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Troubled Interventions: Public Policy, Vectors of Disease, and the Rhetoric of Diabetes Management

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Abstract This essay examines the debate surrounding New York City's controversial diabetes registry program. Exploring the tensions between public health officials and privacy advocates, the article explores how diabetes is imagined in the public sphere. Although rhetorics underscoring privacy may seem the more progressive discourse, I argue New York City's Department of Health and Mental Hygiene has the more forward-looking plan, attempting to reconstitute diabetes not as a chronic condition necessitating individual management but as a disease that requires systemic intervention.

Keywords Rhetoric · Diabetes · Epidemic · Privacy · Registry program

In December 2005 the New York City Department of Health and Mental Hygiene (DOHMH) implemented one of the most far-reaching chronic disease intervention programs in the municipality's history. In an effort to combat alarming surges of diabetes diagnoses and related complications among New Yorkers, the agency established a patient registry to help people monitor blood sugar and motivate at-risk residents to visit doctors when glucose levels are precariously elevated. As most people with diabetes are reminded, persistently high blood sugar can lead to complications such as kidney failure, blindness, foot amputation, and other life-altering conditions. To prevent such ailments from materializing, DOHMH required all laboratories serving New York City residents to report individual A1C scores (blood glucose averages for approximately three months) directly to the department. The plan was groundbreaking because for the first time the government would begin tracking individual data about a condition that is neither infectious nor caused by an environmental toxin. While public health agencies have a long history of intervening in outbreaks like tuberculosis, polio, and yellow fever, this particular intervention was controversial because diabetes is not contagious.[1]

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[1] Mitchell and McTigue (2007, 401-402) rightfully point out that the CDC has monitored noninfectious agents, but these outbreaks (gastrointestinal symptoms, melanoma, and mesothelimoa) involved environmental causal agents (such as methyomyl, ultraviolet light, and asbestos).

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DOHMH officials collect registry data to "assess variations in testing patterns, health care utilization, and glycemic control by age, sex, [and] geographic location" (Chamany et. al. 2009, 550). Mapping vectors of excessive glucose levels enables DOHMH to develop broad health strategies and empower citizens to be more aware of their blood sugar count. The information provides both a systemic glance at diabetes and provides an opportunity for individual interventions. After receiving an A1C score, the department reviews the data and sends a letter to patients, "informing them of their most recent test result, explaining the risk of complications, and recommending that the patient schedule a return appointment" with her or his physician (Chamany et. al. 2009, 552). The letter, which is written in English and Spanish, provides the recipient with a set of questions to ask doctors, ideally empowering patients to have more agency in evaluating their health.[2] The registry also equips doctors with a quarterly report listing all patients' two most recent A1C scores.

The registry troubled privacy advocates because the collected information would be used to make a direct intervention into the maintenance of a person's health without consent. Proponents of strict medical privacy argued the policy was overly intrusive, even though DOHMH assured registrants that personal information could not be legally disseminated outside the department and never be used to deny a person employment, healthcare coverage, or driving privileges. Perhaps the most controversial element of the policy stemmed from the fact that people could not opt out of the registry. Patients could stop receiving intervention materials from the city, but all of the previously mentioned information would continue to be collected and sent to the department. DOHMH defended such measures, contending it could not contemplate workable systemic solutions without a full understanding of diabetes's grip on the city. Privacy advocates retorted that the measure crossed a line, stating the patient-doctor relationship was key to management, not public intervention. This stasis point of the debate, pitting the desire of the government to intervene in the treatment of chronic disease against the rights of citizens to maintain a reasonable degree of privacy, underscores an important manifestation in public health rhetoric as diabetes grows more ubiquitous. The competing projections of personal health highlight a schism between liberal conceptions of personal responsibility and civic humanist understandings of public well-being.[3] Historically, liberalism has been philosophically indebted to a tradition that privileges individual liberties and freedom from state regulation. Civic humanism, conversely, emphasizes civic virtue, public action, and the common good. Elements of each can be traced in contemporary American culture and their components are best understood as motivating political impulses, not wholly discreet philosophies.

At the heart of this conversation is the changing nature of healthcare strategies in America and the ever-increasing ability to manage once deadly diseases. Former DOHMH Commissioner Dr. Thomas Frieden (who was later appointed head of the Centers for Disease Control by President Obama) argued that public health officials had been "asleep at the switch," noting that "local health departments generally do a good job of monitoring and controlling conditions that killed people in the United States 100 years ago. Yet noncommunicable diseases, which accounted for less than 20 percent of U.S. deaths in 1900, now account for about 80 percent of deaths. Our local public health infrastructure has not kept pace with this transition" (Steinbrook 2006, 546). The extension of the human lifespan draws attention to the mission of public health departments and the ways they communicate about the body and its role in public life. If public health's mission is increasingly situated in the realm of

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[2] Under the New York plan, scores over 9 % constitute "poorly controlled" blood sugar. Scores under 7 % are defined as good control.

[3] For more on the relationship among liberalism and civic humanism, see Beiner 2008; Pocock 1992.

noncommunicable diseases, the discourses employed to contemplate and ultimately combat ailments like diabetes and aid citizens are of great consequence.

In this essay, I explore the implications stemming from the tension between individual agency and institutional regard, looking at the dual emphasis on public intervention and personal privacy in noncommunicable diseases. DOHMH positions diabetes in a manner that mirrors infectious disease, revealing the extent to which institutional intervention might act as a strategy for "containment" in popular scientific vernacular. The department stresses the concept of the "epidemic," giving the imagined excesses of diabetes new urgency and offering an alternative to the rhetorical sedimentation that typically characterizes diabetes discourses. However, this model, which is dependent on knowledge *after* diagnosis, continues to pose challenges for implementing preventative measures at the institutional or local level. The emphasis on monitoring and controlling is key to these messages, which rarely addresses the eradication of diabetes. Those advocating the registry consistently utilized the image of the "epidemic," projecting large-scale quantities of people struggling with disease, but without the social baggage of "contagions."

Narrating the early history of clinical health, Michel Foucault noted that the institution emerged from a "medicine of epidemics," remarking that whether contagious or not, an epidemic has an "historical individuality, hence the need to employ a complex method of observation when dealing with it" (1973/1994, 25). The contention that epidemics are intimately political and can be discursively appropriated to discipline and control people has been widely documented, and scholars ranging from Susan Sontag (1978) to Pricilla Wald (2008) have provided ample reason to be suspicious of the frame. Taking a page from Foucault's later writings on discourse, however, this essay analyzes the civic potential of the metaphor of "epidemic," recognizing that the trajectories of discourse are not always easily delimited. In the specific instance of the debate over the New York City registry, the metaphor may help shift conceptions of diabetes from being a privately managed disease to a condition that is collectively and socially engendered. While keeping concerns about state overreach present, I argue the metaphor of "epidemic" might help enable systemic transformation, allowing officials to corral resources that combat diabetes. Despite the recalcitrance of the metaphor of "epidemic," this frame remains more empowering than discourses of privacy, which are entirely impotent, purporting to support actions that save people with diabetes but which secure a model that renders the disease a product of individual maintenance and discipline, not social reform. Those forwarding privacy claims are not mindful of how their discourse reinscribes diabetes as a discretely individualized disease, fortifying the very problem diabetes advocates seek to subsume.

These two factions, however, do not represent wholly disparate discursive positions. While "epidemics" and "medical privacy" appear to reproduce an old divide between public and private, they share a focus on individual treatment in the forms of prevalence and personal data that bring this debate to life in problematic ways for people living with diabetes. Those most marginalized by the condition, including those who have no healthcare, can be erased easily in prevalence reports. New York City officials have a more productive civic strategy, but a rhetorical approach that privileges individual management must be avoided for this program to be transformative.[4]

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[4] This essay explores texts that engage New York City's DOHMH's diabetes program and that offer structured coherence to the thematic narratives about "the debate" surrounding the registry. This included representative texts from Public Health journals, publications posted on DOHMH's web site, and Law journals. Staying close to the emergent themes of "epidemic" and "privacy" from an initial reading of texts, a search of EBSCO and Lexis/Nexis databases was used to employ additional evidence. To further enhance this study, an interview was conducted with Dr. Shadi Chamany to clarify materials found in the literature.

The promise of New York

The history of public health surveillance in America is marked by a tension between the desires of people to keep their communities healthy while simultaneously balancing the privacy of individuals. Although it is easy to conceptualize this dichotomy in traditional political terms, accentuating the conservative tendency to value libertarian individualism versus progressive notions of government intervention, public health policy is vastly more complicated, especially when we consider the evolution of privacy, the stigma attached to particular diseases, and the changing nature of what constitutes a public danger. There has long existed a dialogical tension in surveillance, "bounded by a promise of disease control and a specter of intrusion" (Fairchild, Bayer, and Colgrove 2007, 1). In relation to disease registries, this tension is especially pronounced because of the social impurity imparted on diseases like tuberculosis and HIV.

Although it is not contagious, diabetes is a problem of national significance. Over twenty-six million people in the United States, or about eight percent of the population, have some form of diabetes (National Institute of Diabetes 2011). Roughly one-third of all adults are prediabetic and seven million adults remain undiagnosed. The United States spends roughly ten percent of its healthcare budget on diabetes, which has risen to a cost of approximately $132 billion annually (Krent et. al. 2008, 5). About one third of all U.S. citizens born in 2000 will develop diabetes at some point in their lifetime (Barnes, Brancati, and Gary 2007, 827).

Diabetes is especially lethal in New York City, where almost ninety percent of adults diagnosed with the disease do not know their A1C scores (Steinbrook 2006, 546-47). Between 1990 and 2003, the death rate from diabetes in the city rose by over seventy percent (NYC DOHMH 2009). Two public health experts reflected on the startling nature of the evidence:

> In New York City alone, an estimated 530,000 people have diagnosed and 265,000 have undiagnosed diabetes. Approximately 1800 deaths and 1700 amputations as well as other complications add up to an 8.3 billion dollar cost in New York City. Among the elderly and some minorities, the prevalence is between 12 % and 20 %. It is predicted that 30 % to 50 % of today's children may develop diabetes. (Banerji and Stewart 2006, 169)

This information is further compounded by the fact that New Yorkers with diabetes are hospitalized at a rate nearly 80 % higher than the national average. Along with the emotional, physical, and mental impact on residents in the city, the disease has also proven to be expensive. The cost of diabetic hospitalizations doubled to $481 million in 2003, up from $242 million thirteen years earlier (NYC DOHMH 2007). Despite rising costs, people with diabetes are spending less time in hospitals for treatment and care.[5]

Studies have also found that, for a variety of systemic reasons, a number of sub-populations and minorities are especially hard hit by diabetes in New York. African Americans, Puerto Ricans, and Russian-speaking immigrants all have high rates of diabetes. Asian New Yorkers are more likely than any other ethnicity to have pre-diabetes (NYC DOHMH 2009, 3). The pilot program for the New York City registry began in the South Bronx where 48,000 adults have been diagnosed, and a quarter of those are classified in the danger zone of having "poorly controlled diabetes" (Krent et. al. 2008, 5). These statistics

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[5] In 2000, the average length of a diabetes-related hospital stay was 7.9 days, with the average charge of $17,800 per stay. There is a slow but steady trend of declining length of hospital stay and increasing charges per stay. In 1997, the average hospital stay was 8.9 days and the average charge was $15,400. See *New York State Strategic Plan* 2008.

are compounded by the poverty rate in New York City, which stands over twenty percent, much higher than the national rate of just under thirteen percent.[6]

Registries create a link between the surveillance of a disease and patient care. In the state of New York, there are registries for cancer, Alzheimer's disease, congenital malformations, communicable diseases, lead poisoning, and immunizations. However, in the case of NYC's diabetes registry, observers have noted that, "no health department has ever sought to exercise such thorough influence over care that it does not directly provide" (Fairchild and Alkon 2007, 563). DOHMH officials argue that registries serve an important function because they "provide a mechanism by which providers can identify individuals in greatest need of follow-up or referral and also monitor disease indicators in their patient population over time" (Chamany et. al. 2009, 550). There is evidence that registries can have a positive impact on patient health, but even the most well-known registries raise questions about the motivations of patients, the treatments received, and the privileged position of benefactors.[7]

The registries are intended to spark awareness and the need for more public exchanges about diabetes is evident. Diabetes is a difficult condition to treat for a number of cultural reasons. There are, for example, two common kinds of diabetes and they are regularly conflated in public discourse, even if they have qualities that set them apart. Type-one diabetes is generally diagnosed in teenagers and young adults though the condition can develop at any time. Type-two diabetes, the kind DOHMH is most concerned with, involves older people who are often overweight. Type-two diabetes constitutes about 90 % of all cases and is often most dangerous because it can remain undetected for years. Perhaps the largest difference between the two diseases is cultural: those with type-two diabetes are frequently blamed for their condition and feelings of shame and stigma often haunt people living with its consequences (Rock 2005). Type-two diabetes is frequently associated with excessiveness and overconsumption, eclipsing its more social and public dimensions. Public health officials need to frame messages that empower people but without the baggage of blame that accompanies type-two diabetes. A sense of urgency must be ignited to combat the quotidian sedimentation of the disease and the complacency that can follow. It is in this vein that the metaphor of "epidemic" is useful.

Constituting the "Epidemic"

The role of language in bringing to life medical abstractions is an essential feature of public health rhetorics. Far from being merely descriptive, language and rhetorical tropes such as metaphors give form to discursive aspects of culture, performing what some have called a "constitutive" function in materializing accepted cultural "truths." Language offers presence to unseen illnesses and allows people to communally contemplate otherwise conjectural ideas. The shared meanings produced by language create possibilities for understanding ephemeral phenomena and forging public health strategies. Commenting on the relationship between language and the materialization of collective realities, Judy Segal notes, "the outcomes of health-policy debate are constrained in part by the biomedical terms and

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[6] Notably, poverty alone does not seem to account for the significant rates of diabetes in the city. As one public health scholar put it: "31 % of diabetic patients in commercial managed care and 42 % in Medicaid Managed Care in New York State have an A1C of greater than 9 %, indicative of poor control. Yet only 10 % of people with diabetes are aware of their A1C levels." See Fairchild 2006, 175.

[7] The New York program was modeled in part after a successful registry in Vermont where patients volunteered to participate in the program. There have also been examples of registries run internally by hospitals that have been met with success.

metaphors in which the debate takes place" (2005, 19). Giving attention to the contingent terminologies that structure medicine and public health emphasizes their composition as systems of "norms and values operating discursively" (3). Examining the role of language and framing in public health rhetoric is dependent on a close understanding of context, the emergence of particular terms during opportune political and cultural moments, and the attitudes that such rhetorics inspire.[8]

Public health discourses help to engender the identities of communities in relation to crises. Metaphors and narratives influence how those practicing medicine and "lay" publics understand the consequences of disease, how they imagine threats to the community, and how they conceive solutions. The relational logic of terms, Priscilla Wald has observed, "runs much deeper than state mechanisms and inflects the conception of community articulated in the narratives" (2008, 53). Public health discourses such as outbreak narratives, "actually make the act of imagining the community a central (rather than obscured) feature of its preservation." Nancy Tomes contends that the cultural norms born of such languages are negotiated in the relationship among medical and public health institutions and those in society contending with illness in everyday life. In short, cultural meanings are intellectually dynamic, not distortions of pure scientific knowledge. Tomes asserts that, "scientific precepts become a part of the working hypothesis of everyday life" because "no disease is ever observed in a totally unbiased way; there is always a scrim of culture affecting our perceptions of and attempts to treat illness" (1999, 14, 17). The frames adopted to understand public health crises directly correspond to how we respond to such emergencies.

Public health officials frequently adapt their rhetorical strategies to justify controversial measures. Even when citizens support the actions of a department or when agencies are offered legal backing, officials employ language to already accepted cultural frames to promote public health campaigns. It comes as little surprise that DOHMH has appropriated the conceptual heuristic of "epidemics" to assert the import of the registry and convey the high stakes of successfully implementing the program. Citizens have been primed to see the continued relationship between diabetes, obesity, and personal responsibility, and it is this crisis that has given rise to the necessity of government intervention. Indeed, so common is the signifying power of this discourse that Lisa Keränen notes we are now living with an "epidemic of epidemics" (2011, 224). The frame of "epidemic" is especially pragmatic in two senses: first, it offers urgency to seemingly mundane conditions. Second, despite the popular connotation of communicable diseases, epidemics offer attention to systemic ills.

The word "epidemic" is scattered throughout the literature engaging the registry. It appears on the DOHMH web site, in materials that users can download from the agency, and is commonly invoked by public officials. For example, in a published report defending the program, DOHMH officials noted, "In December 2005, *in characterizing diabetes as an epidemic*, the New York City Board of Health mandated the laboratory reporting of hemoglobin A1C laboratory test results" (Chamany et. al. 2009, 547). The word "epidemic" appears at strategic moments in the DOHMH report, but tellingly, twice in the abstracts (once in the context abstract, once in the conclusions abstract) and twice again in concluding paragraph. For readers skimming the report, the placement of the word is easily identified and drives home the point that diabetes is at critical levels and necessitates immediate action.

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[8] Segal borrows heavily from Kenneth Burke, who has famously quipped that "observations" are "but implications of the particular terminology in terms of which the observations are made. In brief, much of what we take as observations about 'reality' may be but the spinning out of possibilities implicit in our particular choice of terms" (1966, 46).

The incorporation of the term "epidemic" is significant, as the frame constituted by the word brings with it important consequences in delimiting both a crisis and public response. Etymologically, the word "epidemic" means "on the people" and carries with it the connotation of necessitating relief. One public heath advocate contended that by calling diabetes an "epidemic," doctors could "develop public health strategies to prevent or reverse obesity and physical inactivity with the goal of decreasing the development of diabetes and its complications," adding that, "without surveillance, it is going to be very hard to tackle the problem" (Bloomgarden 2006). Epidemics, after all, "require bold public health action" (Barnes, Brancati, and Gary 2007, 829). The framing of diabetes as an epidemic also had the effect of making it populist in nature: disease is not discriminatory through this lens. As Mitchell and McTigue point out, invoking the term epidemic encourages people to view such issues "as a matter of common concern, not a condition afflicting a few isolated individuals" (2007, 394). Or, as Wald puts it, epidemics "dramatize the need for regulation" (2008, 17). Epidemics require immediate attention from the state so they can be monitored and eventually eradicated.

Dr. Shadi Chamany, the director of the New York City Diabetes Prevention Program, has insisted that the framing of diabetes as an "epidemic" was not strategic but simply a term utilized by public health advocates. In an interview, she explained to me:

> I think the term "epidemic," some people are very uncomfortable with that word. But it is epidemic. I think in practicing good public health, we are describing a problem that is epidemic. It's growing. It's affecting more and more of the population. There's no other motive for using that term other than just to describe it. We could say in "characterizing the problems of diabetes increasing rapidly," but I think it's very descriptive. It's a term we use in public health. I do think people have associations with it sometimes that . . . can be kind of scary. You know, when you hear "epidemic" you can think of an outbreak [or] something like that. But it doesn't always have to apply to something that's, you know, right there and it's an infectious disease outbreak. There wasn't any particular reason for us using that word other than it's a term we use in public health.

Here "epidemic" is characterized in a manner described by Cindy Patton as "apparently simple." It is "more cases of a disease than expected" (2002, 39). Regardless of the seemingly conscious opening line of the report that explicitly references the overt characterizing of diabetes as an epidemic, the frame is taken to be a natural extension of public health vernacular. Nonetheless, instinctively adopting this term is equally striking. The appropriation connotes a frame of acceptance that is accessible, ubiquitous, and powerful.[9]

The very suggestion of epidemic connotes urgency, which public health officials frequently see as lacking in patient attitudes about diabetes. The gradual sedimentation of chronic conditions generally allows for a release from language emphasizing urgency because diseases like diabetes are positioned as "manageable." Like many chronic diseases, there is a lack of exigency for receiving care. The language of epidemics offers public health officials a critical frame for reorienting the disease as a *crisis*. If we understand a crisis as a breakdown in meaning, renewed urgency allows for the resignification of disease. As DOHMH pointed out in their initial report, "Resistance to New York City's public health

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[9] For many years public health departments avoided addressing chronic conditions such as diabetes because they did not mimic other disease models. In the instance of cancer, for example, there was a limited mission of looking at incidence and prevalence. See Fairchild and Alkon 2007.

approach to diabetes control may result at least in part from the continued attribution of the current epidemic to individual genetic susceptibility and personal lifestyle choices, neither of which invokes a sense of urgency or validates public health response" (Chamany et. al. 2009, 566). Others in the debate echoed this sentiment, asserting, "patients lack a sense of urgency for the treatment of their chronic disease and also sense a lack of efficacy of many interventions" (Banerji and Stewart 2006, 170). This need not mean that people with diabetes are lazy (though such insinuations are frequent), only that the malaise of daily routines quickly dissipates the imminence of potential consequences.

This urgency is regarded as especially critical in relation to obesity, which is always suggested in diabetes discourse, even when it is not publicly stated or contextually appropriate. The articulation of obesity with "epidemic" is persistent in American culture, constructing a frame that allows for diabetes to be incorporated into the parameters of "epidemic." This is certainly true in the medical literature where articles such as *The Continuing Epidemics of Obesity and Diabetes in the United States* frequently circulate (Mokdad et. al. 2001). This metaphor is equally prevalent in the broader public sphere. A good example is provided in a *Newsweek* editorial penned by First Lady Michelle Obama in March 2010. She writes:

> For years, we've known about the *epidemic* of childhood obesity in America. We've heard the statistics—how one third of all kids in this country are either overweight or obese. We've seen the effects on how our kids feel, and how they feel about themselves. And we know the risks to their health and to our economy—the billions of dollars we spend each year treating obesity-related conditions like heart disease, *diabetes*, and cancer. (Obama 2010)

Again, we should not forget that epidemics are often imagined as populist in nature with the potential to harm anyone, hence the First Lady's emphasis on the contraction "we've" three times in three sentences. Obesity here is collectively related to a number of conditions where the effects are clearly damaging. Again, though, it also hints at the potential in employing the word epidemic, wherein the systemic features that might aid in the very production of childhood obesity are highlighted and the potential for institutional intervention becomes a reality. But the metaphor is never taken to this level of systemic intervention. The gradualism of the problem, its cause, and the solution does not easily fit popular understandings of "epidemics." Still, Sander Gilman's (2011) comments in the pages of this journal about the First Lady's implications that diabetes is a consequence of "laziness" illustrates how easy it is to slip back into a language of personal responsibility. Especially since we know not all fat bodies will develop diabetes (people with a little meat on their bones are actually more likely to survive heart attacks), we would be wise to push on the limits of this metaphor and its public circulation.

Along with a heightened sense of urgency, the frame of "epidemic" has a second important function: it draws attention to systemic harms that transcend personal struggles. In this way, it might be useful to follow diabetes in vectors, to trace it with maps and charts in ways that mimic more traditional understandings of epidemics. Certainly, such vectors can determine the prevalence of disease and make a path for systemic intervention. On a more pessimistic note, diabetes is currently attended to in a reactionary fashion, being addressed only after diagnosis. When public officials argue that surveillance is essential for "identifying clusters, mapping the spread of disease, understanding patterns of contagion, and detecting lapses in hospital infection control," the limitations of such models must be pondered (Fairchild and Alkon 2007, 564). Diabetes does not map well on to any of these features.

While systemic intervention is no doubt compelling in an age when chronic diseases are killing the vast majority of citizens, an important distinction between the mapping of infectious and noninfectious conditions needs to be made. Outbreaks of infectious diseases can generally be contained in a relatively short period of time after their trajectory is determined. Diabetes has no such travel plans. Maps being produced by the city are always pointing to something else, exacerbating the degree to which diabetes is *not* mobile. Like the obese bodies imagined in popular culture, these vectors are relatively stable and predictable. Despite their immobility, residents are simultaneously read as living without personal restraint and excessively transcending the medical order. If infectious disease tells us something about how a disease travels, then assuredly these maps tell us something about how diabetes is remarkably stationary.

This geographic focus suggests that diabetes is always contained but not by the confinement of bodies in quarantine. Isolated by poverty and lacking medical care, these vectors of disease are about the systemic ordering of food choices (or lack thereof), the ability of people to access medical attention, the fortitude to continue battling the disease, and the capacity to digest the emotional, physical, cultural, and social aspects of living with diabetes. As two public health officials put it:

> Simply knowing A1C levels is clearly not sufficient. It is not enough for the patient to "know their numbers" if they do not have the knowledge, resources, or skills to do anything about it. It is not enough for the provider to know the numbers if insufficient resources are allocated to optimize disease management. Resources for diabetes management include safe areas for walking and other physical activity and affordable nutritional options, as well as affordable medications and glucose monitoring devices. Even these are insufficient if society promotes excess food consumption, including sugary drinks, and if healthy affordable food choices of fruits and vegetables are unavailable. In a city with a large immigrant population, food security is an important issue; as people migrate from areas of food scarcity to areas of abundance, the tendency is to overeat, which results in increased rates of obesity and diabetes. Alternatives for healthy eating might also enlist the support of local farms to promote use of fresh, tasty food. (Banerji and Stewart 2006, 170-71)

The data is never pointing simply to bodies so much as they are systemic concerns that must be addressed by government programs, collective action, medical resolve, and a healthcare system that aids people and not profit. As Patton notes, epidemiology must "constantly construct and correlate populations and subpopulations in order to make epidemics visible – hence its reliance on the descriptive and predictive technologies of surveillance and sentinel studies" (2002, 40). In the case of diabetes, the bodies are but signs of larger systemic ills related to available food choices, medical accessibility, and the luxury to make healthy lifestyle decisions like exercising.

The lack of collective urgency underwriting diabetes and its stationary nature hints at the temporal features underscoring this public health agenda. Systems and habits both become solidified gradually, and changing life for people with diabetes is difficult without reforms in other areas of public culture. People often live for a decade without knowing blood sugar levels are slowly killing them. Surveillance cannot be contained to individual bodies but must look at areas of life that enable diabetes and its ramifications to come into being. Even with this knowledge, there is reason to be hesitant about the relationship between bodies, geography, and the epidemic frame.

The very presence of high A1C scores that give DOHMH the opportunity to make an intervention suggests that people are receiving care. Prevalence is dependent on medical detection and those areas most in need of help may always be underrepresented. As Chamany noted in our interview:

> …where are the people who have very high A1Cs? We imagine they'll probably be in the same places where we have very high prevalence. But we don't know that. We should look at it. It may be more scattered across the city. You know, maybe the difficulty in getting control isn't necessarily where the highest prevalence is. We don't know that. We can take a look at patterns of where people are getting their tests, how often people are going to the same doctor versus not.

In short, prevalence is significant to mapping the epidemic, but in relation to diabetes, prevalence is directly related to being diagnosed – perhaps years too late. The general detection of diabetes can still be a positive outcome for initiating the process of combating the condition, but the poorest of areas might still rest beyond the reach of the registry to start.

Despite the limits of DOHMH's rhetoric, its emphasis on publics in the debate over the NYC registry might remain the more progressive rhetoric. Appeals to privacy rarely address the public good, perpetually imagining a diabetic body that is sovereign and detached from cultural contexts. These overtures to privacy also contend that healthcare performed outside the physician's office is generally detrimental. In the next section, I explore arguments from privacy advocates to delimit their understanding of diabetes, interventions, and public life.

Privacy and the frame of civil rights

The histories of medicine and public health are littered with examples that illustrate the detrimental invasion of a person's privacy in the name of the public good. A cursory glance at HIV/AIDS history, for example, highlights the struggle to ensure that people receive care, and that their privacy is protected. Too often patients have been made to fight for their privacy rights against the state and healthcare providers as they attempt to stay well. This "democratic privacy" is a productive exercise in producing activated citizens, but usually comes only after much struggle and often much heartache (Fairchild, Bayer, and Colgrove 2007, 28).

The controversy surrounding informed consent made it particularly surprising that none of the major organizations dedicated to privacy participated in the debates leading up to the implementation of the NYC registry (Fairchild 2006, 176). As Fairchild, Bayer, and Colgrove note, the city "did not initially consult the county, state, and national medical associations. Given the sensitivity of surveillance surrounding HIV case reporting, it is likewise striking that privacy advocates were not included in early discussions" prior to the debates (2007, 242). The department did, however, have public hearings about the plan, allowing for the parameters of the program to be amended.

People living with diabetes often prize privacy because of the stigma and blame frequently attached to the disease. It is worth repeating that those with diabetes are constantly reminded that they need to manage their blood sugar better to stay well. If they do not, they alone are seen as responsible for their personal demise. This social misperception about the ways diabetes functions, along with poor understandings of medicines such as insulin, make individuals with diabetes easy targets for public scapegoating. The American Diabetes Association (ADA) receives approximately two hundred calls each month about discrimination in schools, the workplace, and correctional institutions (Bloomgarden 2006). It is for this reason the ADA's executive committee was shy to endorse NYC's initial policy, only supporting surveillance if the patient offered affirmative consent each time blood-work was completed (Fairchild and Alkon 2007, 571).

A number of critics weighed in on the precedent being set by the registry. For some, the egregious harms that the ADA fights so hard against were being reproduced in the new program. Janlori Goldman, a faculty member at the Center for the History and Ethics of Public Health and Department of Sociomedical Sciences at Columbia wrote, these "initiatives do not balance heightened surveillance and intervention with the provision of meaningful safeguards or resources for prevention and treatment" (Goldman et. al. 2008, 807; Frieden 2008, 1543). Harold Krent, a dean at Chicago-Kent school of law argued that, "the A1C registry will be used to supervise the non-criminal behavior of private citizens, namely, how well diabetics are managing their own blood sugar levels" (2008, 14). Finally, Wendy Mariner of Boston University's schools of Public Health and Law argued that the city "fails to satisfy basic legal principles governing patient autonomy and privacy" (2007, 122). These sentiments were reflected by some citizens during the public hearings, who asked, "Are you going to demand what I can and can't eat?" (Fairchild and Alkon 2007, 573).

The arguments asserted by privacy advocates are compelling and merit serious attention. It is not my intention here to call into question the motives of these scholars and advocates. I believe each of them has real concerns about patient privacy. Rather, I hope to scrutinize the degree of agency they contend to be offering people with diabetes, as their visions often work to privatize disease, deflecting attention away from systemic issues and back on to the individual body. Unlike the public character of the ailment put forth by the city, these arguments reproduce the notion of diabetes as a private disease that merely necessitates individual management. To expand on this point, I turn to arguments made by Krent, Mariner, and Goldman, focusing on the frame of privacy, their concerns about government overreach, and the consequential individuation of disease.

First, these scholars worried that DOHMH was overreaching in its mission and that patients would have their personal data manipulated (if not outright stolen) by government agencies and workers. Krent and colleagues, for example, were troubled by the potential use of the registry for future research without the consent of those enrolled in the program (2008, 18-19). They argued that the registry gives public health officials endless access to people's medical histories without prior consent. They cited a number of concerns, including disclosure in relation to new disability policies, the prospect of hackers, and employees who would sell information for a profit (19-20). For "patients who are not otherwise aware of their diabetes diagnosis or their poor management of diabetes, a registry notification will create a new affirmative duty in the patient to disclose those newly learned material facts" when applying for services or a job (31). The registry, in this work, constitutes a new legal subjectivity whose publicness is inherently risky.[10]

Echoes of liberalism permeate this discourse, with tropes of freedom and individual responsibility highlighting contractual legal metaphors.[11] For instance, Mariner expressed

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[10] To alleviate these concerns, Krent recommended five "safety" implementations: that the statute expressly state that no information contained in the registry may be subject to subpoena (as the city did with HIV and other sexually transmitted infections); that the notification system be based on affirmative consent; that patients be given the right to opt-out of future research unless consent is expressively given; that employers and insurance companies be forbidden to inquire about A1C scores; and that physician names not be disclosed.

[11] On contract metaphors, see Somers 2008.

skepticism of the plan, noting that the city had not met the basic requirements of legality to ensure that patient data has been protected. She argued:

> what begins as a benevolent effort to encourage better medical care may mutate into requiring compliance with a medical regimen as a condition for Medicaid eligibility, private health insurance, public or private employment, or even the general duty to stay healthy. A disproportionate number of diabetics in New York City are Medicaid beneficiaries or disadvantaged minorities and the City would benefit financially from any reduction in the cost of their care. (2007, 122)

The undercurrent of liberalism, wherein the "duty" to stay well is a "mutation" from a more organic state is typical of a language strategy that conceives these interventions as inherently contractual and not actually benevolent. There is already a presumed duty among most people with diabetes to stay well and culturally produced feelings of guilt and shame arise when that imagined level of health is not attained. This is especially true for people with few resources and who are alienated by a rhetoric that emphasizes "freedom" from healthcare. So, while it may be true that the city would benefit from a decrease in healthcare costs, there is no evidence that the city wishes to further marginalize people in need. A far greater concern might be the reintroduction of a language of management that leaves people feeling isolated. Additionally, the claims about medical qualifications and pre-existing conditions seem to be negated by newly minted healthcare legislation. For those who already have insurance, the claim is completely negligible because, as Krent notes, "an insurer would likely have access to A1C test results regardless of whether that information is tracked in the registry. Health insurance companies have broad rights to inspect medical information in order to evaluate medical claims" (2008, 25). Each of the problems outlined above already exist in some form and staying the course with current policies would not effectively alter the trajectory of treatment.[12]

Critics were also concerned that the registry unnecessarily lengthened the reach of the government. Especially since diabetes is not contagious, expanding the powers of the state seemed to them wrongheaded. Mariner claims the law has always been an effective tool to implement public health policy but the measure is invasive.[13] She suggests that laws governing sewage, food, drugs, and vaccinations have a public character not shared by diabetes. "Yet, where the state overrides an individual's right to information privacy, it requires specific justification beyond general appeals to improve health" (2007, 147). The constitutive feature of this rhetoric, wherein diabetes is subsumed to the legal category of "information privacy" and simultaneously without "public" character, illustrates a complete vanishing of the condition in this rhetoric.

Mariner found the expanded concepts of "epidemics" and "disease surveillance" particularly troublesome. She notes that the metaphors "encourage the notion that health departments are entitled to personally identifiable health information about everyone in the state" (132). Epidemics, she relays, are now defined as "any increase in the number of people with a particular disease or condition that is higher than would be expected based on past experience. Thus, we read news reports of an epidemic of obesity or breast cancer" (132).

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[12] Chamany took issue with these arguments, asserting the law and internal DOHMH protocols protected individual information.

[13] Krent notes the federal government has been given broad authority by the Supreme Court to participate in surveillance programs. *Whalen v. Rose* (1977) remains the sole Supreme Court case that allowed for public health surveillance. See Fairchild, Bayer, and Colgrove 2007, 27-28.

Speaking directly to the need for a more nuanced language, she contended, the "absence of language explaining why one disease or condition differs from any other makes it difficult to determine the limits of any principle being applied" (148). Mariner raises an important point when she argues, "We've begun to talk about chronic diseases in the same way we talk about contagious diseases, and so it follows that we would start to take the same kind of public health measures" (Stein 2009). What is overlooked here is that "epidemic" provides wide cultural and legal latitude to agencies eager to make interventions in the face of rhetorics emphasizing privacy. While the frame of "epidemic" can be employed in a draconian fashion, it can also be utilized to resituate diabetes as a problem necessitating urgent public attention and government resources. Not all government intervention need be negatively bio-political.

To resist this positioning of diabetes as a public menace, a recurrent argument surfaces resituating the site of privacy in the physician's office, between the doctor and patient. This trope has a long history in public health debates. At the end of the 19th century through the start of the 20th century, language emphasizing the idea of "privacy" was primarily employed by physicians. When New York began collecting information on tuberculosis in 1897, "physicians resisted on the basis that patient privacy might be violated" (Barnes, Brancati, and Gary 2007, 829). This remained the case with the diabetes registry when some people opposed the program on the grounds that it disrupted the doctor/patient relationship. For instance, the Association of American Physicians and Surgeons, an "organization opposed to the 'evil' of government based or 'socialized' medicine, objected to lab-based A1C reporting as a blatant invasion of patient privacy that will cause many patients to avoid testing and treatment" (Fairchild and Alkon 2007, 573-74). This hyperbolic claim, which creates an unfounded slippery slope, assumes that current individual management practices – including those for people without care - are appropriate for treating diabetes.

Systemic solutions to diabetes are frequently foregrounded in essays attacking DOHMH, but generally retreat into claims about privacy violations. The public character of diabetes is noted but never sufficiently addressed. For example, starting from an argument about the systematic nature of diabetes, Goldman slowly spirals into an individualized notion of disease. Systemic alterations are hinted at, but no solutions for alleviating social ills are given. Goldman writes:

> …the underlying social, environmental, and economic factors that contribute to disease must be confronted, and the doctor–patient relationship must be reinforced with resources that enhance treatment, communication, and trust. In the zeal to ameliorate pressing health problems, public health measures may alienate the very communities and health professionals they aim to serve and reduce a willingness to seek or to provide health care services. (2008, 808)

The system is mentioned, but never attended to in a way that might actually solve problems for people with diabetes. Because Goldman situates diabetes in the private sphere, little can be done to alleviate its public nature. She continued: "although the DOHMH sees a duty to intervene for a population that is economically and medically vulnerable, this same population—as the target of the pilot intervention—is especially concerned about the risk of stigma, discrimination, and a 'blame-the-victim' approach to the disease" (809). However, in rendering diabetes private, Goldman marginalizes public discourses of shame and stigma. That is, shame and stigma are not alleviated but merely moved out of sight. So, claims that assert "physicians treating patients with elevated A1C levels caused by other conditions will be subject to DOHMH intervention, which may further erode trust and confidence in public health officials" seem baseless (809).

DOHMH pushed back on the idea of privacy, arguing for more public understandings of health and wellness. Chamany wrote, "while universal mandatory reporting may include people who do not want their results reported or to receive registry services, a significant proportion of people who would want to be part of the registry and would benefit from its services might not be offered the opportunity for inclusion because of varying practices in obtaining consent unrelated to patients' preferences" (Chamany et. al. 2009, 559). The argument reframes diabetes as a systemic harm that needs attention on many fronts, not simply the burden of individual management.

Moving from managing the epidemic towards systemic intervention

Even a cursory glance at the debates surrounding NYC's registry program will provoke discussions about government oversight, regulation of the body, and our cultural obsession with averages. The state is unequivocally and unapologetically intruding in the quotidian lives of people in the name of keeping the polis healthy. And yet, if it true that roughly eight percent of the U.S. population has diabetes, the more pressing question to ask might be: does NYC have it right? The department has a fluid understanding of the systemic nature of diabetes, and the city is looking to tap into other public works programs and health initiatives to accomplish their goals. Further, when 10-12 % of our national healthcare budget is now constituted by diabetes care, it is difficult to argue that this is a wholly private disease.[14]

By taking a broader look at the "epidemic," diabetes can be attacked at its foundations – but only with vigorous resolve. When health departments attempt to see the big picture, they do not simply see individual bodies but collective and shared notions of struggle. They see neighborhoods overridden with fast food and no grocery stores, as is the case in many neighborhoods in towns ranging from Detroit to Atlanta. They might reconceptualize the very idea of "resources" to help those whose social conditions, not contrived projections of "personal choice," shackle them. To be certain, state and city governments must be careful to incorporate how local customs, practices, and economic systems impact their messages, lest they end up with ineffectual mechanisms that fail to account for people's everyday practices and initiate no change at all (Scott 1998). In that sense, terms such as "epidemic" are but a starting point for instigating collective identification.

To be sure, there is uncertainty in the registry program. DOHMH runs the risk that the program will fail, or be underfunded, or met with legal hostility. Perhaps most risky, especially for people already marginalized by the disease, is the program's potential to slide back into a language emphasizing personal responsibility and lifestyle choices. The reconfiguring of diabetes has not yet been rhetorically manifest and the frame of epidemic may yet be ineffective. Diabetes is an expensive disease and the real test of this program will come in its ability to continue offering services, not reminders that stress only personal management. Otherwise, the registry will become the most suspicious manifestation of "management" yet: a system that tells a person they have diabetes and little more.[15] Diana Berger, the Medical Director of the New York City Diabetes Prevention and Control Program, explained that

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[14] I want to thank Bruce Gonbeck for his insights on this point.

[15] Staff and budget deficiencies may mean the program alone is not enough to combat diabetes in the city. When the program was first introduced, some were skeptical because the initiative offered no resources for diabetes treatment or services. At the program's founding, it only had three staff members and a $950,000 annual budget. Compare this to tuberculosis, which infected only 1000 New Yorkers the same year, had a $27 million budget, and a staff of nearly 400. See Goldman et. al. 2008, 809; Steinbrook 2006, 548; Bloomgarden, 2006.

they “wanted to make sure that this was more than just surveillance . . . [and] to design an intervention that would have impact . . . on quality of life” (Bloomgarden 2006). Notably, despite the appeals to both privacy and epidemics, the language of management seems to resurface continuously in this debate. One doctor who supports the program suggested “that ‘an informed and activated patient’ is needed, in combination with a coordinated healthcare system.” Still, they acknowledged, “we all know this rarely happens.” Berger attributed this failure to “rushed practitioners, a lack of coordinated care and active follow-up, and inadequate self-management training for patients.”

The state’s nuancing of the program as it evolves must be monitored closely to ensure that the complications faced by those with diabetes are truly understood. In defending the program two public health officials wrote, “Either doctors aren’t sharing … information with their patients, or they’re sharing it and their patients aren’t understanding it, or they’re sharing it and the patients forget” (Jones 2005).[16] This three-pronged analysis of life with diabetes is completely centered on the relationship patients have with doctors, mirroring the problematic arguments made by privacy advocates. Certainly, all of these claims may be accurate, but they overlook the point that sometimes people with diabetes are simply drained emotionally by their disease. Sometimes the sedimentation of the everyday mutes the real problems occurring under the skin. And sometimes the emphasis on management is overbearing and simple-minded.

Rather than stress liberal notions of individual responsibility and financial autonomy, the project can mobilize civic leadership for combating the disease. DOHMH underscores this in their report, looking to myriad social, cultural, and fiscal resources. Chamany said, “To promote the self-management of diabetes, the department offers providers additional tools to distribute to patients, such as glucose meters and strips, blood pressure–monitoring cuffs for home use, and free one year memberships to Department of Parks and Recreation centers” (2009, 557). DOHMH is currently assessing how many people are responding to the registry letters, the reaction from healthcare workers, the number of blood glucose monitors that have been distributed to people, and the amount of recreational memberships being taken advantage of in the city. Of course, even progressive measures like the recreation memberships come with their own problems in a city haunted by long winters and geographic obstacles: the memberships assume people can take the time to exercise, have transportation to access it, and the psychological support to succeed. Even with systemic intervention, there are degrees of personal responsibility always inherently at work and those discourses must be carefully monitored.

Despite these limitations, the efforts may well be worth the fight, especially when measured against today’s realities. The everyday tools being provided by DOHMH, including some forms of healthcare, make this initiative innovative. It has enlisted the support of the New York City Health and Hospitals Corporation, which is a $5.4-billion “public benefit corporation and the largest municipal hospital and health care system in the United States.” The system includes “eleven acute care hospitals, six large diagnostic and treatment centers, and eighty community clinics serving nearly 50,000 patients with diabetes” (Chamany et. al. 2009, 565). All limits aside, our culture’s current path is decidedly not working, and programs such as this are worth the effort so long as patients are protected from egregious harms.

Although there was some initial outrage to the program, DOHMH has received little resistance to the registry. Since the implementation of the program, about 90 % of all labs are participating in the initiative. Most doctors, it would seem, did not flinch at the idea of New York City collecting this data. Physicians have become accustomed to intervention by third-party managed “care” organizations, and this government program likely appears less sinister

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[16] I originally found this quotation in Fairchild and Alkon 2007, 568.

than HMOs that have wreaked havoc in their hospitals. Since DOHMH had no plans to penalize doctors who had patients with consistently high blood sugar or publicly identify those who did, the risks are slight (Fairchild and Alkon 2007, 572). It was always thought that doctors working with less advantaged populations would be confronted with people who had higher A1C levels.

The promise of the NYC program is dependent on the system's ability not only to medically support patients, but equally dependent on cultural changes in attitude toward diabetes and moving away from an emphasis on personal management. Currently, both privacy advocates and metaphors emphasizing epidemics do little to produce everyday cultural changes in such attitudes. The former renders the disease back to sector of the individual, doing little to explore the worlds in which New Yorkers live. The latter seeks transformation, even if it lacks a cultural semiotics for more fully contending with diabetes on its own terms. Of course, there is little reason that we cannot have both an emphasis on privacy and a commitment to making diabetes a more public disease free of stigma. But this requires an imagining of the individual as more than a person managing disease on his or her own – it requires vision on a scale that can come only with a broad understanding of the social world occupied by people with diabetes. Tomes reminds us that social reformers have long advocated the civic value of public health strategies and that such approaches are effective so long as illness affects people indiscriminately. However, "if a disease affects only some segments of society, especially those already stigmatized for other reasons, its prevention potentially arouses far more hostility and conflict" (Tomes 1999, 258).

People with diabetes and those who support them need to continue being outspoken about these measures and the need for public resources. Too many people living with diabetes cannot economically, emotionally, or medically manage the disease on their own. People living with HIV/AIDS were able to garner support for a balance between their privacy and their health after long struggles with the medical community and the government. The exigency imparted by those bodies needs to be underscored, as those with diabetes are not always as organized as other communities, likely because of the lack of urgency that frequently accompanies the condition. This organizing need not exclude doctors, many of who have a fluid understanding of life with diabetes. After all, "Providers caring for 83 percent of patients with elevated A1C tests in the department's South Bronx pilot have requested the patient letter service" (Chamany et. al. 2009, 557). To be sure, the lack of organization on the part of local diabetes advocacy groups might fortify notions of privacy because there are few groups dedicated to systemic changes that would enhance quality of life. To avoid being turned into infantile citizens who must keep their disease private or be seen as mere bodies in public health's vectors, citizens in the rhetorical epidemic must develop a new way of approaching this most chronic of conditions.[17]

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[17] For more on "infantile citizenship" see Berlant 1997.

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