatically over the past twenty years that paying for it usually still requires considerable financial means, leading some to take drastic measures to lighten that economic burden.²² Taken one step further, buying-in to an expensive hi-tech treatment system such as insulin pump therapy requires a level of economic privilege (itself historically linked to other privileging factors as well) that creates a unique situation of what I call privileged otherness—a technological marker of embodied difference that simultaneously signifies the patient-user’s socioeconomic advantage. Patient-users’ identities, devices’ cultural associations, what treatment looks like and how it is enacted, and the politics of medicalized privilege are all co-produced at this surprisingly active site of “crip technoscience.” Melding “crip,” the radical queer studies-inspired concept that disability is inherently socially desirable, with “technoscience,” the concept that science, technology, and political life are all co-produced, Aimi Hamraie and Kelly Fritsch center research on locations of “generative frictions”—acknowledging the role of science and technology (and in this case, Medicine) in building both injustice and its dismantling.²³ Though insulin pumps and CGMs

²¹ For more on the intersection of oppressions, see: Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd Edition (New York: Routledge, 2008); For more on the embodiment of privilege and oppression simultaneously, see: Jose Sisneros et al., *Critical Multicultural Social Work* (New York: Oxford University Press, 2008).

²² Both rising insulin prices and life-threatening practices of insulin rationing will be discussed further in the sections that follow.

²³ Aimi Hamraie and Kelly Fritsch, “Crip Technoscience Manifesto,” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (April 1, 2019): 2, <https://doi.org/10.28968/cftt.v5i1.29607>; For more on co-production and technoscience as an analytical lens, see: Sheila Jasanoff, “The Idiom of Co-Production,” in *States of Knowledge: The Co-Production of Science and the Social Order*, ed. Sheila Jasanoff (New York: Routledge, 2004), 2–3; For more on theorizing radical embodied “crip theory” and compulsory able-bodiedness, see: Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: NYU Press, 2006), 2–3.

undoubtedly make considerable changes to the time and labor required for daily treatment of T1D, within the broader social context they come to function as a technological fix that does not, and indeed cannot compensate for the societal inequalities that make those treatments unavailable to millions of people. These issues of access to care, cost of treatment, and insurance coverage are central to the experiences of informants as they interact with their treatments and devices in the context of large-scale health care inequality in the US.

Cost, Insurance, and Informant Barriers to Diabetes Treatment

In 1993, a young girl named Stephanie living near the Mississippi Delta was diagnosed with Type 1 Diabetes. Seven years old at the time, Stephanie remembers being “terrified at first with them sticking a needle in my finger” to test her blood glucose (BG) levels. “I did hate having shots,” she remembers, “but I got used to them pretty quickly”—which makes sense, as her new diagnosis required her to take eight to ten shots of insulin per day. Diabetes did not seem to get in the way of school or her friendships, she recalls,²⁴ but they moved back to her birthplace just a few months later. Four years later, Stephanie’s grandmother—an English teacher who “read everything all the time”—came across an article about insulin pumps while reading up on current trends in Diabetes care (a common practice since Stephanie’s diagnosis a few years earlier). “When she read about the insulin pump, she decided I needed one and bought one.”

There was a pregnant pause. As an interviewer, my automatic verbal response was, “Wow.” It is unusual for individuals to purchase these devices outright, carrying retail price tags upwards of \$12,000, and even with insurance coverage can cost hundreds or even thousands of dollars out-of-pocket. She explained further, “I was her only granddaughter, and she’s like, ‘She’s getting as insulin pump’ and she bought me one. So that’s how I ended up with one.” But Stephanie’s initial telling of the story glossed over what was, in reality, a long and complicated

²⁴ This moment of the interview was complicated, such that I struggle with the most applicable and ethical way to include her comments in-text. Though it was not directly related to her insulin pump story, Stephanie felt compelled to note the racial demographics of her school when she discussed the social implications of her diagnosis. “I hate to speak to, like, demographics of the area, but I was one of like three Caucasian girls in my class, so, I mean, my best friend was this one girl, and I didn’t really hang out with a bunch of other people.” By putting her two points together, she gestures toward the racial segregation of not only her relationship building as a child, but of the school she attended more broadly. Racial inequality is under consideration in this chapter, though primarily at the site of health and care whereas her comments point toward some of the social, economic, and education-related structures privileging her whiteness and disadvantaging her Black classmates. She recognized her own tone, noting a few moments later, “But, ‘Caucasian’ sounds kind of racist, I didn’t mean it to sound that way.”

process filled with obstacles and barriers-to-entry for the then-eleven-year-old's treatment. Coming back to the story a few moments later, she reflects, "It was kind of difficult to get one." When her mother and grandmother first talked to her doctor about switching to insulin pump treatment, the doctor refused. "She thought I was too young to be responsible for an insulin pump," she remembers, a sentiment that has only started to change in the past few years as new monitoring systems allow for more hands-on and 'round-the-clock parental oversight via their smart phones or watches. But age was not her only barrier, as her family's economic position played heavily into her access to care as well. "My mom was a single mom and she was finishing up her degree, so we were poor at the time." That meant that neither she nor Stephanie were enrolled in a private employer-subsidized health plan, "and the [State-Named Medicaid], which is basically Medicaid for children, would not pay for a pump because they didn't call it a medical necessity, they said I could just take shots."

Nevertheless, Stephanie and her family went from doctor to doctor and each denied her the same as the first. Unwilling to accept that answer, her mother took her to a clinic in another city a few hours away. After her second visit there, she says, "he finally put me on the pump." At that point, now that it had been prescribed by a doctor, Stephanie's grandmother paid for the device out-of-pocket and she began her new treatment regimen. Though the disposable supplies she changed out every few days were quite costly as well, her state Medicaid program did aid her family with those costs, "once I had the pump, I think insurance would cover the supplies and everything, they just wouldn't buy the pump from the get-go."²⁵

Stephanie's story highlights many of the barriers-to-access people with chronic illnesses come up against as they advocate for their own health needs and medical treatments. First under consideration here, cost was in the 1990s and remains today a central factor in the medical decision-making processes for people with Type 1. As insulin manufacturers have gouged prices over the past twenty years, tripling between 2002 and 2013 and nearly doubling again by 2016, so too have the disposable devices needed for their treatments multiplied.²⁶ The majority of

²⁵ Stephanie, interview by Stephen Horrocks, female age 31, diagnosed with T1D in 1993, May 23, 2017.

²⁶ Xinyang Hua et al., "Expenditures and Prices of Antihyperglycemic Medications in the United States: 2002-2013," *JAMA* 315, no. 13 (April 5, 2016): 1401, <https://doi.org/10.1001/jama.2016.0126>; Robin Respaut and Chad Terhune, "U.S. Insulin Costs per Patient Nearly Doubled from 2012 to 2016: Study," *Reuters*, January 22, 2019, <https://www.reuters.com/article/us-usa-healthcare-diabetes-cost-idUSKCN1PG136>.

people in the US cannot feasibly pay the nearly \$6,000 annual cost out-of-pocket, making their use contingent on insurance coverage.²⁷ Second, by connection, insurance coverage and insurance companies themselves often determine the medical decisions made by/for people with T1D. Not simply facilitators of the cost of care, insurance companies set parameters within which people do or even can treat and maintain Diabetes on a daily basis. But like Stephanie, even with those barriers in place people with T1D require insulin injections and medical care to survive, and they find strategic ways within (and/or outside) the established channels to get the treatment they need.

Cost Determines Medical Decisions

For people living with Type 1 Diabetes, much goes into their decisions regarding their treatment and general health practices. Work and family scheduling, meal and snack planning, carb-to-insulin ratio calculations, device programming, these and myriad other social and medical factors play into how people go about managing their chronic illness. One factor in particular carries more weight than the others and played a central role in the treatment decisions for every person interviewed for this study. Pharmaceutical and supply costs determine not only what people use in their health practices, but where and when they (can) get them, and how they go about using them as well. As prices for Diabetes-specific medications have risen over the past twenty years, the impact of those costs has intensified for people who need them to survive.

As noted above, retail prices for Humalog and Novolog nearly tripled between 2002 and 2013. These two fast-acting artificial insulins control the US market, and their incremental patent-filing practices over the past ninety years (a practice referred to as “evergreening”) have essentially produced a permanent ban on the production of generic versions.²⁸ Despite a third FDA approved product on the market produced by French pharmaceutical giant Sanofi, Humalog and Novolog are essentially the only ones prescribed by doctors and used by people with

²⁷ Ken Alltucker, “Struggling to Stay Alive: Rising Insulin Prices Cause Diabetics to Go to Extremes,” *USA Today*, March 27, 2019, <https://www.usatoday.com/in-depth/news/50-states/2019/03/21/diabetes-insulin-costs-diabetics-drug-prices-increase/3196757002/>.

²⁸ See: Jeremy A. Greene and Kevin R. Riggs, “Why Is There No Generic Insulin? Historical Origins of a Modern Problem,” *The New England Journal of Medicine; Boston* 372, no. 12 (March 19, 2015): 1171–75, <http://dx.doi.org/10.1056/NEJMms1411398>.

Diabetes. By 2016, the gross cost of insulin reached approximately \$5,700 per person, nearly twice the average paid in 2012, and evidence suggests that those costs nearly doubled again by 2016.²⁹ For patients, that means a range of \$120 to \$400 per vial out-of-pocket without insurance, and since T1D requires three-to-four vials per month that price places these medications out of reach for many who need them. One informant summed it up well: “It’s definitely expensive being Diabetic.”³⁰

That financial cost often comes at the expense of people’s health and wellbeing. Over the past several years, journalists from newspapers around the US have documented the dangerous and often life-threatening ways people with Type 1 attempt to deal with the overwhelming burden of trying to pay for their medications. Some go into debt at high interest rates to cover the costs, while at the same time opting to forgo food or other essentials.³¹ This often leads to poor health outcomes, resulting in more hospitalizations and/or clinic visits layering on even more financial burden.³² Perhaps the most dangerous cost-reducing practice, however, is rationing or cutting-back on insulin in order to make a vial last longer. Rationing insulin, alarmingly common and practiced by as much as 20% of people with Diabetes, entails injecting less insulin than would accommodate the food one eats, yet injecting enough to avoid Diabetic Ketoacidosis (DKA—body-wide glucose shock that turns the blood acidic and dehydrates the body’s cells, a result of life-threateningly high BG).³³ Sustained high BG levels, even when below the risk of DKA, leads to some serious complications in the long-term. Diabetic neuropathy leads to loss of

²⁹ Jean Fuglesten Biniek and William Johnson, “Spending on Individuals with Type 1 Diabetes and the Role of Rapidly Increasing Insulin Prices” (Health Care Cost Institute, January 2019), <https://healthcostinstitute.org/diabetes-and-insulin/spending-on-individuals-with-type-1-diabetes-and-the-role-of-rapidly-increasing-insulin-prices>; Alltucker, “Struggling to Stay Alive”; Respaut and Terhune, “U.S. Insulin Costs per Patient Nearly Doubled from 2012 to 2016.”

³⁰ Amanda, interview by Stephen Horrocks, female age 30, diagnosed with T1D in 1993, August 4, 2017.

³¹ Kyle Harvey, “Insulin Users Decry ‘Debt or Death Dilemma,’” *KUTV*, September 7, 2019, <https://kutv.com/news/local/insulin-users-decry-debt-or-death-dilemma>.

³² Jacquie Lee, “Debt From Diabetes: Financial Burden Doesn’t End at Insulin Cost,” *Bloomberg Law*, May 17, 2019, <https://news.bloomberglaw.com/pharma-and-life-sciences/debt-from-diabetes-financial-burden-doesnt-end-at-insulin-cost>.

³³ John D. Piette, Michele Heisler, and Todd H. Wagner, “Problems Paying Out-of-Pocket Medication Costs Among Older Adults With Diabetes,” *Diabetes Care* 27, no. 2 (February 1, 2004): 386, <https://doi.org/10.2337/diacare.27.2.384>.

limb functions in legs and arms, damaged retinas develop cataracts, and damaged blood vessels increase risks for heart disease, kidney failure, and stroke.³⁴ Worst-case scenario: rationing insulin can lead to DKA-related death.³⁵

For people who use insulin pumps to inject their already over-priced pharmaceuticals, orders of disposable one-time-use supplies add another layer to their expenses. To make matters more complicated, the insurance and billing processes involved in processing an order of pump or CGM supplies can vary widely based on an individual's coverage, obscuring their retail prices. In 2007, it was estimated that the initial price of an insulin pump averaged \$6,500, while infusion sets and cartridges ranged between \$2,000 and \$3,000 annually.³⁶ Thirteen years later, those prices have increased though they are difficult to trace. With insurance, those costs are still significant and are more pronounced at the beginning of the calendar year. As some plans require people pay down their deductible prior to plan benefits kick-in, that can mean serious financial strain that carries throughout the first half of the year. One informant reports having to hit a \$900 deductible, another says theirs is \$1,000, and yet another has to pay \$2,000 out-of-pocket before their insurance will cover 80% of the expenses.³⁷ In these cases and several others, they were required to front that cost during the first two months of the year (which they usually do with one three-month-supply order). After hitting that deductible, most still have out-of-pocket costs ranging from \$350-\$600 per three-month supply (depending on the percentage their insurance covers thereafter).³⁸ Conservative estimates based on these numbers would place their yearly

³⁴ Mayo Clinic Staff, "Hyperglycemia in Diabetes - Symptoms and Causes," Mayo Clinic, November 3, 2018, <https://www.mayoclinic.org/diseases-conditions/hyperglycemia/symptoms-causes/syc-20373631>.

³⁵ Randi Hutter Epstein and Rachel Strodel, "Diabetes Patients at Risk From Rising Insulin Prices," *The New York Times*, June 22, 2018, sec. Well, <https://www.nytimes.com/2018/06/22/well/diabetes-patients-at-risk-from-rising-insulin-prices.html>.

³⁶ Jay S. Skyler et al., "Is There a Place for Insulin Pump Therapy in Your Practice?," *Clinical Diabetes* 25, no. 2 (April 1, 2007): 51, <https://doi.org/10.2337/diaclin.25.2.50>.

³⁷ Ashley, interview by Stephen Horrocks, female age 26, diagnosed with T1D in 2000, June 1, 2017; Stephanie, interview; Heather, interview by Stephen Horrocks, female age 34, child diagnosed with T1D in 2015, August 10, 2017.

³⁸ Ashley, interview; Jessica, interview by Stephen Horrocks, female age 31, diagnosed with T1D in 2000, August 18, 2017; Sarah, interview by Stephen Horrocks, female age 30, diagnosed with T1D in 1993, August 14, 2017; Stephanie, interview; Amanda, interview.

out-of-pocket costs for insulin pump supplies alone between \$1,950 and \$3,400—and this on top of the cost of the insulin these supplies are made to inject.

Both in terms of up-front prices and regular supply orders for insulin pump use, cost plays a central role in the medical and health decisions made by people with Type 1 Diabetes. Amanda, a thirty-year-old registered nurse who was diagnosed as a child, says the pump made such a difference she forgot about all of that financial context. “I didn’t switch to the pump until I was twenty,” she says. “After I got the pump, I was like, ‘This is the most amazing thing ever! I don’t know why I never did this sooner.’” But she does know why, and she immediately walked that statement back. As someone quite active in sports, she did not want a device connected to her body and getting in the way. Then, almost as an afterthought, she notes, “And cost, I mean, even with insurance my parents still had to fork out a couple thousand dollars for a pump.” A few minutes later, Amanda gives a little more insight into what that meant for her treatment decision, “I just feel like I had wanted it for so long, but just financially it just wasn’t the right time.”³⁹

It is this second statement that carries the weight of cost in Amanda’s treatment decision. The right time for the most effective treatment was not determined based on her body and/or medical needs, but her financial situation. That “couple thousand dollars” can be extremely difficult to put together for individuals or families who live paycheck to paycheck, and the so-called right time can be months or even years away. Oftentimes, as Jason detailed in his interview, making that change and paying to continue with it requires scrounging and saving. “I didn’t realize how much of a burden it was on my parents until I had to deal with it myself,” he reflects, “even with the insurance we have, which is pretty good.” Despite having decent coverage, Jason still has to prepare for the significant financial burden of a future device change (while covering his current living expenses at the same time). “I’m putting away money now so that when I have to, I mean I don’t have to,” he notes, “but [for] when I change over from a Minimed to one of the T:slim that’ll integrate with the Dexcom.”⁴⁰ To his understanding, this

³⁹ Amanda, interview.

⁴⁰ Jason, interview by Stephen Horrocks, male age 35, diagnosed with T1D in 1993, June 23, 2017. Here Jason refers to three products discussed earlier in this dissertation: the Minimed insulin pump made by Medtronic, Inc.; the T:slim, an insulin pump system made by Tandem Diabetes Care, Inc.; and the Dexcom CGM system made by Dexcom, Inc. The collaborative integrated closed-loop system by Tandem and Dexcom was first FDA approved in August 2017, a few months following this interview.

combination of devices would aid in his treatment more effectively than what he currently uses (and he discusses later the unreliability of his current CGM system), yet his health and medical needs are deferred due to their financial burden. He must instead save small portions of his monthly income for what will likely be a few years in order to cover his out-of-pocket costs for a new insulin pump system—and all of this with “pretty good” insurance coverage besides.

Similar factors kept one informant from putting her child with Type 1 on a CGM for well over a year. After learning about a Dexcom model that would sync her now-six-year-old’s BG trends with an app on her iPhone, Heather decided it would help both him in his treatment and her as a caregiver. “I can keep an eye on his blood sugar, and that gives me a huge peace of mind.” What is more, she notes, “it allows him to have a little more independence, and we really thought that was important for him.” Unlike their hesitance with insulin pumps, doctors have been increasingly willing to prescribe CGMs for young children as a means of aiding their guardians/caregivers in catching unexpected BG drops or spikes. Despite their MD’s willingness, Heather and her husband were unable to start their son on that device for nearly two years due strictly to its cost. “Obviously there’s the financial side of it—we were finally. . . we finally had the money to do it. It’s expensive, and it took us a little while to save up to be able to do it.”⁴¹ For a four-to-six-year-old child with T1D, that CGM would have made a considerable difference in not only maintaining a more level BG itself, but in the wellbeing of the family in a general sense. The device is, for them, not only a medical one but a social one as well. Once her son went on the CGM, Heather and her husband were able to sleep through the night for the first time since his diagnosis, both because they did not have to wake up during the night—every night—to check his BG with a meter, and because the constant stream of BG data reduced their worry and stress overall. He could also see his own BG while at school or with friends, and among these settings the CGM demonstrated its own social life. But, as demonstrated in this case and as anthropologist Arjun Appadurai argues, that social life is built around the politics of value and commoditization.⁴²

⁴¹ Heather, interview.

⁴² Arjun Appadurai, “Introduction: Commodities and the Politics of Value,” in *The Social Life of Things: Commodities in Cultural Perspective*, ed. Arjun Appadurai (Cambridge University Press, 1988), 3–4.

The cost-barrier to insulin pump and CGM use affects more than the initial access to obtaining the devices themselves. Costs also drive individual treatment decisions once people have access to insulin pump treatment, often in ways that can carry moderate to serious risks. Every time the cannister of insulin inside a pump runs out (approximately every three days, depending on the amount of insulin one needs) it must be replaced with a new cannister containing fresh insulin. Along with it, the infusion set injected below the skin and attached to the body with a length of tubing must be replaced in order to avoid possible infection and scar tissue build-up. As I outlined above, however, these disposable objects are quite expensive themselves, retailing for about \$15 per pump site change (with a net cost to the patient-user varying widely depending on insurance coverage and whether they have met their deductible). In some cases, this leads to individuals stretching the period of use by as much as twice the suggested use-time.

One informant, Stephanie, discusses how often she orders new pump supplies, and interjects a brief nod to the duration of her site changes in passing. “I’m supposed to get them every three months or so,” she shrugs, referencing her mail-order supplies, “but I don’t really change my pump every three days like they tell me to. I change it when it’s empty, so [new orders are] more like every five months or so.”⁴³ Though she does not specify those numbers, either here or later in the interview, her estimation implies that she leaves her infusion sets connected for as much as two days longer than the two-to-three suggested. This practice increases the risk of serious infection, including but not limited to staph infections and Toxic Shock Syndrome (TSS).⁴⁴ For some like Stephanie, however, the financial cost of these devices

⁴³ Stephanie, interview.

⁴⁴ During the late 1980s and early 1990s, when insulin pumps were introduced as viable options for daily treatment of Type 1 Diabetes, one of the major concerns raised by clinical researchers and practitioners was infection introduced via the infusion set. Though many changes to these devices have greatly reduced the risk of infection, the duration of use for a single infusion set still plays a significant role in risk for infection. See: Ernst Chantelau et al., “Acute Cutaneous Complications and Catheter Needle Colonization during Insulin-Pump Treatment,” *Diabetes Care* 10, no. 4 (1987): 478–482; Vikram Hundia, Andrew Pettit, and June Egerton, “Infusion Site Infection in a Patient Using U-500 Insulin Delivered via Insulin Pump: No. 64 in a Regular Educational Series of Brief Illustrated Descriptions of Interesting or Unusual Diabetes-Related Cases and Conditions,” *Practical Diabetes International* 24, no. 9 (2007): 489–489; Martha H. Tanner and John E. Liljenquist, “Toxic Shock Syndrome From Staphylococcus Aureus Infection at Insulin Pump Infusion Sites: Report of Two Cases,” *JAMA* 259, no. 3 (1988): 394–395; Ellen L. Toth, Lesia R. Boychuk, and Patricia A. Kirkland, “Recurrent Infection of Continuous Subcutaneous Insulin Infusion Sites with Mycobacterium Fortuitum,” *Diabetes Care* 18, no. 9 (1995): 1284–1285; C. L. Wickline, T. G. Cornitius, and THOMAS Butler, “Cellulitis Caused by Rhizomucor Pusillus in a

outweighs the physiological cost (and, in actuality, resulting financial costs) of a possible infection. Whereas they *might* have to deal with an infection, patient-users absolutely *will* have to deal with that next expensive supply purchase.

Patient-users run into similar cost-barriers (and by connection, risks) with their CGMs, further establishing and normalizing the role cost plays in treatment decisions. When asked what she uses in her Diabetes treatment regimes, informant Jessica listed her insulin pump and BG meter, followed by the statement, “I occasionally use a continuous glucose monitor.” No other items on her list included qualifiers besides the CGM, and she expounded on that point when I asked her about it several minutes later. “It goes, again, back to, kind of. . . cost,” she landed on, “because the sensors that are used for the continuous glucose monitor are very expensive to use, so I try to use it about two to three weeks every month. So I’ll do, like, two or three back-to-back-to-back.”⁴⁵ Like the insulin pump supplies, patient-users’ out-of-pocket responsibility for CGM supplies depends heavily on insurance coverage, and actually carry a higher per-item price tag. Dexcom sensors—the device housing a sensor wire inserted below the skin and an adhesive pad to attach it—retail for \$150 each and can be worn for up to ten days. The Guardian 3 sensors, made to sync with the Minimed insulin pump + CGM system, go for \$120 per sensor and can be worn for up to seven days.

In the end, the greatest cost for people with T1D is not a financial one. Making medical decisions at odds with doctors’ and manufacturers’ recommendations can lead to health costs that linger for years, even a lifetime. Doing so in order to make the financial burden associated with the use of these pharmaceuticals and devices manageable calls into question who these treatments and devices are intended for in the first place. Every aspect of T1D treatment is outside the realm of reasonable access for most people in the United States, and considered together they create a standard of care that can only be attained by a fraction of the people who need it to survive—in the US, approximately forty percent of people with T1D in the US use

Diabetic Patient Receiving Continuous Insulin Infusion Pump Therapy.,” *Southern Medical Journal* 82, no. 11 (1989): 1432–1434.

⁴⁵ Jessica, interview.

insulin pumps while about thirty percent use CGMs on a daily basis.⁴⁶ This is the very definition of a “technological fix,” as defined by Lisa Rosner in her book by the same name.⁴⁷ Though these medical devices perform their function of regulating BG quite effectively, they can only do so for those who use them, and their very development and commoditization expand the social problems that keep this treatment out of the hands of poor and working class people. At its most extreme, this pricing structure leaves people to choose between debt and death. For those with higher-than-average income, wealth, and employer-subsidized health insurance, that choice is never on the table. For the majority of people with T1D and their families, however, that choice recurs on a regular basis. One of the most powerful factors in that equation—unsurprisingly, given the number of times it was cited as a qualifier throughout this section—is individuals’ access to quality (or any) health insurance.

Insurance Determines Medical Decisions

As I discussed at the beginning of this chapter, insurance coverage is one of the most significant factors in people’s access to care, and by connection, plays a central role in people’s T1D treatment and overall health outcomes. When people are enrolled in an insurance plan, they are more willing to seek treatment and more able to cover the reduced out-of-pocket costs. In the day-to-day experience of people with Type 1 dealing with their care via health insurance, however, it becomes clear that differences among (or even within) health plans determines much about what access looks like. In discussing their treatments, clinic visits, medications, and medical supplies, the people with T1D interviewed for this study describe insurance provider-made channels they are required to navigate in relation to their personal health decisions. At times seemingly benign, these coverage constraints establish norms and practices within health and medicine that place extra burdens on people who need regular care for chronic conditions. These constraints can also set the parameters for treatments individuals *should* have, and thereby limit the types of care they are *allowed* to have—weighting medical decision-making power

⁴⁶ Nicole C. Foster et al., “State of Type 1 Diabetes Management and Outcomes from the T1D Exchange in 2016–2018,” *Diabetes Technology & Therapeutics* 21, no. 2 (January 18, 2019): 67, <https://doi.org/10.1089/dia.2018.0384>.

⁴⁷ Lisa Rosner, “Introduction,” in *The Technological Fix: How People Use Technology to Create and Solve Problems*, ed. Lisa Rosner (New York: Routledge, 2004), 1–2.

away from doctors and patients and toward insurance companies. As one informant sums up, “That’s another part of this whole thing. It’s a lot of, um. . . It’s scary to think they—insurance has so much control over what we get.”⁴⁸

As is the case with most social institutions, the effects of that control are experienced disproportionately based on factors outlined early in this chapter—namely social class, race, ethnicity, gender, age, and geographic location. When individuals have private insurance coverage through an employer, treatment and access to supplies are far more attainable than when they do not. One informant calls attention to this problem via his own privileged position. More specifically, Joshua notes the role of his spouse’s employment status in his own ability to afford his insulin pump supplies. “Because my health insurance is really good through the state, because my wife works for the state,” he adds, “I don’t pay too-too much out-of-pocket for those.” He later specifies that for most of his pump and CGM supplies, he pays no copay or co-insurance at all—an anomaly among participants in this study. “But I’ve seen what they go for, you know, the three-month supply is just outrageous.” Retailing together at about \$1,300 per three-month supply—for the cheapest combination of devices—these disposables alongside the insulin they inject can be overwhelming. And even with his substantial income on top of his wife’s state employment, Joshua muses on his position if her health coverage lapsed: “If I didn’t have insurance I’d be screwed.”⁴⁹

But Joshua is not “screwed” (at least, not yet). Though he has no guarantee it will last, and a loss of his coverage would undoubtedly lead to serious health and financial strain as it has for him in the past, his position as a well-insured, employed, middle-class white man provides some insulation from the worst of T1D’s economic burden. He knows that burden is still there, and that one small change in circumstances could drop it on him and his family at any time, but for now he is allowed respite due to his circumstances and identity.

For some others, the health coverage they have access to never really provides enough support to make their treatment needs affordable. This coverage-cost breakdown is particularly prevalent among informants’ non-pharmaceutical and non-clinical supply needs. “I do have

⁴⁸ Brittany, interview by Stephen Horrocks, female age 35, child diagnosed with T1D in 2016, August 11, 2017.

⁴⁹ Joshua, interview by Stephen Horrocks, male age 39, diagnosed with T1D in 2008, May 23, 2017.

insurance,” says Stephanie, as she discusses the difficulties associated with paying for everything involved in her Diabetes treatment. “In my experience, my entire life (at least with Diabetes), insurance rarely covers even a part of glucose testing strips, and especially the ones that go with the monitor that goes with my pump.”⁵⁰ As I have argued elsewhere in this dissertation, blood glucose testing has become as essential to Diabetes treatment in the twenty-first century as insulin itself.⁵¹ Finger-prick meter readings remain the primary method for determining people’s BG levels, information that makes insulin injection safe and effective, and they require a new test strip to be inserted for every test. Insulin pump systems such as Stephanie’s are built as fundamentally networked systems of devices, and the particular BG meter that syncs with her pump is the only model that can. By refusing coverage for its test strips, Stephanie’s insurance company makes her meter unusable. Paying retail price out-of-pocket is unrealistic for many people with Type 1 who test between five and twelve times per day, and without strips the meter can perform no readings. At the same time, patient-users still need to know their BG in order to properly dose their insulin, and thus turn to other devices that take strips the insurance will cover (or just turn to the cheapest option)—neither of which will send their numbers to the pump’s internal storage. “So I just started buying the cheap ReliOn ones at Walmart, cause it’s nine bucks for like fifty of them.”⁵² Not only must Stephanie now add each BG reading into her insulin pump by hand (which takes time she has not been willing or able to give), but she must experiment with the accuracy and reliability of both her new meters and strips.

Insurance denials such as Stephanie’s above are not uncommon—from insulin to test strips to pumps and CGMs—and patient-users often pursue an appeal process to make the case for special coverage based on need. Mother to an eight-year-old with T1D, Brittany was informed about the Dexcom CGM system soon after her daughter’s diagnosis at age six. She and her partner decided it would aid in their daughter’s treatment and overall quality of life, and reached out to her insurance to begin the purchasing process. “Dexcom. . . we actually applied right away to get a Dexcom and insurance didn’t want to cover it.” With the help of their doctor,

⁵⁰ Stephanie, interview.

⁵¹ See Chapter 2 on the history of T1D treatment, and Chapter 3 on the material experiences of insulin pump treatment.

⁵² Stephanie, interview.

Brittany filed to appeal the insurance company's decision, citing their physician's opinion that it was in the patient's best interest. "We had to fight, I mean, I think we fought for a Dexcom for five months or more, trying to get paperwork done. Dexcom was a struggle to get through insurance." At the root of the insurance company's reason for denying coverage for the CGM: "they felt it wasn't, um, necessary for Diabetes, so they tried everything they could not to give us the Dexcom."⁵³ Regardless of the opinion of the MD overseeing the patient, continuous glucose monitors are not medically necessary according to the insurance company's policy.

In the case of Brittany and her daughter, the drawn-out, bureaucratic appeal process ended in approval. That approval was possible, in part, due to Brittany's careful attention to the paperwork and deadlines set out (and, as she claims above, sometimes undisclosed) by the company and its representatives. Stephanie, whose test strips remain un-covered, was required to file an appeal for her Dexcom as well. "I had to get a special letter from my doctor sent to the insurance company to say that it's a medical necessity," she remembers, a requirement common among informants in this study. "Apparently that monitor wasn't FDA approved to work with the pump," as at the time only Medtronic's in-house CGM—not the Dexcom—was FDA approved to sync with their insulin pump. "I don't know if it just got lost in translation or something, or what, but they never received the letter."⁵⁴ And for Stephanie, that was that. The insurance company informed her they never received it, the appeal was denied, and she therefore does not use the device.

As these examples demonstrate, insurance denials of Diabetes treatment devices rely in part on the company's ability to decide what is medically necessary for their client. They also rely in part on their ability to point to administrative errors on the part of the clients as well. At times these justifications converge, requiring extra labor on the part of both patients and their doctors to push through the appeal system. This shift in patient responsibility and knowledge of biomedicine and its current administrative processes is emblematic of what Adele Clarke, et al. call "scientized" patients within systems of Biomedicalization in the US.⁵⁵ Thirty-five-year-old

⁵³ Brittany, interview.

⁵⁴ Stephanie, interview.

⁵⁵ Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2009), 16.

Jason recalls the case his doctor made for his use of an insulin pump as a twelve-year-old in the mid-1990s. Insulin pumps were fairly new on the market at that time, and MiniMed was the only manufacturer selling in the US after the market consolidated in the late 1980s. During the decade prior, at-home insulin pump use was riddled with functionality and usability issues that made it generally unmanageable.⁵⁶ By the time Jason's doctor was looking into putting him on the pump, only a small segment of people with T1D were eligible for pump use.

"I had an endocrinologist by the name of Dr. [Doe], is what I think his name was, and he was not a normal endocrinologist by any means." It is difficult to ascertain exactly what Jason means by "normal," other than his overt willingness to support Jason's medical needs. "Cause, I mean, him and his office went through hell with my insurance company to get me the insulin pump." As he recalls, he was starting to become resistant to the medium- and long-acting insulins he'd been using since diagnosis, "so. . . I would take a ton of it and it would do nothing." Dr. Doe confirmed the amounts Jason was injecting and expressed his concern about both his short-term well-being and his long-term health. "I was to the point where I was taking between eight and twelve injections a day in order to deal with things, and he was like, 'This is ridiculous. They have these things, let's get one for you.'" The "things" he refers to are insulin pumps, and they use fast-acting insulins that Jason hadn't shown signs of resistance to. Based on these details, his medical need for exclusive use of short-acting insulin was clear, though the insurance company disagreed regarding his need for the device. In the end his appeal was successful, "But, I mean, I know he argued with the insurance companies for months before they got it for me."⁵⁷

One of the most interesting (and frustrating, for informants) aspects of these denial-appeal stories, then, is the ways insurers frame and re-frame each case to deflect responsibility of a denial onto the client. In order to make and support a claim for denial, some form of evidence of a client's inappropriate action or lack of necessary action can be used to close the case (Stephanie's paperwork, for example). This client-responsibility-for-denial framing can, in some cases, be taken-on or assumed by the clients themselves. Reflecting on a past CGM supply denial, Michael claimed some accountability. "When it comes to the appeals I had to do, I believe partially it was my fault and/or my doctor's fault that we had to do that. These [CGM]

⁵⁶ See my discussion of the history of insulin pumps in Chapter 2 herein.

⁵⁷ Jason, interview.

sensors and the transmitters are very expensive, so they thoroughly check you out, and what I failed to do was provide them a log of my blood glucose numbers.” As I noted in the section above, prices for CGM supplies are high enough that few if any people with T1D could pay for them out-of-pocket. What Michael narrates here, however, are the extra steps insurers require of clients for these supply orders to be filled. They need proof, as it were, that you are actually using the CGM in order for them to allow you to order more supplies.

There are many issues with that requirement, covered to some extent below, but here what is particularly noteworthy is Michael’s acceptance of these terms and the “guilt” for his eventual denial—terms which, as he noted later, he was not informed of in the first place. “I failed to do that. [. . .] That was all part of the appeal, they wouldn’t tell us why they denied it, they just kept denying it. So finally, I called them up and had a conversation with the rep, and they just said, ‘Well, you know, provide this.’ And we did that, and we won the appeal.”⁵⁸ Based on the way Michael narrated this insurance interaction, he could not have been “guilty” of failing to fulfill requirements of which he was never informed, yet he accepted that assumption nevertheless. That power dynamic has been normalized enough for Michael that he takes his own guilt for granted, and the insurer’s ability to deny coverage for his medical needs is taken for granted along with it.

But within Michael’s story is another more surprising, and in some ways more suspect detail than even the normalizing of insurance-centered power structures. Michael was required, before he could order new CGM supplies and continue to use his device, to send them a record of his recent BG numbers. He did not elaborate more on this process—either ordering supplies or submitting his numbers. Other informants identified similar requirements, however, and they expounded on both that process and what it means for supply ordering more generally. Heather, a mother of a child with Type 1 referenced in the previous section, discusses the timetables and order sizes for CGM supplies mandated by their insurance plan. “Our insurance will allow us to order supplies every hundred days, so we get a hundred days-worth of supplies. And the transmitters is a different batch, it’s a different group. We get those every six months.” By supplies, Heather refers to the sensor wire inserted beneath the skin and adhered to the body. Dexcom CGMs also require a longer-term transmitter device that attaches to the sensor and

⁵⁸ Michael, interview by Stephen Horrocks, male age 41, diagnosed with T1D in 2010, May 19, 2017.

wirelessly sends the glucose readings to patient-users' phones or reader devices to be visualized and stored.⁵⁹ In both cases here, the insurance company requires clients to purchase a set number of supplies at every order—one hundred days and six months, no more and no less. That also means they are unable to order more supplies until the previous batch is scheduled to be used up. This can be a problem if, for example, a sensor is accidentally knocked off before it was supposed to be removed. An accident once or twice a month (which is not unusual, especially for children such as Heather's child, given its location on the body) can leave people without supplies until they can place a new order. Without the disposable supplies, the CGM cannot be used at all.

At the time of every new Dexcom supply order, Heather is required to revisit the paperwork requirements she filled at the time of the CGM's initial approval by their insurance. "He gets the sensors—they don't require, like, any additional information, but in order to get the transmitters we have to send proof that we're using it, and I think it's like thirty days-worth of the readings." Just as Michael briefly noted above, Heather's new transmitter orders must be accompanied by a month-worth of CGM glucose reading data. In her words, this requirement is in place as a system of proof that the patient-user is actually using the device. Implied therein is an assumption that at any time, each client may be taking advantage of the system in some way and not using the devices as prescribed. "So we just go online and send the Dexcom readings to Dexcom, allow them access to it, and then they do it with our insurance," Heather says. "Dexcom sends it to our insurance, cause it's our insurance that requires all the data. [. . .] And we just use Dexcom because they do it all for us."⁶⁰ And here is the crux of the data-access requirement itself: insurance providers will not payout for supplies unless they receive clients' use data as proof that their payment was not wasted. Never mind that the specifics of people's treatment practices are determined by them in consultation with a physician, or that individuals' BG data is itself protected Personal Health Information (PHI), it must be submitted to the manufacturer and thereby provided to an insurer before continued access to CGM use will be granted. What is more, HIPAA loopholes allow for both manufacturers and insurers to amass

⁵⁹ For reference, the Medtronic brands of CGM transmitters are rechargeable and only replaced if they are broken or faulty. Dexcom, the only other CGM approved by the FDA, requires users to change out the transmitter about every six months.

⁶⁰ Heather, interview.

proprietary data collections from mandatory uploads because (as the terms and conditions state) all of patient-users' data is de-identified—and de-identified PHI is no longer HIPAA protected data.⁶¹

Mandatory data sharing is part of the larger trend of CGM denial identified throughout the informant stories above. As another T1D parent discusses, the initial fight for CGM coverage does not settle the issue. Brittany bemoans the constant appeal and justification process insurance companies require for every new order—a practice that is not a part of most other pharmaceutical or supply orders. “And actually,” she exasperates, “we still fight every six months for the transmitters. For the supplies, and it’s like, ‘we can’t do anything without them,’ so they try everything they can—insurance—to, I don’t know, they just don’t want to cover that.” For some, like Stephanie at the beginning of this section, the constant trouble of ordering and reordering is enough to dissuade them from using a CGM altogether. For Brittany and Heather, the headache is never-ending. “We wanted the Dexcom before the pump, but that just didn’t happen because of insurance, they put up a big fight.”⁶²

These endless submissions and uploads can delay orders from shipping, leaving people without the supplies they need until they (hopefully) arrive. “I have to start the process, like, two-three months before her transmitter are done,” Brittany notes, referring back to the lengthy process of re-approval, “because otherwise. . . the first time I had to do this, I didn’t realize I had to do this, and she went without Dexcom for two months while I was trying to fight for them to give us the transmitters. So now I have to start the process early to make sure she doesn’t go without the CGM.”⁶³ Without supplies, Brittany, her partner, and their then-seven-year-old daughter were forced to stop using her treatment device due to the insurance-mandated hoops they did not know they had to jump through. In the balance was/is her treatment and well-being, all at the behest of a bureaucratic box-checking system meant to dissuade people from using what would otherwise be covered by their plan.

⁶¹ “What Is Considered PHI Under HIPAA?,” *HIPAA Journal*, December 28, 2017, sec. Healthcare Data Privacy, <https://www.hipaajournal.com/considered-phi-hipaa/>.

⁶² Brittany, interview.

⁶³ Brittany.

But all of these examples hinge on an insurance program that eventually *will* cover a CGM, even if it requires immense time and labor to secure and maintain it. For some, those denials are more concrete. James and his wife Mary discussed their one past experience with a CGM, and the circumstances that bar him from using one again. Both in their late-seventies, James and Mary talked through their experiences together, filling in the gaps for one another and painting a rather colorful picture in the process. “When he was first being set up on the pump,” Mary recalled (after she asked James, “Do you remember?” and he replied, “No.”), “they put that on him so that they could get a reading. I think for two weeks he wore one.” They checked it occasionally and had an overall positive experience with the device. “But now Medicare won’t pay for it, and it would be prohibitively expensive to buy it ourselves.” At that, James decided it was not worth pursuing any further and they have never talked to his doctor about a CGM since.⁶⁴

That first two weeks was a one-time deal, pitched as a necessity during the first days after he switched to an insulin pump to avoid dangerous BG fluctuations while they adjusted his daily dosage needs. After that, Medicare informed them it was not a medical necessity and therefore uninsurable. James did not seem to be bothered one way or the other, but Mary was aware of the positive difference a CGM could make to his overall well-being. “My doctor talked to me about James, and told me that he knows people that have them and that it would be a life saver, and it would be just really wonderful, and he should just really do it.” She acknowledged the doctor’s professional opinion and left the office without visiting the subject again. “But we haven’t really talked to James’s doctor about it because Medicare won’t pay for it,” she says, with a slight shrug of her shoulder. Medicare is understood by James and Mary as an institution in and of itself, an appendage of the US federal government with decision-making power that supersedes their doctors’ or their own. When asked if they were ever given a reason for the denial, Mary’s response reflected this sentiment. “Nope,” she says. “You don’t really ever question Medicare, do ya?”⁶⁵

⁶⁴ James and Mary, interview by Stephen Horrocks, male age 75, diagnosed with T1D in 1987, female age 73, August 14, 2017.

⁶⁵ James and Mary.

Even with good health coverage, and even if they approve a particular device or medication, the insurer has the ability to make adjustments to or change how that coverage works at any time. Plans may require low total out-of-pocket responsibility, and they may cover one's specific needs, but as insurance companies sign and terminate contracts with health and pharmaceutical corporations those coverage parameters may shift. When this happens, clients must adjust their treatments, practices, and even doctors to fit the new plan parameters. Along with her endless battle for their child's CGM supplies detailed above, Brittany and her partner have been caught unaware by their insurance company's abrupt changes to coverage for other treatment needs as well. "They just switched her insulin," she sighed. "They decided that they no longer will cover her Humalog, so we just started on Novolog since they'll only cover Novolog now." Though these two insulins—the only two fast-acting insulins on the US market, as I noted earlier in this chapter—are very similar in many ways, some people's bodies respond differently to one than the other. From the outside, such a need for adjustment seems small and manageable. For those dealing with T1D on a daily basis, and for small children with Type 1 and their parents, those minor adjustments require considerable physical, mental, and emotional labor. And more to the point, their specific medical needs are and have been worked out between them and their physician who is licensed to provide those professional opinions. Having *any* say in patient treatment whatsoever falls outside the training and expertise of insurers, but holding such power as to dictate how and when people switch medications is both medically unethical and dangerous.

If that was not enough, Brittany's insurance made yet another change requiring their adjustment and intervention. "We are now going through an appeals process for test strips, because they now all of a sudden don't want to cover her test strips that go into her Omnipod [insulin pump]." They will cover another brand of test strip, of course, but that means she would not be able to use the meter that syncs with her pump (not unlike Stephanie's situation at the beginning of this section). Not only that, she would have to carry yet another device along with her at all times. Brittany filed an appeal to have the pump-related strips covered, and have not yet received a response, "We're still waiting to hear back on that." When all is said and done, these denials and appeals, adjustments and switches, plan decisions and treatment changes add an additional layer of complication and psycho-emotional burden to an already heavy experience

with T1D. Brittany summed it up this way, “You know, the disease is hard enough, and then to have to fight constantly to make sure that she gets what she needs is another stress.”⁶⁶

All of this matters due to the fear and potential ruin associated with living with a chronic condition and lacking access to the health care and support needed to manage it. It is important to remember, as one informant eloquently details, that these health and human management systems are themselves human-made—both in their support for human wellness and their unemotional dismissal of need and even suffering. Jennifer, a thirty-five-year-old policy worker with life-long T1D relates her personal experience with (and without) insurance that unpacks much about the implication of the above stressors and control regimes:

You know, I grew up in an era where getting. . . I was uninsurable as a child. There was no Medicaid, there was no CHIP back then if you were a kid. And my mom really struggled after my dad died making sure that I had what I needed. I mean, there was a lot of stuff put on credit cards; I did not go to the doctor when I should have. Strictly because of money. It was money. I think my mom had a plan for her and my siblings, but she had no plan for me, because no insurance company would give me insurance. You know, I always felt like the ACA was a turning point to where we would never see that again. where a parent has to, like, make decisions about providing. . . because, as you know, Type 1 Diabetes is unique in that if you don’t have insulin, you’re dead within a few days. There is no in-between, you die, that’s it.⁶⁷

To say the stakes are high in these informants’ fights for coverage is an understatement, and the real threat of suffering (or worse) that follows a lack of care is very real. That possibility is real, in part, because it has long been part of the history of Diabetes itself. Without insulin, people with T1D cannot live more than about a week. As I have laid out earlier in this chapter, however, pharmaceutical insulin is very expensive and usually requires health coverage for most people to afford it. Within that system of need—medical and economic—insurance companies have the power to set the parameters for the insured to such a degree that they can all but dictate how they treat their chronic illness. But what are people to do? In such a system, they are compelled to meet whatever expectations are laid before them in order to access the medication or supplies they need to live. Because without insurance, as one informant points out, “you’re making the

⁶⁶ Brittany, interview.

⁶⁷ Jennifer, interview by Stephen Horrocks, female age 35, diagnosed with T1D in 1985, May 22, 2017.

decision of, ‘OK, should I eat? Or should I get my supplies?’ I mean, it’s insane, you know? People should never have to make that decision.”⁶⁸

Forecasting the Technological Fix

In June 2017, an informant from New Zealand attended the 77th Scientific Sessions of the annual American Diabetes Association (ADA) conference, held that year in San Diego. According to Christopher, most of the presentations focused on current research on or development of Diabetes tech. CGMs in particular caught the attention of clinical professionals and researchers, from “revolutionizing” people’s ability to exercise with Type 1 to acting as the technological future for Type 2 treatment. In contrast, he said, repeatedly cited throughout these panels was the statistic that about one-tenth of people with T1D in the US use a CGM. That number has risen dramatically in the US within a very short time, with thirty to forty percent of people with T1D in the US using CGMs in 2018, though globally those numbers remain near ten percent.⁶⁹ Given the way presenters talked about these devices, he was surprised by how few people currently have access to them. As he expounded on these thoughts later during our interview, he began talking through the implications of that problem:

And, you know, if only 10% of Type 1s have got access to a CGM. . . there’s the scientific problem of “How do you manage Diabetes?” And of course there are scientists who focus on that, [. . .] but then there’s the everyday realities of what people living with Diabetes actually are faced with, and the standard of care that they can access, which varies depending on where they live, on how wealthy they are, on a whole group of things that are completely out of their control. It’s just not that clear how much Diabetes research is actually focused on dealing with what Diabetics see as their biggest challenge right now.⁷⁰

It is clear from their prevalence at the ADA conference that CGMs currently hold an important place in the minds and imaginaries of Diabetes researchers, and for good reason. As I have detailed in previous chapters, the ability to keep track of not only current BG levels, rising and

⁶⁸ Joshua, interview.

⁶⁹ Foster et al., “State of Type 1 Diabetes Management and Outcomes from the T1D Exchange in 2016–2018”; Oana Onisie, Hamish Crocket, and Martin de Bock, “The CGM Grey Market: A Reflection of Global Access Inequity,” *The Lancet Diabetes & Endocrinology* 7, no. 11 (2019): 823–825.

⁷⁰ Christopher, interview by Stephen Horrocks, male age 36, diagnosed with T1D in 2013, June 20, 2017.

falling trends has made catching high and low BG episodes early much easier and quicker. That makes for a considerable quality-of-life improvement with both short- and long-term health implications. In fact, several people interviewed for this study refer to their devices as “miracles.”

But as Christopher gestures toward, and as this chapter lays out in more detail, that miracle is only accessible to a small proportion of the people who could benefit from it—and that access is restricted based on cost, insurance, and the myriad social markers that influence individuals’ ability to obtain them. The ADA laudations fall flat for the majority of people with Type 1, and as the push for FDA approval for CGM use in Type 2 treatment comes over the next few years (as Dexcom has already begun marketing with their G6 Pro model) this divide will only become more clear.⁷¹ “So then, what are the actual realities of living with Diabetes, you know? And what can be done about it?” Christopher asks. He did not posit an answer to this question, but for him it was more about asking the question than answering it. That question prompted a realization that serves to point us at least in the direction of some answers. “A lot of the science research, of course, because it’s controlled and because it’s focused on a technological problem, it misses the political problem.”⁷² And therein lies a direction for seeking more equitable access to these types of treatments in the future. The political problems associated with hi-tech medical treatment cannot be solved through technological means unless the social and political structures bearing them up are changed in the process. Given the permanence of social institutions, that technological fix—to again return to Lisa Rosner’s conception—falls short of enacting the kind of change people need now, highlighting the cultural paradox of T1D treatment and hi-tech medical treatment generally: doctors and patients are devoted to the development of biomedical knowledge and treatment, yet disillusioned with the ability of science and technology to make those treatments available to everyone who needs them.⁷³ Without large-scale social change, inequality in health care will likely never be reversed.

⁷¹ “Dexcom CEO Previews New Glucose Monitoring System He Says Will Be the ‘Revolution in Diabetes Data,’” *Mad Money with Jim Cramer* (Englewood Cliffs, NJ: CNBC, March 10, 2020), <https://www.cnbc.com/video/2020/03/10/dexcom-ceo-new-glucose-monitoring-is-a-revolution-in-diabetes-data.html>.

⁷² Christopher, interview.

⁷³ Rosner, “Introduction,” 5–6.

To close, I turn to another informant's "soapbox." In so doing, I hope to highlight that those who are devoted to remedying the political problem Christopher identified above are the key to its possible success:

If there is any soapbox that I'm gonna die on, besides everybody having health insurance: every Type 1 should have access to this stuff. I think it's great to think about cures, that's wonderful, but we have shit right now. Dexcom, the pumps, we have it right now. I have no doubt that my Dexcom has not only saved my life a number of times, but it probably added ten, fifteen, maybe twenty years on my life—of health, of good health. I just get frustrated when I think about people not having access to this. There is no excuse. Every Type 1 should be able to get this stuff, you know, at a reasonable or very low cost.⁷⁴

⁷⁴ Jennifer, interview.

CHAPTER 7: CONCLUSION

On March 10, 2020, Jim Cramer of CNBC's stock market-watch series *Mad Money* sat down with Dexcom, Inc. CEO Kevin Sayer. Dexcom is one of three manufacturers producing FDA approved continuous glucose monitor (CGM) devices in the US, and the purpose of this interview was simple: Dexcom's stock appears to be positioned to continue growing during the global COVID-19 pandemic. After some discussion about the company's decreasing manufacturing costs per-unit and stable sale pricing, Sayer said their success over the past year boils down to Dexcom's unique features. "We offer a lot more," he claimed, "and so far, those who pay for the product have been willing to pay more."

Sayer went on to pitch Dexcom's newest product, the G6 Professional (or G6 Pro). Derived from the G6, their most recent at-home model for everyday use by people with Type 1 Diabetes (T1D), the G6 Pro consolidates all of the necessary devices, peripherals, and disposables into one single-use package to be used by physicians for patient blood glucose (BG) tracking. Rather than a system for continuously tracking glucose levels on an on-going basis, the G6 Pro is meant to provide healthcare providers with a ten-day glucose dataset which can be used for diagnostic purposes or to adjust patients' treatments and overall wellness goals.

But clinic-focused use is not, on its own, the G6 Pro's big selling point. Sayer announced with excitement that "this is not labeled just for people with Diabetes, it's labeled for all people." In response to Cramer's incredulous "Why?!", Sayer answered, "for health and wellness or somebody who may be in a Pre-Diabetic stage." Though their current consumer-base is rather loyal to their CGM products, people with T1D make up a relatively small portion of US and global populations. By pitching this device as useful outside of daily Type 1 treatment and care, Sayer and Dexcom aim to be the site of what he called "the revolution in Diabetes data." Not reserved exclusively for insulin pump treatment, the G6 Pro can be used to measure the effectiveness of treatments for people with Type 2 Diabetes (and Prediabetes, as he noted earlier), and can be pitched to the vague and open-ended market of "all people"—building a new group of potential consumers numbering in the tens-of-millions.¹

¹ "Dexcom CEO Previews New Glucose Monitoring System He Says Will Be the 'Revolution in Diabetes Data,'" *Mad Money with Jim Cramer* (Englewood Cliffs, NJ: CNBC, March 10, 2020),

As I have argued throughout this dissertation, “revolutionary” medical devices structure and are structured by people, bodies, and identities, and their institutionalization produces wholly new socio-technical networks which require adjustments to both individual practices and large-scale systems. That process—fundamentally embodied by the people interacting with those networks—changes the materiality of bodies and health/illness, and reframes how they are understood by patient-users, health professionals, and members of societies more broadly. For people with T1D, treatment is inevitable and, as this study has shown in the case of insulin pumps and BG monitoring devices, can directly lead to significant improvements to day-to-day quality of life. But as treatment regimes become medically and socially compulsory, many of their material and social limits are made painfully apparent and must be confronted if that revolutionary T1D future is to be an equitable one.

Diabetes Treatment: The Next Generation

Dexcom is not the only one hoping to be the next site of a Diabetes treatment revolution, as everyone from private device manufacturers to public biomedical research labs, pharmaceutical companies to Silicon Valley tech giants position themselves for a piece of the global Diabetes market. Already one of the most lucrative markets in the world worth somewhere in the range of \$85 billion annually, Diabetes treatment is and will remain a major focus of health-related research and production for the foreseeable future.² For people with Type 1, all of this focus means there is always something new to be excited about.

In its various forms, blood glucose (BG) testing is an essential component of T1D treatment today and makes up approximately \$9 billion of the Diabetes treatment market world-

<https://www.cnbc.com/video/2020/03/10/dexcom-ceo-new-glucose-monitoring-is-a-revolution-in-diabetes-data.html>.

² This number reflects all Diabetes care, devices, and treatment world-wide, without differentiation by type or form of Diabetes. See: “\$85.6 Billion, Diabetes Care Devices & Drugs Market Size, Share, Global Opportunity Analysis And Industry Forecast (2017-2022),” MarketWatch, accessed March 27, 2020, <https://www.marketwatch.com/press-release/856-billion-diabetes-care-devices-drugs-market-size-share-global-opportunity-analysis-and-industry-forecast-2017-2022-2019-01-30>; “Type 1 Diabetes Treatment Market Exclusivity - Industry Will Drive Huge ROI at USD 9.6 Billion during 2019 to 2025,” *Medgadget* (blog), December 5, 2019, <https://www.medgadget.com/2019/12/type-1-diabetes-treatment-market-exclusivity-industry-will-drive-huge-roi-at-usd-9-6-billion-during-2019-to-2025-market-research-future.html>.

wide.³ As such, BG testing caught the eye of Apple Inc. as a potential site for expansion. In 2010, they announced a plug-in meter built by French pharmaceutical company Sanofi Aventis. Known as the iBGStar, the device used a 3.5mm headphone jack to connect to the bottom of an iPhone, and used an on-screen app to visualize and store the data as it entered via a familiar test strip. The iBGStar did not sell particularly well, and has now been supplanted by the sleeker, mirrored stainless steel-palate Apple One Drop monitor system that syncs with both the Apple Watch and Apple Health.⁴ In both of these ventures, Apple attempted to carve out a niche for itself in the BG testing market as it exists rather than developing toward some sort of “revolution.” Instead, for them, the future of Diabetes treatment is less about something wholly new and more about the convenience of syncing the already-established process with their Apple-everything approach. And here, that networked convenience places one’s BG testing within one of the most controversial sites of technocapitalist production in the twenty-first century, carrying implications for the ways their biomatter can be understood and (re)constructed.

Not only is finger-prick BG testing central to T1D treatment, I have argued that it is also a cumbersome process to be engaged in all day, every day. CGMs such as the Dexcom, which introduced this conclusion, have focused on lessening the number of finger-prick tests required per day by calibrating an on/in-body sensor that reads glucose levels constantly. With their most recent iteration, the G6, Dexcom no longer requires a BG meter test to calibrate the sensor at all. Instead, the company calibrates the sensors in the factory and algorithmically adjusts to the patient-user’s body during the first two hours of use. Dexcom is leaning hard on this feature as a major marketing tool and have even registered the URL nomorefingerpricks.com to promote

³ Mark D. Hughes, “The Business of Self-Monitoring of Blood Glucose: A Market Profile,” *Journal of Diabetes Science and Technology (Online)* 3, no. 5 (September 2009): 1219–20.

⁴ Brian Dolan, “Sanofi Aventis, Agamatrix to Launch First Medical iPhone Peripheral?,” *MobiHealthNews*, September 21, 2010, <https://www.mobihealthnews.com/8950/sanofi-aventis-agamatrix-to-launch-first-medical-iphone-peripheral>; Jonah Comstock, “Connected Health Devices Fail to Improve Costs, Outcomes in Short Term, Scripps Study Finds,” *Healthcare IT News*, January 20, 2016, <https://www.healthcareitnews.com/news/connected-health-devices-fail-improve-costs-outcomes-short-term-scripps-study-finds>; Christina Farr and Kif Leswing, “Apple Continues Expanding into Health Care by Selling a Consumer-Focused Diabetes Monitor in Stores,” *CNBC*, June 27, 2019, sec. Tech, <https://www.cnn.com/2019/06/27/apple-store-to-sell-one-drop-monitor-its-first-diabetes-product.html>.

their CGM in collaboration with the T1D nonprofit Beyond Type 1.⁵ For several years prior to the release of Dexcom's G6 model, first announced in 2018, the FreeStyle Libre produced by Abbot Laboratories was built on a similar no-finger-prick premise but did not have the same loyal consumer base in the US as they had elsewhere in the world.⁶ In both cases, the future of glucose testing is about shifting away from finger-prick systems and toward always-on, always attached sensors which produce large amounts of glucose data. That future, in short, means limited interaction and Big Data—a site with deep-rooted issues surrounding the ownership and use of data produced by and about people's bodies.

Others are attempting to usher in new methods of BG testing from a different, in some ways less physically present and/or painful approach. In 2014, Google Life Sciences (now Verily) announced they would be developing a contact lens that would take constant glucose readings from users' tears and wirelessly transmit the data to insulin pumps and/or other devices. If successful, this device would supplant the need for a device injected into and attached onto the body to take continuous readings, as is required for a CGM. Unfortunately, glucose is difficult to measure in tears, and the project halted research in 2018.⁷ Taking more of a traditional on-skin approach, researchers at the University of California San Diego are conducting a phase 1 clinical trial for a glucose testing tattoo. Designed to be applied with water similar to children's temporary tattoos, this monitoring device uses two electrodes to apply a small charge to the skin, causing glucose molecules to rise to the skin's surface where they can be measured. In so doing, BG testing can be performed in a minimally invasive way which, according to UCSD Center for Wearable Sensors Co-Director Patrick Mercier, could cost as little as \$1 per disposable tattoo.⁸ If

⁵ "No More Finger Pricks," accessed March 23, 2020, <https://nomorefingerpricks.com/>; The first noted entry for nomorefingerpricks.com on the Internet Archives site The Wayback Machine was listed as November 2018. See: "No More Finger Pricks," The Wayback Machine, November 12, 2018, <https://web.archive.org/web/20181112171712/https://nomorefingerpricks.com/>.

⁶ Abbott Laboratories, "Abbott Receives CE Mark for FreeStyle® Libre, a Revolutionary Glucose Monitoring System for People with Diabetes," September 3, 2014, <https://abbott.mediaroom.com/2014-09-03-Abbott-Receives-CE-Mark-for-FreeStyle-Libre-a-Revolutionary-Glucose-Monitoring-System-for-People-with-Diabetes>.

⁷ Angela Chen, "Verily Pauses Research on Glucose-Sensing Contact Lens," The Verge, November 16, 2018, <https://www.theverge.com/2018/11/16/18099193/verily-novartis-glucose-contact-lens-science-health>.

⁸ Yadira Galindo, "Clinical Trial Tests Tattoo Sensor as Needleless Glucose Monitor for Diabetes Patients," UC San Diego News Center, April 19, 2018, <https://ucsdnews.ucsd.edu/feature/clinical-trial-tests-tattoo-sensor-as-needleless-glucose-monitor>.

successful, either the contact or tattoo glucose sensor would make the process of collecting BG information from the body less painful, less invasive and prone to infection or scarring, and—importantly—less bulky with a smaller physical footprint on and near the body. But as I discussed in relation to current networks of treatment devices in Chapter 3, new materials on/in/near the body can have unexpected interactions with physiologies and microbiomes, making eyes and skin of particular concern with the development of these prototypes.

All of these glucose testing innovations, in one way or another, attempt to rethink or redirect current methods for obtaining BG information. That data is useful to people with T1D only inasmuch as it informs their insulin injection and food consumption practices. Insulin injection remains the only means for medically treating Type 1 Diabetes, and as such many of the imagined futures of Diabetes treatment revolve around making injections simpler, requiring less direct interaction and taking up less physical space around patient-users.⁹ Insulin pumps, especially those networked with glucose devices to function as a closed-loop system, are the twenty-first century success story on which many base their interventions. Insulet Corporation has been selling a tubeless insulin pump called the OmniPod since 2005, featuring a covered reservoir that is attached directly to the skin with an infusion set and wirelessly syncs with what they call a Personal Diabetes Manager (PDM). This device acts as the hub for user interaction and insulin injection inputs, and even has a built-in BG meter.¹⁰ Though the tubeless pump is itself a much larger object to be attached to the body than an infusion set, it removes the tangle-related issues of tubed pumps. The company's focus on wireless connectivity, especially as early as 2005, helped nudge the other manufacturers in that direction with the closed-loop and CGM-based systems that have dominated the market since then. As some informants in this study attest, however, the OmniPod's size and adhesives can affect patient-users' ability to use the device itself.

⁹ I invoke the term from Jens Beckert in part due to the world-building imaginary central to med-tech innovation broadly, but in the case of T1D treatment devices (and medical devices generally) his analysis of commonly-held beliefs about what capitalist futures may look like is an important lens into the ways able-bodiedness and the pursuit of a post-Diabetes existence drive these innovations. See: Jens Beckert, *Imagined Futures: Fictional Expectations and Capitalist Dynamics* (Cambridge, Massachusetts: Harvard University Press, 2016).

¹⁰ Medgadget Editors, "The Omnipod™ Integrated Insulin Delivery and Glucose Monitoring System |," *Medgadget*, July 6, 2005, sec. Medicine, https://www.medgadget.com/2005/07/the_omnipod_int.html.

Other researchers have attempted to sidestep the injection side of insulin treatment, at least in the traditional needle-and-syringe sense. One way to get insulin into the bloodstream without a needle, which is currently available though not very widely used, is via inhalation. FDA approved in 2006, Pfizer's Exubera brand insulin was the first inhalable powder-form insulin intended to side-step issues some have with injections (such as needle-phobia). One year later, Pfizer pulled Exubera altogether and inhalable insulin did not return to the market until Sanofi released Afrezza in 2014. Though it is still technically available via prescription, Sanofi pulled its marketing in 2016 and its future is unclear. Though these insulins faced insurance-related issues and showed signs of respiratory side effects, their largest barrier was likely the near-absolute market dominance by injectable insulins produced by Eli Lilly and Novo Nordisk.¹¹

Another, currently experimental method for non-traditional injection is via ingestion. Because pharmaceuticals such as insulin are too large to be absorbed through the stomach or intestines, and would be destroyed by the body's digestive system in any case, researchers have created a small robotic injector housed in a pill casing currently under the name Soma. This robot would, once its casing is dissolved by stomach acid, orient itself against the stomach wall and pop out an internal post to inject the insulin.¹² Currently only tested in rats and pigs, this treatment method would not only circumvent the need for needles and vials, but even mechanical insulin pumps attached to the body. Long-term, this approach could have a significant influence on injected medications generally, though its side effects are largely untested and it would require years of clinical trials before seeking FDA approval. At the very least, introducing technical objects into the body—especially ones designed to attach to internal tissues—has the potential to disrupt the various biological systems functioning within bodies at any given moment.

Mirroring the Soma's non-syringe approach, but gesturing back to an on-skin design, a research group from UCLA, MIT, and UNC have developed a smart insulin patch. The coin-

¹¹ Jacob Oleck, Shahista Kassam, and Jennifer D. Goldman, "Commentary: Why Was Inhaled Insulin a Failure in the Market?," *Diabetes Spectrum : A Publication of the American Diabetes Association* 29, no. 3 (August 2016): 180–84, <https://doi.org/10.2337/diaspect.29.3.180>.

¹² Alex Abramson et al., "An Ingestible Self-Orienting System for Oral Delivery of Macromolecules," *Science* 363, no. 6427 (February 8, 2019): 611–15, <https://doi.org/10.1126/science.aau2277>; See also: Gina Kolata, "A High-Tech Pill to End Drug Injections," *The New York Times*, February 7, 2019, sec. Health, <https://www.nytimes.com/2019/02/07/health/oral-pill-insulin.html>.

sized device, similar in concept to the glucose monitoring tattoo noted above, would automatically inject insulin through pre-loaded microneedles based on BG readings taken from the skin. This would require less intentional interaction with both BG and insulin, essentially automating the injection process without the physical bulk or electronic calculation typical of current closed-loop insulin pump systems. The group has applied for FDA approval for human clinical trials, and as co-author on the project John Buse claims, "This smart insulin patch, if proven safe and effective in human trials, would revolutionize the patient experience of diabetes care."¹³ The revolution in this case, per this co-author's language, is about simplifying patients' experiences with Diabetes, or more specifically their regular daily treatment acts. But as is the case with all of the patch-oriented devices discussed herein, the surface of the skin and the points of insertion can be affected by these materials in unexpected ways, often with long-term visible or tactile traces. And the very concept of making treatments less visible or materially present carries with it a concern for the necessary visibilities of T1D (feeling movements toward high or low BG, for example).

Each of the insulin- and BG-related innovations above is built around both a particular sense of T1D as it exists today, and an assumption about its existence (and therefore a need for insulin treatment) in the future. Those assumed Diabetic futures are challenged by some of the most well-funded and powerful sites of T1D-related research and advocacy in the US and the world. The Juvenile Diabetes Research Foundation (JDRF), established in 1970, is a global nonprofit whose "strength lies in our exclusive focus and singular influence on the worldwide effort to end T1D."¹⁴ Until the mid-2000s, all of their research grant funding and lobbying effort went toward finding the all-illusive cure for T1D. Since then, the company has also advocated for treatments that would improve people's quality-of-life, particularly the closed-loop insulin pump system. As the seventieth largest nonprofit on the Forbes 100 List, JDRF International raises hundreds of millions of dollars per year (\$227 million in fiscal year 2018) and has a

¹³ Jicheng Yu et al., "Glucose-Responsive Insulin Patch for the Regulation of Blood Glucose in Mice and Minipigs," *Nature Biomedical Engineering*, February 3, 2020, 1–8, <https://doi.org/10.1038/s41551-019-0508-y>; University of North Carolina Health Care, "Coin-Sized Smart Insulin Patch, Potential Diabetes Treatment," ScienceDaily, February 4, 2020, <https://www.sciencedaily.com/releases/2020/02/200204163702.htm>.

¹⁴ "About JDRF," Juvenile Diabetes Research Foundation, accessed March 25, 2020, <https://www.jdrf.org/about/>.

reputation for intensely well-backed lobbying efforts.¹⁵ And though the percentage of organization's funds being directed toward research has dwindled over the past few years as administrative pay has risen significantly, they divert about \$75-\$80 million per year toward a cure for Type 1 Diabetes.

A cure for an autoimmune disorder such as T1D means different things for different researchers, but in each case, it must compensate for lost insulin production from beta cells in the pancreas. If new insulin-producing cells are directly transplanted into bodies with Type 1, the immune system will destroy them as it has with the others in the pancreas. A research group from Harvard and MIT (inspired and funded by JDRF) has been collaborating on a method to side-step that reaction by enclosing those cells in a material that would act as a barrier between them and the body's white blood cells. In lab trials with mice, the implanted cells began producing insulin immediately and the housing could stay in the body for about six months without significant scarring.¹⁶ The group has recently experimented with immunosuppressant drugs incorporated into the housing, with the hope that the device could remain in the body without scarring for longer.¹⁷ But at this point, this project's design would still require occasional surgeries to remove and replace devices, thus not qualifying as a "cure" in a permanent sense.

Another approach to side-stepping the body's immune reaction to pancreatic beta cells is directed immunotherapy. A study by Purdue University Veterinary Medicine researchers in collaboration with the Indiana University School of Medicine uses collagen in a mixture with pancreatic cells which is injected into the body with a needle and syringe. Based on a similar premise as the Harvard-MIT unit, the goal with this treatment is to re-introduce insulin-producing cells along with something to protect them from the body's immune reaction—in this case, the collagen. Pre-clinical animal trials showed insulin production within twenty-four hours,

¹⁵ "JDRF International," *Forbes*, accessed March 25, 2020, <https://www.forbes.com/companies/jdrf/>; Antonio Regalado and Michael Waldholz, "Ballot Drive Puts Stem-Cell Funding In Voters' Hands," *Wall Street Journal*, March 31, 2004, sec. News, <https://www.wsj.com/articles/SB108069195199269659>.

¹⁶ Anne Trafton, "No More Insulin Injections?," *MIT News*, January 25, 2016, <http://news.mit.edu/2016/pancreatic-cells-diabetes-treatment-insulin-injections-0125>.

¹⁷ Anne Trafton, "A Better Way to Encapsulate Islet Cells for Diabetes Treatment," *MIT News*, June 24, 2019, <http://news.mit.edu/2019/immune-response-suppressant-diabetes-0624>.

and those cells remained active for approximately three months.¹⁸ This treatment, though focused on re-automating insulin production as with the previous example, is also a short-term treatment lacking the permanence many envision of a cure.

The other major approach to curing T1D is beta cell regeneration, a treatment focused on growing new cells inside patients' bodies and re-activating the few cells that remain in the pancreas. This regenerative research centers on the use of human stem cells, which could be introduced into the pancreas and coaxed into becoming insulin-producing beta cells. Individual centers focused on this research have formed numerous groups around the world such as the Clinical Islet Transplant Consortium (CITC) which focus on transplanting clusters of beta cells, called islets, from human cadavers (largely due to restrictions on certain human stem cell research, particularly in North America).¹⁹ Cadaver islets are limited, however, and the process of making them safe and transplantable is complex. Using lab-reproduced stem cells to create islets, researchers have completed phase 1 and phase 2 clinical trials that have regulated BG levels for several months post-implantation.²⁰ Though cadaver transplants have been studied for decades, their application has been small-scale and primarily in high-need cases. The safety of stem cell-produced beta cells as a long-term treatment of T1D has not been thoroughly studied either, so while these treatments show promise, they are not likely to be used widely in the short-term. This, as with each of the attempts at a cure for T1D, operates under an assumption that a non-Diabetic life is preferable to a Diabetic one—a fundamentally ableist conception of the experiences of people for whom T1D is a material and social reality. While these efforts promote a future-building project which envisions health options for those with often overwhelming chronic illnesses, the millions of dollars funneled into cure projects frequently bypass the actual people living with Type 1 today.

¹⁸ Kayla Wiles, "New Type 1 Diabetes Therapy Shows Promise for Long-Term Reversal in Both Humans, Dogs," *Purdue University News Service*, accessed March 27, 2020, <https://www.purdue.edu/newsroom/releases/2018/Q3/new-type-1-diabetes-therapy-shows-promise-for-long-term-reversal-in-both-humans,-dogs.html>.

¹⁹ Rita Bottino et al., "The Future of Islet Transplantation Is Now," *Frontiers in Medicine* 5 (July 13, 2018), <https://doi.org/10.3389/fmed.2018.00202>.

²⁰ Frances McFarland, "Regenerative Medicine in Type 1 Diabetes: Opportunities and Obstacles," *EndocrineWeb*, November 26, 2019, <https://www.endocrineweb.com/professional/type-1-diabetes/regenerative-medicine-type-1-diabetes-opportunities-obstacles>.

Complicating the Diabetes Revolution

Each of these attempts to revolutionize treatments for Type 1 Diabetes—from simplifying and/or hiding necessary BG testing, to automating insulin injection or making it less-intrusive, to “curing” Diabetes through implants and/or immunotherapy—claims that their innovation will fundamentally change the lives of people who live with the chronic illness every day. And in many ways, those claims are quite likely. The history of T1D treatment includes cases of such revolutions. Most significantly, implementation of insulin therapy in the 1920s turned a terminal acute illness into a chronic one, in a sense replacing rapid decline and death with pharmaceutical-supported life. Daily glucose testing has made extreme hyperglycemia and hypoglycemia much less common since its global adoption in the late 1980s and 1990s, reducing the prevalence of neuropathy-related side effects as well as risk of both heart disease and stroke. The advent of insulin pump therapy in the early 2000s made insulin injection more hands-off, and networking those automated injections with constant streams of CGM data over the past decade has led to the (admittedly in-name only) artificial pancreas, a.k.a. the closed-loop system. Each of these innovations and treatments not only changed what treatment looks like, but they changed the nature of the disease itself and therefore people’s experiences with it.

But each of those interventions has also included an array of adjustments to bodies, material experiences, treatment acts, social dynamics, and cultural representations that require new attention (and carry new physical and psycho-emotional burdens) for everyone living with T1D. Insulin-sustained life carries with it the wholly new T1D experience of low BG, a new world of needles and vials, not to mention the loss of limbs and eyesight as a result of Diabetic neuropathy—material experiences people with T1D never lived long enough to develop prior to insulin treatment. Socially, unequal access to treatment has increased at an unprecedented rate over the past twenty years, as insulin-sustained life requires a patent-bound pharmaceutical product. BG testing not only restructures the very way T1D bodies are understood,²¹ they also require multiple daily finger pokes which produce scarring and callousing, as well as an abundance of biowaste in the form of used test strips which have received little focus regarding

²¹ See my discussion of how numerically quantified Type 1 bodies reorient understandings of the body and insulin treatment practices in: Stephen Horrocks, “Materializing Datafied Body Doubles: Insulin Pumps, Blood Glucose Testing, and the Production of Useable Bodies,” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (2019): 1–26. See also my discussion of the material experience of BG testing in Chapter 3 of this dissertation.

methods for disposal. Insulin pumps and CGMs, though carrying their own influences individually, both puncture the body and adhere to the skin round-the-clock, producing immune reactions in the form of scarring and rashing, and are easily snagged and pulled out during daily activities. Both require supplies packaged in an abundance of non-recyclable plastic waste and printed paper products, and like test strips make up new forms of biowaste as they are attached and then removed after use. Both devices are also incredibly expensive, furthering the inequalities associated with insulin treatment itself. In short, every breakthrough in Diabetes treatment has unintended consequences and side effects that not only affect people with T1D, but alter the networks of medical, economic, and cultural connections of which they take part. These changes are wide-reaching and normalized over years, decades, and now centuries, and without critical attention to their effects they go unchecked and reproduced in each new breakthrough of “revolution.”

And here I return to the discussion of the Dexcom G6 Pro which introduced this conclusion. As he gestured toward their goal to expand their consumer-base beyond people with T1D, CEO Kevin Sayer identified the G6 Pro’s new feature that sets it apart from previous devices. Doctors will have the option of choosing between “Blinded Mode,”²² where physicians can turn off patients’ ability to see their real-time glucose information and reserve that data for in-clinic use and analysis, and an un-blinded mode where patients can see their own glucose levels throughout the ten-day period. As Sayer describes it, the Blinded Mode can aid doctors in observing at-home practices of their patients, to find out: “Are you taking your meds? Are you going with the routine?” It can be used, in other words, to surveil patients in order to identify non-compliance. Encouraging patients to follow prescribed medical advice and treatment routines is difficult, especially in cases such as T1D when nearly every treatment act is conducted by individuals outside a clinical setting, but those practices are also essential to their general health and wellbeing. Moving from discourses of encouragement (even at its extremes that function as social compulsion) into the realm of institutional surveillance, however, is concerning in respect to individuals’ privacy, agency, and bodily autonomy. And because the proprietary software required to download and view the Dexcom’s stored data allows the

²² The deployment of disability as a descriptor for medical, technological, and/or scientific systems relies on cultural assumptions of able-bodiedness—and its use here in the hands of medical authorities makes the power structures involved in defining and maintaining definitions of disability particularly apparent.

manufacturer access to the disaggregated data as a whole, that surveilled information is also made available to a non-medical entity to be used in the development and marketing of their future products. For most patient-users, however, the quality-of-life benefits of CGMs outweigh their concerns about these power imbalances, and they opt-into these mandatory surveillance systems in order to do so.

As I argued in Chapter 3, most of the informants who were interviewed for this study identified a novel sense of freedom associated with their procurement and use of their insulin pumps and CGMs. There was something liberating about their ability to, in a sense, plug-in and shut-off for a while. The freedom that these people feel is, at least in part, about a perceived increase in their individual decision-making power—a shift facilitated by the functions and information made accessible by their devices. It provides a significant step away from the clinic, a step away from the heavy reliance on their doctors' authority required by the particulars of their chronic condition.

At the same time, these devices maintain (and in some ways even expand) the authority centralized within institutions of Medicine and device manufacturers. As evidenced by Dexcom's G6 Pro tactics, the ambiguous individualizing trends typical of twenty-first century Medicine, defined by Clarke, et al. as a period of Biomedicalization, have simultaneously shifted responsibility toward individuals and further encapsulated authority within institutions of Medicine.²³ What was designed as a device to provide more treatment autonomy to patient-users has been re-ensconced within the clinic in the form of the G6 Pro. This model is for physician use on patient bodies, and not for patient use in any direct sense. Inasmuch as the Pro model can function as marketing for its at-home counterpart, in Sayer's words, patients can come along for the ride, to "learn about themselves" from their clinical device and try it before they buy it, but it is not intended for their personal treatment needs. And here it is important to specify Sayer's language when describing this CGM's role in the future of Diabetes care. He did not say they were interested in facilitating a revolution in Diabetes treatment, or a revolution in Diabetes care, but instead a "revolution in Diabetes data." This interview was conducted on the air of a stock market round-up program, after all, and it is in the constant flow of data from millions of devices

²³ Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham: Duke University Press, 2009), 1–2, 11.

about millions of people's bodies that Dexcom constructs its market value. Dexcom will remain economically valuable primarily because that source of value, according to the company's CEO, will always be there. "People are always going to have Diabetes," he notes off-the-cuff, "and people who rely on this technology can't give it up."²⁴ And in a deceptively dark sense, Sayer is correct: people with Type 1 cannot live without their treatment devices.

This is not to say that all of the examples of Diabetes-related research cited above operate under the same paradigm laid out by Sayers and Dexcom here. On the contrary, though most individuals leading these projects have some form of vested interest in the clinical (and market) success of their designs, most of the work being done is focused on providing new modes of care and wellness for people with T1D. But as I have shown throughout this dissertation, even interventions that make significant improvements to patient-users' health and wellbeing can alter their lived experience in ways that are not always net-positive. Creating new ways to measure BG levels, particularly with less-invasive designs, could alleviate much of the pain and more generalized stress involved in current finger prick and CGM measurement methods. On the other hand, devices applied onto one's cornea or adhered to the skin can carry unexpected physiological consequences. And in more automated designs, those measurements do not produce numerical stand-ins for the body in the same way meters and CGMs do, leaving patient-users to re-learn their physiology through new visualizations or navigate a system without them at all. Likewise, implantable devices and immunotherapies will introduce materials into the body's microbiome that can alter its composition in ways that may take years of study to identify and understand, making that new embodied T1D experience something wholly new in itself.

Whatever form they may take, future technological, medical, and cultural networks of Diabetes treatment will structure people's lives, their bodies (and understandings thereof), and the cultural values constructed around the devices and treatments that make up that system in significant ways. As I have argued, insulin pumps and networked BG-reading devices alter patient-users' bodies and identities as they become integrated within their physiological and social systems, and come to function as co-productive actors in those systems themselves. Future treatment paradigms will, in their own way, produce new bodies and systems requiring critical

²⁴ "Dexcom CEO Previews New Glucose Monitoring System He Says Will Be the 'Revolution in Diabetes Data.'"

tools to make sense of them, and it will be vital to take individual's experiences with these treatments seriously in building that understanding.

Regardless of which revolutionary treatments above become institutionalized and which are all but forgotten, the future of T1D treatment in the US will necessarily be an outgrowth of those health care systems. Access to insulin remains a site of severe inequality, and manufacturers' recent actions in response to congressional pressure will do little to circumvent their own monopolies.²⁵ Because access to insurance, care, and health outcomes are so deeply related to social position, as I argued in the previous chapter, this problem will continue to affect working class people, people of color, people with disabilities, and both the young and elderly disproportionately. And since less than half of people with T1D use insulin pumps and just 10% use CGMs, most of the groundbreaking treatments centered on hi-tech devices will be out of reach for a majority of those who could benefit from them as well. Unless the Diabetes revolution includes a social or political one, these largescale structures of inequity are not likely to go anywhere.

But the future of Diabetes and its treatments will also be embodied, and this will be both a means of intense vulnerability and of potentially revolutionary claims to techno-medical agency. The ability to claim treatment devices as one's own situates that human-object relationship under the umbrella of individual decision-making power—a move made all the more significant with devices that function as extensions of patient-users' biological systems. In more than a conceptual sense, I have argued, these devices become a part of the people who use them, and this may become even more pronounced as implanted and/or internalized devices are used broadly in T1D treatment. That techno-embodied autonomy, however, is challenged by the claims manufacturers, insurers, clinicians, and others are able to make to all or part of those very devices. The tension born of these ambiguities will likely be a site of shifting power dynamics in future treatments as it has been with current ones, and an important focal point for scholarship moving forward.

By analyzing the layered and intersecting sites of insulin pump treatment together, this dissertation has detailed how medical technologies, health identities, bodies, and cultures are co-

²⁵ “Novo Nordisk to Cut Insulin Prices in the U.S.,” *Reuters*, September 6, 2019, sec. Business News, <https://www.reuters.com/article/us-novo-nordisk-usa-idUSKCN1VR1JO>.

constructed and co-defined in ways that bind them together—mutually constitutive, cultural and social. New bodies and new systems come with new (in)visibilities, and while this new technologically-produced legibility of the body provides unprecedented management of the symptoms and side-effects of the disease, it also brings with it unforeseen social consequences that require changes to people's everyday life and practices.

In bringing these conversations—and especially the people who experience T1D themselves—to the fore of discussions about Diabetes and its treatments throughout this project, I aimed to maintain a sense of humanness among the too-often sanitized, objective discussion of medical devices. As I have shown here, these devices are imbued with the human; as human productions themselves, as objects produced with the sole purpose of sustaining human life, and even as objects that take-on bits of human bodies through use, Diabetes treatment devices are a material record of just how bittersweet twenty-first century American life can be.

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PUBLICATIONS

An earlier version of “Pumping and Passing” was presented at the Semitics Society of America (SSA) annual meeting in October 2015 and was revised for inclusion in as SSA publication the following year. The text of the *Catalyst* article below was written simultaneously with the first draft of Chapter 3 of this dissertation, and my primary conclusions in the article inform the ways I have conceptualized and written through body images in the second half of the chapter herein. The forthcoming chapter in *Diabetes on Display* was originally proposed for inclusion in this dissertation but was removed with the committee’s approval in consideration of time and space.

[Forthcoming] Horrocks, Stephen. “How to Wear (and Hide) Your Insulin Pump: Managing Device Connectedness with Gendered Bodies Online.” In *Diabetes on Display: Complicating Social, Political, and Cultural Representations of Diabetes*, edited by Bianca C. Frazer and Heather R. Walker.

Horrocks, Stephen. “Materializing Datafied Body Doubles: Insulin Pumps, Blood Glucose Testing, and the Production of Useable Bodies.” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (2019): 1-26.

Horrocks, Stephen. “Pumping and Passing: Mediating Diabetes Treatment and Health Identity through New Media.” In *Semiotics 2015: Virtual Identities*, edited by Jamin Pelkey and Stéphanie Walsh Matthews, 55-63. PDC, 2016.