ABSTRACT

HAMPTON, CHELSEA. Under Control: Mediating Diabetes. (Under the direction of Dr. Jeremy Packer).

This dissertation examines glucose monitoring technology to contribute to the area of media and technology studies. Further, this project examines theoretical discussions of ‘materiality’ as related to technology and the interplay with the human body. Taking a critical approach, this dissertation provides four different ‘case studies’ related to glucose monitoring, used by diabetics to gain a modicum of ‘control’ over their errant bodies after the failure of the pancreas. This dissertation unites critical analysis with autoethnographic accounts of using glucose monitors to highlight the intricate interconnections between technology and human users. First, a history of glucose monitoring as a media technology is provided. Second, the impact of different forms of glucose monitoring on the individual diabetic is explored through a first-person narrative account. Third, this project examines the interplay between the providers and the hackers of diabetic technology. And finally, this project considers the materiality of the body.
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DEDICATION

To all of us who hope for a cure, rather than these technological solutions.
BIOGRAPHY

Chelsea Hampton was born in the United States, but spent many of her formative years abroad in the Kingdom of Thailand. When she was twelve years old, she was diagnosed with Type 1 Diabetes, which provided the inspiration for this dissertation project. Upon graduating from high school, she returned to the United States to earn her undergraduate degree from Messiah College in Grantham, Pennsylvania. After working for a few years, Chelsea returned to school to earn her Masters in Communication Studies from Villanova University. Chelsea began her PhD work at North Carolina State University in 2012, in the Communication, Rhetoric, and Digital Media program. Her work has looked at the intersections of digital media with everyday life in a variety of contexts, from examining the ways in which such technologies are redefining global borders to how digital health technologies impact individuals.
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CHAPTER 1: 
Introduction: Diabetes, Control, and Monitoring

Diabetes and Control

The first time I watched the show *Parks and Recreation* (NBC), I was surprised and excited by the episode in season two called *Telethon*, which depicted the characters putting on a fundraiser for diabetes research. It was the first time I could recall ever seeing the disease I had been diagnosed with as a child in my entertainment media. However, as a Type I Diabetic, I was quickly disappointed because the show was only referring to Type II diabetes, and they didn’t even bother to make that clear to their audience. The ‘diabetic’ in the town of Pawnee, Indiana, was a sad, overweight soul addicted to Sweetums candy, who could have prevented the disease if only they had made better, healthier choices. This focus on the self-control (or lack thereof) in diabetic individuals is hardly new. In his collection of historical and literary texts relating to diabetes, Dietrich von Engelhardt (1989) describes a variety of characters from literature in the twentieth century who are diabetics. One, a widowed woman, blames her diabetes on her uncontrolled grief over losing her husband. In a different story, an elderly man loses all sense of self-control and eats himself to death with sweets. Finally, to contrast, Engelhardt showcases a poet who directs his audience to laud the diabetic’s virtue in “discipline” of the self (p. 9-10). These narratives highlight the theme of “control” over the diabetic body’s processes. Such representations of diabetes and focus on control in popular media reflect the strict focus on control that provides the foundation of diabetes management in the medical community.
The lack of differentiation between different types of diabetes demonstrated in Parks and Recreation is fairly common in conversations about diabetes, in my experience, particularly as most of the diabetics in the United States are diagnosed with Type II Diabetes. According to the most recent data available from the United States Center for Disease Control (CDC), in 2014, roughly 29.1 million people in the United States had a form of Diabetes (National Diabetes Statistics Report, 2014). Globally, the World Health Organization (WHO) estimates that in 2014, there were 422 million adults with diabetes, comprising roughly 8.5% of the global adult population (Global Report on Diabetes, 2016).

There are three conditions grouped under the banner of “diabetes” - Type I (formerly known as Juvenile Diabetes, also known as diabetes mellitus), Type II (formerly known as Adult Onset Diabetes), and Gestational Diabetes (which generally only lasts the duration of the pregnancy). The CDC (2014) defines this family of disorders as “a disease in which blood glucose levels are above normal. Most of the food we eat is turned into glucose, or sugar, for our bodies to use for energy,” and diabetics are unable to properly process glucose (p. 4).

The vast majority of Americans (roughly 90 to 95% according to the CDC) diagnosed with Diabetes fall into the Type II category, which can be managed via diet and exercise (“National Diabetes Statistics Report,” 2014). Insulin-dependent diabetics, or Type I, represent around 5% of the diabetic population. Along with insulin, Type I diabetics must adhere to strict dietary and lifestyle regimens in order to stave off diabetes related complications (which include organ failure, blindness, and amputation of extremities). Given the seriousness of the disorder, it has become an important area of research in multiple fields.
Academic research regarding diabetes within the fields of communication and media studies tends to focus on health communication practices - how to make them more efficient and minimize misunderstandings. Recent articles by Martin (2015) and Ho, Lalancette, and Leung (2015) focus on communicating across linguistic and cultural barriers in order to ensure that patients understand their medical advisors and can monitor their own disease and exemplify this research trend.

Beyond looking at communication practices between doctors and patients, these types of studies also focus on how to help the individual diabetic perform better self-management. A recent study by Heidi Sisler (2015) focusing on the efficacy of educational campaigns by the American Diabetes Association (ADA) provides an excellent example of this type of research focus. Sisler (2015) analyzed seven years worth of ADA campaigns to raise public awareness about the symptoms and possible prevention of (Type II) diabetes in order to measure the effectiveness of how the campaigns framed their messages. Sisler discovered that the campaigns’ identification of the diabetic “individual as barrier” in conjunction with the aggressive and patronizing language used in several of the message themes actually functions to suggest that the organization might even be blaming “at-risk” patients for their own health problems” (emphasis mine, p. 34). For all diabetics, no matter the type, management of or “control” over their disease rests primarily on the individual.

“Control” in diabetic terms equates to living in such a way that the diabetic mimics the function of a healthy body as closely as possible. Primarily, this means attempting to control blood sugar levels via glucose monitoring and adjusting medications (most
commonly insulin) accordingly. The American Diabetes Association (ADA) provides the following definition of the goals of glucose control:

Tight control means getting as close to a normal (non diabetic) blood glucose level as you safely can. Ideally, this means levels between 70 and 130 mg/dl before meals, and less than 180 two hours after starting a meal, with a glycated hemoglobin (A1C) level less than 7 percent. The target number for glycated hemoglobin will vary depending on the type of test your doctor's laboratory uses (“Tight Diabetes Control,” 2015).

While I provide a more comprehensive look at the practice of glucose monitoring in later chapters, I want to highlight the importance of the glycated hemoglobin (A1C) test: this particular blood test analyses the RANGE of blood sugar fluctuations over a period of months. The lower the range of fluctuations, aka, the more the individual stays within that 70-180 range over the day, the lower the A1C level. “Control” is tied to glucose levels throughout the body, but the blood provides the easiest way to monitor the glucose levels, both for individuals and medical practitioners. To do this on a day to day basis, diabetics use a variety of media that allow them to gauge their sugar levels, most primarily depending on a digital meter that reads a small blood sample and provides an estimate of blood glucose.

Below is a picture of the many glucose monitors I currently possess:
Figure 1.1. My many glucose monitors. Most of them are ‘backups’

Whenever I leave my house, I carry two forms of glucose monitoring; a regular hand held monitor (specifically the meter in the top right corner) in my purse, and a Constant Glucose Monitor, where the transmitter device is attached to the skin of my stomach and the receiver application on my smart phone. In contrast to the portrait of diabetes offered by *Parks and Recreation*, I would like to put forward the figure of a media-dependent, self-monitoring diabetic made possible by advances both in insulin but also glucose monitoring technology. For the purpose of this dissertation, I argue that diabetes control rests on three
aspects of management: diet, insulin, and monitoring media. Of these three, this project focuses on diabetes monitoring media from a critical, media studies oriented perspective. My goal in this introductory chapter is to provide a theoretical overview of the media scholarship to ground my discussion, some basic information regarding diabetes management in terms of diet and insulin to provide a foundation for my exploration of diabetes monitoring media, as well as a brief explanation of how my own status as a Type I diabetic impacts this project.

First I provide a brief biographical and theoretical note on the framing of this dissertation project, then I take a look at the basics of dietary diabetes management, followed by a brief history of the development of insulin, and end with an overview of each chapter’s analysis of a different aspect of diabetes media.

**Me and My Diabetes**

August 6th is my “diabeteversary” - the day I was diagnosed with diabetes mellitus in 1997. I had just turned twelve years old. While I provide more details about that experience in later chapters, I wish to contextualize how that diagnosis and my nearly two decades of dealing with diabetes influences this dissertation project. Initially, I strenuously resisted the idea of including any sort of personal experience in this project. I deeply dislike talking about diabetes; for most of my life, it has been a thing - *not me*, although located within my body - that I have to control and that caused constant worry, pain, and stress not only in my life, but in the life of my family. In a letter to family and friends following my diagnosis, my father wrote:
Prior to the diagnosis, we were completely without a clue as to what was going on with her. At one point we sat at the dinner table and Chelsea laid on the couch nearby, unable to eat. [My son] Phillip asked me, “Daddy, is Chelsea going to die?” With a lump in my throat, I didn’t even know how to answer him... (The Hampton Herald, 1997).

My diabetes marked an epochal moment for my family, with a distinct ‘before’ and ‘after’ that impacted almost every aspect of our lives. The changes were quickly subsumed into getting into a daily management routine that has varied very little in the years since. In order to be less of a worry and burden to my family, and to function as a person, I buried my memories and feelings about my diagnosis and living with a chronic illness deep; in fact, until I began to write this dissertation, I had forgotten that my diagnosis date was August 6th entirely. I only knew, in a vague sort of way, that I had been diagnosed in summer because I remembered missing the first few weeks of seventh grade.

In the years since my diagnosis, my way of dealing with diabetes was to put it into a box separate from my life and only discuss it when I absolutely had to (for example, at the doctor’s office). And this was how I wanted to approach my dissertation project as well: my diabetes merely meant I was aware of diabetic monitoring media because I used them; there was no need for me myself to intrude on my analysis of said media. I longed for a critical distance from diabetes in my dissertation work that I obviously can never experience in everyday life. My adviser suggested a semi-autoethnographic approach but I resisted.
“It feels like I would be whining,” I told him firmly. I most especially did not want a “pity-pass” from my dissertation committee.

In planning this project, I envisioned myself examining the technological developments of glucose monitoring, in the vein of Jonathan Sterne’s work on the stethoscope in his book *The Audible Past*. In examining the history of the development of the stethoscope, Sterne also traced the ways in which this particular technology impacted the field of medicine: how doctors and patients interacted with each other, as well as what new types of knowledge and observations were made possible through the use of this auditory implement. The similarities with my own goal of looking at the technologies associated with glucose monitoring were quite obvious to me. The development of glucose monitoring technology has shifted the relationship between individual diabetics and medical professionals, and the technological affordances of different types of glucose monitoring media allowed for new types of knowledge and the observation and storage of data regarding biological processes. Focusing on these technological developments and processes from a critical media perspective would involve no emotional messiness.

With this in mind, I was drawn to the work of scholars such as Friedrich Kittler (2010), whose focus on the functions of media rather than human experience of them felt strangely comforting. Perhaps in distancing myself in such a way from the media that structured my life so completely I could find some insight not only into media theory, but into my own experiences. Kittler’s approach to what he termed “technical media” sought to expose the “underlying structures” that allow such media to “store, transmit, or process
signals” (p. 25). Simply put, in Kittler’s take, the “message” can be arbitrary, but must match the technological transmission system through which it is being transmitted to allow for the reconstruction of the message (p. 45-46). In looking at glucose monitors, I hoped to further this area of inquiry within the area of media studies, as well as exploring the concept of “technical media” in a biomedical context.

**Observation and Epistemic Virtues**

I would argue that his focus on practices, processes, and technical capabilities is what makes Kittler valuable to media scholars. While not proceeding from a Kittlerian perspective, Daston and Galison (2007) approach the history of scientific observation with the goal of defining broad social and historical shifts in how “objectivity” came to be a standard of practice within scientific communities. They use the term “epistemic virtue” to describe “norms that are internalized and enforced by appeal to ethical values, as well as to pragmatic efficacy in securing knowledge” (p. 41). “Objectivity” and “subjectivity” are always paired in their account – “there is no objectivity without subjectivity to suppress” (p. 33). New epistemic virtues required “techniques of the self” – repeated practices that produced the “scientific self of objectivity” (p. 38). In their account, new technologies able to capture and store data (for example, cameras and photographs) had a profound impact not only on what types of knowledge were considered authoritative, but how such knowledge was presented.

These shifts were concurrent with the production of “distinct epistemic virtues” – “not only truth and objectivity, but also certainty, precision, replicability” (Daston & Galison,
“New ways of seeing” allowed for new forms of knowledge, as Lisa Parks (2005) demonstrates with her exploration of how satellites facilitate new forms of exploration and perspective (we can now see the earth from a distance). Sterne (2007) argues that “technologies manifest a designed mechanical agency” – allowing for particular actions and cultural habits (p. 8). Further, “instrumentalization” allows us to understand “human senses” as “mechanisms” as well (Sterne, p. 58). This group of scholars approach their media analysis using an approach that Packer (2013) describes as a “Foucauldian media history” that unites Foucault’s archeological and genealogical approaches to “systematically focus upon three interlocked concerns (1) the production of knowledge, (2) relationships of power, and (3) modes of subjectification” (p. 2). In this vein, I attempt to explore what new forms of knowledge are produced with various forms of glucose monitoring and provide a more in-depth look into examples of a “Foucauldian media history” in the next few sections.

**Control, Biopolitics, and Protocol**

It seems trite to say, but digital technologies restructure and extend human capabilities in terms of data processing and storage (as Kittler notes) but also in terms of how populations are formed and maintained. Galloway (2004) appropriates the “material” aspect of Kittler’s arguments, but adds the question of “whom does it [media] work for?” to Kittler’s focus on “how media works” (p. xii). Following Kittler’s engagement with media standards and norms that structure mechanical relationships and abilities, Galloway suggests that the concept of “protocol” is how best to understand current social assemblages because “the social and the political are not external to technology” (p. xii). He uses the example of
computer code to demonstrate this – just as “code” is “a set of procedures, actions, and practices” that determine what a computer can do, so too are human individuals and populations constrained within particular protocols (p. xii).

To make this move, Galloway (2004) draws on the work of Deleuze and Foucault. Deleuze (1995) suggests that we are moving into an age of “control societies,” following from Foucault’s disciplinary societies. He describes the practices that organize the oncoming control society as “constantly changing” and further suggests that “machines” within a society “express the social forms capable of producing” and using them (p. 179-180). Galloway (2004) connects the concept of a control society with Foucault’s “biopolitics” and “biopower.” Specifically, Galloway argues for an “isomorphic biopolitics” that recognizes how “the concept of “protocol” is related to a biopolitical production, a production of the possibility for experience in control societies” (p. xx) Foucault describes biopower as “the set of mechanisms through which the basic biological features of the human species become the object of a political strategy, of a general strategy of power” (p. 1). It is a material conception of power. This is fundamental to Galloway, who argues that the structuring logic of current social relations can be best defined as “protological” – “Protocol is doubly materialist—in the sense of networked bodies inscribed by informatics, and in the sense of this bio-informatic network producing the conditions of experience” (p. xviii-xx). Clough (2008) suggests that “biopolitics individualizes as it massifies” (p. 19). “Protocol” thus functions to structure relationships from the individual to the mass via distributed forms of control.
Galloway argues that “protocol” transforms the lines between “body and technology, between biologies and machines…Individual subjects are not only civil subjects, but also medical subjects for a medicine increasingly influenced by genetic science” (p. xx). This is the focus of Eugene Thacker’s (2004, 2005) work on biomedia – referring to how “biological components are technically recontextualized” (p. 6). He echoes Kittler’s concern with what media can do and applies it to the body (p. 25). Clough (2008) describes “biomedia” as “a technical reconditioning of the body” that increases the body’s ability to be informational.

Following Kittler, Thacker is not particularly interested in subjectivity as much as the processes through which the body-as-data can be transmitted across multiple media formats or “substrates.” In considering Shannon’s model of communication, Kittler focuses his media studies in the following way: messages can be arbitrary (content is not the important aspect). However, the message must match the technological transmission system and the system must be able to reconstruct the message (p. 45-46). For Thacker (2005), focusing on the techniques and technologies that allow data to move from biological to digital forms and back again has political as well as technological implications (p. 3). Regarding the body within a technologized context allows Thacker to consider how the networked nature of digitized information systems extends concerns about ethics and biology from individual labs more global contexts.

**Interactive, Digital, and Surveillant Media**

While many of the previous examples tended to highlight specialized contexts requiring particular kinds of scientific or technological expertise, I would like to transition to
examining diabetic media explicitly by briefly discussing implications of the ‘control
society’ for non-expert individuals. The majority of diabetics who use glucose monitoring
technologies are primarily concerned with how to optimize their technologies to better their
health rather than the political implications of digitized information systems. I would also
suggest that the majority of us probably do not have the computer skills necessary to
understand the intricate layers of code used by our digital devices, although this is certainly
not true of everyone in the diabetic community, as I will discuss in Chapter Three. “Control”
in the diabetic community refers to the success or failure of an individual’s management
practices as related to glucose levels. The better your control, the more ‘normal’ your blood
sugar levels in comparison to non-diabetics, which the American Diabetes Association
defines as levels between “70-130 mg/dl” before eating and under 180 mg/dl two hours after
eating (“Tight Diabetes Control,” 2015). Control in this context is dependent on following
rigid rules in relationship to diet, insulin injections, and glucose monitoring.

In the realm of critical media studies, and particularly in relation to the burgeoning of
digital networks, “control” has a different connotation. Deleuze (1995) suggests that
“control,” unlike surveillance, depends on flexibility and diffusion rather than enclosure
within particular institutions such as schools, hospitals, or prisons. Focusing on how people
interact with Internet contexts, Andrejevic (2007), suggests that instead we need to consider
instead the “digital enclosure” or “the creation of an interactive realm wherein every action
and transaction generates information about itself” (p. 2). The algorithms used by Google and
Amazon that track consumer travels through the internet and their purchases in order to craft
personalized advertising and product suggestions are an excellent example of what Andrejevic is describing. These personalized suggestions no longer elicit much of a reaction in users, they have become so normalized. Crandall (2005) suggests “we internalize the condition of surveillance. It enters into the logic of perception…We are both origin and object: the one who tracks and who keeps track.”

I would like to highlight the connections that medical monitoring technologies have to these arguments, particularly given the greater ‘control’ that digital technologies afford diabetics in terms of the effectiveness of their self-monitoring. In diabetic control, tracking and keeping track of data forms the foundation of diabetes management. According to Kittler, media produce, store, and transmit data. The affordances of digital technical media allow for the capture and manipulation of new and different types of data. Sterne (2005) describes this process using the stethoscope, while Thacker (2004, 2005) focuses on forms of digital Biocomputing. Sterne (2005) and Foucault (1973) both describe how the stethoscope allowed doctors to acquire new types of information regarding the inner workings of their patients – leading to shifts in how medical knowledge was created and practiced. Biomedical processes and devices that Thacker describes (2004) are not readily available to private individuals.

However, in the decade since 2004, some of the technologies Thacker describes as potentials, such as Constant Glucose Monitors (CGMs), have in fact become realities. With the proliferation of smartphones and apps that monitor everything from how many steps one walks in a day to how many calories one consumes, health monitoring and data have become
part of the everyday “digital enclosure.” We have become our own monitors, as Crandall notes, although historically the diabetic population’s self-monitoring pre-dates the current enthusiasm for data by several decades. The case of the glucose monitor, specifically, highlights some of the social and technical shifts described by the scholars I have cited in this discussion. Currently, the Center for Disease Control (CDC) depends on a yearly survey of diabetic patients to track trends and monitor the “diabetic population.” This survey depends on the mediation of medical professionals in terms of gathering data from this particular population. The increasing sophistication of glucose monitoring technology, however, enhances the ability of individual diabetics to self-monitor. Obviously, this has necessitated shifts both in medical practice, but also in terms of how that data is utilized and stored.

**The Value of an Autoethnographic Approach**

In considering glucose monitors, I could see the value using Kittler’s approach: looking at how the technological and biological processes of glucose monitoring function. Managing diabetes is fundamentally a matter of managing and responding to data - the ‘messages’ of the glucose levels in the blood. In glucose monitoring, the “messages” of glucose levels, the transmissions systems and the physical media of the monitors that enable the reconstruction and reception of the ‘message” have an unavoidable biological component. A media history of glucose monitoring would therefore also necessitate an engagement with the larger medical history of diabetes as a disease in order to properly contextualize the technological developments and subsequent changes to social and medical practices.
However, when I began researching the history of diabetes, I found myself overwhelmed with sensory memories of my own diagnosis, and unable to separate myself from the horror of reading about the starvation diets of early diabetes care and the painful death that was inevitable for diabetics prior to the discovery of insulin. The work of material feminist scholars who dealt with issues of embodiment offered a way for me to move past an explicitly technological focus, but I still felt that simply including the biological body in my analysis was not enough.

I went back to my advisor and admitted that I would need to include myself to write the dissertation. I turned to the field of autoethnography to explore how effectively include my own experiences in a project that was originally primarily focused on a history of diabetic media that de-centered the human. Ellis, Adams, and Bochner (2011) define autoethnography as “an approach to research and writing that seeks to understand and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (p. 273). Similarly, Adams, Jones, and Ellis (2015) emphasize the importance of “stories” in autoethnographic research, stories that are “artistic and analytical demonstrations of how we come to know, name, and interpret personal and cultural experience,” and more specifically, offers “specific knowledge about particular lives, experiences and relationships, rather than general information about large groups of people” (p. 1). Personal experiences become the site of enquiry, individual subject formation the lens through which wider phenomena can be understood and considered. In this way, my personal experience with glucose monitoring becomes a site from which to consider the
implications of the technological systems of transmission in the Kittlerian sense.

Throughout this project, I attempt to use my own experiences to contextualize specific phenomena - I certainly make no claims as to the universality of my experiences, nor would I wish to do so. My experiences with diabetes would have been very different had I been diagnosed and grown up in the United States, and this project would no doubt have been different also.

Specifically in the realm of autoethnographic accounts dealing with medical narratives, the work of Carolyn Ellis (1999), Susan Greenhalgh (2001), and Susan Wendell (1996) has been invaluable to me as I have sought to find a way to include my own personal narrative in the larger histories of glucose monitoring, data collection, online communities, and the role of chronic illness in discussions of bodies and materiality. Ellis (1999) describes her interactions with a PhD student who wished to use an autoethnographic approach in her dissertation project on breast cancer survivors, but is uncertain of the value of such an approach. Ellis (1999) tells the student, herself a breast cancer survivor, that the student’s perspective would be invaluable, encouraging her that “honest autoethnographic exploration generates a lot of fears and self-doubts - and emotional pain,” but that such exploration is necessary (p. 672). The student later tells Ellis that she has discovered the importance of autoethnographic and ethnographic research because, in the case of her research, “…cancer is more than a medical story; it’s a feeling story...” (p. 678). As Denzin (2013) notes, such an approach “allows the researcher to take up each person’s life in its immediate particularity and to ground the life in its historical moment” (p. x). The feelings
experienced by the cancer survivors as well as their loved ones have a place in the record, as well as the medical facts of each case. For many years, I have focused on the medical facts of my own ailments, and ignored the “feeling stories.”

Similar to my own project, Greenhalgh (2001) looks at chronic ailments, specifically chronic pain, or fibromyalgia, that “lack a known organic basis and are difficult to diagnose...All are chronic and treatable to a certain extent, but incurable” (p. 3). By utilizing an autoethnographic approach, Greenhalgh (2001) pushes back against the idea that “medicine can reveal the truth of our bodies because medicine is a science that claims to have direct, privileged access to the truths of nature” (p. 4). She specifically connects her work to Foucault's concept of the “medical gaze” (p. 4). She suggests that autoethnographic endeavors can provide a challenge to the medical gaze and the biomedical point of view, “to shed light on a darker side of medicine that tends to get lost in the shadows of triumphal narratives of doctors performing miracles and of patients achieving personal victories in the face of serious illness” (p. 7). My work is aimed at looking at medical technologies and the triumphal narratives that surround them, and their role in helping diabetics achieve victories in managing their disease. Similarly, Susan Wendell (1996) uses her own chronic illness to provide a framework for thinking about the need for a feminist ethics of the “rejected body,” or bodies that do not adhere to the social and cultural definitions of productivity. While her work plays a large role in Chapter Four, her method of using her own experiences to frame her philosophical and theoretical arguments has provided a guide for including my own experiences in this work.
Given that I have dealt with diabetes for nearly twenty years, and I only began to work on this project in the last two years, I do not have detailed field notes that Ellis (1999) suggests for most of the anecdotes I use to frame my research in each chapter. Unlike several of the examples I have mentioned here (Ellis, 1999, in particular), I did not conduct in depth interviews with other diabetics to incorporate experiences other than my own. I have relied on my own memory, the memories and letters of my parents, conversations with my medical team(s), medical records, and the digital data collected by my various monitoring technologies. Of necessity, I started paying close attention to my own experiences for inclusion in this project; you will note that the many of the anecdotes I have included took place fairly recently, particularly as I only started using a Constant Glucose Monitor in October 2015. The work of Norman Denzin (2013) was helpful as I determined when and how and which stories to include; particularly in his discussion of writing an “autoethnographic life story,” which creates the “conditions for rediscovering the meanings of a past sequence of events” in order to gain new insight or understanding (p. 22).

Because I approached this dissertation first as a critical media project, my own accounts are therefore not the primary focus of each chapter, although my lived experience grounds and makes visible the complexities of living with diabetes and monitoring technology for a non-diabetic audience. Thus, this project is not a straightforward autoethnography, but my personal experiences act as a frame for the various aspects of diabetes control and media that I explore in this project. Greenhalgh and Swinglehurst (2011) suggest that ethnography is a key methodological tool for researchers attempting to
understand the role of technology in health care, particularly as the focus of many researchers in these contexts is on the data such technology generates and is overwhelmingly “hopeful and technophilic” (p. 1). They identify the following four characteristics of research published on health technology, which are portrayed as:

- potentially able to [a] incorporate (and thereby drive uptake of) evidence-based protocols and decision support; [b] overcome human failures and idiosyncrasies; [c] ensure that clinical information is more complete, accurate and accessible; and [d] improve efficiency of healthcare transactions. (p. 1-7).

All of these characteristics are present in the history of glucose monitoring that I present in Chapter One, as well as in the narratives I share surrounding my own experiences with healthcare professionals who utilize these beliefs in their assessment of my own ‘control.’ Ultimately, Greenhalgh and Swinglehurst (2011) argue that such beliefs are too strongly “determinist” in the sense that they focus too heavily on technological function - and that utilizing ethnographic and autoethnographic methods allow researchers to recognize the ways in which technology and human behavior inform and shape each other. Technology allows for certain actions to “become possible,” while humans program technologies to perform some actions but not others.

A recent project looking at mobile medical devices highlights how important my own experiences can be in filling the gap between the proposed uses of glucose monitoring technology, and how the user experiences them. Kane, Rogers, and Blandford (2014) set out to look at ‘mobile medical’ devices because such technologies are “becoming increasingly
popular based on the financial need to move healthcare outside of clinical settings” (p. 987).
They decided to utilize an autoethnographic approach because they wished to discover the
“subtleties” of “user experiences when using mobile medical devices in context” (p. 988).
To accomplish this goal, one of the researchers used a “non-invasive wrist blood pressure
monitor” to see how the usability of the device would impact and be impacted by her
everyday routine as well as abnormal events such as a wedding. This approach allowed the
group to “comprehend the experience of using the device not normally available to them
during other kinds of user studies” (p. 990). Most particularly, I am interested in the ways
my personal experiences can bridge the gaps in discussions about diabetic media: what they
are SUPPOSED to do, and how they actually function in the every day. Utilizing an
autoethnographic approach and my own personal perspectives and experiences allows me to
explore the epistemological aspects both of being diabetic and a media scholar interested in
mediated forms of observation.

The material relations of bodies and technologies are haunted by the economic
processes that structure access to technology and treatments, and as such, the economic
realm becomes part of my considerations at various points. Packer and Wiley (2012)
suggest that “the economic is not seen as a separate realm of the real underlying
communication and culture; rather, it is understood as a logic of social and material
organization - one logic among others - operating in a number of different contexts” (p.
109). In this project, I attempt to follow infrastructural approach (as described by Peters
(2015)) to understanding both the function of glucose monitoring technology as well as
exploring how such technologies interact with and re-inscribe the (my) human body: How are internal bodily processes such as glucose control translated into data that is able to be ‘transcribed’ (or inscribed) by and on various media, from paper to the digital cloud? What “protocols,” technological or otherwise, are at play in diabetes management? And further, what types of management practices do such technologies allow or encourage? Diabetes management depends on glucose monitoring media - particularly in relation to insulin treatments.

The Basics of Diabetes Management

Over the centuries, the standards of diabetes management for all diabetes types have relied primarily on diet and insulin when necessary (or available). Given the seriousness (and inevitability) of complications, “control” is the foundation of diabetes management: attempting to mimic the normal glucose levels and bodily functions of non-diabetics by strict control of diet and medication. While chapter one delves more completely into the history of diabetes and related monitoring technology, as well as theoretical ideas surrounding “control,” this introduction contains important information regarding diabetes management from which the history of monitoring technology springs.

Diet ancient history-present. Prior to the development of insulin or glucose monitoring, diet was the first and only way to address the symptoms of diabetes mellitus, which included drastic weight loss and sweet urine from the excess sugar. Before researchers identified the pancreas as the faulty organ, some physicians thought that the sugar in the urine was a signal that the body was losing too much sugar and suggested that their patients
eat more sugar to replace the loss (Tattersall, 2009). Tattersall (2009) offers the examples of other early physicians and their sometimes wild (by current standards) suggestions for treating this disease: one who suggested an oatmeal diet, and another who recommended isolation treatment for his patients. While isolation treatments seem rather extreme, as medical knowledge about diabetes developed and medical practitioners realized how key a strict diet was to keeping their patients alive, live-in clinics where diet and care were strictly implemented became the standard (and only marginally effective method) of diabetes care. By the early twentieth century, most physicians agreed that a low-carbohydrate and low-sugar diet was optimal for diabetes treatment, using sugar levels in the urine (or glycosuria) as the way to gauge how effective their efforts were in the cases of individual patients. Westman, Yancy, & Humphreys (2006) describe the method of physician Frederick Allen prior to the discovery of insulin in the early 1920s:

In the treatment of diabetes mellitus in humans, Allen employed fasting, then a stepwise reintroduction of macronutrients to find the threshold at which glycosuria developed (Allen 1915a 1915b, 1920). First, the patient fasted until glycosuria was no longer present. Then carbohydrates in the form of green vegetables were introduced, starting at 10 g/day and increased until the glycosuria threshold was reached. The carbohydrate intake prior to the appearance of glycosuria was considered the optimal amount of carbohydrate. This level was maintained and then protein was added to the diet, beginning with 1–1.5 g protein/day, to find the glycosuria threshold for the combination of carbohydrate and protein. Finally, fat was added to the diet, to provide
calories for weight gain or weight maintenance; fat was observed to have little effect on glycosuria. For some patients, a weekly fast day was recommended. (p. 77-78).

Elliot Joslin, one of Allen’s contemporaries, and the founder of the Joslin Diabetes Center, made recommendations similar to those of Allen; Joslin’s regimen consisted of a 70% fat, 10% carbohydrate diet. Joslin carefully listed carbohydrate-containing foods by their carbohydrate content, advising patients to eat only vegetables with less than 5% carbohydrate content (p. 80). The Joslin Diabetes Center is an example of the strict clinical practices that accompanied these diets: given the precision of the food ratios, patients lived at the Center and had their food administered to them by nursing professionals so that they couldn’t “cheat” or sneak in other edibles. This also relieved the patients’ families of the burden of seeing their loved one waste away from the failure of their internal organs once the disease progressed beyond dietary control. Diet is still an important aspect of diabetes control - particularly in terms of “counting carbs” in order to maintain lower glucose levels and to calculate proper insulin doses (“Diabetes Meal Plans and Healthy Diet,” 2015).

**Era of Insulin 1920s-Present.** Given the dire circumstances and limited effectiveness of the dietary approach, the development of insulin as a viable treatment was nothing short of “miraculous,” to use Bliss’ (1982) turn of phrase. Now a diabetic patient could stabilize their glucose levels beyond what strict diet could achieve, and ‘control’ meant more than just watching what the patient ate. Life outside the clinic was suddenly a viable option, as were ‘normal’ things like marriage and parenthood, so long as the diabetic was
faithful to their injection regimen and continued to follow a strict diet. Green and Riggs (2015) explain that

insulin was discovered in 1921 by an unlikely scientific team at the University of Toronto, led by a young orthopedic surgeon without laboratory training, Frederick Banting, and a medical student, Charles Best. After improving their technique of extracting the active insulin (initially termed isletin) from whole animal pancreas, they produced enough to treat the first patient, Leonard Thompson, in 1922. A patent was not filed until later, however, in part because academic medicine viewed the patenting of biomedical research products with some distaste. (p. 1171).

While Banting and Best had originally experimented on and extracted insulin from dogs, biomedical researchers quickly determined that pig insulin was more optimal for human consumption. However, the initial insulin extracted from animals had a very short shelf life, meaning that the efficacy of the drug was time sensitive, leading to efforts to extend the viability of insulin. By the 1970s, researchers had moved beyond simply extending the purity and shelf-life of animal-based insulin with the discovery that it was “possible to produce human insulin through recombinant technology” which led to the biotechnology sector seeking to capitalize on the medicine “after Genentech scientists produced the first recombinant DNA human insulin in 1978 by inserting the cloned insulin gene into Escherichia coli bacteria” (Green and Riggs, 2015, p. 1172). While the earliest forms of insulin were not patented, these new “recombinant human insulins” were patented by the companies who developed them, including two current giants in the diabetes supply
field, Lilly and Novo Nordisk. Beyond the fact that these new human insulins were obviously more compatible with human diabetics, these advances also led to the development of insulins with different ranges of efficacy after injection. Green and Riggs (2015) describe how the company Lilly first brought “Humulin R (rapid) and N (NPH) — to the U.S. market in 1982” (p. 1172). It is hard to overstate just how revolutionary these new insulins were to diabetes management. As Green and Riggs (2015) note, “Humulin R” is a rapid acting insulin, meaning that it began to impact bloodsugars within half-an-hour to an hour of injection, but ceasing to impact the bodily system within a few hours. Insulins like “N (NPH)” had a longer period of impact - up to eight hours after injection. These insulins also had a “peak” window of effectiveness, before and after which the insulin dose, while still working, was less potent (Beren, Ewen, and Laing, 2015). Newer fast acting insulins like Humalog and Novolog begin acting within five to ten minutes of injection, and long acting insulins like Lantus begin to act within a similar time frame but remain potent for roughly 24 hours with no peak, allowing the user to achieve a true ‘normal’ baseline blood sugar level throughout the day. Particularly with these newer insulins, diabetics now have the ability to provide a stable ‘baseline’ blood sugar with long acting insulin (called the basal rate), and addressing spikes to levels from eating with rapid or fast acting (called bolusing), suddenly, diabetic “control” could mean “keeping blood sugars in or closer to normal ranges” as the ADA described above, rather than merely “keeping blood sugars below deadly.”

With the development of human insulins, older forms of animal extract insulins have been discontinued. Despite the fact that the newer insulins are more effective than the
original forms, Green and Riggs (2015) argue that discontinuing the cheaper insulins is contributing to diabetes as a growing public health crisis:

The history of insulin highlights the limits of generic competition as a public health framework. Nearly a century after its discovery, there is still no inexpensive supply of insulin for people living with diabetes in North America, and Americans are paying a steep price for the continued rejuvenation of this oldest of modern medicines. (p. 1175).

This holds true for diabetics around the world, particularly in countries where insulin is hard to obtain to begin with. Beren, Ewen, and Laing (2015) report that insulin costs are one of the largest barriers to effective management for diabetics in developing nations, costs that have only risen with the phasing out of the older, less effective insulins. The World Health Organization’s 2016 Global Diabetes Report reports that “[a]vailability of insulin, metformin and sulphonylurea(s) is very limited in primary care facilities in low-income countries,” along with the limited testing done in said countries to diagnose the disease (p. 67). Further, this report found that “[b]asic technologies for early detection, diagnosis and monitoring of diabetes in primary care settings are generally not available in low-income and lower middle-income countries,” meaning that two out of the three foundations of diabetes management (insulin and glucose monitoring) are limited to people in places with the income to access them (p. 67). Indeed, when I was first diagnosed, we were living overseas in the kingdom of Thailand, and my parents had to import both a glucose monitor and the insulins I needed
because they were not readily available. I find it unfortunate that so little seems to have changed in the nineteen years since my diagnosis.

**Standards of insulin treatment.** Barranco (1998) describes how National Diabetes Data Group (part of the NIH) outlined classification standards in 1979 that allowed for “classification and overall treatment goals” for diabetes mellitus to become “well established” (p. 7). The basis for these standards relied on the development of “intensive insulin therapy,” which has only grown more achievable with the development both of more potent insulins types as well as with increasingly precise technologies, including the insulin pump. The Mayo Clinic (n.d.) defines “intensive insulin therapy” as “an aggressive treatment approach designed to control your blood sugar levels. Intensive insulin therapy requires close monitoring of blood sugar levels and multiple doses of insulin.” It is a more flexible regimen dependent on blood sugar levels as well as other factors, but in order to control your blood sugars you must be able to measure them to dose them properly.

To contrast, “conventional insulin therapy,” developed before glucose monitoring was available to individuals outside of a clinic, was extremely rigid and depended on “one to three daily injections that are the same every day” (“Conventional Insulin Therapy,” n.d.). My own insulin regimens have spanned both of these options. When I was first diagnosed, I was put on a conventional therapy that depended on the same doses at the same time everyday, primarily because, even though I had access to glucose monitoring, the health professionals in the country I lived in were unfamiliar with the newer, intensive forms of insulin therapy. This of course necessitated a very specific diet to match the insulin.
“Control” depended primarily on how consistent I was about dosing and eating from day to day, and the more consistently I performed, the better my health would be. I remember my doctor telling me that to be REALLY under control, I would only need one shot a day. Five months after my diagnosis, my mother and I returned to the United States to visit Duke Medical Center and talk to a pediatric endocrinologist. She was horrified when I mentioned the “one shot a day” goal, and explained that multiple shots were far more effective, as they more closely mimicked the function of the pancreas.

When I returned to the United States for college, I learned more about intensive insulin therapy and, having access to up-to-date medical experts, I began using a sliding scale for insulin injections (based on sugar levels and carbohydrate counts). Rather than a set dose for each meal, I calculated the dose based on what I planned to eat. Instead of a set number of insulin units a day, I had a range of units per meal. Next to an insulin pump, intensive insulin therapy has the best chance of producing “near-normal glycemia - average plasma glucose 155 mg/dL (versus 231 md/dL with conventional therapy) and HbA1c -7.2% (versus ~9.0% with conventional insulin therapy)” - intensive therapy thus results in a severe reduction in diabetes related complications (Barranco, 1998, p. 9). The disparities between my treatment options given by Thai and American medical professionals draws attention to the global disparities in treatment options. Krall (1995) noted that “a great portion of the world has neither adequate insulin nor treatment facilities, the added burden of frequent home blood glucose monitoring and multiple daily insulin injections makes the task almost insurmountable;” an observation that sadly holds true today (p. 286). To summarize:
The implementation of a program of intensive therapy involves patient self-management in terms of altering insulin dosages, food intake, and/or activity in an attempt to achieve the target level of glycemia selected. In motivated patients willing to embark on such a course of therapy, intensive insulin therapy can be worthwhile. (Hirsch, Farkin-Hirsch, & Skylar, 1990, p. 1265).

In addition to the types of insulin, methods of insulin delivery have also improved. While bottles and syringes are the most basic (and cheapest) form of insulin consumption, companies like Novo Nordisk and Lilly sell their insulins in ‘pens’ that are more accurate in measuring doses. Insulin pumps, which are worn at all times and attached to the body via infusion sets and tubes, seek to mimic the pancreas by releasing small amounts of fast-acting insulin over longer periods of time, leading to a baseline insulin level without the use of a long-acting insulin like Lantus. Below I have included a table with my own current management plan:

Table 1.1. Insulin Management Plan

<table>
<thead>
<tr>
<th>Plan Basis</th>
<th>Intensive Insulin Therapy</th>
<th>Multiple Daily Injections (MDI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long acting insulin (Basal dose)</td>
<td>40 units of Lantus Insulin Pen (calculated based on my baseline blood sugar level; adjusted based on illness or menstrual cycle that result in consistently higher or lower glucose levels.)</td>
<td>1 injection nightly</td>
</tr>
<tr>
<td>Fast acting insulin (Bolus doses)</td>
<td>Sliding scale of Novolog Insulin Pen (calculated based on blood sugar levels and carbs consumed)</td>
<td>3-8 injections daily (prior to meals and for correction of high blood sugars)</td>
</tr>
</tbody>
</table>
Without glucose monitoring, I would still be able to give myself insulin injections, but I would have little to no idea of their effectiveness until my doctor measured my A1C levels to see the range of my glucose fluctuations. I rely on my glucose monitors to make decisions on a daily and hourly basis about my own treatment, and they are necessary to my achieving the tight control that will improve my life expectancy as well as overall quality of life. I argue that self-management, and thus diabetic control, depends on glucose monitoring as well as insulin, making the glucose meter a crucial part of achieving glucose control. And in contemporary diabetes management, control is reliant on multiple forms of digital and physical data.

**The Importance of Monitoring**

While I discuss the impact of glucose monitoring more completely in future chapters, I would like to reiterate that insulin treatment, particularly the more contemporary, intensive regimens, would not be possible without glucose monitoring. Daily glucose monitoring relies primarily on small, digital glucose monitors that diabetics use to analyze blood samples at a minimum of four times a day. These meters allow diabetics to define individual glycemic targets, as well as live a more ‘normal’ life in terms of what they can and cannot eat and do because they are able to better calculate their insulin doses (Clarke & Foster, 2012, p. 89). In this way, glucose monitors generate important data regarding the diabetic’s health and control, and increasingly store this data. In this sense, the development of glucose monitoring has followed a similar trajectory to the development of other forms of mobile digital
technology, as explored further in later chapters. Of glucose monitors in particular, Clarke and Foster (2012) suggest that

Most of the progress in the development of blood glucose meters has centered on data management and the trend towards the connectivity of information technology systems, especially for glucose systems for the hospital market. In addition, greater consideration has been given to the special needs of persons with diabetes in the design of meters, operation and data management. (p. 89).

As mentioned above, I put glucose monitoring in the category that John Durham Peters (2015) calls “logistical media,” or “infrastructural media.” Glucose monitors allow their users to deal with the logistics of the various aspects of controlling their disease; they are the media that “stands under” diabetes management. I have used various forms of glucose monitors for nearly twenty years, the vast majority of my life. At the risk of sounding dramatic, access to home glucose monitoring has saved my life and allowed me to achieve far greater control over my Type I Diabetes than was possible when insulin was first discovered. Insulin alone cannot control diabetes; the glucose monitors I examine in these chapters are currently the foundation to precision in diabetes control. The specific technical capabilities of glucose monitors generally and CGMs specifically offer a chance to explore what types of knowledge (or data) different forms of technology produce, and how such knowledge can be understood and applied. On a broader scale, the technological advances in monitoring technologies have both changed or maintained the ways that “diabetes” itself is defined and diabetic populations determined globally. At the individual level, different forms
of diabetic media produce different diabetic subjects. Each chapter in this dissertation focuses on a slightly different aspect of monitoring media.

**Mediating Control: The Production of the Diabetic Subject**

In chapter two, while providing a contextual anecdote of my own diagnosis, I focus on providing a comprehensive history of diabetes and of the development of diabetic glucose monitoring technology, as well as an exploration of relevant media theory, specifically Peters’ (2015) exploration of “logistical media.” I provide a media history of glucose monitoring, ending with the most recent development of wearable Constant Glucose Monitors. I contextualize the development of wearable glucose monitoring by examining the historical methods of observing diabetic symptoms and the media used to record and store that information. In addition to Peters (2015), this chapter relies on the work of Foucault, Kittler and other critical media theorists like Sterne (2005) and Thacker (2005) to offer a theoretical framework for examining glucose monitors as media. This history covers roughly four types of monitoring that overlap but also follow a rough timeline related to technological development: haptic monitoring, which relied on sense-based observation (eyes, taste, etc.) and was dependent on human memory and written records for storage; reagent or chemical monitoring (use of bodily fluids and chemical reactions) and also relied on human memory and archival storage mechanisms; reagent/digital monitoring, which began the shift from written to digital storage; and digital/wearable monitors, which have shifted almost completely to digital storage.
This chapter also examines the types of data each form of glucose monitoring generates, how said data is stored, and what said data can ‘do’ in terms of controlling diabetes. The development of monitoring technologies also precipitated changes in the relationship between diabetics and doctors; with the ability to produce more ‘precise’ forms of knowledge about the body’s glucose levels comes the ability to produce more precise forms of treatment protocols. While attempting to focus on a “non-human” centric history of glucose monitoring, this chapter looks at data generated from my own glucose monitors in order to demonstrate the types of data such monitors produce.

**Self Control: Dealing with Data**

Chapter three looks more closely at the ways in which glucose monitoring technology impacts the everyday life of the user. This chapter uses my own experiences with various glucose monitors and is framed using Foucault’s “technologies of the self.” Additionally, this chapter examines “technological utopianist” accounts of the role that digital technology will play in revolutionizing health care (represented by Eric Topal, 2015) and more critical perspectives from scholars such as Deborah Lupton. In examining the “digitizing” practices related to health care, I provide an argument that diabetic media should be included in discussions of digital health, given that self-tracking as a practice has been a basis for diabetes management long before the triumph of devices like the FitBit. I also examine the different legal designations of health-related digital media to demonstrate the difference between health-managing technologies like glucose monitors and non-regulated fitness trackers. These sections provide a greater technological context from which to consider
diabetes-related media, and highlight the uniqueness of how they function in the everyday life of a diabetic.

In the second half of the chapter, I examine the variety of glucose monitors I have used in my life, to provide specific examples of how different technological capabilities engender different management practices. Specifically, I look at how each type of diabetic monitoring media described in chapter one depends on specific biological components and technical interfaces with the body in order to generate data, and how useful or precise each set of data is in relation to achieving diabetic control. Further, my experiences as an “informed patient” act as a way to examine the effectiveness of health care practices by incorporating various technological and social “preconditions” that determine health and patient outcomes. My account also demonstrates that “more technology” does not necessarily result in better control right away; rather each set of technology and its attendant data requires a new set of knowledge and practice to operationalize.

**Hacking Control**

As chapter three suggests, technology does not offer an immediate or magical solution to diabetes management. The fourth chapter looks at other aspects of diabetes management - the mental and emotional aspects that are not obviously mediated by glucose monitors but have an impact on the overall well being of the diabetic. While glucose monitors provide information on the physiological health and glucose levels of the diabetic, tests to diagnose mental and emotional disorders are performed only when the diabetic is not ‘performing’ well enough to achieve control. Online communities can provide the emotional
support that is lacking in the medical community, as well as offering a forum in which diabetics and their loved ones can share knowledge gained from experience. This reflects what Levy (1997) calls “universal intelligence,” enabled by digital networks that allow for knowledge to be shared and maintained by many different participants in real time. Websites dedicated to crowd sourced diabetic knowledge offer an important alternative to the strictly biomedical sources of knowledge. Donna Haraway’s cyborg provides a way to consider the interaction of the technological systems with the human body.

This chapter also looks at practices of hacking - taking “hacking” to mean challenging the limits of particular systems, whether digital or not. In a context where health is so dependent on blood glucose data, working with and using technology that is not user friendly can be very difficult for diabetics and their loved ones. While the generation of biological data is a given in glucose monitoring, the user’s ability to access to the data is dependent on the monitor’s system. For CGMs, in particular, access to the data generated has often proven difficult. This chapter provides specific examples of the ways in which the diabetic community have taken the available technology and modified or expanded them to better address the needs of diabetics, as well as the role technology plays in moving ever farther from the clinical model of medicine.

**The Myth of Control**

In the fifth chapter, I build off of the cyborg theme to explore the agency of the body through the lens of material feminist scholarship through a grounding in the work of Susan Wendell (1996) on the “rejected body.” I also examine the limits of technological
intervention in diabetes care. The “myth of control” that Wendell (1996) describes arises out of Western conceptions of medicine that are supposed to ‘fix’ the sick body. However, studying the chronically ill or “rejected body” through a focus on diabetes demonstrates the limits both of medicinal and technological intervention. Using my own experiences to provide particular examples, I examine how a desire for greater control over glucose levels, for example, is constrained in multiple ways, including economic and geographic limitations.

In this chapter I also explore “the agency of the body” through an examination of materiality and determination via the work of material feminist scholars who seek to re-visit the importance of the body and reconceptualize agency beyond the subject, most particularly through examining the concept of “intra-agency,” as theorized by Karan Barad (2003). Further, considering agencies engendered by the particular biological and technological configurations of diabetic media sheds light on larger concerns in critical theory regarding the relationship between technology, culture and the individual subject. These concerns are connected to larger concerns about the ultimate effectiveness of diabetes technology and how narratives about such technology contribute to the “myth of control.”

**Conclusion: Under Control**

In the conclusion, I reflect upon my own (albeit brief) experience with using a CGM and the ways in which this technology has helped my own diabetic control. Despite my own misgivings about the use of the CGM, using one has changed my understanding of my diabetes and myself. This dissertation documents the process re-learning my management practices to incorporate the data provided by the CGM, which has bearing on many of the
theoretical arguments that frame this dissertation project. In addition to providing a brief summary of the major theoretical and thematic points of the project, I suggest several directions and foci for future research into this area. Glucose monitors, while in use by a small subset of the global population, offer an important opportunity both to consider the question of what ‘media’ includes, but also how media and people interact. Hopefully this project will lay a foundation for further enquiry.

Packer and Wiley (2012) discuss the “material turn” in communication and media studies, and offer the following areas of “strategy” for examining the ways in which media can be considered materially and beyond content: economy, technology, space, body, and discourse. While each of my analysis chapters contain elements of each of these strategies, overall, I have chosen to focus primarily on the technologies of glucose monitoring, (the explicit mechanical processes and related bodily tissues), as well as the implications for understanding bodies, and the relationships between bodies and technologies.
CHAPTER 2:
Mediating Control: The Production of the Diabetic Subject

“With diabetes there is no cure and, without a lot of knowledge, not only the quality of life but life itself may be impaired. The volume and variety of information needed make the task almost insurmountable except for the most apt and compliant person” (Krall, 1995, p. 286)

“Media are not only devices of information, they are also agencies of order” (Peters, 2015, p. 1)

“Chelsea (age 12) is doing very well. The training she received from Duke Medical Center has allowed her to have better control over her blood sugars. She is very grateful for all the folks who made it possible for her to have the time at Duke...” (Hampton Herald, March 1998).

A Focused History of Diabetes

Diabetes mellitus (or Type I) is an autoimmune disease, which, left uncontrolled, results in a litany of horrifying health complications. A history of diabetes is a story not only of triumph, but also suffering and death, from individual diabetics prior to treatment options, to diabetics who submitted to the starvation diets popularized by clinicians such as Elliot Joslin in the hopes of gaining a few months or years more of life, to the innumerable dogs and other laboratory animals used by researchers such as Charles Best in their quest for insulin, to women who were sterilized because diabetes was deemed too harmful a disease to mix with pregnancy. It is also the story of how treatments of diabetes shifted from strict
guidelines and education towards the more fluid model of management enabled today by various digital monitoring technologies.

In writing about diabetes mellitus, I find it impossible to start exploring the history and treatment of the disease without grounding the clinical advances in the human experience of this particular chronic illness, specifically my own. I was diagnosed with diabetes mellitus in the summer of 1997 after being hospitalized due to a weight loss so extreme that I was unable to do simple things like climbing a staircase without feeling like I was going to pass out. Initially, my parents and I suspected an eating disorder; I was a pre-teen girl, I had admitted to wanting to lose weight. We had moved to a new country and not-eating gave me a feeling of control. Alternatively, I was nervous about starting a new school; in the past I had been so nervous about going to school I was unable to eat. I promised I would try to eat more. In addition to the weight loss and emaciation, I felt thirsty all the time. At first, being thirsty seemed reasonable. Thailand is a hot country, after all, and central air was not common. It made sense that I would drink water to fight the heat. But as I continued to grow weaker, the family doctor recommended a stay in the hospital to get me stabilized. By the time I was admitted to the Chiang Mai Ram 1 hospital (the newest and most up-to-date hospital in the city), I was slipping in and out of consciousness.

The doctor told us that he suspected a thyroid problem – assuring me that should that be the case, I would only have to take “one little pill” a day for the rest of my life. No big deal. The other option, he said, was diabetes, but he was positive that the blood work would rule diabetes out. He was wrong. My blood work showed that my glucose levels were over
700 mg/dl, which was more than three times the readings determined to show insulin intolerance in children by the National Diabetes Data Group in 1979. My pancreas had stopped producing insulin, which acted, according to the doctor, as a little bridge between the blood cells and the sugar from food. I was tired because without that insulin-bridge, my body was unable to break down food properly into energy. I was losing weight and feeling weak because my starving body had broken down all my fat reserves and had started on the muscles. The excess sugar in my blood stream had turned into poison, and was being passed through my urine. The doctor was sorry, so very sorry. “Control” became a theme of my life: control over blood sugars, self-control over food, control over routine to minimize the likelihood of diabetes-related complications and maximize my health outcomes. Rather than taking “one little pill” a day, I was faced with the need to test my own blood sugars and inject my own insulin for the rest of my life – or be forced to stay at home with my mother forever.

My own diagnosis came roughly seventy-six years after the development of synthetic insulin in the 1920s, and roughly thirty years after the development of home glucose monitoring, but the disease itself has been observed for centuries. In other words, diabetes mellitus has been treatable for less than one hundred years, and truly manageable for about forty. Often in histories of diabetes mellitus, the focus rests on the identification of insulin as the missing biological piece in correctly diagnosing patients and the development of insulin as an injectable drug. Similarly, as a child, and even as an adult, my own relationship with diabetes has focused primarily on insulin: my biological inability to produce my own, how to get prescription insulin, can I afford it, am I on the right dosages? As insulin is literally a
matter of life and death, this focus on pharmaceutical history is understandable. But as a media scholar, I have become deeply interested in the role various communication and media technologies have played in diagnosing and managing the disease. As Krall (1995) notes in the chapter’s opening quote, diabetes management is dependent on information and correct behaviors, and as Peters (2015) suggests, media organize information and act as “agencies of order” (p. 1). In this chapter I propose to demonstrate the ways in which diabetic media are infrastructural (to use Peters’ term), as they ‘stand beneath’ and are foundational to modern methods of diabetes control. To explore this premise of diabetic infrastructural media, I take a look at the history of diabetes mellitus itself in relationship to the various media that allowed for the production of particular forms of knowledge. Additionally, this chapter takes Kittler’s (2007) emphasis on the storage capabilities of media to provide a comparative analysis of how different forms of monitoring technology and associated medical records have impacted diabetes management.

The recorded history of diabetes mellitus spans from observation of symptoms, through the scientific and medical discoveries - carefully recorded, printed, and shared by researchers - that made diagnoses and insulin treatment possible, through the digital revolution which is enabling new, more precise, forms of treatment. As I noted previously, most discussions of diabetes and diabetes management have focused on insulin; I instead focus my discussion on the media that makes diabetes management possible. I contend that without glucose-related media, true diabetes management is impossible. In this chapter, I present a media-focused history of diabetes to both explore the development of specific
monitoring media (the Constant Glucose Monitor) as well as how the media affordances of different monitoring technologies serve to help create Krall’s “apt and compliant” diabetic.

Towards a Mediated History of Diabetes

In attempting a “media history” of diabetes, I draw on a variety of media scholarship, but have chosen to center my definition of and focus on media using what might be termed a “Kittlerian” approach, but with some important reservations. “A media studies without people” is the phrase John Durham Peters uses in his introduction to Kittler’s Optical Media to describe Friedrich Kittler’s approach to studying media as well as his opinion of the role of the human in considering media. In this, Kittler exists as the antithesis of cultural studies or the study of media effects – his interest lies not in exploring how people experience media, but rather exploring media’s underlying, technical structures. He defines the three functions of technical media as the ability to “store, transmit, or process signals,” and argues that the computer is the “only medium that combines these three functions” (p. 25-26). Kittler radically de-centers the human from media studies: arguing that the body itself can only be known through media. While media may extend the capabilities of the human body, they also offer “models and metaphors” for understanding human senses (Kittler, 2010, p. 26). John Durham Peters notes that “[f]or Kittler, the subject is always subordinate to the object: human perception is an interface with physical realities” (p. 3). In terms of this chapter, then, I seek to balance my own experiences with an analysis of the technical capabilities of each monitoring technology and the value individual technologies have in diagnosing and monitoring diabetes.
Focusing on “process” (in terms of media’s technical capabilities) rather than (human) “experience” of media, Kittler’s model of media studies offers a model of “abstraction” in considering questions about current media formations. Peters compares his approach to “early Foucault” - Kittler’s focus on “social change through everyday practices” is not concerned about the individual as much as larger “historical rupture” (p. 5). Galloway (2004) argues that Foucault similarly “diminishe[s] the importance of individual expressive actors” – instead the importance lies within the relationships allowing individuals to act (p. 82). While Kittler himself was uninterested in “so-called humans,” his work has important implications for understanding the practices and standards that have a role in shaping current understandings of the relationships between humans and media, as well as the production of knowledge. Specifically in the case of diabetes mellitus, I argue that the “diabetic body” can only be known through media and the data generated through a variety of monitoring media and techniques.

**Technologies and Techniques**

Media related to diabetes have, I suggest, a very specific and unique history of development, as easy as it is to see newer, digital media such as the Constant Glucose Monitor as the result of “new media” such smart phones. John Durham Peters (2015) rejects the distinction between “old” and “new” media. Instead, he distinguishes between the “mass” media of the twentieth century and digital media practices. He connects digital media practices to a lengthy tradition of media used for “recording, transmitting, and processing culture, of managing subjects, objects and data; of organizing time, space, and power” (p. 19)
Diabetic media fall into the older category – the goal of glucose monitoring has historically been to record, measure, and manage the diabetic subject over time. Peters differentiates between “techniques” and “technology” – techniques “practices of know-how, handicraft, and corporeal knowledge that interact with bodies or instruments” (p. 90). Further, according to Peters, “[t]echniques have both biological and artefactual histories; they consist both of suites of actions and of materials, even if those materials are the body of the user” (p. 91). Technologies, in contrast, “externalize” techniques into “durable form” that can be preserved and reproduced at a distance and over time (p. 91). The techniques associated with managing diabetes, and particularly regulating blood sugar, have always depended on technologies, particularly in terms of the data that glucose-monitoring technologies provide and store.

Jonathan Sterne (2003) offers the following definition of “technologies” as “social, cultural, and repeatable processes crystallized into mechanisms” that “manifest a designed mechanical agency,” with a “set of functions developed from and linked to sets of cultural practices” (p. 8). In this definition he attempts to address the tension between technological determinism and other ways of viewing technological development – we need technology for specific purposes and development often arises out of a specific set of needs and circumstances. He discusses the processes of “instrumentation” in the development of technology, specifically of the stethoscope. *Instrumentation*, Stern demonstrates, “allowed for new phenomena to be observed, which in turn led to conceptualizations of the human senses as and through instruments” (p. 58). Foucault (1973) notes that the development of the stethoscope was in part motivated by the social disgust felt by upper class doctors for
their lower class patients – the stethoscope both enabled physicians to observe hitherto unobservable phenomenon, it also distanced them from the patient. This technologically enabled distance re-organized medical practices - mediating not only the "auditory relation" between the doctor and the patient, but also by "keeping intact the physical distance implied by social distinctions" (Sterne, p. 117). Sterne elaborates that these re-organized practices denoted a shift away from a dependence on tactile modes of observation, as well as a move away from dependence on patient narratives and visual observations to other methods of diagnosing bodily ills. Instrumentation, then, both allowed for and enabled empirical modes of thought. This movement has been of huge importance to the medical field as a whole, and the proliferation of digital tools promises to both extend medical capabilities and allow patients greater control over their care. But for Type I diabetics in particular, the development of digital monitoring technologies has been revolutionary in terms of the precision and flexibility in treatment options, and the corresponding greater access to the ideal of control in managing their bloodsugars.

**Definition of Key Terms Related to Diabetes and Diabetic Media**

Building off the history of insulin and insulin treatments that I provided in the last chapter, below I have attempted to break down some of the key components of providing (and explaining) a media history of diabetes. This chart functions as a visual shorthand for the longer history I provide in this chapter regarding both the specifics of technological and medical development, and lays the foundation for the autoethnographic account I provide in the next chapter about how these technologies and practices function in (my) everyday life.
While diabetes is most commonly understood as an inability for a specific pancreas to produce insulin, in fact both the diagnosis and the treatment of diabetes relies on multiple media. With this in mind, I have provided information regarding the various types of monitoring technologies and strategies and bodily tissue use, as well as what data is generated, storage capabilities, and the treatment options made possible by the data generated by the various monitoring processes.

I also highlight the precision and associated usefulness of each method. I chose to use the term “precision” rather than “accuracy” because with all of these monitoring technologies, the user or medical professional must work with the data provided by the method. In each case, it is impossible to be completely accurate given the limitations of the technologies that are available as well as the constant fluctuations of the body’s processes. The purpose of glucose monitoring is to translate biological material into a form that is usable by the user. To borrow from the Shannon and Weaver (1949) model of mediated communication, there is always some “noise” involved in the transmission and translation of biological data into operationalizable data. I use “precision” to reflect how operational the data provided by each technology under consideration is in terms of achieving glucose control and lowering the diabetic’s A1C test results. To that end, I designate whether a monitoring technology’s precision is Very Low (lack of precision), Low (more precise but not particularly useful in determining responsive action), Medium (precise enough to determine beneficial action), Medium-High (more precise), and High (the most precise technology available to the individual user). To further demonstrate operationalization of
data, I note whether or not the monitoring method has **Diagnostic** (helpful in diagnosing or determining Diabetic symptoms) or **Management** (helpful in determining specific actions the individual can take to react to their Diabetic symptoms) value.

**Types of monitoring.** This chart column provides specific examples of monitoring techniques used to identify and monitor certain symptoms of diabetes. The information here roughly corresponds to historical trajectories of development and can be connected to other historical developments such as the development of observation (Daston and Galison, 2007) as well as birth of the clinic and the institutionalization of medicine (Foucault, 1963).

**Haptic Monitoring** - I use this term to designate techniques of observation that rely on human senses. While unequal to the task of providing the ability to diagnose and monitor diseases like diabetes without the addition of methods relying on more invasive or precise use of bodily tissues, these monitoring techniques are still used in a diagnostic fashion today.

**Chemical or Reagent Monitoring** - With the development of more precise observational technologies and the scientific method, scientists and doctors were able to determine tests that combined bodily fluids with various chemicals that would result in a chemical reaction. The color variance of the chemical reaction allowed the tester to determine deviance from a norm via visual comparison.

**Reagent and Digital Monitoring** - A method still reliant on color comparison, but not on the human eye. Reflecting light through the blood sample allowed the digital
receiver to determine glucose levels based on the color of the reaction of the blood sample to the reagent strip.

**Digital and Biosensor Monitoring** - The continued development of digital technologies resulted in biosensors small enough to replace the reflectance method to provide more precise measurements of glucose in smaller blood samples. Instead of depending on color variance, these tiny biosensors are able to read the glucose levels in the blood sample.

**Biosensor and Wearable Monitoring** - Using a thin biosensor inserted into the skin, this method of monitoring provides a continuous stream of data, but is less precise than monitors that rely on blood samples. In addition to the wearable biosensor, these monitors require a transmitter and a receiver technology in order to view the data generated.

Table 2.1 - History and precision of diabetic monitoring

<table>
<thead>
<tr>
<th>Type of Monitoring</th>
<th>Sensor Type</th>
<th>Time Frame</th>
<th>Tissue/Bodily Product Used</th>
<th>Storage Capabilities of Tissue Used</th>
<th>Data Generated</th>
<th>Level of Precision and Usefulness</th>
<th>Primary Storage Capabilities of Monitoring Technology</th>
<th>Supplementary Storage Media</th>
<th>Treatments Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embodied Monitoring</td>
<td>Eyes</td>
<td>150 AD-present</td>
<td>Observation of emaciation, excessive urination</td>
<td>Body breaking down fat reserves, excessive urination</td>
<td>Visible Symptoms of Bodily malfunction</td>
<td>Very Low - symptoms could apply to multiple health issues. Diagnostic Value</td>
<td>Human Memory</td>
<td>Writing and archival storage</td>
<td>Diet - low fat, low carbohydrate</td>
</tr>
</tbody>
</table>
Table 2.1. Continued

<table>
<thead>
<tr>
<th>Type of Monitoring</th>
<th>Sensor Type</th>
<th>Time Frame</th>
<th>Tissue/Bodily Product Used</th>
<th>Storage Capabilities of Tissue Used</th>
<th>Data Generated</th>
<th>Level of Precision and Usefulness</th>
<th>Primary Storage Capabilities of Monitoring Technology</th>
<th>Supplementary Storage Media</th>
<th>Treatment options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embodied Monitoring</td>
<td>Tongue</td>
<td>150 AD-present (see: Where there is no Doctor)</td>
<td>Urine, later blood</td>
<td>Ketones</td>
<td>Taste of sweetness</td>
<td>Low - more specific symptom, still unable to form specific diagnosis. <strong>Diagnostic Value.</strong></td>
<td>Human Memory</td>
<td>Writing and archival storage</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nose</td>
<td>150 AD-present</td>
<td>Urine, Blood, Breath</td>
<td>Body emitting “fruity” smell</td>
<td>Smell of sweetness in urine, fruit on breath</td>
<td>Low - more specific symptom, still unable to form specific diagnosis. <strong>Diagnostic Value.</strong></td>
<td>Human Memory</td>
<td>Writing and archival storage</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ear</td>
<td>19th Century-present</td>
<td>Heartbeat, lung function</td>
<td>Irregularities in rhythms/patterns</td>
<td>Sound of irregularity in heartbeat and shortness of breath</td>
<td><strong>Very Low</strong> - symptoms could apply to multiple health issues. <strong>Diagnostic Value.</strong></td>
<td>Human Memory</td>
<td>Writing and archival storage</td>
<td></td>
</tr>
<tr>
<td>Type of Monitoring</td>
<td>Sensor Type</td>
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<tr>
<td>Reagent/Digital Monitoring</td>
<td>Reagent Strips, Digital Reader Example: One Touch Basic</td>
<td>1971- Present</td>
<td>Capillary Blood</td>
<td>Glucose Levels in bloodstream</td>
<td>Reflectance method - how much light is absorbed by dye in reagent strip.</td>
<td>Medium - more sophisticated and precise than visual comparison. Diagnostic and Management value.</td>
<td>Limited digital memory - One Touch Basic could store up to 75 results (18 days)</td>
<td>Varying digital memory capabilities; One Touch Ultra could store up to 150 results (one month); the Contour Next can store 800 readings</td>
<td>Personal blood sugar logs; optional computer storage</td>
</tr>
<tr>
<td>Digital/Biosensor Monitoring</td>
<td>Biosensor Strips, Digital Reader Example: One Touch Ultra, Precision Xtra, Contour Next</td>
<td>Early 2000s-Present</td>
<td>Capillary Blood</td>
<td>Glucose levels in blood stream; Ketoness in blood stream (in case of Precision Xtra)</td>
<td>Biosensor or converted blood sample informatior to receiver via electrica l current</td>
<td>High - most precise and accurate form of home or self monitoring due to the use of capillary blood. Diagnostic and Management value.</td>
<td>Varying digital memory capabilit ies; One Touch Ultra could store up to 150 results (one month); the Contour Next can store 800 readings</td>
<td>Personal blood sugar logs; optional computer storage</td>
<td>Diet, Insulin, Pump compatibility (Contour Next)</td>
</tr>
<tr>
<td>Type of Monitoring</td>
<td>Sensor Type</td>
<td>Time Frame</td>
<td>Tissue/Body Product Used</td>
<td>Storage Capabilities of Tissue Used</td>
<td>Data Generated</td>
<td>Level of Precision and Usefulness</td>
<td>Primary Storage Capabilities of Monitoring Technology</td>
<td>Supplementary Storage Media</td>
<td>Treatment Options</td>
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</tr>
<tr>
<td>Digital/Biosensor Monitoring</td>
<td>Biosensor or Strips, Digital Reader (Example: One Touch Ultra, Precision Xtra, Contour Next)</td>
<td>Early 2000s - Present</td>
<td>Capillary Blood</td>
<td>Glucose levels in blood stream; Ketones in blood stream (in case of Precision Xtra)</td>
<td>Biosensors or converted blood sample information to receiver via electric current</td>
<td>High - most precise and accurate form of home or self monitoring due to the use of capillary blood. <strong>Diagnostic and Management value.</strong></td>
<td>Varying digital memory capabilities; Some models could store up to 150 results (one month); others can store 800 readings (roughly six months)</td>
<td>Personal blood sugar logs; optional computer storage</td>
<td>Diet, Insulin, Pump compatibility (Contour Next)</td>
</tr>
<tr>
<td>Digital/Biosensor Wearable Monitors</td>
<td>Biosensor or, Transmitter, Receiver (Example: DexCom 4, DexCom 5)</td>
<td>2006 - Present</td>
<td>Subcutaneous Tissue</td>
<td>Glucose levels in subcutaneous tissue</td>
<td>Biosensors or worn on stomach transmits glucose information to receiver</td>
<td>Medium-High - Capillary blood is a more immediate bodily tissue, than subcutaneous tissue. <strong>Diagnostic and high Management Value</strong> due to blood sugar trends.</td>
<td>Up to 24-hours monitoring on Receiver Screen (separate receiver or phone app)</td>
<td>Automatic Cloud Storage</td>
<td>Diet, insulin, pump compatibility (DexCom 4)</td>
</tr>
</tbody>
</table>
As the table demonstrates, while there is a historical trajectory of development, often the newer technologies are used in tangent with older forms of glucose monitoring. As an example, I have a current prescription for Ketostix, which are reagent strips used to test for ketones in urine. While I do not use this monitoring method regularly, it acts as a diagnostic method in addition to my blood monitoring. When my blood sugars have been running high, testing for ketones in my urine allows me to know how far out of control my glucose management has gotten, and whether or not I should see a medical professional. Each era and method of monitoring represents not only a particular technology, but each requires specific techniques and results in specific types of data. The more precise the monitoring method, the more precise and effective the management options for the diabetic are, resulting in tighter control. Similarly, the more precise the monitoring technology, the more flexible treatment options are available, particularly in conjunction with the development of insulin described in the previous chapter. The shift from paper records to digital records coincided with the development of flexible treatments and also marked a shift from a primarily clinically based management system to individual management.

**Embodied Observation: learning how to ‘see’**

A brief look at the history of glucose monitoring demonstrates the potential for a more in-depth media study to understand both the technological developments, but also the related social practices in managing and monitoring the disease. In terms of observing the physical symptoms related to diabetes, historical accounts of diabetes-like diseases stretch back surprisingly far, preserved in the writings of ancient observers. Or, as Davis (1998)
memorably describes it, the history of diabetes is a history of a "disease [that] has always been (mis)diagnosed and (mis)treated" (p. 70). According to Clarke and Foster (2012), “the Egyptians first made mention of diabetes around 1500 BC,” although the term ‘diabetes’ was coined several centuries later by a Greek physician (p. 83-84). The disease was identified primarily by external symptoms such as thirst and weight loss, as well as excessive urination (Tattersall, 2009). Dods (2013) traces a history of the observation of diabetes back to the Ebers Papyrus – which dates to around 3400 BCE. He suggests that this papyrus, which describes symptoms such as emaciation, unquenchable thirst, and polyuria, connects a group of symptoms that we associate with diabetes today. Dods’ history of diabetes, then, focuses on the identification of symptoms and the development of treatments related to these outward indications of ill health, and depends on the ancient writings and archives that have lasted until today. He pinpoints Aretaeus of Cappadonia (81-138 AD) as giving “the first accurate account of the disease in about 150 AD” and giving it the name “diabetes” (p. 25). Aretaeus thus explicitly grouped symptoms – including a very short survival time as well as excessive urine and wastage of the sufferer’s body. Again, these observations focused primarily on the external symptoms of diabetic bodies – speculations about where, internally, the disease could be situated, were of necessity dictated by the external symptoms. Aretaeus suggested that the kidneys were the internal site of the disease (Davis, 1998). Galen (around 150 AD) also suggested kidneys as the source of the disease, due to the “violent thirst” experienced by the sufferer (Dods, p. 26). Indian scholar and physician Sushruta added “sweet urine” to the list of symptoms in the 5th century AD. Even today, in the latest edition of popular medical
guide Where There Is No Doctor, Werner, Thuman, and Maxwell (2015) suggest tasting the urine for sweetness of a patient when diabetes is suspected and the doctor lacks access to medical technology. One of the first things I learned after my own diagnosis is that the most common Thai phrase for diabetes (โรคน้ำตาล or rok bao waan) translates to “sweet urine.”

However, the ability identify this particular set of symptoms did very little to provide treatment options. And so, along with observation of symptoms, physicians have sought methods to treat diabetes. Dods (2013) suggests that the Ebers Papyrus, in addition to listing symptoms, also contains early suggestions as to treatment via diet. Unsurprisingly, Dods (2013) notes that medical understanding of diabetes as a disease was necessarily “accompanied by major analytical advances,” most primarily in the form of glucose monitoring. These early forms of glucose monitoring were not precise, and depended on “taste, fermentation tests, and evaporation of the urine to yield sugar crystals” (p. 43). Dobson, a physician practicing in the 1600s, first connected excessive sugar in urine to the possibility of excessive sugar in the blood, and identified diabetes as a kidney-related disease based on the information available (Dods, 2013). Dobson also championed diet as a treatment, which remained the only viable option until the development of insulin in the 1920s. Davis (1998) describes the work of seventeenth century physician Thomas Willis, who focused on the urine as the indicator not only of disease, but as proof of "the patient's inability to exercise control" (p. 72). A popular "diet" that was recommended during this time was known as the "animal diet," where the patient would eat no plants, just meat, and specifically "rancid meat" (Davis, 1998, p. 74).
A case from the work of Robert Watts (1808) demonstrates the ways in which symptoms were classified and treatment was prescribed during this period, as well as how medical knowledge was being preserved and circulated within the medical community. Of note is the fact that diabetes and consumption were often grouped together by physicians as "wasting illnesses" because the external symptoms of both diseases (weight-loss, fatigue, and eventual death) were very similar. In treating M. Drummond, a thirty-five year old laborer in rural England, Watts noted that Drummond had been originally diagnosed with a case of "galloping consumption," although Watts himself rejected this diagnosis (p. 7). Watts had reached a different conclusion based on Drummond's great thirst, dry skin, and "surprisingly sweet urine," which Watts describes as having "a light straw color, with a tinge of green; it had a fragrant sweet smell, and tasted like honey and water" (p. 5). Watts put Drummond on a regimen of castor oil and "animal food," which Drummond (surprisingly) did not enjoy (p. 3). Through his cataloguing of his work with Drummond and other patients, Watts was attempting to come up with a definitive set of symptoms, although at the time, while sweetness of urine had been observed in relationship to diabetes for centuries, it was not universally agreed upon as a symptom by the medical establishment. By conducting minute observations of his patients and keeping detailed notes, Watts was surprised to conclude that "the cases" of his various patients were "so exactly alike" in constancy of symptoms (p. 196). He admits that the symptoms he cataloged had often been noted by various physicians, but argued that his casebook brings them "into one view" and offered a comprehensive picture of
the symptoms of diabetes (p. 196). He concludes his casebook by offering the following "capitulation of symptoms":

In Diabetes, the arid skin, the foul mouth, the constipated bowels, the indistinct vision, the chilly state of the body, the depression of the spirits, and various other apparently remote symptoms, are, perhaps, of as great importance as the altered secretion of the urine. The complete recovery of the patient depends on the removal of all of them. By overlooking these, practitioners have often been deceived. They have imagined, they have cured the patient, when they only relieved one symptom by aggravating another. (p. 195)

Watts' attempt to argue for a conceptualization of diabetes beyond specific or isolated symptoms, the search for causes rather than focusing on treating symptoms, exemplifies what Davis (1998), drawing on Foucault's work in Birth of the Clinic and The Order of Things, describes as "the tangible codification of the body's functionings, abnormal and normal" (p. 73). Foucault (1973/1994) describes this shift in terms of the “clinical gaze,” which sought to "see, to isolate features, to recognize those that are identical and those that are different, to regroup them, to classify them by species or families" (p. 89). The "medical gaze" was organized in new ways, institutionally: "...it was no longer the gaze of any observer, but that of a doctor supported and justified by an institution" who had the power to intervene, moving away from attempting to produce essential truths about a singular patient to looking at deviations from an established norm that could be applied across populations (p. 89). Watts’ (1808) attempt to categorize the symptoms of his patients in connection to each other and in
conversation with the observations of other medical professionals demonstrates the operation of this ‘clinical gaze.’ These changing practices and norms resulted in changes to the “form of knowledge, a reorganization of the hospital field, a new definition of the status of the patient in society, and the establishment of a certain relationship between public assistance and medical experience, between help and knowledge” (Foucault, 1973/1994, p. 196).

The "accumulation of knowledge" about the symptoms of diabetes led to the formulation of a "coherent 'theory' of diabetes treatment" and a focus on the diabetic patient's "lack of control" (Davis, 1998, p. 75). In 1883, physician George Rees identified an excess of sugar in a diabetic patient. At this point, urine samples could be used to determine abnormally high blood sugars, but diet remained the only way to manage the disease until 1921 when three researchers identified insulin (Dodds, 2013, p. 84). With diet-treatment, diabetics underwent a "programme of intense observation" where their every morsel of food was scrutinized and controlled by medical professionals, especially in live-in clinics such as that run by Elliot Joslin (Davis, 1998, p. 78). The discovery of insulin "allowed the medical profession to alter the doctor-patient relationship" and led to a "more indirect mode of control" where medical professionals "determine the proper course of treatment, while simultaneously shifting the burden of potential failure to the patient (p. 78-79). Early monitoring techniques required close medical observation as well as strict dieting because of the lack of precision in turns of measuring blood glucose accurately. The increasing precision in the available monitoring technologies brings the “control” of diabetes closer to the concept of “control society.” These accounts also highlight the focus on insulin in academic literature
as the primary development in diabetes treatment - which is not incorrect but neglects the mediated nature of Davis' (1998) "cognitive frameworks" that generate knowledge about diabetes and determine treatment options.

**Visual Glucose Monitoring**

In the nineteenth century, a variety of chemical methods – including the “copper test” and the “yeast method” – were developed to measure sugar in the urine in the interests of “providing a better way of monitoring the success of treatment than tasting the urine” (Tattersall, 2009, p. 19). The ‘copper test’ used urine “heated with blue cupric (copper) sulphate,” when there was excessive glucose in the urine sample, a “red cuprous oxide was formed” (p. 19). This was a complicated process, and Tattersall (2009) suggests that the copper test was primarily a “useful test of the progress or otherwise of treatment” rather than a day-to-day monitoring technique. The discovery that diabetics had high levels of glucose in their blood as well as their urine offered another avenue for monitoring diabetes. However, using blood instead of urine at this early point in time “needed large volumes of blood, plenty of time, and meticulous technique” to process – which did not lend itself to regular use in medical and clinical practices, much less for individuals, “until the development of micro-methods after the First World War” (p. 19). Even so, urine testing remained the mainstay for diabetic sugar monitoring for over fifty years (Dods, 2013). In the 1920s, the development of dry-reagent litmus paper eliminated the need for the complicated copper test (Clarke and Foster, 2012). These dry-reagent tests depended on the enzyme glucose oxidase, and over the next few decades, the “quest for a more convenient and specific method culminated in the
‘drip and read’ urine reagent strip, Clinistix, in 1957” (Clarke & Foster, 2012, p. 85). Clarke and Foster describe how the mixture of glucose oxidase, peroxidase and orthotolidine worked when combined with a urine sample:

In a coupled reaction, glucose oxidase catalyzed by the oxidation of glucose to gluconic acid and, in the presence of oxygen, formed hydrogen peroxide, which is catalyzed by peroxidase for the oxidation of orthotolidine to a deep blue chromogen (p. 85).

Despite the ease that Clinistix introduced into the process of using urine to monitor sugar levels, using urine in diabetic monitoring is limited in terms of precision. Given the complexities of bodily processes, urine only offers a “retrospective of current glycaemic status,” as well as being impacted by factors such as fluid intake (Clarke & Foster, 2012, p. 86). Urine sampling also does not allow a diabetic to know if their sugar levels are normal or low, which is another huge drawback to using it as a primary method of managing day-to-day diabetes care. Blood sampling offers a better picture of “‘real time’ blood glucose concentrations,” and so researchers turned to exploring whether the Clinistix technology could be effective if blood was used instead of urine (Clarke & Foster, 2012, p. 85).

By 1957, researchers had demonstrated that Clinistix could be used with blood rather than urine. In 1965, Dextrostix – which required a drop of blood as opposed to urine – were released (“Timeline for Blood Glucose Monitor,” n.d.). While similar to Clinistix, Dextrostix used “a paper reagent strip which used the glucose oxidase/peroxidase reaction but with a semipermeable membrane which trapped red blood cells but allowed soluble glucose to pass.
through to react with the dry reagents” (Clarke and Foster, 2012, p. 85). The reaction would instigate a color change in the strip, which was then compared to a “color chart” to indicate a “semiquantitative blood glucose value” (p. 85). Clarke and Foster note that this process was still very imprecise: in addition to merely eliciting a basic range for the amount of glucose in the sample, readings could be impacted by the type of lighting in the lab. At this point in time, these tests were used by medical professionals within medical institutions. To know how their treatment regimes were working, individual diabetics would have to come to a hospital, clinic, or lab for monitoring. The limitations to “visual monitoring” practices, whether using urine or blood, “became the trigger to develop an automatic, electronic glucose test strip reader to improve precision and give more quantitative blood glucose results” (Clarke and Foster, p. 86). Additionally, the data generated by such practices had to be recorded in a second medium in order for the data to be preserved. With more precise methods of determining glucose levels came the opportunity for the medical profession to develop more precise treatment methods.

**Digital Glucose Monitoring**

The first glucose meter patent was granted to Anton Clemens in 1971, and by the mid-1990s home glucose monitors were the norm in diabetes management, at least in the United States. The initial glucose monitors on the market depended on the “reflectometer” that Anton Clemens invented – and which formed the basis of the “Ames Reflectance Meter” (Newmann and Turner, 2005). Gebel (2012) explains how the “reflectance” method worked: “Early strips measured blood glucose by using an enzyme to convert the glucose in a
proportional amount of dye,” which would then be measured by detecting how much light was absorbed by the dye when the meter flashed light through the sample. The development of glucose monitors coincided with the development of the HbA1c test – which measures glycated hemoglobin in the blood (“Use of Glycated Hemoglobin and Microalbuminuria in the Monitoring of Diabetes Mellitus,” 2003). The HbA1c test measures glycated proteins in blood plasma, offering a look at the long term glycemic control in an individual (Koga, 2014). This allowed medical professionals to have a better overview of a diabetic’s overall glucose control, and the new forms of daily glucose monitoring allowed them to know more precisely patterns of glucose management on a day-to-day basis. The Ames Reflectance Meter, and the other glucose monitors that soon came into the market, offered individual diabetics the opportunity to monitor their glucose levels without needing to go to the lab.

Newman and Taylor (2005) identify Abbott Laboratories, Bayer Pharmaceuticals, and Life Scan as major players in the development and distribution of glucose monitors and associated diabetic supplies. These companies are still dominant in the sales of handheld glucose monitors. Abbott was key to developing the biosensors for the FreeStyle line of glucose meters, which today are marketed as "accurate, affordable" monitors that are sold in stores from Wal-Mart to Walgreens. Their test strips cost so little (allegedly under $20 for 50 strips) that a person would not need to be insured to be able to afford their supplies ("My Freestyle," 2016). Bayer originally introduced Dextrostix to diabetes care and currently sell the Contour Next line of glucose monitors (Newman & Taylor, 2005). Life Scan produces the One Touch Meter line – which is the brand I have used for most of my life. Newman and
Taylor (2005) highlight their FastTake test strips design, which "automatically pulls [the] blood into the test strip, so it is no longer necessary to target blood onto the top of the strip" as in the original reagent-based models (p. 2448). Newman and Taylor (2005) note that the biosensor technology that forms the basis for most glucose monitoring systems changed very little between 1980 and 2005, suggesting that "[m]eter companies have been very slow to introduce new technology and have relied on a strategy of putting existing technology in a new box" (p. 2449).

**Standard protocol for glucose monitoring.** As hard as it is to imagine now, given the central role glucose testing plays in current diabetes management, the medical benefits of home glucose monitoring had to be demonstrated to the medical industry through intense studies. Jarrett and Keen (1980) note that within the medical community, it “is widely accepted, though not yet proven beyond all reasonable doubt in man, that the better the blood glucose control of diabetes the lower the risk of diabetic complications” two years after the introduction of the reflectance glucose meter (p. 31). As an editorial (1980) in the Lantus journal describes the reactions to early studies of self-monitoring through the use of a reflectance meter:

To some this seemed a revolutionary departure while to others it was a logical extension of the doctor’s reliance on blood-glucose measurements in the hospital setting. An editorial made some far-reaching suggestions—that wherever possible patients should be taught to adjust their insulin doses on the basis of blood rather than urine glucose measurements... (p. 187)
As this quote suggests, the ability to self-monitor had serious implications for diabetes management as a whole, and necessitated a reevaluation of treatment options. Blood represented a more immediate bodily medium - given the way that the body breaks down carbohydrates into glucose, the levels of glucose in the blood provide a more accurate picture of how controlled a diabetic is in their management. By the time glucose appears in the urine, the body has been at dangerously high levels of glucose for several hours. The sooner a diabetic can see and treat high glucose levels, the lower their chances of complications. The blood-based reflectance monitoring system allowed diabetics to have this immediate knowledge for the first time.

As noted before, prior to these digital forms of glucose monitoring, it was thought to be a medical impossibility for Type I diabetics to achieve “normal” human blood sugars (Mendosa, 2000). The first monitors were not designed for individual use, however. Initially, doctors’ offices were the imagined market and the device was intended merely to help screen patients for high blood sugars (Mendosa, 2006). But demand for home glucose monitoring led to the production of the Glucometer by Bayer (“Timeline for Blood Glucose Monitoring,” n.d.). Within two years of the development of home-glucose monitoring machines, innovations regarding insulin regimes followed. Specifically, moving from a strict number of daily units to adjusting doses based on glucose readings became a viable method of treatment (“Home blood-glucose monitoring: Revolution, revelation, or rip-off,” 1980). While the new digital monitors offered both doctors and diabetics more precise knowledge of glucose levels, the memory of the meters was still so limited that paper journals were required to preserve
the readings. Diabetics were encouraged to track their glucose readings, insulin doses, as well as information regarding food, physical activity and other factors that influence glucose levels. For the first time, individual diabetics were able to both see and address their own health data in a meaningful way, and while medical records continued to be important, private tracking methods became more and more common. The first glucose monitors available to the public were extremely expensive, but the popularity of glucose monitoring led to the production of more cost effective models. I would argue that glucose monitors are the primary basis for the management of diabetes. Without knowing your blood sugar levels, it is impossible to precisely calculate the amount of insulin you need.

In order for glucose meters to be useful, it was necessary to teach Type 1 diabetics how to generate “their own blood-glucose profiles” in order to gain greater control over their glucose levels and especially to guard against low blood sugar, or hypoglycemia (Walford, Gale, et. al, 1978, p. 732). Hypoglycemia results when the blood sugar drops as a result of too much insulin. In non-diabetics, the body self monitors and maintains a balance, but in a diabetic body, this ability to self regulate is faulty. If I have to choose between the possibility of a high or a low blood sugar, I err to the side of high, as low blood sugars are more immediately deadly.

Prior to blood-based glucose monitoring, catching a low would be a matter of identifying bodily sensations - feeling shaky, confused, hot and frightened - and reacting accordingly by eating something or consuming some fast acting glucose. However, as the physical symptoms for hyperglycemia, or high blood sugars, are similar - shaky, ill,
frightened - but requires the opposite treatment in a dose of insulin, the ability to differentiate between these two physical phenomena was a major breakthrough for diabetics. Because low blood sugars did not involve ketones, urine tests were useless in determining hypoglycemia. Indeed, even if glucose testing using a blood-based method was suspect at first, it was common knowledge that “urine tests provide only a "guesstimate" of the blood-glucose and may be directly misleading” (“Home Glucose Monitoring,” 1980, pp. 187-188). The use of reflectance monitors to analyze blood samples allowed for diabetic patients to see their own patterns and work to improve them. “Self-monitoring” became an option, and treatment became more precise. Walford, Gale, et. al (1978) suggest that

Unlike the measurement of the HbA1c, which only detects poor diabetic control, self-monitoring also shows how to improve it. Patients found self-monitoring to be more informative than urine tests; their active involvement in the management of their disease resulted in better motivation, greater understanding of diabetes, and a sustained improvement in control. (p. 782).

The use of self-monitoring via digital technologies allowed for a more active, knowledgeable diabetic subject, and a safer one. With greater knowledge, however, comes greater responsibility. With the ability to test blood sugar, the practice became standardized.
Table 2.2. Standard Protocol

<table>
<thead>
<tr>
<th>Name and Date</th>
<th>On Rising</th>
<th>1 hr after breakfast</th>
<th>2 hr after breakfast</th>
<th>Before Lunch</th>
<th>1 hr after Lunch</th>
<th>2 hr after Lunch</th>
<th>Before Tea</th>
<th>1 hr after Tea</th>
<th>2 hr after Tea</th>
<th>Before Retiring</th>
<th>During Night</th>
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</thead>
<tbody>
<tr>
<td>Time of Blood Test</td>
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<tr>
<td>Blood Sugar</td>
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<tr>
<td>Urine Test</td>
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<tr>
<td>Portions of Food</td>
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</tbody>
</table>

The chart above (adapted from Walford, Gale, et al., 1978) represents the “standard protocol” for glucose monitoring that was developed when home glucose monitoring became available. The study that produced this protocol was attempting to see just how much better diabetic control could be when the patient could track and see their own glucose results and make treatment decisions accordingly. In order to gain as complete a picture of glucose patterns as the hand-held monitor would allow, testing pre- and post-meals was key, particularly in determining the efficacy of insulin doses over time. Testing during the middle of the night was necessary to establish a baseline of how well the management regime is working. To elaborate, a reading of 230 at 2 am would show that something was wrong with the daily
regime and the basal dose of long acting insulin, whereas a reading of 120 at 2 am would demonstrate that the insulin and dietary practices are working well and the blood sugars are under control because the basal dose was correctly calculated. As the chart shows, at this early stage, urine testing for ketones was still an important part of day-to-day diabetic life, and in the transition to glucose monitoring as the primary monitoring method of achieving better control, urine tests acted as a calibration technique. Due to the inconsistencies of the early reflectance meters, using a urine test “provided a simple method of estimating the renal threshold” (Walford, Gale, et al., 1978, p. 733). The information recorded in such a table would allow the individual to chart their readings over time and see larger patterns. Despite the concerns regarding the accuracy of the glucose meters in their study, Walford, Gale, et al. (1978) concluded that using a glucose monitor had “distinct advantages over other methods of monitoring diabetic control. Spot urine tests are convenient but unreliable if the renal threshold for glucose is higher or lower than normal,” in addition to blood tests and the information they generated ‘making sense’ to the patients (p. 734). The patients that Walford, Gale, et al. (1978) observed were able to use their blood-glucose profiles to detect “poor control” and to correct it.

Precision in glucose monitoring is therefore of the utmost importance to effective diabetes management. The development of biosensor technology allowed for glucose monitoring to become more precise than the reflector-based meters. Today, the test strips used in handheld glucose monitors are small and flexible, and contain small sensors that allow for more accurate reads on glucose levels than reagent strips. These sensors transmit
data from the blood samples to the processors within the glucose monitor and result in a reading of glucose levels. Specifically, sensors that allowed for plasma calibration resulted in more precise meters, primarily because they allowed medical professionals to "compare the results obtained from a meter with results from the laboratory" - most specifically the A1C test (Newman & Taylor, 2005, p. 2451). The biosensors used in glucose monitors made up “approximately 85%” of the world’s biosensors in 2004, and continue to dominate the global biosensor market (Newmann & Turner, 2005). Chansin (2015) estimates that "printed disposable blood glucose sensors" (or test strips) "generate $6 billion of revenue” annually.

The most common method of creating the biosensors contained in each test strip is “screen printed carbon electrodes” (Das, 2014). Chansin (2015) notes that printed biosensors are "made on plastic substrates, offering the advantages of mechanical flexibility, thinness and lightweight." These features led to smaller glucose monitors as well as test strips and paved the way for wearable glucose monitoring technology. As early as 1982, researchers experimented with what they termed "affinity sensors" to improve glucose monitoring and the eventual goal of developing implantable sensors, utilizing optical technology to break down the different proteins and plasmas in the blood to gain an accurate glucose reading. They concluded that while implantable sensors were feasible, more work was required to achieve the proper calibration and to miniaturize the technology for wearable devices (Schultz, Mansouri, & Goldstien, 1982). The first constant glucose monitor became commercially available in the late nineties and are growing in popularity, given the ease of connecting the device with smart phone technology.
Just as digital technology revolutionized glucose monitoring, networked technologies expanded the types of storage options possible for the data generated. Clarke and Foster (2012) note that the first glucose meter with data storage capabilities was called the Glucometer M, released by Ames in 1986. These storage capabilities were very limited, however, no matter the model. The first glucose meter I used was the One Touch by Lifescan, which could only store up to roughly a week’s readings at a time. This necessitated a secondary record on paper, similar to the chart of the glucose protocol above. In 1997, companies like Bayer released computer programs to allow users to download their meter data (Clarke & Foster, 2012). This greatly expanded the digital storage of glucose data, but at this point in time, paper journal records were still the norm. Over the years, digital memory in the glucose monitors themselves has improved incredibly. My current model, the ContourNext, holds up to six month’s worth of reading without needing to connect to a computer. I have stopped using paper journals in my everyday life almost all together. I will return to these personal practices more explicitly in the next chapter.

Constant Glucose Monitors, while obviously monitoring the body’s glucose levels, have some key differences to the standard glucose monitoring technology that relies on using blood. First of all, CGMs are comprised of three main components: the biosensor inserted into the “interstitial space” under the skin, where, surrounded by fluid, it reads the glucose concentration in the fluid via an enzyme glucose oxidase and breaks down the glucose to create hydrogen peroxide...

[which] then diffuses to a base metal layer where it’s oxidized and broken down into
hydrogen oxygen and electrons which we measure as a current... which is proportional to the person's glucose concentration. (Moastrototaro, 2011, 1-1:53).

The second component is the transmitter which attaches to the biosensor and sends the glucose readings to the receiver device, or the third component, via Bluetooth.

Figure 2.1. Pictured: The DexCom G5 transmitter (bottom right) and sensor inserter

The receiver device displays the most current glucose reading and also a chart of the most recent twenty-four hours of readings. As I noted in the chart above, the primary value of a CGM is not to provide information regarding insulin treatment, as the interstitial fluid is less precise in terms of immediate glucose level compared to meters that use capillary blood. In fact, given the unreliability of glucose levels in the interstitial fluid, the FDA only cleared certain CGMs for use in making treatment decisions in late 2016, meaning that the user must
continue to test with a blood-based monitor in order to determine insulin dosages. However, as the table indicates, the CGM has very high Management value for the user because of the stream of data the CGM provides. An instructional video for the Medtronic CGM explains, “with CGM the focus is not on the number but on the trends. Knowing the speed and direction [of] glucose movement is more useful than individual values” (“Why sensor glucose won’t always match your blood glucose,” 2014, 2:11-2:21). By charting the trends of the glucose levels, the user is able to see overall patterns in daily blood sugars, as well as being alerted when sugars are trending too high or too low via the receiver device. The receiver shows the user both the most current glucose reading, but also whether glucose levels are trending upwards or downwards.
As the screenshot above demonstrates, the CGM receiver (in this instance the DexCom G5) shows the user several specific things: first, the number in the circle represents the most recent glucose reading. The border surrounding the number also indicates what direction the glucose levels are trending via the smaller triangle on the right side of the border. At the moment of this particular screenshot, the glucose levels are trending steadily within a normal range. At the bottom of the screen, there are two lines: yellow is the upper limit of ‘normal’ glucose ranges and red denotes the lower limit of ‘normal,’ meaning that any level that goes above or below would require some sort of response and the device alerts the user accordingly. The smaller dots in between the lines represent the time stamp and level
of each glucose reading. To provide more context, on this particular day, my blood sugars were running a little high for a morning reading (roughly 150 mg/dl around 7 am, right before breakfast and after a night of fasting), and there was a small spike following the morning meal which began to trend downwards again around 8:30 am. This downward trend represents both the workings of the digestive process as well as the peaking of the fast-acting insulin dose I gave prior to eating breakfast. My sugars as of this particular moment have reached the ‘baseline’ reading prior to breakfast, demonstrating that while I could tighten my control to get a lower baseline (probably by adjusting my long acting insulin basal dose), my breakfast dose of insulin was correctly measured.

To come to a similar approximation of glucose trends with blood based monitors, the user would need to follow a protocol similar to the one above provided by Walford, Gale, Allison, and Tattersall (1978) to help their patients create glucose profiles - and such a profile would require multiple glucose tests both before and after meals as well as in the middle of the night. In fact, at my most recent doctor’s appointment, I was given a similar protocol log, printed in 2013, showing that such a method of monitoring is still a common option, in part because CGMs are not as widely used as blood based monitoring. Even so, such tests could not show whether the levels are trending up or down without multiple tests within a short amount of time. For example, if I were to test my blood sugar after a meal and it was in the high range (not unexpected), I would have to test again in half an hour to see if the levels had continued to climb or if they were falling back towards normal range. In comparison, CGM technology, through the constant collection of glucose levels, allows the user to easily see
that data, and using software associated with specific CGMs, the user is able to visualize a variety of information. As an example, I have provided a data-collection from my use of a DexCom G5 Glucose monitor, taken from the DexCom Clarity software. The data below from my DexCom G5 is uploaded to the DexCom cloud and can be accessed via the DexCom Clarity portal.

![Figure. 2.3. My Best Glucose Day](image)

This chart provides the readings for my “best glucose day” within a specific 30-day period. Again, the yellow and red lines on the graph denote high and low limits. On Tuesday, May 10, 2016, I remained within these limits except for one mid-morning low at around 10 am (perhaps due to an overzealous morning insulin dosage) and one after-noon high at 1 pm (most likely due to a lax insulin dose with lunch). The little gray circles with “C” represent
calibrations where I entered glucose levels from a blood test with a regular glucose monitor. The DexCom Clarity site allows the user to look for trends within their collected data, as well as examining specific periods of time both through charts like the one above as well as comparing two specific days. The Clarity site also provides an estimation of the user’s A1C levels based on the data collected over a three-month period. The use of “estimation” in this context is key, because as noted above, the CGM does not provide the most precise readings of glucose levels, but is instead a tool to see overall trends, both within a specific moment as well as over longer periods of time. In my experience, CGM devices tend to lose precision when glucose levels go above or below the parameters of ‘normal’ glucose levels, and often require re-calibration using a blood-based glucose test as demonstrated in this screenshot:
Figure 2.4. Screenshot from June 3, 2016

As you can see, once the glucose readings captured by the CGM go above the “normal” range, the screen turns yellow to alert the user to slow down and take some insulin (I imagine). Of note here is the abrupt drop around 2 pm. To explain, once I got the alert that my sugars had gone above 250, I watched my sugars trend steeply upwards and realized I miscalculated my lunch insulin, and so gave myself some extra units to compensate. However, the glucose levels kept trending upwards, so I took a blood test to see if I needed to
take more insulin. While the CGM reading was 330 (which is extremely high), my blood test only showed my levels at 263 (still high, but only slightly out of the ‘normal’ range). When I entered this lower glucose reading into the CGM, the CGM adjusted to account for the more precise reading by the blood-based monitor.

Therefore, just as the various monitoring technologies I have described in this chapter vary in precision and use in managing diabetes, so too do different bodily fluids have varying levels of usefulness in achieving diabetic control. Here, I present the four types of bodily fluids discussed in this chapter and provide a focus on their use in managing diabetes from least to most precise:

Table 2.3. Fluids and Precision

<table>
<thead>
<tr>
<th>Type of Fluid</th>
<th>Monitoring Type</th>
<th>Level of Precision</th>
<th>Use in Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urine</td>
<td>Haptic, Reagent Monitoring</td>
<td>Low - only useful in demonstrating High glucose levels.</td>
<td>Demonstrates failure of control. (Glucose levels have been high for too long.)</td>
</tr>
<tr>
<td>Interstitial fluid</td>
<td>Biosensor, Wearable Monitoring (CGM)</td>
<td>Medium-High - useful in collecting data and visualizing glucose trends for the user.</td>
<td>Demonstrates control (or lack thereof) over time via trends and constant data collection.</td>
</tr>
<tr>
<td>Capillary Blood</td>
<td>Reagent, Biosensor Monitoring</td>
<td>High - by far the most precise method of home-monitoring a diabetic can use.</td>
<td>Provides specific data on glucose levels at a particular moment in time. Useful in calibrating CGM technology. Currently necessary in determining insulin dosages, allowing for the achievement of control via insulin treatments.</td>
</tr>
</tbody>
</table>
Table 2.3. Continued

<table>
<thead>
<tr>
<th>Type of Fluid</th>
<th>Monitoring Type</th>
<th>Level of Precision</th>
<th>Use in Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemoglobin (Red Blood Cells)</td>
<td>A1C Glycated Hemoglobin Test (Lab based)</td>
<td><strong>Very High</strong> - measures the levels of glucose in the hemoglobin over the past three months (the lifespan of a red blood cell)</td>
<td>Acts as a calibration for entire diabetic regime. A lower A1C level equals better control.</td>
</tr>
</tbody>
</table>

Despite the use and importance of glucose monitoring, particularly blood based monitoring, there are limitations to the technological processes. Glucose monitors can be influenced by drugs like acetaminophen (Tylenol) (a fact I learned to my dismay while taking Dayquil), environmental issues including humidity and altitude, as well as other operational and physiological complications (Tonyushkina & Nichols, 2009). Given the dependence on interstitial fluid, CGM technology can be derailed if the user is dehydrated. And while blood-based monitoring is currently the most precise way for diabetics to make treatment decisions, “pure blood” samples are also not the most precise sample of glucose levels because “glucose levels are unstable in whole blood” (p. 971). But without these imperfect technologies, diabetes would be an automatic death sentence as it was before the development of insulin. A history of diabetes and treatment necessarily is a history of the monitoring media that makes management of the disease possible. From haptic methods involving observation and sensory tests to today’s glucose monitoring, the technology available determined the production of knowledge and actions to create particular diabetic subject: one who performs the proper actions and maintains particular glucose levels.

**Control and the Diabetic Subject**
Matthew Davis (1998), in musing on the changes in diabetes care he had personally witnessed following his own T1 diagnosis, suggested that for diabetics, "one's identity [is] inscribed by medical knowledge" - particularly discursive formations of control (p. 69). While diabetes is often newsworthy, Davis argues that the disease is "seldom … investigated to reveal the manner in which both the disease and approaches to its cure reflect immediate changes in medical practices and general tendencies in biomedical control" (p. 70). He notes that diabetes rarely figures in discussions about biomedical control, both in the academic and popular realms, suggesting three possible reasons: first, that perhaps the populations most impacted by diabetes (the poor, the elderly, women) are not of primary interest to researchers and health professionals. Second, he notes the continued lack of a cure for the disease, and finally, he suggests that as a chronic disease, "diabetes negotiates the two discourses that dominate cultural studies approaches to disease – discourse about incurable diseases and discourse about formerly incurable diseases" (p. 70). Davis suggests that at the point he is writing, having had diabetes mellitus for six years, he has noted a "transition" from "a disease which was largely self-monitored to one which now calls for close interaction with an increasingly large group of medical professionals" (p 70). A closer look at the history of managing diabetes, however, demonstrates that the nature of the relationship between diabetics and medical professionals has always been necessarily close, and the introduction of monitoring devices changed how such a relationship is conducted. While I agree with Davis (1998) regarding the centrality of medical knowledge and biomedical control, I would posit that he is missing a key component in his discussion of diabetes and self-monitoring:
the importance of media in diabetes management. Specifically, as I have attempted to show in this chapter, the development of diabetic monitoring media have allowed for greater control over diabetes management for the individual, moving the primary onus of diabetic care from the clinic to the individual’s home. At the same time, the data collection and networked nature of many digital monitoring technologies means that medical professionals have access to a great deal of data on each patient.

Far from separating patients from the medical apparatus, Deborah Lupton (2014a) suggests that the digitization of healthcare allows the “medical gaze [to] extend well beyond the clinic...It is clear that health monitoring technologies and personal data are fixed as significant opportunities for digital developers” (p. 7070). In this sense, digital technologies appear to offer ‘solutions’ to health-consumers where digital technology and the data they generate are presented as providing users easy access to healthcare information and extending their knowledge about treatment options (Lupton, 2014b, p. 1347). Given the lack of a cure for diabetes, “solutions” via technology are the best that we can do at this point, and as this chapter demonstrates, the technology of glucose monitoring has played a crucial role in moving diabetes from a disease that can be survived to one that can be managed with a great deal of effort.

Kittler’s (2010) interest lies not in exploring how people experience media, but rather exploring media’s underlying, technical structures, in contrast to the user- and content-focused discourses (where the content of the medical devices improves the lives of the users) of the technological-utopianists Lupton (2007) describes. To recap, he defines the three
functions of technical media as the ability to “store, transmit, or process signals,” and argues that the computer is the “only medium that combines these three functions” (p. 25-26).

Kittler radically de-centers the human from media studies: arguing that the body itself can only be known through media – while media may extend the capabilities of the human body, they also offer “models and metaphors” for understanding human senses (Kittler, 2010, p. 26). In looking at glucose monitors, focusing on “process” (in terms of the various devices’ technical capabilities) rather than (human) “experience” of using them, Kittler’s model of media studies offers a model of “abstraction” in considering questions about current media formations. Glucose monitoring, from early forms of reagent sampling to the latest in CGM technologies, are designed to perform specific processes and generate specific data: in this case, translating the levels of excess glucose in the diabetic body into data that the patient can use to make treatment decisions. Treatment aside, glucose monitoring, especially CGM technologies, process biological samples, store (and display) the glucose level, and in the case of networked machines like a CGM, transmit that data.

Sterne (2007) argues that “technologies manifest a designed mechanical agency” – allowing for particular actions and cultural habits (p. 8). Further, “instrumentalization” allows us to understand “human senses” as “mechanisms” as well (Sterne, p. 58). This leads to understandings of the human body that allow for the interconnections between the body and technology, as well as the body and other material entities. In terms of monitoring glucose, the development of batteries, biosensors, and digital interfaces and code coincided with medical advances in identifying "problem areas" of the body. But just as important, the
shift in storage capacity from paper records to today’s cloud storage of CGM data played a huge role in how diabetes is understood and treatments have moved from rigid routines to more flexible actions based on glucose trends and data. To explore this shift in treatment practices, in the next chapter I focus on my own experiences with changes in glucose monitoring in a more autoethnographically focused examination of diabetes technology and its role in my own life.
CHAPTER 3:
Self Control: Dealing with Data

“The average diabetic patient is remarkably resilient and often manages his or her disease with great skill in the face of many difficulties. Anything which makes life easier or reinforces motivation ought to be welcomed by both the consumer and the doctor. Home glucose monitoring does have distinct advantages” (The Lancet, 1980, p. 187).

“Wherever data and world are managed, we find media” (Peters, 2015, p. 22).

“At about 6:30 am, the school day routine begins. Chelsea begins her day with an insulin shot and testing her blood sugar levels...” (The Hampton Herald, August 1998).

Technologies of Myself

I started using a glucose monitor, one of the earliest iterations of mobile media, nearly two decades ago – long before personal cell phones were common and pagers were associated primarily with doctors in emergency rooms (or drug dealers). My personal glucose monitor instantly became an indispensable accessory – without it I could not adequately gauge how well my insulin therapy was working with my new, strict diet. And it meant I had to learn how to extract my own blood multiple times a day. I only braved giving myself my insulin when my mother pointed out to me that I would never be able to go to a sleepover, or even back to school, if I didn’t learn to take care of myself. In addition to learning how to give myself injections and prick my fingers, my life changed in other, perhaps not so dramatic, ways. Previous to my diagnosis, carrying a purse was something I did to emulate my mother – a sign of a more grown up identification with femininity. Now, I had to make
sure I had access to my glucose meter at all times, as well as my insulin and all the associated supplies (test strips, syringes, alcohol swabs) and glucose tablets in case of an emergency low blood sugar. My personal well-being now depended on a variety of new technologies, techniques, and practices of self-management, or what Foucault (1973) terms “technologies of the self” (p. 225). In this chapter, I use a Foucaultian approach to examining specific processes of subject formation that are enacted through diabetic monitoring technologies. My personal experiences serve to highlight how these processes function and provide a context from which to understand and discuss the production of the “diabetic subject.” This chapter also seeks to examine how diabetic monitoring technologies fit into discussions of role technology plays in healthcare and the uses and values of personalized, digital health data.

Foucault (1973) discusses how the concepts of “know yourself” and “care for yourself” have been inverted from their original relationship in Greek philosophy – where knowledge “appeared as the consequence of the care of the self” (p. 228). Given the personalized monitoring devices available today, “knowing yourself” can now include a variety of data, but how that data can be used varies. And such technology is being geared towards everyone, adult and child. For example, the Octopus Watch, currently on Kickstarter, promises to teach children “good habits and the concept of time,” fostering “independence, responsibility and self esteem” (“About this project,” 2016). The technology becomes a method of teaching and moderating “good behavior.” The overall goal of the Octopus Watch project is to revolutionize family time for parents with “no more stress, no more power struggles, only precious moments spent focusing on what really matters: quality
family moments,” which seems like a lot to ask of a watch. However, this kickstarter project exemplifies what many people imagine technology can do in terms of reshaping our lives. Within many current discussions regarding the potential for digital media to specifically revolutionize healthcare, knowing more is equated to being healthy. In a recent Ted Talk, statistician Talitha Williams encourages her audience to take “ownership of your data” through various daily measurements (temperature, weight, etc.) to “become the expert on your body. You become the authority” (Williams, 2014, timestamp 15:18). Her presentation finished with her leading the audience in a chant of: “Show me the data!”

How nice, I thought sarcastically, watching the video of her earnest presentation, how nice for your self-monitoring to be a choice. At the most basic level, diabetes mellitus changes how I interact with the world around me – from physical reactions and feelings to emotions as well as the numbers and other information generated by various monitoring technologies. Knowing my data, in other words, is not an interesting personal choice, but a necessity. The more I know, the better care I can take of my “self.” Data generated by digital glucose monitoring becomes an indispensable method of self-knowledge. Foucault (1963) discusses the changes that the development of the clinical system of medicine made to the concept of the patient, specifically the “possibility for the individual of being both subject and object of his own knowledge” (p. 197). In discussing the “objectivising of the subject,” Foucault (1982) describes what he terms the “dividing practices” that operate to ‘objectify’ the individual “inside himself or divided from others” (p. 777-778). In my case, my diagnosis immediately ‘divided’ me into the ‘diabetic population.’ Internally, I now had to monitor
myself to gain control over my body’s unruly functions, and externally, I was now obviously
different from my friends and classmates.

As a middle schooler, carrying around a small digital device was odd and unusual.
Pricking my own fingers and testing my blood for my glucose levels was even more so. Once
I convinced a classmate I was a drug addict to amuse myself – between my glucose
monitoring and my insulin, I exhibited enough familiarity with needles that he believed me
(for a short time). Drug addiction was more recognizable or familiar than diabetes, even
though the community I was a part of was small and this classmate had probably prayed for
me when I was in the hospital prior to my diagnosis. Given that I had to test my blood at least
15 minutes prior to a meal, there was no real discrete way for me to test my blood in private
while I was at school. Fifteen minutes before the lunch break was during class time – and it
was simpler to merely attempt to quietly prick my finger and perform the test towards the end
of the class period. The primary reaction from my peers to my blood tests were statements
about how gross the process was; blood is nasty after all.

To help my siblings, classmates, and teachers understand, my parents encouraged me
to perform glucose tests for them using my machine. (And a clean needle, of course.) Despite
the “gross” factor, most of my classmates were eager to try. However, they discovered they
felt terribly frightened of the needle I used to prick them. They shrieked and flailed their
hands – and decided that I was very brave to have to do this to myself, even though it was
still gross that I had to use blood. As I grew more comfortable (read: less concerned with
following the rules strictly), I began to push off testing my blood until I could do so alone,
even if it was fewer than fifteen minutes before I ate. I had to be brave and prick my finger; I preferred to do so in private when possible.

**Digital Revolutions in Healthcare**

Today, most personal technologies such as mobile phones have health monitoring components, and health technologies such as FitBit and Apple’s iWatch are lauded as novel ways for individuals to take greater control over their own health. From calorie trackers to monitoring the wearer’s heartbeat, these technologies are geared towards helping individuals lead healthier lives. In this vein, the premise of Erik Topal's (2015) most recent book *The Patient Will See You Now* is straightforward and simple: he argues that smart phones have ushered in a “new model” of democratized, patient centered medicine (p. 4). Via smart phones and tablets, we now have access to apps that are, according to Topal, “more accurate than most doctors” (p. 4). In his view, doctors are too often obstructive; patients are kept out of the loop in matters of their own medical treatments and information. The digital age will allow individual patients to take control of their own medical information – information that is “eminently accessible, analyzable, and transferrable” – all without a medical professional acting as an intermediary (p. 4). Topal’s arguments reflect what sociologist Deborah Lupton’s (2013) terms “techno-utopian discourses” (p. 256). Lupton notes that similar claims about technology in medicine have been around since the 1970s and generally focus on the “patient as consumer” – where digital technologies become a way for patients to become active participants in their medical care (p. 256). Such claims are a part of a longer history of what Carey and Quirk (1989) call the “technological sublime” – or the belief that
technology provides salvation from social ills. They trace this attitude from the printing press through the development of digital technologies, noting

Despite the manifest failure of technology to resolve pressing social issues over the last century, contemporary intellectuals continue to see revolutionary potential in the latest technological gadgets that are pictured as a force *outside* history and politics. (1989, p. 191).

Prefacing his first chapter with a quote from Marshall McLuhan, Topal presents digital medical technology as an unprecedented triumph over the inequities of the medical industry. However, Lupton (2014b) identifies “three waves of digital technology adoption” in specifically in healthcare (p. 707). The first two waves, in the 1950s and 1970s, had an emphasis on “establishing systems for more efficient data management and processing” (p. 707). The third, current wave, moves digitization beyond medical institutions to create “an overarching framework that incorporates data” both from within the healthcare system and other actors (p. 707). This wave encompasses the type of digital interactions that Topal describes – although it is important to note that the data that individual patients now have access to do not exist for the patient alone. The framework that Lupton refers to here incorporates data generated via the apps Topal discusses. These processes do not simply serve the patients’ individual knowledge but also the very institutions and professionals that Topal wants digital media to replace.

The improvements to medicine and individual control and knowledge that Topal (2015) presents is relentlessly optimistic: he does not question the potential downsides of
“terabytes of data about you” being available, nor to whom this data will be available, instead focusing on the “democratizing” of medicine (p. 4-5). Not surprisingly, this book has generated a wide variety of responses. Some, like Sandeep Jauhar (2015), laud Topal’s audacity as a visionary. In his review of the book for the New York Times, Jauhar suggests that the digital “insurgency” in the medical realm “couldn’t happen soon enough,” agreeing with Topal that “healthcare has been stymied by paternalistic restrictions on patient involvement.” Also writing for the New York Times, Abigail Zuger (2015) takes issue with Topal’s premise that digitizing healthcare is solely empowering of patients. Among the criticism she levels, Zuger points out that privacy is of huge concern, especially for such sensitive information as medical data, given that all digital data is at risk of security failures. Further, she argues that “medical care is considerably more than data management” – information is not the only, or most important, factor in considering digitizing health care. John Durham Peters (2015) notes that our current “boom in data, much of it proprietary, does not necessarily mean an advance in democratic control,” particularly as the processes through which digital media collect, store, and transmit data are often “cloaked” from users (p. 7). However, Topal’s (2015) arguments have clearly struck a nerve, both within medical contexts and in popular discussions. I would add another criticism: what data can these digital devices generate, and what can that data “do” in terms of improving an individual’s health? In an era when “wearable tech” is becoming more common, it is important to note that there are distinctions between “health” related devices and “medical” devices. Trackers such as Apple’s HealthKit and my Constant Glucose Monitor both generate data, but my
CGM is a medical device that has a specific purpose and has gone through a vastly different approval process for consumer use. The CGM also generates data that is immediately necessary to my diabetes management.

One key difference between technologies like the FitBit and the glucose monitor is that many of the “wearable” health related technologies are concerned with primarily with “fitness.” However, Rosenbaum (2015) recently noted that information from a FitBit, while of interest to the individual wearing the device, often provides their medical professionals with little to no useful information about their actual state of health. As Herz (2014) points out, many of these health applications and wearable technologies are not designed for individuals with a chronic illness, but rather are more concerned with individual fitness. The assumption underlying these applications being that if one is fitter, one is healthier. This negates the need for technology companies interested in creating health related applications to deal with the FDA or other regulators that deal with medical specific devices. The FDA differentiates between Mobile Medical Apps (MMAs) that make “generalized” claims regarding health and fitness (for example, weight tracking) and strictly medical devices that make “specific” claims related to particular diseases or conditions (such as glucose monitors) (Dolan, 2015). The fifty-three wearable devices that Vandrico, a company that specializes in developing wearable tech, classifies as “medical” devices range from running equipment to fertility tracking via monitoring temperature, falling into the FDA’s MMA category and requiring less oversight by government regulators (“Devices used for Medical Application,” n.d.). A key feature of most of these MMAs is that they often rely on data that can be
gathered via contact with the wearer’s skin or via motion sensors, or via the input of information from the user (such as calorie counts). In contrast, glucose monitors (and other specifically medical technologies) require a more invasive process – a more intimate relationship with the user (or wearer).

This might explain why, even though all forms of diabetes (Type I and Type II, as well as gestational) require a plethora of monitoring practices, both personal and increasingly digital, diabetic monitoring technologies rarely figure in discussions about medical technology. Glucose monitoring falls into the more strictly regulated category of medical devices. Topal (2015) discusses diabetes primarily in terms of the possible genetic components of the disease – identifying, monitoring, and possibly “correcting” issues in the genome rather than looking at the ways in which diabetics use various digital technologies, not to replace their doctors, but to simply function in a way that approaches ‘normal’ or ‘healthy’ in everyday life. Likewise, Brown and Webster (2004) do not include diabetes in the index of their book New Medical Technologies and Society: Reordering Life, despite discussing the implications of individual monitoring technologies and changing social and cultural norms. They describe “GRID’-based medical devices, including mobile sensors placed on people … to relay information automatically to a central clinical sight on a daily basis – what might be termed an ‘e-panopticon’ for medicine” (Brown & Webster, 2004, p. 1-2). While this is an excellent description of glucose monitoring (even though CGMs are a fairly recent phenomenon, glucose monitors have been paired with computer programs since the early 2000s), glucose monitors are not even acknowledged. Indeed, at the bare minimum,
a diabetic needs a blood-based glucose monitor, and with the proliferation of networked technologies, options for viewing, tracking, and recording glucose data have increased.

**Digitizing Diabetes**

In addition to glucose monitors, diabetes related apps are becoming more popular as they allow users to enter and track their glucose readings, insulin dosages, and dietary information for their own information as well as for their health care providers. Ganguly (2015) notes that as there are more than 350 million individuals dealing with diabetes globally, digital technology can be invaluable, particularly in places with fewer medical personnel – and showcases Diabeto, a start-up based out of Mumbai and New Jersey that seeks to offer diabetics digital tools tailored to their disease. Diabeto is a digital device that “can be plugged into a wide range of glucometers” and is able to transmit data and readings to a mobile app which “uploads and stores diabetes data on cloud” which is then accessible to patients, their family, and medical professionals. It offers a similar set of services as the DEXCOM app, although Diabeto uses and Android-based operating system while DEXCOM uses an IOS operating system. This is the digitation of practices long used to record and manage diabetes, as diabetes has always required multiple modes and media of management, as I discussed in chapter one.

The digital apps mentioned above, and even those that work in connection with the DEXCOM and other monitoring devices depend on the data mediated by glucose monitors – data that requires invasive bodily procedures. For example, I use an application called Insulin Calculator – which, rather unsurprisingly, helps me calculate how much insulin I need to give
with each meal, based on blood glucose readings and how many carbohydrates I am planning to consume. The application then uses an algorithm to calculate my dosage based on the blood sugar reading, carb count, and the parameters of my insulin sensitivity, set by my doctor. I have a 1 unit of insulin to 3 carbohydrate count (at breakfast) and 1 unit of insulin to 4 carbs for later meals, with a sensitivity factor of 30 and a target blood sugar of 120. The app also has the capability of exporting dosages to compatible apps that track and record glucose readings and insulin doses. (I have never utilized this function, however, because unless my doctor tells me to record something I don’t bother.)

![Insulin Calculator Screenshot](image)

Figure 3.1. Screenshot of Insulin Calculator from June 7, 2016
As useful as this application is (I use it multiple times a day, and it is indispensable to my intensive insulin therapy), I had to set the initial parameters for calibration, and each time I use the app I need to input the values for carbohydrates and latest glucose readings. Both values are optional in that if I just input my glucose reading, or just input a carb count, the app will still calculate me an insulin dose. But to get a truly effective insulin dose estimate, I need both pieces of data. The carb count can be more or less precise - if I am cooking at home and can read the packaging of the food I want to eat I will have a better insulin ratio; if I am out and have to estimate the carbs, I will learn whether or not my efforts were successful based on my next glucose reading.

As for the glucose reading, at present there is no non-invasive way to obtain this information with the precision necessary to calculate insulin treatment. In March 2015, Google was granted a patent to develop a glucose monitor in a contact lens through its biotech research division called Verily Life Sciences (US Patent No. 2015/0061837 A1, 2015). The idea behind this potential monitoring system is to develop a “reader for communicating with both an eye-mountable device and a display device” that “includes a sensor configured to obtain measurements related to glucose in tear film” (US Patent No. 2015/0061837 A1, 2015, p. 1, 26). One could argue that this wearable technology is still ‘invasive’ in the sense that it must be worn at all times, but the fluids the device would read do not need to be extracted in the same way that blood does for the basic glucose monitor, or require a that a sensor be inserted under the skin like the Constant Glucose Monitor (CGM). But given the need for precision in data for diabetes monitoring, I personally suspect that
such a non-invasive technology would still need to be paired with older forms of glucose monitoring in order for diabetics to treat themselves appropriately. And in fact, experts in the medical field agree with me, although Google insists that its venture into glucose-sensitive contacts is a viable and near-future option for glucose management despite critics calling the project an “example of Silicon Valley arrogance” (Piller, 2016). A scientist named John Smith explained to journalist Charles Piller (2016) that glucose technology that relies on tears or other bodily liquids that do not require invasive procedures ultimately fail in terms of diabetes management because “[n]one of those fluids offers glucose readings that reflect the levels of glucose in blood.” As I discussed in the last chapter, the current most precise bodily fluid for glucose monitoring is blood, and not even a CGM can provide information that is reliable enough to calculate insulin dosages. Blood remains the most effective sampling system for managing diabetes. Monitoring and treatment of diabetes are imbricated processes that depend on a variety of medical, personal, and media related practices.

Given the growing popularity of self-tracking, and the glowing visions many have regarding the role technology can and should play in medical contexts, I ground this chapter in my own experiences of relying on digital monitoring for the majority of my life. Despite the apparent positivity surrounding Topal’s (2015) claims regarding the role technology can and should play in everyday life, Thacker (2004) points out that some forms of biotechnologies engender particular “cultural anxieties,” particularly regarding “genetic cloning, gene therapy, and bioterrorism” noting that the reportage of these issues formulate “a discourse of the body, and a discourse that articulates specific kinds of bodies” (p. 1).
According to Foucault (1994) discursive practices “are characterized by the demarcation of a field of objects, by the definition of a legitimate perspective for a subject of knowledge, by the setting of norms for elaborating concepts and theories. Hence, each of them presupposes a play of prescriptions that govern exclusions and selections” (p. 11). Discursive practices extend to and “take shape in technical ensembles, in institutions, in behavioral schemes, in types of transmission and dissemination, in pedagogical forms that both impose and maintain them” (p. 12). In choosing to employ an auto-ethnographic approach here, I seek to bridge the gap between the bright future Topal (2015) claims digital technologies will provide, and how such technologies actually function within the constraints and messiness of every-day life. As I mentioned in the last chapter, Greenhalgh and Swinglehurst (2011), in arguing for the inclusion of ethnographic elements in studies focused on the use of medical technologies, suggest that “[o]verall, the health informatics literature is hopeful and technophilic,” and technology is presented as able to “[a] incorporate (and thereby drive uptake of) evidence-based protocols and decision support; [b] overcome human failures and idiosyncrasies; [c] ensure that clinical information is more complete, accurate and accessible; and [d] improve efficiency of healthcare transactions” (p. 1). Glucose monitoring has indeed allowed for more precise treatment protocols, as well as helping individual diabetics to overcome bodily failure and achieve a semblance of normality. However, the success of glucose monitoring is embedded in a milieu of practices, and the individual diabetic bears a great deal of responsibility to manage their own health; presenting my own experiences will highlight how glucose monitoring “technologies and the humans who are meant to use them actually
perform under real, particular conditions of use” (Greenhalgh & Swinglehurst, 2011, p. 3).

As May and Ellis (2001) put it, “the introduction and implementation of ‘hard’ technologies (systems hardware) can be undermined in practice by conflict about the application of ‘soft’ technologies (the practices through which evaluative knowledge is produced)” (p. 989). Of course, there are measurable positives to telemedicine - such initiatives allow for cost-effective medical (tele)presence in communities or regions without other access to medical facilities. May and Ellis (2001) suggest that this has been a driving force in medical technology development. However, they push back against the idea that there is “a story,” a unifying, whole truth regarding technology in medicine available to researchers, making patient accounts valuable in evaluating how such technologies function in the day-to-day rather than relying on the bright promises or protocols set by industry experts. In exploring how technology and patients interact, Greenhalgh (2009) suggests an “ecological model” to frame the experiences of patients dealing with chronic conditions. In this model, the “informed patient” is supported by an informed healthcare team (including the use of technology) in dealing with “wider preconditions” such as the legal system, cultural norms and literacy regarding illness, support networks, and the individual’s “material conditions” (p. 630). In the earliest days of my diagnosis no one understood my tiny machine; nowadays, small personal technologies are more common. There is even ‘diabetic bling’ available - cool packs for carrying insulin and monitoring gear, tape for the CGM transmitter in interesting colors and shapes and so on. When I was buying my DexCom 4 receiver, I could pick the color I wanted in order to ‘express’ myself.
While personal mobile digital media are a social and cultural norm for much of the world, they did not spring from a void, fully formed. While many (if not most) of the health-related applications available for use with smart phones, tablets, and other digital devices seem like a logical extension of our bright digital future, I contend that this premise demands a critical examination, particularly from a media focused theoretical perspective. Diabetes is a disease that requires multi-modal, multi-media forms of management. The plethora of digital apps and claims like Topal’s that promise the digital will offer us something “new and different” threaten to obscure the story of diabetics as early adopters of personalized medical monitoring devices. This chapter seeks to build off the history of mediating diabetes provided in the last chapter within the context of wider social and medical practices as well as the specific context of my own history of diabetes monitoring.

**Specificity of the body/the content of a medium is always another medium**

As the previous chapter demonstrates, the advances in glucose monitoring were enabled by a variety of technological developments. However, it should also be clear that these advances were (and are) entirely dependent on the biological matter of the human body. McLuhan (1964) posited that ‘the content of a medium is always another medium,’ and in regards to glucose monitoring this statement becomes abundantly clear. In the earliest forms of sensory monitoring, physicians used their eyes and mouth and sense of smell to isolate the fact that the urine of a diabetic was discolored and overly sweet. The urine, then, acted as a medium for the inner bodily processes that were not functioning properly. Sensory diagnostics were able to determine that the urine contained excessive sweetness, leading to
the isolation of sugar. From there, it remained for researchers to isolate the sugar in the bloodstream, leading to reagent forms of chemical monitoring through to the biosensors in use today, both for ‘regular’ blood-based glucose monitors and for the CGM devices that monitor the glucose in the fluid beneath the skin. To reiterate, I have included this chart denoting the types of bodily fluids used in glucose monitoring from the previous chapter:

Table 3.1. Fluids and Precision

<table>
<thead>
<tr>
<th>Type of Fluid</th>
<th>Monitoring Type</th>
<th>Level of Precision</th>
<th>Use in Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urine</td>
<td>Haptic, Reagent Monitoring</td>
<td>Low - only useful in demonstrating High glucose levels.</td>
<td>Demonstrates failure of control. (Glucose levels have been high for too long.)</td>
</tr>
<tr>
<td>Interstitial fluid</td>
<td>Biosensor, Wearable Monitoring (CGM)</td>
<td>Medium-High - useful in collecting data and visualizing glucose trends for the user.</td>
<td>Demonstrates control (or lack thereof) over time via trends and constant data collection.</td>
</tr>
<tr>
<td>Capillary Blood</td>
<td>Reagent, Biosensor Monitoring</td>
<td>High - by far the most precise method of home-monitoring a diabetic can use.</td>
<td>Provides specific data on glucose levels at a particular moment in time. Useful in calibrating CGM technology. Currently necessary in determining insulin dosages, allowing for the achievement of control via insulin treatments.</td>
</tr>
<tr>
<td>Hemoglobin (Red Blood Cells)</td>
<td>A1C Glycated Hemoglobin Test (Lab based)</td>
<td>Very High - measures the levels of glucose in the hemoglobin over the past three months (the lifespan of a red blood cell)</td>
<td>Acts as a calibration for entire diabetic regime. A lower A1C level equals better control.</td>
</tr>
</tbody>
</table>

Just as the various glucose monitoring technologies I have described have specific memory affordances and technical capabilities, so too do the bodily fluids themselves
provide specific types of data and possess specific “memory” capabilities. The cells in bodily fluids act as media in the Kittlerian sense of the word by engendering particular forms of biological data storage and transmission processing. Urine stores longer-term data, while blood provides more immediate data in terms of day-to-day testing, and A1C testing of hemoglobin longer term data, but in a more precise way than the urine. All of these tissues store glucose data – glucose monitoring technology translates this data, stores and sometimes transmits the data depending on the network capabilities of the device. However, these technologies do not automatically collect glucose data; even with the CGM, the device must be calibrated using a blood test. All the glucose monitoring requires the individual to record or enter certain types of data, such as insulin intake, carb intake, exercise and sickness. In this they digitally recreate the early paper records that form the basis of modern diabetes management, extending both the capability of human memory as well as enabling the individual to self-monitor the bodily processes related to glucose levels.

In working on this dissertation, I have become more acutely aware of the role that self-monitoring plays in my own everyday life and the types of data I use, sometimes unconsciously, to make decisions regarding treatment. I use all four forms of glucose monitoring presented in the chart; my doctor performs the Hemoglobin A1C test every three months to see how well I am performing in achieving control. I recently started using a DexCom 5 Constant Glucose Monitor. I test my blood at least five times a day using a Contour Next glucose monitor. I keep ketone sticks to test for ketones in the case of illness or long periods of high blood sugars. All of these methods serve to validate or correct my
constant, often unconscious, proprioceptive self-monitoring. Extreme blood sugars elicit physical reactions - low blood sugars trigger dizziness, sweating, confusion, irritability and hunger. High blood sugars can also result in confusion and irritability, and for me, thirst and pain behind my eyes and tension in my back. My use of digital monitoring technologies affirms/denies/makes clear my bodily sensations by providing data about my glucose levels that are not obtainable by sensations alone. I literally cannot function without this technology if I wish to maintain tight control over my glucose levels. However, as I hope to make clear in this chapter, it is important to understand that my glucose monitoring devices are not completely automated devices of data collection: I must use them in specific ways and require specific knowledge to make decisions based on the data that they generate.

**The Logistics of Glucose Monitoring**

The need to test glucose levels structures my life in very specific ways. Currently, I test my blood at least four times a day, usually more. Rather ironically, since getting a CGM my blood tests have increased because I am obsessed with calibration (more on that below). Although my routine (particularly in regards to food) has become more flexible over the years with better insulin and more precise glucose monitors, I follow roughly the same pattern or protocol set down by my doctors when I was twelve. I wake up early in the morning, test my blood, give my morning insulin, and eat the same breakfast in order to attempt consistency in sugar levels. Throughout the day, I strive to balance physical activity and food with two different insulins: long-acting insulin to provide a baseline glucose level and short acting insulin to cover mealtime carbs.
Because my fast-acting insulin lasts for roughly four hours after injection, I try to space out my meals so that the doses don’t overlap and cause a low blood sugar, making sure my last dose of fast acting has had time to peter off before I give my evening dose of long acting insulin before I go to sleep. Managing these doses would not be possible without my glucose monitor(s) and associated digital apps. John Durham Peters (2015) points out that “[d]igital media serve more as logistical devices of tracking and orientation than in providing unifying stories to the society at large” (p. 7). He suggests that the logistical nature of digital media allow humanity to ground ourselves in “time and space, index our data, and keep us on the grid” (p. 7). Digital media therefore allow for the “fundamental tasks of order and maintenance” in society, with a particular emphasis on the proliferation of data and tracking (p. 8). Peters connects this with “infrastructure,” which he notes can be “large in structure, infrastructures can be small in interface...all of them gates to bigger and submerged systems” that undergird and make possible civilization (p. 31). Infrastructure is “invisible” because it is ordinary - social infrastructure of “basic categories and standards are formed” (p. 35). I see glucose monitoring as a gateway to bodily infrastructure - the interface of the monitor acts as the gate to the submerged and invisible biological systems within my body. By the same token, my monitoring devices are a gateway to the digital systems that store and transmit my biodata. These technologies are logistical media that provides me with important data and allows me to manage an incurable disease.

In addition to the meter itself, glucose monitoring requires a myriad other technologies and techniques in order to mediate glucose readings for a diabetic. In addition to
the glucose monitoring machine, you also need compatible test strips, for the handheld monitors, or a wearable sensor for the Constant Glucose Monitors. Basic glucose monitoring on a handheld meter requires the following: first, and most importantly, test strips for the blood sample – and the strips must be compatible with the machine you are using. Second, a lancet to prick finger – any finger except the thumb. Based on the calluses on my own hands, I tend to use my ring and middle fingers the majority of the time for testing. Pressure on the calluses on my pointer fingers can often be painful, and they do not provide blood easily. My pinky fingers are smaller and usually generate a lot of blood – but they are more sensitive and bleed longer. Despite being right-handed, I tend to use my left hand for pricking and my right hand for bleeding, perhaps because it is easier to maneuver the blood from my finger to the test strip with my dominant hand.

A “lancing device” that holds the lancet is optional, since you can poke the finger with the lancet alone, but I prefer to use a “lancer” because it is quicker and also I am rather squeamish when it comes to causing myself to bleed. These are usually fairly small and easy to use regardless of whether you use your dominant hand to operate them. You select the depth of the prick (based on how calloused your fingers are), cock the device, set it against the finger, and push the button to pierce the skin. The lancing device is a simple technology that makes glucose monitoring far easier – if I had to stick the lancet into my finger using my hand, chances are I would not test as often as I should. Even with the device to prick my finger, there are still times that I hesitate and think how it is a good thing I can’t actually see the needle moving.
Technically, you are supposed to use an alcohol swab to clean the finger before and after you draw the blood. At this point, almost nineteen years after diagnosis, I can honestly say the only time I do that is if a medical professional is watching me. Generally speaking, I poke my finger and use whatever is handy to clean off the excess blood – tissues, my tongue, or napkins. In the same vein, (pun intended) you are supposed to use a new lancet every test. I only change the lancet when it is clear to me that the lancet is dull. I determine the dullness of the lancet based on a few things: how many times I have attempted to prick multiple fingers and gotten no blood; whether or not I am cold, hot, or dehydrated; whether or not I feel like my sugars are low or high; trying to remember when I last changed the lancet and failing. Familiarity breeds contempt – and it is possible to become blasé about piercing your own skin multiple times a day.

Even though my routine has remained roughly the same since I was diagnosed, the data I work with each day has changed and become more precise and far-reaching with the development of glucose monitoring technology. While my own monitoring has relied primarily on a variety of digital monitors, I am always dependent on multiple media to manage my diabetes. As an example, the limited memory of earlier glucose monitor models meant that I needed to write down my sugars in a separate log book; currently I use both a blood-based glucose monitor as well as a DexCom 5 CGM. A mixed media approach to diabetes monitoring, if you will. Each method has its drawbacks, and none of them fully account for all of the information I need to make treatment decisions nor do they fully collect all pertinent data. In centering myself as an “informed patient” in Greenhalgh's (2009)
ecological model, I hope to sketch out a snapshot of how diabetic media function within my “wider preconditions.”

**Limited Storage, Secondary Memories**

When I began to write this chapter, I could not initially remember when I was given my first glucose meter, the Onetouch Basic. I assumed I received it at the hospital before I was discharged to go home. My parents remember more of the early days than I do. For me, it’s all hazy and confusing. According to my mother, following my initial diagnosis, the medical personnel at the hospital expected me to come back each day for my insulin shots. The only reason they let me learn to inject myself, my mother remembers, was because she herself was a nurse and was competent to teach and monitor me at home. Most Thai patients at that time came back to the hospital twice a day for their insulin because otherwise, the doctors told my parents, they wouldn’t take their medicines at all and relapse into ketoacidosis. There were no glucose monitors available for home use in Chiang Mai, Thailand, in 1997; my parents had to have one sent to us from friends in the States. Initially, the insulin options were limited also; in fact, Thailand was about 20 years behind in diabetes management practices and education compared to the United States. My initial endocrinologist was the only pediatric endo in Northern Thailand, and her knowledge of diabetes was limited to what she had learned in medical school decades before. To deal with the lack of insulin options, my parents’ friends would carry my insulin for me when they traveled from the States to Thailand. Eventually, my dad remembers, one single pharmacy in the Night Bazaar began to stock newer insulins from Bangkok, just for me. “They carried
them up from Bangkok in little cooling pouches,” he told me. By that point, my mother added, glucose monitors were more readily available too, and so were test strips. I remember that pharmacy; it was above the Burger King in Chiang Mai Plaza. We would go once a month after night church to pick up my supplies.

My One Touch Basic was large and bulky and took about 45 seconds to test the blood sample. The strips it required were thin rectangles of plastic with a strip of reagent paper and a circle that the user had to fill with blood. Although I did not understand reflectance technology at the time, I did notice that when I turned a used strip over, the back would be stained a shade of blue-purple. The whole circle on the top of the strip had to be covered with the blood sample, otherwise the test would fail. Sometimes, if I was quick enough, I could apply more blood to the strip before the final five seconds (there was a light that flashed below the strip) and the test would work. Otherwise, I would have to start the whole process again, from finger prick to wait. Given my limited access to test strips, I had to be especially careful in order not to waste a test.

The strips came in batches with specific codes – if I failed to make sure the code on the monitor matched the code on the strips, the test would be less accurate. These codes were to identify “quirks” within a specific batch of test strips for the meter to increase reading accuracy (Gebel, 2012). The test strip had to be inserted into a plastic “holder” above the reader, where the light was reflected through the sample. This piece was detachable from the rest of the machine, in part because this model required regular cleaning to maintain precision. If the holder was not attached to the machine properly, the monitor was unable to
get a proper read on the blood sample’s reaction to the strip. The One Touch Basic/II owner manual explains that “certain compounds on the test strip react with the blood to form a blue color. The OneTouch® Basic® Meter reads the color to determine the blood glucose level” (2003, p. 8). In other words, this model relied on the reagent strip technology of the early glucose monitoring systems, and the technical capabilities of the processor were similarly limited. The machine also had the capability to give me warnings if my blood sugars were too low or too high by flashing the message “DANGER CALL.DR” (One Touch Manuel, p. 2).

Figure 3.2. One Touch Basic Image taken from the site “Texting my Pancreas”
I no longer have my own original One Touch model, but the image above shows a very similar model that gives an idea of what the interface looked like. The strips were inserted in the grey holder underneath the half-moon shaped one button. The screen that showed the readings looked similar to a basic calculator. It was not a beautiful machine, and I was often embarrassed to use it.

In terms of memory storage, the One Touch Basic model could store "up to 75 results with time and date" (Manual, p. 82). With four tests per-day being the basic requirement of my regimen, this device could only store about 18 days worth of readings. There was a data port on the side of the machine, but I never received any information about how to use any related computer programs. (I suspect that I had not even received the original owners manual as it came from the States and my mom showed me how to test my own blood). As my doctor’s appointments were every six months, this particular model necessitated a secondary memory bank: a written "glucose log" that I was supposed to fill in whenever I tested my blood. My doctor would give me a new logbook every time I visited her. This log was very similar to the glucose profiling protocol outlined in chapter one. Sometimes I would lose the official log and make do with a regular notebook, but I was supposed to include the relevant information: glucose reading, carbohydrate count (if a meal was involved) and insulin dose. Often I would go for days without recording my readings; then I had to “remember” and write numbers for the record. To give the impression that I had been keeping the log correctly, I would switch pens for different ink. Sometimes I would even smear blood on the pages to provide an impression of immediacy in my recording practices -
if there was blood on the record, I must have been recording right after a test. As might be expected, this was rather useless in terms of accurately monitoring my disease from my doctor’s point of view.

I migrated from the One Touch Basic to the One Touch Ultra around 2001 – we came back to the United States for a few months out of worry that Y2K would disrupt things so much that I wouldn’t be able to get my imported insulin and testing supplies. I was amazed by the improvement in glucose monitors. The One Touch Basic had been large and bulky, about the size of my hand. The One Touch Ultra was sleeker and smaller, about the size of my palm. It was adorable. John Durham Peters (2015) notes that “[t]echnologies are never only functional: any device always has an element of social display or ‘bling’” (p. 36). The marketing slogan for this model was “The Comfort of Control,” and besides a reduction in size, the One Touch Ultra had a larger digital display, with more information available to me as the user. In terms of memory, the Ultra could “recall up to your last 150 test results,” or a roughly a month’s worth of readings if the user tested the recommended four times a day (Manuel, 2003, p. 33). In addition to the extended memory, the machine also offered 14 and 30-day averages, as well as a data port to connect to a computer to download the results. I was still strongly encouraged to keep a paper log of my readings so that the doctor could see patterns in my highs and lows. When glucose readings were over 240 mg/dL, the monitor would ask “Ketones?” as a hint to perform a urine test, and when under 70 mg/dL, asked LO?
Most importantly, the One Touch Ultra no longer relied on reagent strips, instead utilizing printed biosensor strips that needed to be inserted directly into the monitor, rather than held above the scanner for light to pass through the blood sample. Instead, the (much smaller) blood sample was converted into an electrical current, which is transmitted through the strip and read by the meter (Gebel, 2012). Specifically, this model utilized a “glucose oxidase biosensor” that allowed for this meter to generate readings in “plasma-equivalent units” that matched laboratory tests (Manual, 2003, p. 56, 36). The new test strips still used coded batches, meaning that the code on the meter had to match the code on the test strip.
containers in order to generate an accurate reading. This model boasted finger tip AND arm sampling for blood - although I never used the arm as it was too frightening and painful. As another improvement over the One Touch Basic, the required blood sample was much smaller at one micro liter and an amazing 5-second test time (p. 22). But these improvements came at a steep cost - without insurance, test strips for this model cost roughly a dollar a strip.

The sheer expense of diabetes supplies was quite a shock when I returned to the United States to attend college and became responsible for acquiring my own supplies. I also learned that the diabetes supplies an individual ends up buying are not determined by the best products on the market. They are determined by a mixture of what your insurance company will pay for and your doctors require. As an adult, I have acquired multiple monitors; mostly in the Lifescan One Touch line. Some of them my doctors gave to me – the machines are often free from a medical professional because the test strips cost so much. In college, my insurance only covered 100 strips a month; with four readings a day, I usually came up short.

Sometime around graduating from college, I moved onto using the OneTouch UltraMini – this model is shaped more like a finger rather than a palm of the hand – long and thin. It is quite similar to the One Touch Ultra: it too only required 1 micro liter of blood and boasted a 5 second reading, utilizing the same biosensor technology as the Ultra. The most amazing aspect of the Mini was the fact that this model was able to store “a maximum of 500 blood glucose test results,” which translates to roughly four months of readings (Manual, 2007, p. 29). Given that I was supposed to see my doctors every three to six months, the
paper diary of my readings was no longer strictly necessary, as the doctor could download my readings directly from the machine.

After I completed my masters’ degree, and before the passage of the Affordable Care Act, I became uninsured for about a year. This meant that overall my diabetic costs skyrocketed – without insurance just one of my insulin prescriptions costs over $600. OneTouch test strips were roughly $1 a strip – which meant that a month’s supply added another $100 at least to my tab. And when my prescription refills ran out, I couldn’t refill them without visiting a doctor. In desperation I called a diabetic help-line listed on the website of the American Diabetes Association and found out that Wal-Mart carries a basic glucose meter with Wal-Mart Brand supplies. This meter, the ReliOn Prime, cost $19.99 and test strips were $9 for a box of 50 – meaning that a month’s supply of 100 cost less than $20 – which was far less than anything I had ever paid for test strips, even on insurance. The Prime was shaped similarly to my old OneTouch Ultra – which felt reassuring when I was so overwhelmed by trying to figure out how to even marginally manage my diabetes when I could no longer afford better forms of treatment. This meter uses a variant of the Medisense biosensor, developed by Abbott laboratories, and has consistently been one of the most affordable meters on the market, although you have to buy supplies directly from Walmart pharmacies (Newman and Taylor, 2005). This meter required a smaller blood sample than my One Touch machines at 0.5 micro liter of blood, and had a 7 second reading time (Manual, p. 12). The ReliOn Prime was able to store 250 readings as well as provide 14 and
30-day averages. The manual also offers the following description of how the glucose testing process works:

These capillary action test strips require only 0.5 micro-liter (µl) of blood and provide an end-fill sample application tip for easy blood application. The ReliOn® Prime Blood Glucose Monitoring System measures the amount of glucose (sugar) in fresh capillary whole blood. When a drop of blood is added to the sample application tip, the sample is drawn into the test strip reaction site. The glucose in the blood reacts with the enzyme on the test strip. This reaction produces a current, proportional to the amount of glucose in the blood. The meter detects the current and converts it into a blood glucose reading. (Manual, n.d., p. 12)

After I got back on an insurance policy, my new doctor gave me a new meter – Bayer’s Contour Next. This meter was compatible with her office’s software – and all of her patients used this same model. It is one of the more precisely calibrated non-constant glucose monitors available. Some models in this line of meters also can be calibrated with Meditronic’s insulin pump (“Optimized Insulin Delivery Made Easy,” 2010). Similar to the One Touch machines, the Contour Next provides readings in 5 seconds, and similar to the ReliOn Prime, it required a small blood sample. However, the Contour Next is capable of storing roughly 800 readings - which equates to a record of over six months. A paper log is no longer necessary, or required - my doctor can (and does) download my readings and compare that data to my A1C results.
Figure 3.4. Picture of my Contour Next glucose monitor, with lancer (left) and test strips (top).

Above is my current monitor, the Contour Next. As you can see, it is more compact than the original One Touch, and the strips are inserted directly into the machine. It requires are much smaller blood sample than the One Touch as well. The lancer is roughly the same design as the one I initially started using when I was diagnosed.

The final hand-held glucose monitor I have used is the PrecisionXtra – which was developed by Abbot Laboratories (Newman and Taylor, 2005). I was given this model for a drug trial through UNC Medical system. The PrecisionXtra had a smaller memory (450
readings) but in addition to testing blood glucose, this meter also has the capability to test ketones in the blood. The ketone test required different strips and had a slightly longer test time (15 seconds compared to 5), but it offered a more precise measurement of ketones than other methods of measuring ketones. To measure ketones, urine sampling via reagent strips is still used, but only when glucose levels have been running high consistently or there is a sharp spike in blood glucose readings. Similar to the A1C test, a urine sample’s level of glucose can indicate that blood sugars have been consistently high – while not precise as to the body’s current glucose levels, using urine can provide a picture of a diabetic’s overall control. I have a prescription for Ketostix (pictured below), the current home urine testing method, that I keep in my medicine cabinet “just in case.” The PrecisionXtra made Ketostix unnecessary for as long as I was in the study. As a requirement of the study, I had to test for ketones whenever my levels were above 300 mg/dl.
In addition to testing for ketones, the study required me to keep a secondary, paper log of my blood sugars, ketones, insulin doses and other assorted data. At first, I did not see the point of keeping such detailed logs - the point of the study was to see if a new drug would work to keep my blood sugars within a particular range and decrease my dependence on insulin. Wouldn’t an A1C test demonstrate if my control was improved? Couldn’t they just download the results from the monitor they had provided? Why did I need to wake up at three am to test my blood sugar? Surely there must be an app that would replace the need for paper.

I soon came to realize that the paper logs acted as a visual shorthand for the nurses conducting the study: the records I made allowed them to see patterns in my glucose readings.
and connect them more easily to other listed factors, factors that were not easily captured by automated data collection processes such as my glucose monitor. Prior to participating in this study, I had thought of my blood sugars primarily as isolated data points rather than considering them as part of larger patterns of data. That is to say, while I looked for an explanation for a particular high or low (party the night before, exercised in the afternoon and didn’t eat a snack), I had had not seen the particular value in looking at longer trends, assuming that tests like the A1C and the averages provided by my glucose monitor were a fine way to see how well-controlled my sugars were. But seeing the trends for myself demonstrated how weak my control could be - rather than seeing a high or a low reading in connection only with immediate events, I could now see them within a larger context and adjust my behaviors accordingly. Although I had briefly worn a constant glucose monitor at the behest of my regular doctor, I had not seen the data provided as something worth having all the time. Participating in the UNC study and seeing the value in tracking trends carefully began to change my mind and I began to seriously consider starting to use a Constant Glucose Monitor.

**Overwhelmed with Data: Starting a CGM**

My endocrinologist encouraged me for years to get a CGM. I felt hesitant; cost was an issue. And, just as my middle school self resented having to test my blood sugars in the middle of class, my adult-self balked at the idea of having to wear a monitoring device all the time. To appease my doctor, I agreed to wear one for a week in May 2013 for diagnostic purposes. Just a week would allow her to see patterns in my glucose levels that my normal
five-tests-a-day with a regular monitor simply could not capture, particularly during the
night. A Constant Glucose Monitor has several different components – the sensor – which
remains attached to the user, the transmitter that connects to the sensor, and a receiver device
that displays the readings. The CGM they gave me was an older model, and because it was a
loan, I was not given the receiver. The data instead was transmitted directly to the doctor’s
office. If I were to get a CGM of my own, my doctor said, I could see the data without her
intervention. Enticing. It wouldn’t hurt, she assured me.

It did hurt. After the nurse inserted the sensor and attached the transmitter, I had a
hard time moving, sleeping, and I had an angry red welt on my stomach for weeks, even after
I’d removed the sensor. The data the loaner elicited, however, was fascinating. Suddenly I
could see how my sugars tended to trend up in the early evening hours, and sometimes
plummeted after midnight. The early morning lows were now part of a larger picture rather
than isolated incidents that I could see in graph form, rather than waking up and attempting
to puzzle out if I’d eaten too much or too little or trying to isolate other factors in one-to-one
correlations. But even the prospect of additional data failed to make me want to get a CGM
of my own. The information offered was tantalizing. But who else had access to it? While
wearing this loaner, I attended a conference called “Taking Control of Your Diabetes.” Most
of the panels I attended spoke of CGM and insulin pump technologies as unmitigated
positives for the user. I decided to ask about the data. One speaker assured me I that only I
and my doctor would have access to the data generated by a CGM. I found this to be highly
unlikely. A (younger) speaker at a different panel admitted that said data would be stored and
owned by the company producing the technology. My suspicions confirmed, I decided I wasn’t ready for a CGM of my own.

Fast-forward two years. I turned 30. I ‘celebrated’ having diabetes for 18 years. Perhaps, I considered, it was time to take things more seriously if I wanted to live 18 years more. Participating in the UNC study had given me a better idea of what I needed to do in the day to day to achieve better control, but the constant pressure of performing for the study made me happy when it ended and I could go back to seeing a medical professional once every three months rather than once every two weeks. After a A1c reading that showed less improvement than she wanted, (7.4, which is above the ADA recommendation of staying below 7.0), my endocrinologist told me in no uncertain terms that she wanted me to start using a CGM. “If you have to choose between an Insulin Pump and a CGM,” she said, “pick a CGM.” I agreed to attend an informational session and figure out if either option was affordable. The diabetic educators proctoring the session also worked directly for the technology companies – meaning that they were constrained in what they could tell us. If you have a smart phone, one of them assured us, all of these devices are intuitive. Digital technology has become so widespread that it is comfortable, normal. I decided to see if I could afford a CGM while I was still on my graduate student insurance.

About a month after I attended the session, I brought my newly acquired CGM to the doctor’s office. My doctor was pleased that I followed her advice. “You’re doing all right,” she told me. “Your A1C hasn’t changed from your last visit. I think you’ll find you’ll be able to do more to bring that down with all the data the CGM will give you.” I admitted I’d been
too afraid to set it up myself; the idea of injecting a sensor beneath my skin was too much to handle alone in my apartment. A nurse kindly took me in hand and talked me through the process.

“You’ll be fine,” she assured me. “You give yourself shots! This is about the same amount of pain as using a syringe. Have you used a syringe before or have you just used an insulin pen?”

“I used to use syringes,” I said. As much as I like the precision and ease of the pen, there was something dramatic about using a syringe that I miss sometimes. “And I know that soon this will be as normal as pricking my finger or giving myself a shot.” I thought back to middle school, when I had to learn these things. The worst part of the whole CGM attaching process is that the sensor applicator is not spring loaded, like the lancer I use to prick my fingers. It truly is like giving a shot with a syringe, but with a huge one that requires both hands to operate. I was not sure where I should place it on my abdomen – picking out what to wear certainly has been more challenging. It did not hurt as badly as the last time I wore a CGM; perhaps because I was the one in charge of the attachment process. Or perhaps, as multiple people had assured me throughout the decision process, the sensor technology improved and is less painful for all users. Once I managed to get the sensor on and the transmitter attached, the nurse explained that the graph will start showing readings in two hours, after I test my blood sugar on my normal monitor to calibrate the receiver. “And don’t make any treatment decisions regarding insulin based on the CGM,” she added.
This didn’t make sense to me, but she had another appointment so I went home and dug out the user manual. Sure enough, it states boldly:

**WARNING:** Do not use the Dexcom G4 PLATINUM System for treatment decisions, such as how much insulin you should take. The Dexcom G4 PLATINUM System does not replace a blood glucose meter. Always use the values from your blood glucose meter for treatment decisions. Blood glucose values may differ from sensor glucose readings. (“Dexcom G4 PLATINUM User’s Guide,” 2015, p. 59).

*So much for making my life easier,* I thought. I tossed aside the manual and checked the Dexcom receiver to see if I could calibrate it yet. The warning of the manual was promptly borne out in the hours following my initial calibration. To calibrate the receiver, I have to test my blood sugars twice in a row on my hand held monitor and enter the values manually into the Dexcom Receiver. The first reading was 102, and the second was 101. After I entered these numbers into the Dexcom, it showed my first reading as 97. *Not bad,* I thought. That’s not a huge variation in terms of glucose value, so I decided the machines must be fairly “correct” in terms of mediating my current blood sugars. I tried to get back to work but instead I found myself checking and rechecking the Dexcom Receiver – watching the numbers change and reading more of the instruction manual.

Twenty minutes after my initial calibration, I received an alert that my sugars have plummeted below 70, and are therefore in the “low” range. Puzzled, since I had not felt any physical symptoms of being low, I pulled out my regular meter to check. I got a reading of 90 – *well,* I thought, *I know that glucose readings can be up to 30 points different (higher or*
lower) than the actual levels in the body. Possibly the Dexcom needs to be further calibrated, so I entered the new glucose reading. The Dexcom then showed a value of 80. Satisfied, I tried to get back to work. The readings on the Dexcom began to show a downward trend, even though I’m still above 70. I got some water and came back to find that I have again, apparently, plummeted below 70 and am now hitting the upper 50s and lower 60s. I still felt no physical symptoms, but now I also felt kind of panicked about this particular life choice – I was not sure this added level of data is helpful. Do I trust the CGM, the Contour Next, or my own physical symptoms? I checked my blood again using the regular glucose monitor. It read 86. I tried to get back to work, but I couldn’t stop refreshing the Dexcom receiver to see if my sugars are trending back towards normal. They remained stubbornly at or below 70 – but since I still didn’t feel shaky or sweaty, I decided that instead of taking glucose tablets I would just eat dinner a little early. My regular monitor then gave me a reading of 82, so it felt safe to assume that I was borderline low, even if the new CGM was reading lower than my regular monitor. I wondered if I should recalibrate my regular monitor. I wondered if the CGM is worth this new layer of anxiety.

Hours after dinner, I received an alert from my new CGM that my sugars have now gone above 200, so I am high. The specific reading the graph shows is 218. I pulled out my regular glucose monitor again, just to check. I get a reading of 193. I entered this number into the Dexcom and get a new reading of 185, but trending upwards. Five minutes later I was at 197. This is worse than checking Facebook, I thought to myself. Exhausted, I decided to call it a night. I gave my evening insulin and decided to figure out the mysteries of calibration in
the morning. I carefully deposited the receiver next to my bed so that it can easily receive overnight readings from the transmitter, but neglected to turn off the alert for high blood sugar readings. The receiver buzzed every hour or so to inform me that my sugars were running high. This was not conducive to a good night’s sleep, which, ironically, would probably have helped my sugars to level out. When I woke up the receiver had lost connection to the transmitter altogether and so I went to see what I can do about resetting it. According to the manual, it should just reset itself. In about fifteen minutes, it chirped a reading in the upper 200s. Blearily, I checked my blood using my handheld monitor. It gave a reading of 307. Perhaps I really was low yesterday, I thought, remembering what a nurse told me about the liver releasing extra glucose in the event of a low. This often causes a high, since my body doesn’t produce any insulin to balance out the additional sugar. I calculated the amount of insulin necessary to treat both the high and my breakfast and attempt to complete my normal morning routine. Except I spent the next two hours refreshing the receiver to see if my sugars were coming back down into normal range. To my chagrin, they kept trending higher and higher. Should I give more insulin? I wondered. Or should I wait until I eat lunch and hope that these numbers are simply reflective of my breakfast carbs breaking down?

On the bus to school, the receiver noted that my sugars have started trending downwards, with two arrows facing down to denote that it is happening quickly. Do I need to worry about going low now? I thought, panicking. By lunchtime, (three hours later), the CGM was reading at 170 – within the ‘normal’ range established by my doctor. I checked my
blood using the Contour next and got a reading of 148. If I hadn’t spent the morning freaking out about the extreme highs recorded by the CGM, I would have been pleased. Clearly my insulin dose at breakfast was fairly accurate (although a slightly higher dose might have lowered my blood sugars even more firmly in the ‘normal’ range). The day before, I wouldn’t have questioned myself at all until checking my sugars at lunch. After starting a CGM, I spent the day awash in worry and uncertainty. My doctor was certainly correct that I would have a lot of new data from the CGM, but in terms of knowing how to better treat myself, I just felt overwhelmed and confused. Over the next few months, I grew more used to the device. I even began to find it useful to see my sugars at a glance, but I remained skeptical of the overall value of using the CGM until I began to see positive results in my Hemoglobin A1C test results. My overall improvement in control was not due to the CGM alone, however, and I explore this point further in later chapters.

To Technologize or not to Technologize?

Contrary to Topal’s (2015) enthusiasm for medical digitization, I am skeptical of the idea that technology, in and of itself, can fully address the weaknesses in health care. I fall more in line with Lupton’s (2013) cautions regarding the extent that “data” can be useful. For example, today, I would not be able to calculate my insulin dose without my Insulin app, although since I was first diagnosed I calculated each and every shot by hand until I bought a smart phone. Including technology in my treatment plan is never completely simple, and sometimes conforms more with what my doctor desires than my own comfort. As Greenhalgh (2009) notes:
Most conventional chronic disease self management programmes and policies take a biomedical view of the self, characterised by capacity and motivation to perform certain goal oriented tasks expected by doctors and nurses... that health care [for diabetics] should be seen not as a series of decisions made by the patient or clinician at particular times (as in shared decision making) but as never ending, full of surprises, and having continuously to adapt to the messy reality of life. (p. 630)

While my own life has been structured by and dependent on different forms of data (from glucose levels to carbohydrate counts), I am still ultimately responsible for using the technologies available to me, and a new technology (such as the CGM) did not automatically make my life easier or diabetic control better. Rather, introducing a new technology required a new set of practices and for me to learn how to interact with this new stream of data, as I discuss further in the next few chapters. With the introduction of new, more complex, monitors, my own knowledge about data has evolved as well. Additionally, the rise of networked technologies has allowed not only for devices like the CGM, but also for communities dedicated to sharing knowledge gained by experience, which is the focus of the next chapter.
CHAPTER 4:

Hacking Control: Building Communities, Becoming Cyborgs, Exploiting Systems

“Making constant adaptations and extracting strength and endurance from a self under siege are everyday actions of courage in a life of chronic sorrow” (Roos, 2002, p. 33).

“My initial premise is based on the notion of a universally distributed intelligence. No one knows everything, everyone knows something, all knowledge resides in humanity. There is no transcendent store of knowledge and knowledge is simply the sum of what we know” (Lévy, 1997, p. 13-14).

When Education is Not Enough

“Oh, I probably shouldn’t eat that, but thank you,” I say. “I have diabetes.”

Sometimes I say, “I’m a diabetic.”

“I had no idea!” they tell me. They don’t, because I’ve never mentioned it. Or, they say, “I forgot, I’m so sorry!”

“I don’t usually talk about it,” I explain matter-of-factly, smiling, making it sound unimportant.

I have had this same conversation countless times since I was diagnosed with Diabetes Mellitus (or Type I, formerly known as Juvenile Diabetes) just over nineteen years ago. It is a matter of pride and also privacy to keep my diabetes to myself – when people are surprised by the revelation of my illness, I have successfully performed “normalcy.” I haven’t let my disease define me. A “normal” life is a common goal of diabetes management – in fact, as I’ve been writing this paragraph, I received an email from a diabetes educator
telling me that “You're an incredible person and you are not defined by your diabetes!” Yet I am. Choosing when to self-disclose my diabetes to others offers me a small measure of personal control, but in very material terms, my life is defined by the failure of my pancreas – blood tests, injections, dietary guidelines, insurance hurdles, and a veritable army of medical professionals shape my everyday existence, no matter how well I hide my chronic disease from those around me.

Having diabetes, being a diabetic. One statement differentiates the disease from the person; the other defines the person by the disease. Though I exercise control over when and to whom I self-disclose my diabetes to others in my personal life, disclosure is demanded in medical settings. “Control” in terms of managing my diabetes is predicted on my compliance to the rules of diabetes management and being honest about my personal practices to my team of medical professionals. This chapter looks at the ways in which diabetic communities push back against various “inscriptive practices,” to use John Durham Peters’ (2015) term, that define diabetes management. In particular, I look at the ways that the wider diabetes community uses networked digital media: both to build communities of support as well as to improve glucose monitoring technologies.

Patient education is the official foundation of modern diabetes treatment – education regarding diet, glucose monitoring, and insulin regimes. Access to education in addition to the basics of diabetes supplies, however, is still very much reliant on where in the world you are, your economic class, and your technological literacy, as I noted in the introduction. One of the first things my doctor did when I returned to the United States was to enroll me in a
carb-counting class so that I would be better able to manage both my diet and my insulin
doses. Within the United States, organizations like the American Diabetes Association
(ADA) take the lead in providing access to information about diabetes outside of the medical
realm. The individual diabetic is therefore responsible for self-monitoring on a variety of
fronts – even and perhaps especially with the development of technology. Glucose
monitoring technology fits in well with the definition John Durham Peters (2015) provides
for logistical media: “logistical media...organize and orient... They both coordinate and
subordinate, arranging relationships among people and things... logistical media set the terms
in which everyone must operate” (p. 37). I wake up in the morning, test my blood using a
handheld monitor to calibrate the CGM and to calculate my insulin dosage for breakfast,
using various iPhone apps. As I detailed in the previous chapters, the precision of monitoring
technologies “set the terms” for diabetic treatment - I use my monitors to determine how
much insulin I take and when, what I eat, exercise, and so on. These “terms” for attempting
to live a healthy life are onerous, but I recognize that without them, I would never have left
the hospital in Chiang Mai following my diagnosis. Early forms of diagnosis, such as urine
analysis, did not set terms that allowed for precise treatments. They confirmed the physical
ailment, and sometimes provided guidelines as to treatment via diet, but truly operational
treatment was only possible following the development of insulin. Insulin itself, while key, is
most effective when used in tandem with monitoring technologies that generate data
regarding blood sugars, as I detailed in the introduction.
Technologies are used to monitor and collect data on the diabetic individual, in a more comprehensive manner for Type Is then Type IIs, setting the terms for treatment and behavior of the diabetic population(s). However, while newer forms of monitoring technology are ever more precise in terms of the types of data they can gather and store, technology alone cannot determine the success or failure of managing diabetes. As I discussed in the last chapter, diabetic monitoring technologies function as “technologies of the self” - shaping my own actions and self-knowledge. To become a diabetic subject is to be individualized via constant self-monitoring and data collection, while at the same time being categorized into medical populations which are constantly in flux as medical knowledge evolves.

**Building Digital Communities**

In short, managing diabetes is *exhausting*. The same action can have a different reaction at different points in time. Day in and day out, diabetics repeat their medical regime, awash with knowledge about their inner workings, but with limited ability to adequately address their bodily failure. To keep on keeping on, as it were, requires enormous reserves of determination and a high tolerance for pain. Krall (1995) notes that the *attitude* of diabetic patients is a foundational part of treating diabetes regardless of medical or technological advances (p. 286). However, rather unsurprisingly, the pressure of managing diabetes often results in psychological and emotional disorders. In recent years, online communities have sprung up to connect diabetics and their families. These communities allow for diabetics to discuss our experiences with each other and gain insight and knowledge from experiences
that aren’t always covered in the educational literature. As Type I diabetics constitute roughly five percent of the total diabetic population, having Type I can feel profoundly isolating. While the American Diabetes Association and other groups sponsor a growing number of support networks for Type I children and their families including workshops and summer camps, I was unable to attend diabetic camps as a teenager. The first time I ever encountered a group of Type I diabetics was when I attended the “Taking Control of Your Diabetes” Conference in the spring of 2014 when I was twenty-nine years old. I was amazed to see and hear from so many other people who had struggles like mine. I signed up for listservs and I took pamphlets for support groups - determined at last to find a supportive community. What I found was that the support in these instances usually focused on the same sort of “relentless positivity” evidenced by the email I described above. “You are more than your diabetes!” - but you must follow all the rules and stay positive, otherwise you will develop complications and die. Was there room for negative emotions in the diabetic community, I wondered? So I went down the Google rabbit hole and discovered online networks of diabetics working not only to expand the research foci of the medical community, but also to provide outlets for those more ‘negative’ feelings and experiences that are often hard to acknowledge given the focus on “attitude.”

One such online network is called “Glu,” and it is the online arm of the TD1 Exchange, which is an organization dedicated to “driving faster, better research to improve outcomes in Type I diabetes” by focusing on “patient-driven” data (“Glu: About Us,” 2016). In other words, Glu provides a forum for Type I diabetics, or the parents and guardians of
Type I diabetics to participate in surveys and share tips and experiences with other users. To see the research, you must participate in the polls and forums. There is an option to search the site’s database of Type I users (currently at around 26K) to see how many other members compare to your own treatment regimens. For example, when I search for patients who use both a CGM and multiple daily insulin injections (MDI) like I do, there are only 406 users or about 1.5% who use this same treatment plan (“T1D Discover Search,” 2016). When I remove the CGM from the search criteria, the number of users goes up to roughly 40%, which is about equal to the number of users who use an insulin pump (at 42%). As I explained in the introduction, insulin pumps are attached to the user’s body and provide a constant stream of insulin in an attempt to mimic the function of a pancreas. As I sometimes feel like I’m a technophobe when it comes to managing my diabetes because I don’t use a pump, it is interesting and also comforting that many other people, for whatever reason, still rely on injections over a pump. Personally, I have remained on injections primarily because of costs; but secondarily, I do not like the idea of technology pumping insulin to me. The CGM collects data and transmits it elsewhere, so if there were a malfunction I would not die because I have other methods of self-monitoring. I feel wary of depending on a pump for my insulin needs given how delicate the balance is between “too little” insulin and “too much.”

Only ten percent of all Glu Type I users use a CGM, which is unsurprising given the relative newness of the technology (available since the early 2000s) compared to the insulin pump, which has been in use since the 1990s. While these data are not universally conclusive, they do provide a snapshot of the ways in which Type I diabetics are utilizing the
technologies available to us. This database and related research allows the T1D Exchange to push back against decisions like the recent United Healthcare announcement that designated a particular type of insulin pump as the “preferred” choice for United Healthcare customers. Bell (2016) points to data that shows that diabetics want a choice in the types of technologies and therapies they can access, choices based on ease of use as well as effectiveness rather than some sort of industry standard imposed by insurance companies and supplier companies. Lack of coverage and insurance restrictions are one of the primary reasons diabetics do not chose to start or are forced to stop therapies involving insulin pump or CGM technologies, meaning that ‘choice’ for diabetics are not limited only to what technologies are available, but also what technologies are accessible (Bell, 2016). When faced with such stringent options, a community like Glu can provide more than a repository for information: it also provides a community of support.

A recent poll on the Glu Forums (2016) asked the question: “Where do you receive the majority of your emotional diabetes support?” This is an open poll, sent out as a “Poll of the Day” to Glu members and has no closing date. The possible responses were: Parents/Guardians, Significant Others, Siblings, Online Diabetes Communities, Healthcare Professionals, and No Answer. It is perhaps telling that while the majority of people responded to the poll answered that they find their emotional support from their significant others (roughly 44% of the responses as of this writing), but the second most popular answer was “online diabetes communities” with roughly 24% (as of this writing). Siblings had the lowest response rate (with 1.3%), and Healthcare Professionals was the next lowest with
roughly 9% of responses. I found this unsurprising, as the question of *emotional* support in my experience has rarely, if ever, come up in conversations with medical professionals. The focus of the medical professionals that I have interacted with has been on making sure the diabetic individual (i.e., me) is properly utilizing the knowledge and education that standardizes treatment options. *Parents/Guardians* and *No Answer* were roughly equal at 10.5% and 11.4% respectively. While this poll is very informal, it demonstrates the need for resources beyond the “facts” of diabetes management. The results also suggest that emotional support is an important issue for many Type I diabetics, with the obvious caveats that the sample size of this particular poll is limited in that they are the responses of people who a) appear to be demographically adults (given the dependence on significant others rather than parents) and b) have the ability to voluntarily participate in an online forum.

With that said, the fact that a group like Glu, which is designed to support T1D, would offer a poll focusing on emotional support demonstrates the importance of extending the conversation around diabetes control beyond the “facts” to include other factors. Further, it also demonstrates the ways in which online spaces expand communities and facilitate patient oriented and driven research. Sites like Glu and Facebook groups like “CGM in the Cloud” allow parents of and individuals with Type I diabetes to discuss issues and tips that may not come up in the doctor's’ office, but are still relevant and impact everyday life. Pierre Lévy (1997) envisioned digital networks as enabling what he called “collective” or “universally distributed intelligence,” which is “constantly enhanced, coordinated in real time, and resulting in the effective mobilization of skills” (p. 13). A recent discussion in the
“CGM in the Cloud” Facebook group was started by a mother frantic to get her child some extra insulin while the child was at a summer camp. Responses from other parents in the area started rolling in almost immediately, with suggestions about how to get insurance companies to pay for replacement insulin to people volunteering their extra insulin to hold the child over. I can only imagine how helpful a community like this would have been for my parents when I was first diagnosed, and I myself would have benefited from such forums when I was in college and trying to navigate the American health care system by myself.

Sites like Glu and other online communities therefore enable the coordination of knowledge about living with diabetes and allow everyone who knows something to contribute the knowledge of diabetes beyond the medical establishment. As an example, Brown (1985) notes that “teaching pertinent information is not sufficient to insure learning,” and demonstrates that “grief” is a factor that impacts a diabetic’s ability to self-manage (p. 54). There has been growing interest on the toll that self-management takes on the diabetic, particularly in children who are diagnosed with Type I, who deal with their own feelings regarding their disease but also may have to deal with the feelings of their parents or caregivers (Dahan & McAfee, 2009). Dahan and McAfee (2009) suggest that a “therapist can be instrumental in helping the family as a unit react to the myriad changes necessitated by a diagnosis of diabetes in a child” (p. 80). Grief and sorrow have been observed in relationship to a variety of chronic illnesses, although I was never told this by any medical professional in the nearly two decades since my diagnosis.
It has gotten to the point in my own life where I know there was a “before” when I didn’t have to devote a significant portion of my waking (and sometimes sleeping) hours to managing a chronic disease, but I cannot remember what that was like. When I was diagnosed with clinical depression in college it never occurred to me (or any of the therapists I have worked with since) to connect it to dealing with diabetes. It was simply another way in which my body had betrayed me - I couldn’t trust my own mind on top of everything else. Roos (2002) prefers to use the term “chronic sorrow” to refer to the grief experienced by individuals with chronic illness, suggesting that

[c]hronic sorrow is not about endings; it is about living with unremovable loss and unmending wounds. It is about losses requiring - and demanding - persistent courage to cope with crises and making the adaptations necessary in order to live a life of one’s own (p. xv).

The term “chronic sorrow” was coined by Simon Olshansky in the 1960s to “refer to the normal, profound, and pervasive grief responses of parents following a diagnosis of a child’s mental retardation or other severe developmental disability,” and which was expanded in the nineteen-nineties to include sufferers and families of people with various chronic illnesses, including HIV and schizophrenia (p. 23-24).

Roos (2002) suggests that the concept of “chronic sorrow” allows for a paradigm shift in the therapeutic community by normalizing the ongoing grief that people feel when faced with a chronic illness, wherein “the intensity of grief continues to be resurgent” (p. 22). In the months following my thirtieth birthday, coming up on the eighteenth anniversary of my
diagnosis, I sank into a deep emotional morass that was hard for me to comprehend. I had dealt with this disease for years; I’d even become more open about discussing it. I thought I had come to terms with my “abnormalcy.” And yet, I felt overwhelmed with a profound sadness and sense of exhaustion when I considered continuing to live with the need for such close self-monitoring and management. When I was younger, I would say that if there WERE a cure, I wasn’t sure I’d take it, because I felt that suffering had made me a better person. Nearly two decades on, I found enlightenment and solace in Roos’s (2002) description of the “essence of chronic sorrow is a painful discrepancy between what is perceived as reality and what continues to be dreamed of. The loss is ongoing since the source of loss continues to be present. The loss is a living loss” (p. 26). I had never before considered my diagnosis with Type I diabetes as a loss; I had considered myself lucky to be alive. But conducting this research offered another way to think of my life: of course I am grateful to be alive, but I can also recognize that I have lost many things - from the obvious - not being able to eat everything I want - to the not so obvious - there may never be a cure, and I will have to decide how much unstoppable bodily disintegration I am willing to live with as I age.

Hayes (2001), in conducting research into the diabetic experience of “chronic sorrow” identifies that diabetics are up to three times more likely to be diagnosed with clinical depression than the non-diabetic population. In 2005, a group of researchers developed a diagnostic test called the Diabetes Distress Scale (DDS) for use in clinical settings to determine the stress related to “emotional burden subscale, physician-related distress subscale, regimen-related distress subscale, and diabetes-related interpersonal distress” for
diabetic patients (Polonsky, Fisher, et. al, 2005, p. 361). More recently, Garrett and Doherty (2014) point to research that suggests that high rates of depression among diabetics is connected both to issues of “non-adherence to treatment” as well as the toll of the physical complications related to diabetes (p. 669). The first time I encountered the DDS was at the Taking Control of My Diabetes conference. When I mentioned the test to my endocrinologist she knew what I was talking about, but explained that they only used it in cases where it was clear the patient was not handling things well. Since I was more or less doing what I was supposed to do (apt and compliant), it had never appeared necessary for her to mention. In identifying “diabetic stress,” the goal is to identify particular problems standing in the way of diabetes management - are you failing to control your diabetes because of a fear of needles or because of bad eating practices? The emphasis in diabetes education on “attitude” stems from the goal of equipping diabetics to have a better chance at successful management - which results in a longer, and hopefully happier life. Those are not horrible goals, but as communities like Glu and T1D Exchange demonstrate, attitude is only one piece of the complicated puzzle of actions, technology, emotion, and support that go into diabetes management. Online communities offer opportunities for diabetics and their caregivers to connect and learn from others who are dealing with the same problems, rather than focusing on optimizing the performance of diabetes control.

In particular, communities like Glu demonstrate the multiple roles technology plays in managing diabetes by expanding the ways in which media operate to produce networks of support and knowledge production outside of data collection and the medical community.
There are also severe frustrations related to issues of accessing technology and ease of use - particularly for younger diabetics. Digital media function as “logistical media” by defining the terms within which diabetics operate and attempt to thrive, but they also provide platforms from which diabetics may challenge those terms. For example, digital networks such as the “My Diabetic Secret” tumblr offer emotional and mental support for diabetics, and research oriented online communities like “Glu” allow Type I diabetics and their caregivers to participate in non-medical studies that get to the every-day aspects of living with Type I. Such efforts offer the medical and regulatory communities lived data to tailor their research effort as well as providing information about living with diabetes to individuals with access to online digital networks (granted, this is a formidable barrier to many).

Given the complexities of the relationships diabetics have with various forms of technology, I suggest that the figure of the cyborg, proposed by Donna Haraway (1991), provides a foundation from which to consider the ways in which technology and the diabetic body are co-constituted. I use the “cyborg” here as a way to transition from historical and personal histories of glucose monitoring I have provided in the previous chapters as I return to Haraway and the work of other feminist scholars in the next chapter. The cyborg, Haraway says, “is a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction.” Haraway’s goal for proposing the cyborg was to provide an alternative foundation for feminist activism, moving away from the idea that there is a singular “women’s experience” from which to advocate for specific political goals. Rather
than presuming some sort of shared universal identity or experience, Haraway proposed that *affinity* should form the basis of activism, arguing that

> There is nothing about being 'female' that naturally binds women. There is not even such a state as 'being' female, itself a highly complex category constructed in contested sexual scientific discourses and other social practices. (1991).

Similarly, to be a diabetic is to be put firmly into particular medical categories that are based on criteria that have evolved over time and with the advent of more precise technologies. While Type I and Type II diabetics are lumped together by the word “diabetes” as well as guidelines provided by various medical authorities, there are debates surrounding whether or not Type I and Type II Diabetes even belong under the same umbrella. Recent medical research has determined that while they share some similar symptoms (lack of insulin), their causes are different - in Type I the pancreas ceases to produce insulin and is classified as an Autoimmune disease, Type II is connected with identifiable genetic factors as well as weight and diet. Recently, the non-profit organization TD1 Exchange called for the Center for Disease Control (or CDC) to clarify their 2015 report that “co-mingled” data regarding the rising numbers of diabetes diagnosis, arguing that Type I and Type II should not be considered the same disease:

> Comingling of the data, particularly from the leading national public health institute of the United States, perpetuates the myth that diabetes is one disease sharing a name, while the reality is that Type I and Type II diabetes are actually two different diseases in the diabetes family. Among key differences is that unlike Type II diabetes, Type I
diabetes is not lifestyle-dependent; it is the result of relentless autoimmune destruction of the insulin-producing cells of the pancreas. Once insulin cells are destroyed, individuals spend their lifetime closely monitoring blood sugars and dosing insulin in an attempt to mimic the function of the pancreas. Type II diabetes is a metabolic disease with many confounding factors including genetics, diet, activity and weight; it can be managed by oral medications and lifestyle changes. Type I and Type II diabetes require very different approaches to clinical care; each also requires different models for research and development programs. (“Glu: Call to Action for the CDC,” 2016).

While the different “types” of diabetes have long been categorized together, and while individuals dealing with both types do indeed share some common goals and needs, Haraway’s “affinity” is a far better way to think about these shared aspects of our mutual classification rather than asserting some sort of inherent diabetic identity, especially given the disparate, assumed biological causes. So while Haraway was attempting to provide the cyborg as an alternative to the concept of inherent identity in regards to women’s movements, the term holds relevance for understanding other populations, and in this case, diabetics who wear and use a plethora of machines, who deal with particular social realities and polite fictions like the possibility of perfect control. The “cyborg” concept unifies the “self-control” required of the diabetic individuals and the systems of technological and medical control that produce the diabetic subject. Crucially, Haraway (1991) rejects the drastic dualisms that have plagued critical discussions of humanity and technology,
suggesting that “cyborg imagery can suggest a way out of the maze of dualisms in which we have explained our bodies and our tools to ourselves.” The dependence that diabetics have on technology, the necessity of using technology to maintain biological functions, demonstrates the blurring of the lines between users and the tools. Haraway (2004) elaborates that “[n]etworks of co-constitution, co-evolution, communication, collaboration abound to help us rethink issues of collaboration and control at the heart of the cyborg figure” noting that the relationships between humans and other players, including technology, necessarily form the basis for critical analysis (p. 315).

When writing her original essay in the nineteen nineties, Haraway drew consciously on the realm of science fiction (the cyborg) rather than the realm of myth (the goddess) to argue for a politics of affinity rather than a dependence on any sort of presumed innate “identity.” Since that essay was published, the lines between science fiction and reality are rapidly more blurred in terms of what technology is capable of and what is available to ordinary people. The constant glucose monitor technology is fantastical - a device that is able to track the ebb and flow of glucose levels without a blood sample was unimaginable to me when I was first diagnosed. While digital enthusiasts like Erik Topal (2015) are convinced that the realm of the digital will challenge and change the realm of medicine forever, technologies like the CGM already have changed the lives of an admittedly small population. Diabetics are hybrids of biology and technology, dependent on myriad networks of data collection and transmission. Wearable technologies such as the CGM and the insulin pump blur the boundaries between biology and technology, and while they function primarily as
agents of data collection and distribution in the vein of Kittler’s definition of media, they also offer their users the ability to reset the logistical terms within which they live and operate. It is important to note that while the CGM resets diabetic logistics primarily in terms of data collection and range of information, the insulin pump presents an automation of insulin distribution and a different set of management practices. The figure of the cyborg, Haraway (1991) suggests, “is about the power to survive, not on the basis of original innocence, but on the basis of seizing the tools to mark the world that marked them as other.” The proliferation of digital technologies and networks allow diabetics to achieve better control by enabling more precise intervention into the body’s biological processes, but also allows us to connect with wider networks of support and knowledge production. The body becomes a central component to the digital networks - CGM technology literally depends on a biological component to function. The CGM receiver device might turn on and off, but without the glucose readings, there is no data to be generated, transmitted, or stored without the body being hooked up to the CGM transmitter.

While digital technologies and their attendant networks set new terms within which diabetics function (and even thrive), these technologies set new limits that are not always advantageous, leading to users attempting to ‘hack’ these technologies. I would also suggest that diabetic media allow their users to ‘hack’ their diabetic control at multiple levels. While ‘hacking’ is most commonly associated with computer networks, I argue it has relevance here in connection with Haraway’s cyborg - as we are becoming cyborgs, we are ever more a part of the networks that shape our daily lives so intimately. Indeed, there is growing interest
in what is termed “medical hacking,” with hackathons sponsored by MIT and organizations such as the Hacking Medicine Institute. These entities wish to intervene in digital settings to enable better healthcare options, in the vein of Eric Topal (2015). However, in contrast to Topal, who focuses on how digital applications can increase access to certain kinds of medical care and knowledge, these hackathons focus on making the digital technologies themselves more efficient and useful. Organizations and events such as these highlight the fact that the ‘hacker’ is no longer simply the genius breaking into a closed system of popular imagination, and demonstrates that ‘hacking’ as a practice is common, and even necessary given the predominance of digital media in everyday life.

In this chapter I play with the concept of “hacking’ as a description of particular technological processes, but also a metaphor for gaining some sort of control over self - not just in the sense that diabetes education lays out, but also in allowing diabetic users to “exploit” the technological systems that define their lives beyond the limits set by the system producers, to use Galloway and Thacker’s (2007) term. They note that the relationships between the biological and the technical require ‘protocols’ to function, which “are the rules that make sure the connections actually work,” which are especially true in the case of technology like the CGM (p. 29). The CGM interacts with the body in specific, protocologically defined ways that both generates a constant stream of glucose data, but also limits who can access said data after it has been stored in the CGM servers. This lack of access presents a problem for the people who use CGM technology, as well as the people who care for them. To explore this conundrum, I look at the NightScout Project community -
a group of individuals who provide open source program hacks to the DexCom CGM system to provide more access to real time data beyond that which is provided by the DexCom receiver or the DexCom Share Application. As I noted in the introduction chapter, I myself am not a hacker. Given that I am an adult and on my own, I also find that the ‘regular’ methods of accessing my DexCom data are generally sufficient for me. However, I benefit from this ‘cyborg’ community that is enabled by and continues to challenge the limits of digital networks.

**A History of Hacking**

To contextualize NightScout community and other hackers working specifically with diabetes-related technology, I offer a broader look at conversations surrounding the practice of hacking. In the literature surrounding the phenomenon of “hacking” a few major themes emerge: the need for creativity on the part of the hacker, the transgressing of barriers (digital or otherwise), surmounting difficulty, and the importance of the rise of global digital networks. And of course, the popular image of the hacker as a rebellious figure of intrigue figures largely in the conversation. Jordan (2001) argues that “[h]ackers have been present in computer networks from the moment networks began to exist” and the term is used to “describe those who wanted to find novel uses for computers and other technologies,” highlighting the practice of ‘hacking’ a particular technology or network as a transgressive act (p. 8). While “hacking” is of interest to media scholars, it is of necessity extremely important in the realms of computer programming and network security. Anto (2012), who provides network security training to computer professionals, defines the ‘hacker’ more
loosely as a “person who uses his [sic] creativity and knowledge to overcome limitations, often in technological contexts,” which acknowledges the transgressive nature of challenging a system’s limitations, but offers a broader perspective on what systems and limitations can be transgressed (p. 2). By this definition, diabetics certainly fit the bill - overcoming our own bodily limitations via a variety of biological and technological contexts everyday through the use of a variety of technologies and practices.

Similarly, Lee (2014) suggests that the “history of hacking is the history of human ingenuity, understanding a system and altering its function,” which, specifically for security professionals, translates to the fact that knowing a system’s weaknesses allows the systems strengths to be enhanced (p. 1). McCormick (2013) identifies the Massachusetts Institute of Technology as the ground zero for the development of the culture of hacking that we know today. In the later part of the twentieth century, the Tech Model Railroad Club first applied the term “hacking” to the “harmless pranks and practical jokes” students would play on each other. Among other tricks, they discovered that “toy whistles produced the right frequency” to hack the telephone system and “place long distance calls for free” (p. 24). In this vein, Anton (2012) equates ‘early’ hackers with computer programmers, noting how the digital overlap with telephone networks provided new venues for hackers to “test their skills” - while the popularization of personal computers in the 80s caused hacking to really “take off” (p. 4). Delascio (2016) notes that the “increased connectivity” as well as “lax security practices” have encouraged hackers to “break into computer systems for fun, profit, or spite;” highlighting the negative side of hacking. The 90s and 2000s saw “the emergence of the
Internet as a global communication network gave hackers a vast playground to put their skills to the test” leading to the current era, which provides new modes and technologies to hack with the proliferation of ‘smart’ and networked machines (Anton, 2012, p. 5).

While the modern iteration of hacking has a relatively short history, Lee (2014) traces the history of the word “hacking” back to the thirteenth century. While noting that “hacking” is most commonly associated with gaining illicit access to computers and digital networks, Lee connects the practice of hacking as intervening in specific systems to military history: “the first electronic computers were developed to crack German military ciphers” (p. 1). On a broader scale, the practice of hacking ties to themes of protection and security, with obvious connections to the history of cryptography - and uses the examples of ancient practices in Greece, (which included tattooing messages on a slave’s head and growing hair to cover it), and medieval books of cryptographic practices and cipher breaking which lead to the creation of the “state sponsored cipher cracker” (p. 2). The potential for such “cracking” and need for the talents of cryptographers increased with the “invention of telegraphy in the middle of the 19th century...Messages sent over wire telegraphs could potentially be intercepted or simply copied by telegraph operators” (Lee, p. 3). The introduction of radio further complicated and expanded the potential interception, although that was not the intention in the development of new technological networks. Lee notes that “inventors of new technologies rarely envisage how their technology may be subverted by a malicious action,” and each technology requires its own specific modes of intervention (p. 3). Hacking the first electronic computers was as simple as changing clock timekeeping or password breaking, whereas intercepting radio
messages required being on the same frequency, and older forms of cryptography required different tactics and knowledges to break and utilize the information contained within the transmitted message.

The institution of systems seems to inspire people to seek to break into and change them, as Lee suggests, “[t]echnology can be seen as much more than a machine, but representative of an organization or a regime, and as such can become the focus of anger or protest” (p. 3). Jordan (2001) calls this “hacktivism,” defined as the politically motivated sector of hacking where groups of people utilize “network attacks” or, “infiltrations of targeted networks, in order to protest” (p. 9). “Hacktivism” is “a modern form of protest that combines high-tech computer hacking with more traditional forms of political activism” (Delascio, 2016). The hacker collective “Anonymous” provides a well-known example of how hacker groups tend to operate as “loosely organized collectives composed of individuals pursuing a common goal under a common banner.” Anonymous arose out of the Reddit forum websites and in the last decade performed numerous high-profile online exploits, including their connections to the Occupy Wall Street movement.

While the medical hacktivists who focus on modifying diabetic technology might not be as well known as Anonymous, they play a significant role in challenging and improving extant diabetes tech and pushing development in ways that are beneficial to users. Linebaugh (2014) notes that “Chronic diseases such as diabetes, asthma and heart conditions - where cross references data can help improve health - have been an early focus of hacking.” Within the world of hacking diabetic technology, the groups that perform hacks on CGMs and
insulin pumps are collectives of individuals with diabetes who desire to modify their technology as well as parents and caregivers who seek to help their loved one gain greater control over diabetes. Hacking resets the logistical terms that diabetic media set for users, allowing users to extend the management of their diabetes via specific technological systems.

**Hacking and Protocol**

Throughout the literature on hacking, the “dualisms” that Haraway (1991) suggests are often employed to “[explain] our bodies and our tools to ourselves” are readily apparent - most notably the idea that hackers work with (primarily) digital systems outside of themselves. Systems and networks exist external to the human body, and hackers seek out their weaknesses to exploit them or change them for the better. Thomas (2005) attempts to overcome the binary between code and hacking by viewing hacking as a performance. He notes the “binary distinctions” of the prevalent narratives surrounding technology and technological development: new technology is often simultaneously proclaimed a “breakthrough” heralding a new age of comfort and progress and “threatening” to our way of life (p. 647). Drawing on Heidegger, Thomas argues that technology holds an uneasy place in human imagination, and seeks to “position - or perhaps reposition - the idea of technology between two terms that often function in opposition to one another: code and performance” (p. 648). Specifically, he wants

...to look at technology not as a product but as a process that generates meaning through the negotiation of these two conceptual and material elements...examining
the poles not as mutually exclusive options but rather as anchoring points, or nodal points” (p. 648).

Thomas (2005) defines “the meaning of hacking as resistance,” specifically resistance to a system (p. 649). In digital contexts, the system is defined by codes, which functions as a “system of regulation, a regime, which is both structured and structuring,” in other words, “the primary function of code is normative” (p. 649). This definition echoes the arguments of Galloway (2004), who posits that “computer code is always enacted. Code is a set of procedures, actions, and practices, designed in particular ways to achieve particular ends in particular contexts,” highlighting the active and constitutive nature of code (p. xii). He uses the concept of protocol to further explicate his notion of code as an active component in setting the parameters of network functions – and rather than being a ‘new’ force in the world instituted by the digital revolution, he ties his definition to older understandings of protocol as proper etiquette.

Before computing, Galloway demonstrates, protocol “referred to any type of correct or proper behavior within a set of specific system of conventions” (p. 7). Just as Peters (2015) discusses logistical media as organizing multiple relations, Galloway argues that “[p]rotocol is a language that regulates flows, directs netspace, codes relationships, and connects life forms” (p. 74). By regulating, directing, coding, and connecting, protocol by necessity promotes some actions while excluding others within the parameters of operations. It “sets the terms” of possible action, to borrow from Peters. Protocol and code allow digital spaces to feel “warm and friendly” to users via “technical standardization, agreement,
organized implementation, broad (sometimes universal) adoption, and directed participation” (Galloway, 2004, p. 142). Protocol functions in part because it is invisible to the majority of participants - an underlying and active “set of procedures” that determines the possibilities within a particular digital system. Galloway notes that hackers are commonly painted either as terrorists or libertarians: curious people who “want information to be free” but at a cost to the system (hence the “terrorist”). Rather than seeing hackers as threats to protocol, Galloway instead argues that “hackers do not forecast the death (or avoidance or ignorance) of protocol, but are instead the very harbingers of its assumption” (p. 157). “Hacking,” is resistance the system through an “‘autonomous agent” rather than the “unified group” (p. 159). Rather than destroying protocol, hackers understand code so well they are able to utilize it in ways that might be unimaginable to the writers of the original code, but still work within the particular protocols that set the parameters of the system itself. “Code,” then, is “multidimensional” in that it “draws a line between what is material and what is active” within a protological system - code is the “enactment of meaning” within that system (Galloway, 2004, p. 166). In sum, “protocol is synonymous with possibility,” and to exploit as system of code, hackers must utilize the parameters of the possibility, the “terms” within which the system operates (Galloway, p. 167). Thomas (2005) agrees, noting that “the most basic functions of computer code...describe the parameters of what is both possible as well as what is acceptable” (p. 646). He compares computer code to the arguments that Lawrence Lessig makes about the law - code, like the law, actively constitutes normative functions within a given system.
To further this view, Thomas (2005) brings in the arguments of Friedrich Kittler, who offered the example of how code “transforms” writing, to demonstrate that “code is the means by which writing becomes alien to us” (p. 650). Therefore “code has a second, equally important quality: the ability to make itself disappear” to users, as the “most effective systems of regulation and social control are presented as always pre-existing, natural or essential” (Thomas, p. 650). Peters (2015) echoes this argument when describing the “infrastructural” role that logistical media play - they provide the infrastructure of everyday life, and by that token, recede from view. However, Peters is primarily concerned with how the technical and the infrastructural logistics of media impact the wider social and cultural realms. Familiarity results in invisibility, both in the realm of the technological and in the social arena. “The notions of secrecy emerge as almost the very definition of code” according to Thomas (2005, p. 651). The parallels here to diabetes education seem fairly obvious: if we take Galloway’s view of protocol as determining function within a particular system, diabetes education attempts to set the parameters within which individuals must act in order to achieve the end goal of ‘control.’ The protocols of diabetic management attempt to intervene or employ multiple interlocking systems, both biological and technological. The failure of the diabetic’s biological body necessitates an intervention to produce a functionality enabled by the introduction of outside regulation via synthetic insulin and glucose monitoring. To achieve ‘control’ requires, as discussed in previous chapters, the consistent production of particular types of data that then determine other actions such as insulin dosages and dietary consumption. The behavioral protocols are upheld by the
technological protocols of the monitoring devices themselves, but as my look at the history of glucose monitors suggests, the technological protocols of the machines were developed out of the need for particular medical data.

Thomas (2005) suggests that, in his view, human behavior or Performance, however, is different. It is the opposite of code... Performance, at least in the sense that this article wants to use the word, deals with what is essentially unrepeatable. Of course, both code and performance repeat (or, in the strictest sense of the word, fail to), but what differentiates them is their direction. The goal of code is infinite repetition without difference, while the goal of performance is the production of an irreducible, unrepeatable event - a singularity (p. 651).

To provide a counterpoint to code as normative, Thomas discusses the open source movement as “performative and transgressive” (p. 652). Regarding technology and corporeality, Thomas clarifies that “in its most general sense, code regulates and defines not by attaching itself to particular bodies, but by abstracting notions that appear to apply to all bodies,” while performance is dependent on the fleshly body (p. 654). As discussed, the goal of diabetes education and management is to teach diabetics to perform as effectively as code: to unlock the right repetition of actions to gain the best or most ‘normal’ results. To use Thomas’ (2005) terms, in regards to diabetes, attempting to perform as effectively as code will always be doomed to failure.

In a similar vein, Mazzini (2014) makes the popular argument that networking via digital means has changed humanity in unprecedented ways, but from there points out that
there have been few in-depth cultural histories since the ‘digital revolution’ is an ongoing process. In attempting to provide such a history, he suggests that “[w]hat distinguishes the spread of a digital product from that of other technologies is the lack of infrastructural limits and of any pre-distribution procedure of evaluation on those supplying the infrastructures” (p. 186). While medical technologies have followed a different trajectory of development and distribution than the communication technologies that Mazzini references, the increasingly networked nature of all digital technology denotes a new chapter in how to understand the history and functionality of medical technology. Particularly as technology like CGMs require applications to function properly, or rather, such applications are required for the user to access the functionality of the CGM. The opportunity that digital technologies offer for change to be facilitated by users of technology as well as distributors makes study and theorizing difficult because things are constantly changing, making research “out of date” quickly (see: most hacking texts from the early aughts). In particular, the transient nature of the digital realm makes finding and preserving sources difficult for the historian.

Additionally, Mazzini (2014) suggests that extant academic work on “hacking” as a cultural phenomenon “overemphasize the role played by a few stereotypical and ‘heroic’ individuals, for explicit celebratory purposes” (p. 188). Such work focuses on “big” or flashy hacks - of big social networks. Mazzini (2014) points to Castells’ argument that hackers are “representatives of a culture based on the idea of freedom: the freedom to access computer codes and systems, the freedom to alter them as one wishes” (p. 193). But as Galloway (2004) would caution, these “freedoms” that Castells imagines, freedom of access and the
freedom to enact change within a digital system, extends only so far as working within the limits set by the system itself. While technologies like the CGM promise the “freedom” to control your own body as a diabetic, you are only able to do so within the parameters of the machine itself, leading to issues regarding access to your own data as well as the need to address issues of functionality and technological limitations.

**Hacking the body**

Given the possibilities that recent technologies provide, the “body hacking” movement comes as no surprise. Duarte (2014) defines this movement as the **voluntary use** of technology to modify the body - “body and technology fusion performed by individuals without any disability willing to augment their ‘natural’ and corporeal possibilities” (p. 275). The key here is “without any disability:” the individuals who attempt to modify their own bodies have no medical need to do so, they simply want to see how far they can push the limits of their own bodies:

This research field focuses on extreme body modification practices, assembling experimentations performed by body hackers, self-made cyborgs, or grinders, who are hobbyists and scientifically inclined individuals taking on techniques and knowledge from a variety of disciplines - including the medical field - to break themselves free from their natural body, enhancing its possibilities. (Duarte, 2014, p. 276).

The emphasis here is on *enhancement*, rather than ‘replacement’ or some other term that reflects what medical technologies do for diabetes and other chronic ailments. Of course,
Duarte (2014) notes that “the addition of technological components in the human body is not a novelty in itself,” highlighting technologies such as contact lenses, various implants, and various kinds of biomedical engineering as examples of previous technological extensions of the body (p. 276). However, he makes three arguments in relation to the body hacking movement: first, the process highlights the “entangled agencies between organic and inorganic entities,” resulting in new articulations and relations, second, the process results in modifications that are “combinations of organic hybridization,” and third, using the movement allows for analyzing “the association of man and technology” in new, and more complex ways (p. 277). Duarte suggests that the “technical-body” (or the technocorps) has no “a priori borders which are settled involving man and technology” (p. 277-278). He offers the example of body artists implanted with RFID chips to “allow integrated interaction with the environment providing the possibility of storing data and controlling it remotely” (p. 278). Within the body hacking community, questions regarding ‘what counts’ as body hacking have gained steam. Why should technologies such as RFID chips count as ‘enhancement’ while technologies such as the implantable intra uterine device (or IUD) do not? Rose Eveleth (2016) uses her own implants to raise this question, pointing out the gendered ways in which we define technology:

I can unlock my phone with [the RFID in] my hand. It’s a nice party trick. But my IUD gives me a far more powerful type of control, and is a far more important part of my cyborg life. Outside the movies and hand-wrining found in the press, women are hacking ourselves all the time. We’re just not called bodyhackers.
Eveleth suggests that as “bodyhacking has become technology, (which it wasn’t always) it has become the realm of men.” She draws a comparison between the way she suggests that IUDs are ignored as a body hack and the initial omission of period tracking on Apple’s Health App. Sunny Moraine (2016) builds directly off of Eveleth’s thesis that “bodyhacking” should encompass more than cool tricks like sticking a chip in your hand. In response to Eveleth’s piece, Moraine (2016) ties her arguments explicitly to Haraway’s cyborg, and the construction of the self through “an enmeshing between the organic and the technological lies not only in what it allows one to do but in what it allows one to be.” Diabetics who use wearable technologies like the CGM or insulin pumps would not fit into Duarte’s (2014) definition of body hacking, which seems to presume that any sort of modification with an ‘institutional’ component cannot count. These technologies do not ‘enhance’ the body, and while CGMs are voluntary (for now), they replicate a particular bodily function rather than providing the body with a new functionality. With that being said, I would argue that CGM technology fits in well with Duarte’s (2014) concept of the “technical-body,” and the ways in which Eveleth (2016) and Moraine (2016) expand the purview of bodyhacking are of importance in this discussion. While CGM and medical technologies may not fit into how bodyhacking is popularly understood, the role that they play in allowing diabetics to have control over their own bodies is, in my opinion, as amazing as an RFID chip implant that allows a person to unlock a smartphone with a wave. CGM technology allows the user to manage the functions of their own body.

Hacking Diabetes
Given the widespread interest in Big Data and self-tracking, it is perhaps unsurprising that health monitoring applications and devices have received attention from hackers. The many and varied uses that self-tracking can have for people who deal with chronic conditions has resulted in the need to modify basic apps and technology is of growing interest and concern (Rutkin, 2015). Particularly because diabetes requires the tracking of so much data, developing applications and trackers has become an important question, even for developers outside of the larger technology companies that produce medical technologies. And despite my distaste for Topal’s (2015) overall arguments, he is correct to note that digital technologies and applications for smart phones can in fact help bridge gaps in medical care. HealthPlix MD was developed in Bangalore and India to address the needs of the region’s growing number of diabetics (McIntyre, 2016). Rather than replacing doctors, HealthPlix allows diabetics to enter their data and have a doctor review it from a distance. Applications like HealthPlix and Diabeto were developed by individuals who have loved ones with diabetes or who have diabetes themselves. As I noted in the introductory chapter, the number of diabetics is rising globally. The 2016 Global Diabetes Report from the World Health Organization estimates that the number of diabetics has “quadrupled” since 1980, and reports that the “[p]revalence is growing most rapidly in low- and middle-income countries” where access both to doctors and to basic medical supplies like insulin and glucose monitors is limited (p. 31). Given that diabetes requires such specific medical knowledge, the fact that “access to even the most basic health professionals with appropriate training in diabetes management is not available” for vast swathes of the global population shows that

“*We are not waiting*”

As for technologies like the CGM, people have become deeply interested in modifying and improving the system. And because of the large numbers of children who have been diagnosed with Type I diabetes, many of these ‘medical hackers’ are parents and caregivers, as well as adult diabetics. Just as the CGM offered ways for diabetics to hack their own bodies, the CGM system itself has received attention for modifications to make it more effective in everyday life. Early iterations of the CGM allowed the data to be viewed only on the receiver device. This presented a problem for parents of children using the devices - they wanted to be able to monitor their children from a distance, while the child was at school. A group of parents felt that DexCom wasn’t moving fast enough to address their concerns, and so they developed The Nightscout Project, which is “an open source, DIY project that allows real time access to a CGM data via personal website, smartwatch viewers, or apps and widgets available for smart phones” (“The Nightscout Project,” n.d.). In response, DexCom released a separate app called “DexCom Share” that would allow the DexCom user to designate up to five people to receive glucose readings from the CGM. However, the Nightscout Project highlights an important issue related to medical technologies: because medical technologies are not necessarily developed by the people who use them, the technologies do not always meet the needs of their users. Hence the development of projects like Nightscout, which is developed and maintain by the people who
use DexCom CGMs. Hanselman (2015) points out that DexCom, in early 2015, only supported data transmission on Apple devices, which not everyone can afford. Nightscout, on the other hand, gave him “more control over his data.” The open source nature of the project “freed” his data from the confines of DexCom’s code and allowed him and his family to interact with his data in a more in-depth way.

Figure 4.1. Photograph taken from the NightScout website

The graphic above is from the NightScout website to explain why, even with the introduction of the DexCom Share app, the NightScout community was continuing with the
The main plus of using NightScout is the cross platform compatibility. As of this writing, DexCom is still only compatible with iOS devices; meaning that for people who cannot afford Apple Products, or do not wish to consume Apple Products, the accessibility to DexCom is severely limited, particularly now that they are moving to a phone-based receiver system. In contrast, NightScout is a more flexible program, developed by users who have a tangible stake in the effectiveness of the technology.

Storni (2012) notes that, similar to Topal (2015), technological advancements have shifted the way Western healthcare systems operate, leading to a “shifting to outpatient care; prevention and wellness; and spreading the notion of self-care, personalization and patient empowerment” (p. 1277). This has lead to what Storni (2012) terms a change in “the geographies of care” to refer to the “transfer of care from formal and clinically controlled settings, such as homes and institutions” to the patients themselves, reflecting Deleuze’s description of the shift from a disciplinary society to a control society. However, unlike Topal’s (2015) assertion that this shift will allow patients to take control of their own health, Storni (2012) argues that this model has the potential to “become problematic and fail to empower patients” (p. 1278). He suggests that the “traditional clinical perspective” which had an “acute disease-centric model” is sometimes uncritically translated into the design of support technologies because such development is “typically undertaken from the perspective of the medical expert” (p. 1278, 1279). Storni (2012) draws on literature that suggests that “technology supporting self-care in chronic disease should enable flexible usage, the negotiation of actions” to enable “proactive patients” with chronic condition (p. 1279). The
group that developed the Nightscout technology were concerned with these issues: the original iteration of the DexCom 4 did not allow for flexible usage - only a person with the receiver could see the glucose data. For a child in elementary school, this is not an optimal situation, particularly if the school has rules regarding personal technology in the classroom.

Even for an adult, the ability to transmit glucose data and receive high and low alerts would allow for Storni’s “negotiation of actions.” He further notes that in the context of Type I Diabetes, the “effects are so intrinsically linked to so many everyday activities that is practically impossible to compartmentalise the disease,” which on the other hand makes technological support desirable, but only if a “one size fits all” strategy in terms of treatment is rejected (p. 1282). The technology should not mimic a clinic’s surveillance and the asymmetrical power dynamics of doctor and patient. Rather, diabetic technology should “support the patient to adjust their medication to better fit their lives (as opposed to technologies that dumbly impose compliance with universal solutions)” (p. 1288).

Technology alone cannot achieve this - the patient's needs should be the guiding factor in the developmental stage, including their need to control where their data is stored and shared.

A Wall Street Journal discussion of Nightscout Project highlights parent Jason Adams, described as a “a business-development executive by day and a molecular biologist by training, had never considered himself a hacker,” until his young daughter began using a DexCom 4 (Linebaugh, 2014). Because of DexCom’s Bluetooth system of data collection, in 2014 the data the CGM gathered was not transmittable to other devices. Nightscout changed that by hacking the DexCom and transmitting the data to Internet-connective devices. The
Nightscout Project was originally developed by two parents: John Costick, in 2013 when he discovered a way to “upload the DexCom receiver data to the Internet using his software, a $4 cable and an Android phone,” and Lane Desborough, who had designed the original Nightscout program. When Costick tweeted a picture of his setup, a nation-wide network of parents and caregivers started to grow and the Nightscout Project took off. Linebaugh (2014) notes that Nightscout is far from perfect, “drain[ing] cellphone batteries...and hasn’t been approved by the Food and Drug Administration.” Despite these flaws, Linebaugh argues that Nightscout’s “home-built setup is part of a shift in the way Americans relate to the medical industry and their own healthcare” that allows individuals, particularly those who are tech savvy, to modify their own medical devices that “record and control bodily functions” with the desire for “greater access to data and faster innovation than is possible under formal regulatory process.”

Torrance and von Hippel (2015) argue for the importance of “innovation activity” wherein individuals “create products and services they personally need” (p. 795). They suggest that such innovation should be protected through “greater awareness of existing legal protection for innovation coupled with more careful and innovation-conscious regulatory design” (p. 796). Their arguments connect health innovation to individual rights for privacy:

Individuals are generally permitted to accept or reject medical care from physicians. Alternatively, they may choose to engage in medical treatment of themselves. In fact, they may decide to modify aspects of their own bodies... User creation or modification of medical treatments may, in some cases, turn out to be dangerous, but
such practices can also lead to new insights into human health or even successful new medical treatments (p. 808).

The NightScout Project encourages a “pay it forward” mentality when it comes to users, because the program is open source and maintained by volunteers who “understand the burden of ‘not knowing the number,’” (Facebook post by Jason Adams, May 12, 2014). The main goal of Nightscout’s research is to prioritize the needs of users above companies or medical professionals. Of the movement’s slogan #wearenotwaiting, they explain:

What does #wearenotwaiting mean? Will we wait for vendors who disagree to integrate the hardware we need into forms we can use? Will we trust an algorithm that we cannot improve and test ourselves? Will we accept arbitrary limits on how with whom we can share data our? Will we take advantage of the opportunities to work with vendors and FDA to improve the safety and efficacy of our care? What role should our community have in helping the next generation of products? ("Nightscout and Data," 2015).

Linebaugh (2014) compares the work of the Nightscout Project to the people who “have been tweaking hearing aids...[and] using 3-D printers to make their own prosthetics,” although she acknowledges that the FDA and DexCom had concerns about the tinkering given the CGM’s status as “Class III medical devices,” which require intense levels of regulatory approval. However, given the slow approval processes and the deep impact that technology has on diabetic users, the FDA “doesn’t want to be seen as standing in the way of innovation.” More recently, Linebaugh (2016) covered people who have created a “robotic
pancreas” - which she describes as “the Holy Grail of Type I diabetes technology,” long sought but only unofficially available currently, despite advances both in glucose monitoring as well as insulin pump technology. In part, this is due to the FDA’s cautions against using CGM data to determine insulin treatment, given that the interstitial fluid read by the CGM biosensor is not as precise as the readings provided from blood samples. However, to be so close to the dream of a working pancreas, albeit an external, technological device, is hard for Type I diabetics and their caregivers and loved ones to bear.

And some people are done waiting, as Linebaugh (2016) and the NightScout community demonstrate. Linebaugh (2016) focuses her article around the caregivers of children with Type I, highlighting the “tinkering” of father Jason Calabrese, who “followed instructions that had been shared online to hack an old insulin pump so that it could automatically dose the hormone in response to his son’s blood-sugar levels.” The aforementioned limitations to CGM readings are the main reason for the FDA’s reluctance to approve such a device, although some newer models of the insulin pump and the DexCom have the ability to ‘speak’ to each other, the process does not directly impact insulin release. While hacked devices are not approved by the FDA, as long as the tinkerers are not selling them or receiving monetary benefit from them, the FDA does not interfere. The hacking instructions followed by Calabrese were created by Dana Lewis, dubbed OpenAPS, and gained attention after she tweeted about her system. The drawbacks to such a self-created system is the need for computer programming skills - although the people Linebaugh (2016) interviewed found major benefit in having their blood sugars regulated without the chance
for human error in calculating insulin doses. Given the imprecision of CGM technology, however, I have to wonder if they experienced any unexpected high or low glucose levels. Drawing on the work of Kittler in their discussion of military observational media, Packer and Reeves (2013) suggest that “strategic technical developments are answers to the human problem, as humans are recognized to have emotional and physical vulnerabilities to which machines are not susceptible” (p. 311). More times than I can count, I have stopped and wondered, did I actually give my insulin? Because I perform the same actions over and over, there is no real way to determine from my memory whether or not I took my insulin. I have no way to check until my dose (or lack thereof) becomes apparent in my glucose readings. An automatic system that would both regulate my glucose levels and supply the appropriate insulin dose would certainly cut down on my own mistakes. However, the fact that these OpenAPS devices are ‘homemade,’ as it were, means that should the device malfunction in any way, since our technological systems are not yet error free, the user is left with no official support team or easy way to replace faulty parts.

**Technological Determination**

When I first began to learn about and think about starting a CGM, my main issue was who had access to the data generated. My concern was less about what the data could do for me and more about what my data was doing once it was stored in the DexCom cloud. However, in the course of this project, and having started a CGM myself, my concerns shifted away from the issue of privacy and towards the issue of access to the data. That is the driving force of the NightScout project - the ability to access the data on multiple platforms,
less constrained by the protocols that seek to lock the DexCom data into iOS operating systems. My own lack of understanding in regards to the technological systems that underlie and manage my life means that the technological protocols Galloway (2004) describes are indeed invisible to me, which can sometimes lead to difficulties.

Some three months after I began using the DexCom G4 system, (which requires a separate receiver device, although you can pair that system with an iPhone app), DexCom sent me a free upgrade to the DexCom 5 with two new transmitters. The DexCom 5 has no need for a separate receiver device and it can be paired directly with the iPhone. The DexCom 5 is compatible with all other aspects of the DexCom system, meaning that it does not require a different biosensor. It is also connected to the DexCom Clarity site, which allows me as the user to access all the data the machine has generated, reminiscent of the NightScout project. However, what I did not know when I began to use the DexCom 5 is that this generation of transmitter has an extremely limited frame of functionality. While the DexCom 4 was designed to last for six months, the DexCom 5 is only designed to last for three, which was the reason I had received two transmitters with my free upgrade.

Beyond being glad that I no longer had to carry an extra receiving device around with me, I did not think deeply about the change. But six months after I received the free transmitters, I began receiving calls from DexCom that I needed to replace the transmitters right away. When I called the representative back to get some clarification, she explained that the G5 transmitters were programmed to stop working after three months, which meant I needed to replace them within that time frame. The G4 system, in contrast, allowed the user
to keep on using the transmitter beyond the six month deadline, although DexCom could not
 guarantee that the G4 system would last much longer than that time period. However, the
 receiver device that paired with the G4 DID have a termination date, so really I had to decide
 if I wanted to pay for transmitters that would stop working promptly, or pay for the
 transmitter that would last LONGER but also have to pay for the receiver technology. I opted
to keep using the G5, although I didn’t believe the transmitter would actually stop working
 when the representative said it would. However, within a week, I began receiving alerts from
the DexCom app to tell me that I would soon need to pair a new transmitter. And on July 13,
the transmitter stopped working altogether and the app informed me that I needed to pair the
new one, whether I liked it or not.
Despite Levy’s (1997) vision of the digital ushering in an era of universal intelligence, the example of my DexCom 5 demonstrates how potent the coded limits technologies can be. At the same time, the various communities I have mentioned in this chapter, from the Glu research community to the Nightscout community and their (sometimes overlapping) membership enable diabetics to push back against the social and technological constraints they face. In the face of a more permanent biological solution or cure for diabetes, “hacking” these various systems remains very important to increasing their...
effectiveness. In addition to hacking monitoring and pump technologies, hacking insulin is on the radar of some biohackers. The “Open Insulin Project” commenced in January 2016. Their ultimate goal is to “demonstrate the technological feasibility” for generic insulin production, lowering costs and making insulin more accessible to diabetics everywhere (Smith, 2016). The biohackers behind this movement have been “attempting to resurrect an older product to address the lack of generic insulin,” given that producers let the production of older insulins lapse when their patents expire in favor of newer, more expensive forms. These newer forms are often more potent, but they are extremely cost prohibitive - which is what the Open Insulin Project is designed to address. The material ‘failure’ of the body places the diabetic within particular mediated relationships that necessitate constant self-monitoring and intervention. As I argued above, Haraway’s (1991) cyborg is a helpful way to begin to understand the complicated logistical and social relationships between the diabetic, the diabetic body, and the technology necessary to maintain a ‘normal’ life. In the next chapter, I take a closer look at questions of materiality and bodily failure.
CHAPTER 5:

The Myth of Control: Diabetes and the “Rejected Body”

“Control: in health, most of us take for granted our bodily functions, the way our bodies seem to manage themselves. We have learned, moreover, to exert control over our bodies, trying to bend them to our will” (Birke, 1999, p. 85).

“Most people are deeply reluctant to believe that bad things happen to people who do not deserve them, or seek them, or risk them, or fail to take care of themselves. To believe this as a general proposition is to acknowledge the fragility of one's own life; to realize it in relation to someone one knows is to become acutely aware of one’s own vulnerability” (Wendell, 1996, p. 107).

“In short, the agency of the body demands an acceptance of unpredictability and not-quite-knowing” (Alaimo, 2008, p. 250).

“The agency of human beings is a question we should answer, not a fact we should assume” (Peters, 2015, p. 89).

Bodily Failure

Last September, I went in for my regular eye exam. In addition to the normal check-up, tests, and photographs, having diabetes necessitates that I get my eyes dilated so that the optometrist can shine a light into my pupils to make sure that the blood vessels in the back of my eyeballs are healthy. On this particular visit, the technician who did the photographs and initial sight test asked me several times how many years I had been a diabetic. “Eighteen years,” I told her, wondering why she needed to ask - it was in my file. I told the optometrist I’d been having headaches as she adjusted my prescriptions. “Hmm,” she said, staring at the
digital photographs provided by the lab technician. “And how long have you had diabetes?” Feeling a bit unsettled, I told her the same as the technician. She dilated my eyes and left me to wonder while the solution worked.

“It looks like you have calluses on your corneas,” she told me as she shone the light into my pupils. “Try not to wear your contacts so much. Your eyeballs need to breathe.”

“Okay,” I said. “Will that help with the headaches?”

“Probably,” she said. She paused. “Well, it looks like you have some slight swelling in your left eye,” the optometrist continued, looking at the photographs of my retinas. “Probably you have the beginning of diabetic retinopathy.”

I was silent a moment, trying to decide if I could speak around the sudden lump in my throat without crying. Every visit to a medical professional feels like a game of Russian roulette, hoping that there are no complications, hoping that I had not messed up TOO badly - and this time I had lost. “What does that mean?” I finally managed to ask in what I hoped was a mature, even tone. “Can I do anything about it?”

She didn’t look at me as we talked; instead she focused on my charts. “Well, it’s not uncommon in people who’ve had diabetes for over fifteen years. That’s when it typically appears, in fact. Basically it means the smaller blood vessels in your eye start hemorrhaging and the blood can pool and cause swelling.” I’m not sure what my face looked like, because she added, “The vessels are just, leaking a little bit.”

(At least it isn’t my fault, if it happens normally, I thought, still trying not to cry.)
She smiled at me briefly. "Lower your A1c," she suggested. "They say every point you lower your A1c, you lower your chances of retinopathy by fifty percent."

For a moment I was distracted by trying to figure out the mathematics of this - a fraction that always grows smaller but never would never equal perfect for my diabetic body.

"Yes, you have some slight hemorrhaging in your left eye. But no swelling."

She showed me on the photograph. The dilation had just allowed her to visually confirm what the camera had already captured. "I'll send your doctor a letter so you can discuss it with her at your next checkup - which will be soon?"

I assured her that it would be soon. "And I want to see you again in six months to make sure it's not getting worse." She smiled at me.

"That would be great." I lied, smiling back, fighting against the tears. "One of the most unfortunate side effects of eye-dilation is the length of time your eyes remain dilated, precluding driving."

I paused. "Or to see if it gets better." She smiled at me.

"That all-important word - control. That all-important word - control." I lied, fighting against the tears.

"My control had never been perfect, and complications were inevitable. How would I test my blood or give my insulin if I went blind?"

For a moment I was distracted by trying to figure out the mathematics of this - a fraction that always grows smaller but never would never equal perfect for my diabetic body.

"Yes, you have some slight hemorrhaging in your left eye. But no swelling."

She showed me on the photograph. The dilation had just allowed her to visually confirm what the camera had already captured. "Yes, I'll send your doctor a letter so you can discuss it with her at your next checkup - which will be soon?"

I assured her that it would be soon.
scholarship, this chapter focuses primarily on the materiality of the body. My own experiences become a way of exploring what happens when a body fails. Particularly, this chapter looks at the diabetic body from a materialist feminist perspective.

**The Myth of Control**

This dissertation project has, in many ways, been a meditation on the disjointed ways in which discourses around technology, in particular medical monitoring technologies, present a very clean and data focused narrative, but neglect the messiness of the organic components involved in how data actually function in day-to-day life. Living with diabetes is messy, from the blood and injections to the internal processes that can be influenced by insulin, exercise, and diet but can never be completely controlled, even with the advances of technology. The creation of the “diabetic subject” arises out of many interrelated processes - from the technology of the monitor, the protocols of education, and the networks that support diabetics beyond the medical industry. Birke (1999) suggests in the quote opening this chapter that “we” humans do not tend to think about our bodies’ processes while they are functioning in an acceptable way, and that we seek to “control” malfunctioning processes through our own will. Certainly, the ‘relentless positivity’ of diabetes education I described in the last chapter is focused on the will and attitude of the individual diabetic in attempting to achieve an always-better level of control over blood sugar levels regardless of the fact that perfect control is impossible. Wendell (1996), in writing about disability and chronic illness, describes how the “myth of control” functions within social and medical discourses to elide the fact that human bodies are fragile and that complete control is impossible. When bodies
fail, Wendell (1996) suggests, they deviate from the idealized norms of bodies, leading to what she terms “the rejected body” to describe “those aspects of bodily life (such as illness, disability, weakness, and dying)... that are feared, ignored, despised, and/or rejected in a society and its culture” (p. 85).

In writing about her own diagnosis with a chronic condition, Wendell (1996) muses on the ways in which health conditions and disability are understood and constructed within institutions and cultural discourses. She suggests that definitions of ‘‘impairment’’ and ‘‘disability’’ seem to imply that there is some universal, biologically or medically describable standard of structure, function, and human physical disability” (p. 14). “Impairment” of the body, whether chronic medical conditions or physical disability, is defined in various ways by different entities invested in deciding who needs health and community resources, and “the power to define is not necessarily in the hands of those who are most affected by the definitions” (p. 24). And of course, the experience of ‘‘impairment,’’ however defined, changes based on wider structures of support in society. The limitations people face in different social and cultural settings is of an uneven nature; Wendell uses the example of her own physical limitations due to chronic fatigue. Walking to her car tires her, but she is still able to function in a way that is deemed “productive” by her social and cultural setting in a way that she would be unable to do if she lived in a place where “abled” depended on being able to walk long distances for water.

Wendell (1996) is careful to distinguish between the biological reality of physical impairment and the “social response to and treatment of biological difference constructs
disability from biological reality, determining both the nature and severity of the disability” (p. 42). Case in point: it is ‘easier’ for me to exist as a diabetic in the United States than it was in Thailand when I was a teenager, simply because the relative accessibility of diabetic supplies is so much better Stateside, not to mention the access to medical professionals who are trained in the latest treatments of diabetes. However, the US is behind many European countries in terms of approval for new technology and treatment options, and I would add that nations with universal healthcare make living with diabetes far more affordable, although access to some forms of diabetes technology is still restricted. Australia, for example, has a health care system that provides “universal coverage” for nationals visiting state and government run medical institutions and that covers most medications (“Health Care System and Health Care Policy in Australia,” 2015). Constant Glucose Monitors, however, are not covered by the government at this point in time (Cohen, 2015). In terms of other types of diabetes care, some experts estimate that American diabetics pay “between 5.7 and 7.5 times more than those in the UK” for insulin and other diabetes-related drugs (Idlebrook, 2015). As I discussed elsewhere, one of the primary factors affecting lack of access to insulin globally is the discontinuation of the older, cheaper animal based insulins in favor of the more advanced (and effective) human insulins (Green and Riggs, 2015). The disease of diabetes mellitus is the same no matter what country you live in: the associated risks and potential complications are always potential threats, but the likelihood of developing said risks or complications varies depending on what treatment options, medical knowledge, and technologies you can access. The will to control the disease is not the only
factor in play. “Control” can only be as good as the treatment options available, accessible, and affordable.

Within the United States, access to diabetes related medical supplies, from insulin to test strips, not to mention more sophisticated technologies like the CGM or the insulin pump, has long depended on the type of insurance diabetics were able to obtain. Prior to the passage of the Affordable Care Act in 2010, diabetes was classified as a “pre-existing condition” for which insurance companies could refuse to extend coverage. The Affordable Care Act also required many preventative services related to identifying and dealing with diabetes to be completely covered at no cost to the patient (“Key Features of the Affordable Care Act by Year,” 2015). When my insurance coverage lapsed between my masters program and beginning my PhD just prior to the passage of the ACA, I was denied coverage by multiple companies because I had Type I diabetes, as I noted previously. Even when insurance coverage is extended, the coverage doesn’t always cover the costs for diabetes supplies entirely. For the past four years, I have been covered through North Carolina State University’s graduate student plan. On this plan, my prescriptions range from $20-40 each month at the campus pharmacy. However, as I discovered when I miscalculated when my supplies would end over this past Christmas break, this insurance plan covers far less at other pharmacies. Given that my normal bill at the NCSU pharmacy was around $70 a month, I was deeply shocked to be handed a bill for $700 at Walgreens.
(“Are you sure you want to fill them?” asked the pharmacist, trying to be helpful. The answer was no, but since I needed the insulin, I said, “I’m sure,” and pulled out my credit card.)

To further complicate things, this insurance plan does not deal directly with DexCom for CGM supplies, and I cannot purchase them in any pharmacy. Instead, a third party, Edgemark Services, has a contract with the BlueCross BlueShield insurance company, and I buy all of my supplies through their website. These supplies are then shipped directly to my apartment. This caused some confusion when I was receiving notices from DexCom to reorder my transmitters, because the Edgepark site would not let me order online. I had to call Edgepark directly to verbally re-order the transmitters.

A recent story from the state of Mississippi amply demonstrates the issues that come with this confusion of institutional players. While the Affordable Care Act requires that insurance companies accept diabetic customers and also requires individual states to provide insurance through programs like Medicaid to diabetic children within certain economic categories, the states themselves are ultimately responsible for determining how this coverage is dispensed. Earlier this year, Nicole Nichols, who has a daughter with Type I diabetes, learned the drawbacks of this patchwork system the hard way. While her Medicaid insurance is supposed to cover diabetes supplies, Nichols’ home state uses a third party system like Edgepark to distribute pump related supplies (Smith, 2016). And the third party’s payment system would not accept Medicaid. Upset, Nichols wrote to various state legislators to gain assistance in straightening the situation out, one of whom charmingly responded by
asking her if she had considered “buying the supplies with the money that you earn?” seemingly unaware of how expensive supplies for insulin pump supplies run without insurance coverage (Hampton, 2016). Fortunately, the online outrage that Nichols’ social media accounts sparked enabled her to talk to a Medicaid representative, but it is ludicrous that using technology that has been proven to reduce complications should be so inaccessible. Even though technologies like the CGM and the insulin pump are more readily available in the United States than they are in other places, access to them are still heavily restricted by insurance industry requirements that are not always apparent until you are in the middle of trying to obtain them in order to gain better control.

**Managing the “Errant Body”**

A history of diabetes, both in the official sense but also in the context of my own experience, is also the history of managing and seeking to control the diabetic body, whether through insulin regimes and glucose monitoring, through diets and correct behavior, or through maintaining the correct, positive attitude. Matthew Davis (1998) describes this history as focused on the “diabetic patient’s inability to control bodily functions. Meanwhile it marks the exchange for the physician to the patient as the force that directly administers treatment and thus controls – or fails to control – the errant body” – where fault in failure is placed on the patient, and any success credited to physicians’ “carefully crafted treatment regime” (p. 82). Lately, this treatment regime has necessarily grown to include more forms of technology, of which the CGM has been a key focus for this project. The disconnect between the treatment regime and goal of control and the lived experience of dealing with an “errant
body” is necessarily draining, physically and mentally, as I discussed briefly in the last chapter. Wendell (1996) points out that

A major obstacle to coming to terms with the full reality of bodily life is the widespread myth that the body can be controlled. Conversely, people embrace the myth of control in part because it promises escape from the rejected body. The essence of the myth of control is the belief that it is possible, by means of human actions, to have the bodies we want and to prevent illness, disability and death. (p. 93-94).

Further, Wendell (1996) argues that this “myth that the body can be controlled is part of the general assumption of the modern Western scientific project that nature can be controlled” specifically by fostering “the myth of control by focusing overwhelmingly on cures and life-saving medical interventions, and by tending to neglect chronic illnesses” (p. 94). I will never be able to achieve perfect control over my own body, and I have the graphs to prove it.
Figure 5.1 Screenshot from July 21, 2016. Portrait of frustration.

The screenshot above shows my glucose trends on July 21, 2016. I included this particular screenshot because, as you will note, my levels were been trending in the high ranges, for no particular reason that I could identify, as I did the same things I had done the day before to wildly different results. Instead of falling back into range following breakfast, my levels continued to climb with a steep drop off around 9 am, when I walked to the library. The same pattern occurred at lunch: I was in a more ‘normal’ range (at 164 md/lg) prior to eating; I calculated my insulin dose, and three hours later I was still in the 240 md/lg range,
despite multiple corrective fast-acting insulin doses. While my instinct in this moment was to give another dose of insulin, I also did not want to overcompensate and drive my glucose levels too low. Even with the CGM, I have no idea of how my sugars will be trending five minutes from now, and this data is only a rough guide to how I should address this particular trend. Even the “best day” in the data from the past week available through DexCom Clarity shows that I am not always in target range.

Figure 5.2 Screenshot from July 19, 2016.

In the case of diabetes, technology functions as a solution rather than a cure, and the emphasis on using technology is only growing. The move that Alaimo (2008) makes in suggesting that in considering the agency of the body must involve the “acceptance of unpredictability and not-quite-knowing” beautifully illustrates the experience of dealing with a chronic condition where the same habits and actions can result in different results (p. 250).
Having spent the majority of my life struggling to gain control over my body, trying to monitor correctly, trying to maintain a positive attitude, following Alaimo's encouragement to accept “unpredictability” is a relief. In this chapter I wish to examine what Alaimo (2008) terms an “agency without subjects,” looking at the non-subjective agency of the diabetic body itself rather than the diabetic individual’s struggles to gain and maintain control over the unruliness of the body. As I have noted in previous chapters, “materialist” perspectives represent a growing interest among media scholars, and through the work of material feminists, I wish to connect a “material” media perspective with a materialist perspective on the body.

**Materialist Perspectives on the Body**

Discomfort with genetic or biological explanations of human behavior has long been a hallmark of critical feminist scholarship. Birke (1999) argues that feminism has historically been opposed to biology because to “be determined by biology is to surrender to limitations, to deny the possibility of change” whereas “[f]eminism…assumes social and political change to be not only possible but desirable” (p. 1). This stance is a stand against biological determinism, but Birke confesses that such a strict rejection of the biological results in a feminism that theorizes the body’s interiority through psychoanalysis, but otherwise “seems to always end at the body’s surface... What goes on inside the biological body remains a mystery, to be explained (if at all) only in the esoteric language of biomedicine” (p. 2). Wilson (2015) argues that there would be “feminist theoretical gain in relation to” incorporating “biological data” in thinking about “minded and bodily states” in her
examination of depression and the body (p. 1). Specifically, Wilson suggests that feminism’s critical sophistication has been developed at biology’s expense. Critical techno-scientific feminists such as Stacey Alaimo and Donna Haraway, along with Eugene Thacker who theorizes “biomedia,” present what might be termed “critical/material” perspectives on the body. Instead of focusing on consumer practices in relation to technologies, as Lupton (2007) describes, this approach follows Kittler in de-centering human experience and consciousness, and focuses instead on how technological and human processes interact with and inform each other. Such a move requires not only rethinking the body and technology, but also issues of agency.

A major theme of feminist critical work has been the rejection of the notion of an “essential” female identity – pushing back against (in particular) Western concepts of self and other that centered “male” as normal and “female” with “other.” Wendell (1996) discusses what she terms the “idealization” of the human body - pointing to longstanding feminist work on the commodification and objectification of the body, particularly in relation to media representation. Wendell extends this critique to suggest that healthy bodies are commodified, and in relation to disability or chronic illness, the body becomes “other” in the sense that the individual cannot function in ways deemed productive or appropriate in the social paradigm of “healthy.” This idealization implies “the rejection of some kinds of bodies or some aspects of bodily life,” ignoring that “real human bodies are exceedingly diverse - in size, shape, colour, texture, structure, function, range and habits of movement and development - and they are constantly changing” (p. 85). The foci of the scholars interested
in these questions vary but central to their work is the concern that we reject broad categories of essentialism while also dealing with issue of difference and the material. Wilson (2015) notes that feminist work related to the body has “demonstrated how bodies vary across different cultural contexts and historical periods, how structures of gender and sexuality and race constitute bodies in very particular ways,” but argues that feminist theorizing also needs to engage with biological data (p. 3).

Alaimo and Hekman (2008) note that the turn towards “social constructionist models” that focus on "the role of language in the constitution of social reality" was a very productive turn for feminist scholars, and has "fostered complex analyses of the interconnections between power, knowledge, subjectivity and language" (p. 1). While not a scholar of technoscience, Ang (2003) demonstrates both the power of a discursive approach as well as its limitations as she discusses the inevitable failure of feminisms that simply seek to be “inclusive” and allow everyone to “have a voice.” She argues that dominant forms of feminism (specifically that of White, Western Feminists) use dialogue with non-dominant feminists as a “containment strategy” and assume that “the diversification of discourse would eventually lead to a broader, more inclusive representation of ‘all’ women” (p. 193, 195). Ang highlights important economic and social disparities, yet her solution of a “politics of partiality” is still dependent on the discursive model. In Gender Trouble, Butler (1990) draws on the work of Foucault to examine the ways in which “the body gains meaning within discourse only in the context of power relations” (p. 125). Butler’s (1990) rejection of “gender” as a “stable identity” and her concept of “performativity” are important to feminist
scholarship, but scholars such as Alaimo and Hekmen (2008) suggest her conceptualization was too limited in scope. Alaimo (2008) argues that Butler's “discursive model” is not enough for feminists interested in materiality because she does not deal with “nonhuman creatures” (p. 247). Coleman (2008) goes so far as to suggest that Butler criticizes “any notion of matter” (p. 65). This “rejection of the body” in favor of a focus on the discursive constructs about the body is a sticking point for feminists interested in dealing with issues of materiality, and as such Butler stands as an important figure to critique and build on through an expansion of the concept of performativity. The drawback to the purely discursive approach is, as Barad (2003) provocatively states, “[l]anguage has been granted too much power” (p. 801). Getting away from the “language/real” dichotomy is a key concern for material scholars. As noted above, Alaimo and Hekman (2008) discuss this discomfort with the “material,” arguing that generally feminist scholarship operates on a “material/discursive” dichotomy. They suggest that while the focus on discursive constructs of gender represented by Judith Butler have been valuable, feminist scholars need to re-embrace the material. This theoretical approach explores ways to move beyond the apparent dichotomy of the “material” and the “discursive,” specifically as related to bodies and gender through engaging with the work of feminist scholars involved with science and technology studies.

Haraway (1991) represents an important move towards recognizing the “material” as an important and helpful concept within feminist scholarship. Through her “cyborg,” Haraway envisioned a feminist politics that dealt not only with the discursive construct of
“woman,” but also the complex relationships between “machine and organism.” As I suggested in the previous chapter, the figure of the cyborg is a helpful concept from which to consider the relationship between the diabetic body and the attendant technology. In this chapter I wish to extend the conversation even further, beyond Haraway’s work. Hekmen (2008) identifies Haraway’s work as an extremely important move in attempting to “deconstruct the discourse/reality dichotomy,” but ultimately she posits that “Haraway’s project failed” due to the discursive turn in feminist critique (p. 86). In a similar vein, Braidotti (2006) argues that “Haraway’s work dislocates the centrality of the human, in favor of the in/non/post-human and of bio-centered egalitarianism” (p. 199). How to deal not only with the production of human subjectivity but also with the non-human material world is a key tension within these discussions.

Regarding ‘the body’ in feminist scholarship, Alaimo (2008) suggests that there has been an overemphasis “on how various bodies have been discursively produced, which casts the body as passive, plastic matter” (p. 237). Disassociating the body so completely from the material world neglects “agency” beyond human consciousness. She provides the example of chronic illness as a tangible example of the ‘negative’ agency of corporeality, since the actual symptoms, as well as their severity, can vary from day to day and even within the course of the same day… even the combined information from physicals, medical research, support groups, and the experiential data of one’s own body will not result in some sort of
crystalline understanding, since there are many (how many?) forces continually intra-
acting. (Alaimo, 2008, p. 250)

Knowing the details of how the body is supposed to work and what the effects of a chronic illness may be does not fully capture the way such processes actually unfold. Hypoglycemic episodes (low blood sugar) and Hyperglycemic episodes (high blood sugar) for individuals with Type I Diabetes provide an example of what Aliemo (2008) is talking about. Extreme blood sugars occur for a variety of reasons, from miscalculating insulin doses to exercise, acute anxiety or stress, to illness.

Figure 5.3. Screenshot from July 5th, 2016.

For example, the screenshot above depicts my DexCom G5 readings from the early morning of July 4 to noon on July 5th. As you can see, my numbers were fairly consistent during my sleeping hours, with a dip around four am and then a sudden spike around five am, and a continued sharp rise to the mid-200s. One could assume that I ate breakfast around six
am and thus the spike was the result of an inadequate insulin dose. In fact, these readings reflect the stress I felt as I went to get my fasting blood work done. I woke up slightly high, and then as the technician attempted (and failed) to find an adequate vein in my arm, my readings shot even higher. Once he finished and I was able to resume my day, you can see that my glucose levels quickly returned to normal between nine and ten am. The CGM makes visible the physical responses to certain ‘feelings.’ Sometimes, however, there is no obvious reason for such an event to occur – and without an obvious external reason, the inner processes of the body require technological mediation to be understood. As an “informed” and responsible patient, it is up to me to respond in ways that take into account the visualization of my glucose data, the physical reactions my body has to various biological and emotional phenomena, as well as the options available to me to respond. Daston and Galison (2007) refer to this sort of interpretive process as “trained judgement,” where the observer draws on a variety of knowledges in order to interact with the mediated presentation of the data (p. 19).

Alaimo and Hekmen (2008) identify Donna Haraway’s (1991) concept of the ‘cyborg’ as one of the first attempts to re-think the complex connections of human and technology. To reiterate, Donna Haraway (1991) predicates her concept of the cyborg explicitly on the concept of hybridity: “a cyborg is a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction.” The fiction of coherent identities or social realities is a key point in her argument for a re-understanding of how the politics of identity are deployed in attempting to achieve
“liberation.” But since the “fiction” of such constructs is so precarious, Haraway argues for political mobilization or ‘unity’ through “affinity, not identity.” The ‘cyborg’ presents a helpful model to contemplate how “human” becomes an identity that is deployed in specific ways, similar to how Haraway suggests that that the concept of a “women’s experience” is a construct created for a particular political aim: the creation of a collective experience sought to achieve a particular form of liberation. In the last chapter, I suggested that a similar approach to understanding how the term “diabetes” is often used indiscriminately to refer to both Type I and Type II. While both types share some experiences, the biological realities of each type are not the same (Type I is unquestionably dependent on insulin; it is possible for Type II to be managed via other means). Finding affinity between these groups - such as shared struggles to gain access to technology and medication - rather than relying on a singular diabetic ‘identity’ could be a productive move. Framing advocacy and research in terms of affinity would result in achieving particular types of political and institutional interventions into treating the different diabetes types. However, Alaimo and Hekman (2008) suggest that Haraway does not go far enough in de-centering the human from discussions of humans and technology, pointing instead to Barad’s (2008) post-human performativity to further explore how “agency” beyond human choice.

Alaimo and Hekman (2008) and the scholars they reference are primarily interested in deconstructing the “discursive turn” in feminist studies and arguing for the need of the “material” as a corrective to feminist (and critical) scholarship. Alaimo (2008) defines “material feminisms” as seeking “to understand materiality as constituted by various forms of
power and knowledge” without falling into the dichotomies of “nature versus culture” or “language versus reality” (p. 243). Smelik and Lykke (2008) explicitly connect their collection to the realms of feminist scholarship, technoscience studies, and cultural studies to demonstrate the kinds of questions that should be asked about new assemblages of biological and technological. They explain that “the figuration ‘bits of life’ is meant to be an evocative term that can help us map changes and transformations and strike a middle road between the metaphorical and the material,” and evokes a “technophilic sensibility” in relating the biological with the non-biological (Kindle Location 138). Lykke (2008) looks at technoscience as a “cultural activity, as signifying practices, and as everyday life practices” (p. 12). How to deal not only with the production of human subjectivity but also with the non-human material world is a key tension within these discussions.

Important to both groups of scholars, Karen Barad’s work offers a way to move past both the “discursive/reality” dichotomy and to re-conceptualize the relationships between the material and the discursive through a “posthuman performativity.” Barad herself positions her work in line with that of Neil Bohrs, and she draws on the work of Foucault, Bergson and Deleuze among many others to construct her philosophical framework. Barad notes the importance of Butler, arguing that her performativity “shifts the focus from linguistic representations to discursive practices” (p. 807). Barad’s reconceptualizing of performance depends not on turning “everything (including material bodies) into words,” but rather to examining practices that define the “differential boundaries” between “human” and “nonhuman” (Barad, 2003, p. 802, 808). In this, Barad is drawing not only on Butler, but
reconfiguring Foucault’s “analytic of power” in the following ways: First, Barad seeks to account for the “body’s materiality” – suggesting that Foucault “does not tell us in what way the biological and the historical are ‘bound together,’” and that he fails to account for the how the body’s “materiality plays an active role in the workings of power” (p. 809). Second, Barad argues that power cannot be reduced to the “social, and scholars need to examine the “material-discursive practices” that mark out ‘human’ and nonhuman’ (p. 810). This calls for what Barad calls “onto-epistem-ology” – the study of practices of knowing, and “agential realism” – which “proposes the intra-action of matter and discourse” (Hekman, 2008, p. 104).

**Intra-Agency and the Human/Other**

One of the central concerns about a “return” to materiality is the fear of a return to the notion of “biology as destiny” (Aliamo, 2008, p. 241). Grosz (2008) goes back to the work of Charles Darwin to challenge the idea of “inevitable” trajectories. Rather than reading Darwin’s work as an argument for biological determinant subjectivities, Grosz instead suggests that his work can be seen as a “way beyond dichotomies” as he advocates the view of the material world as a ‘field of potentialities,’ with no set outcome but a multiplicity of options. Recognizing “material history and the ways in which women’s biology had produced a gender system” must also emphatically refute that “such a history is inevitable” (Colebrook, 2008, p. 65) But as Braidotti (2006) points out, the “what exactly counts as human” has been destabilized by “technologically mediated social relations” (p. 197). In the spirit of Haraway’s (1991) cyborg, Lykke (2008) argues that feminist discussions must deal
with “technobodies: machine humans, or machine animals” (p. 12). This demonstrates the need to be able to deal with issues of not only human life and subjectivity, but also the various forms of non-human life and the non-biological entities that currently play a role in structuring human and other subjectivities. Of pivotal importance is the recognition that “matter” cannot be seen as passive, just as bodies are not “passive, plastic matter” (Alaimo, 2008, p. 237). And with this recognition comes the further responsibility for feminist scholars to recognize agency and life beyond that of the human.

In an attempt to expand feminist conceptualization of “life,” Braidotti (2008) differentiates between what she terms “zoe” – “vitalistic, pre-human, generative life” and what she terms “bios” – “a discursive and political discourse about life” (p. 177). While “bios” results in particular forms of ethics and discussion, recognizing “zoe” as part of feminist discussions complicates discussions of subjectivity and ethics, noting that “[s]ustainable ethics is a process, not a moral imperative. This is where the non-individualistic visions of the subject as embodied, and hence affective and interrelational, is of major consequence” (p. 188).

This is where Karen Barad’s concept of “intra-agency” becomes key. If the “subject” has been destabilized by new formations of biological and technological entities, how can the subject even be measured? Barad (2008) rejects “representationalism” – “the belief that words and things are primary units with inherently determinate boundaries” in favor of an “agential realist account” (p. 170). Instead, Barad (2003) looks as practices that define the “differential boundaries” - rejecting “interaction” as presupposing the “prior existence of
independent entities” (p. 815). Discourse, for Barad, does not equal language. Instead, “discourse” “is that which constrains and enables what can be said” which “emerge from a field of possibilities” (p. 819). Further, “agency” does not equate strictly to consciousness – as Alaimo demonstrates by using the example of chronic illness. She notes that even with “the combined information from physicians, medical research, support groups, and the experiential data of one’s own body,” the experience of chronic illness often follows no discernible pattern and cannot be “controlled” (p. 250). This, Alaimo suggests, is an example of the “intra-agential” processes Barad describes.

The “material” has become an issue of interest and concern for feminist scholars seeking to deal with current, complex, configuration of the human, the technological, and other forms of life. Ecological feminists have long highlighted the connections between the human and the natural world (McNeil, 2008). For other strains of feminist scholarship, however, the long equation of “nature” with “woman” (as opposed to “civilization,” “culture,” and “man”) resulted in the so-called natural world being ignored in favor of a focus on the discursive construction of the subject, ala Foucault and Butler (Colebrook, Hekman, Alaimo, et al.). Incorporating the “material,” however, raises fears of a return to the simplistic dichotomies I have described. I would argue that the work of Haraway (1991) and Barad (2003, 2008) both offer theoretical positions that allow feminist scholars to incorporate the gains of the discursive turn as well as the recognition of materiality. Lykke (2008) identifies “technoscience studies” as focusing on examining technoscience as a ‘cultural practice’ – seeking out a ‘middle way’ between the discursive and the strict determinism of
previous scholarship (p. 12). Lykke and the scholars in *Bits of Life* thus place Haraway and her work on the cyborg at the center of their reconceptualization of materiality in relationship to critical feminist analysis. In contrast, Alaimo and Hekmen (2008) and the scholars they include in *Material Feminisms* rely more heavily on the work of Karen Barad, and her complex and often confusing work on “intra-agency” and “post-human performativity.” For scholarship involving the relationships between ‘human,’ technology and agency, however, these essays provide invaluable histories of the “material turn” in feminist scholarship as well as important frameworks for continued exploration. I find these frameworks particularly important in considering the intricacies of my own relationship with technology and agency, my own conscious agency in terms of attempting to gain better control, and the agency of my chronically ill body.

Drawing on Barad’s work on intra-action and intra-agency to explore alternative critical feminist approaches, Wilson (2015) explores “the condensation of viscera and mood, exemplified in the term *melancholia*” - providing a historical account of how depression has been understood and treated throughout Western medical history. Just as digital technologies are often characterized as “ephemeral” despite their material components (servers, screens, etc.), Wilson seeks to push back against the characterization of mental illnesses as somehow non-material, and also located primarily in the brain. Specifically, she argues that the “neurological is not synonymous with the cerebral” (p. 5). By using the term “melancholia,” Wilson seeks to evoke a specific history of disorders that ties back to the ancient theory of the “four humors” - an attempt to explore how the “mind” is not separate from the rest of the
bodily systems. “Melancholia,” Wilson suggests, has always been mutable - demonstrating that depression is “contingent” (p. 8). As I noted in the previous chapter, individuals with diabetes are highly likely to develop chronic depression also. However, since “depression” is considered a neurological problem, my endocrinologist never discussed the connection with me since I was performing adequately in terms of achieving control. Likewise, my therapists never spoke of the connection either, because as experts in “mental” issues, the endocrine system was not a part of their purview. My diabetes was a problem that related to my mental health, certainly, but neither group of experts saw these issues as part of a material whole: they were separate issues that I, personally, needed to face and control, whether via insulin or therapy. The point that Wilson makes, that mental illnesses are in fact imbricated in the body, is an important one, and I would suggest that recognizing the materiality of chronic illnesses is an important extension of her observations.

The Materiality of Diabetes

As noted earlier, a common mantra in diabetic circles is “you are not your diabetes!” In some ways, this is certainly true - I have thoughts and feelings and experiences unrelated to the disease directly. But in very material terms, my life is defined by the failure of my pancreas – blood tests, injections, dietary guidelines, insurance hurdles, and a veritable army of medical professionals shape my everyday existence, no matter how well I hide my chronic disease from those around me. In writing this dissertation, I found it strange to realize that I am comfortable believing that genetics (or some other unknown biological or environmental factor) “determined” my body’s failure while at the same time feeling that I must deny that
diabetes has an impact on my life beyond the obvious tests and injections. Topal (2015) would argue that better medical technology would “determine” a better outcome in my health regime, whereas the push in diabetes education is to embrace self-determination - your own self-control results in better health, although this self-control is highly dependent on medical technology, and of course, access and the ability to pay for it. However, having data means nothing if you do not act on it. All the same, the push to use technology is growing; while I fought against using an insulin pump or a CGM, these technologies are becoming the foundation for diabetes management. While the information about blood sugar control provided on the American Diabetes Association website pertains primarily to regular glucose monitoring, the Joslin Diabetes Center suggests that the CGM, in particular, marks a “new era of diabetes management” (Wolpert, n.d.). This tension between self-control and technological advancements roughly reflects debates within media studies more generally, in short, the great debate about whether culture or technology is the determining factor within social relationships.

Until recently, I fell heavily on the side of the “cultural” side of the “culture versus technology” debate. It seemed obvious to me that scholars like Marshall McLuhan were ignorant of, or purposefully ignoring, social and cultural inequities that technology alone simply could not address. Williams’ (1974) critique of technological determinism as “an untenable notion” due to its excluding “real social, political, and economic intention” for “the random autonomy of invention” gets at this very issue (p. 133). At the same time, I could not deny that technology, as McLuhan so aptly put it, “extends” particular capabilities – both at
the individual human level and at other levels of human social and cultural interaction. My own dependence on glucose monitors made that abundantly clear: monitoring technology makes possible my attempts to control an incurable medical condition. However, I still rather firmly believed in my own ability to control diabetes and never really thought about the ways in which monitoring technologies structured my life. In fact, as I discussed in chapter three, I actively resisted using technologies like the CGM and the insulin pump; partly out of financial reasons, but also because I felt that these technologies would mark me as ‘other;’ without them, I could keep my blood tests and my insulin shots to myself, if I chose. Wearing a transmitter or an infusion set would take that privacy away from me. Receiving a diagnosis of diabetic retinopathy, however, provided a dire reminder that my own abilities in terms of managing my chronic disease were not enough in and of themselves, and was the catalyst for me to start using the CGM. And despite being overwhelmed initially at the deluge of data provided by my CGM, I have come to rely on my ability to see the patterns and trends of my blood sugar levels. A CGM does not necessarily solve the mysteries of my highs and lows, but it does provide knowledge that allows me to better address my own glucose extremes.

In an attempt to find a balance rather than opposing technology and culture, Slack and Wise (2005) reject both “technological determinism,” which they describe as positing technology’s effects as the “principal determinant of cultural change,” and “cultural determinism,” which places culture as the determinant cause of change (p. 45). They suggest that a better way is needed than these two extremes, and they attempt to lay out an understanding of technology as “articulation and assemblage” – and recognize the contingent
nature of the relationships of culture and technology (p. 100). Slack and Wise (2005) offer a “technological cultural model” to attempt to demonstrate that “technologies are integral to culture, not separate from it” (p. 5). In a similar vein, rather than arguing for a straight “technological” or “cultural” divide, I would suggest that it would be more productive to think of instead of this debate as a continuum, with a wide range of definitions of technology and of culture, and more specifically for this particular project, the necessity of incorporating bodies into discussions of determinism. Particularly in the case of managing diabetes, wherein technology is absolutely necessary, and so is the recognition of social and cultural factors, as well as non-human agency.

In an interview with Jeremy Packer (2012), John Durham Peters explains that “the debate about technological determinism is caught on a false dichotomy,” pointing out that humans are “conditioned” and “determined” by numerous elements, including oxygen. In pondering questions of determinism more deeply, John Durham Peters (2015) whimsically considers the ways in which our primary medium of air delineated humanity’s media development from that of sea mammals: sea mammals “live in an environment closed to material fashioning and their bodies show it” (p. 57). Whales and other sea mammals communicateaurally, but lack the storage technologies that humans are able to fashion by virtue of having hands and living on land. Peters (2015) further discusses the ways in which “technological determinism” is rejected in “the name of popular agency,” but suggests that doing so “not only underestimates the power of devices but also overestimates the power of people” by “keeping subjects and objects in separate boxes” (p. 88-89). To contextualize his
observations within the conversation at hand, the emphasis on medical technology
overestimates both the power of medical devices and the conscious agency of humans and
ignores the “negative” agency exhibited by bodily processes outside of conscious control.
Barad (2003) argues that “[a]gency is not aligned with human intentionality or subjectivity...
Agency is a matter of intra-acting; it is an enactment, not something that someone or
something has,” emphasising the importance of ‘boundary-making’ processes that allow us to
understand the dynamic world we inhabit (p. 826-827). Alaimo (2008) encourages scholars
to realize that

Acknowledging that one’s body has its own forces, which are interlinked and
continually intra-acting with wider material as well as social, economic,
psychological, and cultural forces, can not only be useful but may also be ethical (p.
250).

The diabetic body presents a helpful site at which to examine the intra-action of
internal and external forces. Barad (2003) argues for the need to “question the givenness of
the differential categories of ‘human’ and ‘nonhuman,’” and to examine “the practices
through which these differential boundaries are stabilized and destabilized” (p. 808). The
CGM certainly destabilizes the boundary of my skin, making the internal processes of
glucose levels ‘visible’ in a way that a regular glucose meter cannot do. While there has been
research into how medical technologies have changed understandings of the body and
humanity’s relationship with technology, often these studies focus on how digital
technologies represent the body. Scholars such as Kim Sawchuk (2000), Catherine Waldby
(2000) and Helen Burgess (2002) note that imaging technologies such as the X-ray and the MRI impact our understandings of what the body is, how it functions, and how such technologies impact subjectivity. And in one sense, the examining CGM technology can fit rather comfortably into this set of research into health-related technologies.

Kim Sawchuk (2000) looks at how medical imaging technologies such as microscopes and MRIs “visualize and enlarge somatic space,” changing both how we understand and imagine our own bodies (p. 9). She suggests that “subjectivity, our sense of who we are as human beings and of our capacity for agency and action in the world is marked … by the proliferation of technological possibilities” (p. 20). Similarly, Burgess (2002) argues that these imaging technologies “offer opportunities to conceptualize the body and the subject in new ways.” Waldby (2000) focuses on the ways in which imaging “technologies effectively render the human body, or more precisely the appearance of the body, into digital information, decomposing the body’s fleshly complexity into the simple on/off logic of binary code” (p. 28). The CGM is not precisely an imaging technology in the same way that an MRI or X-Ray machine is, offering an interesting point from which to engage with bodies and agency, as well as the boundaries between bodies and technologies.

While not providing images of the internal spaces of the body, CGMs provide a visualization of specific internal processes and obviously impact the individual subjectivities of the people using the technology. Daston and Galison (2007) differentiate between the “representation” that technologies such as the camera provide to scientific archives, and the “presentation” that digital and nanotechnologies allow via the capability to provide “pattern
depiction” that is knowable and understandable via “trained judgment” (p. 371). Prior to starting a CGM, as described in previous chapters, I thought of my blood sugars as an unknowable set of processes (if I thought about it at all), a set of data points gained by individual blood readings that provided important information about that particular point in time, and allowed for general assumptions about overall trends. If my blood sugars were high at lunch, for example, chances were that I had miscalculated my breakfast insulin, and so on. But the CGM fills in the gaps by providing a continual stream of data points, and helpful indicators of which way blood sugar levels are trending.

Figure 5.4. Screenshot from July 5, 2016.
Following the stressful blood work appointment on the morning of July 5th, my sugars dropped rapidly - the result of my stress dissipating but also due to the high dose of insulin I gave at breakfast to combat the abnormal morning high combined with a walk to the library. Without the CGM, I would have gone from a 256 mg/dL morning reading to a 65 blood-monitor reading two hours later and been very surprised, especially if I hadn’t felt the physical symptoms of a low blood sugar level. Because I had the trend warning, however, I was able to treat the low before it got to be a low.

Given how narrow the ADA’s guidelines for “normal” blood sugars, (70-130 for the vast majority of the time), access to see which way glucose levels are trending, or how long they have remained at a certain level is invaluable. The goal of diabetes control is to get the A1c test below 7.0, and to minimize the range of blood sugar levels, with an obvious need to keep them from going and remaining too high. However, when blood sugars are too consistently low, the A1c level is lowered, but in the short term, low blood sugars are more immediately deadly, leading to a coma and death in far less time than uncontrolled high glucose levels. When this situation occurs, the doctor is likely to require the diabetic to RAISE their A1c in order to maintain healthier levels. To offer a comparison, when I was diagnosed at twelve with my glucose levels over 700 mg/dl, I had not yet gone into a coma (although I was nearly there) and my sugars had been far too high for an unknown amount of time previous (but likely at least six weeks). Comas from low blood sugars can result as soon as the diabetic hits 70 mg/dL, or the lower end of the ‘normal’ spectrum, meaning that the
CGM, which can both depict downward trends AND provide an alert to the user about dangerous levels can be a legitimate lifesaver.

**The Rejected Body and the Sacrificial Other**

The diabetic body offers a prime example of how agency within a bounded set of living organisms operates beyond and often in spite of human consciousness, and also functions as a way to think about intra-action and agency between humans and “other.” Diabetes constitutes a complex set of intra-agents - human and non-human, biological and technological. As discussed in the introduction, the “discovery” of insulin depended, in large part, on the experiments Frederick Banting and Charles Best performed on dogs (Bliss, 1982). To be precise, this involved removing the pancreases of each dog, partially or fully, to test and see how long it took the dog to die of ketoacidosis, or untreated high glucose levels. In removing dog pancreases, these biomedical pioneers made it possible for people like me to live, and yet, reading about the brutality perpetrated against these dogs filled me with a visceral response. I had assumed that the development of insulin had happened in some pristine lab, with serious people in lab coats mixing bodily tissues (obtained how? unimportant) carefully in petri dishes. Bliss (1982) describes how insulin changed the life of diabetics forever:

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Insulin’s impact was so sensational because of the incredible effect it had on diabetic patients. Those who watched the first starved, sometimes comatose, diabetics receive insulin and return to life saw one of the genuine miracles of modern medicine. They were present at the closest approach to the resurrection of the body that our
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secular society can achieve, and at the discovery of what has become the elixir of life for millions of human beings around the world. (p. 11, emphasis mine).

Even though I directly benefit from the nearly miraculous invention of insulin, my mental image of the pancreas-less dogs dying and bloating in the sun is hard for me to forget. While Alaimo (2008) presents the chronically ill human as a way to think about intra-action and agency beyond the conscious human subject, Haraway (2008) offers the example of dogs as humanity’s companion species in such a way that denotes the ways in which humanity is inextricably intertwined with other species. Noting that dogs are used as pets as well as experimental animals in labs, Haraway suggests that “people and animals in labs are both subjects and objects to each other in ongoing intra-action,” using this particular type of complicated inter-species relationship as a way to think about agency, brutality, and the concept of sacrifice (p. 71). The dog companion acts as a substitute for the human body within the experimentation process, demonstrating the material limits of bodies and the ethics which guide which bodies are allowed to be violated. Haraway decries the strict hierarchy that places the human above animals and designates the non-human as the “sacrificial other,” regrettable but unavoidable, what Haraway calls a “logic of sacrifice” underpinning scientific enquiry (p. 72, 78). Something must be lost in order to progress. I would suggest a “logic of sacrifice” also underpins Wendell’s (1996) myth of control - prick your fingers, wear a CGM, have a positive attitude in order to live a better, complication free life.

In the months immediately after I began to wear my CGM, my blood sugars were out of control - sky high no matter what I did to treat them. Seeing the constant stream of high
numbers on the screen was frustrating, and I continuously felt like a failure. At my next doctor’s appointment, I discussed my difficulty in controlling my morning blood sugars, expressing my frustration that even though I was performing all the “correct” actions, they were still inordinately high. I wondered if there was anything I could do about them without waking up at 2 am every morning to test and give insulin if necessary. We discussed several possibilities for the source of these highs, but could come to no conclusive answers.

“Last week on my spring break my sugars were perfect,” I told her. “I was less stressed out - could that have an impact on my sugars?”

It was a eureka moment. Her eyes lit up and she nodded. “Ah, so stress has a real impact on you,” she said. “Well, there’s not a whole lot insulin can do about that.” She joked that she couldn’t tell me to just be less stressed, but encouraged me to find ways to manage the stress. I told her I’d put it on my list of things to do. My conscious attempts to control my body’s processes were not successful.

As the appointment wound down, my doctor pointed out that an insulin pump would almost certainly cut down on the nightly highs, because the constant stream of fast acting insulin would replace the dose of the long-acting Lantus I currently take. While I had assumed that Lantus lasted an entire 24 hours, she explained that while it was supposed to last that long. However, depending on the batch, a Lantus dose could last an hour or two longer than 24 hours, or an hour or two shorter. The only way to avoid an insulin gap of that kind was an insulin pump, she assured me. It would cut down on my own miscalculations, and, if I got the right model of pump, it could ‘speak’ to my CGM and be prepared to go
completely automated when the FDA finally approved a closed pump-to-CGM system to create a bionic pancreas. Control would be easy then. But would it? While automated technologies like the CGM and the pump promise a more controlled future, Wendell (1997) cautions against falling too thoroughly for Western medicine’s “myth of control.” At the same time, any sort of diabetic control depends on monitoring technology, as well as knowing how to best utilize the data each sort of technology generates. When I began this project, I tended to think of my self, my technology, and diabetes as separate and distinct entities. But in thinking about the technology that allows me to manage my blood sugars, and the realities of living with a chronically ill body, the work of the scholars I’ve discussed in this chapter were crucial in highlighting the complexities of these relationships.
CHAPTER 6:

Conclusion: Under Control

“Nearly Normal”

A thread running through this project has been my own ambivalence towards the technology I rely on to live a nearly normal life. From my frustrations as a child with having to test my sugar and be obviously abnormal compared to my peers, to my feelings of despair when I began to wear my DexCom CGM and was promptly overwhelmed both with a stream of data, as well as the sudden need to decide which method of monitoring to trust – my own sensations, the regular meter, or the CGM. Obviously, my own sensations are often faulty, but the CGM isn’t even approved for helping me determine insulin doses. I resented that such a complex technology still required regular blood tests. I decided to depend on the regular, blood based Contour Next monitor and wear the CGM to make my endocrinologist happy, even though she was not particularly pleased when in the March visit following starting the CGM, my A1C was still at 7.4, as I recounted in the last chapter. As she told me to manage my stress, I felt a surge of vindication: I had been right all along that more technology was not going to ‘fix’ me. At the same time, I also felt betrayed - I had done the ‘right thing,’ and complied with my doctor’s request to start a CGM, and yet, I had failed to achieve better control.

In the weeks before my most recent doctor’s appointment (in early July), I felt sick with worry. When I checked my estimated A1C on the DexCom Clarity portal in June, it had been at 7.1, so I was deeply apprehensive about how I had improved, if at all, in the weeks
since then. My stress levels were still through the roof; I was testing more frequently on my regular monitor and trying to be more active and eat healthier, but I honestly did not see how my A1C would be any better than it had been in March. I had also missed my follow-up eye appointment. If my eyes and my retinopathy had worsened, I reasoned, I didn’t want or need to know just yet. And of course, the morning of my appointment, my fasting blood sugar was over 200 mg/dl, to my embarrassment.

Because I had switched from the Dexcom G4 to the Dexcom G5 transmitter, I no longer had the separate receiver to show the nurse and allow her to download my data. We joked together as I signed her into my Dexcom Clarity account; almost immediately after she left to print off my data, I received a text message inviting me to join the practice’s own application that would pair with the DexCom Clarity site and offer me yet another way of looking at my data stream. The nurse ushered me to the next small examination room to wait for the doctor, who would look over my Dexcom information, my blood-based monitor’s printout, as well as my latest blood work and tell me how I was doing in terms of overall control.

When the doctor finally appeared, she asked me how I was doing, so I told her, as a preemptive measure, that I was very stressed out still. She sat across from me and perused my paper work. “Well,” she said finally, looking up and smiling. “The DexCom Clarity site estimated your A1C would be 6.9” - I sagged in relief - “but actually, according to your bloodwork, it is 6.5! You are doing a fabulous job!”

I burst into tears.
“Don’t worry,” she said. “This is why I have tissues in my office.”

As I drove home, I wondered how, exactly, I had managed to lower my A1C by that much, particularly given my resentment towards the CGM. Probably I had learned, consciously or not, new ways of interacting with this new data stream, beyond checking it obsessively in between meals and passively watching the trends go up and down. In short, I had had to learn a new set of techniques to deal with this new technology, and to integrate the data provided by the CGM into my control regimen ways that benefited from the type of data it offered.

Re-Learning how to “See”

In reviewing the previous three months, I realized that the single major change I had made in interacting with the CGM data was, in fact, to act on the data. Prior to the CGM, I had gone quite happily about my business between meals and blood glucose checks; I rarely gave insulin outside of mealtimes and my evening fast-acting doses. I only checked my post-meal glucose levels if I felt like I was going low or high, or if a medical professional required me to, as when I participated in the study at Duke Medical Center. As I noted in chapter three, the first morning I wore the CGM I was thoroughly shocked to see how high my glucose levels trended between breakfast and lunch; even though my glucose had been back in “normal” range at lunch, those prior high levels had an impact on my A1C, and I had no idea how many mornings prior to this new monitor that my sugars followed a similar pattern. And yet, in the first few months after I started wearing the CGM, I kept following a similar pattern of behavior - I watched my glucose levels go up and down, but I did nothing to
address them outside of my regular insulin habits. After my March doctor’s visit, I became bolder with my insulin injections. Having been reminded through researching this dissertation that my glucose levels should be under 180 mg/dL two hours after eating, I started giving extra fast-acting insulin in between meals and before bed when warranted by a continued high. The CGM was now a tool to gauge when I should perform a glucose test and possibly give an additional insulin dose, rather than simply a digital distraction that was passively collecting my biological data for the benefit of my doctor.

Figure 6.1. Pictured: A Nearly Normal Day (July 15, 2016)
Above is a recent screenshot of what I term a “nearly normal day” - I am not quite in non-diabetic ranges, particularly following lunch, but you can see at the drop occurring at 1:30 pm, after I gave an extra dose of fast-acting insulin to help bring my levels down. I did not stray above or below the lines set by my doctor, mostly because the CGM allows me to be more aware of how my levels are trending, and to react accordingly.

This evolution in my personal management behaviors is reminiscent of how Daston and Galison (2007) describe the shifts in what they term “epistemic virtues” in tracing the history of scientific objectivity, which they describe as a “form of unprejudiced, unthinking, blind sight” (p. 16). While obviously glucose monitoring is very different, both in practice and objective from the scientific atlases Daston and Galison examine, their account of the evolution of interacting with different forms of knowledge production is helpful. At the risk of oversimplifying the complicated history of glucose monitoring, I suggest that the relationship between monitoring technology and the related knowledge produced in using said technology follows a similar trajectory to the one Daston and Galison describe. In their examination of scientific atlases, they define three different “ways of knowing” based on the types of images available throughout history. Early atlases relied on an episteme of “truth-to-nature,” which sought to provide “the characteristic, the essential, the universal, the typical” (p. 20). This approach can be seen in chapter one in the accounts of John Rollo (1797), the doctor who was attempting to catalogue a comprehensive list of external physical symptoms related to diabetes in the days prior to glucose monitoring.
With the development of insulin and later the invention of blood-based glucose monitoring, the management of diabetes moved into a phase similar to the “mechanical-objectivity” Daston and Galison (2007) connect to the development of photography. This phase in the development of scientific atlases focused on capturing individual objects via the camera in an “attempt to capture nature with as little human intervention as possible” (p. 20). In diabetes control, I would equate this to the extremely strict dietary and behavioral guidelines that sought to respond to limited insulin choices - the “one shot a day” method. With so little flexibility in medication, reducing human error was key. The introduction of home-glucose monitoring served to provide the diabetic with “snapshots” of their glucose levels. This is the way I have approached blood sugar control for the vast majority of my years as a diabetic: I would test my blood sugars and react accordingly, based on a number of other factors, as described in previous chapters. While logbooks helped demonstrate overall trends in my glucose levels (if I bothered to properly keep a log), my personal monitoring options were unable to reflect the vast majority of my glucose levels.

The third type of episteme that Daston and Galison (2007) describe is that of “trained judgment,” which “mixed the output of sophisticated equipment with ‘subjective’ smoothing of the data” (p. 21). This is what I am learning now, with so many types of data at my disposal. To use the CGM effectively, I had to let go of my desire for it to provide me with concrete information that I could act on without drawing blood. I also had to examine the role my own senses play in how I self-monitor: if the CGM says I’m low, but I don’t feel low, I must take other steps (such as a blood test) to “smooth” the data I am being provided.
Usually, my physical reactions are a better gauge of low blood sugars than my CGM (although sometimes I am surprised when the blood test backs the CGM up). The disparity between my last A1C (6.5) and DexCom’s estimation (6.9) was a fairly striking one, and demonstrates the overall accuracy of the CGM is somewhat lacking. But precision is not the goal or intended function of the CGM technology. Rather, the CGM’s goal is to provide the user with data trends to allow for behavioral modifications to result in better overall control. This means that I also can and need to react to the data provided: now that I have a visualization of my glucose trends on my phone, I can better determine how to dose myself with insulin. Daston and Galison (2007), drawing on Foucault, discuss the “techniques of the self” - or repeated practices that produced the “scientific self of objectivity” (p. 38). I have had to learn new “techniques of the self” that produce a more controlled diabetic subject. I am simultaneously always the subject and the object of my own monitoring, both via the sensations of my own body as well as the digital mediation provided by my plethora of glucose monitors. My monitoring allows me to manage the many aspects of my physical condition.

My process of re-learning has also benefited, ironically, from coming to terms with Wendell’s (1996) ‘myth of control.’ Wendell suggests that, despite the promises of Western medicine, we cannot exercise complete control over our toxic bodies (to use Alaimo's (2008) term). By coming to terms with my inability to completely control my errant body (as much as I would like to), I opened myself to the idea that my monitoring technology could help me at least refine my control in more precise terms. All the same, it is impossible for me to be
unaware of how fragile access to the possibility of control remains for the majority of the world’s diabetic population. In very material terms, diabetic control is predicated on the use of very particular types of technologies: access to expensive insulin and any form of glucose monitoring is constrained by a variety of factors, from geography to economic considerations, as well as the dearth of knowledgeable medical professionals. Desire to control diabetes is not enough to obtain better control and technology alone cannot address other issues of access and availability.

**Further Control**

In many ways, technological utopianists like Eric Topal (2015) are correct to say that digital technologies can and will revolutionize healthcare. The technological advances that led to the invention of blood-based glucose monitoring and newer technologies like the constant glucose monitor are indeed life changing for insulin-dependent diabetics. In my own lifetime, glucose monitors have advanced from a clunky device with imperfect precision and extremely limited memories to the data streams of the CGM. Online networks and websites geared towards the diabetic community allow for diabetics and their communities to interact with those in similar circumstances: sharing knowledge and mitigating some of the isolation that is attending on chronic illnesses like diabetes. As I noted in chapter four, I spent hours going through various diabetic forums when I first found out about the online diabetes community. Beyond feeling less isolated, I gained helpful tips about how to better use my technologies. One site recommended extending the use of the CGM sensor by stopping and restarting the device at the one week mark (when you are supposed to change sites), while
another recommended using sports tape to keep the sensor and transmitter secure on the stomach when the adhesive loses its stick. Tips like these help diabetics circumvent not only the technological restrictions programmed into the device, but also to get around strict insurance programs that may not pay much to help cover CGM supplies. (Unlike the pump, the CGM has yet to become considered a necessary management tool, although things are changing, according to my doctor).

In focusing on glucose monitoring as an understudied form of digital media, I have attempted to create a project that addressed a variety of concerns and issues within contemporary media theory and analysis, particularly in examining the glucose monitor as a contemporary example of John Durham Peters’ (2015) “logistical media.” The glucose monitor’s primary function is to generate, store, and with newer models like the CGM, transmit biological data based on the body’s glucose levels. Unlike the FitBit, or even Apple’s Fitness Tracking apps, glucose monitoring, and particularly constant glucose monitoring, are carefully regulated and have a specific health related purpose beyond “fitness.” In the absence of any sort of biological cure to repair the pancreas’ function, technology, most specifically glucose monitoring and insulin, remains the only way to manage diabetes in all its forms. I have heard that a cure for diabetes is “ten years off” since I was diagnosed. Technology functions as a management strategy for this disease, not a cure, even with technology like the insulin pump to mimic the function of the pancreas. And while I am grateful for the means to maintain even a semblance of a normal life, there are arguments to be made regarding the myriad aspects of maintaining a population that is
completely reliant on technology to manage a specific aspect of bodily functionality. Glucose monitoring technology, both the traditional blood based models as well as CGMs, are necessary to only a portion of the global population. Further research both into the historical developments related to glucose monitoring as well as the intricacies of the current complex system of biotech companies, governmental regulation, and insurance companies enabling the use of glucose technology would be of value for media scholars, as would a broader ethnographic project to incorporate the voices of other diabetics and their particular circumstances and relationship to technology.

I believe that a more in-depth look at the technological developments that allowed for the development of insulin would be an important step for my future research to take, as well as examining the specifics of diabetic management that were the standard of treatment in institutions like the Joslin Diabetes Center and how they changed specifically in response to technological advances. I have provided a broad overview of these relationships in this project, but I barely scratched the surface of these developments. Further, the most glaring weakness of this project, in my opinion, is that I do not touch on insulin pump technology in my discussion of diabetic technology, primarily because I myself do not use an insulin pump. After the blood-based glucose monitor, the insulin pump is the most widely recognized and utilized digital diabetic technology. Current models are able to connect with both regular glucose monitors as well as some CGMs and provide ‘suggestions’ as to dosage levels based on that information, although a fully automated system (like OpenAps) is (as of this writing) only available by hacking the technology. Extending the analysis of glucose monitors to
insulin pumps could provide other insights into the nature of networked technologies and the interaction between the technological and the biological.

In many ways, this project came down to what Peters (2015) calls the “practices of inscription” - the ways and means through which meaning is “etched” into matter (p. 263). Peters (2015) identifies writing as “perhaps the primal form of disembodied communication” - the link that enables our connection to the past, over distance, and even to the future (p. 265). Further, Peters suggests that the “body…is our most fundamental infrastructural medium” - “composed of many internal environments” where “the boundary between organism and environment does not lie only at the skin” (p. 267). The materiality of the body, of the blood, and the glucose monitoring that renders the inner workings of the body visible represents the complications of such boundaries between organism and environment. My chapters examined the inscription practices of data and memory (technological), self-inscription practices (technology and protocol), communal inscription (challenging the technology and protocols), and the inscription of the disease itself on my body. As personal monitoring technologies become more common, questions regarding inscription practices and the techniques and practices associated with them will be important to media scholars. Hopefully my project provides a starting point from which to consider how such technologies and their associated techniques impact how users understand themselves and the potential types of data their bodies generate.

After I dried my eyes in the doctor’s office, my doctor grinned and asked expectantly, “So, when are you going to get an insulin pump?”
I told her I would think about it.

An insulin pump would be a project in and of itself. Maybe someday.
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